

A hastened death by self-denial of food and drink

Boudewijn Chabot



Over the past seven years Dr. Chabot MD PhD has systematically collected empirical data in the Dutch population about a total of 110 individuals who had abstained from food and drink and had died. The results were published in Dutch in a PhD study at the University of Amsterdam in 2007.

This book does not take a preconceived position for or against a hastened death by stopping eating and drinking. The literature provides conflicting opinions as to whether it might be a good or a horrible death without offering extensive documentation. Dr. Chabot has tried to disentangle the knot of conflicting information by analysing the many cases that were reported by relatives, nurses and doctors. In this book he outlines what circumstances may have promoted a good death and what circumstances may have turned other cases into a bad death.

The central aim of this book is to stimulate communication at the end of life between patients, their relatives, physicians and nurses who might become involved with a hastened death by self-denial of food and drink in elderly or very ill persons.

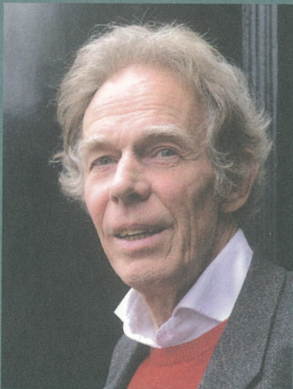


FOTO C. BOGAERT

Boudewijn Chabot (born 1941) was trained as a psychiatrist and psychotherapist at the Erasmus University in Rotterdam and at the Institute of Psychiatry and Maudsley Hospital in London. He did research in psychotherapy at the University of Amsterdam and later specialized in psychiatry for the elderly. In 2007 he was awarded a PhD in medical sociology, with a survey study in the Dutch population on hastening death by self-denial of food and drink.

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Preface

This book is based on more than a hundred reports from relatives, nurses or doctors about someone who had died after seven or more days of not drinking. Forty percent of the deceased were reported to have a diagnosis of cancer and another thirty percent had suffered from advanced neurological, cardiovascular or other diseases. The remaining thirty percent were of old age and handicapped. After many discussions with someone they trusted and (sometimes) with their doctor they had made their final choice to strive for a hastened death rather than live on for some more months or years.

In the medical literature the road to death they had chosen is referred to in different ways and with different abbreviations: hastening death by voluntarily stopping eating and drinking, Voluntary Refusal of Food and Fluids (VRFF), to abstain from food and drink, or self-denial of food and drink.^{1*)} In this book we will use them all but with some preference for hastening death by STopping Eating and Drinking (STED).

Over the past seven years I have systematically collected empirical data in the Dutch population about a total of 110 individuals who had abstained from food and drink and had died. The results have been published in Dutch in a PhD study at the University of Amsterdam (Department of Social Science 2007). They will be published in English.

The central aim of this book is to stimulate informed communication at the end of life between patients, physicians, nurses and relatives who might become involved with a hastened death by STED. Chapter 1, Chapter 2 and 4 are written for laypersons. In Chapter 3 physicians are provided with research data that are immediately relevant to understand why stopping food and fluids can be tolerated if adequate care is provided. Laypersons with a special interest in the subject should be able to understand the evidence presented.

This book does not take a preconceived position for or against a self-directed death by stopping eating and drinking. The literature offers conflicting opinions as to whether it might be a good or a horrible death that

*) Footnotes at the end of this preface and of each chapter.

are illustrated by few cases without extensive documentation. I have tried to disentangle the knot of conflicting information. I will outline what circumstances may have promoted a good death by *STED* and what circumstances may have turned other cases into a bad death. A good or bad death depends to a large extent on the quality of care offered by well prepared and informed relatives, by nurses and by GP's who have been trained in palliative care. However, other factors are also important and will be discussed. I have learned a great deal from a few cases where the person or patient² who had hastened death by self-denial of food and drink was a retired physician himself.

Only a few hundred copies of this book will be printed because it is intended as a pilot project for an expanded book on the same topic. I would therefore be grateful for any suggestions with regard to correcting mistakes and clarifying obscure paragraphs.³ I am aware that, unfortunately, my English leaves much to be desired as long as it has not received the professional attention of an editor.

Amsterdam, October 2008

Footnotes

1. Respectively by Quill 1997, Ganzini 2003, Chabot 2007, Warnock 2008.
2. Throughout this book I alternate between 'persons' and 'patients' to refer to those who have died by *STED*.
3. Mail address: see Appendix 1.

CHAPTER I

Three individuals who hastened their death by self-denial of food and fluids

I.1

Mrs B (86) '*Dying's hard work*'

This report is based on separate interviews with Mrs B's daughter and her general practitioner.

Social situation and personality

Mrs B, age 86, had always been a housewife and had been a widow for twelve years. She had good contact with her two supportive children. She lived independently, had many social contacts and led a varied and interesting life. Her daughter describes her as a strong woman, caring and considerate of others and emotionally stable.

Medical condition and decision-making process

Mrs B suffered from mild hypertension. In the months leading up to her decision to end her life, she suffered several transient ischaemic attacks (TIA's) with temporary loss of function. She had asked her GP whether a TIA could be the precursor to a cerebral haemorrhage with permanent paralysis and/or loss of speech (aphasia) which he confirmed. She also had late-onset diabetes, which was well managed with medication in tablet form. A few weeks prior to her death, her eyesight suddenly deteriorated drastically, so that she could no longer read the subtitles on the television screen.

Mrs B was not afraid of death resulting from any subsequent circulatory disturbance, but she was afraid that her TIA could be a precursor to a partial paralysis or speech loss (aphasia), which would make her dependent on care. She realised that she would then have to be admitted as an invalid to a care or nursing home. That would mean the end of her independent existence, which for her represented the essence of the person that she had become and wanted to remain. Moreover, she felt that she had lived life to the full and that her time had now come.

Over a period of several months, Mrs B spoke to her GP about her desire to end her life while it was still good and how she could take responsibility for this without burdening him:

‘There is no question of unbearable suffering, so I don’t want to ask you for an assisted death. I don’t want to make someone else responsible for my death. I’d rather take responsibility for her my death while I still can.’

She discussed with him at length the possibility of death through stopping eating and drinking. The GP deemed Mrs B to be competent to make this vital decision. She did not discuss her intention to end her life in this way with her children in the decision-making phase.

Three weeks before Mrs B’s death, her daughter asked the GP to come and see her mother, because she was not feeling well: ‘She says she feels nauseous and wants to stay in bed.’ After the previous discussions about her wish to die, there was something about Mrs B’s mood that day that made the GP ask, in the presence of her daughter, ‘Do you want to die?’ The response ‘yes’ came as a shock to the daughter. Mrs B made a joke of it: ‘Dad said you don’t need to bother eating, you’ll get something up there.’ She would not allow any discussion about her decision that the time had now come to stop eating and drinking in order to die. The daughter asked the GP: ‘How will I know whether she really doesn’t want to eat any more?’ The doctor picked up a plate of food that was next to the bed and offered it to Mrs B. She shook her head: ‘I don’t want it.’ The doctor said to the daughter: ‘You can keep offering it, and just see what happens.’ This reassured the daughter somewhat. ‘If mother really wants to die, that’s how she’ll let me know.’ The GP left a few sleeping tablets and sedatives with Mrs B in case she was unable to sleep or had any other unforeseen problems. The day before she announced to the GP and her daughter her decision to actually start her fast she had still cooked a meal for her daughter.

Course of events

Almost imperceptibly to those around her, Mrs B reduced her food and fluid intake in the first week. Even after the first week, she continued to take small drinks now and again, but soon reduced this further to just the occasional ice lolly or a small sip of coffee. If one of the grandchil-

dren came to visit, she would eat a tiny amount 'to be sociable.' The children took it in turns to be with her and make a fuss of her. After two weeks, she was clearly becoming weaker, but she remained lucid until the day of her death. In the last week, she took half a sleeping tablet on two occasions in order to pass a more peaceful night. Several days before her death, she experienced difficulty breathing and became anxious as a result, but this was brought under control with a sedative. She kept up the mouth care with the help of the children and she did not complain of being thirsty. She did say towards the end: 'Dying's hard work, you know, you have to do it on your own. Dad can't help, mother and father are no use either.' She died during the night while her son, who was keeping vigil, was making a cup of coffee. He heard a sigh and when he got to her it was over. The period that had elapsed from the point at which she started reducing her food and fluid intake amounted to three weeks in all; during the last ten days, she had not drunk anything at all.

The daughter remarked: 'This has been a worthwhile time in our lives because we were all able to care for her and make her dying bearable. We made sure that there was a good atmosphere and that there was something to keep her occupied when she was awake. It was important for her and for our peace of mind that the doctor visited every day and gave us so much of his time.'

Comments in hindsight

In comparison to the case that follows, this end-of-life process was remarkably peaceful. This was helped by the following factors:

- Both the daughter and the doctor described Mrs B as a strong, well-balanced person. She wanted to take responsibility herself for the end of her life.
- She was well aware of what to expect from discussions with her GP.
- The doctor visited daily and provided sleeping tablets and sedatives as a precaution. Painkillers did not prove necessary; the odd sleeping tablet and tranquiliser turned out to be enough. It is a recognised phenomenon in palliative care for terminally ill patients that the treatment of pain or other symptoms is often more effective if the individual can regulate the dose of the analgesic or other alleviating medication him/herself. This reduces the fear that he/she could succumb to uncontrollable suffering at any moment.

- Mrs B stopped eating and then drinking at her own pace. It is a known fact in the process of fasting that the feeling of hunger quickly subsides once the intake of carbohydrates has ceased altogether. It is not clear whether thirst is more tolerable with the gradual cessation of fluid intake or when this is stopped abruptly and completely. This may vary from person to person.
- The loving children and grandchildren made the process less arduous by keeping her occupied during her waking hours and making a fuss of her. Mrs B did stress at the end, however, that you have to do 'it' yourself and that it is still hard.

1.2

Mrs G (83) *'I've got enough willpower to see it through'*

This report is based on an interview with her son and daughter-in-law; and on information over the phone from her general practitioner.

Social situation and personality

Mrs G, age 83, had been a widow for twenty years. There was good contact between her and her only son and daughter-in-law, who visited her several times a week. She was remarkably lively and up to the age of 81 had still played tennis every week, gone for long walks with a friend and had a circle of friends with whom she had played bridge. All her life, Mrs G placed great store by being immaculate in her appearance and maintaining high standards of decorum. She went her own way; her son described her as strong-willed and even forceful.

Medical situation and decision-making process

Two years before her death, the neurologist found that there had been minor bleeds in the white matter of the brain, resulting in progressive symptoms of Parkinsonism: increasing difficulty in swallowing and speaking, a strong tremor and spasticity in the left arm. Treatment with the medicine Madopar gave only temporary relief.

A year before her death, Mrs G moved, with extreme reluctance, from her own house to a care home for the elderly because the Parkinsonism meant that she could no longer manage the stairs. At first, she made new

social contacts there. However, as her difficulty with swallowing increased, she began to dribble and no longer wanted to be seen at mealtimes or at the bridge table as a result, because she was 'a dreadful sight'. It was also becoming more and more difficult for her to make herself understood and she was no longer able to do so at all when there was a group of people. She became socially isolated.

At the time of her request for a physician-assisted death, she could no longer get out of bed and had to be lifted out with a hoist. Her food was liquidised, but even then it was very difficult to swallow. She coughed a great deal and it became more and more difficult for her to clear the phlegm from her airways. Expectorant medication provided little relief. Because she could not swallow the phlegm, she would become short of breath, sometimes to the point of suffocation. She realised that this dependency was only going to get worse. The social isolation caused by her inability to speak clearly when she was with other people was what made her decide that she did not want to live any more.

With hindsight, her son and daughter-in-law feel that these handicaps and their implications for her had not been adequately discussed with the GP. Mrs G had waited to fill in and sign her request for a physician-assisted death. When she again almost suffocated because of the phlegm she became very frightened and decided she did not want to wait any longer.

In retrospect, both the GP and the two family members deemed her to be competent, capable of making this decision, after consideration of the arguments for and against. The GP did not think that she was depressed. She signed her written request for a physician-assisted death, because of her problems with speaking, swallowing and dribbling. She had crossed the boundary of what for her was a meaningful social life. The daughter-in-law was present during the conversation with the GP in which Mrs G requested lethal medication. Now that she had waited a year to sign the written request, she had expected that the doctor would comply with her request within a short space of time.

The GP did not refuse the request for reasons of principle, but because he felt that he was being pressurised by Mrs G. He was impressed by the fact that Mrs G had continued to play tennis regularly until she was over eighty years old. He felt that she was finding it difficult to accept the disabilities because she had always been in such excellent physical condition. Compared to the other residents in the care home, he did not find the

inability to speak comprehensibly and the dribbling particularly unusual. Other elderly people who could not swallow their saliva and spat it into a tissue did manage to come to the table and join in with bridge. When he talked to her on a one-to-one basis, he could understand her. The doctor could not see, therefore, why the disabilities were unacceptable to Mrs G. Lastly, not the least reason for his rejection of her request for physician-assisted dying was the fact that there was no terminal illness.

The following weekend, Mrs G decided to take her death into her own hands by not eating and drinking anymore, a method which she herself called degrading. Her son and daughter-in-law were unable to dissuade her and she said: 'I'm going to stop drinking, because the doctor won't help me. I've got enough willpower to see it through.'

Course of events based on entries in the nurses' record

On the problems Mrs G was having with swallowing and coughing up phlegm, the nursing staff noted: 'She is eating and drinking very little because she chokes a lot; she turned blue on one occasion.'

Day 1: 'Patient has decided to refuse all medication, food and drink in the hope that she will die quickly; she did drink one glass of water last night.'

Day 2: 'Ate and drank nothing, did not pass water and complained of pain when handled. GP prescribed 500 mg paracetamol suppositories up to 6 times daily. Doesn't want to be lifted out of bed into the chair.'

Day 3: 'Still refusing food and drinks. Says she hopes her GP will give her a lethal dose of barbiturates.'

Day 4: 'Still complaining of pain. Paracetamol suppositories increased to 1000 mg.'

Day 5: GP requested a visit by a SCEN doctor¹, and said this visit was not urgent.

Day 6: 'Patient complained of pain. When she woke up, she said: "Am I not dead yet?"'

Day 7: 'Diminished response and has blisters in her mouth.'

Day 8 and 9: no report.

Day 10: 'During the visit by the SCEN doctor, she was no longer comprehensible. GP prescribed Durogesic 25, which is morphine via a plaster. That is a high dose, equivalent to 60 mg morphine in tablet form.'

Day 11: 'Patient is comatose. She died in the presence of the family.'

About the days 8-9 for which there was no report, her daughter-in-law said: 'She was in a disgraceful state. Some nurses were coming out of her room in tears.' Her son said: 'I should have held a pillow over her face. The blisters and scabs around her mouth were a terrible sight.'

The GP had had a telephone conversation with a colleague on Day 5. They discussed how she was not only putting pressure on the GP but also on herself, by turning her fasting into a battle of prestige. During the discussion, it was noted that the patient appeared to be competent and her request voluntary and properly considered. The assessment of an independent consultant was certainly required, but this came too late.

According to the GP, there was no unbearable suffering on Day 5. He felt as if he was being blackmailed by the patient ('if you won't help me, I'll starve myself to death').

Comments in hindsight

Both doctor and patient missed opportunities to discuss physician-assisted dying within a reasonable space of time. In her independent life style, Mrs G was used to putting words into action and had not realised what ending a patient's life would mean to her doctor. After she had made her decision, any further discussion about alternatives or postponement was impossible. Her son clearly understood her feelings that enough was enough and he also knew her to be 'forceful', so he did not intervene.

It is not unusual that conflicting views arise between doctor and patient. In this case, the Parkinsonism caused disabilities which, in the doctor's experience, many other elderly people find tolerable. But Mrs G and her loved ones saw her disabilities in relation to her own life style. There was an irreversible disability in terms of walking and going to the toilet, but above all in terms of speaking and swallowing, which meant that she was incomprehensible and dribbled in the company of others and this was for her the reason for withdrawing from social interaction. For someone as physically active and social as she was, an irreversible disability in terms of walking, speaking and swallowing meant an *increasing and irreversible loss of dignity* which was equated by the Dutch Supreme Court in 1984 with 'unbearable suffering'.² This was not discussed at a stage in which Mrs G could have convinced her doctor how important this was to her or when, seen from the other side, the doctor

could still have suggested other options. If the patient's conversation with the GP had not escalated in the way it did, an emergency consultation might have succeeded in mending some fences.

As one would have expected, the consulting doctor's visit on Day 11 was pointless, as the patient was no longer capable of holding a conversation. The GP did not make daily visits to a patient dying an emotionally and physically painful death. The family and the carers in the home did not feel that they had received the necessary support.

Mouth care: from Day 7, there were painful blisters in the mouth, which would indicate inadequate mouth care. For the nursing staff it appeared to be emotionally difficult to care for someone who is not terminally ill but wants to die.

Palliative medication: the doctor prescribed paracetamol, the first 'rung' on the 'analgesic ladder'. In some cases, that is sufficient. No sleeping tablets were offered to shorten the patient's waking hours. It is not clear from the nursing notes why these were not given. The doctor said afterwards that the patient had not complained of difficulty in sleeping, but her son believed that she had been too proud to ask the doctor for any medication. One could perhaps conclude from the missing reports of Days 8 and 9 that the carers felt that the situation had deteriorated beyond description. The daughter-in-law's remark that some nurses were coming out of the patient's room in tears would tend to suggest that this was the case.

Some doctors equate the deliberate cessation of food and drink with suicide. This may evoke a moral judgement and, as a consequence, a refusal to provide palliative care. In this case the moral judgement also resulted in a 'code of silence' in the communication between physician and nursing staff.

In cases where a doctor personally feels that the wrong decision has been made by a competent individual wishing to end his/her life by voluntarily refusing food and fluid, the doctor is nonetheless obliged under the Dutch Medical Treatment Contracts Act to continue to be mindful of 'the duty of care of a good health care professional'.³

1.3

Mr. R (84) '*Since my wife died I don't want to live any longer*'

This is a translation of the report I received from his physician.

Mr R, a retired bankmanager, died in a home for elderly somatic patients where rehabilitation for his most recent handicap was offered. His request for physician-assisted death by oral medication was turned down by his physician. He died ten days after he had stopped eating and drinking with the explicit purpose of dying.

Social situation

His wife had died five years previously. She had suffered from Alzheimer's disease. He had cared for her at home until she had a stroke and had to be admitted to a nursing home. He did not really want to live on after her death, but carried on as well as he could. In a sense the amputation he had to undergo was the last straw.

He has one daughter and a granddaughter; he has a good relationship with both.

Medical condition and diagnoses

- Recent amputation below the knee of his left leg due to arterial ischaemia;
- diabetes
- visual handicap due to diabetic retinopathy;
- cardiac arrhythmia for which he had received a pacemaker;
- hearing-aid for his mild deafness.

The purpose of his admission was rehabilitation during which he would be supplied with an artificial limb and learn how to move about again. However, Mr R insisted: '*Since my wife died I don't want to live any longer and I don't want this rehabilitation. My only leisure interest is gardening which has become impossible since the amputation. Please give me the medication to die.*' His daughter confirmed that he had often expressed his wish to die since the death of his wife.

The physician consulted a SCEN-doctor¹ who came to the conclusion that the conditions under which euthanasia would be allowed did not

apply. Though the patient's request was voluntary and well-considered, the patient's suffering could be treated since there was a good prospect of recovery by rehabilitation. The physician explained to the patient that there was a reasonable alternative to a physician-assisted death and that his request had therefore been turned down.

Mr R stuck to his wish to die. In a meeting with the patient and his daughter the doctor explained that there was an option of last resort if he really wanted to die: "It is possible to hasten your death if you stop eating and drinking." Later in that meeting he added: "The nurses and I will do all we can to make this road to death tolerable though it will surely take a great effort on your part to stick to your decision if you would decide on that course. Give it some time to think it over."

Mr R then did start his rehabilitation program. Three weeks later he was completely determined: "I am not continuing this, I will stop eating and drinking altogether." There was another family meeting in which he confirmed his decision. The doctor promised to provide adequate palliative care. What he meant by this will become evident from the day-to-day report:

Day 1: In the morning the doctor stopped all medication including the anti-diabetic medication. The patient was given a nebulizer to moisten his mouth as often as he liked. During the night he was permitted to use temazepam 20 mg and to ask the nightnurse for another one if necessary.

Day 2: all nursing staff have now been informed about this unusual regime. All were instructed to give special attention to mouth care (ice cubes, artificial saliva, for details see Chapter 2.5). The patient was placed on an anti-decubitus mattress.

Day 3: He has slept well on temazepam. During the day he is alert, complains of some thirst which is tolerable thanks to meticulous mouth care.

Day 4: He gets thirsty more often, becomes drowsy but wakes easily when spoken to.

Day 5: He dozes quietly a lot, becomes bored when awake and feels it's taking a long time to die. He refuses music, tv or radio. Sleeps well on temazepam.

Day 6: He complains of more thirst. The doctor feels that the patient has clearly demonstrated a strong and unwavering wish to die for 5 days and nights. He judges that some palliation is appropriate and starts with 10 mg Midazolam subcutaneously 4 times daily.

Day 7: Thirst has become tolerable. He sleeps more during the day; when awake he is in good spirits; there is no confusion. Midazolam dose unchanged.

Day 8: He can still be woken. Midazolam was increased to 4 times 15 mg subcutaneously in view of the rapid habituation to Midazolam.

Day 9: The doctor judges that after 8 days and nights the process of dying by deliberate dehydration has become irreversible. Therefore he adds 10 mg morphine 6 times daily to the Midazolam. The patient's sleep deepens, he does not respond when spoken to.

Day 10: No changes. He dies at the end of day 10 at 23.30.

The relatives, doctor and nursing staff all felt that the course of events had been 'good'.

Footnotes

1. The consulted physician in the Netherlands has to be a member of the organisation for Support and Consultation in physician-assisted dying (SCEN). This is a nationwide network of doctors who receive additional training in the assessment of requests for physician-assisted dying and in the improvement of palliative care.
2. Supreme Court, Schoonheim case, NJ 1985 nr 106
3. Medical Treatment Contracts Act (WGBO), article 453: 'In the performance of his duties, the care provider must be mindful of the duty of care of a good health care professional and act in accordance with the responsibility vested in him, based on the professional standards governing health care professionals.'

Information on stopping eating and drinking

2.1

Four options of last resort at the end of life

Several authors have distinguished four options of last-resort at the end of life.¹ Only the first one, stopping eating and drinking, will be discussed in this book.

1. *Hastening death by stopping eating and drinking*

Definition: A person who is otherwise physically capable of taking nourishment makes an explicit decision to discontinue all oral intake and, if this decision is sustained, will die of dehydration or some intervening complication.

Warnock and Macdonald observe in their book *Easeful Death*: 'Because of the resolve and determination needed to discontinue eating and drinking there can be no doubt as to the voluntary nature of this decision on the patient's part. Both ethically and legally the right of an individual to refuse treatment, including food and water, is well established.'

One should be aware of three other last resort options at the end of life.

2. *To discontinue life support or forgo life-sustaining treatment*

If the patient is receiving life-prolonging interventions, he or she may consider discontinuing them, in consultation with the physician. There is growing acknowledgment that some patients experience unacceptable levels of suffering toward the end of their terminal illness, even though they are receiving state-of-the-art palliative care, and that some of these patients are capable of making rational decisions to hasten death when they are not clinically depressed or delirious. They are allowed to discontinue life support or to refuse further treatment (e.g. radio- or chemotherapy), even when this decision is motivated by their wish to die sooner rather than later. The General Medical Council² is explicit on this adult competent patient's "right to refuse treatment even where refusal

may result in harm to themselves or in their own death.” (section 13, quoted in full in the appendix to this book)

3. *Intensive pain treatment and terminal sedation*

Patients who have been taking a lesser amount of opioids for their pain so as to maintain alertness at one point in their illness may at a later stage request or accept more risk of sedation to achieve better pain relief as death approaches. If the pain or other symptoms remain unrelieved, the physician may legally administer terminal sedation. In terminal sedation the suffering patient is sedated to unconsciousness, usually through ongoing administration of barbiturates or benzodiazepines. Terminal sedation is generally reserved for patients whose death is imminent and whose physical suffering has become severe and otherwise unrelievable.

The U.S. Supreme Court has acknowledged the legal acceptability of providing pain relief even to the point of hastening death, if necessary.³ Either sedating to unconsciousness or withdrawing nutrition and hydration could be used by a physician intentionally to hasten death and therefore resemble physician-assisted suicide. This makes terminal sedation and withdrawing hydration problematic for some clinicians and for some patients even in those cases where they are legally permissible. In the Netherlands palliative experts agree that there is only a proper medical indication for palliative sedation in cases of suffering that is otherwise untreatable (e.g. persistent delirious behaviour, vomiting, unrelievable pain). If these symptoms cannot be relieved by standard palliative measures, they can be alleviated by putting the patient into a deep sleep until death occurs. Fluids are not usually administered in such cases as the patient is in a terminal phase of the disease.⁴

4. *Physician-assisted dying by oral medication:*

A physician provides the means, usually a prescription of a large dose of barbiturates, by which a patient can end his or her life. This fourth option of last resort at the end of life has become legal in Oregon but it is forbidden by law in other states, as it is in England and Scotland. In Oregon, physician-assisted dying is restricted to patients who are suffering from a terminal illness and for whom palliative or hospice care have become either ineffective or unacceptable.

‘Physician-assisted dying’ is a phrase that was introduced by the

american oncologist Timothy Quill and ethicist Margaret Battin in a volume on palliative care and patient choice. They prefer this term to 'physician-assisted suicide' because it is 'descriptively accurate and carries with it no misleading connotations':

'Although suicide can be considered heroic or rational depending on setting and philosophical orientation, in much American writing it is conflated with mental illness, and the term suggests the tragic self-destruction of a person who is not thinking clearly or acting rationally. Although depression and other forms of mental illness must always be considered when a patient requests a physician-assisted death, patients who choose this option are not necessarily depressed but rather may be acting out of a need for self-preservation, to avoid being destroyed physically and deprived of meaning existentially by their illness and impending death.' (p. 1-2)⁵

Also in the Netherlands the word 'suicide' carries associations of mental illness, of a death that is carried out impulsively by someone who is not competent, and who uses a method that mutilates the body (e.g. hanging, jumping, shooting). In the four options of last resort described above, relatives, friends or nurses are intensively involved over the last period of life. Thus, it is highly unlikely that any of these methods for a hastened death have been chosen impulsively by an incompetent person. I will therefore avoid the term 'suicide' in this book and will refer to hastening death by stopping eating and drinking as one option of last resort for a self-chosen death in consultation with one or more trusted persons. In section 2.5 I will return to the often implicit association of suicide with incompetence.

2.2

Survey of the course of events in STED

Someone opting for a hastened death by stopping eating and drinking should know the course this would normally take, what problems might occur and how they can be avoided. I will provide evidence that for some elderly or sick people this may be an acceptable way of ending their life.

Not all doctors know this and not all doctors know how to supervise a death such as this. Before someone decides on this method of ending

his or her life, there has to be consultation with family members or other trusted persons and with a doctor. This is because the day-to-day care by relatives and nursing staff is indispensable during the process.

Patients who are not yet terminal and who try to accelerate their death often stop eating and drinking at the same time. If they sustain this, death occurs after 7-15 days in 70% of cases (see section 2.5). Others stop eating first and later, in a matter of days or sometimes even weeks, gradually stop drinking. In these cases, death takes longer to occur (16-30 days in 20% of cases) but there are indications that the process itself is less harsh. Once drinking has ceased, the patient will only ingest fluid through mouth care. Half a small glass of water (about 50 cc) is sufficient for this, and this amount can be ingested by moistening the mouth from time to time with an atomised water spray (3 puffs contain about 2 cc) and by sucking half a cube of crushed ice (about 5 cc) wrapped in gauze a few times a day. Section 2.6 looks more closely at mouth care.

Many people think that stopping eating and drinking to hasten death will cause a great deal of suffering. However, research (see Chapter 3) has shown that this does not necessarily have to be the case if the mouth care and any necessary pain management are administered effectively. Mouth care can be provided by a nurse with the help of relatives or trained caring staff. This will preferably, though not necessarily, take place under the supervision of a GP or other doctor who has been trained in the provision of end-of-life palliative care.

The mind remains lucid in the first few days. At that stage, someone is still able to talk to relatives about whether the wish to die is definitive or not. Abstaining from eating and drinking could turn out in practice to be too hard for someone, or relatives might persuade their loved one to postpone the decision to die, so that he/she starts eating and drinking again. A person can change his or her mind at any time about hastening the moment of death, and that is not unusual during the first few days. The responsibility for continuing to refuse food and fluids rests with the individual. Apart from the atomised water spray a glass of water should always be within reach of the person, unless he or she has insisted that the glass of water should be removed. He or she will confirm the decision to continue with *STED* by not finishing the glass of water that is within reach. Research in Oregon as shown that approximately one in every six people who consciously refused to drink in order to hasten

death and who received excellent palliative care changed their minds. That was often the result of insistence by the family who did not agree with the person's decision to hasten death.⁶

Once someone has stopped eating and drinking, general weakness will set in after a while. This weakness resembles the last phase of a fatal illness but without the symptoms of pain or breathing difficulties. Death is caused by the cessation of fluid, by dehydration, not by the cessation of food. In the absence of any fluid intake, the kidneys will stop producing urine after about seven days, which means that the metabolic waste products can no longer be removed from the blood. Most persons become drowsy after a period of not drinking because their kidneys are no longer able to excrete urea. Many do not find this drowsiness unpleasant. It has been reported that this drowsiness may be reduced by drinking some water, which will enable the kidneys to excrete some of the urea. Drinking some water does prolong the dying process, but some individuals prefer to have lucid moments in which they recognise loved ones, however weak they may have become. In the end, the heart can no longer beat regularly and the person will die while asleep from a cardiac arrest.

2.3

Variations in the process in different groups

Abstention from eating and drinking in order to deliberately hasten death should be distinguished from the case of demented elderly patients who are no longer capable of giving informed consent. Many demented patients diminish eating and drinking *spontaneously* over months or even years before they die. I will concentrate exclusively on the well-considered and conscious refusal of food and fluid that expresses a deliberate decision to hasten death. The contents of this book do not apply to incompetent, demented patients.

In patients with cancer, appetite frequently diminishes *spontaneously* as well so that eventually they virtually stop eating and drinking altogether while still competent. However, these patients do not make a deliberate decision to hasten their death by stopping their fluid intake. Patients with cancer or dementia who stop drinking *spontaneously* also die as a result of dehydration, but their dehydration is the result of the illness and *not* of a decision to hasten their death.

For some, the idea of fasting to death conjures up images of people in the prime of their life, such as hunger-strikers or patients suffering from anorexia nervosa. These individuals have a whole life ahead of them, but fast because of political ideals or as a result of a psychiatric illness. In their case, death usually occurs after a long period of suffering, which even good mouth care can do little to alleviate.

In the case of some terminal cancer patients who have stopped eating and drinking to hasten their death, physicians will sometimes prescribe medication which will put the patient into a deep sleep to prevent suffering from thirst. If this deep sleep extends until death, this resembles a case of 'terminal sedation' (see section 2.1). The voluntary refusal of fluid in order to hasten death does not, however, necessarily cause suffering if proper care is given and if no delirious state occurs. As long as the suffering can be palliated by less radical means than taking consciousness away, there is no medical indication for putting the patient into a continuous sleep till death occurs.

Some persons feel anxious because they expect to suffer once they stop eating and drinking. Fearful expectations mean that adequate information should be provided about how good mouth care can make the process bearable and preferably this should be practiced before the start of STED (see section 2.5). Anxiousness can be a reason for some form of analgesia if the patient requests it, or for a sedative if someone is particularly tense. If someone nonetheless remains too fearful to take control of abstaining from food and fluids, he or she is not yet ready to take the responsibility for a self-directed death by not drinking.

In some religions, 'abstinence from food and drink' prior to death is not uncommon. In Jainism in India, fasting to death signifies the victory of the spiritual being over the body and that is held in high regard. There are accounts of hospices in Benares (India) where elderly people who have recently stopped eating because they feel that their time has come are admitted with their family to say their goodbyes.⁷ For the family and for the elderly person, the refusal to eat is not a sign of a depression but an act of control over their death.

In western countries individuals sometimes want to take control over their death, with or without a specific spiritual meaning attached to the method chosen. They may consider stopping eating and drinking an option of last resort. Physician-assisted dying is not permitted by law and

therefore a doctor can never be required to honour the request for ending someone's life. In Oregon and a few European countries (Switzerland, the Netherlands and Belgium) this is permitted by law.⁸ In the case of a decision by a competent patient to refuse food and fluid in order to die, a doctor can play a role because palliative care remains important to alleviate the suffering that accompanies the refusal of all food and fluids, including artificial hydration. The General Medical Council (GMC) guidelines state in section 42 and 43 (Appendix 2):⁹

Section 42: You [i.e. a physician] should bear in mind that you are bound to respect an adult patient's competently made refusal of treatment even where complying with the decision will lead to the patient's death.

Section 43: A physician should offer the patient the opportunity to discuss how their care would be managed if such a decision were made. This should include:

- arrangements for providing nursing care and other appropriate treatments
- the patient's preferences about who should be involved in decision making or in providing additional support if they become incapacitated
- what might be their palliative or terminal care needs should death become inevitable and how these would be met.

We will return to this guideline in section 2.8. It should be noted here that the obligation to respect a refusal of treatment continues to apply even if the physician is not in agreement with the patient's decision (see GMC section 13).¹⁰

In closing off this section I want to look very briefly at the difficult position of those children or other confidants who become involved with someone who wants to die by *STED*. At least some family members and friends will often oppose the decision. Confronted with a determined wish to die, they can be overwhelmed by anger, helplessness and other emotions. Some can no longer bear to watch a loved one choose to hasten his or her death and will withdraw from the discussions. Others who wish to remain in contact until the end must force themselves to show tact and respect. The decision to stop all food and fluid is sometimes made amid

an intense emotional struggle with loved ones. Informants in my study have spoken of many conflicting sentiments. Loyalty to the person with a deeply felt wish to die clashes with their internal opposition to being forced to part from a loved one. Some relatives are less troubled by this ambivalence because they suspect that they themselves would make the same decision were they to find themselves in the same situation. In my interview study many informants were remarkably reticent afterwards about their struggle with themselves and with the deceased, even years later. It seems as if they fear that they will sully the memory of someone who had 'taken matters into their own hands.' Perhaps that is why they only allow a veiled glimpse of the fact that the death of their loved one made them feel rejected, certainly after doing all they could to help the person to continue with a meaningful life rather than end it.

This book deals exclusively with individuals who knowingly, in consultation with relatives, decide to bring about their death by refusing to eat and drink. They are choosing a difficult but not impassable path. The question of whether the patient and his/her carers know how to make this journey more bearable makes a huge difference in this respect. My population based study in the Netherlands has unveiled some characteristics of those who choose this road to death (section 2.4), how long it took them to die (2.5) and what palliative measures might be helpful (2.6 and 2.7). We will turn to this evidence now. The reader should be aware that it is not known to what extent these empirical data apply to the United States, England and Scotland. No comparable research has been done there on the prevalence of *STED* or the duration of the process leading to death for those individuals who died at home.

2.4

Some research findings in the Netherlands¹¹

Before 2007 no research had been published on hastened deaths by stopping eating and drinking in the Dutch population. This gap in end-of-life research has prompted me to find out how such a planned death was executed by competent persons. An informant could be any person (relative, friend, nurse, physician, or right to die activist) who had been confided in by the individual about his/her wish to hasten death.

In December 2003, a large sample was randomly drawn with the assistance of a research institute. This institute took great care to draw a sample that was representative of the Dutch adult population in terms of sex, age, education and geographical location. About 21,500 persons were approached online about a possible personal experience with someone who had stopped taking food and fluids and had died. The anonymity of the informants was protected by the research institute. After a very stringent selection process I was convinced that 97 informants were in fact reporting on a deliberately hastened death by stopping food and fluids.¹²

Eighty percent of the deceased were over age 60 and sixty percent were women. Half of these deaths by *STED* occurred at home while the other half occurred in a care institution for the elderly, in a home for physical rehabilitation of the elderly, or in a hospice. Most of those who died got at least some palliative care either at home or in the institution. One out of three had a living partner which is a normal rate for persons of this age. The 97 deaths by *STED* that were reported online can be subdivided into three groups, depending on the diagnosis reported:

- 40% of the informants reported that the deceased had had a diagnosis of cancer; the cancer had not yet reached a stage where death was expected within days; some patients were in a stage of cancer where a cure had become unlikely; they had refused further curative treatment and later decided to abstain from food and fluid.
- 32% of the informants reported that the deceased had had a serious somatic (often neurological) disease. The case of Mrs G (see Chapter 1.2) falls within this group. In 16% of these cases a psychiatric diagnosis was reported which, according to the informant, did not interfere with a competent decision to die by *STED*.
- 28% of the informants reported that the deceased had had no major diagnosis such as cancer or ALS but had suffered seriously from ailments of old age (blindness, deafness, walking impairment, arthrotic pains, speech and/or memory impairment). The case of Mrs B (Chapter 1.1) falls within this group.

The informants answered 100 online questions about demographic and medical characteristics of the deceased; about how the decision to die had been reached and the course of events once food and fluid intake had

been greatly reduced or stopped. An important question at the end of the questionnaire informed whether the deceased would have judged his/her death by STED as a 'dignified death': 74% answered 'yes', 17% 'no', and 8% answered 'unknown'. This finding is in stark contrast with the negative opinion many people have about a deliberately hastened death by stopping eating and drinking. Especially so, because the two sub-groups without a diagnosis of cancer, together involved 60% of the deceased.

2.5

How long does it take to die?

Forty respondents reported that a hastened death had occurred within seven days after all fluid intake had been stopped. I have excluded these 40 cases from those reported in the table because if someone dies within seven days after the cessation of all fluid intake, it is likely that some illness or medication (morphine) has contributed significantly to this quick demise.

Table. *Timescale from start of refusal of all fluids until death, subdivided according to severity of illness, in a total of 97 deaths by STED reported by relatives, nurses and others.*¹³

	fatal illness	serious illness*	no fatal or serious illness
7 - 9 days	10	9	5
10 - 12 days	10	7	4
13 - 15 days	8	4	10
16 - 18 days	3	0	1
19 - 30 days	8	4	3
31 - 60 days	0	6	2
> 60 days	0	1	2
Total	39	31	27

* e.g. a diagnosis of ALS, MS, AIDS, COPD, cardio-vascular disease, cerebro-vascular accident.

Some people who had stopped drinking altogether appeared to have died in as few as 7-9 days, especially those with a fatal or other serious illness. The majority (70%) died within 16 days. The reports indicated that these individuals had not drunk any fluids at all but had only used an atomised water spray to moisten the mouth or crushed ice cubes. Another 20% died after 16-30 days: they had stopped eating from one day to the next but had reduced their fluid intake gradually to virtually nothing (less than 50 cc). Those remaining (slightly over 10%) had stopped their food intake and at first continued unrestricted fluid intake for some time. They had restricted their fluid intake in the course of the second or third month.

These data show that someone who decides to hasten death by restricting food and fluid intake and who is not in a terminal phase of an illness is able to influence how long it takes to die. Death can be delayed by allowing oneself some water. Death can be speeded up by not drinking at all, though some informants reported that this had made the process more difficult.

In the case of some illnesses, such as cancer or AIDS, one of the recognised symptoms is the spontaneous decline in the need for food and drink. Patients wishing to accelerate death will in such cases suffer less from hunger and thirst after their decision to stop eating and drinking. Many cancer patients are unaware that, because of their reduced appetite, they can hasten their death by quite some time if they also restrict fluid intake. Physicians do not give this information to a competent patient with cancer who could still live for weeks or months but has repeatedly expressed a well-considered wish to die soon. This wish might not necessarily be influenced by distressing somatic symptoms; it could also be prompted by the patient's desire not to postpone the inevitable once life seems rounded off and completed. Many physicians are reluctant to tell those fatally ill patients who have a deliberate wish to die that *STED* is an option of last resort by which they can manage their own death if they are really determined to do so. Chapter 4 will discuss some ethical questions that face a GP who is considering giving that kind of information to a patient who asks specifically about options of last resort that might be available in order to hasten death.

If someone dies *after seven or more days* of virtually no fluid intake, it is safe to assume that death was in part caused or at least accelerated by

dehydration. A death which was brought about deliberately, is often labeled a 'suicide' as it is a deliberately self-chosen death. I avoid the term 'suicide' because of the implicit understanding that a suicide is always irrational and a sign of underlying pathology. Several cases were reported by relatives who emphatically distinguished a 'suicide' from a 'natural death' by a refusal of food and fluid. For instance, one of them responded:

'My mother with a CVA diagnosis would never even have considered suicide! She had no doubts about stopping eating and drinking in order to die once she realised that this might be, with adequate care, a humane death. For her this death surrounded by her children, taking turns in caring for her, was a completely *natural* way of dying far removed from suicide.'

Quill and Battin consider the label 'suicide' misleading in many cases of a hastened death by options of last resort. The moral philosopher Mary Warnock and the oncologist Elizabeth Macdonald seem to concur with the idea that 'suicide' may not be an adequate description of a hastened death in cases of a severe and incurable illness. 'Suicide' often implies mental incompetence by a depression and may serve the purpose of disqualifying someone's decision to die:¹⁴

'It may be argued that there are situations where suicide is a rational choice, though a sad one. In the case of Diana Pretty, for example, her desire to commit suicide was based on a perfectly rational preference for avoiding the inevitable and clearly foreseen horror of her death, if she allowed 'nature to take its course'. Suicide was in her best interest. Had she been physically able to take her own life she would have done so, nor are there many who would have failed to understand her choice. There would have been no grounds for saying that she killed herself only because she was suffering from a clinical depression which could be cured. Considering such cases as hers, it must be wrong, and insulting, to argue that all suicide is the outcome of mental incompetence.'

2.6

Adequate mouth care is indispensable

Many people know from experience of temporary fasting that the feeling of hunger disappears after a few days of strict fasting and is replaced by a sense of well-being. This is because when the intake of sugar or other carbohydrates ceases, the body produces a morphine-like substance which has a positive effect on mood. Another effect of strict fasting is that when fatty acids are broken down, the body produces certain substances (ketone bodies), which have an analgesic effect.¹⁵

It is essential that the individual him/herself and the relatives realise that the feeling of thirst is caused by dehydration of the mucous membranes of the mouth. If the mouth can be kept lubricated, it appears that the feeling of thirst can be tolerated. That has been the experience in terminal palliative care.

There are three products that can be used to reduce the feeling of thirst: those which refresh the mouth, those which stimulate the secretion of saliva and saliva substitutes (see p. 32). Each of these products appears on the market under various brand names. A fourth product is essential to cleanse the mouth in order to prevent fungal infections which can occur if the mouth's natural cleansing process is disturbed because someone is no longer eating or drinking. A pharmacist will be able to advise on the products that are available locally.

It can often build confidence if someone who is considering a self-chosen death by refraining from food and drink can experiment beforehand to find out what sort of mouth care alleviates thirst. The American physician Stanley Terman tested this on himself by eating and drinking nothing over a four-day period while he was in good health. He thus gained some useful experience in respect of which mouth care products suited him best and which he did not need. Terman rated his thirst every few hours on a scale of 0 (no thirst) to 10 (extreme thirst). His score was never higher than 5. On the same 0-10 scale, his feelings of hunger never rose above 2. An extract from his book illustrates what can be learned from thorough preparation.

'I did not follow the usual advice to counteract thirst by sucking crushed ice in a piece of gauze, because I was afraid that I would do this too often and thus ingest too much water. Nor did I use any lemon drops

with sugar or any soft drinks, because the sugar they contain would stimulate insulin production and thus trigger feelings of hunger. Every few hours, I used a mouth spray with a saliva substitute, which refreshed the entire oral cavity. Sugar-free chewing gum was also refreshing in the mouth. Using a piece of gauze, I rubbed a saliva substitute in gel form on my gums and on the roof of my mouth, because a gel prevents dehydration of the mouth while sleeping. For toothbrushing, I used an extra soft brush and children's toothpaste, which is less of an irritant for the mucous membranes. To freshen up my face, I used rose-water or glycerine. I kept my lips moist with Vaseline. I did not need a nasal spray or eye gel during these first few days, but I had them to hand in case I needed them.¹⁶

The precautions mentioned in this extract show that a healthy person who does not drink for four days does experience thirst but that this can be bearable. There are indications that thirst diminishes as one gets older. In studies conducted in hospices, experienced nursing staff gave an average score of 8 – 'good' – for the quality of the death of patients who had accelerated the process by STED.¹⁷

The level of consciousness is at first not affected by not drinking, as long as there is no fever-inducing illness and no sedatives are given. About one week after the cessation of fluid intake, the kidneys will no longer be able to remove urea from the blood and drowsiness will set in. This need not be uncomfortable and will not interfere with contact with relatives.

Summary of the main methods and products used in mouth care:

There are four types of remedy, all of which are equally important. They can be made up by nursing staff or bought in a pharmacy.

1. The mouth can be refreshed with:
 - crushed ice wrapped in a piece of gauze, which can be sucked;
 - a sugar-free ice lolly;
 - water in a small vaporizer or plant spray;
 - lemon swab sticks are available without prescription (lemon juice can, however, be painful on broken skin and may cause irritation).

To counteract bad breath, there are mint-fragrance oral sprays (3 puffs sprayed on the tongue 2-3 times a day).

2. Saliva-stimulating products:
 - sugar-free chewing gum,.
3. Saliva substitutes. These prevent dehydration of the mucous membranes of the mouth for several hours. This is extremely important during sleep. They are supplied as a spray or a gel. These products are available without a prescription; preference for one or the other will vary from person to person.

In patients who breathe through their mouth, the mouth may dehydrate in spite of these precautions. It may help to hang a humidifier (an apparatus that produces steam) above the bed near to the mouth.

4. Cleansing of the mouth to prevent fungal infection, 2-3 times a day with a denta-swabstick (not impregnated) or a piece of gauze dipped in an alcohol-free chlorhexidine solution or in a physiological salt solution. This is rubbed 2-3 times daily over the tongue and on the inside and outside of the gums in order to clean away any deposits.

Instead of a physiological salt solution, one could also use a mixture of lukewarm boiled water with half a teaspoon of cooking salt or with camomile tea. This is refreshing if the mouth feels sticky.

Do not forget: after cleansing the mouth, lips should be kept in good condition by applying Vaseline to prevent chaps.

The use of an extra soft (children's) toothbrush is recommended.

Apart from mouth care there are other important measures to prevent discomfort during the process of STED. For instance, dentures may cause irritation because after a few days there will be no saliva. These should not, therefore, be worn unless the patient feels it is important to do so. When visitors come the dentures can be put in with a saliva substitute for the sake of appearance and comprehensible speech.

Another example of an important preparatory measure is to ensure that the colon is cleared by using a mild laxative when someone starts with STED. If this is forgotten, there may be problems after a week or so because the large intestine will fill up with food remnants from the time when the patient was still eating. By then the person will be too weak to be able to strain effectively. An obstipated rectum is known to facilitate a confused and anxious state of mind ('delirium') which is a very negative experience for all concerned. This confusion will seriously disrupt contact with loved ones in the last days of life.

For a dignified death by stopping all food and fluid intake it is indispensable to collect information and materials for mouth care beforehand. In the Dutch study on STED that has just been reported, one in five persons who died by STED had received information from their GP and one in ten from a member of an association for a dignified death. In other cases it had to be collected once the decision to start with STED had been taken. Almost half of the deceased had neither asked nor received any information beforehand on how they could make the dying process bearable. This omission had been stressful for all involved.

As mentioned before (section 2.4), when asked about their experiences, the relatives and other informants reported that death had been dignified in 74% of all cases. This contrasts with the negative description ('degrading') which one sometimes reads in respect of someone who died 'from thirst' or 'from starvation and dehydration.' This negative image created or reinforced by emotive language¹⁸ is one-sided and misleading because simple provisions for mouth care had not been taken. The degrading course of events in the case of Mrs G (Chapter 1.2) was caused by the fact that neither she nor her family had the faintest idea of how they could make the process bearable. Her GP had failed to provide information and adequate palliative care.

2.7

Advance statement

If someone stops all food and fluids in order to die but has not reached agreement with the treating physician regarding this option of last resort, he or she should draw up an advance statement which meets the legal requirements of the country in question. One should also appoint a legal representative who can take decisions regarding treatment on behalf of the person if he/she is no longer competent. This representative will ensure that the directive refusing artificial feeding and a hospital admission is respected. The General Medical Council states in section 13 (see Appendix):

Adult patients who have the capacity to make their own decision [about refusal of treatments] can express their wishes about future treatment in an advance statement.

For an elderly person who has no children or other trusted person to act on his or her behalf, it may be hard to find a representative but it is an essential precaution. In the Netherlands there have been cases in which a GP, sometimes a psychiatrist, has threatened to declare as incompetent an elderly person who has not been eating and drinking for some days to hasten death. The consequence of a physician's judgement that someone is 'incompetent' may be that the person will be taken against his or her will into a hospital where artificial nutrition and hydration might be administered to prevent death.¹⁹

2.8

Refusal of food and drink and the provision of adequate palliative care

The elderly and the sick usually take more than one form of medication. A competent patient may ask for information from the attending physician regarding whether death can be hastened by stopping a particular medication. Now and then a patient who has taken a well-considered end-of-life decision may take the initiative to stop all medication in the hope that death will come sooner. In the case of some types of medication, such as insulin, diuretics and others, this may cause unnecessary problems. It is much better, therefore, to stop taking medication only af-

ter consultation with the doctor. According to the General Medical Council, doctors are legally bound to respect the decision of a competent adult patient to refuse treatment "... even where refusal may result in harm to themselves or in their own death." (section 13, see Appendix). If someone has taken the precautionary measures discussed in sections 2.6 and 2.7 and stops eating and drinking attended by relatives who have (a) understood the reasons for this decision and (b) agreed to do all they can to ease this final journey, then palliative care provided by a doctor becomes important. The General Medical Council has not, to my knowledge, written guidelines for ethical conduct in such a situation. However, sections 42 and 43 of the "Guidance for doctors 'Withholding and withdrawing life-prolonging treatments'" (Appendix 2) seem relevant in the absence of a statement on self-denial of food and drink:

'Where the possibility of withholding or withdrawing a life-prolonging treatment is an option, you should offer the patient the opportunity to discuss how their care would be managed if such a decision were made. This should include:

- arrangements for providing nursing care and other appropriate treatments
- the patient's preferences about who should be involved in decision making or in providing additional support if they become incapacitated
- what might be their palliative or terminal care needs should death become inevitable and how these would be met.'

A doctor may have conscientious objections to providing palliative care in a specific case. Section 28 may also be relevant in a case of STED:

'... doctors who have a conscientious objection to the decision (to withhold or withdraw life-prolonging treatment) may withdraw from the care for the patient. In doing so they must ensure, without delay, that arrangements have been made for another suitably qualified colleague to take over their role, so that the patient's care does not suffer.'

To a someone who has made the difficult decision to hasten death these quotes may sound impersonal and rather official. In practice it is important to have reached, in the course of many conversations, a good mutual understanding with one's doctor about why the wish to die has

become so urgent that one is prepared to take responsibility for this hard STED-option of last resort. If a doctor understands, though not necessarily agrees with, the reasons for STED, mutual respect will guide the interactions once all fluid intake has stopped. Equally important is that the doctor feels confident that, in providing palliative care, he stays within the limits of the law and of professional ethical conduct.

It is hard to see how adequate and proportional palliative care in such a situation can be regarded as an illegal act. Experts agree that palliative care does not shorten life if carried out with expertise. Many doctors are prepared to provide palliative care out of compassion once they understand why death is the only acceptable option that remains for a particular individual.

My research only pertained to Dutch patients who had died by STED, therefore no conclusions regarding other countries can be drawn. About 60% had received a prescription to alleviate symptoms that had occurred: sleeplessness, anxiety, pain, confusion, or extreme discomfort. Some doctors had prescribed analgesics (e.g. paracetamol 6 times 1000 mg per day or Diclofenac 50 mg suppository 3 times a day); others provided a benzodiazepine for the night (e.g. temazepam 20 mg or in some cases 40 mg). If consciousness had become confused accompanied by restlessness and/or anxiousness, a low dose of an antipsychotic (e.g. Hal-dol or Nozinan) had been prescribed.

Morphine was given in approximately 40% of cases, especially if someone had a diagnosis of cancer though not necessarily in an advanced stage. In two cases where the patient was a retired doctor himself who had chosen, for religious reasons, a death by STED, they had prescribed for themselves 2 times 10 mg morphine by mouth right from the start of STED. This was not because of pain but to induce a state of comfort. Both doctor-patients remained comfortable on *the same dose* until they lost consciousness and died on day 13 respectively day 15. When it became impossible to swallow the tablets during the final days, the same dose of morphine was administered by subcutaneous injection by the children. In the case of Mr R (Chapter 1.3) the discomfort caused by not drinking became serious on day 6. By then the doctor had become convinced that Mr R was determined to die by STED. He decided to palliate the discomfort on day 6 with Midazolam (4 times 10 mg per day subcutaneous) which was increased on day 8 (to 4 times 15 mg). He then added mor-

phine (6 times 10 mg subcutaneous) on day 9. These examples are not meant as recommended medications as any doctor trained in palliative care has his own clinical judgement that is determined by specific circumstances. The foregoing is only meant to illustrate a few examples of what has been prescribed by doctors who wished to remain within the boundaries of the law and to report on the modest dose of morphine they sometimes permit themselves while not drinking.

It should be mentioned for laypeople that morphine can have a disadvantage in a patient who has drunk virtually nothing for a few days. The dose of morphine quickly becomes too high because kidney excretion is reduced. Morphine not infrequently induces a state of confusion accompanied by hallucinations. This makes contact with loved ones impossible, which ruins the chance of a dignified and conscious parting. In cases where the patient is confused, doctors sometimes tend to think that dehydration is the cause of the confusion, rather than morphine. Instead of reducing the dose of morphine, or stopping it altogether, they occasionally increase the morphine or add a benzodiazepine (e.g. midazolam) which causes drowsiness. Some experts in palliative care see this as a mistake.²⁰ Adding midazolam to the morphine will have the effect of reducing the level of consciousness rather than raising it. It is the family carers or nursing staff who have to make the doctor aware of this, as the patient can no longer do so him/herself because of the confused state. A visit by a palliative care consultant may be required and the family can insist on this. A consultant may recommend that the morphine be stopped or the dose reduced and may recommend a low dose of an anti-psychotic to counteract the confusion.

The idea of the foregoing is not to delve deeper into the various types of palliative medication at this point but to illustrate that for the STED process to be as favourable as possible, it requires preparation on the part of the individual and expertise on the part of the physician. Doctors still know too little about a self-directed death by voluntary refusal of fluids because not enough attention is devoted to it in the training and retraining of GPs in terminal care. In Dutch authoritative sources of reference about palliative care, a deliberately hastened death by STED is not usually mentioned at all.

Some cases have been reported in which the physician refused to provide adequate palliative care (see Chapter 1.2 Mrs G). A hastened death

by STED is still feasible without a doctor's supervision, but advice and support from an experienced palliative care nurse will in that case be indispensable.

2.9

Summary of measures to make the STED process bearable

This chapter has been written for both physicians and patients in the hope that they will be able to communicate better about abstaining from food and drink as a last resort option to end life. The process can be favourably influenced but hardly any research has been done to find out what the determinants are. The first two examples in Chapter 1 show that there is a world of difference between the last days of Mrs B's life (a dignified death) and those of Mrs G (an undignified death). Both were surrounded by family members and nurses, but the doctor in each case played a very different role. Mrs B received hardly any palliative medication but it was a positive experience nevertheless. The patient-doctor relationship in the case of Mrs G had turned into a power struggle which had a negative effect on the quality of the nursing. In this concluding section, we will set out the measures that play a role in making a death by STED tolerable.

1. Preparing mentally for the definitive passage from life

In order for the process of STED to run smoothly, the inner acceptance of death is the most important factor. The beliefs of the individual who is going to die will determine the form that this mental preparation for death will take. This book focuses on the hows of a self-directed and dignified death and does not, therefore, go into more detail in terms of the mental preparation.

2. Acceptance by relatives and physician of the decision to die by STED

Even if someone is able to accept his or her own death as inevitable, a child or a doctor may not yet be able to do so. This may lead to conflict on whether and how to implement the decision to die. The example of Mrs G shows how conflict with the doctor can make the process difficult. She thought she would be able to persuade him to help her by showing that she really was determined to die, but he felt as if she was black-

mailing him and he dug his heels in. If there had still been a basis for trust, the doctor could have explained to her that the assistance in dying she had requested was beyond his moral boundaries. If he had made this open to discussion, he might have been able to reassure her that he could support her if she wished to end her life by abstaining from eating and drinking. In conflicts like this, it is extremely important that a doctor initiates a family discussion to seek a way out together. If the doctor is part of the conflict, an independent mediator will be required.

3. *The difference between starvation and dehydration*

There is much evidence to suggest that when someone stops eating, the feeling of hunger often disappears in 2-4 days, provided the person drinks water only. As soon as small amounts of carbohydrates are ingested, for example the sugar contained in soft drinks or chewing gum, the body responds by secreting insulin and the feeling of hunger may return.

When someone stops drinking, the best strategy is less obvious. To stop drinking altogether is extremely difficult. Informants have reported that a gradual reduction of fluid intake is often more bearable. For example, the usual 2 litres of fluid per day can be consistently halved: one litre the first day, then half a litre on day 2, quarter of a litre on day 3, and so on. On the sixth day, the patient would already be drinking less than 50cc of water, which is the equivalent of half a glass. The patient could then maintain this level or stop altogether. It is also possible to reduce fluid intake 'by feel', as in the case of Mrs B, who died after three weeks.

4. *Mouth care*

Of all the practical measures to make the STED process more bearable, mouth care is the most important. Section 2.6 gives detailed measures how to prevent the dehydration of the mouth. What works well for one person may not be appreciated by another. For instance, crushed ice wrapped in gauze that can be sucked is found by many to be soothing, but others will not allow themselves that comfort. A hand-held atomizer filled with water provides relief. The amount of water ingested per day by someone using an atomizer (± 2 cc in three puffs) and occasionally sucking half a crushed ice cube (± 5 cc) is negligible (total preferably

less than 50 cc per day). It may sometimes be possible to hang a humidifier above someone's face to keep the air moist. A palliative nurse can advise on the various possibilities. If that expertise is not available, the person in question should, with the help of others, experiment *beforehand* to find out what works and what does not. Because once dehydration of the mucous membranes has caused ulcers and sores in the mouth, it will be impossible to get rid of these at a later stage in the process.

5. *clearing the bowel*

Shortly before STED is started or during the first two days, it is a good idea to ensure that the colon has been emptied. If this is overlooked, there may be problems after a week because of a large intestine that contains food remnants from the time when the person was still eating. After a week of fasting, one may have become too weak to be able to strain effectively. An obstipated rectum is known to cause some persons to become confused (delirium) which may disrupt contact with loved ones.

6. *Alleviating medication*

Morphine may offer comfort but it may also cause the patient to become confused. If this happens, it should be discontinued or the dose diminished. If this is not possible because of the pain from cancer, a palliative expert should be consulted. A recognised phenomenon in palliative care is that the patient complains of pain less if he/she is able to manage it by adjusting the level and timing of the dose him/herself. Mrs B's GP used this approach by leaving a few sleeping tablets and some tranquilisers with Mrs B at the beginning of her STED process, medication which Mrs B used only sparingly.

Not all physicians are willing to do this, certainly if they still doubt whether the person really wants to die. Some doctors do not provide alleviating medication in the early stages because they believe that a patient needs to show that he/she is serious by withstanding the initial phase of not taking any food or drink without the benefit of alleviating medication. This approach may be caused by a lack of mutual trust. Some patients who have died by STED had saved some sleeping tablets or other alleviating medication beforehand in case the doctor refused to prescribe these later on. This indeed meant that conflict with the doctor could be avoided, but did nothing to improve the basis of trust.

7. *Other practical measures*

A special mattress to prevent pressure sores is extremely important and can provide great comfort during the many hours spent on it by patients too weak to get out of bed. If a patient is at home, mattresses like this can be hired from a home-nursing association.

A catheter will not be required as long as the patient can still get out of bed to go to the toilet. Once he/she has become too weak to do so, the use of a urinary catheter is recommended in order to minimise the discomfort caused by changing. Others feel that a good incontinence pad is less uncomfortable than a catheter, certainly in view of the fact that the amount of urine produced will decrease as time goes on. There is one exception to this rule: some patients may suddenly produce a large amount of dark urine about 10-14 days after the start of STED. This is a sign that, because of the lack of nutrients, muscular tissue cells have been broken down, whereby water that was contained *inside of the cells* suddenly enters the blood and is excreted by the kidneys. It is a sign that the dying process has become irreversible.

This summary can never be comprehensive. Daily visits by a doctor and advice from an experienced palliative nurse can be of great comfort to the patient and the family. Their advice can help to ensure that the feeling of thirst remains bearable and that the dying person, who dozes or sleeps many hours, may have conscious moments now and then for as long as possible.

2.10

Notes for a hastened death by STED at home

Necessary preparations:

1. The patient's wish to die by STED should be set out in a signed and dated letter to the doctor. This will contain instructions not to administer any life-prolonging treatment or rehydration and not to allow admission to a hospital.
2. A representative must be appointed and given a copy of this advance statement.
3. Arrangements need to be made with the doctor in respect of his/her visits and availability.
4. Contact should be made with a district nurse, trained in palliative care, who usually will have been informed of the situation by the doctor.
5. The local organisation for home-care will have to be notified of the decision to hasten death and to inform the carers who will be visiting the house.
6. There should be an anti-decubitus mattress for comfort and to prevent pressure sores (decubitus). This can be hired through a local organisation (e.g. in England the Red Cross), as can other items (urinal, etc) which might be required by the carers.
7. There should be a journal in which all arrangements and details are recorded on a daily basis.
8. The products required for mouth care should be available in the home (see section 2.5).
9. The bowel should be cleared with a laxative shortly before fasting starts.

After the patient stops drinking:

10. The carers (family or other trusted persons who have undertaken to provide some of the care) should receive instructions from the district nurse on how to perform mouth care.
11. The doctor may advise on a daily basis about alleviating medication in the case of distressing symptoms (anxiety, agitation, breathing difficulties, and so on).
12. The carers should know who to call in the event of unexpected symptoms.
13. The wishes of the individual should be accommodated as much as possible and all efforts should be directed at making him/her as comfortable as possible.

Footnotes

1. Quill 2000, Brock 2004, Warnock 2008
2. General Medical Council 2002 Withholding and withdrawing life-prolonging treatments.
3. *Vacco v Quill*, 117 S.Ct. 2293 (1997); *Washington v. Glucksberg*, 117 S.Ct. 2258 (1997).
4. The Royal Dutch Medical Association (2005) has published guidelines for terminal sedation.
5. Quill and Battin 2004
6. Ganzini 2003
7. Bilimoria 1992; Madan 1992; Justice 1995.
8. For a discussion of the law regarding physician-assisted dying in these countries, see Griffiths 'Euthanasia and Law in Europe' 2008.
9. For a discussion of the law in England and Wales regarding physician-assisted dying, I refer to the chapter by Penney Lewis in Griffiths 2008. The present book is not written to discuss the law but to improve communication between lay people and their treating physician assisted by the General Medical Council guidelines.
10. Full quotes in appendix 2.
11. B.E. Chabot PhD in medical sociology (in Dutch), University of Amsterdam 2007. For the sake of readability, constant references to this study will be avoided. Methodological and statistical assistance was provided by methodologist and statistician professor Harm 't Hart PhD, mathematician Arnold Goedhart PhD and by the Government organisation *Statistics Netherlands*.
12. A detailed description of definitions, screening procedure, the questionnaire, statistical analysis and the frequency estimation of the prevalence of *STED* in the Dutch population is given in Chabot 2007.
13. Chabot 2007, Chapter 6
14. Warnock 2008 p. 23
15. Chabot 2007 pp.33-35
16. Terman 2006
17. Ganzini 2003
18. See Ahronheim and Gasner 1990 in the *Lancet*: 'The sloganism of starvation'
19. Chabot 2007 gives two examples of this 'warning' by Dutch psychiatrists. The threat of artificial nutrition proved legally untenable after the involvement of a lawyer, who took out an injunction. The psychiatrist then accepted the refusal of artificial nutrition. Patients and their families are usually not aware of this kind of legal procedure.
20. Verbal information (autumn 2006) from Wouter Zuurmond, professor of palliative care, Free University, and from nursing-home physician Siebe Swart, Erasmus University.

CHAPTER 3

Some research findings: subjective experiences and changes in metabolism

Laypeople may find this chapter difficult to read. I have, therefore, tried to summarise for them the main relevant findings at the end of each section.

3.1

Changes in metabolism during strict fasting

I am not aware of any research into changes in the metabolism in individuals who had started to hasten their death by stopping all food and fluid intake. This is hardly surprising, as a conscious decision to stop eating and drinking for the purpose of ending life is by many considered to be a suicide that should be prevented. Thus, the course of events that leads to a hastened death by the voluntary refusal of food and fluids has never been investigated in its own right. Therefore I had to derive the pathophysiological and biochemical aspects which underlie the clinical course of events in STED, from research in other situations.

Much research has been done on metabolic aspects in long-term clinical fasting as a therapy in cases of obesity. Strict fasting for religious reasons (detachment) or on political grounds (hunger strike) have also been studied. The course of events described in section 3.1 is derived from research conducted in these three groups, but particularly in fasting as a therapy for obesity, in which drinking is *not* restricted.¹

Under normal circumstances, the body derives its energy from the combustion of carbohydrates, particularly glucose. In the event of fasting, the metabolism switches from carbohydrates to fats after 24 to 72 hours and body protein will also be broken down eventually. The feeling of hunger disappears after several days, as long as strict fasting is maintained. This is not the case if carbohydrates are still ingested occasionally. For example, any small amount of glucose in soft drinks will disturb the course of events described below.²

During the process of fat combustion, which begins after a few days, the body produces ketones (waste products of fatty acids), which are

thought to have an analgesic effect. This is shown by animal experiments, in which an increased pain threshold was observed when these substances were present. The protein reserves are initially unaffected and the glucose level in the blood remains normal. Only after a period which varied per individual (from a few days to a week) does the glucose level fall and combustion turns increasingly from glucose to free fatty acids from the fat reserves and also to amino acids from reserves in the liver. The brain starts to produce glucose from amino acids (neoglucogenesis).

After approximately one week of fasting, the energy supply switches entirely to ketones. The kidneys thereby have less urea to process. After fasting for a while (the length of time is not certain) the body starts to produce its own endorphins. These are substances which have a morphine-like effect on mood.³ This is the physiological background to the empirical evidence in religious circles that fasting can induce a state of well-being or euphoria. The clarity of consciousness will in principle not be affected, unless there is a febrile illness or unless sedative medication is administered.

Once the fat reserves have been burned, the protein reserves have to be used, starting with the proteins in the muscles, thus causing further weakening. If no fluid is ingested, urine production falls to a minimum, defecation ceases altogether and the secretion of mucous in the respiratory tract is reduced. This often relieves the dying individual since the strength for basic physical actions like coughing or evacuation no longer exists.

The breakdown of protein results in the production of more urea, which can no longer be excreted by the kidneys when no fluids are ingested. As a consequence there is a sharp increase in urea levels in the blood, which causes a pleasant drowsiness. If someone experiences this drowsiness as unpleasant and wishes to maintain lucid periods in which to converse with loved ones, he or she can try to attain this by drinking a small amount, whereby urea would be excreted in the urine. The concentration of urea in the blood will then drop and consciousness may become clear. This does prolong the dying process, but some patients prefer to have lucid moments until shortly before death.

If abstinence from drinking is sustained, ultimately the concentration of sodium and potassium in the blood will change and that is thought to be the eventual cause of death.⁴ The flow of potassium ions through

the membrane of heart cells causes a cardiac arrhythmia (ventricular fibrillation) which causes instant death.

Summary

In strict fasting, the body produces its own substances (ketones, endorphins) which can have an analgesic or mood-lifting effect. After some time urea can no longer be excreted by the kidney's. It is not yet known after how many days the heightened blood level of urea produces drowsiness. Individual variation in changes in metabolism is considerable and therefore the reported experiences may vary in time.

3.2

The experience of limited fluid intake with proper mouth care

The main question in this section is what has been shown by research about the clinical course of events in cases of a severely limited intake of fluid. First, I will look at the few laboratory observations regarding people who were not ill and who stopped drinking completely for a short time. I will then summarise a study in which hospice nurses were interviewed about fatally ill patients who have hastened death by *deliberately* stopping eating and drinking. Lastly, this section will look at clinical observations regarding patients with a fatal illness who *spontaneously* stopped eating and drinking as a result of the development of the illness itself.

The literature discussed in this section was found by means of a Medline search using a number of key words.⁵ I came across one experimental study into clinical dehydration in men who were not ill.⁶ Healthy elderly men (around 70 years of age), who were given nothing to eat or drink for 24 hours in laboratory conditions, were compared in terms of subjective and physiological variables to a group of healthy young men (from 20 to 30 years of age). It transpired that, on average, the older men suffered much less from feelings of thirst and that after 24 hours they were less eager to drink in order to replenish the fluid deficit. This can be explained by the fact that older people have a higher thirst threshold. An American physician, Stanley Terman (age 65), has described an experiment on himself in which he did not take any food for 96 hours and only ingested less than 40cc (one ounce) of fluid per day over the same

period. He had examined in detail the various possibilities for mouth care, all of which he tried during his experiment in order to discover which option was most effective for him. He occasionally administered an analgesic suppository (Diclofenac) 'to control my moderate pain'. On a scale of 0 (not hungry) to 10 (extremely hungry), he never scored higher than a 2. On the same scale for thirst, his highest score was a 5, 'which I considered as quite uncomfortable'. Thanks to several products for mouth care, it was possible to sustain abstinence from drinking: 'Refusing food and fluid is really peaceful [...] partially due to some mild dulling of my mental functioning after a couple of days'. He ascribed this to the ketones which are produced during strict fasting (see section 3.1).

These observations relating to *temporary* dehydration in healthy individuals correspond to the bearable process of *persistent* dehydration until death in the case of an elderly woman who did not have a fatal illness and who stopped eating and drinking to hasten her death (see Chapter 1.1 Mrs B).

How do hospice nurses who had cared for fatally ill patients view the dying process after a conscious decision to refuse food and fluid? Ganzini and co-workers have sent a questionnaire to all (429) experienced hospice nurses in Oregon asking about their most recent experience with a patient who had consciously refused food and drink, with whom they had discussed this decision and whom they had cared for. She obtained information about 126 cases which 307 nurses (non-response 33%) had reported and which satisfied the following definition of refusing food and drink in order to bring about death:⁷

'Voluntary refusal of food and fluids (VRF) describes an action by a patient who voluntarily and deliberately stops all food and fluids with the primary intention of hastening death. This does not include stopping food and fluids for other reasons such as loss of appetite or inability to eat or drink because of disease.'

This definition is almost identical with the one given on p 18. Of these 126 patients, all of whom were in a hospice, 102 died as a result of fasting and dehydration and 16 (13%) had abandoned the attempt, often at the urgent request of family members. In eight cases, it was not known whether the patient had sustained the fasting. The average age of the patients was 74, with slightly more women than men. Life expectancy when

fasting started was estimated at more than one month (47%) or 1-4 weeks (45%). The diagnosis was usually cancer (60%), a neurological illness (23%) or heart disease (16%). The average length of time until death amounted to ten days and 85% died within fifteen days. The patients' reasons for deciding to die by voluntary refusal of food and fluids (as recalled by the nurses) were compared to those of patients in Oregon who had received physician-assisted dying. There were no significant differences between the two groups on any of the answers, with one exception: the *desire to control* the dying process had been greater in cases of physician-assisted dying than among those who had stopped food and fluid intake.

The hospice nurses gave a median score of 8 to the quality of death on a scale of 0 (very bad) to 9 (very good). No research has been conducted among non-respondents (33%). It is, therefore, possible that the responses were made predominantly by nurses who had positive experiences to report. Unfortunately, this study did not report on the palliative medication which could have affected the rating of the quality of death by the nurses. It might be that some of their reports were about patients who had been deeply sedated in the last phase of the VREF process.

Summary

There is some experimental evidence that elderly persons suffer less from thirst than younger persons. There is anecdotal evidence that a healthy elderly person who has stopped all fluid intake, who is thoroughly prepared to apply mouth care and who receives analgesic medicines, experiences only thirst that is 'quite uncomfortable' (i.e. 5 on a scale from 0-10). A study in Oregon questioning hospice nurses about their experiences with patients in the last weeks or months of life who had deliberately hastened death by VREF, rated the quality of death on average as 8 ('good') on a scale from 1-9. About 13 % of the patients who had chosen to die by VREF in a hospice had started drinking again, often urged by the relatives.

3.3

Patients who spontaneously diminished food and fluid intake

Two prospective studies have been reported on cancer patients who were nursed in a hospice and who spontaneously diminished eating and drinking over a period of weeks or months. In the end, they had almost completely stopped eating and drinking.⁸ The patients in these two studies differ from the individuals reported in this book (Chapter 1), who consciously stopped eating and, sometimes a little while later, drinking, with the express intention of hastening their death. However, I think it is helpful to discuss the meticulous study by McCann (1994), which shows that the cessation of drinking can be compatible with the well-being of cancer patients in the last weeks or months of life, provided they receive the best possible mouth care.

McCann investigated the effect of the gradual cessation of eating and drinking on the well-being of terminal patients in a hospice. He collected observations on 32 patients with cancer for which all treatment options had been exhausted and who had a life expectancy of less than three months. Only hospice patients who remained lucid until shortly before death were able to participate in this study, as they had to be asked about feelings of hunger and thirst several times a day. The average age of the patients was 75 (with a range of 44 to 92); the average duration of admittance was 40 days (range 4-99 days). Dietary restrictions were lifted and each patient was given whatever he or she wanted, but they did not have to take it. As much attention as possible was given to mouth care and to the administering of analgesics, although attempts were made to avoid drowsiness. It transpired that of the 32 patients, 20 never felt any hunger, while 11 only felt hungry 'at first'. The feeling of thirst was only experienced in the initial stages by 20 of the 32 patients. In all cases, the feeling of hunger, thirst or a dry mouth could be alleviated by giving a small amount of fluid, such as a crushed half ice cube, or by simply moistening the lips and tongue. The amount of fluid needed to alleviate the thirst was much smaller than the amount that would have been required to prevent dehydration. In approximately one third of cases, the patient continued to experience recurring feelings of thirst, but these were also relieved each time by mouth care. An 'overall comfort' score was calculated. In four of the 32 patients, there was 'some discomfort' during part of the

period; in the case of the others, thanks to intensive care by the treatment team, there was a virtually continuous sense of well-being. These findings were corroborated in a subsequent prospective study of a similar group of patients.⁹

Surprisingly, hardly any research has been done into what is the determining factor for feelings of thirst in severely ill patients might be. The studies referred to above relate to cancer patients for whom it is normal to stop eating. Fluid intake is also often reduced from the usual 1.5 litres a day to less than 0.5 litre. Some doctors believe that the concentration of sodium in the blood determines sensations of thirst.¹⁰ They maintain that, if the sodium concentration in the blood is neither too high nor too low, which is called 'isotonic dehydration', the thirst sensation might not be caused by too much or too little sodium, but purely and simply by the dehydration of the mucous membranes of the mouth. Blood tests on hospice patients with terminal dehydration have shown, however, that even if the sodium level in the blood is too high or too low, the patient will not necessarily feel thirsty.¹¹ It is possible but not confirmed that in a terminal patient a number of other factors might be at play that determine the reduced thirst sensation because of the underlying pathological processes.¹²

Finally and for completeness sake, I should mention that studies have been conducted into whether the well-being of terminal patients can be improved by artificial hydration. The prevailing conclusion in the literature is that this is generally not the case.¹³ Although this is of little relevance to people who no longer want to eat or drink in order to hasten their death, I submit the conclusion of the article by Peppersack, who is more explicit than others:

'Artificial nutrition and hydration of terminal patients is a futile treatment which does not benefit well-being but which can cause complications. Cessation thereof can improve the sense of comfort. Artificial nutrition of terminal patients is neither medically nor ethically justifiable.'

Summary

In cancer patients who have spontaneously and gradually diminished eating and drinking in a hospice, comfort could be maintained in almost all cases by giving the small amount of fluid that is contained in half a crushed ice cube (about 5 cc), or by moistening the lips and tongue with three puffs from a vaporizer (less than 2 cc). The opinion of some clinicians that the sensation of thirst is largely determined by an abnormal sodium concentration in the blood has not been confirmed by clinical research in terminal patients. The available evidence suggests that the thirst sensation in seriously ill and in elderly persons who have stopped eating and drinking is predominantly caused by the mucous membranes of the mouth that have become desiccated.

Footnotes

1. Cahill 1970, Kerndt 1982, Hamm 1985.
2. Sullivan 1993
3. Kerndt 1982, Owen 1983, Hamm 1985.
4. Oral information from Prof P.A.M. van Leeuwen, Free University Amsterdam.
5. Last Ovid Medline Search in October 2006 using as key words: voluntary starvation, voluntary refusal of food and fluid/drink, dehydration & end-of-life, voluntary starvation & quality of life, dehydration & terminal care, fasting-to-death & right to die, hastened death & treatment refusal, (conscious) starvation & terminally ill. Using Ganzini 2003, a forward search was done. Only a small proportion of the references found is mentioned in this chapter.
6. Phillips 1984
7. Ganzini 2003, see also Andrews 1989 and Harvath 2006.
8. McCann 1994, Vullo-Navich 1998.
9. Vullo-Navich 1998, see also Huang 2000.
10. Billings 1985.
11. Vullo-Navich 1998.
12. Since the eighties there has been an increasing flow of publications by clinicians on dying while food and fluid intake had been diminished or stopped. Often quoted are for instance Billings 1985, Printz 1992, Bernat 1993 and Sutcliffe 1994. Docker 2007 mentions many of the early publications on fasting to death. These early studies pertained mostly to dying from dehydration in terminal cancer patients who had spontaneously diminished food and fluid intake. Terman 2006 has discussed death by dehydration in more or less demented, incompetent patients with an advance directive that prohibits artificial nutrition and hydration. Most of these studies do not clearly distinguish between (a) deliberately hastening death by stopping eating and drinking following a decision by a competent adult and (b) a death caused to a greater or lesser extent by dehydration *as part of an illness without a conscious decision* to die. Therefore these studies are of limited relevance to the experiences reported in this chapter of a hastened death after self-denial of food and drink.
13. Pepersack 2003, Viola 1997, Cassarett 2005, Ganzini 2006.

CHAPTER 4

Ethical issues for physicians and their patients related to STED

In most countries, physician-assisted dying (PAD) by oral medication is not a legal option. Many patients facing death because of illness and/or high advanced age give serious thought to other options of last resort in which the final decision to die would be their own. However, they do not want to inflict upon themselves or their relatives one of the mutilating methods like hanging or jumping. A lethal cocktail of medication that effectively causes death during sleep is difficult to collect and requires timely preparations. Most patients, therefore, give up trying to manage their own death.

Those individuals who are brave enough to ask for a physician-assisted death usually understand that this is really asking too much in view of the prevailing law, under which their physician risks a jail sentence. A few persistent individuals ask their doctor for other options of last resort, for instance information on decisions to refuse or withdraw further treatment that may hasten their death. Although most patients who suffer from a lethal illness realise that stopping eating and drinking will bring about death within 2-3 weeks, they fear an inhumane death. Rightly so, because without the mental support from relatives, detailed information on mouth care and without basic palliative care, it may indeed become a horrible death (see Mrs G, Chapter 1.2). Neither patients nor most doctors know how to turn this method for hastening death into a humane farewell. Since the discoveries made by doctors trained in palliative care to soften suffering without taking consciousness away, determined individuals like Mrs B and Mr R are able to attain a humane death with the compassionate support of their doctor who remains *within the limits of the law and of the ethical code of conduct*.

I will first deal with the issue whether a physician is allowed to give adequate information about hastening one's own death by refusing all food and fluids. I will then ask whether or not a doctor is allowed to provide palliative care to a competent adult patient who has chosen to has-

ten death by this option of last resort.

Physicians have a duty to provide information, even in respect of decisions which they themselves consider unwise. Consider the request of an elderly female patient with cancer who has undergone a round of radiation and chemotherapy and who puts this question to her GP:

'Will you help me to die a humane death at home by giving me information and palliative care if I refuse to have a second chemo/radiotherapy? My oncologist thinks it would be very unwise to refuse because the treatment would give me a about 20 % chance of complete recovery. If I don't have a second chemo- or radiotherapy, life will be over soon. More than dying soon, I fear the return of the miserable consequences of further chemo- or radiotherapy with an 80% chance of death. I'd rather have another two months in my present reasonable condition and then I am prepared to die.'

There is a consensus that a physician should assist a patient with cancer to arrive at a decision "regarding the overall acceptability of any treatment" (GMC code section 13 quoted in the Appendix). The patient's views about her quality of remaining life are essential for the decision to accept or refuse further treatment.

Let us suppose that our imaginary patient, fully informed, decides to refuse the operation referred to above. Three months later her tumour causes serious symptoms. The patient who has gone against the oncologist's advice while fully aware that she will thereby shorten her life by months or years, has not forfeited her right to palliative care. She now asks her GP how she might take responsibility to hasten her own death in a humane way. There is growing consensus in medical-ethical opinion that the doctor should provide information about all the available *legal* options that remain. Under the circumstances (a life-expectancy of at most a few months), a physician who gives the patient information on a hastened death by abstaining from food and drink as an option of last resort, fully remains within the limits of the law. Alternatively, he may refer the patient to the information contained in this book.

So far about information on hastening death by *STED*. What might be the doctor's position regarding adequate palliative care? *Adequate* palliative care after a patient has initiated self-denial of food and drink with

proper mouth care, usually involves sleeping tablets for the night right from the start; if bouts of panic arise a mild sedative may well be indicated; in case of pain analgesics might be prescribed, perhaps also morphine depending on the symptoms caused by the progressing illness (for more details see Chapter 2.6 on mouth care and 2.7 on palliative support).

Let us assume that our imaginary patient returns with her two children to the doctor who had referred her to the information on STED as an option of last resort. She says she has read it and discussed it with her children who appear to support her decision and are willing to take care of her. She now presents a written advance statement in which she refuses any artificial nutrition and hydration once she has stopped eating and drinking to hasten her death. This time her question is:

'In view of the quickly diminishing quality of my life, I have planned to hasten my death by not eating and drinking next week. My children will take care of me at home. I very much hope you will be willing to provide adequate palliative care.'

She may perhaps refer to the General Medical Council guidelines, sections 42 and 43 (see Appendix).

The doctor might at this stage express a fundamental objection to any form of cooperation with a patient who has started on a course that will hasten her death with some weeks. Section 28 of the GMC guidelines state:

'...doctors who have a conscientious objection to the decision (of a competent adult patient to withhold life-prolonging treatment) may withdraw from the care for the patient. In doing so they must ensure, without delay, that arrangements have been made for another suitably qualified colleague to take over their role, so that the patient's care does not suffer.'

The physician may, alternatively, refer a patient to a community palliative care team or he may decide to seek supervision from a colleague who is experienced in palliative care.

If the doctor consents to provide adequate palliative care, it would be reasonable if he could be explicit about his moral boundaries. For instance,

to prevent any misunderstanding about what he means by 'adequate palliative care' after she has started with STED, he might state that, in his opinion, there will be no indication for palliative sedation (i.e. continuous sleep until death), *unless* a symptom (e.g. a delirium) occurs that cannot be treated by other, less radical measures. Of course, in some cases there may arise a medical indication for subcutaneous injections of a benzodiazepine to induce temporary sleep or for a low dose of an antipsychotic to counteract confusion and restlessness. In a dose that is *proportional to the symptoms* – not too much but neither too little – these medicines carry no risk of hastening death.

Summary

A physician may provide detailed information to a severely ill patient about how the dying process by STED can remain peaceful and tolerable, though he should warn that, after some days it may become severe. If it becomes too severe for the patient, he/she may drink some water and perhaps then resume the STED process. Taking one step back and then start anew, sometimes is the best strategy to attain one's goal. A doctor may provide the relatives and nursing staff with information on the best possible care, on what pitfalls are to be expected and how these can be overcome. By giving information to all involved, by supporting those who care, by providing adequate palliative care, and by being available if something unexpected happens, a doctor remains entirely within the parameters of the law. The same applies to all who are involved in caring for the patient.

Epilogue

Dying by STED: the 'Cinderella' of end-of-life research

For many years, the sloganism of starvation has hampered any meaningful discussion about a hastened death by self-denial of food and drink. Only after the Oregon 'Death with Dignity Act' in 1997 did clinicians and researchers start to distinguish carefully between on the one hand deliberately hastening death by STED following a decision by a competent adult and, on the other hand, a death caused to a greater or lesser extent by dehydration as part of an illness without any conscious decision to that effect having been taken beforehand. However, no systematic day-to-day observations have been collected at home yet in a significant number of cases of STED. Following a death by self-denial of food and drink, the following information is rarely available:

- a. The duration until death from the moment that less than the content of an English teacup (about 200 cc) was used for mouth care or to alleviate thirst;
- b. The quantity of water used for mouth care and/or drunk each day;
- c. The complications that arose and in what phase of the dying process they occurred (e.g. fear, agitation, delirium);
- d. The kind of medication and the dose used to aid sleep and to counteract fear, pain or discomfort;
- e. The quality of death as judged afterwards by a family member who had cared for the deceased, a nurse and/or the doctor. That judgement should be given during private conversations with an independent interviewer and only after the funeral or cremation, once there has been time to take a step back from what has happened.

In the case of the three individuals discussed in Chapter 1, some of this information is available, but not all. These cases (details were provided about Mrs G and Mr R by day-to-day reports) show the importance of information about these aspects to assess what made the dying process more or less dignified. The proponents of STED often refer to the death of the 85-year-old mother of Professor David Eddy. She died 'a gentle death' on the sixth day of abstinence from eating and drinking, after her doc-

tor had prescribed 'adequate medication to control discomfort'. Derek Humphry commented on this case in his chapter on self-starvation:

"David Eddy supervised his mother's end, ensuring that she had enough morphine patches to control the pain of starvation. Doctors listen to doctors, especially one of Dr. Eddy's eminence, and this was Mrs. Eddy's good fortune."

Though Humphry demonstrates sloganism by his use of 'self-starvation', he makes the valid point that no information on medication is given, while Dr Eddy claimed that his mother died 'a gentle death' by stopping food and drink. Most probably it was a gentle death thanks to morphine. In my research I came across a few examples of STED in which elderly or very ill doctors had palliated themselves, or a close relative, with even more care than their patients.

Until 2008, death by STED was not discussed in medical training in the Netherlands. These days general practitioners begin to realise that this deliberate death occurs on average once every 3-5 years in their practice, either with their knowledge or behind their back supported by a palliative nurse. Many Dutch doctors have not yet made up their mind how to deal with a request for information about STED or with a request for palliative support once STED is in progress. I suspect that in other western countries too, doctors learn little about how to support the STED process by a competent adult. I am not aware of any reference work about palliative care which devotes more than a single paragraph to this subject. Dying by STED is the 'Cinderella' of end-of-life teaching and research.

No prospective study has yet been done by researchers into the course of a hastened death after stopping all food and fluids. The research by McCann in 1994 (see Chapter 3.3) was one of exceptional quality. But it was conducted in respect of terminal, competent hospice patients in the last stage of life, in which the intake of food and fluids diminished spontaneously and *not* with the intention of hastening death. What is needed is to collect information about the course of STED, in particular when it occurs at home, at the same level as McCann. In the home setting, STED sometimes takes place with palliative care by the GP, but in the Netherlands it also occurs without a doctor's support. This last course of events

has become possible on the basis of information about a hastened death by STED, published for the general public in a Dutch book by the *Foundation for scientific research into a humane self-chosen death*. That information is comparable to what is discussed in this book.

Dan Brock (2004) and Warnock & Macdonald (2008) have recently summed up five disadvantages of STED as a last-resort option to end life. I will use their formulations in a slightly condensed form:

1. It may last for weeks and increase suffering from hunger and thirst.
2. It may place intolerable anguish on the family and professional careers.
3. It may provoke subtle coercion to proceed if no drink is offered; yet such offers may be viewed as undermining the patient's resolve.
4. The decision to forgo eating and drinking may not be informed and cases of treatable depression may be missed.
5. Patients are likely to lose mental clarity toward the end, which raises questions about whether the action remains voluntary.

All this might indeed occur if the information that is provided in this book has not been collected beforehand. Especially so, because the treating physician often does not know how to respond to the request to receive adequate palliative care that remains completely within the limits of the law. I know of no other end-of-life situation where *deficiencies in medical training* are shifted from doctors and presented as *deficiencies of the method of last resort* to hasten a dignified death. Regarding the first disadvantage, hunger is not a problem for anyone who is aware that taking a zero caloric diet will take away feelings of hunger after 2-4 days and in many persons will induce a state of well-being (Chapter 3.1). This is only partly true for thirst sensations in elderly and/or very ill patients. However, the research by Ganzini (Chapter 3.2) shows that the experiences of hospice nurses who rated the dying process by STED on average as 'good', do not conform with the increase in suffering from hunger and thirst that is stressed by the authors above. Take disadvantage 4: the decision to start STED may not be well informed and a treatable depression may be missed. It's curious to read that Brock does not consider this an insurmountable problem in case of a request for physician-assisted dying, while he suggests that it is a serious risk in STED cases. Ten years ago Sullivan, Ganzini and Youngner have argued convincingly that psy-

chiatrists should not 'serve as gatekeepers for physician-assisted suicide' though, surely, some cases of treatable depression will be missed. Their arguments are not only relevant for physician-assisted dying but apply even more forcefully to hastening death by refraining from all food and drink. Lastly, to counter the fifth 'disadvantage' of stopping eating and drinking: why should questions be raised about whether the action remains voluntary once a patient has lost mental clarity, *if* that patient has written an advance statement? A person who forgets to do that brings trouble to him/herself and to all others involved. According to GMC guidelines, it would be inappropriate, if not illegal, to raise questions if there is an advance statement available.

An epilogue is not the place to discuss all the foregoing disadvantages of STED. Some of them are more immediately relevant than others. Of course, 'patients are likely to lose mental clarity toward the end', just as most patients dying in a hospital bed will. A very serious problem in my opinion is a delirium after some days of not drinking because that is sometimes difficult to take away with the proper low dose of an anti-psychotic. However, we have no idea how often a delirium occurs in a STED process that is properly attended. It might well be provoked by morphine given in a state of relative dehydration. No efforts have been directed to teach relatives and other carers to recognise an early stage of a delirium and to alert the doctor immediately. In my opinion, the lack of proper research and the deficient training of doctors should be blamed for most of the disadvantages listed above, *not* automatically the method.

From the data that have been presented in Chapter 3 on changes in metabolism and from the few clinical- and hospice research data currently available, it is evident that the STED option of last resort holds some modest promise for the future: it might well be a dying process that can be managed by patients with their relatives and with adequate palliative care. *If only* researchers, clinicians and university teachers of palliative care would give serious attention to this option of last resort. Self-denial of food and fluids at the end of life is an option that is available to competent individuals who have a few dedicated carers around them. They may be able to convince a compassionate doctor that nothing illegal would be done if he were to provide adequate palliative care during some difficult phases in the process.

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Appendix 1

How this book can be ordered

This book can be ordered from the Glasgow-based organisation Friends At The End (FATE).

It costs € 15,- (postal costs not included).

For members of FATE it costs 12,50 euro (postal costs not included).

Ordering mail address: info@friends-at-the-end.org.uk

In case of comments regarding the contents of this book, one may send these to the mail address above. Please add: "forward to Dr. Chabot"

Appendix 2

General Medical Council (2002).

Withholding and withdrawing life-prolonging treatments.

Good practice in decision making.

Section 13 page 8:

Adult competent patients have the right to decide how much weight to attach to the benefits, burdens, risks and the overall acceptability of any treatment. They have the right to refuse treatment even where refusal may result in harm to themselves or in their own death, and doctors are legally bound to respect their decision. Adult patients who have the capacity to make their own decision can express their wishes about future treatment in an advance statement.

Section 14, page 9:

Any valid refusal of treatment – one made when the patient was competent and on the basis of adequate information about the implications of his choice – is legally binding and must be respected where it is clearly applicable to the patient's present circumstances and where there is no reason to believe that the patient had changed his mind.

Section 28, page 15

Where a decision to withhold or withdraw life-prolonging treatment has been made by a competent adult patient, or made by the senior clinician responsible for the care of a patient who lacks capacity to decide (following discussions with those close to

the patient and the healthcare team), doctors who have a conscientious objection to the decision may withdraw from the care for the patient. In doing so they must ensure, without delay, that arrangements have been made for another suitably qualified colleague to take over their role, so that the patient's care does not suffer.

Section 42, page 19:

You (i.e. the physician) should bear in mind that you are bound to respect an adult patient's competently made refusal of treatment even where complying with the decision will lead to the patient's death. If a specific treatment is requested which, in your considered view is clinically inappropriate, you are not legally or ethically bound to provide it. However, you should give the patient a clear explanation of the reasons for your view, and respect their request to have a second opinion.

Section 43, page 20:

Where the possibility of withholding or withdrawing a life-prolonging treatment is an option, you should offer the patient the opportunity to discuss how their care would be managed if such a decision were made. This should include:

- arrangements for providing nursing care and other appropriate treatments
- the patient's preferences about who should be involved in decision making or in providing additional support if they become incapacitated
- what might be their palliative or terminal care needs should death become inevitable and how these would be met.

Discussions of this sort, handled sensitively, may help to build trust and provide opportunity for you to get information about the patient's values and priorities that might be helpful in further decision making.

Section 81, page 33 deals with artificial nutrition and hydration; only the first sentence is quoted here:

Where patients have capacity to decide for themselves, they may consent to, or refuse, any proposed intervention of this kind.

(The section continues about cases where patients lack capacity to decide for themselves).