



THE DANISH COUNCIL OF ETHICS

End of life

ETHICAL CHALLENGES
AND PROBLEMS

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Preface

This publication consists of a series of three publications in which the Danish Council of Ethics has focused on ethical challenges and problems at the end of life. It is the translation of three reports previously published in Danish. However, we are pleased to present the three reports, “Spiritual Care for the Dying”, “Treating the Dying – The Difficult Decisions”, and “Euthanasia – Legalizing Killing on Request?”, to a still wider audience, as the topics are universal. The three reports were prepared and published successively, from 2002 to 2003, but should be seen as conceptually coherent. The three Danish publications are therefore being published as one in English.

Spiritual Care for the Dying

The part on spiritual care for the dying contains three sections. The first section provides an account of what the Council of Ethics understands by spiritual care in this publication. In addition, four personal portraits depict the approach of different experts to spiritual care for the dying. The second section contains the Council’s general deliberations on the ethical challenges and problems arising in providing spiritual care for the dying. In the third section readers will find the Council’s recommendations to the health sector and carers in managing spiritual care for the dying.

Treating the Dying - The Difficult Decisions

Part two deals with ethical principles and deliberations of relevance in situations where decisions need to be made about initiating, maintaining or withdrawing so-called life-prolonging treatment of dying patients. The report is divided into four sections. The first section contains a description and discussion of ethical principles of significance in this context for dying patients, their next-of-kin and health professionals. The second includes conceptual clarification of

medical and value-based components included in assessing whether or not a given treatment is futile. The third contains a series of real-life patient case histories illustrating the principles and problems described in the first two sections. In the context of the patient case histories, the Council further describes ethical issues associated with individual types of treatment, such as intravenous fluid therapy and palliative sedation. The fourth section contains the Council of Ethics' recommendations.

The Council has chosen to concentrate its recommendations on decision-making capacity in treating the terminally ill and on the assessment of futile treatment. In addition, the section contains a recommendation on the patient's right to have treatment withheld or withdrawn.

Euthanasia - Legalizing Killing on Request?

The first section of the last chapter focuses on some concepts central to the linguistic usage that characterizes the debate on euthanasia. It also presents the Council's reasoning for using the term "euthanasia" rather than "mercy killing" or "assisted suicide", more often employed in Denmark. The second section of the report examines why the Danish Council of Ethics advises against the legalization of euthanasia, describing the arguments against legalizing euthanasia, as represented on the Council. The third section contains a more in-depth and discussive examination of common arguments for and against euthanasia.

Ole J. Hartling
Chairman

Berit A. Faber
Head of Secretariat

Acknowledgements

The publication was drawn up on the basis of discussions on the Council's working party on "Life for the Dying". The working party's chairman was Ole J. Hartling, the other members being: Frederik Christensen, Mette Hartlev, Nikolaj Henningsen, Lisbet Due Madsen, Anette Roepstorff Nissen, Karen Schousboe, Katrine Sidenius, Ellen Thuesen and Erling Tiedemann. Thomas Laursen, MA, project manager at the Council of Ethics' secretariat, acted as secretary to the working party and collated the manuscript.

Great thanks are extended to the four who, with their experience and commitment, have been willing to have their work on spiritual care for the dying portrayed in the report, *Spiritual Care for the Dying*. Those four are: Preben Kok, hospital chaplain at Vejle Hospital; Hans Martin Svarre, clinical psychologist at the Copenhagen University Hospital in Herlev; Marit Wengel, a nurse working in domiciliary care and at St. Maria's Hospice in Vejle; and Hans Henriksen, a doctor at St. Luke's Hospice in Hellerup. Thanks also go to the same people and Christian Juul Busch, hospital chaplain at Rigshospitalet, the National University Hospital, for having read the manuscript and made suggestions for changes.

Special thanks go to the following people, whose knowledge and experience have helped the working party to rework and come to terms with the issues in the report, "Treating the Dying – The Difficult Decisions": Robert Smith Pedersen, Hospital Consultant, Esbjerg Centralsygehus, Hans Henriksen, St. Luke's Hospice, Margit Søb, nurse, and Elisabeth Hersby, legal expert, National Board of Health, Denmark.

For the sake of good order, it should be added that responsibility for the text rests solely with the Council of Ethics.

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Preface

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In addition, four personal portraits depict the approach of different experts to spiritual care for the dying. The second section contains the Council's general deliberations on the ethical challenges and problems arising in providing spiritual care for the dying. In the third section readers will find the Council's recommendations to the health sector and carers in managing spiritual care for the dying.

The Council of Ethics has continuously discussed the statement at its plenary sessions and approved it for publication at its meeting in February 2002.

The statement was drawn up on the basis of discussions on the Council's working party on "Life for the Dying". The working party's chairman was Ole Hartling, the other members being: Frederik Christensen, Nikolaj Henningsen, Lisbet Due Madsen, Karen Schousboe, Katrine Sidenius, Ellen Thuesen and Erling Tiedemann. Thomas Laursen, MA, has acted as secretary to the working party and elaborated the manuscript.

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Erling Tiedemann
Chairman

Berit Andersen Faber
Head of Secretariat

1. What is spiritual care?

In the Danish literature on caring for the dying, the term “spiritual and existential care” has become common fare.¹ The reason is that spiritual care may otherwise be perceived purely as a religious form of care. In the present publication, therefore, “spiritual care” is used synonymously with “spiritual and existential care”. That is, care that includes both specifically religious care and regard for the existential issues and concerns that can arise in any dying person, regardless of whether those issues and concerns on the part of the individual are more or less or by no means characterized by religious aspects.

Precisely by verging on death, a dying person will be particularly confronted with great existential questions about the meaning of the life lived, about the loss of life and the relationship with the next-of-kin, about faith in a god, about faith in life after death and so on. These are examples of existential and religious issues that may assume particular significance for the dying person.

In this publication the Council of Ethics will primarily elucidate what it considers to be the core of spiritual care, by which it means forms of care whose purpose is to help the dying with the spiritual and existential issues and concerns that are accentuated in connection with the approach of death.

Furthermore, the Council of Ethics has considered it essential to highlight the importance of universally human care, which in practice is part of spiritual care for the dying. This is understood to mean forms of care whose purpose is to help the dying to be able to live and find succour in the lifestyle and even the view of life that have become part and parcel of the dying person’s essential identity and self-knowledge during the course of that life.

¹ See e.g. National Board of Health, Denmark (1999).

Death as a universal human plight

A person facing the prospect of death from an incurable disease will experience a series of agonizing losses. The conditions under which the person was previously able to preserve social relations and activities change and often become more difficult as a result of the impairment to their health.

Spiritual care must therefore include helping the dying person to handle such new conditions, helping to improve them, wherever possible, and providing support for reconciliation when such conditions cannot be improved.

The inexorability of death gives rise to some very distinctive needs.

Examples worth highlighting include: The need to relate and "come to grips with" one's life story, and the need to achieve closure around any conflicts or to see particular people before death occurs. To this, of course, can be added emotional reactions such as anger, fear, sorrow and denial of death. For many, the prospect of dying and the inevitability of the situation will result in an existential crisis.

The religious dimension

Faith and religiousness are significant aspects of many people's outlook on life and their way of living, and are of crucial importance to people's quest for the meaning of life. In that case the religious dimension is an integral part of the person's way of relating to life, but may take up more or less space in different situations. Religious conviction often includes belief in resurrection and life after death.

Those caring for a dying person need to realize that many people begin having religious thoughts precisely when they find themselves in a crisis.

Healthcare professionals must be alert to this and to the fact that the individual may need to find an expressive outlet for religious thoughts and scruples. There is no telling whether the religious dimension will be of major, minor or no importance to a person in crisis.

The point of religious care is not to triumph over death. On the contrary, it maintains that the situation is ultimately one of impotence, i.e. outside and beyond the power vested in any human being. The difference made by religious care is to help the dying person to recognize the limits of his or her own power and to come to terms with this in acknowledging that his or her God is taking over.

The Danes and their religion

One thing most Danes have in common is that their lives include a religious dimension, and from time to time it plays an essential part in their existence.

Eighty percent of all Danes thus think of themselves as believers, irrespective of whether or not they attend church. To these can be added sixteen percent who are sceptics, while only four percent are fully confirmed atheists.

This large group of Danes, however, cannot quite agree what it is right to believe in. So there is disagreement among a small group of just under twenty percent, for whom God plays a large role and who regularly attend church, and the fifty to sixty percent who have more diverse notions about what they believe in and perhaps attribute less importance to it in their day-to-day lives. This is reflected in, among other things, this large group's more hesitant attitude towards regular church attendance, though this does not prevent the same group of people from being able to have a more privatized religious practice. In total, forty to fifty percent of Danes occasionally say a prayer or meditate.

Sources: Gundelach, Peter (ed) (2002): *"The Danes' values"*.

1.1 Examples of spiritual care for the dying

What follows is four accounts of spiritual care. Each description is a personal portrait of a carer who has many years' experience with spiritual care for the dying. The portraits provide a picture of spiritual care from different angles, namely from a hospital chaplain's, a psychologist's, a nurse's and a doctor's. Because of the concrete way in which the carers' practice is described, examples of care occur that

move in an interdisciplinary borderland, sometimes eluding sharp definition as spiritual, psychological or ordinary humane care. In addition, of course, the examples do not give a completely adequate picture of the many different ways in which spiritual care can be practised, just as they do not represent all the spiritual needs that occur. But they have been chosen with a view to hinting at their diversity and giving the reader some impression of what spiritual care and spiritual needs *can* be. The Council of Ethics presents these descriptions, knowing full well that other carers might possibly express themselves differently and hold different views about what constitutes spiritual care for the dying.

Example of spiritual care in a christian tradition



At Vejle Hospital staff often call in the hospital chaplain, PREBEN KOK, to attend to dying patients who respond with an anger that is hard for the next-of-kin to understand and makes the patient hard for the healthcare staff to approach.

He tells us: “The staff have learned that when a patient responds with an anger they cannot release, there is every chance that the anger is due to a feeling of powerlessness that life is the way it is, and this anger can often be released by being directed at God”. According to Preben Kok, this is because anger is subject to the same basic law of psychology that applies to all other emotions too: “Anger can only be released if directed at the right person. If the emotion is directed at the wrong person, it returns as a bad conscience—or at worst as fear or depression”.

To Preben Kok’s mind, then, anger that “life is the way it is” must be directed at the one who created the world, the way it is. If that is not done, that anger can be misguidedly directed at the immediate surroundings: the family and nursing staff. This only helps to compound the patient’s loneliness, hence the feeling of powerlessness and the anger, which in turn redoubles the loneliness.

Preben Kok’s work on breaking this vicious circle is one example of spiritual care that is based on a Christian outlook on life and the basic Christian narratives.

Over the years he has learned that dying people who respond with anger have in many cases been helped by directing their anger towards God and experiencing how that anger is requited with love: “Suddenly, there is a ‘Who?’ to respond to that anger, and a number of “Why?” type questions thus take on less significance. This applies irrespective of how the dying person previously felt about the Christian faith. Dying people suffering this anger are therefore offered a chance to talk to Preben Kok.

He is suggested to the patient as a person who is good to talk to in that situation, and it is also mentioned that he is the hospital chaplain, of course.

Preben Kok builds spiritual care on the central Christian story, the account of the last day of Jesus’s life:

“On the evening of Maundy Thursday Jesus eats together with his friends (the disciples), knowing what is to happen the next day at the crucifixion. When the meal has been taken, Jesus and the disciples walk into Jerusalem and come to the Garden of Gethsemane.

Here Jesus asks his closest friends to wait outside the garden while he himself enters to pray to be spared of what awaits him. On Jesus’s return, his friends have fallen asleep. He wakes them and asks them to remain vigilant, and this they promise to do—but it turns out that they cannot keep their promise”.

Of the link between the disciples failing Jesus and the loneliness of dying people, Preben Kok goes on to say: “Many people who themselves notice life disappearing from them sense a loneliness which they feel to be due to their own poor family relationships or friendships. For a great many of these people it is a relief to hear that it is apparently a condition of life that death brings with it a loneliness that no one can reach into. God knows from His own son that life’s like that”.

“When Jesus was in the throes of powerlessness and senselessness on the cross, he expressed it by crying out: ‘My God, my God, why have you forsaken me’. After that he was able to die with the words: ‘Into your hands I commend my spirit’.”

Preben Kok says: “Modern people have a hard time letting out this cry to God. But given that anger can only be released if directed at the right person, this very cry *has* to be conveyed—that is, when the patient’s anger is anger at life being the way it is. Many people sense God replying to that cry by expressing His closeness.

It may take the form of a feeling or of words one thinks are being said to one, or suchlike. The dying are soothed by perceiving themselves to be loved, as they are, even when expressing their anger”.

In many people the effect of this spiritual care is at least twofold: “Firstly, the family and staff are no longer the target through whom the dying person fails to achieve release despite lashing out at them. Secondly, it is conducive to the dying person attaining the calm imparted by a declaration of love from God”.

Preben Kok’s exercise of spiritual care is a clear and distinct example of Christian pastoral care that supports individuals’ capacity for reconciliation by giving them an opportunity to articulate their anger about death. It is this interlinking of dialogue with God and release of anger, in particular, that makes Preben Kok’s spiritual care Christian pastoral care, for as he says: “Only a God that loves is a God that can be successfully rebuked”.

Example of spiritual care provided by a psychologist



HANS MARTIN SVARRE is a clinical psychologist employed at the Multidisciplinary Pain Centre at Herlev University Hospital. Here he is primarily involved in psychological help for severely ill and dying cancer patients.

Patients are referred to Hans Martin Svarre by their doctor when the patient’s pain is deemed to be brought on largely by psychological factors.

It may be fear of death, desperation, anger or difficult relations with next-of-kin. Hans Martin Svarre tells us that a dying mother with an adolescent child is an example of a situation in which the help of a trained psychologist will very often be needed, both for the dying person and for the dying person’s child. This is due to the generally difficult clash that occurs psychologically between the child’s natural need to break away and the well-founded urge to be solicitous and present around the mother. The example can also illustrate how the psychologist, unlike the priest, places the emphasis on his contribution to spiritual care: “Put in slightly crude terms, the psychologist works horizontally, the priest vertically. The priest works

with the person and that which is higher than the person. The psychologist works with the person and with relationships with relatives, the life lived and so on,” he says.

In specific conversations with the dying, Hans Martin Svarre is particularly inspired by a conviction that the dying person’s feelings fluctuate from almost unbearable despondency and grief to joy and a form of hope. Given the proper attentiveness and an active dialogue, it is possible to make constructive use of this pendular motion.

Part of the point of such a conversation can sometimes be to work through a dying person’s denial of his or her situation. Hans Martin Svarre recounts the experience of a consultation with a dying person and his wife, where the dying person is talking about undertaking a long wished-for journey in the summer. However, it is as plain as can be that he is not going to live that long.

Hans Martin Svarre attempts to follow the “pendulum” here in the hope being experienced by the dying person, by encouraging the person and the next-of-kin to talk about the journey and explain why they are looking forward to it. It creates a breathing space in the earnest conversation, because the energy is now being channelled into describing the place to which the journey has been planned, and the joys they are going to have together and may previously have had on similar journeys. During this conversation, the pendulum will travel all the way up the joy side, but at some point the measure will be full and the pendulum will swing back in desperation, precisely because the conversation is about the journey and the shared life with his wife, which he knows full well death will separate him from. This is expressed in the form of the patient suddenly saying that he knows, after all, that he is nevertheless deteriorating more and more, and that the journey will probably never materialize. To this the psychologist says: “Well, it may be that the journey is not going to materialize, and how do the two of you feel about that?” This is followed by tears and a kind of despondency. But Hans Martin Svarre’s point is that, having followed the couple’s hopes and created a shared picture of them, the tears are made not just tears of despondency but also tears of emotion at what they have together, which is now to be taken from them. The conversation about the journey creates images and associations, including those of the couple’s previous experiences, and hence a common joy is experienced, one which soothes in the midst of the suffering.

It is not just psychologists, of course, who should have the ability to empathize properly and converse with dying patients. To some extent, the other healthcare staff should also be capable of doing this. However, there are situations in which the assistance of a psychologist can be an advantage for the dying. Hans Martin Svarre mentioned, among other things, that some patients express relief by being able to speak to a person "they do not need to be mindful of". Patients depend on their day-to-day carers, so some are more cautious than others about what they say to them.

Furthermore, the psychologist can preserve the continuity of the cycle, even after the event, in relation to the surviving relatives. At non-specialist hospitals the care staff do not always have the resources for this.

Finally, situations do occur in which the day-to-day health professionals lose their patience with a patient's emotional responses.

Here the psychologist can usefully be brought in, both in order to avoid a poor relationship between carer and patient, but also because the situation can be a sign of "abnormal" psychological problems in the dying person.



A nurse's approach to spiritual care

MARIT WENGEL is a nurse, employed in domiciliary care and as a relief-worker at St. Maria's Hospice in Vejle. She also has many years of experience in caring for the severely ill and dying at hospices as well as on a cancer ward, a pulmonary medicine ward and general medical wards.

Over the years Marit Wengel has experienced a tendency for nurses on hospital wards to avoid contact with the dying and only to attend the dying person when there is an altogether specific nursing task to be carried out.

When asked about the reason for this embarrassment concerning any form of contact with the dying person other than a purely nursing-related one, she replies: "I think that, above all, it has something to do with the fact that, as nurses, we want to be able to 'fix' things; we have to be good at solving problems, so we may feel scared

about encountering something we don't have a quick fix for".

Among the means of overcoming this embarrassment and fear, Marit Wengel particularly emphasizes the courage to enter into a dialogue with the dying and establish contact, during which the dying do not have to hold back their need to share their thoughts and musings with the nurse. According to Marit Wengel, establishing contact requires the nurse above all to show a genuine interest, show that she is taking the time to enter into a dialogue with the dying person and is not afraid of any differences in faith or attitudes. By way of example, Marit Wengel mentions that a dying person may express his or her frustration in the course of the daily nursing routine by saying: "There's no point in living now". "Then I have to dare to ask: 'What do you mean by that?', because the dying person's question can be a test to see whether I retreat and just say comfortingly: 'I understand perfectly', or whether I take time out to pursue the dialogue".

On the question of how to evaluate the patient's spiritual needs, as a nurse, Marit Wengel replies that the most important thing is to dare to take the initiative to ask the patient. She says: "Whenever we wonder about something or have our doubts about something, we have to be capable of daring to examine our wonder with the aid of questions to the patient, including those about spiritual and existential things—a thing we once tended to call encroachment. Better to ask one question too many than one too few, to be inquisitive in a loving way and think that the difficult conversation can be very simple, although it's not easy!" One example she mentions relates to a situation in which she came to realize after a patient's death that she had waited too long to ask questions. The case in point was a dying person who was oppressed and not really contactable. "It turned into a chat about something and nothing", as she puts it. The priest who spoke to the patient had the same experience.

On a suitably opportune occasion, she asked the patient whether it would mean anything for him to receive Holy Communion. "He sprang to his feet like a jack-in-the-box," Marit Wengel told us, "and said: 'Oh yes, I've been thinking about that for ages now, and I should like to have my wife with me.'" But unfortunately he died shortly after, before his wish could be fulfilled.

After the event, she and the priest were surprised to discover that neither of them had touched upon the possibility of taking Communion rather earlier, in conversations with the dying person.

One of the few belongings the patient had brought in from home was a reproduction of the Lord's Supper. Marit Wengel wonders that she had not asked about the picture in more detail and its importance to the dying man earlier on in the course of things. After all, if she had, there would have been every chance of her having "stumbled across" the spiritual need which this patient had to take Communion earlier on. She concludes: "The story says something about the importance of what is in the dying person's surroundings—is there a book or a few pictures around somewhere?—because things like that can always form the starting point for a conversation about whether such things mean something to the dying person, spiritually or existentially".

Furthermore, Marit Wengel stresses that the nurse can often act as a natural facilitator between the patient and the next-of-kin in subjects that can be hard to broach because both parties wish to protect the other from painful worries. The nurse is close to the dying person, daily, and if there is comfortable and confident contact between them, the patient will sometimes share with the nurse thoughts from which the patient is protecting the next-of-kin, but which it will nevertheless give both parties relief to talk about.

By way of example she mentions a mother who expresses her grief to the nurse that she will not be seeing her teenage child grow up. In the conversation with the dying person and the next-of-kin, the nurse can be the one verbalizing the concern: "Your mother is upset about not seeing you grow up". Once she has paved the way for the conversation about the loss, the nurse can also report other things the mother has said which she herself does not have the strength to say in the situation, such as: "Your mother would also like to tell you that she's sure you'll make a good father". And in so doing, by being in day-to-day contact with the dying person, the nurse acts as a potential communicator of those things the dying person wishes to get around to saying but is holding back, out of an urge to protect her next-of-kin from confronting death.

The dying person will rarely have any expectations of the nurse attending to spiritual needs. That is why Marit Wengel emphasizes the nurse's duty to take the initiative in this area.

This applies to asking questions and showing an interest in the dying person's thoughts and concerns. It also applies in terms of showing the possibilities available to the dying person to take part in activities of great importance to the person concerned. She says: "The

feeling of still living, rather than just existing, with one's disease and the hair that is no longer there, provides meaning in the midst of meaninglessness: Being able to wander down the high street and buy a blouse, even though you know you'll never get to wear it, or being given the offer of going to the theatre with a volunteer, even though it involves being taken there in a wheelchair”.



Spiritual care from the doctor's point of view

HANS HENRIKSEN is a doctor at Saint Luke's Hospice in Hellerup, where he works exclusively on palliative treatment for the dying. He provides treatment for patients staying at the hospice but also visits dying people in their homes, in which case they are registered with the outreach team at Saint Luke's Hospice.

Hans Henriksen would like to stress that, generally speaking, the doctor should not think of himself merely as a “medical technician”, but as a “medical humanist”. When treating the dying, it will become particularly clear that, by examining the dying person's physical symptoms, the doctor is invariably intervening directly in the dying person's spiritual and existential life. He says: “Examining a severely ill patient with a limited life expectation is not the same, after all, as a person visiting the GP for a routine check-up. For the dying person the doctor's examination has a more fateful significance. The dying person will wonder whether what the doctor notices on his body is the very thing he is afraid of. The doctor will feel the patient's stomach, for instance, to assess the size of the liver, and the patient generally knows that any enlargement of the liver is a sign of the illness degenerating rapidly. Consequently, it is an existentially loaded situation, not just an objective examination”.

A particular characteristic of the doctor's contacts with the dying person is their relative brevity compared with those of the nurse, but conversely, to quote Hans Henriksen, they are intense and have a very special role to play for the spiritual and existential concerns of the dying: “What the doctor says and does finds great resonance in the patient. Often we do experience that every word the doctor utters remains in the patient's recollection, being turned over and over”.

In the relationship between the dying person and the doctor it is *time*, in particular, as an existential condition, that takes on importance, because especially in the patient's eyes the doctor is the one who has the insight and the authority to "mete out time" for the dying person. Hans Henriksen assigns a central position to this special relationship between the dying person and the "judiciary doctor" when describing the need for the doctor to provide *spiritual care* as part of his care as well.

He relates how the dying person will very often refer to the doctor's most recent communication on prognosis and incurability as his "death sentence".

"No matter how gently or brutally it has been said, it is something that completely changes the person's perspective and purpose in life.

Once the doctor has thrown the patient into chaos like this, I feel it is only natural for the doctor to be there too to help follow up on the spiritual and existential care. It cannot be the role of the doctor alone to throw the patient into chaos, leaving nurses and priests to 'pick up the pieces'".

He believes that the doctor must build a relationship of trust with the dying patient and thinks that the confidence between the doctor and the dying person has a special content because it is primarily the doctor who speaks to the patient about the progression of the disease in intense moments of great spiritual and existential significance to the patient.

But what can the doctor do to provide spiritual care, in parallel with his function as a treater of physical symptoms, and in parallel with his function as a communicator of knowledge to the dying person about the development of the disease? In order to illustrate this, Hans Henriksen describes, among other things, situations in which the dying person's body and state of health are not at the same stage as the dying person's mental approach to having to die. For example, a common situation is when the dying person feels ready to die, while it is clear to the doctor that the person is likely to live for some time yet. Here the doctor possesses knowledge of which the patient is devoid, which the doctor has to communicate, knowing full well that the patient's attitude is not, as it were, "in sync" with actual conditions. "The painful and difficult thing for the dying person in this situation", he relates, "is to lend meaning to the time ahead. It is important for the doctor not to recoil from the existential—to help the

patient talk about the whole point of still being here”.

The opposite situation also occurs, of course, i.e. that death is much closer than the dying person is prepared for. Hans Henriksen provides spiritual care here by asking the patient what is important to him or her right now: “I talk to the dying person about the things that are important to accomplish. By acknowledging the importance of getting those things done now rather than putting them off, you signal indirectly that there is not very much time left”.

Apart from these situations Hans Henriksen also mentions an example which illustrates that, in the very general treatment of symptoms in dying people, the doctor is only a good practitioner of medicine if he brings in the spiritual dimension. A dying person will often end up suffering from dyspnoea, and this very symptom evokes a strong association in everyone of the actual notion of dying: “If, as a doctor, you go exclusively by the physical, without an eye for anything else, the result will be poorer treatment of symptoms and poorer medical practice. Being unable to breathe is highly anxiety-provoking and brings death right into the ward.

If you know your Latin and Greek, the word dyspnoea per se virtually tells you that it affects the breathing. It is important, therefore, not only to dispense medicine that alleviates dyspnoea but also to talk about dyspnoea, what it is and what it means. It is my experience that great comfort and reassurance are provided by telling patients what we can do for dyspnoea and taking it seriously without glossing over the rough bits. As a doctor here, you have to dare to talk about something highly anxiety-provoking on the one hand while providing information about the little, concrete things we can do to relieve the symptom on the other hand”.

If you ask Hans Henriksen what can be carried over from the hospice philosophy to the rest of the health sector, he will say it’s all about the doctor’s alertness to the spiritual and existential dimension. That alertness can certainly be enhanced under the present circumstances, though as a hospice doctor he is only too aware that he is privileged to enjoy more time and continuity in relation to individual patients than doctors in most other places that treat the dying. The doctor’s willingness and ability to take spiritual care seriously is important, even though spiritual care can and should be provided by many other specialist groups. “Because,” as he says, “experience shows that both the patient and the next-of-kin often

request a talk with the doctor despite having been thoroughly informed about the disease. It also has something to do with the authority conferred on the doctor. That's why it is important that the doctor can attend such interviews and make his special contribution to spiritual care”.

2. Ethical considerations

2.1 The intimate sphere and spiritual care

Spiritual care goes to the very heart of a person's most personal and intimate convictions and feelings. By its very nature, therefore, spiritual care is something of great intimacy. In as much, however, it does not differ from physical care, which often entails encroachment of the private sphere, for example by means of altogether pedestrian questions about bowel elimination patterns or bodily care. For most patients such encroachments of the intimate sphere would be perceived as necessary evils brought about by a situation in which doctors and nurses, based on their professional activity, are only doing what they can to achieve the best possible quality of life for the dying person.

Most patients, albeit with varying degrees of difficulty, will accept a diagnosis and interference with the intimate physical reality as long as they feel convinced it is happening in their own best interests.

If a particular form of physical care or pain therapy is known from experience to provide alleviation and hence a better quality of life, there are basically no ethical misgivings about offering the patient the relevant treatment, nursing and care.

For spiritual care the same must apply, in principle. In exercising spiritual care, however, it may be harder to be sure what will benefit the patient, deep down, and what will run counter to his or her innermost wishes. As a result, the ethical considerations concerning what to offer the patient have become more thorny.

Respect for the patient's self-determination will be crucial. Just *offering* spiritual care can seem presumptuous. The ethical problem is to establish when, on the other hand, not providing such a service would be a failure. It cannot be taken for granted that the patient is aware of his or her spiritual needs or has the courage to voice them.

In some cases it may be right to act custodially. For instance, there

may be situations where the patient is judged to be acting against his or her own interests, based on other, but obviously unreasonable considerations. An example might be dying patients who do not wish to take leave of their next-of-kin because they do not wish to be seen in a state in which they feel undignified. Consideration should perhaps be given here to influencing and changing the patient's perception of the situation.

There may also be cases where the patient's religious or other deep-seated spiritual convictions engender deep disquiet, which may appear unreasonable or unnecessary to those around. It may, for instance, be a case of people who think, based on their religious conviction, that the illness and the death process are a punishment meted out by a censorious God. In that situation the solution may be to offer the patient spiritual care in the form of a priest, who cannot only use the patient's faith as a point of departure but also perhaps allay the disquiet which it causes the person in question.

It is common for the prospect of imminent death to shake and challenge the faith that the person has held throughout life. It may be either that a person begins to doubt otherwise solidly grounded convictions, and it may be that owing to the prospect of the advent of death a person becomes more interested in religious convictions that have previously been doubted or whose relevance has not been realized. Health staff should be alert to the possibility of this, even in cases where challenging the dying person's outlook does not directly cause any dramatic and immediately obvious mental pain.

Another outlook-dependent source of suffering has to do with the general call and desire for self-reliance that is prevalent in our age. In many people this can result in unbearable, self-imposed requirements in terms of also being able to master or manage death in the same way as one has coped with other of life's problems. Here that help may be the pastoral care that permits the patient to be powerless and to remain in that state of powerlessness.

It may be right and proper to help the patient to not have to live up to demands of one kind or another that merely serve to inflict even more despair on the patient. Sometimes respect for the person's integrity will weigh more heavily than the desire to relieve the suffering considered to be caused by the outlook on life. Other times an attempt to change the patient's perception will be both acceptable and desirable, yet not possible. However, where it is considered

correct to attempt to influence the dying person's perception or outlook, because it may save him or her manifest suffering, it should always be done on the basis of the dying person's own experience of suffering and its meaning.

The following story from a hospice exemplifies this. A dying patient with a background from a church environment where there is little tolerance of being a doubter, expresses her fear of death. The patient has the desire to live and experience many things yet.

However, she feels pressurized into having to look forward to meeting her God soon. The nurse encourages the dying woman not to make overly great demands of herself, but to take solace instead in the fact that God is with her now that she is having a rough time of it. The dying person is relieved that there is someone willing to listen to her who does not take her doubts amiss.

In this situation the nurse deploys resources within the dying woman's own faith to steer her perception in a more positive direction, and in so doing perhaps achieves some diminution of the woman's suffering.

2.2 Vulnerability of the dying

The relationship between the professional care-giver and the patient is characterized by an inequality that can be concisely formulated: The care-giver is clearly there to help the patient, not vice versa. The dying person depends on help and will therefore not be able to dismiss the care-giver's views to the same extent as in a relationship of equals between friends. In the case of the dying person, owing to the nature of the help situation, pressure will occur to perceive the care-giver's attitudes and advice as being unconditionally relevant to the patient's own well-being.

The patient's trust in the relevance of the care-giver's advice and care is incredibly important, therefore. The more the dying person can trust the care-giver, the less the patient will need his or her own powers of judgment and energies to make a critical evaluation of the situation him/herself. As a result, it can also be said that the importance of trust increases in step with the reduction in the ability and wherewithal needed to apply personal judgement. In other words, trust is especially important in situations where the patient needs to use his or her more or less depleted physical and mental

energy in areas other than critical evaluation of the help on offer.

Since the patient is particularly dependent on the trust being built up in the relationship with the professional carer, the party providing the care is required to take the dying person's integrity and personhood as a basis.

Otherwise, for example, the patient may be pressurized into taking part in dialogues that do not match the patient's needs, but he accepts either because he has faith in the relevance of the care-giver's care and himself refrains from taking a critical stance on it, or because he is unable or unwilling to opt out on account of his dependence on the care-giver.

On the other hand, however, the care-giver's access to knowledge about the patient may make it necessary to ask about intimate subjects normally only conveyed in very close emotional relationships between individuals. Proper spiritual care, therefore, is conditional on contact that in many situations challenges respect for the boundaries of the intimate sphere—respect whose presence is particularly necessary in the relationship between the professional care-giver and the patient.

Misguided care

Care must be taken not to overburden the dying person, however well-intentioned the motives, with existential tasks that the latter may have no desire whatever to take on. Many health professionals will undoubtedly give a nod of recognition to the normative preconceived understanding that dictates that openness about feelings and inner emotions is an absolute benefit for every person. It is no doubt easier to help a person with conversation if that person is relatively open about his or her feelings and problems. But for the care-giver it is important to assess whether a person's lack of openness torments the person himself or whether in reality the lack of openness only torments the care-giver as a result of the outlook she holds herself.

Influencing the dying person's outlook on life is a patent encroachment when done for its own sake rather than to provide for the patient's relative well-being.

It can be very difficult to define when such influencing is no longer being done with a clear eye for the sick person's specific needs. This, of course, is due to the fact that care-givers are almost always well-intentioned and presume that their actions are guided by consideration for the patient.

Neglected care

At the other end of the scale, towards neglecting spiritual care, it is quintessentially all about the care-giver consciously or unconsciously shrinking away from the fact that the dying person has particular spiritual needs.

Negligence can occur at many levels and can be due to a variety of different barriers. Right from the most palpable in the form of lack of time, unsuitable work schedules and counterproductive layout of the institution in question, to less tangible things in the form of embarrassment at talking to the patient about death and religious or existential problems.

There may be several reasons for this embarrassment. One of the most important reasons is surely that we humans instinctively shrink from confrontation with death and hence also from our dislike of meeting the dying, who remind us that we will eventually die. Another reason is certainly that people readily identify spirituality with religiousness and belief in God, when asked what spirituality is.² Marrying this thought with the widespread perception in modern western culture that religion is a private matter, it is not hard to understand any reticence there may be on the part of the healthcare staff.³ In many cases, then, reticence can be an unfortunate consequence of the care-giver's respect for the dying person's religious privacy, just as some care-givers may conceivably wish to protect their own religious integrity. For example, there has been discussion as to whether a nurse can be required to assist the patient with religious rituals such as prayers and bible-readings, irrespective of whether or not she herself professes some other religious conviction.

² See e.g. Hermann, Carla Penrod (2001).

³ Cf. Mjølnerød, Hilde (1997), p. 6: "Vang (1995) claims that the idea of neutrality as a value may be one of the reasons that religion and philosophy of life are poorly catered for in healthcare establishments". [Translated from Norwegian]

3. The Council's recommendations on spiritual care for the dying

3.1 The Council's general attitude towards spiritual care for the dying

Specialist care for the dying must include care for more than just the purely physical. Universal human and spiritual care for the dying is therefore something that has to form part of any course of basic and further health training. Health personnel must be capable of understanding and, wherever possible, catering for the dying person's spiritual needs. This will require training in conversing with the dying, and it calls for respect and empathy.

When it comes to the religious component of spiritual care, however, this is a different matter. The Danish Council of Ethics feels that the public health services are obliged to ensure that the dying are informed about their options for having their religious care needs accommodated, regardless of whether a person is in a hospital, a care home, a hospice or at home.

Thus it is an obligation for the institution or health visitor etc. to arrange for religious care to be available, visible, present and up to date within the ambit of the institution itself as well as in the home. But providing this religious spiritual care, where needed, is a task for the church and the priesthood.

Equal status for religious persuasions

The Council of Ethics wishes to stress the importance of giving all dying people, regardless of religious persuasion, equal status wherever possible with regard to the spiritual care options available relating to the individual's particular religious beliefs. It is not uncommon for dying people with religious needs other than Christian ones to have a strong religious network. Consequently, requests of a religious nature or calls for help from public resources will be rarer for them than for the Christian contingent of the population. However,

this should not detract from alertness to the fact that dying Muslims, Jews or others may have needs for religious care that are not being met. Institutions and care-givers, therefore, should also be sensitive to the need to provide facilities and opportunities for the different rituals connected with death and the dying person's situation within different cultures and religions. To a large extent, institutions where people die should have the facilities and opportunities for conducting diverse rituals such as Extreme Unction, blessings, Holy Communion or Eucharist, ritual ablutions, prayers and holding a vigil for a dying person.

Assessment and competence

Doctors and nurses must be expected to have the requisite qualifications for being able to assess and attend to the spiritual needs of a dying person. Depending on the situation, this can take place in the form of brotherly support and counselling about existential concerns, or it can take place by referral to a psychologist or priest, for instance, if the doctor or nurse considers that their competence is no longer up to a specific requirement. But above all, of course, such referrals should take place at the dying person's request or be brought about by the care-giver's assessment and questions of the dying person about his or her spiritual needs.

3.2 Recommendations concerning the priest's exercise of spiritual care

The Danish Council of Ethics recommends that two principles, *openness and respect for the person's autonomy*, be made guiding factors. The Council of Ethics is of the conviction that dying patients should be informed of the full range of spiritual care options available, including the option of having a priest as their interlocutor.

This openness must derive from making spiritual care part of the overall therapeutic offer, which also includes access to physiotherapy, psychological assistance and social counselling, for example.

The Council of Ethics is aware that administration of spiritual care by a priest entails ethical problems.

One of the most significant issues consists of achieving a considered balance between the role of the priest as preacher or advocate and the role of care-giver, among others, at the institution the dying person is at.

The priest's task is to act as an advocate, of course, but it must be done with respect for the patient's commitment and interest in the religious dimension. To put it another way, the priest must not subordinate consideration for the patient to religious standards or rituals. The same consideration, of course, must be applied to ministers and clergy from faith communities other than the Christian religion. Conversely, it is true to say that the dying person, by consenting to receive help from a priest of a particular religious persuasion, is implicitly acknowledging the positive value of that particular school of religion.

There may be cause to highlight another particular problem, which involves distinguishing between psychological symptoms, which may be perceived as a natural reaction to being about to die, and mental suffering, which according to the customary criteria must be perceived as pathological and requiring treatment of a kind other than spiritual care. If the priest is to act as a care-giver, to some extent he must be capable of assessing, say, when a dying patient is simply in a sad mood and when there is actual mental suffering, which calls for the dying person to be offered psychological or psychiatric assistance.

The priest's role in the interdisciplinary community

The priest has a very special relationship with the professional health community.

For example, a hospital chaplain is a priest who has acquired special skills in administering spiritual care for the dying, while at the same time being a representative of a religious faith community, which in the case of the majority of Danish hospital chaplains will be synonymous with the Danish National Evangelical Lutheran Church.

The priest can help the dying by performing religious acts like prayers, confessions, the Sacrament, ointment and officiating at weddings. Information about a dying person's wishes concerning spiritual care of this kind should be recorded in the patient's records. Among other things, this is vital to the priest's possible participation in conferences on the patient's course of treatment.

The Council of Ethics, however, thinks that in the majority of cases it will not be apt or relevant for the priest and other religious care providers to take part in joint conferences at which the patient's health is discussed. In practice the priest generally has no need to know the subtle details of the dying person's health. First and

foremost, religious care should be based on conversations with the patient. Above all, this is because religious care is about the patient's own understanding of his or her situation, not what is “wrong” with the person in any objective sense.

The Council of Ethics does recognize, however, that there may be cases where it is useful for the priest to actually take part in interdisciplinary conferences on the patient's treatment. The Council of Ethics also acknowledges that the individual institution under the hospital services must have the freedom to adopt its own general guidelines on the topic. Here two implicit conditions must be met. Firstly, that the priest observes his duty of confidentiality in relation to the patient; and secondly, that, if need be, the priest's participation in conferences on the treatment of individual patients can be arranged so that the priest attends only when information is given out about patients who have provided their explicit consent for information to be passed on to the priest.

3.3 Recommendations concerning the care-giver's provision of spiritual care

The Danish Council of Ethics feels that care for the spiritual aspects of the dying person's situation is a natural and integral part of the health staff's activities, in as much as what may possibly be the most essential part of the sick person's suffering is spiritual by nature. However, there are essential ethical concerns and principles that have a bearing on everyone engaged, like health professionals, in spiritual care for the dying. The players here can be nurses, social and health service assistants, doctors, psychologists, physiotherapists and social counsellors. They may also be volunteer visitors (or hospital buddies) who as such form part of the care team for the dying at public institutions.

Empathy—the core of spiritual care

Empathy means sympathetic insight and is a quality possessed by most people in varying measures. But for nurses, doctors and others who provide spiritual care, it must be considered particularly important that this quality be developed into a proper skillset. Here the Council of Ethics would stress those components of empathy that make it a desirable skill to develop in spiritual care:

- **Openness** is a necessary prerequisite to empathy. The courage needed to help the dying to deal with their plight must not be overly restricted by embarrassment or by the care-giver's own, perfectly natural inadvertency or fear of death.
- **Sympathy** involves the care-giver's ability, in the given situation, to 'parenthesize' his or her own outlook on life and to listen and ask questions instead, so that the care-giver understands the patient's suffering and thus affords the dying person the best help.
- **A sense of diversity** is part of sympathy, above. People respond with immediate compassion when they encounter a fellow human being who is suffering because of, say, physical pain and pangs of loss. A sense of diversity, on the other hand, is the care-giver's ability to be attentive and alert, and to intuit the causes of suffering or the need for spiritual manifestations and utterances which are not recognizable from the care-giver's view of life.
- **Knowledge** is important in order to be able to pick up on the patient's particular outlook on life and spiritual needs. The care-giver must know something about how to communicate with dying people about existential and religious topics, and preferably have insight into different philosophies of life, cultures and faith communities.

Respect for the care-giver's religious freedom

The Danish Council of Ethics does not think that every care-giver has a mandatory duty to offer assistance with the dying patient's religious acts. Instead, the Council would urge that such care provision be made voluntary for the individual health professional, but that the utmost be done on a case-by-case basis to ensure that the dying person can obtain the requisite help with religious assistance, either from priests or volunteers outside the institution, or from health professionals who have no objection to providing such assistance.

The Council acknowledges that the dying person may benefit greatly from the help of a nurse to carry out religious acts but maintains that it reflects an overburdening of the nurse and a lack of respect for her religious freedom if she is to be professionally obligated to take an active part in rituals connected with a religion she does not share, for example.

The Council of Ethics would justify its views in the following way. A severely ill and dying person being cared for in the public sector will

see his or her life circumstances undergo changes and curtailments on many levels compared to what that person has been used to throughout life.

A large portion of the spiritual suffering on the part of a dying person is down to a deterioration in the options available for maintaining essential relations and interests. The professional health practitioners should do their utmost, of course, to make sure that this deterioration is kept to a minimum.

But doing their utmost does not involve fulfilling every imaginable need or remedying every conceivable situation or shortcoming.

As far as religious assistance is concerned, this is an activity that will impinge on the nurse's own religious life and the core of her outlook on life. To claim anything else would actually be tantamount to trivializing and technologizing religious actions.

Active religious tolerance

Although, in the Council's conviction, health professionals must be able to say no to helping to carry out religious acts at odds with their own outlook, the Council nevertheless feels that it is fair to stipulate an extensive degree of religious tolerance in publicly employed care-providers. One implication, for example, is that it must be regarded as gross negligence of spiritual care if a doctor or nurse does not do whatever is within his or her power to procure a dying patient religious assistance within the relevant faith, if so requested by the sick person. This must be an ethical challenge to everyone providing care for the dying, irrespective of their religious standpoint.

But it also means, in the Council's opinion, that the doctor or nurse should go to great lengths to provide the desired religious assistance him/herself in situations where denying it may mean the patient simply having to go without such help. In each specific case, therefore, the individual health professional will have to very carefully weigh up the importance of such help for the wellbeing of the dying person against the degree of discomfort and aversion he or she feels as a result of assisting with religious acts that are alien to him or her as the care-giver.

The Council also wishes to add that such desirable religious tolerance also implies an awareness that there is no need for the person him/herself to *profess* the religious conviction which he/she is *assisting* another person to exercise. However, these ideal require-

ments in terms of the care-giver's tolerance do not alter the fact that the individual doctor or nurse is ultimately the one who decides where to draw his or her own line in the sand as regards personal assistance with religious acts.

In practice the problem outlined above is probably not as consuming as concerns about the doctor's and nurse's assessment of whether the dying person has spiritual needs of a specific religious nature. How should such an assessment be made, and how should the care-giver provide information about the possibility of the dying person receiving help from a priest, for instance? Here the Council of Ethics agrees on the importance of respecting the dying person's own outlook and autonomy. For this reason, religious care must always be provided on request or in accordance with the express acceptance of the patient.

The need for openness

Conversely, however, the Danish Council of Ethics finds that respect for the person's integrity must not result in exaggerated reticence and restraint. Communications between a health professional and a dying patient hinge not only on rules and principles, but to at least an equal degree on intuition and human empathy. There is no doubt, then, that it is perfectly normal for the empathetic care-giver to intuit an unspoken need on the part of the dying person that may need to be homed in on by asking carefully phrased questions. Any solicitous and diligent care-giver will sense that it is only right to help foreground those things that the dying person can benefit from, things that often remain hidden, precisely because the dying person is in a vulnerable and enfeebled state. But the requirement to help is clearly part of a power situation and, as everyone knows, such situations can be abused, with a greater or lesser degree of intent. Communications, therefore, must be cautious on the one hand and avoid being exaggeratedly guarded on the other.

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Treating the Dying

THE DIFFICULT DECISIONS



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Preface

This report deals with ethical principles and deliberations of relevance in situations where decisions need to be made about initiating, maintaining or withdrawing so-called life-prolonging treatment of dying patients. The report is divided into four sections. The first section contains a description and discussion of ethical principles of significance in this context for dying patients, their next-of-kin and health professionals. The second includes conceptual clarification of medical and value-based components included in assessing whether or not a given treatment is futile. The third contains a series of real-life patient case histories illustrating the principles and problems described in the first two sections. In the context of the patient case histories, the Council further describes ethical issues associated with individual types of treatment, such as intravenous fluid therapy and palliative sedation. The fourth section contains the Council of Ethics' recommendations.

The Council has chosen to concentrate its recommendations on decision-making capacity in treating the terminally ill and on the assessment of futile treatment. In addition, the section contains a recommendation on the patient's right to have treatment withheld or withdrawn. The Council of Ethics has continually discussed the report at its plenary sessions and approved it for publication at its meeting in September 2002. The report was compiled on the basis of discussions on the Council's working party on "Life for the Dying". The working party's chairman was Ole Hartling, the other members being: Frederik Christensen, Nikolaj Henningsen, Lisbet Due Madsen, Karen Schousboe, Katrine Sidenius, Ellen Thuesen and Erling Tiedemann. Thomas Laursen, MA, acted as secretary for the working party and collated the manuscript. Special thanks go to the following people, whose knowledge and experience have helped the working party to rework and come to terms with the issues in the present report:

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1. Introduction

For most people death occurs very peacefully. The expression about "a person passing away quietly in his sleep" is an excellent way of capturing the scenario that is most common. So-called death throes are a rare occurrence.¹ However, there are death scenes where it may look as if the dying person is unable to attain precisely such peace. Such images make a strong and indelible impression on those who are witness to them.

These days a fatal pathology can be protracted. The time of death can be deferred by keeping vital functions going. Great medical advances like antibiotics, dialysis and intensive care seem to go hand in glove with a sense of insecurity that has to do with the fact that, the more we are able to do, the more uncertain it makes us about what we *ought* to do. There is often no doubt that resort should be had to treating disease and that treatment is beneficial, but there are situations in which the physician, the next-of-kin and the actual patient have second thoughts, wondering whether their efforts may just have entailed more suffering. There is a sense in which it is felt that there is something we have not mastered, i.e. deciding when a treatment is right in relation to the overall objective, which is to benefit the patient as much as possible.

The view often encountered is that "modern technology" is instrumental in rendering a person's "sunset days" more inhumane, precisely because the dying person seems unable to find peace. At the same time, there is a tendency to forget that palliative treatment has

¹ The renowned doctor, William Osler, was the first person to demonstrate this systematically: "Statistics of 486 cases", written ca. 1904; not published but synopsised in *Science and Immortality* (no. 5250, p. 19): "Ninety suffered bodily pain or distress... eleven showed mental apprehension, two positive terror, one expressed spiritual exaltation, one bitter remorse. The great majority gave no signs one way or the other; like their birth, their death was a sleep and a forgetting."

also been developed and is available to a far greater extent than it once was. Effective and gentle pain therapy, anaesthesia, muscle relaxants, anti-nauseants, anti-convulsives, and drugs for respiratory distress and other symptoms currently provide far greater scope to make the death process less agonizing and hence also more peaceful.

However, the array of engineering by which the dying person may be surrounded, particularly on hospital wards—and this applies to electronics, monitoring screens, electrodes, tubes (catheters) in e.g. the nose, mouth, urethra and veins—will be extremely alien to most people from outside the ward. In practical terms it may be hard for the dying person's next-of-kin to get close for pieces of apparatus, dressings and so on, and to get really close up to touch their loved ones, for instance. Furthermore, all the medical paraphernalia etc. may mean that the next-of-kin fail to notice the care actually being provided by the professional staff—including painstaking monitoring and careful diagnostics. For the health staff the technology represents indispensable technical aids with which *they* are familiar, but the next-of-kin rarely so; and when the picture of a closely related person who is dying is overshadowed by the technical and the alien, many people will instinctively think: *This looks wrong; it shouldn't be like this.*

The legislation and accompanying provisions speak of "life-prolonging treatment", a term perceived in many people's minds as being synonymous with pointless or futile treatment, because it implies that the treatment aims to prolong life in situations where there is no point, because it brings with it more suffering than good. The purpose of treating patients, however, is to cure or alleviate symptoms, never purely to prolong life. The expression "life-prolonging treatment" is misleading in part, therefore, but must be accepted as having gained a foothold.

In this connection it should be emphasized that, more often than not, it is only in retrospect that a treatment can be characterized as purely life-prolonging. With the wisdom of hindsight it becomes clear that any treatment that failed to cure a patient or improve his lot was purely life-prolonging and therefore served only to protract a state of suffering and put off a peaceful death. In other words, it is obvious that this patient would have been better off without continued diagnosis and treatment. But looking forward, i.e. before we know how it all ends, it is naturally harder to dismiss the possibility that treatment may relieve or improve his condition.

Treating the dying involves certain difficult choices in dilemmas. It has therefore been important for the Council of Ethics to shed light on the ethical problems connected with treating the dying and examine the ethics of the decisions that need to be taken, for example whether to halt treatment that may be considered futile.

1.1 Ethical aspects

It is difficult to decide which standards and considerations should be allowed to direct policy and be weighted most heavily when faced with having to make decisions to initiate or terminate life-prolonging treatment. For example, a doctor may well think that he should stick to assessing purely medical indications for a patient's medical treatment. But in order to know where to draw the line between medical and non-medical indications, some *normative* agreement must actually have been reached already as to the ultimate purpose of the treatment. And indeed, such a fundamental consensus on the purpose of practising medicine is also in place, i.e. agreement to cure, relieve and preserve life. Nonetheless, there can be different views of how to accommodate the interests of the patient, next-of-kin and society, and how to weigh them against each other in terms of healing, alleviation and preservation of a person's life.

1.1.1 The principle of preserving human life

Preserving human life is such a basic ethical principle that most people would consider it pointless to question it. Nevertheless, there are two possible ways of understanding the principle: *firstly*, the principle may be felt to apply in absolute terms, which is to say that it is wrong to contribute to causing a human life to cease to exist, whatever the circumstances. This radical variant of the principle of preserving human life implies that everything from homicide in self-defence (for example, in a state of war) to the interruption of life-prolonging treatment is morally wrong, whatever the particulars of the situation. *Secondly*, the principle of preserving human life may be thought to have *prima facie* validity; that is to say that it is *basically* wrong to help cause a human life to cease to exist. Espousing this less radical variant of the principle, there must be weighty reasons for departing from the principle of preserving human life.

The first variant of the principle has the strengths and weaknesses that absolute principles often have. Its strength is that it is very easy to determine what is right and wrong. Its weakness is that the principle has consequences which most people will find highly unacceptable. One of those consequences is that life-prolonging treatment of a dying person must not be terminated, even if rejected by the person concerned, or even if the treatment is extremely painful.

Most people will certainly feel that the principle of preserving human life has *prima facie* validity. That means that the more relativist variant of the principle allows for the possibility that other ethical interests may weigh more heavily than the interest in sustaining life.

To illustrate types of deliberation, three clinical situations can be mentioned. Firstly, a situation in which parents and doctors have to adopt a position on treating neonates with severe disorders. How severe and incapacitating long-term sequelae will the parents accept on behalf of their child? When will parents and doctors be able to decline intensive treatment? This will invariably lead to weighing up the circumstances in which life is worth preserving.² That is to say that the principle of preserving human life is weighed against notions of quality of life. Secondly, a situation can be mentioned in which a person competent to make a decision refuses to receive life-prolonging or even curative treatment without which the person will die from the illness. In most instances, under law and in practice, a person's right to control his own life will weigh more heavily than the principle of sustaining life. Thirdly, mention can be made of very rare cases in which doctors and parents have to take a stance on treating Siamese (conjoined) twins. Here there are examples of court cases where it has been accepted that the weaker of the twins had to die as a result of the operation that would give the stronger twin a chance to survive. Regard for the survival of another is used here to justify the contribution being made to the death of the weak twin, since failure to treat would lead to the death of both.

As the examples show, applying the principle of preserving human

² Practice indicates that it cannot even be taken for granted that only the prospect of a totally incapacitated life determines whether people opt out of treatment. Thus, in a Danish study at a neonatal ward, it was a small group of absolute newborns that failed to receive treatment despite the fact that, given maximum treatment, there was every likelihood of survival without severe long-term sequelae. Cf. Bjergager, Mia et al. (1999).

life in any absolute form appears to be very difficult. When it comes to hands-on decisions, the preservation of human life is part and parcel of the trade-off against other considerations, such as self-determination and quality of life.

How one perceives and relates to the principle of preserving human life will depend on how one views the question of whether human life per se has any value. Some people will adhere rigorously to this, referring to the fact that any departure from this basic view will invariably lead to respect for human life being undermined in many other contexts. Others will feel that it is not life as such that has value, but rather everything for which life is a possibility condition. For the latter the crux will, to a greater extent, be what value or presumed value an individual life holds for the person living it.

1.1.2 Self-determination

We value self-determination chiefly in two different ways. Self-determination can be a tool for achieving the things in life we treasure, and for avoiding what is worthless, or even brings pain and suffering. We see this form of self-determination as an ‘instrument’ that can be used to fulfil needs and desires for ourselves and others. This, then, also includes what might be called *self-care* or *self-welfare*.

But self-determination is not just an instrumental benefit. It is also prized for its own sake. That is to say that merely “self-determining”/“asserting oneself proactively” is perceived as a value, whatever other values we use it to achieve. This form of self-determination could be called *independence*.

The former is the kind of self-determination that can be exerted by others to some extent when a person is not in a position to do so himself. Taking over, among other things, self-care for a patient in this way is only relevant when a patient himself cannot utter his own views on his interests, or cannot gauge how his needs and interests are best served. Examples of people who are unable, to varying degrees, to gauge their own best interests are children, the demented and people with acute or chronic mental disturbances. In this case, we refer to incompetence or to a patient being incompetent.^a Examples of

^a Translator’s note: The words *incompetent* and *incompetence* are used here strictly in the legal sense, i.e. to mean “lacking in decision-making capacity”.

people who cannot convey their needs and wishes are patients who are unconscious or simply so debilitated by illness that they cannot communicate and make decisions regarding their own health.

A person's right to make decisions about interventions of vital importance to himself is weighted very heavily, both in the legislation and in health professionals' practice. Respecting a dying patient's self-determination is important for the health professional's endeavours to ensure that the patient lives out his final days in as good a way as possible. That entails the health professional communicating with the dying person as best possible, of course, and acquiring a knowledge of the person's desires as regards treatment pathways.

1.1.3 Regard for the patient's best interests

Often, however, dying patients' ability to exercise self-determination may have partially or wholly lapsed. This can be due to incapacitation or debilitation and hence a simple lack of the energy and resources needed to take any decisions in such a difficult situation. But precisely because the dying person is vulnerable and at risk of losing his ability to exercise self-determination, it is important to consider how doctors and care staff can and should relate to those who provide the dying person with care and welfare. The point of departure must be to try and achieve what the patient himself would presumably have sought to achieve, had he been in a position to do so.

When competent, a person can credibly express altogether individual and possibly even idiosyncratic preferences. This is reflected clearly in Danish legislation, since a competent patient can reject even life-saving treatment—refusing to receive blood, for instance. If the patient is not competent, however, the doctor is not at liberty to presume that the patient would decline such treatment, not even if the next-of-kin give that assurance. Here the doctor must base his actions on an implicit and presumed universal interest in receiving life-saving treatment, even though it may subsequently turn out that the doctor has acted against the patient's innermost wishes by saving that person's life.

1.1.4 Decision-making capacity and the substituted judgement issue

It is not uncommon for healthy individuals to voice concern and fear about coming to be overly reliant on the help of others in their old age and at the close of life. It is not hard to understand why people prefer to hang on to their independence for as long as possible and live in freedom until they die. Loss of independence is not infrequently described as a form of indignity. This applies equally in the public debate on assisted suicide or euthanasia, and to decisions regarding the withdrawal of medical treatment for the terminally ill. It must therefore be stressed that in other contexts the concept of dignity is used, on the contrary, to indicate that people, whatever they are capable of, possess a fundamental dignity that must be cherished. Thus, proxy care for a dying person who has either lost or never had the capacity to exercise self-determination is identical with protection of the dignity the dying person possesses as a human being, regardless of that person's functional level at the time.

But what principles or standards can proxy decision-makers (be they doctors, next-of-kin or courts of law) call on for support when faced with making decisions that hopefully represent that very protection and respect for the dying patient's dignity? The literature on bioethics generally talks of three possible standards that may serve as guides for surrogate decision-makers:

1. The patient's self-determination, as expressed and documented,
2. The substituted judgement,
3. The patient's interests³.

Re 1)

The self-determination based standard can only be relied on where actual documentation is available as evidence of the patient's wishes. Here in Denmark, for instance, this may be a living will or advance directive, but it can also be previous verbal statements made to health professionals by the patient and expressed in connection with the relevant treatment. Where the person concerned is terminally ill and has completed a living will, there is no need for surrogate decisions; the patient has made his decision and that decision is legally binding.

³ Cf. Beauchamp, Tom & James Childress (2001), p. 99ff.

In other situations there is greater scope for interpretation: Is the patient currently in just the sort of situation he has previously expressed views about? Is it reasonable to assume that the person still feels the same as when he voiced his opinion about the situation?

Re 2)

Substituted judgement denotes a procedure in which another person makes a decision on the patient's behalf. The decision-maker relies on an assessment of the patient's values and, based on these, attempts to gauge what he would have preferred in that particular situation. This is dogged by considerable sources of error and uncertainties. The surrogate person may, for example, stress the importance of a particular trait in the dying person and make a decision in keeping with the surrogate's own value-based preferences.

Re 3)

The third standard is based on an assessment of the decision that best serves the interests of the patient. In contrast to substituted judgement, this standard is not motivated by a desire to reconstitute the patient's life values, distinctive or otherwise, but is directed rather by universal human interests.

2. Assessing futile treatment

The following section outlines some problems arising in connection with futile treatment of patients. The most problematic examples of futile treatment are found in patients subjected to medical interventions and examinations with no substantial likelihood of offering any prospect of either improvement, cure or alleviation. For dying patients futile treatment not only produces temporary frustration or pain but also ruins the chances of the final days of their life being marked by a level of tranquillity and of them enjoying freedom from alienating and possibly distasteful treatments. One important aspect of this problem complex, of course, is that it is often very difficult to predict the effect of various treatments, just as it is a complicated process for the physicians in charge to even reach the conclusion that a particular patient is incurable and terminally ill. Even when a patient has been declared terminally ill, it can be hard to determine whether an intervention will produce any essential changes in his quality of life.

2.1 Conceptual clarification

When medical treatment is futile or pointless, it means that it will not benefit the patient's state of health. However, there are different ways in which treatment can be said to be futile.⁴

2.1.1 Assessing futility based on medical indications

A course of treatment can be futile because it does not relieve the patient's illness and associated symptoms. These may be treatments

⁴ Cf. Snyder, Jack & W. & Martha S. Swartz (1993), p. 180. One suggestion for a concise definition of futile treatment encapsulating both forms of futility (hopelessness and pointlessness) reads: "Medical futility is a treatment that does not increase the odds of survival or of meaningful survival (meaningful in relation to the patient's life aims and wishes)". Cf. Asch David A. et al. (1995), p. 289.

that have no impact on the physiological suffering they aimed to remedy, and treatments that neither remedy suffering nor prolong the patient's life. Of course, it is the health professional (usually the doctor) above all who has to conduct the strictly health-professional assessment, but it can be difficult to establish with any certainty whether a treatment is medically futile.

2.1.2 Assessing futility on the strength of value-based indications

In most situations the strictly medical assessment of futility will need to be supplemented with an evaluation of what, on the strength of value-based criteria, can be pointless treatment. The medical assessment is thus made with sensitive allowance for whether and when a terminally ill and incompetent dying person is in such a state that, for the person concerned, just being alive is undesirable or no longer has any bearing. An American study of the rationale for suspending life-prolonging treatment shows that the most frequent reason was poor prognosis as a result of multiple organ failure, while it was much rarer to opt out of life-supporting therapies solely on account of the patient's anticipated poor quality of life.⁵

The patient's or next-of-kin's wishes are of vital importance in assessing whether it is expedient to continue or withdraw treatment. This is because fulfilling the patient's wishes for the latter days of life is one of the factors of extreme relevance in actually evaluating the quality of life that clinical decisions aim to improve.

So treatments that are futile in the medical sense are seen to be kept up in order to accommodate the terminally ill and/or their next-of-kin. For example, it is possible to imagine maintaining life-prolonging treatment purely and simply to allow the next-of-kin time to take leave of the dying person.

Under no circumstances does a doctor have any duty to carry out treatments that have no effect. That means a doctor can interrupt treatment of an incompetent dying patient if the reasoning is that the treatment is not going to prolong the patient's life materially or improve the patient's condition. The doctor's duty to avoid futile treatment is reinforced, of course, in the event that treatment will actually inflict greater suffering on the patient without any slight extension of the person's life to outweigh the burden constituted by

⁵ See Keenan, Jean P. et al. (1997).

that suffering. Similarly, it cannot reasonably be demanded that the doctor should go against his professionally based insight into what is detrimental to the patient.⁶

According to current legal regulatory procedures, the doctor is in control of initiating and terminating treatment for patients deemed terminally ill, i.e. expected to die within days or weeks, despite the treatment administered. In such cases, then, the doctor and the health professional can be expected to provide the next-of-kin with relevant information and be willing to listen to their wishes as regards treating the dying person. It is important to find solutions that both health professionals and next-of-kin feel comfortable with. But there are instances of the next-of-kin being at odds among themselves as to whether or not some treatment of a terminally ill person is futile. In such cases, of course, the doctor with the decision-making capacity will have to rely largely on the principle of preserving life, always provided that the life-prolonging treatment is not deemed to entail any increased suffering for the terminally ill person. In cases where the incompetent patient is not terminal, but possibly incurable, under Danish legislation it is the closest relative or guardian who has the right to grant informed consent on the patient's behalf, which includes the right to say no to life-prolonging treatment. The situation here is that in some cases the doctor may find it medically expedient to continue treating whereas the closest next-of-kin does not wish to do so on the strength of value-based considerations. If the relative's decision cannot be said to result in the immediate death of the patient, the doctor is obligated by law to go with the closest next-of-kin's decision.⁷ However, it is important to emphasize that, with the

6 For example, a doctor will be entitled to reject resuscitation attempts unless they are likely to restore heart function or breathing, or if it can be foreseen that the patient will subsequently experience more heart failures with ensuing death. In the latter case the doctor's ethical legitimation in any conflict arising with the next-of-kin's wishes can even be rooted in the duty not to cause harm. Cf. Snyder Jack W. & Martha S. Swartz (1993), p. 180.

7 In practice, disagreement may arise as to who is the closest next-of-kin. A guidance note from the National Board of Health, Denmark, provides only limited guidelines as to who can be thought of as the closest next-of-kin: "The closest next-of-kin is taken to mean: Co-resident spouse or partner, partner in a registered (domestic/civil) partnership, relatives consanguineous in the direct line and, depending on the circumstances, siblings. Adopted and foster children can also be regarded as the closest next-of-kin. According to circumstances, more particularly ➤

support of the Department of Medical Officers of Health, the doctor can forbear from complying with the closest next-of-kin's decision if this is patently at variance with the patient's interests.⁸

where there is no spouse, cohabitee or children, relatives the patient enjoys a close affinity with or is closely related to by marriage will also be eligible for consideration as close next-of-kin. The family relationship need not always be the deciding factor. In a particular situation, a person to whom the patient is closely attached will also qualify for consideration as the closest next-of-kin, e.g. a friend, a social-security guardian or a support and contact person." (Cf. *VEJ* no. 161 of 16/09/1998: Guideline on information and consent and on disclosure of health data etc., subs. 2.1.2.1.).

⁸ Cf. Lov om patienters retsstilling [Danish Act on the Legal Status of Patients], Section 9, subs. 4: "If the health professional considers the closest next-of-kin or the guardian, cf. subs. 1, to be managing consent in a way that will obviously harm the patient or therapeutic outcome, the health professional can carry out the treatment, provided that the relevant department of medical officers of health gives its endorsement for such.

3. Examples from the modern health service

Below, the Danish Council of Ethics will describe the problem of evaluating the state of health of the severely ill and dying person, as encountered in hospitals. The difficulties to be focused on here are bound up with "modern hospitalized death", if you like, where doctors with expertise in different fields work with the rest of the healthcare staff to form a joint assessment of the patient's health. It is a great challenge for hospital staff and management to ensure that well-founded decisions can be made about treating and refraining from treating. Among other things, it calls for good communications with the healthcare staff and the medical specialists about the individual patient pathway and the patient's overall condition.

The following examples from the modern health service illustrate various problems relating to decisions as to whether or not something is futile.

3.1 Illustrating the difficult choice

Patient case history

An 89-year-old man is admitted to a medical ward with an impaired level of consciousness, vomiting and diarrhoea, with a resultant lack of fluids, low blood pressure and dysuria (infrequent urination).

The patient has type-2 diabetes. As a result of his diabetes he has kidney complications, and he is also suffering from heart disease as a result of arterial sclerosis (hardening of the arteries). He has a history of cardiac embolism and was admitted a month ago with cerebral embolism. Since then he has not been able to walk, and he has an indwelling bladder catheter. On admission the patient is hazy and disoriented in time, space and patient givens; he seems to understand but does not reply when addressed.

Fluid therapy is commenced. The patient is given diuretic

medication and a drip set up with glucose water, containing glucose, insulin and potassium (GIP infusion). It is decided that there is no indication for treatment with kidney dialysis or, in the event, resuscitation.

The following day the patient is very tired, but he is alert, contactable and gives relevant replies to questions. He eats very little, virtually nothing, and still has diarrhoea. The medical ward consults the in-house renal expert and it is established that there is no indication for dialysis or medicine to stimulate the heart and circulation.

Five days after hospitalization, the patient contracts a fever and there is discharge from inflammation of the urethra. Treatment with antibiotics is initiated, and it is again noted in the record that resuscitation is pointless.

On the sixth day the patient's condition deteriorates. His blood pressure drops, there is low oxygen content in the blood, bluish discolouration of the skin and cool extremities. He is attended by a junior medical doctor, who starts oxygen therapy (oxygen through a nasal catheter) and fluid therapy. Following ward rounds a few hours later, various blood and stool samples are ordered, as well as fluid balance measurements every third hour. Suspecting blood poisoning, treatment is commenced with three different antibiotics. The patient is considered to be suffering from moderate dehydration and to be in shock owing to blood poisoning (septic shock). Dopamine drip treatment is therefore started to stimulate kidney function (dopamine is a chemical with a similar action to adrenal medulla hormones). The plan is conservative (i.e. expectant and non-active) treatment and there is no indication for intensive treatment or, if relevant, resuscitation.

On the seventh day after hospitalization, paralysis of the facial nerve occurs. The patient is drowsy but responds with a nod when addressed. There is no indication for neurological surveillance. After conferring, a gastric tube is put in place with a view to tube-feeding. A check X-ray, however, shows that the tube has been mispositioned. It is therefore removed with a view to deciding whether or not to re-install it the following day.

On the eighth day the patient is uncontactable and does not react when addressed or respond to pain stimuli. Since the patient's prognosis is poor, there is judged to be no reason to start tube-feeding. Intravenous fluid is still administered (GIP and dopamine drips). It is

noted that if the patient comes to, a fresh decision must be made about tube-feeding.

By the eleventh day the patient has been tapered off the dopamine drip. There is still no progress, and active treatment is deemed futile still. On the record it is noted that if the condition remains unchanged for 3-4 days, tube-feeding must be considered rather than GIP drip.

On the fifteenth day tube-feeding is initiated since the condition remains unchanged.

Apart from the evening of the sixteenth day, when the patient looks up when addressed, he is uncontactable, and he dies eighteen days after being admitted.

This case history is a partial reproduction of a longer one. As presented to the Danish Council of Ethics, there are no details about any contact there may have been with the next-of-kin, and needless to say it cannot be inferred that such contact—which the Council considers particularly important—did not take place.

Like this one, with hindsight, many therapeutic procedures can easily end up appearing to reflect a rather erratic course, but in any given situation this need not be the case, so it is not necessarily censurable. And indeed, the case history is intended above all to illustrate how difficult it is to make decisions in such situations. In addition, the following comments also need to be made on the example:

The patient is an old man who suffers multiple organ failure, partly owing to blood clots in both brain and heart. At the time of hospitalization, the central nervous system, the gastrointestinal tract, the circulation and the kidneys are impaired, and it is decided to refrain from intensive treatment (e.g. dialysis) and not attempt resuscitation, should the situation arise. During the 18-day course of the illness at the hospital the patient undergoes various diagnostic examinations and medical interventions, which are more or less incongruous with the decision to adopt a line of therapeutic reticence.

For example, on the eighth day tube-feeding is not considered warranted if his condition fails to improve. Some days later consideration is given to replacing the intravenous fluid drip with tube-feeding, precisely because his condition is poor and remains unimproved. (As to the indications and reasons for administering

intravenous fluid and tube-feeding, see page 76ff.)

Different diagnostic tests conducted on the sixth day ought possibly to have been undertaken even on the first day, when the patient's symptoms gave cause for such tests. Results of the tests and samples, and more frequent evaluation of data from the patient's central nervous system, gastrointestinal tract, circulation and kidney function might have resulted in faster elimination of therapeutic choices, including treatment with dopamine, for example.

3.2 Special problems relating to PVS patients

Patients in a persistent vegetative state (PVS) are people who, owing to irreversible damage to the brain, have permanently lost consciousness as well as all other functions apart from the most basic biological mechanisms, such as the cycle between the waking and the sleeping state. The patient can feel nothing and has no alertness, either to himself or to the world around him. This state is called "vegetative" because a person in such a state is alive only in the crude biological sense, and all the other abilities and qualities we associate with human life are lost to the person. Under current Danish legislation, PVS patients fall under point 2 of a living will about situations in which the patient has lost the ability to take care of himself, mentally and physically. In the event of the PVS patient having expressed the wish, through a living will, not to receive life-prolonging treatment in such a situation, this wish is for the guidance of the doctor, but not legally binding. A PVS patient is not covered by point 1 under a living will since the patient cannot ipso jure be defined as terminally ill.

The patient is not suffering from a disease diagnosed as fatal but is living in a chronic state of unconsciousness that has very little or no chance of changing. Conversely, albeit seldom, the state can persist for months or even years if life-prolonging treatment is not discontinued. In Denmark there has not been very much public debate about these kinds of patients and their treatment, and legislation in the field is somewhat fuzzy⁹. Abroad, however, human

⁹ Cf. Vestergaard, Jørn (2000), p. 413: "Patients in a comatose, pseudo-comatose or a persistent vegetative state may be mentioned in this context, too. The law concerning such cases is somewhat unclear, and fundamental ethical and legal issues regarding discontinuation of treatment for such patients have not been a focus of debate in Denmark".

plights like this, in particular, in which people have been utterly reduced to mere biological life, have fuelled the debate on futile life-prolonging treatment.

3.2.1 Three illustrative court rulings from abroad

In cases concerning PVS patients the conflict between two very influential ethical basic values is brought to a head: on the one hand, the notion of the inherent value and sanctity of life, and on the other hand the ideal that dictates that we have the welfare of the patient in mind. Three cases from the USA and the UK will illustrate this conflict.

In two cases the final outcome at the courts of law was that medical authorities were able to withdraw artificial feeding and other life-prolonging treatment for the patients, who would subsequently slide into death. But the rationale behind the ruling was different in both cases¹⁰:

In the case of Nancy Cruzan from the USA, the next-of-kin had to prove that on the balance of probabilities the patient had voiced a desire not to be kept alive, were she to end up in a hopeless and terminal situation like the one in which she actually found herself now. The case came down on the side of the next-of-kin, purely because they were able to present the Supreme Court with sufficiently credible evidence of Cruzan's wishes. Ethically speaking, this ruling is founded on the principle that the value of the individual's life can only be assessed by the living person himself, and that life-prolonging treatment cannot therefore be withdrawn unless there is a well-founded supposition that the patient himself has stated a wish to this effect. Here, then, it is the patient's self-determination that is considered weighty enough to override the principle of sustaining life, irrespective of the nature of that life.

In the case of Anthony Bland from England, on the other hand, the ruling was based exclusively on deliberations as to what best served the patient. Bland was a 17-year-old boy who had become persistently vegetative as a result of a tragic accident at a football stadium in Sheffield, where many people lost their lives. In this case the procedure was at no point a matter of finding out whether Bland had expressed wishes about what should happen to him in such a situation. The issue being explored here, rather, was to assess when

¹⁰ See Singer, Peter (1999), p. 297ff.

life is such that the person living it can no longer have any interest in maintaining it. The case of Anthony Bland is significant for two reasons. Firstly, it breaks with the principle that the inherent value of life is incontrovertible and that a person's self-determination is the only right that can override the principle of sustaining life. Secondly, the case is an example of an instance where withholding artificial sustenance and other treatment is done neither at the request of informed consent nor with the primary purpose of alleviating the patient's suffering, since the patient was so profoundly unconscious as to be free of pain. The decision to withdraw artificial feeding, which led to death, was based on the evaluation that a person entirely void of consciousness and feeling about himself or the world at large (and with no hope of this changing) cannot possibly have any interest in maintaining his life.

A third case from 1989, that of Helga Wanglie in Minneapolis, is ethically speaking one of a conflict between, on the one hand, the next-of-kin's right to demand continuation of life-sustaining treatment and, on the other hand, the right of the doctors and the hospital to discontinue treatment they deem to be futile. Helga Wanglie was an 87-year-old woman admitted to hospital after a fall, with a resultant hip fracture. At the hospital it became necessary to support the woman's breathing with a respirator. It was later decided to transfer the woman to another hospital in the hope that she might come off the respirator here. However, Helga Wanglie suffered a cardiac arrest during this readmission. She was resuscitated, but her brain had suffered irreparable damage and she was now in a persistent vegetative state. She was transferred back to the original hospital, where she was on a respirator and received nourishment through a tube. When Helga Wanglie had been persistently vegetative for several months, the doctors ascertained that continuing the treatment was pointless. But Helga Wanglie's husband and children agreed that this would be a wrong decision. On the strength of their own and the patient's philosophy of life, they insisted most adamantly that her life be sustained, regardless of the odds of any improvement. The case was brought before the courts and finally ended in 1991 with Helga Wanglie's husband being awarded the right to make surrogate decisions on the health of his spouse. This, then, is an example of a case in which regard for the next-of-kin's outlook, and not least the credibility of the next-of-kin's statement about his spouse's outlook, was weighted more

heavily than the doctors' assessment of the futility of treatment.

What would the outcome of such a case be in Denmark?¹¹ It is worth noting that the answer depends on whether or not the PVS person is perceived as being terminally ill. If the patient *is* perceived as terminally ill, then in legal terms and in principle it is the doctor who has the right to decide to discontinue the life-sustaining treatment. If the person is not perceived as terminally ill, it is the closest relative who has the right to make any decisions concerning the patient's medical treatment. However, it is not altogether clear whether proxy consent also applies in cases involving decisions about life-sustaining treatment. No direct stance has been taken on this in the Danish Act on Patients' Legal Status and it is thus the next-of-kin or the guardian who is basically able to make decisions regarding life-sustaining treatment of permanently incompetent patients. If the next-of-kin's or the guardian's decisions harm the patient or the result of the treatment, however, the health professional can carry out treatment with the support of the Department of the Medical Officers of Health.

3.2.2 Ethical aspects

In the event of a person being in the persistent vegetative state, which is to say without any internal perception of the self or the world at large and with minimal prospects of being able to return to life, regard for that person's next-of-kin and for society, in particular, should perhaps be the determining factor in sealing the person's subsequent

¹¹ In its letter of 11 July 2001 the Danish Council of Ethics asked the National Board of Health, Denmark, about attitudes and practice in relation to persistent vegetative patients. The National Board of Health's reply of 4 March 2002 draws attention to a rough definition of "the terminally ill" (cf. page 53, note 25). Examples of the terminally ill listed include: "Patients with irreversible failure of multiple organ systems (e.g. heart, lungs, kidneys, liver) where, despite maximum support therapy, continued deterioration of the physiological functions is seen". It is not clear whether persistent vegetative subjects can be subsumed by this definition, and the Board provides no answer to this, just as they cannot provide information about medical practice or about the number of PVS patients in Denmark. However, the reply does mention: "For each individual patient a concrete evaluation must always be made by the doctor in attendance of the patient's condition and prospects as well as the therapeutic options available, and it is the doctor's responsibility to undertake this all-round evaluation and act on it accordingly, under the responsibility vested by the Danish Medical Act, *inter alia*."

fate. To what extent the actual PVS person can even be said to be involved in weighing up the ethical considerations depends on the degree to which a human being felt to be entirely devoid of consciousness or feelings can have any interest in the outcome of a decision whether or not such life-prolonging treatment should be kept up. On the face of it, there would seem to be only two factors that can advocate such a decision being capable of making any difference to the PVS person.

Two possible regards for the PVS patient

Firstly, it is obvious that there may be some interest in clinging to the chance, however small, of "awakening" from the persistent vegetative state. Even a microscopic chance of re-awakening to some sort of life is worth taking on board, precisely because the patient does not suffer in the slightest from being kept alive. Whether or not the person concerned would wish to be kept alive, based on this interest, thus depends how diminished and disabled a life the individual would consider it worth waking up to again.

Secondly, it is worth highlighting one form of interest that is not linked to the patient's current or eventual chances of re-experiencing something. It is fair to assume that a form of objective interest associated with the person's autobiography must be taken into account, i.e. regard for whether or not the person in question would have any desire to preserve his biological life for as long as possible. The decision here might be based on some evaluation of what fate the actual person would presumably have found most apt in relation to his own autobiography without having allowed for the patient's lack of opportunity to experience the state in question.

3.3 Special problems concerning people with dementia

Dementia sufferers make up a rather large group of principally elderly people. The current situation is that the majority of care-home residents suffer from dementia to some degree. Dementia puts a topical slant on ethical dilemmas specifically related to decisions to withhold or withdraw treatment owing to the fact that demented people are generally conscious and, to a limited extent, able to express their condition and needs, whereas their intellectual ability to function is so diminished that others necessarily have to make

decisions on their behalf.

Dementia does not refer to one illness, but a whole series of conditions characterized by impairment of the intellectual functions—especially the memory. Alzheimer’s disease is the most common and best known illness that causes dementia. Blood clots in the brain and intense alcohol abuse also deserve a mention, however, and these are merely two of more than a hundred possible causes of dementia.¹²

In the case of Alzheimer’s, dementia typically progresses in such a way that there is a gradual deterioration of the memory and other intellectual functions. This is also followed by weakening of the physical condition: the walking function is impaired, control of urine and stools ceases, and finally the ability to sit up disappears, just as the swallowing reflex gradually ceases to function. As a rule, this process lasts 1-2 years, and once the patient is no longer able to sit up with support, life expectancy is normally limited to 2-3 weeks. Apart from memory loss, dementia caused by circulatory disturbances in the brain leads to these patients suffering from increasing fatigue and deep sleep. They often develop more cerebral haemorrhaging or blood clots in the brain, and these may be the direct cause of death.

At any rate it is true to say that dementia is a disorder that occurs in many different degrees (mild to severe dementia) and at many different stages (incipient to advanced dementia). Depending on the degree or stage, a demented person can have more or less poor recall, better or worse motor function; the sufferer can be aggressive and extroverted or more introverted, in a good or a bad mood, and so on. A characteristic of demented people, therefore, is that far into the progression they will be able to formulate their feelings and desires, albeit in a limited way, while at the same time being unable to be said to be capable of exercising self-determination.

Proxy consent, and the role of the next-of-kin in particular, becomes especially crucial when treating the demented during their latter days. It is extremely important that decisions be made while enjoying good contact and dialogue with the next-of-kin. A Danish questionnaire survey of the next-of-kin’s satisfaction with doctors’ provision of information to the dying and themselves shows that only just over half were satisfied, while every fifth respondent expressed

¹² Cf. Dr Gunhild Waldemar, MD, at www.sundhed.dk

out-and-out dissatisfaction. The cause of dissatisfaction most frequently cited, incidentally, was that doctors did not allow themselves enough time to inform the dying person or the next-of-kin. In addition, there was dissatisfaction that the next-of-kin did not have access to a dedicated interview room where they could enjoy some privacy. One consistent feature of the survey, which included 462 responses out of 619 forms sent out, was that doctors' solicitude and information were rated lower than those of healthcare staff. But there was a preponderance of "don't know" responses to questions about respondents' satisfaction with doctors' information-giving and care for the dying. This may possibly mean that the doctor simply does not have sufficient contact with the next-of-kin. Incidentally, the degree of dissatisfaction was considerably less in the case of intensive wards than in the case of medical and surgical wards.¹³

Patient case history about good communications with the next-of-kin and a good end to life for a demented man

A 65-year-old man diagnosed with Alzheimer's dementia as a 55-year-old spent the final years before his death in close-care accommodation for the demented. He had a spouse and two grown-up children.

His wife was a nurse with specialist skills in the field of dementia, acting throughout the course of the dementia as the primary care-giver and providing the spouse's informed consent.

The man was physically healthy, conscious and able to cooperate, but he was severely demented and needed help with everything, including eating, which took place in the form of feeding. He had had incorrect swallowing during bad periods.

The patient was first admitted because he became uncontactable in connection with Stesolid treatment for convulsions. After 36 hours he was sent home after having received intravenous fluid therapy. The patient's swallowing function was failing.

A short while after, he was re-admitted for a few days owing to pneumonia. He was treated with antibiotics, fluids and nourishment through an intravenous drip and a gastric tube. His condition stabilized and the swallowing function was assessed as normal. The patient nevertheless retained the tube to the stomach, partly to ensure the intake of medicine. The patient was subsequently discharged to his

¹³ Cf. Andersen et al., 2001.

close-care accommodation. During the next two days he jerked the tube out twice. His wife and his GP wondered whether the continued failure of his swallowing function resembled previous episodes or whether there had been some deterioration in condition.

Owing to the continued malfunction in his swallowing, he was admitted a third time. A gastric tube was again put in place and fluids administered intravenously. On the second day of admission, in a conversation between a consultant, a nurse and his wife, it was felt that his condition was due to progression of the dementia. It was agreed to wait and see and to discuss the situation again 10 days later. At that time, a decision would be made whether or not to stop treatment. There was agreement that all treatment, including the artificial supply of food and fluids, should cease if there was no improvement in the advanced dementia on the tenth day. In that case the artificial supply of food and fluids would serve a solely life-prolonging purpose.

On the ninth day the patient pulled the gastric tube out twice. His wife was sure at that point that the spouse's life was on the verge of ending. During the agreed conversation on the tenth day, it was agreed to cease treatment, including food and fluids. Although there was consensus on the evaluation and the decisions, it was essential for the wife to know that the doctors had expressed the view that they regarded treatment as futile. She agreed with the decision but was not held responsible.

After the meeting on the tenth day, the staff at the patient's close-care unit were contacted. Discharge was planned subject to an agreement that any pain treatment would be controlled by the hospital doctors dealing with the patient.

The patient passed away quietly and peacefully after a further ten days, having shown no signs of thirst, pain or fear. In the wife's opinion, a contributory factor was that he was being cared for by staff who had known him for a long time and were used to looking after him.

Withdrawing treatment, and particularly withdrawing the artificial supply of food and fluids, are sensitive subjects that require deliberation and good communications between health professionals and a demented and dying person's next-of-kin. For both the next-of-kin and the health professionals it may be hard to accept that the supply of nutrition to a living person must be terminated. Firstly, many people will perceive the provision of sustenance as an

altogether basic provision of care that to all intents and purposes should never be strayed from by choice. Secondly, it is unpleasant if a next-of-kin believes that the dying person is going to thirst and suffer without an intravenous supply of fluids (for more details about this, see the following section). In the sequence above, demented patients' inability to ingest fluids and food was indeed felt to be an inevitable part of the progression of incurable dementia. Thus the artificial delivery of food and fluids could be viewed as life-prolonging treatment that could be interrupted. The patient case history thus highlights how decisions about withdrawing artificial nutrition delivery can be made in a comfortable manner.

3.3.1 Ethical deliberations in connection with tube-feeding and intravenous fluid infusion

An American study on the withdrawal of life-prolonging treatment in 211 dying patients showed that intravenous fluid supply was far and away the most frequently occurring life-prolonging treatment and at the same time the one doctors were most reluctant to withdraw.¹⁴ A Norwegian study further showed that intravenous fluid supply is routine "when hospitalized patients are no longer drinking enough during their last days".¹⁵ In a Danish retrospective study of 15 dying AIDS patients the most frequent reason for starting and continuing intravenous fluid supply was the mere observation that patients were not drinking enough.¹⁶

The rationale, often unuttered, behind intravenous fluid therapy and tube-feeding seems to be a concern that the patient will experience thirst or hunger. The provision of food and fluids is regarded as a moral obligation because the experience of hunger and thirst is one of the worst things imaginable. To this must be added the fact that doctors and nurses do not always think of tube-feeding and intravenous fluid supply as treatment proper. Despite being a not entirely uncomplicated technical intervention, it is nevertheless equated with ingesting food and drink the natural way. Fluid therapy, therefore, is indiscernibly institutionalized as an action motivated by

¹⁴ Asch, David A. et al., 1999, p. 155.

¹⁵ Venborg, Annegrete & Bodil Forman (2000).

¹⁶ Venborg, Annegrete & Bodil Forman (2000).

ethical and humane reasoning—quenching another’s thirst and assuaging his hunger.

In order to understand why this attitude to intravenous fluid supply in the dying even involves ethical deliberations, it is worth explaining briefly that reduced water content in the body (dehydration) resulting from the sparing intake of fluids in the dying is not an obvious indication for fluid therapy. Of course, there can be good reasons for initiating or maintaining tube-feeding and/or intravenous fluid supply, but since the treatment often entails drawbacks for the dying patient, it is important as a health professional not to think of the treatment as obligatory. Fluid therapy through a probe or intravenous drip may not only be pointless in some cases, but even out-and-out problematic, because it does more harm than good.

Symptoms of dehydration include thirst and dryness of the mouth. Physiologically, these two symptoms are not identical, but they can be perceived by the patient as one and the same phenomenon. Thirst, or the desire to drink, is a neurological signal to redress the fluid balance by drinking, whereas dryness of the mouth can be a physiological result of dehydration or be due to other determinants such as earlier radiation treatment. The dying person’s feeling of thirst is often impaired. Dehydration in a dying person is not necessarily critical, therefore, in the same way as in otherwise healthy subjects.

The old dictum was: “The patient must not go thirsty whatever happens”. The paradox is that, taking this as a basis, it is possible to end up overtreating a presumed objective state in the patient’s organism (dehydration as a result of observed sparing fluid intake) and undertreating the patient’s subjective symptoms (dryness of the mouth). In other words: dehydration is treated, whereas the feeling of thirst, which in the dying is closely bound up with dryness of the mouth, is not countered. In the Danish study already mentioned of 15 dying AIDS patients, all patients were given an intravenous fluid supply, whereas only a few received regular dental and oral hygiene care¹⁷.

Moreover, the artificial delivery of nutrition through a probe or drip does not—as has been assumed—prevent e.g. bedsores by improving the state of nutrition, nor does it safeguard against

¹⁷ See Venborg, Annegrete & Bodil Forman (2000).

incorrect swallowing and the possibility of resultant pneumonia (aspiration pneumonia). What is more, the treatment can even have adverse consequences and entail a series of discomforts not offset by a corresponding palliative or curative effect¹⁸. As well as the inconveniences of implanting a tube or installing a drip with infusion fluids, a number of side-effects occur that are connected with the actual supply of fluids: Oedemas (fluid build-ups) including those of the skin, the GI tract and the airways, which can lead to a poorer supply of blood to the skin and a tendency to nausea and breathing difficulties. Furthermore, the treatment can produce an increased tendency to infection, increased secretion in the airways and greater incontinence. (For a dying patient, limiting e.g. incontinence may translate into considerably improved quality of life because the person avoids having to go through the tricky installation of a catheter, bed-changing, bedpans and so on.) Finally, fluid therapy through a probe or drip impedes scope for social contact and makes for general malaise. This is particularly the case if the treatment is accompanied by various forms of fixation in order to prevent the patient jerking the probe or drip out of the vein.

The conclusion is that in a dying and possibly also demented patient, discontinuing the administration of food and fluids is often more considerate than continuing it. There are other ways of supporting the patient than by technological medical aids: open and close contact with the patient, frequent visits, touching, massage etc.

3.4 The agonizing situation and the wish to die

Patient case history from a hospice

A 58-year-old man is admitted to a hospice from an ear, nose and throat ward. He has cancer of the pharynx, spreading to the surrounding tissue. There is no possibility of a cure. He has been treated with radiotherapy and has had a tracheostomy (opening from the windpipe to the front of the neck), since his breathing was threatened.

The patient has no voice and cannot swallow. He is being fed with the aid of a gastric tube. He is plagued by pain which is difficult to relieve, and by ptyalism (excessive salivation) with periodic bleeding. He has to constantly sit with serviettes and bags. The jaw and neck have changed radically as a result of the disease and the radiotherapy.

¹⁸ See Finucane, Thomas E. et al. (1999), Gillick, M.R. (2000), and Kaasa, Stein (1998).

Both on arrival at the hospice and for the following three days, the patient repeatedly and clearly makes it known (by writing on a communicating pad) that he wishes for a swift death, his reasoning being that "this is excruciating", for his family too.

Pain and salivation are successfully brought under control, however, and he now enjoys a few days of calm with frequent visits from spouse and children. There is good, intense contact, and he makes no mention of this death wish. But when he develops breathing trouble and the pain worsens, he again becomes unsettled and desperate.

Since the patient is terminally ill, it is decided to offer a more continuous supply of sleeping medicine (palliative sedation), deemed to be the best and only form of relief in the current situation. The patient, who is alert and lucid, is informed that he will become drowsy without feeling respiratory distress or pain. The patient is also informed that he will no longer be able to communicate. With a nod and visible signs of relief, he indicates that this is his wish. The spouse and two children, aged 25 and 27, are involved in the deliberations and also express relief, finding the proposed solution to be the right one. Furthermore, there is agreement between the physician in charge and the nurses looking after the patient, who have come to know him. A few doses of the sedative are given in order to gauge its effect. The continuous supply is then brought on stream via a hypodermic needle. The patient settles down and sleeps peacefully—until death occurs 2? days later. The wife and one of the children are present.

3.4.1 Ethical deliberations in connection with palliative sedation¹⁹

The case history raises the question of whether it is acceptable to alleviate a dying patient's suffering by drugging, that is to say by placing the patient in a more or less unconscious state²⁰. The treat-

¹⁹ It should be noted that in early 2003 the National Board of Health, Denmark, published a guideline on drug-based palliation during the terminal phase. By the very nature of things, the Council of Ethics has not had a chance to incorporate this guideline in its work on the present report.

²⁰ A Norwegian report from 2001 (*"Palliative sedation for the dying. Guideline proposals"*) distinguishes three degrees of palliative sedation. The mildest degree is called drowsiness. Here the patient has very limited experience of stimuli, but can be aroused by shouting and so on. The next step is full sedation, in which the patient does not experience anything but still maintains vital functions such as breathing spontaneously. The last and "strongest" form of sedation is called surgical anaesthesia level. Here the patient's breathing and circulation must be kept going artificially.

ment can be called palliative sedation for the dying, though terminal sedation is a common expression for the same action. “Palliative” is a better term, however, since the aim of the treatment is not to “terminate” the patient’s life but to allay his suffering. Palliative sedation can therefore be defined in the following way: “Palliative sedation for the dying is a treatment in which medication is given to reduce consciousness with the purpose of alleviating suffering that cannot be remedied in any other way”.

The treatment has been a controversial issue, however, because palliative sedation for dying patients often persists until such time as death occurs. Some people, therefore, will think that it can be difficult to separate palliative sedation for the dying from assisted suicide, or even that such treatment is a form of “slow assisted suicide”. But palliative sedation for the dying is not assisted suicide. Unlike normal pain therapy, which deadens the pain in order to support a relatively positive experience of life, palliative sedation eliminates the experience of life (the consciousness) in order to eliminate the suffering. Based on well-meant intentions, assisted suicide can be said to serve the same purpose (eliminating suffering) but the difference is, of course, that assisted suicide removes the actual life.

Palliative sedation is a treatment whose primary intention is to eliminate the patient’s suffering by deliberately reducing the patient’s consciousness. This reduction of consciousness may be complete, so that the patient experiences or perceives nothing at all. Naturally, then, it is a more radical intervention than ordinary pain therapy and should only be initiated as a last resort. In Denmark it is permitted for doctors and regarded as an ethically acceptable option to administer pain therapy which, as an inadvertent side-effect, can result in accelerating the time of an otherwise inevitable death. The reason for this is that alleviating suffering can be more important in some cases than ensuring maximum life expectancy. Although there is no consensus as to whether palliative sedation per se is life-shortening, the ethical reasoning for palliative sedation must overlap partly with the reason for accepting life-shortening pain therapy. The common feature is that suffering is weighed against the patient’s scope for preserving his awareness of living.

However, it is questionable whether the actual dying person can have any interest in being kept unconscious if, for the sake of alleviating suffering, this condition is going to persist till the onset of

death. In the Norwegian report on palliative sedation alluded to, the problem was phrased thus: “The purpose of medicine is traditionally to contribute to making possible the experience of life and self-expression, whether done by prolonging life or improving conditions for the quality of life. This purpose is not addressed if the patient is kept unconscious until life peters out”. At first sight a parallel can be drawn with the aforementioned PVS patients: If it is granted that their state is futile and legitimizes the withdrawal of life-prolonging treatment, how can it be legitimate to actually send a dying patient into the same state? Advocates of assisted suicide might, at a stretch, aver that palliative sedation of the dying does the same as assisted suicide, only in a way that transforms the final days of a patient’s life into an unconscious state that some will find unhappy and undignified. The argument may therefore be that actual assisted suicide on demand would be a more humane treatment. One of the essential counterarguments to this is that palliative sedation includes a cooling-off period when given in a way aimed at reducing consciousness, not shortening life. Sedation can be intermittently interrupted or reduced in order to gauge whether the suffering is still so severe that it cannot be remedied other than by palliative sedation.

As mentioned, it is a principle of Danish legislation that expediting death is legitimate if it is an inadvertent side-effect of palliative treatment. But how can one be sure that the doctor or health professional does not have an ambivalent intention, i.e. both to alleviate pain and to accelerate death? The Norwegian report provides a straightforward answer: there is no way of knowing or controlling subjective intentions. But the realized intention can be read from the way in which the palliative sedation is dosed. If the intention is to accelerate death, the drug will be given in doses higher than those needed to simply reduce the patient’s consciousness.

4. The Council's deliberations and recommendations

4.1 The Council's recommendations on decision-making capacity

In what follows, the Danish Council of Ethics wishes to concentrate mainly on an ethically grounded stance on the position of decision-making capacity in cases where the terminally ill person is incapable of exercising self-determination and decisions relating to medical treatment of the patient can no longer be made purely on the basis of the doctor's professional insight into the patient's state of health. The reason for focusing on this situation is first and foremost that this is primarily where doubts can arise as to whether the professionally competent doctor is the one who should make and be accountable for the final decision. All the Council's members, however, subscribe to a practice that gives the doctor final responsibility for the decision while simultaneously giving the doctor and the healthcare staff the duty to dialogue with the incompetent dying person's next-of-kin and listen to what they have to say about the patient's life and presumed wishes.

4.1.1 The doctor should still have the final decision-making capacity

The Council of Ethics thinks that the doctor should still be the one with the definitive authority and competence, as well as the responsibility, for decisions concerning treatment or cessation of treatment for terminally ill patients incapable of exercising autonomy. The Council of Ethics does not feel, therefore, that next-of-kin should be able to override the health professional's decision concerning treatment of incompetent and terminally ill patients, not even in cases where treatment decisions cannot be said to have been made solely on the basis of medical indications, but involve an overall evaluation of what is best for the patient. The doctor, then, should still be responsible for clinical decisions relating to incompetent and dying patients, including when a choice between, say, discontinuing

and continuing life-prolonging treatment has no predictable therapeutic significance except to actually prolong life.

The Council of Ethics adopts this stance on the grounds of its conviction that, in principle, only the patient is in a position to make decisions that involve evaluating the kind of life the person concerned wishes to maintain, and hence *when* that person no longer wishes to have life-prolonging treatment. The patient's self-determination must be respected to the greatest possible extent, but once a dying patient has lost his ability to grant informed consent, it must be realized that it cannot be replaced completely by any representative or proxy from either the health professionals or the next-of-kin²¹.

²¹ In this connection it should be mentioned that the Council of Ethics voiced its agreement in 1998 concerning the continued assignment of decision-making capacity for organ donation to the next-of-kin closest to brain-dead individuals (see "*Organ Donation—Informed or Presumed Consent?*", available in English, Council of Ethics, (1999). Some of the Council's members thought that the next-of-kin's possibility of rejecting organ donation in cases where the donor had granted his express consent for such should be maintained. Others felt that a change of law would ensure that the next-of-kin's decision is only admissible when no decision is available on the part of the deceased (in the form of a donor card or some other statement about donation). The closest next-of-kin's decision-making capacity was and remains safeguarded in these cases by the Danish Act on Medical Examination of Bodies, Autopsy and Transplantation etc. However, the obvious question here is, with what reasoning ought the closest next-of-kin be able to exercise surrogate consent for a brain-dead person, whereas they ought not to have ultimate responsibility for decisions relating to life-prolonging treatment of the incompetent and the terminally ill. In both instances, after all, the patient's self-determination has been irreparably lost. The Council of Ethics believes there are two crucial differences between the two situations:

1. If you accept that brain death is a death criterion, you also accept that the brain-dead person does not have the interests and rights of a living person. On that basis you may say that the next-of-kin's decision-making capacity as regards organ donation does not hinge primarily on surrogate protection of the brain-dead person's interests, but rather on the protection—legitimate in this case—of their own interests in relation to their deceased relative or friend. The incompetent and terminally ill individual, on the other hand, is a living person incapable of expressing his wishes about life-prolonging treatment. In ethical terms, then, the interests and concerns decisive to the treatment of a deceased person are different to those for a dying person. Therefore, it is ethically acceptable to entrust the decision-making capacity to the brain-dead person's closest next-of-kin, but not to the dying person's next-of-kin.

If responsibility for treating the incompetent dying patient reverts to the doctor, therefore, it is not because the doctor is seen as a representative of the patient. On the contrary, it is because self-determination is regarded as having been irretrievably lost in this situation, with a concomitant need to have the decision-making process guided by other principles. The patient no longer has the scope, within what is acceptable and legal for the medical profession, to make end-of-life decisions based on his own life values and wishes. In this situation the Council of Ethics recommends that doctors and health professionals base their actions on the principle of preserving life and on regard for the good of the patient.

4.1.2 The principle of preserving life

In order to avoid any chance of interests other than those of the dying subject becoming a motivating factor for medical decisions, the doctor should embrace the principle of maintaining life as his basis. This general principle is particularly relevant in situations where neither regard for the good of the patient nor consultation with the next-of-kin produces any basis for a decision. The next-of-kin, after all, may disagree over what should be done, and in that situation it

2. Another important difference between the two situations is comprised by the next-of-kin's role as decision-makers. In both cases the next-of-kin will have to arrive at some decision concerning matters in which they are heavily involved emotionally; and subsequently have to live with the awareness of bearing the responsibility for this decision. But the consequences of bearing the responsibility for a decision about life-prolonging treatment of a terminally ill person can be more serious than cases that involve shouldering the responsibility for a decision concerning organ donation. If the next-of-kin are having grave doubts about organ donation, they will often plump for the "safe" solution of saying no, as a matter of course. In such cases, any subsequent doubt or change of heart regarding the decision will not be a matter of having done the right thing or not for the person in question. Rather, at most, it is possible to conceive of some people being in two minds as to whether, with their decision, they failed to help prospective recipients of healthy organs. Decisions to continue, initiate or terminate life-prolonging treatment in a dying patient may give rise to rather thorny deliberations. Even though the doctor will be obliged to give his assessment of when a treatment only sustains life for a short while and does not enhance the quality of life, the next-of-kin will always be potentially in two minds as to whether their decision—not to initiate treatment, say—shortened the dying person's life unduly. Such doubt will pose a severe existential strain on the next-of-kin, one that advocates placing actual decision-making capacity with the doctor, who is not emotionally involved in the same way.

would be wrong of the doctor to opt for the solution expected to produce "least" sustenance of life. It would be just as wrong of the health professional to terminate life-prolonging treatment, unless it were rooted in consideration for the good of the patient, even if the next-of-kin wished the opposite, based on his statements, for example about wishes guided by the patient's religious beliefs.

Possible grounds for justifying decisions to discontinue treatment might be regard for an equitable distribution of resources in the health service, or might be that the doctor felt he was more familiar with the patient's wishes than the next-of-kin. The latter possibility has been excluded, since this would be an inappropriate attempt to act as a representative of the patient's self-determination. The first line of reasoning may appear cynical, but must nevertheless be taken seriously because priority-setting in the health service is absolutely imperative. Any evaluation of resourcing, however, must never undermine people's confidence in the expectation that the health service will do its utmost to preserve life, unless there are weighty reasons militating against such. For this very reason it is important for doctors to have the requisite tools and proficiency to assess medical futility or what amounts to the same thing: to assess which health-specific reasons are weighty enough to refrain from attempting to maintain life in cases where the patient himself has made no decision to this effect.

4.1.3 Regard for the good of the patient

Where a patient can make a rational case for his wishes, such statements will form such an essential source in evaluating how best to serve the patient that the patient's requests should always be complied with unless he requests something that is illegal or expressly falls outside the doctor's remit. If a dying patient is incompetent and cannot express his wishes, on the other hand, the doctor will be required to decide what a person with the ability to feel pain and pleasure would want in the situation under review.²²

²² Cf. Olsen, Henrik Palmer (1997), p. 22: "The objective test repudiates the idea that it is supposed to be possible to reconstruct the patient's self-determination, stressing instead the importance of assessing whether the burden in the form of pain etc. through being kept alive is outweighed by the benefits of preserving life". See also: Center for Bioethics, University of Minnesota (1997), p. 7: here a distinction is made between three standards: a subjective standard, a substituted judgment standard and an objective standard.

In their assessment of what serves the good of the patient, the healthcare staff should, of course, regard the next-of-kin as the best “witnesses” of the patient’s life values and wishes, even though they will never be able to become guardians and assume decision-making capacity. Along any clinical pathway the dialogue with the next-of-kin will usually have a great bearing on the doctor’s decision to cease or continue life-prolonging treatment. There will often be no conflict if the doctor’s assessment is that treatment will involve considerable pain and minimal improvement; and in situations where the doctor’s impartial assessment of the patient’s situation cannot yield any clear-cut choice between terminating and pursuing treatment, it will often be the next-of-kin’s contribution to the assessment that weighs most heavily on the scales. Yet even in these cases it is important to establish that the doctor is the one responsible for the decision. An additional reason for this is that such responsibility will often be far too heavy a burden with which to shoulder the next-of-kin, who are deeply involved emotionally.

Summary

The Council’s members find that the doctor should have the final competence and hence full responsibility for decisions relating to life-prolonging treatment of terminally ill patients who have permanently lost their capacity for self-determination. Doctors and the rest of the healthcare staff should involve the next-of-kin as the most essential source of information about the patient’s life values and wishes, but not as representatives of the self-determination which the patient has irretrievably lost the ability to exercise.

4.2 The Council’s recommendations on assessing futile treatment

As emerged from the discussion in Chapter 2, it will always be a great challenge for doctors and nursing staff to assess what is expedient and correct in professional medical terms, and to gauge the patient’s or next-of-kin’s preferences based on values. In the terminally ill, clinical decisions about different life-prolonging or palliative therapies have a direct bearing on whether the dying person will experience a death process in keeping with the life values the person lived by. On the one hand it is a task for the health service, wherever possible and within the limits of the law, to accommodate patients’ and next-of-kin’s

requests regarding such value-based preferences. On the other hand it is inappropriate to think that the way we die can be fully controlled and, as it were, made to measure like some bespoke commodity. Consequently, the worst conceivable rule of thumb for a doctor in these situations will be to envisage the patient purely and simply as a resource-intensive consumer. Instead, it is only fitting to view care for the dying patient as a task requiring *communication in a situation full of powerlessness*.

When doctors and nurses have to assess whether it is beneficial to initiate, withhold or withdraw medical diagnosis and treatment of the terminally ill, the Council of Ethics believes that they might do well to bear in mind the following:

- 1) The best possible plan should be made, taking into account status and responsibility.
- 2) There should be the best possible dialogue with the patient and/or next-of-kin.

1) The best possible plan, taking into account status and responsibility

It is crucially important to forge a treatment plan as early on as possible, attempting to clarify the extent to which curative or palliative treatment is to be initiated. In the patient case history set out on pages 65-67, for example, there seems to be no such plan. For the sake of a patient's overall course, it is a high-priority ethical requirement at hospitals to create an opening for the doctor in charge to attend the patient and draw up a treatment plan as early on as possible during the hospitalization period.

Status

In order to plan and implement a course of treatment with the proper weighting between treatment to combat symptoms and any reticence concerning more or less intensive medical operations, it is important to know as much as possible about the patient's health status and life situation generally. The choice is often more complicated than the choice between curing a patient's illness and merely alleviating the suffering entailed by the illness. Rather, the assessment will often hinge on whether such efforts have any bearing on how the patient can carry on living with underlying diseases. This is particularly true

of the dying, of course, where the objective is not to cure but to preserve or optimize the quality of life.

Evaluating how aggressive medical efforts should be thus depends entirely on the medically founded supposition about the state to which such efforts can return the patient. Every hospital ward, therefore, should do its utmost to obtain relevant knowledge, not merely about the patient's current symptoms but also about the state of health the person was in during the pre-admission period. Taking the patient case history on pages 65-67 about the 89-year-old man with diabetes as a starting point, it is worth highlighting that it would have been important to know, *inter alia*, how the patient's kidneys, heart and central nervous system were working after the most recent discharge from the hospital, following his admission for cerebral haemorrhaging. In addition, of course, it is vital that the patient's status include not merely current symptoms but also factors like general condition (and hence ability to withstand disease and respond to treatment), and intellectual function, vigour and mobility prior to hospitalization. It would also be relevant to have information from the care home about the patient's attitude to being admitted: Whether he was willing to undergo intensive treatment, or whether he was more resigned as a result of his advanced age and multiple health problems across the board. Any information about his wishes, approach to life etc. should be taken on board.

This pooled knowledge will then be used to make a prognostic assessment of the quality of life that could be achieved for the patient, subject to his health and in a best-case scenario.

Responsibility

Having someone take responsibility has a direct bearing on the patient's comfort and well-being, because it is a prerequisite to a cohesive, consistent and transparent progression. The dying person will often be old and suffer from a variety of different disorders, sequelae and organ failure. Given that there are so many strands to keep together, the emphasis is on the general importance of coordination between the doctors involved and responsible governance.

2) The best possible dialogue with patient and/or next-of-kin

It goes without saying that high quality of communication with the patient is recommended. It is also important to involve the next-of-

kin in as open and confidence-building a process as possible—not only to form a picture of the patient’s life aims and wishes but also to ensure that the next-of-kin understand the kind of examinations and treatments the patient is going through. A Finnish study of next-of-kin’s experiences of futile treatment shows that there is an increased likelihood of the next-of-kin considering medical intervention futile when they are unhappy on the whole with the treating institution and their dealings with it.²³ It is only natural for the next-of-kin’s judgement of individual actions and decisions to be coloured by a generally poor relationship of trust.

Informed consent on the part of a legally competent patient

The information from doctor to patient should include a comprehensive description of the incurable disease as well as a description of the therapeutic options (including treatment opt-outs) available and the probable consequences of each (cf. Lov om patienters retsstilling [Danish Act on the Legal Status of Patients], (1998), Section 7, subs. 1-6). The patient can then decide on the treatment options open to him. The doctor can offer the patient advice with regard to which of the possible treatments the doctor feels is best, based on his specialist, expert knowledge and experience. In all likelihood the doctor will very frequently have a crucial consultative role, and the patient will have faith in the doctor’s assessment. With regard to the patient’s self-determination, this means that the patient should have a genuine opportunity to make up his mind without any advice other than that consisting of a description of the disease, professionally sound treatment options (possibly including omission of treatment) and their consequences.²⁴ Especially in cases where a patient opts out of life-prolonging treatment, it is crucial that doctor and care staff provide detailed and extensive information about the patient’s palliative care options and heed the patient’s wishes as regards organizing them. It is important that the patient has no doubt that, even if he declines a particular medical treatment, there will be no let-up in nursing and care. The treatment also includes spiritual care for the patient, i.e. attending to

²³ Miettinen T.T. & Rejo S. Tilvis (1999), p. 29.

²⁴ Cf. also General Medical Council (2002), Section 30: “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”.

the patient's spiritual needs (on this subject, see: The first report in this publication *Spiritual Care for the Dying—Statement from the Danish Council of Ethics*).

Conversations about treatment options during the final period and decisions about possible withdrawal or opting-out of treatment are very difficult for the patient, of course. The Council of Ethics therefore feels that the doctor should inform the patient about the possibility of a next-of-kin or some other familiar person being able to join in the conversation, if the patient so wishes. At the same time, however, it needs to be realized that this in itself can cause difficulties. For instance, it is not certain that the patient's and the next-of-kin's concerns will be the same or will be expressed in the same way or at the same time.

If the legally competent patient and the doctor have different assessments of whether a treatment is futile

Conflicts may arise if the patient's choice goes against the grain of what the doctor views as good medical practice. This may be the case, for example, if the patient wishes for treatment which the doctor considers futile and of more harm than good to the patient. For instance, it might be a case of a terminally ill patient voicing a wish to undergo a course of intensive medical treatment, e.g. a "chemo-cure", or wanting major surgery which, in the doctor's judgment, will be futile either because the chances of a felicitous outcome are very small or because the treatment, if successful, will yield a very short respite.

In such cases the doctor ought to take pains to accommodate the patient's wishes, as the patient's desire to live as long as possible, regardless of his current state and prognosis, should be assigned major weight. But if the doctor regards the operation as capable of inflicting undue suffering on the patient, he ought to express this to the patient clearly, possibly on the grounds that it is a doctor's duty to provide the patient with the best possible treatment.

By questioning, if need be, the doctor can investigate whether the patient has a more or less precise idea of his health situation or the prospects held out by the relevant treatment. Conversely, of course, the doctor should also listen to the patient's views to find out whether there is anything in them that may change the doctor's opinion that the particular treatment is futile. If the patient is well informed and

still wishes for some treatment the doctor considers unjustifiable, the doctor should seek advice from qualified colleagues and possibly entrust responsibility for treatment of the patient to another of these doctors.

Discussion with a non-competent patient's next-of-kin about withdrawing, initiating or withholding treatment

Whenever possible, the next-of-kin of a legally incompetent terminally ill patient should be involved in the decision-making process, based on the argument that the next-of-kin are the best witnesses of the dying person's life. On the other hand they should not be regarded as surrogate decision-makers for the dying person.

Involving the next-of-kin not only serves the purpose of obtaining information about the dying person's wishes and previous state of health; it is also for the sake of the next-of-kin themselves. First and foremost, it is the dying person's interests and well-being that doctors and care staff must attend to. But that does not mean that the next-of-kin are not also entitled to care in a situation where decisions so vital to the life and death of a close one are going to be made. The next-of-kin's relationship with the dying person is intimate and existentially decisive in an entirely different way to the relationship between healthcare staff and the dying. For example, the next-of-kin's recollections of the dying person's final period will have great resonance for them after the event. Naturally, it is important for doctors and care staff to do whatever is within their power to inform the next-of-kin and create a climate of dialogue in which the next-of-kin perceive that there is openness and time to talk about their worries and views concerning the dying person's course of treatment.

4.3 The Council's recommendation concerning the patient's right to have treatment withdrawn

The Danish Act on the Legal Status of Patients gives competent patients the right to informed consent. Informed consent involves the right to forego treatment, i.e. the patient can refuse to have treatment carried out and can demand that any treatment already initiated be interrupted. If a patient can be defined as terminally ill, this right of self-determination applies absolutely; but if the patient wants to be able to live longer with life-sustaining treatment—a respirator, say—

and withdrawing this will lead to the patient's immediate death, the doctor cannot comply with the patient's request to interrupt treatment without the potential occurrence of a conflict with the Danish Penal Code provision on killing on demand. In the explanatory notes to Section 6, subs. 3, of the "Bill to Amend the Danish Practice of Medicine Act (provisions concerning information and consent)" that entered into force on 1 October 1992, it thus states: "Interruption of treatment by a doctor at the patient's request resulting in the decease of the patient immediately thereafter will, however—provided that the requisite intent may be presumed to be present—qualify, depending on the circumstances, to be regarded as covered by Section 239 of the Danish Penal Code on killing on demand, cf. white paper 1184/1989, Chapter 2". As regards non-terminally ill patients, then, a discrepancy may arise between a doctor's obligation not to coerce a competent patient and the duty to observe the Penal Code. In other words, if the doctor abides by the letter of the law, the doctor can end up in a situation where he infringes other provisions in the legislation, whatever he does. If the doctor refuses to interrupt treatment at the request of the competent and non-terminally ill person's request to do so, that doctor will be duty-bound to adhere to treatment that has been refused, thus violating Section 6 of the Danish Act on the Legal Status of Patients. If, on the other hand, the doctor interrupts treatment and this leads to the immediate death of the patient, Section 239 of the Danish Penal Code on killing on demand may have been infringed, depending on the circumstances.

Out of respect for patient and doctor alike, the Danish Council of Ethics wishes to insist on the competent patient's right to determine whether treatment offered should be initiated or treatment already implemented should be withdrawn. This should apply, therefore, even if opting out of the treatment leads to the patient's immediate death. It must be emphasized that, in the Council's opinion, this is not a matter of assisted suicide. The Council of Ethics therefore recommends that current law be qualified in this way, so that the competent patient's right to demand that treatment be extended applies in equal measure to the terminally ill and the non-terminally ill. The doctor must not be laid open to doubt as to whether it is actually legal to comply with the patient's rightful wishes.

Appendix 1:

Legal provisions concerning decision-making capacity in connection with treating the dying

General rules concerning information and consent in connection with medical treatment

In the Danish Act on the Legal Status of Patients (Consolidation Act No. 272 of 1 July 1998) the basic principle is that the actual patient determines whether he will agree to receive the treatment chosen by the doctor in accordance with his professional competence as the best in the case in hand.

The doctor's duty to exercise diligence and conscientiousness —Section 6 of the Danish Medical Act

Section 6 of the Medical Act invests the doctor with the authority—and the duty—to choose the best treatment in medical terms (Practice of Medicine Act—Medical Act (Consolidation Act No. 272 of 19 April 2001, Section 6): A doctor exercising his profession shall be obliged to display diligence and conscientiousness, including in the economical prescription of medicinal products, drugs, use of an assistant etc.).

Consequent to the provision in Section 6, doctors are obliged to observe the standard of good medical practice in force at any time. The content of this standard must be laid down partly by the National Board of Health, Denmark, and partly through the practice of the Patients' Board of Complaints.

The provision takes the form of a legal standard, and specific evaluation of whether a doctor has shown the necessary diligence and conscientiousness will change with time and medical developments. What is regarded as careful and conscientious medical practice depends not only on medical knowledge and technical possibilities but also on the requirements society makes of the doctor's activities and otherwise created by social developments in general.

The patient's decision-making capacity

The principal rule in Section 6 of the Danish Act on the Legal Status of Patients concerning informed consent entitles the patient—through his informed consent—to determine whether medical treatment should be initiated or continued. For the patient this right is a right to accept or reject the treatment option proposed by the doctor on the basis of his professional judgement. Sections 6 to 12 of the provisions of the Act on the Legal Status of Patients regulate the obtention of informed consent. Respect for the principle of self-determination, however, is closely bound up with the principle that the patient also has the right "not to know". The patient can ask not to be told information, if that is what the patient wishes.

As regards children under the age of 15, the custodial parents make the decision about treatment. Whenever possible, the child must be informed and involved in the decision unless this can harm the child, cf. Section 11. Children who have attained the age of 15 have the authority to make up their own minds about treatment. However, the custodial parent must also be given information, cf. Section 7, and be involved in the minor's decision.

Section 6,1. No treatment may be initiated or continued without the patient's informed consent, unless otherwise specified in law or by provisions set down in pursuance of law or by Sections 8-10.

Subs. 2. The patient can retract his or her consent at any time in accordance with subs. 1.

Subs. 3. In this Act, informed consent shall mean consent granted on the basis of comprehensive information given by the health professional, cf. Section 7.

Subs. 4. In accordance with this Part, informed consent may be written, verbal or, depending on the circumstances, tacit.

Subs. 5. The Danish Minister for Health shall stipulate further rules governing the form and content of such consent.

Section 7. The patient is entitled to obtain information about his or her state of health and about available therapeutic options, including the risk of complications and side-effects.

- Subs. 2.* The patient is entitled to ask not to be given information in accordance with subs. 1.
- Subs. 3.* The information shall be provided continuously and shall convey a comprehensible account of the disease or disorder, the examination and the treatment contemplated. The information shall be given in a considerate fashion and tailored to the recipient's individual conditions with regard to age, maturity, experience and so on.
- Subs. 4.* The information shall include details of relevant preventive, therapeutic, and nursing and care options, including information about other, medically defensible treatment options, as well as information regarding the consequences of not initiating treatment. The information shall be more extensive if treatment entails an obvious risk of serious complications and side-effects.
- Subs. 5.* Where the patient is otherwise deemed to be ignorant of considerations of significance to the patient's decision—cf. Section 6—the health professional shall provide information about this, in particular, unless the patient has asked not to receive information, cf. subs. 2.
- Subs. 6.* The Minister for Health shall stipulate more detailed rules concerning the form and content of the information.

Minors

- Section 8. Any patient who has reached the age of 15 can provide his or her own informed consent for treatment. The custodial parent shall also be given information, cf. Section 7, and shall be involved in the minor's decision.
- Subs. 2.* If, on the strength of an individual assessment, the health professional considers a patient who has attained the age of 15 unable to understand the consequences of his or her own decision, the custodial parent can provide informed consent.
- Subs. 3.* A patient who has reached the age of 15 is entitled to access personal documents in accordance with the provisions in Part 4 and can grant consent for the disclosure of health data etc. in accordance with the provisions in Part 5.

Patients permanently incapable of granting consent

For a patient who is permanently incapable of granting informed consent, the rule is that the closest next-of-kin can provide informed consent for treatment. If a patient is under guardianship, the guardian is the one to make the decision. If there is no closest next-of-kin or guardian, the health professional can carry out contemplated treatment if another health professional who has professional insight into the field, and neither has taken nor plans to take part in treating the patient in question, provides his endorsement for such. The rules governing this will be found in Section 9 of the Danish Act on the Status of Patients:

- Section 9. For any patient permanently incapable of granting informed consent, the closest next-of-kin can provide informed consent for treatment. However, in cases where the patient is under guardianship that covers personal aspects, including health conditions, cf. Section 5 of the Danish Guardianship Act, informed consent can also be granted by the guardian.
- Subs. 2.* If a patient permanently incapable of granting informed consent has no closest next-of-kin or guardian, the health professional can carry out contemplated treatment if another health professional who has professional insight into the field, and neither has taken nor plans to take part in treating the patient in question, provides his endorsement for such.
- Subs. 3.* In cases covered by subs. 2, however, the health professional can carry out contemplated treatment without the involvement of another health professional if the treatment is less invasive in nature with regard to scope and duration.
- Subs. 4.* If the health professional considers the closest next-of-kin or the guardian, cf. subs. 1, to be managing consent in a way that will obviously harm the patient or therapeutic outcome, the health professional can carry out the treatment, provided that the relevant department of medical officers of health gives its endorsement for such.

Wherever possible, the incompetent patient shall be informed and involved in the decision unless this may harm the patient, cf. Section 11.

The right to undertake urgent treatment (instant treatment requirement)

If a patient is unconscious or for other reasons does not have the ability to decide for himself, and there is a situation which is life-threatening, the health professional shall be entitled to undertake treatment that is vital or in some other way urgent.

Section 10. If a patient temporarily or permanently incapable of granting informed consent or under the age of 15 is in a situation where instant treatment is required for the patient's survival or to improve the patient's chances of survival in the long term or to yield a materially better therapeutic result, a health professional can initiate or continue treatment without the consent of the patient or custodial parent, closest next-of-kin or guardian.

Involvement of the patient

Section 11. A patient unable to grant informed consent himself/herself shall be informed and involved in discussions of the treatment in as far as that patient understands the therapeutic situation, unless this may harm the patient. Where topical and germane, feedback from the patient shall be attributed importance.

The health professional's responsibility

Section 12. The health professional responsible for the treatment is obliged to see to it that

- 1) informed consent is obtained in accordance with Sections 6-8 and Section 9, subs. 1,
- 2) there is endorsement from another health professional in accordance with Section 9, subs. 2,
- 3) there is endorsement from the relevant department of medical officers of health in accordance with Section 9, subs. 4, and
- 4) the patient is informed and involved in discussions of the treatment in accordance with Section 11.

Rules for the dying—situations involving a right or duty to abstain from vital treatment

In certain instances the doctor will be entitled—or even obliged—not to commence or continue therapeutic measures.

The doctor's right to abstain from treating is primarily of importance where such measures are only (briefly) able to defer the time of the incompetent patient's death.

A patient is terminally ill when there is every likelihood of death foreseeably occurring within days or weeks despite having resort to the therapeutic options available. Deciding whether the patient is terminally ill is a purely professional medical assessment.²⁵

Opting out of life-prolonging treatment

The patients and the doctors in charge are authorized to opt out of futile treatment and resort to the necessary palliatives, even if this involves shortening a patient's life, where the patients involved are terminally ill.

Section 16 of the Danish Act on the Legal Status of Patients entitles the patient to opt out of treatment if terminally ill (Section 16, subs. 1). In the event of the terminally ill patient no longer being in a position to exercise his right of self-determination, the health professional has the right to refrain from instituting or continuing life-prolonging treatment (Section 16, subs. 2).

Section 16. A terminally ill patient can reject treatment that is only able to defer the occurrence of death.

Subs. 2. If a terminally ill patient is no longer capable of exercising his or her right of self-determination, a health professional can refrain from instituting or continuing life-prolonging treatment, cf. Section 17, subs. 3.

²⁵ In Denmark there is no clear-cut definition of when a person is terminally ill. The nearest we get to a definition is to be found in a guideline issued by the National Board of Health, Denmark, which deals with doctors' obligations in relation to living wills. Here it states: "In general, it is not possible to define the situations and time-frames in which a patient is terminally ill. In terms of the contents of a living will, the Board takes the view that a patient is terminally ill when death is expected in all likelihood to occur within days or weeks, despite having resort to the therapeutic options available, based on the available knowledge of the underlying disease and any resulting conditions. Cf. National Board of Health, Denmark: Guideline No. 158 of 15 September 1998.

Subs. 3. A terminally ill patient can be given painkillers, sedatives or similar drugs needed to relieve the patient's condition even if this may bring about acceleration of the time of death.

Living wills

The Danish Act on the Legal Status of Patients, Section 17, provides for the possibility of a patient indicating his wishes as to what should happen if he ends up in a situation where the right of self-determination can no longer be exercised by the actual patient. Section 18 obligates the Minister to set up a register of living wills, which the doctor is bound to consult in cases where consideration is being given to undertaking life-prolonging treatment on a patient who cannot exercise the right of self-determination and is terminally ill.

Section 17. Anyone having attained the age of 18 and not under guardianship that covers personal aspects, including health conditions, cf. Section 5 of the Danish Guardianship Act, can make a living will. In that living will the person in question can express his or her wishes with regard to treatment, were he or she to enter a state in which the right of self-determination can no longer be exercised by the actual patient.

Subs. 2. In a living will, inclusion can be made of provisions to the effect that:

- 1) no life-prolonging treatment is desired in a situation where the testator is terminally ill, and
- 2) no life-prolonging treatment is desired in the event of disease, advanced senile decrepitude, an accident, cardiac arrest or suchlike having inflicted such severe disablement as to render the testator permanently incapable of taking care of himself/herself physically and mentally.

Subs. 3. Life-prolonging treatment shall mean treatment where there is no prospect of cure, improvement or alleviation, but purely of some degree of life extension.

Subs. 4. If, in the event of the actual patient not being capable of exercising his or her right of self-determination, a health

professional is contemplating initiating life-prolonging treatment of a terminally ill person or continuing life-prolonging treatment in a situation as mentioned in subs. 2, no. 2, the health professional shall contact the Register of Living Wills, cf. Section 18, with a view to checking whether any living will exists.

Subs. 5. The testator's wish in pursuance of subs. 2, no. 1, shall be binding on the health professional, whereas a wish in accordance with subs. 2, no. 2, shall be for the guidance of the health professional and shall be included in the latter's deliberations concerning treatment.

Section 18. The Minister for Health shall set up a register of living wills and shall lay down further rules governing the creation, formulation, registration and retraction etc. of a living will.

Subs. 2. The Minister for Health shall lay down provisions concerning fees for the registration of living wills.

Withdrawal of treatment

The rules of the Danish Act on the Legal Status of Patients cover both initiation and continuation of treatment. In principle, then, a patient can also demand that treatment already started be interrupted, even if that treatment is vital for life. However, a proviso is that a patient does not have the right to demand withdrawal of treatment where the situation is that death is not ineluctable and complying with the patient's request will have the effect of bringing about the immediate decease of the person in question. Any doctor complying with the patient's request in this event may incur criminal liability, depending on the circumstances (see the Council's recommendations on this point, pages 92-93).

As a general rule, a doctor is not authorized to single-handedly withdraw life-prolonging treatment of a terminally ill, mentally competent patient once already initiated. A thing like this must not be done contrary to the patient's wishes, and the patient's consent will normally be a proviso. The doctor could not just summarily withdraw respirator treatment, oxygen or fluid supply, therefore, even if it were possible to ascertain with certainty that the patient would have but a very short time left to live anyway. This is stipulated for the purpose of

the general principles governing information and self-determination, including the obligation set out above to organize treatment in accordance with the patient's wishes.

Alleviating terminal patients' suffering (palliative treatment)

The attending physician is entitled to use palliative drugs if the patient is terminally ill, even though this may bring about acceleration of the time of death. If the patient is unconscious or in some other way lacking the requisite competence, the use of painkillers depends on the attending physician's considered judgement.

If the patient is mentally competent, the legality of using painkillers so as to possibly accelerate the time of death in some way presupposes that informed consent is available in the customary fashion.

The legality of this treatment presupposes that the administration of palliative drugs is not aimed at causing the patient's death. And if the doctor's actions are undertaken with intent to kill the patient, the doctor may be held criminally liable, either for wilful murder or, depending on the circumstances, killing on demand.

Killing on demand

The current legislation may result in the following conflict: On the one hand a patient has the right to determine whether he wants to discontinue life-preserving treatment. The doctor may not continue the treatment forcibly but nor may he, say, turn off a respirator with the result that the patient immediately dies. This may constitute an infraction of the Danish Penal Code provision on killing on demand. Section 239 of the Danish Penal Code states:

“Any person killing another at the specific request of the latter shall be punished with up to three years' imprisonment or not less than 60 days' simple detention.”²⁶

²⁶ Cf. the Council's recommendation on pages 92-93 “concerning the patient's right to have treatment interrupted” and the comments on Section 6, subs. 3, in the Bill to Amend the Danish Practice of Medicine Act (provisions concerning information and consent), which came into force on 1.10.1992: “Interruption of treatment by a doctor at the patient's request resulting in the decease of the patient immediately thereafter will, however—provided the requisite intent may be presumed to be present—qualify, depending on the circumstances, to be regarded as covered by Section 239 of the Danish Penal Code on killing on demand, cf. white paper 1184/1989, Chapter 2”.

A patient who is not terminally ill thus has no right to have treatment withdrawn if compliance with the patient's request will have the effect of bringing about the death of the person in question immediately or within the space of a very short time. Any doctor complying with the patient's request for such may, depending on the circumstances, incur criminal liability for killing on demand.

Concluding comments

The ranking of the right to determine medical treatment and interventions for dying patients who are incompetent therefore depends on the following three questions:

1. Is the patient terminally ill?

As mentioned, a patient is terminally ill “when death is expected in all probability to occur within days or weeks despite resort to the therapeutic options available.” Deciding whether the patient is terminally ill is a purely professional medical assessment. If a patient *is* terminally ill, the health professional has the right of determination. If the patient is not terminally ill, the guardian or closest next-of-kin assumes the incompetent patient's informed consent as his basis. As mentioned in section 3.2, a PVS patient, for example, can be perceived as a patient who is not terminally ill. If the health professional considers a guardian or closest next-of-kin to be making a decision that may harm the patient, that person can carry out the treatment against the wishes of the guardian or next-of-kin if the health professional receives the endorsement of the relevant department of medical officers of health. Moreover, it can be argued on the strength of other provisions of Danish law that the health professional is the one who should have the decision-making capacity to treat incompetent patients when the decision involves life and death. So the next-of-kin/guardian cannot refuse to have an incompetent patient treated with blood or blood products, nor do they have decision-making capacity where the patient is terminally ill cf. Sections 13-16.

If the patient is incompetent and terminally ill but has completed point 1 of the living will (see the “Living wills” section in this appendix), the doctor will be obliged to accommodate the patient's wish. In principle, therefore, the patient himself has the right of determination here, even if he is currently incompetent. If the incompetent patient has completed point 2 of the living will, this is for the doctor's guidance.

2. Will treatment withdrawal possibly result in the patient dying immediately afterwards?

If the patient is not terminally ill, depending on the circumstances, withdrawing treatment may constitute an illegal action if this subsequently results in the immediate decease of the patient. In such a case the competent and non-terminally ill patient does not have the right to demand the withdrawal of treatment. The health professional, therefore, is not obliged—nor, depending on the circumstances, entitled—to comply with such wishes. (See the Council’s recommendation on amending this provision in the “Recommendation concerning the patient’s right to have treatment withdrawn” on pages 92-93.)

3. In the situation involved, does the health professional’s right to undertake urgent treatment apply?

The doctor is entitled to initiate urgent, vital treatment when the patient is incompetent and not terminally ill. This applies both when the urgent treatment is potentially life-saving and when it is capable of securing a better therapeutic result (see “The right to undertake urgent treatment” section in this appendix). There may be times, then, in treating an incurable patient who is not terminally ill when the health professional is entitled to initiate treatment without obtaining the informed consent of the closest next-of-kin or guardian, but doctors are not duty-bound to do so.

Appendix 2:

Definitions of key concepts²⁷

Life-prolonging treatment:

Life-prolonging treatment is defined in the Danish Act on the Legal Status of Patients, Section 17 (on living wills), subs. 3:

“Life-prolonging treatment shall mean treatment where there is no prospect of cure, improvement or alleviation, but purely of some degree of life extension”.

Futile treatment:

The Danish clinical dictionary “*Klinisk Ordbog*” (1999) defines futile treatment thus: “Futile therapy: ongoing level of therapy which, even given a maximum level of input for the patient, brings about no improvement in the state of the critically ill person within days. The patient’s state is then referred to as futile, whereafter active therapy is limited or ceased altogether”.

An American work, *Taber’s Cyclopedic Medical Dictionary*, includes a number of descriptive words for the type of treatment in its definition: “Futile treatment. In clinical practice, any intervention that will not improve a patient’s health, well-being, comfort, or prognosis.”

In the English *The New Dictionary of Medical Ethics*, the concept is explained in context and perhaps from a slightly prejudiced point of view: “Futility is a term used to refer to medical *treatment* that is unlikely to achieve its desired aim, and thus to justify a medical judgment not to provide life prolonging treatment requested by ‘unrealistic’ patients, parents or relatives. Problems with the concept include the uncertainty of prognosis in individual cases, differing value judgments about probabilities worth chancing, and whose

²⁷ Sources: *Klinisk Ordbog [Clinical Dictionary]* Holm-Nielsen, Niels (1999), *Taber’s Cyclopedic Medical Dictionary*, Venes, Donald (2001), *The New Dictionary of Medical Ethics*, Boyd, Kenneth M. et al. (1997).

desired aims are to count. While doctors have no obligation to provide treatment they judge futile, careful explanation of the therapeutic options and efforts to reach a joint decision with the patient and/or family are preferable to invoking futility as a *fiat*.”

Decision-making capacity (DMC):

The New Dictionary of Medical Ethics: "The capacity to understand relevant information ('explained in broad terms and simple language'), to consider its implications in the light of one's own *values* and to come to a communicable decision. DMC may be partial or fluctuating, *communication* may be non-verbal, and the decision may be to let another person decide. Conscious patients should be presumed to possess DMC. If in doubt, the test (to be decided on the balance of probabilities) is not the patient's status ('patient' or 'too young/old') or the decision's outcome (whether it would 'be made by a person or ordinary *prudence*')—but whether the 'individual is able, at the time when a particular decision has to be made, to understand its nature and effects'. Legal tests of decision-making capacity for some purposes—e.g. making a will—can be more stringent than those for consenting to or refusing medical treatment”.

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Euthanasia

LEGALIZING KILLING ON REQUEST?



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Preface

The Danish Council of Ethics herewith publishes its report on euthanasia. The report is the third and final outcome of an ongoing project in which the Council has focused on ethical challenges and problems at the end of life. The report should be seen as an extension of the Council's previous two publications: *Spiritual Care for the Dying and Treating the Dying—The Difficult Decisions*.

This report, Euthanasia—legalizing killing on request?, deals with the question of whether it should be permitted for doctors in Denmark to take the life of severe sufferers and, in some cases, dying patients who so request. The report consists of three sections and an appendix on euthanasia legislation in selected other countries. The first section focuses on some concepts central to the linguistic usage that characterizes the debate on euthanasia. It also presents the Council's reasoning for using the term 'euthanasia' rather than "mercy killing" or "assisted suicide", which are in more general use in Denmark. The report's second section examines why the Danish Council of Ethics advises against the legalization of euthanasia, and the section describes the arguments against legalizing euthanasia, as represented to the Council. The third section contains a more in-depth and discussive examination of common arguments for and against euthanasia.

Section 2 on "The Council's arguments against legalizing euthanasia" thus forms the backbone of the report and can be read independently of section 3 on "Arguments for and against euthanasia". Section 3 gives the reader the possibility of acquiring greater background knowledge about the debate as a whole, not least about common arguments in favour of euthanasia, which are obviously not amplified in section 2. Members of the Council of Ethics do not necessarily support the individual views and arguments set out in section 3.

The Council of Ethics has continually discussed the report at its plenary sessions, adopting it for publication at its meeting in September 2003. The report has been drawn up on the basis of discussions on the Council's working party on "Life for the Dying". The chairman of the working party is Ole Hartling, the other members being: Mette Hartlev, Lisbet Due Madsen, Anette Roepstorff Nissen, Katrine Sidenius and Ellen Thuesen. Thomas Laursen, MA, project manager at the Council of Ethics' secretariat, acted as secretary to the working party and elaborated the manuscript.

Ole Hartling
Chairman

Berit Andersen Faber
Head of Secretariat

1. The concept of euthanasia

In this report the Council of Ethics takes as its point of departure the following definition of euthanasia: Euthanasia consists of a doctor taking the life of a severely suffering and possibly even dying patient who requests the doctor to do so.^{1, 2}

The Council of Ethics' line of argument against euthanasia must thus be seen as a counter to the argument in favour of legalizing such medical practice. Some adherents of euthanasia in the above sense propose that euthanasia should be an option available only to the dying who are severe sufferers, whereas others think that euthanasia should also be an option for people who are in a severely agonized condition but not necessarily dying in the medical sense.³ The Council of Ethics' argument against euthanasia holds good for both proposals.

The Council of Ethics uses the word 'euthanasia' rather than "assisted suicide" because, for the Danish reader at least, euthanasia, unlike the word 'assisted' in "assisted suicide", appears to be a less value-laden

¹ Reference is also made to the definition in Section 239 of the Danish Civil Penal Code, which any doctor performing euthanasia would now be in violation of: "Any person killing another in accordance with the specific request of that person shall be punished with up to three years' imprisonment".

² The Council of Ethics is aware that the term 'euthanasia' may evoke recollections of involuntary active 'assisted dying', especially on account of the German Nazi regime's euthanasia programme in the 1940s. But here the Council is only taking a stance on the question of whether to permit euthanasia, in the sense of taking the life of a human being at that person's request—which goes to the very heart of the present-day debate.

³ An elaboration of the complex issue of when a patient can be said to be dying will be found in part two of the present publication: Treating *the Dying—The Difficult Decisions*.

term and because euthanasia is an internationally familiar and customary term for the above practice. The Council of Ethics is sensitive to the fact that euthanasia (in ancient Greek) means “good death” and hence is not value-neutral either. With time, however, euthanasia has become a technical term, in which the loading is not nearly as clear as in the concept of “assisted suicide”.

2. The Council's arguments against legalizing euthanasia

With this statement the Danish Council of Ethics wishes to advise against the legalization of euthanasia. The Council's recommendation is unanimous but is based on a number of different lines of reasoning. The individual members of the Council attribute varying importance to these reasons and do not necessarily agree on all of them. The Council of Ethics' statement on euthanasia follows on from the Council's two previous publications: *Spiritual Care for the Dying* and *Treating the Dying—the Difficult Decisions*. The Council's attitude to legalizing euthanasia ties in with the recommendations and the outline of current rules set out in these two publications as they relate to the care that should be available for the dying and the suffering, and to the possibility of breaking off futile treatment. The first report mentioned thus focuses on tending to the existential and religious questions and concerns that arise on the part of the dying. In the latter report the Council gives its recommendations on palliative treatment and on the ethical issues associated with decisions concerning whether or not to cease futile treatment.

The following arguments are directed primarily against *legalizing* euthanasia and hence against putting in place a common and planned practice for euthanasia.⁵ The Danish Council of Ethics' members acknowledge that no one can dismiss out of hand the possibility of ending up in an extraordinary situation, born of necessity, in which the most correct thing may be to take the life of another human being. Some such situations may rightly be viewed as parallels to euthanasia. In each specific case, then, the act can be the

⁵ The Danish Council of Ethics takes as its basis the following definition of euthanasia: Euthanasia consists of a doctor taking the life of a severely suffering and possibly dying patient who asks the doctor to do so. It is thus noted that euthanasia in this context is used only of an act initiated on the basis of a voluntary request.

result of *force majeure*. However, it is not possible to predict or regulate *force majeure* type situations, and the Council of Ethics does not view the existence of *force majeure* as a key argument in favour of legalizing euthanasia.

2.1 Euthanasia is at odds with the inviolability of human life

The principle of the sanctity of human life is a fundamental ethical norm. Legalizing euthanasia is at odds with this norm and will be instrumental in undermining respect for life.

Regard for the person alive is not the *only* thing served by the principle of the inviolability of life. The principle should thus be adhered to because human life per se is characterized by deserving to be protected, which cannot *exhaustively* be explained on the basis of regard for the individual person and for the personal value life has for the individual concerned. The ban on taking the life of another human being is not detracted from *prima facie*, even if the person requests that an end be put to his or her life and even though the person is in a severely agonizing condition. The Danish Council of Ethics wishes to maintain that something invaluable is lost whenever a human being dies, irrespective of how the actual person, or others, values the life situation in question. For some, this view is further founded on a belief that man is created in God's image, while others do not wish to underpin their view religiously. However, the following approach is shared: a definitive agreement between two people to the effect that one will take the life of the other is tantamount to disavowing that life is *also* an end unto itself and cannot be definitively deemed worth less than dying. The value of life is not negotiable. Any relativization of the principle of the inviolability of human life will also mean that caring for ailing people does not consistently side with life as a matter of course. Nursing and palliative care should be confined to making life for the patient as bearable and good as possible until such time as death occurs. Removing the suffering by arranging matters so that there is no longer a patient to take care of, on the other hand, is a contradiction of the very nature of caring. The essence of caring consists of helping people as part of their existence. By supporting and alleviating the patient's physical and/or mental suffering, the carer's *intention* is to have the patient experience life as being more tolerable. Euthanasia cannot have this

aim, as the success criterion for euthanasia is to have the patient pass away and thus not experience anything whatsoever. Euthanasia, then, is not alleviation of suffering.

In specific instances, the ethical motivation for upholding the principle of the inviolability of human life is also rooted in the individual person's interest in preserving his or her life. That does not mean, however, that one can take the life of people who have declared they no longer have an interest in continuing to live, because for them death appears to be the better of two evils. Society's safeguarding of people's right to live is of such crucial importance to the possibility of a secure and good life between people that the existence of a blanket ban on taking people's life—be it on request or not—is necessary. Euthanasia cannot be legalized, therefore, for the sake of those extraordinary and rare cases where it might *possibly* be ethically acceptable to take the life of a human being at his or her request.

2.2 Euthanasia violates a taboo: thou shalt not kill

Legalization of euthanasia is at odds with a fundamental taboo that most people intuitively embrace with respect. In the vernacular, the word 'taboo' is used either of something not talked about or something not done (because it is wrong, without being able to justify it further). Here the word is used in the latter sense.

Many people will be able to imagine being in a situation where they themselves would wish to have their life taken because the situation was so hopeless and unbearable that death could only stand out as the lesser of two evils. But ask a person at random whether they would be capable of being the executor and taking the life of a close relative or some other person in distress, and the vast majority will readily reply that they could not. Anyone using their imagination to empathize with this situation will immediately be able to sense a stark aversion to being the one who takes the life of another. Such aversion is due not merely to the grief felt at the loss of a close person. It manifests itself when a similar aversion is experienced at the thought of taking the life of a stranger making the same request. It also makes itself felt in as far as the death of a close relative can in some situations be viewed as a release for all parties, without making the aversion to taking that relative's life any the less pronounced. In both instances the aversion and the distaste will be suffused with pity that the person

has to die and wishes to die. Moreover, that aversion will be characterized by the sense of weighty responsibility a person brings upon themselves in taking the life of another.

The members of the Danish Council of Ethics are aware that individuals who overcome the ban on taking the life of another in specific situations often do so out of compassion for another person. There is a conflict between two feelings, then, each laudable in its own right: compassion versus the aversion to taking life. Nonetheless, the Council of Ethics feels that the intuitive aversion to and distaste at the idea of taking the life of another person should direct any assessment of euthanasia and hence provide the reasons why its legalization should not take place.

2.3 Euthanasia is a misplaced response to suffering as a basic human condition

Legalizing euthanasia is unacceptable because a person is a person as long as he or she is capable of suffering. The view is that suffering is inextricably linked with the passion inherent in a person. Passion is the quality of being able to suffer, and that quality can no more be chosen than can other qualities: it is fate.

The view is grounded in religion, ultimately, making it impossible to define a person without taking suffering into the equation. Passion cannot be chosen, and no one is capable of changing it themselves. God alone can do that, and great changes as well as a general growth in passion can take place when suffering. Life conditions change as a result of suffering, and this can be a testimony to new meaning for the familiar and the acquired. Suffering is inflicted and lived through in the hope that a new and more profound reality is in the process of being revealed. The fact that people are capable of suffering is an allusion to a creative force, because suffering makes it perfectly clear that one is not a free agent. Euthanasia represents a radical challenge to this creative force because suffering is reduced to mere pain and fear. It precludes the possibility that it may also involve a time and a place for new hope, however short-lived that might be.

2.4 The Council of Ethics' attitude to autonomy in connection with euthanasia

One of the most frequent arguments adduced by adherents of euthanasia is that legalizing euthanasia promotes scope for enabling people who are suffering unbearably, possibly even dying, to exert greater influence over the way their last days are lived. It is the Danish Council of Ethics' view that this argument derives its quintessential strength from the widespread notion that the alternative to euthanasia in modern health services is to be kept alive by the technology of modern medical science for as long as possible, regardless of the suffering it might give rise to in the form of a severely reduced life. Often, then—though not always—the right to control one's own death is put forward on the basis of the postulated injustice that dying is supposed to have suffered at the hands of modern health service. Against this, the Council of Ethics would point out, firstly, that it is now possible in the vast majority of cases to relieve physical suffering for the dying. Particularly thanks to modern technology, pains and symptoms such as hiccups, nausea, itching, shortness of breath and so on can be remedied far better these days. Secondly, the Council finds that undignified death is not rarely associated with the dying being reliant on the help of others during the final period of life. But the fact that sick, ageing or dying people grow dependent on others' help has nothing, in the Council's opinion, to do with unworthiness. On the contrary, this beholdenness, this indebtedness is the positive counterpart of independence. These days average life expectancy is longer, and increasingly more can be done to save people with physical infirmities and disorders having to die from them, allowing them instead to live a useful life in spite of these. The important thing here is to give that help in a dignified way, not to avoid making people dependent on help at all costs. The Council of Ethics believes that it would be unfortunate if dependence were identified with a lack of dignity and if that view were cemented by society and fixed in people's self-knowledge. By contrast, society and politicians in particular need to do their utmost to strengthen care for the dying—palliative efforts and the creation of more hospice places—thereby ensuring that no one can justifiably argue in favour of euthanasia on the basis of the presumed bleak alternatives.

Moreover, two different forms of criticism of the autonomy-based line of argument in favour of legalizing euthanasia are represented on

the Danish Council of Ethics. The first is a criticism of the ideology generally underlying even the demand for self-determination and autonomy. The other focuses on the fact that, in practice, euthanasia is incompatible with actual self-determination for patients.

2.4.1 Criticism of the ideology surrounding autonomy

The desire to legalize euthanasia can be seen as an expression of a trend in modern society to assign priority to the ideal of personal autonomy in a way that is out of kilter with the actual conditions governing human life generally. The tendency to place personal autonomy at the centre is unfortunate, ethically speaking, because it ignores the fact that people are always *dependent* on one another's outlooks, decisions and judgements. It must be stressed that the members of the Danish Council of Ethics appreciate the individual's possibility of being accountable for his or her own way of life and for the ideals which the individual considers morally commendable and rewarding for life. Often, however, the ideal of personal autonomy also entails a notion that the individual is supreme in shaping his or her own identity by means of value-related preferences on which no one except the actual individual has any influence. Hence, the ideal of personal autonomy is also characterized by extreme individualism. This is a delusion that misdirects the focus away from the fact that the individual person is always *a priori*—i.e. prior to choosing this or that—a particular person by dint of the interhuman correlations and history with which that person is bound up. From this, the following conclusion is drawn in relation to an ethical assessment of euthanasia:

Legalization of euthanasia will depend on extending individualism with regard to patients' right to freedom of choice. The ever increasing focus on individual freedom of action will erode the alternatives (such as palliative initiatives and hospices), which are based on the premiss that suffering is relieved by interhuman care, not by endowing individuals with freedom of choice in terms of their death.

2.4.2 Exercising autonomy in connection with euthanasia is not possible

The institutional framework of health services will preclude euthanasia from being able to become the object of really autonomous choice with sufficient certainty. The following three factors, above all, mean that legalizing euthanasia actually restricts patients' autonomy:

The compulsion to choose

The provision of information and necessary dialogue between doctor and patient are such that, in practice, it will be impossible to implement an ideal model whereby that information and dialogue on euthanasia are only initiated once the patient has voiced a wish to this effect. Consent for any treatment is given on the basis of information about the therapeutic options available. Such information will invariably open up the choice-making situation for the patient, however neutrally it is attempted to provide the information. That is why suffering and dying patients are not free, in real terms, to choose to take a stance on euthanasia, if legalized. The entire group of patients for whom it is envisaged legalizing euthanasia is being burdened by *being empowered* to choose between life and death, even though such a choice might otherwise never have occurred to them, or they had no wish to be given such an alternative.

The overburdened patient

Choosing between life and death is an enormous task and a great responsibility to impose on a person in a very difficult situation to start with. Many factors will be taken on board as the patient weighs up the issue—for example, regard for next-of-kin and consideration of the medical advice given. This complex weighing-up process in a difficult situation is not the proper setting for an autonomous decision, as the scope for exercising autonomy will often not be present, given that the patient's capacity and competence may have been impaired by fear, despair, feelings of hopelessness and a sense of being unwanted—a state that can be almost quasi-psychotic.

Choosing euthanasia in the face of few alternatives

Conditions for autonomy are also impaired because there is a danger of euthanasia emerging as the best alternative in an environment where palliative efforts may be anything but adequate. Thus a patient may have an incentive for viewing euthanasia as a good opportunity if the nursing and medical facilities at the home or hospital are not up to par. The very risk of such a situation being able to arise weighs heavily in the decision to advise against legalizing euthanasia.

2.5 Euthanasia is incompatible with an ethically defensible patient-doctor relationship

Euthanasia is basically at odds with the ethics applicable to the medical profession. Legalizing euthanasia will mean that taking the life of another person becomes an act that it will be incumbent on physicians to perform by virtue of their profession. The fact that doctors must perform euthanasia will entail an unacceptable change in the practice of medicine and in the way patients and doctors engage and interact. In its ethical considerations, the Danish Council of Ethics finds that, overall, this will have a greater detrimental effect than any good that might come of exercising euthanasia in the case of the very few whose sufferings seem so unbearable and difficult to assuage that they can wish death upon themselves.

It is important to insist that a doctor's actions always serve the purpose of healing and/or alleviating disease and suffering in the context of illness and infirmity. It is also a task for doctors and other health-care professionals, therefore, to be conducive to helping dying people secure relief and thus have an opportunity to experience their final days as a time when life goes on being lived, without pain, fear and a lack of awareness entirely getting the better of the dying person and alienating them from their own life. So doctors have a responsibility to ensure that dying patients are given relief and nursing. In part, there is support to be had from the hands-on experience of hospices, where patients in agony can receive palliation, and an initial wish for euthanasia is not pursued because it ceases to be relevant in the course of the treatment. The Danish Council of Ethics does not think that definitively controlling the conclusion of life can fall within the practice of medicine by turning the doctor's actions into the actual cause of death. The ethics that establishes the framework for the medical profession must preclude any such means being taken into service. That applies despite the possibility that the patient or others may perceive euthanasia as the very means of bringing about a good end or preventing a poorer conclusion to life. The following aspects, in particular, should be highlighted in the rationale behind euthanasia being incompatible with medical practice:

The trust between doctor and patient is undermined

The patient's relationship with his or her doctor should be marked by

trust that the doctor's intention at all times is to cure disease and/or alleviate the patient's suffering. That trust is particularly important because the doctor has authority over the patient. That authority consists of the doctor having special insight into the patient's general state of health and thus occupying a privileged position as an adviser on matters of crucial importance to the patient's life. Legalizing euthanasia will mean that an alternative to alleviating suffering—namely eliminating the *life* that is suffering—will be added to the doctor's as well as the patient's considerations when deciding what treatments to initiate or omit. The patient may therefore doubt whether the doctor is able to discount euthanasia if this is given as an option. In other cases, however independent and used to assimilating information he or she might be—the patient will have to have greater faith in the doctor and be guided by the doctor's judgements. In this situation, too, the consequences can be unhappy: The trust in the authority responsible for the medical assessment that there is no longer scope for alleviation will thus influence the patient's decision to request euthanasia. For this and other reasons, the doctor and patient should not be able to consider euthanasia as an option.

Quality of life assessment should not lead to euthanasia

Proposals to legalize euthanasia include conditions that, in order to be allowed to choose euthanasia—as a last resort—a person must be suffering unbearably. Assessing this is the responsibility of the doctor, irrespective of whether euthanasia is proposed as a negative or a positive right. Very few envisage euthanasia being freely available to everyone on demand, so that the doctor's evaluation of the patient's condition plays a great part, even if it is intended to safeguard the patient's autonomy in full. Since actual sustenance of life is being weighed on the scale opposite suffering, the doctor's evaluation will centre to a worrying extent on what condition it is no longer worth living in, what lives are not worth preserving. Graduating the value of human life is precarious in its own right, and vesting special authority to gauge the value of life in a particular—and in this context, random—professional group can only be additionally precarious. In this respect, in 2003 the Danish Council of Ethics can endorse the view in its 1996 majority statement on euthanasia, which says: "Doctors are not, by virtue of their profession, in possession of any special technical or moral expert knowledge that entitles them of all

people to have special powers conferred upon them in connection with decisions to shorten life. Any such decision is not medical by nature” (Council of Ethics, Denmark (1996), p. 136). To this, supporters of euthanasia might perhaps say that doctors already make life-shortening decisions on the basis of their assessment of the value of life, i.e. when they decide to desist with or omit life-prolonging treatment for those terminally ill who are not legally competent. Yet that is not correct. In the view of the Danish Council of Ethics, the key ethical difference between letting someone die and shortening life in contexts where a patient is suffering from an incurable disease will be that euthanasia as an act is sufficient to bring about death, whereas averting life-prolonging treatment is not sufficient per se to cause death. In the case, for example, of patients in a persistent vegetative state, the treatment can be said to have been originally initiated for the purpose of improving the patient’s condition. Accordingly, removing life-prolonging treatment is rooted in a judgement that the treatment does not serve the purpose for which it was originally initiated. By contrast, euthanasia is not an action that relates to whether or not a previous treatment was successful. Euthanasia can be viewed as an essential new action with a purpose all of its own.

2.6 Legalizing euthanasia imposes on others a duty to kill

Legalizing euthanasia will mean that the law of the land makes it a duty to take people’s life in some situations. Thus, in reality, euthanasia will not merely be an exception to the *ban* on killing on request, but an *order* for doctors in certain situations (when there is a request and when the patient is suffering unbearably and may even be dying) to take people’s life. The Danish Council of Ethics does not feel that legalizing euthanasia is practicable without engendering such an obligation. Although a law on euthanasia can exempt the individual doctor from being obliged to perform euthanasia, it will be necessary to ensure that everyone entitled to have euthanasia carried out under the particular law can actually gain access to it as well. Society, therefore, and more specifically the health services, will be obliged to make arrangements for authorized individuals to take the life of people who request it and meet the conditions to qualify for euthanasia. Thus the right to request euthanasia cannot be introduced without simultaneously introducing a duty and an order

for some people to take the life of others in certain situations. The existence of even a much qualified obligation to take people's lives is a serious undermining of respect for the value of human life. In addition, society's commitment to euthanasia will potentially result in some doctors—at the time of their appointment, for instance—feeling pressured (against their better convictions) into declaring their willingness to perform euthanasia.

Conversely, the current legislation, where killing on request is forbidden, retains a rule that it is wrong to take people's lives. Cases in which it will be ethically acceptable, where so requested, to have a hand in another human being dying are few and exceptional, as previously mentioned. These few, exceptional cases should be left to the personal decision and conscience of the immediate relatives under the terms of the law, and not form the basis for a general breakaway from standards in the law of the land and hence in society's institutions.

2.7 Euthanasia is the start of a slippery slope

The Danish Council of Ethics emphasizes the patent danger of euthanasia paving the way, with time, for actions and slipping standards that represent an evil even greater than euthanizing patients who find themselves in a hopeless, heart-rending and agonized situation, and ask for their lives to be taken. In particular, it is important to highlight the risk of the following three developments:

Euthanasia without the patient's request

In all likelihood, legalizing euthanasia will develop to the point where euthanasia without the express request of the patient is accepted in certain cases. The Danish Council of Ethics takes the view that the key argument in favour of euthanasia is not, therefore, respect for the patient's self-determination. In so saying, it is clear that few—if any—advocates of euthanasia think that all people, irrespective of their state of health, should be allowed to undergo euthanasia if they so request. The main argument is regard for the benefit of the patient in agony - an agony corroborated by medical assessment as well. Euthanasia would therefore be seen as a benefit for all those deemed to have need of it, not just those capable of asking for it. There is every probability, therefore, that legally incompetent and dying patients, on

whose behalf the doctor can currently decide to avoid life-prolonging treatment, will be potential subjects of euthanasia, despite being incapable of requesting it. The Danish Council of Ethics feels partly that studies of Dutch practice underpin the fear of such a trend. A Dutch study from 1990 chronicled 1,000 cases of euthanasia in which the patient was not capable of requesting it.⁶ The slide from accepting euthanasia when the patient's express request is present to accepting euthanasia without a request in certain cases is supported by the following quotation, which is the Dutch committee of enquiry's "justification" for the 1,000 cases:

The ultimate justification for the intervention is in both cases the patient's unbearable suffering. So, medically speaking, there is little difference between these situations [the majority of the 1,000 euthanasia cases without a request] and euthanasia [in the Netherlands, euthanasia is consistently used to mean taking the life of a person *at his or her request*], because in both cases patients are involved who suffer terribly.⁷

Extending criteria for access to euthanasia

It is impossible to lay down clear and enduring limits for the state a patient may be in to qualify to have euthanasia performed with the support of the law, as it is not possible to objectively define what constitutes unbearable suffering. If unbearable suffering or similar criteria are the rationale behind euthanasia, it will open up broad vistas for euthanasia to become accepted for new kinds of patients. A patient's wish for euthanasia will often be due to suffering of a non-physical nature. Such suffering, for instance, may comprise fear about the course of death or a feeling of being totally dependent on others' help. How to decide whether such existentially conditioned suffering is sufficient or not to warrant euthanasia? Moreover, a desire to die can be brought on by the patient having depression proper. Can mental suffering deemed to be unbearable and incurable also be the rationale behind euthanasia? Or can the existential suffering associated with the prospect of dying lead to a patient requesting euthanasia? The risk of such a drift in the criterion for entitlement to

⁶ Cf. minutes of the study in Keown, John (2002).

⁷ Quote from The Rummelink Report. In Keown, John (2002), p. 116.

euthanasia is present because suffering is a complex phenomenon. But the risk is also a real one, because judgement concerning the degree of unbearableness of the suffering is made in a confidential relationship between doctor and patient, which cannot be subjected to control mechanisms capable of ensuring that a uniform definition of unbearable and incurable suffering would be used in all instances. Evaluating suffering in relation to the value of life is so subjective and complex by nature that it should not be institutionalized and form the basis for a decision as serious and definitive as euthanasia. That will result in random evaluations of unbearable suffering becoming normative, with time—and hence also creating social pressure—as regards the view of when performing euthanasia is acceptable. Apart from these problems, it will be difficult to maintain a uniform evaluation of when a demand for euthanasia as a *last resort* can be said to have been fulfilled. The point at which particular suffering is no longer considered capable of being alleviated in some way other than taking the life of the sufferer will depend largely on the attendant practitioner's available resources and knowledge in the field of palliative treatment. In the process, too much responsibility is entrusted to the relevant medical assessment in cases where the outcome of the doctor's judgement determines whether the patient lives or dies and the decision cannot be evaded.

Stigmatization of severe sufferers

Legalizing euthanasia further involves the risk of stigmatizing the extremely ill, the ageing and the dying. When euthanasia is a legal action, exceptions to the absolute ban on killing will exist for a more narrowly defined group of people, i.e. those who are suffering unbearably, are incurable and possibly even dying. Legalizing euthanasia not only involves society accepting these people's wish to die at a self-elected moment in time. It is also a question of society committing itself to taking the life of these people when they wish to die. That in itself will then make it different to be a person who is suffering unbearably and possibly dying, since the society around has stipulated in law that being such a person *also* means being a person who can go to an authority and ask to have their life taken. This extra option is perceived by euthanasia adherents as a justified prerogative for patients with unbearable and incurable disorders. The Danish Council of Ethics feels, conversely, that this particular option will be

perceived by a large group of people as something they are *expected* to take a stance on. Of all people, those in highly agonized and difficult situations are likely—in the light of legal euthanasia—to feel *classified* as people for whom a preference for death must seem understandable. Such a perception of one's own life situation may be understandable in concrete and extreme cases, perhaps, but the problem with legalizing euthanasia is *also* that, presumably contrary to the intent of such legislation, it will sway people who are in a very special situation to begin with to consider whether death might not be preferable. The severely ill will be forced to take a stance on their quality of life. In so doing, most of them will also be influenced by what others (doctors and relatives) think about it, just as their decision may also be influenced by regard for relatives tasked with having to nurse them or resignation in the face of an insufficient array of therapeutic and nursing services. In addition, there is the danger of groups such as, say, the chronically ill and the disabled seeing themselves as candidates for euthanasia, even though a law on euthanasia would conceivably and supposedly not include these groups.

In this way, legislation becomes not merely a tool for regulation. In the Danish Council of Ethics' view, legislation—and in this case legalization of euthanasia—is instrumental not merely in accentuating the beneficial value that is patient self-determination (autonomy), but also in forming the axiological basis against which individuals perceive themselves or their situation. Legalizing euthanasia may have such an adverse influence on this axiological basis that regard for the very few cases in which euthanasia might be the ethically correct choice cannot counterbalance the detrimental effects of legalization.

3. Arguments for and against euthanasia

The following sections set out the most important and most frequently adduced arguments for and against euthanasia. Each section takes as its basis one aspect of the debate (for example, autonomy in 3.1 and the inviolability of life in 3.2), describing how it is possible to argue both for and against euthanasia, respectively, on the basis of the same aspect. The account will include such arguments as take a positive point of reference in the individual concept as well as some that take critical issue with it (section 3.1, for instance, describes arguments that home in on the incompatibility of euthanasia with autonomy, whereas among other things section 3.2 contains arguments that are based on a critique of the actual concept of the sanctity of life).

3.1 Autonomy

People's autonomy or self-determination is an important concept in the debate on legalizing euthanasia. Proponents argue that the ban on euthanasia imposes too great a limit on the individual's scope for controlling the end of his or her life and what shape death will take. Opponents, on the other hand, argue that self-determination would be false autonomy with respect to euthanasia, or that self-determination regarding euthanasia should not weigh more heavily than the principle of not killing.

The debate presupposes that people entertain some notions of what self-determination and autonomy can mean. The word autonomy is a compound made up of the ancient Greek words for 'self' (autos) and 'law' (nomos). In one sense of the word, then, autonomy is about the person who is autonomous *granting* himself his own *determination*. Underlying the idea of autonomy, therefore, is the notion that the individual himself should have the freedom to

define the parameters that determine his life and choose his ideals regarding the way life ought to be lived. That does not necessarily mean that everything is perceived as being equally good and equally acceptable, as long as it is the individual himself who has made that determination, because regard for the individual's autonomy does not exclude the relevance of observing other considerations too, such as regard for others' lives and lifestyles and regard for the values of the community. But if it is felt that the individual ought basically to be treated as an autonomous being, it is because relatively great weight is attached to humankind's ability and responsibility to choose how to determine or plan its own life conduct.⁸ It should be noted that this concept of autonomy does not rule out an autonomous person continually choosing throughout life to base his life conduct on a set of values and standards from a religious persuasion, a political party or suchlike. Anyone who does advocate autonomy simply needs to recognize the value of the individual himself having the possibility of relating to his values and choosing them freely, or choosing whether they should still be the same.

There is good reason to stress the above meaning of autonomy or self-determination, because for the purposes of the debate on euthanasia self-determination is otherwise often used to describe only *freedom of choice*. Promoting the individual's scope for self-determination, in this sense, means extending the field of actions that others may carry out on one's behalf if so asked. If the possibility of being self-determining is associated primarily with the *extent* of legal options, there will not be the same degree of focus on the independent value of autonomy as above, but rather on the value of the course of action under review. In other words, one can argue from the baseline that personal autonomy *per se* is something to be aspired to, or one can imply that autonomy chiefly signifies freedom of choice and is thus a *tool* for achieving a goal worthy of aspiring to, which in the case of euthanasia is to die.

8 Cf. Childress, James (2000), p. 149: "Autonomy does not imply that an individual's life plan is his or her own creation and that it excludes interest in others. The first implication focuses on the source, the second on the object of autonomy. Neither implication holds. Autonomy simply means that a person chooses and acts freely and rationally out of her own life plan, however ill-defined. [...] Thus, personal autonomy does not imply an asocial or ahistorical approach to life plans. It only means that whatever the life plan, and whatever its source, an individual takes it as his own".

3.1.1 Arguments in favour of euthanasia based on self-determination and autonomy

Self-determination as a positive or a negative right?

Adherents of euthanasia advocate the legalization of killing on request in carefully circumscribed situations. However, the choice is not merely one of whether euthanasia should be legal or illegal. There is also a need to create some clarity about the way in which it is wished to legalize euthanasia. It is important to distinguish whether the reasoning argues for a positive or a negative right of self-determination regarding euthanasia. A positive right of self-determination implies that a person can *demand* to have euthanasia carried out, providing the criteria for being able to request euthanasia are otherwise met. A positive right of self-determination regarding euthanasia, therefore, implies that the duty to perform euthanasia is imposed on someone. A negative right does not, however, imply any *entitlement* to demand that euthanasia be carried out. Legalization here would merely mean that euthanasia is an action that is not illegal. No one is *obliged* to comply with the request for euthanasia, but it is legal to carry out euthanasia if the individual meets the qualifying criteria for having euthanasia carried out. If arguing for the legalization of euthanasia as a negative right, the practical implementation of euthanasia will depend on there being some people among those able/entitled to carry out killing on request under such a law who are willing to do so. If arguing for the legalization of euthanasia as a positive right, a legitimate request for euthanasia will result in individuals or institutions being obliged to accommodate that request. But the positive right can be graduated in terms of the authorities or persons in whom that obligation is vested. In one radical variant, it is possible to envisage all doctors being obliged to carry out euthanasia. A less restrictive variant might mean that the health services as such were obliged to arrange for euthanasia to be carried out, while leaving the individual doctor free to choose whether he or she wishes to perform euthanasia.

Apart from the variety of practical consequences, whether one is a supporter of a positive or a negative right of self-determination regarding euthanasia is significant in principle. A positive right of self-determination regarding euthanasia cannot be introduced without simultaneously acknowledging that, in certain cases provided for in law, society is duty-bound to take the life of a human being. A negative

right of self-determination regarding euthanasia, on the other hand, can be introduced on the grounds that euthanasia, under certain circumstances provided for in law, is a matter for the judgement and conscience of the individual. The fundamental difference is that the first form of legalization, more so than the second, turns euthanasia into a communal, general matter, which must be acknowledged by society as a whole as being worthy of aspiring to ethically.

Autonomy as a value worth protecting

For some adherents, the prime purpose of legalizing euthanasia would be to promote autonomy or at least eliminate unnecessary barriers to it, given that they perceive autonomy as an essential value of human society worth protecting. These adherents of euthanasia will often base their views and arguments on the first meaning of autonomy (cf. the introduction to this section of the publication), which is all about the individual himself having the freedom to define the framework of his life and choosing his ideals as regards how that life should be lived and ended. Justifying their views will involve two different tasks. Firstly, it will be necessary to explain how euthanasia is essential to human autonomy. Secondly, they will have to argue against the legalization of euthanasia having detrimental side-effects that might outweigh the benefit they see in promoting autonomy in the above sense.

If these adherents advocate self-determination regarding euthanasia, but do not feel that euthanasia should be a duty that has to be performed, their defence of the legalization of euthanasia can be formulated thus: In some (enactable) cases, it is not unconscionable to take the life of a human being. Therefore, it must not be illegal to perform euthanasia in those cases. In the following, only the adherents' positive reasoning for saying that euthanasia is important for personal autonomy will be set out.

The positive reasoning for legalizing euthanasia is that euthanasia is perceived as a good action. For adherents, the good thing about taking a suffering person's life on that person's request lies particularly in promoting the person's scope for self-determination and hence their own control over events of vital, critical significance to the person's identity and life history.

In that sense, personal autonomy is about the individual's scope for shaping his or her life and imparting sense and meaning to it. The

way people die is of great importance to individuals' overall perception and understanding of their existence. Adherents of euthanasia are therefore able to point to the particular importance of being able to influence the circumstances surrounding one's own death in societies that generally attempt to create a framework for individuals' freedom to define their lives themselves and choose their own values. For a supporter of personal autonomy in the above sense, the wish to die can be made understandable if the way the person dies, or the way the person can look forward to dying, is fundamentally at odds with the framework and values around which the person has built his or her life.

Even adopting this point of view as an adherent of euthanasia, there is still scope for graduating one's views as to who is entitled to have euthanasia performed. Thus the attitude towards autonomy can be supplemented by acknowledging that euthanasia involves some person who has to carry out euthanasia. That person has a responsibility of his or her own, for which reason the action may be subject to some restrictions that do not apply either to suicide or to the patient's right to interrupt or refuse life-prolonging treatment. In addition, it can be pointed out that euthanasia is an action which, unlike interrupting life-sustaining treatment, leads per se to death. To a greater extent, therefore, the action involves the doctor's responsibility, and it is an action that cannot be regretted or undone. If the emphasis is placed on these considerations as well as autonomy, it may make sense to confine euthanasia to an option for the dying and not, therefore, for people (totally paralyzed patients, for example) who may be enduring unbearable suffering but are not dying.

3.1.2 Arguments against euthanasia based on self-determination and autonomy

Opponents of euthanasia can criticize adherents' arguments about autonomy by questioning whether the legalization of euthanasia would promote the individual's scope for practising self-determination. This criticism can be put forward despite the consensus-in-principle that autonomy in the above sense is a benefit and a value central to a person's life.⁹

Some argue (a) that a decision about one's own death is something fundamentally different from other life decisions and life choices, and therefore that a person's own death cannot meaningfully be said to be

the subject of a free and autonomous choice. Others argue (b) that the concrete circumstances surrounding the choice scenario in the form of the role played by the doctor, society and the next-of-kin mean that the request for euthanasia will have arisen partly or wholly out of a situation in which autonomy cannot be practised, either because the person is not competent or because of direct or indirect pressure from their surroundings.

a. Autonomy and euthanasia make odd bedfellows

Although people are actually in a position to choose to commit suicide of their own accord or to ask to be killed, the idea is that the very choice of death cannot be the sort that involves making a serious and lucid decision beforehand which brings that choice into line with one's integrity as a human being. That view is predicated on a basic assumption that human life is lived on certain unavoidable terms, which include birth and death. In light of this, choosing to die can be said to be a choice that denies the basic conditions of humanity, and hence an essential part of the individual's general identity as a person. Any choice that seeks to improve life by doing away with it completely is irrational, according to this view, because that choice is made to look absurd when held up against the basic human condition.

Another aspect of this criticism that can be highlighted is the lack of scope for regretting or undoing euthanasia. Regret can lead to a reversal of that choice or, where this is not possible, to evaluation and possibly even remorse. Both can be perceived as essential parts of autonomy. Some also emphasize that choosing one's own death is a choice like no other, because it intrinsically results in the person who is doing the choosing becoming no one.

b. Euthanasia is incompatible with autonomy as a result of the circumstances surrounding the choice scenario

This view focuses on the institutional framework within the health services, with which the legalization of euthanasia is most often

9 A critical approach to euthanasia may also result from being sceptical about the ideal of human autonomy altogether. It may be felt that the ideal of autonomy values individual scope for action too highly and ignores interpersonal care. This critique of autonomy is not examined here but is represented in the Council's arguments in section 2.4.1.

associated. The critique includes three different points, all of which have to do with the circumstances surrounding the choice scenario.

Firstly, it may be claimed that a law on self-determination pertaining to euthanasia in the health services will invariably lead to euthanasia becoming an offer that severe sufferers and dying patients cannot avoid having to take a stance on. Even if euthanasia is not mandatory, the choice scenario surrounding euthanasia will be forced on patients, solely because the possibility is provided.

Secondly, it is worth pointing out that, given the choice scenario, patients who already find themselves in a very difficult situation are saddled with an excessive burden of responsibility. Many factors will be taken on board as the patient weighs up the issue—for instance, regard for next-of-kin and a decision based on the doctor's advice. The gist of these misgivings is that, in a highly fraught situation, this complex deliberation does not provide the proper circumstances for making an autonomous decision, for which reason patients should not even be given the option at all. The possibility of exercising autonomy will often not be present, as the patient may be in a non-competent state due to fear, desperation, a feeling of futility and a sense of being superfluous—a state that can be psychosis-like.

Thirdly, people may be sceptical about the terms of autonomy because there is always the danger that euthanasia will appear to be the best alternative in an environment where palliative efforts may be anything but adequate. Thus a patient can be pressured into viewing euthanasia as the proper action as a result of care and medical initiatives in the home or at hospital not being up to standard. The mere risk of such a situation being able to occur will weigh heavily in the anti-euthanasiasts' deliberations of the merits and demerits of legalizing euthanasia. Legalizing euthanasia may result in there being less focus on existential support and palliative treatment. For the individual it can result in less security and more uncertainty as to what he or she may be subjected to at the conclusion of life. Such uncertainty may also be perceivable as a lessening of autonomy, because lack of confidence in society's readiness to provide care itself engenders a poorer setting for personally coping with changes in living conditions.

Logically, the attitude underlying these criticisms implies scepticism about the possibility that legalizing euthanasia—even as a right that cannot be demanded—can ensure that the choice scenario

is not forced upon doctors or patients. In a health service, consent is obtained on the basis of information about treatment options. It may be thought, then, that such information will invariably open up the choice scenario for the patient, however neutral the information dispensed. Moreover, it is worth pointing out that the mere awareness of the possibility of choice will be present, whatever happens, despite the patient not being informed directly before requesting euthanasia of his or her own accord.

3.2 The inviolability of human life

The fundamental conception that it is wrong to kill another human being is one of the weightiest reasons why euthanasia poses a dilemma: Why discuss the reasonableness of taking the life of a person at his or her request unless there were something rudimentarily understandable about the ban on intentional killing? Most people, on the contrary, can agree that taking the life of another human being belongs to those actions that are morally reprehensible in the highest degree. At the heart of such general consensus is a distinction between people's life, which has value in its own right, and physical objects, which have *no* value in their own right but roughly speaking only by reason of whatever use people find for them. The feeling that people's life has value in its own right leads to the view that people's life should not be violated or destroyed. Physical things can be destroyed if they no longer serve their purpose and everyone agrees that they are of no value to anyone. But when it comes to a human being, the idea is that the being is always its own end, too, and that destroying life with reference to the worthlessness of life is a violation, because a person's life cannot be worthless.

How exactly people interpret the sanctity-of-human-life principle and make up their minds about it is tightly bound up with the way they perceive the special value or dignity associated with humankind. In the debate on euthanasia, widely divergent views of this are represented. Naturally enough, adherents and opponents disagree as to what the sanctity-of-human-life principle involves. But also internally, among the ranks of opponents of euthanasia, there are different readings of the principle.

3.2.1 Arguments against euthanasia based on the inviolability of life

For opponents of euthanasia the principle of the inviolability of life can be put forward on either a humanist¹⁰ or a religious footing. That is to say: in the humanist variant, the special value of human life can be viewed as a result of human qualities or as a result of humane recognition of this value; and in the religious variant the special value of human life can be viewed as being rooted in a divinity and hence in an authority outside the human world. Religious points of view will often differ from humanistically oriented ones in as far as killing is not merely perceived as a crime, but the individual also has an obligation to live, which is not due solely to any obligation to oneself or other people.

a. The inviolability of life from a religious point of view

Viewed from any one person's own angle, the principle of the inviolability of life is easy to empathize with. The fact that the principle is virtually a moral intuition, whichever approach to life one endorses, is certainly due above all to it being about protecting the innocent person's right to live. Religious and humanist conceptions of the principle have this element in common. But for a Christian viewpoint, for example, the sanctity-of-life principle functions not 'just' as another formulation of the prohibition on killing. Life, according to Christianity, is something God-given, and something which everyone therefore has a duty to cherish.¹¹ This also means that the privileged status of human life cannot be derived from human qualities or from historical developments of interhuman standards. Human life, by contrast, possesses a special value, one worth preserving, ultimately because man is created in God's image

10 The term 'humanist' is used here not in the sense of 'human' or 'beneficent', but of a philosophy of life that, unlike religious views, interprets life without reference to a superhuman reality.

11 Cf. for instance the *Declaration on Euthanasia, prepared by the Sacred Congregation for the Doctrine of the Faith* (the Catholic Church): "Most people regard life as something sacred and hold that no one may dispose of it at will, but believers see in life something greater, namely a gift of God's love, which they are called upon to preserve and make fruitful". This view is more or less representative of the monotheistic religions in our part of the world (both within Christianity in the form of Protestantism and Catholicism, and within Islam and Judaism). Sacred Congregation of the Faith (1980).

and thus forms part of a suprahuman semantic context.¹² Therefore, resistance to euthanasia, founded on a Christian interpretation of the inviolability of life, can assume a more restrictive and dutiful form than resistance based on a secular interpretation of the sanctity of life. In such a religious outlook on life, the focus will not be just on regard for the individual's right to life but also on protecting the sanctity of life as such.

A clear example of this is found in the Catholic Church's approach to euthanasia. According to this, suicide (and hence being euthanized on request) should be regarded as murder, even though it is acknowledged that suicide sometimes takes place under the influence of psychological factors that can diminish responsibility or even eliminate it completely on the part of the suicide candidate.¹³ The authority responsible for judging the value of life is not deemed to be the actual person, therefore—neither the one living the life in question nor others viewing it “from without”. Human life has an inalienable value; and whatever happens, taking the life of an innocent person will be a crime, and caring for life a duty. This attitude does not necessarily involve a heroic approach to modern medical methods of prolonging life, but it may do so. Furthermore, such a conviction will logically result in some scepticism towards the perception of autonomy presented in the previous section. The ideal here is not that people should control their life conduct themselves, but live their lives in accordance with guidelines that originate from a suprahuman authority instead.

12 See e.g. Andersen, Svend (1999), p. 305: “The point of the prohibition on killing must be seen in the context of belief in Creation as the vital prerequisite to the biblical perception of human life. Belief in Creation means that human life is viewed in terms of some authority external to man, i.e. God as Creator. In keeping with belief in the Creation, the actual fundamental fact that a person exists is not due to that person him/herself, but is a blessing from the hand of the Creator.” [Translated by The Danish Council of Ethics]

13 Cf. the *Declaration on Euthanasia, prepared by the Sacred Congregation for the Doctrine of the Faith* (the Catholic Church): “Intentionally causing one's own death, or suicide, is therefore equally as wrong as murder; such an action on the part of a person is to be considered as a rejection of God's sovereignty and loving plan. Furthermore, suicide is also often a refusal of love for self, the denial of a natural instinct to live, a flight from the duties of justice and charity owed to one's neighbour, to various communities or to the whole of society—although, as is generally recognized, at times there are psychological factors present that can diminish responsibility or even completely remove it”. Sacred Congregation of the Faith (1980).

b. The inviolability of life from a humanist point of view

There are a number of secular views as to what the inviolability of life means. Only two main types will be mentioned here, both of which may of necessity entail human beings being said to have an inalienable right to live and a duty not to kill—a right and a duty so valued that it would normally be morally unacceptable to legalize or perform euthanasia.

One main type of view might be called *regulative*, because the prohibition on killing and the inalienable right to live are perceived as principles that have a highly *regulative* and hence instrumental value in facilitating communal life between people. These principles can be claimed to belong to the basic conditions or possibility conditions governing sociability and should be valued as such. Within this point of view it is quite possible to opine that euthanasia in some instances would benefit the party requesting it while simultaneously insisting that euthanasia ought not to be carried out. The rationale is that the framework we humans decide to adopt for the sake of our social lives would suffer irreparable damage from doing so.¹⁴

The other main type of view is not based on the assumption that the sanctity-of-human-life principle has regulative value only. On the contrary: here it is maintained that the principle is valuable because people's life per se is actually characterized by being worthy of preservation, a fact that cannot be explained exhaustively on the basis of regard for the individual and the personal value life holds for that person. The result here is the same deference for the inherent value of life as arrived at via the religious point of view. But in one way the perception of human life's self-validity is more radical than in the Christian religious tradition, where the special status of human life is explained on the basis of a binding dependence on a suprahuman authority, the very result of which is ultimately to cancel out the intrinsic validity of that person's life. What is meant by the intrinsic value of life in secular traditions can only be hinted at with examples.

¹⁴ Reasoning of this ilk is set out in a report from the British House of Lords' Report of the Select Committee on Medical Ethics (1994), p. 49: "to create an exception to the general prohibition of intentional killing would inevitably open the way to its further erosion whether by design, by inadvertence, or by the human tendency to test the limits of any regulation. [...] we believe that the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life."

For instance, one might ask: Is most people's idea that we ought to do whatever we can to prevent the human race becoming extinct in a couple of hundred years' time based on some regard for those who do not yet exist? No, that description does not seem to pinpoint the moral intuition or feeling nearly as well as if we merely assumed that life *per se* is worthy of preservation. The same mental exercise can be performed in relation to euthanasia: Is the idea that something is lost by taking a person's life explicable *solely* in terms of the value that life possesses for the individual and his or her nearest and dearest? No, some will say, because the individual's life must be protected on the strength of that life having an inalienable value in its own right. However, it must be said that this humanist intuition about the inviolability of human life is less conclusive in relation to euthanasia than the religious variant described: a more open-ended question would be whether the individual can assume responsibility for pondering and ignoring the inviolability of life, for instance if life no longer has any personal value for the individual.

3.2.2 Arguments in favour of euthanasia as a critique of the inviolability-of-life principle

Critics of the inviolability-of-human-life principle do not say that the prohibition on killing is irrelevant. However, they do suppose that regard for the inviolability of human life hinges on regard for the individual, who has no interest in being killed, under normal circumstances. This can therefore be said to be a general rule that does not apply in the absolute sense but should be observed in all situations where the rule serves to safeguard the individual's interest in continuing to live. If the prohibition on killing is primarily and chiefly about protecting the value vested in the individual by virtue of being alive, that prohibition can no longer apply unless the person requesting euthanasia associates being alive with some positive value. The view is as follows: It is morally wrong to kill because it will deprive the individual of a specific number of years of life, complete with the positive value associated with those years. But as one of the champions of this view states: "The problem of the inviolability-of-human-life principle in the context of euthanasia is precisely that the person desirous of assisted dying *is* able to signal that he has no desire to carry on living, since he has anything but good years ahead of him to live" (Holtug, Niels & Kappel, Klemens (1993), p. 59. Translated by

The Danish Council of Ethics). According to critics of the inviolability-of-human-life principle, it makes no sense to talk about life having a value besides its personal value as perceived by the individual. Such an outlook is bound to have absurd consequences in the form of life having to be preserved at all costs, wherever possible, regardless of the degree of suffering involved for the person living it: “but even if it were possible to defend the view that life always has some value, it would affect not only active, assisted, but also passive suicide. If life were always valuable, no matter how bad, presumably there would also be something problematic about omitting to administer treatment if a life were curtailed in the process” (Holtug, Niels & Kappel, Klemens (1993) p. 60. Translated by The Danish Council of Ethics.). Of course, it is also possible to feel that although the general principle of the sanctity of human life should be a weighty one for regulative reasons (see above), it should not weigh more heavily than regard for those people for whom death is purportedly better—owing to unbearable suffering—than continuing to live.

3.3 Killing and allowing to die

In the debate on euthanasia, there is major disagreement over what constitutes the ethically crucial difference between killing and allowing to die. The discussion arises because the majority of opponents of euthanasia are simultaneously willing to accept the interruption or omission of life-sustaining measures for the dying or patients in a persistent vegetative state (PVS)¹⁵ who cannot give consent for such themselves. The “crunch factor” will be that life-sustaining treatment is considered futile. In addition, there is general consensus that “a terminally ill patient can receive whatever palliative, sedative or similar agents are needed to alleviate the patient’s condition, even if this may result in hastening the time of death” (Danish Act on the Legal Status of Patients, Section 16, subs. 3).

Advocates of euthanasia stress that the ethical assessment must be

¹⁵ Patients in a persistent vegetative state are people who, as a result of irreversible damage to the brain, have permanently lost consciousness and all functions generally other than the most basic biological mechanisms, such as the cycle between waking and sleeping states. The patient can feel nothing and has no alertness, either to himself or to the surrounding world. See p. 66ff.

identical for euthanasia and for the end-of-life medical decisions mentioned. Conversely, many opponents of euthanasia will insist that there is a clear ethical difference in typical euthanasia scenarios between the doctor allowing the patient to die as a result of the patient's condition and the doctor taking the life of the patient by actively intervening.

3.3.1 Equating euthanasia with avoiding life-prolonging treatment in ethical terms

Most people will feel that refraining from sustaining a person's life is less challengeable in moral terms than killing a person. The philosopher James Rachels, however, elaborated on the issues surrounding this view in an article on so-called active and passive euthanasia from 1975.¹⁶ The article is constructed around a supposition made for the sake of argument, which has since become a much-used tool in the pro-euthanasiasts' battery of arguments. It should be noted from the outset that this intellectual experiment revolves around allowing to die and killing in a completely different context than the one applicable to euthanasia or cessation of treatment. The situations are not parallel, therefore. However, the object of this experiment is to test what constitutes the ethically relevant difference between actions usually classed as killing and those usually classed as allowing to die. Rachels' point is that it is not the actual killing that is ethically more problematic than the allowing to die. Rather, the intention behind the action is what counts. According to Rachels, then, the fact that killing is normally more objectionable ethically than allowing to die is due to the incidental aspect that the intention of killing is usually more problematic. This point is then transferred to the debate on euthanasia to demonstrate that euthanasia (based on comparable intentions) should be equated with avoiding life-prolonging treatment.

In the article, James Rachels asks whether it is worse, per se, to kill than to allow to die. He answers the question by imagining two situations that are completely identical except that a person in one situation kills another person, whereas a person in the other situation allows another person to die without intervening: in one situation Smith drowns his six-year-old cousin in the bathtub, because he will

¹⁶ Rachels, James (1975).

inherit a fortune in the process. In the other situation Jones sneaks into the bathroom with the same intent and motive towards his six-year-old cousin, but Jones is 'lucky' and is able to observe his cousin accidentally slipping, hitting his head, falling down into the bathtub and drowning. In this instance it is obvious to anyone that Jones failing to intervene is just as objectionable as Smith killing his cousin, even though Jones's action is not the direct cause of the cousin's death. Rachels acknowledges that the intellectual experiment does not have much in common with the doctor-patient situation in which the problematic issue of euthanasia is set. He is merely using the example to highlight the fact that neither the active action nor avoidance *per se* makes a moral difference, but rather the intention underlying the action as well as the act of omission.

Rachels' intellectual experiment shows that the presence of moral responsibility is not absolutely dependent on a person causing the death of another directly through his actions in the physical sense. In other words, if a person's active deed is the cause of another person's death (and that deed is performed deliberately, with insight into its likely consequences), the agent will always have a moral responsibility, but conversely it cannot be inferred that a person who does not cause the death of another through his or her active deed never has a moral responsibility for that person's death.

The ethically significant difference between euthanasia and avoidance of life-prolonging treatment cannot be comprised of "allowing to die" as one action with "taking the life of" being the other. The extent to which an action whose consequence is another person's death is morally acceptable must be explained on the basis of other differences, for example the difference in intent. If it is maintained that the intent of euthanasia—like accepted medical interventions at the conclusion of life—is to avoid unbearable suffering, then that which advocates such interventions must also advocate euthanasia. In other words, it is not acknowledged that the intent of euthanasia is to take the life of the patient, whereas the intent of avoiding life-prolonging treatment is only to avoid futile treatment or undue pain. On the contrary, it is maintained that the intent of both is to avoid undue suffering, and that the actual consequence—of the patient dying—is in both instances something that is not desired *per se*.

By way of experiment, then, it can now be admitted that it is the intent, not the nature, of the action of "allowing to die" or "taking the

life of” that is ethically crucial. Accordingly, as an opponent of euthanasia, one can object to the intent of euthanasia actually being to take the patient’s life, whereas the intent of avoiding life-prolonging treatment is to avoid undue suffering or to grant a possibly legally competent patient’s right to exert control over his treatment. But even accepting this difference of intent, an argumentational challenge arises for opponents of euthanasia who advocate doctors being able to interrupt life-prolonging treatment of PVS patients. Continuing to be alive does not cause the patient any pain, so avoiding treatment cannot be said to be palliative by nature. The patient is not legally competent, so avoiding treatment cannot be justified on the basis of the patient’s right to determine himself whether legal treatments are to be continued or interrupted. The only thing that would seem to be left is the considered view that dying is at least no worse than living for a person in PVS. Adherents of euthanasia can therefore aver that no good reason for interrupting this type of patient’s treatment is given that would not be an equally good reason for performing euthanasia.

3.3.2 Criticism of equating euthanasia with avoiding life-prolonging treatment in ethical terms

Many opponents of euthanasia will assert that the difference between “allowing to die” and “taking the life of” has sound and well-founded ethical significance for precisely the sort of situation most often encountered in discussing euthanasia, i.e. the incurably ill, suffering and possibly dying, because these people are already in an unavoidably progressive state, which is no one’s choice, simply one of life’s vicissitudes. In this situation, then, there is a marked difference between allowing the person to die—whether it be by opting out of further treatment or by interrupting treatment already initiated—and taking the person’s life.^{17, 18}

¹⁷ Cf. Gesang, Bernward (2001), and Callahan, Daniel (1992).

¹⁸ The difference can also be elucidated by referring to the arguments adduced by the defence for a person charged with murder in a case from the USA. With the aid of a respirator etc., doctors attempted to give the victim life-saving treatment. When it became clear that the treatment was futile, it was halted. It was now claimed by the defence attorneys that death had been caused not by the accused but by those who had stopped the treatment. This view was not reflected in the sentencing, however. Cf. Graves, F. A. (1989), pp. 976-7.

Permitting a person to die in these situations is an action that allows something already in progress to happen which, even then, is the result of something unmerited and inevitable in the form of severe disease or injury. The taking-away of life-sustaining treatment is different from euthanasia in as much as the action is not the only condition necessary for the decease of the patient. If the patient were not in a critical state to start with, taking away that life-sustaining treatment would not lead to the patient's death.¹⁹ It is different with euthanasia. This action leads to the death of the other person, regardless of the condition that person is in. It can thus be ascertained that there actually *is* an essential difference between allowing a person to die and taking a person's life.

So what if, as an opponent of euthanasia, one acknowledges that the rationale for avoiding life-prolonging treatment in certain cases is very much akin to the reasoning for euthanasia (i.e. acknowledgement that life is no longer preferable to death)? Here it can be argued that therapeutic intentions cannot be merely postulated—they must also be able to be gleaned from the types of action initiated. The ethically vital difference between allowing death and curtailing life in contexts where a patient is suffering from an incurable disease is that euthanasia as an action will *suffice* to bring about death, whereas avoiding life-prolonging treatment is not sufficient per se to bring about death. In conjunction with PVS patients, for example, treatment can be said to originally have been initiated for the purpose of improving the patient's condition. Discontinuing life-prolonging treatment is subsequently justified by reasoning that the treatment is not serving the purpose for which it was originally initiated. Euthanasia, on the other hand, is not an action that relates to whether or not previous treatment was successful but is a new action with a purpose all of its own.

¹⁹ Cf. Callahan, Daniel, 1992, p. 329: "A lethal injection will kill both a healthy person and a sick person. A physician's omitted treatment will have no effect on a healthy person".

3.4 Unbearable suffering and compassion

When debating euthanasia, it is not primarily objectives and motivations that are up for discussion. Thus proponents and opponents of euthanasia seldom disagree that preventing or assuaging people's suffering is a commendable deed in medical and humane terms, and that the feeling of compassion is generally a valued emotion. Disagreements and differences of opinion are more to do with the extent to which the end justifies the means, i.e. to what extent eliminating pain and suffering can justify performing and/or legalizing euthanasia. Furthermore, the appeal for compassion for people who are suffering unbearably is particularly germane to the question of the role and practice of medicine in the context of euthanasia, for alleviation of suffering ranks among the most ancient objectives of medical practice, in as much as it was obviously possible to allay suffering associated with disease and sickness long before it became more widely possible to cure disease.

In the discussion about suffering it is particularly important to relate to the questions:

What human conditions does the concept of suffering cover?

What states of suffering are so severe that they can allegedly justify the desire for and possibly even the right to euthanasia?

It is important to examine possible meanings of the concept of suffering, because existing euthanasia laws in the Netherlands and Belgium (see Appendix) determine that the patient must be going through unbearable suffering in order to qualify for euthanasia. Moreover, the problem is already hinted at by an important difference between the two laws: In the Netherlands the law merely mentions unbearable suffering, whereas the Belgian law talks about unbearable physical or mental suffering. The provision in these laws on unbearable suffering is also an expression of a general consensus among proponents of euthanasia that euthanasia should not be an option open to just anyone asking for it. The debate rarely sets out the reasoning for not arguing in favour of completely free access to euthanasia. This is probably due to agreement that suffering as a criterion for access to euthanasia is based on an approach that is taken for granted and regarded as self-evident. It is an approach shared with many opponents of euthanasia: The ethical acceptability of one person taking the life of another at the latter's request and based on a feeling of compassion will depend, as a minimum, on the

situation involved being one of extraordinary suffering and agony that cannot be relieved. The approach, in other words, is that euthanasia is not a straightforward panacea that can be offered to everyone. On the contrary, existing euthanasia laws and the trend-setting arguments in the domestic debate reflect a realization that euthanasia is a measure prompted by necessity—a “last resort” reserved for people for whom life is so full of suffering that death appears to be the kinder of two evils.

But what does suffering mean? Firstly, it must be noted that suffering is not identical with the experience of pain caused by physicalities. Some bioethicists will think that suffering and physically caused pain are two essentially different phenomena, whereas others will assert that physically caused pain is merely one of many ways of suffering.

Pain and suffering are two different phenomena, and suffering is a personal phenomenon

Suffering can be perceived as a subjectively experienced reaction to critical changes of life—in connection with illness, for example. Physical symptoms may be the source of suffering, but the treatment of that illness, the isolation in relation to normal social life and the fear in terms of the illness developing, for example, can also be sources of suffering.²⁰ Physically caused pain, then, is one of just many possible sources of suffering—a fact recognizable to most people because it is possible to envisage being in an agonizing condition without experiencing physically caused pain. But the difference in nature between suffering and pain is also seen in the experience of severe physical pain not being simultaneously perceived as actual suffering in some people, whereas the experience of less severe physical pain in others largely gives rise to suffering. Doctor and bioethicist Eric J. Cassell has established the model of a person-centric view of suffering, and as an example of the dependence of suffering on personal factors states the following:

One patient, who said he was not suffering, had metastatic cancer of the stomach from which he knew he would shortly die. On the other hand, a woman who felt her suffering bitterly was waiting in the hospital for her blood count to return to normal after it had been long

²⁰ Cassell, Eric J. (1991), p. 32.

depressed by chemotherapy. Aside from some weakness, she was otherwise well and would remain so. (Cassell, Eric J. (1991), p. 31)

Cassell thus perceives suffering as something quintessentially ascertainable only by asking the patient. He highlights the challenge for the medical profession posed by the subjectivity of suffering. In tandem with healing disease, alleviating suffering is a central objective of medical therapy, yet at the same time suffering is a phenomenon that cannot be reduced to biomedical scientificity, as a matter of principle. Suffering, unlike the physical symptoms, is not accessible per se to a third-person perspective. To a large degree, however, Cassell views it as the medical profession's purpose to address and allay suffering, including suffering that is not linked directly to physical symptoms but typically arises nevertheless as a result of severe states of ill health. Based on his own medical experience, he defines this suffering as a "state of severe distress associated with events that threaten the intactness of person". This problem complex has a bearing on the discussion of whether an evaluation of suffering can be included in justifying a patient's entitlement to euthanasia. Discussion of this is continued in sections 3.4.1 and 3.4.2.

Pain is one of many other forms of suffering, and suffering is an objective phenomenon

A slightly different yet related description of suffering is found in the Dutch bioethicist Stan van Hooft. According to this description, different types of suffering exist, and objectively they can be described as suffering, without the personal perception of such always being crucial. Van Hooft's point of departure is that the fulfilment of specific aspects of human existence may be universally perceived as units of measurement that determine whether a person is complete and therefore preserves his or her integrity. He highlights four central areas (drawing inspiration from Aristotle's science of the soul): "[1] people's biological functions, [2] their emotional and volitional functions, [3] their practical and rational life, and [4] their feeling of meaning to their existence". Van Hooft consequently perceives suffering as "prevention of the tendency to fulfil these various aspects of our life" ²¹. For

²¹ Back translation from Danish, Hooft, Stan van (1998), p. 126.

example, he views disease, handicap and physical injuries as suffering in the objective sense—i.e. without regard for what people who have been subject to such states think about it. Disease is primarily suffering in the sense that it works counter to people's biological and bodily function. That is to say: disease, by definition, is a disruption to a human's biological functions. In addition, however, disease will generally result in some degree of suffering in relation to the person's senses and emotional make-up. Disease brings with it a change in one's relationship with one's body, just as debilities not necessarily serious in themselves (for instance, fever, nausea and so on) involve a change in a person's sensuous relationship with the outside world, a change representing the source of discomfort and suffering in van Hooft's sense.²² Furthermore, disease *can* result in suffering in relation to a person's life conduct, but that will depend on the objectives the individual has, and on the way the individual is capable of adjusting his objectives while keeping his contentment intact—hence the disappointments that person will experience in terms of his courses of action being thwarted. Finally, it is possible, but not certain, that disease will lead to suffering in the form of the person's sense of meaning to life changing and becoming uncertain.

Although, according to this model, suffering is suffering, no matter how it is perceived by the individual, the difference between this model and Cassell's description is not very great. The greatest difference lies in van Hooft's description, which implies the slightly contra-intuitive aspect that PVS patients, for instance, can be said to suffer even though they do not experience anything. Furthermore, that perception will imply that disabled people suffer, regardless of their own thoughts on the subject. The latter consideration is mostly hair-splitting, however, since on the basis of the "objective model" disabled people might be said to *have* a disorder, but not necessarily to suffer from it, because despite the biological functional suffering, they do not perceive suffering on the other functional levels (in their emotional life, in their life conduct and in the dimension that deals with the view of the meaning of life).

²² Cf. Hooft, Stan van (1998), p. 127: "Even the things that we normally enjoy doing, such as listening to music or conversing with friends, lose their lustre when we are ill. The world seems to have a pall cast over it and our relationship to it is vitiated. If the inherent goal of this aspect of our being is an inchoate form of enjoyment and rapport with the world, then malady destroys this relationship".

3.4.1 Reasoning in favour of euthanasia based on the regard for alleviating suffering

As previously mentioned, any argument in favour of legalizing euthanasia based on the regard for alleviating suffering must address the fact that any evaluation of suffering, and to a great extent any evaluation of unbearable suffering, will vary according to who is in the condition described. At the same time, if the suffering criterion that qualifies people for euthanasia is to play an independent part, the job of evaluating such suffering clearly cannot be left solely to the person requesting euthanasia. In that case the criterion would no longer be a constraint on access to euthanasia and self-determination would be the only crucial requirement. The argument only makes sense, therefore, if the patient's affirmation of unbearable suffering is a necessary but not a sufficient condition of the patient's eligibility for euthanasia. In other words, it must be a minimum requirement that certain objective and highlightable aspects of the patient's condition must have been met before the patient's statement about unbearable suffering and the request to have euthanasia performed can actually result in the doctor accommodating the patient. If suffering is perceived as something other or more than physical pain, the argument further presupposes that the purpose of medicine is partly acknowledged as preventing or alleviating suffering bound up with the patient's self-perception, integrity and spiritual dimension.²³ As described in section 1.3, the pro-euthanasiasts' assertion that people have a right to a dignified death is all about promoting such an end. Although such an end for the medical profession would enjoy widespread recognition, it is only fair to mention that acknowledging it is not a matter of course. For example, van Hooft, mentioned above, is an exponent of the view that it is not within the medical profession's power to prevent or alleviate this form of suffering, though doctors and others would naturally be obliged to ensure that treating patients resulted as little as possible in such suffering.²⁴

Euthanasia as an ethically defensible means of preventing unbearable suffering

As mentioned, most adherents of euthanasia do acknowledge that

²³ The implication here being that euthanasia is accepted as a means.

²⁴ Cf. Hooft, Stan van (1998), pp. 130-31.

euthanasia must be a last resort. That is to say that the suffering must be truly unbearable and considered as incapable of being allayed in any other way. It is possible to conceive of different angles of approach to unbearable suffering as justification for euthanasia.

One line of argument can take as its basis Cassell's above-mentioned definition of suffering: "A state of severe distress associated with events that threaten the intactness of person".²⁵ Furthermore, it is worth emphasizing that severe disease, injuries and bodily decay will very often constitute events that threaten the person's intactness and self-perception. Although the degree of appreciable suffering caused by physical pain and other frustrations brought on by disease depends on the individual, some factors relating to pain associated with severe disease can be highlighted that will generally lead to an appreciable degree of suffering. Cassell himself lists certain points that indicate when pain is a source of suffering: if the pain is overwhelming; if there is no hope or faith that the pain can be brought under control; if the pain is constant and unavoidable; and if the painful symptoms are alien and unexplained to the patient.²⁶ The subjective component of suffering and its many different forms are arguably justification for making the doctor, in collaboration with the patient, the one to assess whether the suffering is unbearable, just as the doctor must assess whether enough has been done to allay the suffering in other ways (for example, by explaining what the symptoms are due to). This presupposes trust in the doctor's ability—for example, with the above or similar criteria in mind—to assess whether the patient is suffering unbearably and whether the suffering has been caused by the disease interfering with his or her life.

The approach described here involves partly foregrounding features of the backdrop to pathologically determined suffering that are not random, and partly highlighting trust in proper medical judgement and good communications between doctor and patient. A slightly different approach would be to recognize to a greater degree

²⁵ It should be noted that Cassell's deliberations on the nature of suffering is not part of a debate on euthanasia.

²⁶ Cf. Cassell, 1991, p. 38: "That this is the relation of pain to suffering is strongly suggested by the fact that suffering can often be relieved in the presence of continued pain, by making the source of the pain known, changing its meaning, and demonstrating that it can be controlled and that an end is in sight".

that suffering in the above sense (Cassell's definition) is subjective and existential, and in return to introduce a restriction that constitutes a safeguard against any random assessments of unbearable suffering playing too crucial a role. One such restriction on entitlement to euthanasia may be that euthanasia is only one option for terminally ill patients. As a supplement to the self-determination and unbearable-suffering requirement, this eligibility criterion can be viewed as a safety device for ensuring that the damage connected with any random evaluation of unbearable suffering is contained. But it can also be rooted in a notion that dying people, being close to death, run a particular risk of suffering unbearably as a result of the fear of becoming estranged from their own lives during their final days, owing to a lack of mobility, pain and invasive treatments. It is thereby possible to argue that, of all people, the dying have a special need to be able to request euthanasia. As a euthanasia supporter, then, one may feel in principle that everyone (including the non-dying) risks suffering appreciably from crippling disease and the prospect of living a life and even dying a death at odds with one's overall life story and philosophy of life. At the same time, for pragmatic reasons, one may wish to restrict euthanasia to being an option for the terminally ill. For the attitude may be that it would be considerably more difficult for the non-dying to dismiss hopes that the patient's current situation will cease to be full of unbearable suffering. This applies equally to people with chronic and incurable pain or disability, because hope in the cessation of suffering is not just hope in the cessation of physical pain, but also hope that physical pain and infirmity will gradually become bearable and liveable-with—that is, a hope in new meaning and existential stability.

3.4.2 Criticism of euthanasia as a means of alleviating suffering

Criticism of justifying euthanasia on the grounds of alleviating unbearable suffering is naturally based on the impossibility of measuring suffering and hence the impossibility of setting even tolerably clear bounds to determine when a person might meaningfully be said to be suffering so unbearably and so unavoidably that euthanasia is the best choice. The introduction to this section shows how many different forms of suffering can be brought about by severe illness or disease. Surely, then, it is only natural to enquire what forms of suffering euthanasia should be able to be used to eliminate?

Because apart from the question of whether there are other options less serious than euthanasia in a specific situation, the physician will also need to be clear as to whether only physical pain needs to be evaluated, or also the suffering that arises as a result of becoming more dependent on help and no longer being able to perform the most basic bodily functions.

On the one hand it might be thought safest if suffering were taken to mean physical pain only. On the other hand it seems to be ill-founded to say that the very suffering that arises as a result of physical pain should entitle people to euthanasia while other suffering, which can be just as unbearable, if not more so, is insufficient justification. Furthermore, criticism of the pro-euthanasia suffering argument can focus on the unsuitability, in very general terms, of euthanasia as a means of preventing pathologically determined suffering. In relation to the argument that euthanasia is only for the dying and for patients with unbearable suffering, it may be stated that the appropriate way of relieving existential suffering associated with death is spiritual care, not euthanasia. It can be said that regard for preserving the integrity and self-perception of a dying person should not result in the manner of dying being tailored to the patient's former way of living (level of activity, self-control etc.). If anything, it should lead to health professionals taking into account the patient's life story and basic value set in their endeavours to help the patient live with the more or less pronounced loss of meaning and control.

3.5 Euthanasia and slippery slope arguments

For some opponents of euthanasia, arguments that legalizing euthanasia will have adverse knock-on effects are more important and more central than arguments rejecting euthanasia on the principle of the inviolability of life. That is to say that someone opposed to legalizing euthanasia may feel that these effects make it ethically unacceptable to legalize euthanasia. At the same time, it may be felt without any contradiction that euthanasia per se is not an unethical action under all circumstances. Opponents who place the greatest stress on the adverse knock-on effects of legalization or institutionalization may even concede that, in certain particular instances, unbearable suffering in the terminally ill constitutes the very circumstance that renders the actual action of euthanasia

ethically acceptable. They will merely maintain that the negative effects of turning euthanasia into a legitimate action are greater than the ethical benefits achieved by accommodating the request for euthanasia in those who are suffering unbearably, may even be dying and cannot be helped further with palliative care. An important element of this argument is the general agreement that there are relatively few people in Denmark who will be in the situation described.

As a rule, when up against this type of argument, adherents of euthanasia will seek to demonstrate that the fear of negative effects is ungrounded. They cling to the fact that the legislators and health services will be able to keep practice within the object intended by proponents of euthanasia: to help people suffering unbearably and possibly dying to die when they so request, and when the palliative treatment options have been exhausted.

3.5.1 Slippery slope arguments against legalizing euthanasia

The slippery slope argument occurs in two different variants. Firstly, an ethical justification of euthanasia may be thought to entail the justification of other actions by a process of logic, for example euthanasia without the patient's request. The logical correlation asserted (which is amplified below) between euthanasia and euthanasia without request can thus be stated as the reasoning for the supposition that future practice will follow on the heels of the logic that underpins the desire to legalize euthanasia but also justifies euthanasia without request as a result. This variant of the slippery slope argument can be called the logical slippery slope argument. Secondly, one may feel that in practice there will be great difficulty interpreting and complying with provisions stipulating *who* can request euthanasia, i.e.: whether they are suffering unbearably, whether their request is autonomous and intended seriously, and possibly whether they are terminally ill. Here, then, the focus is on the framework for performing euthanasia, and it is asserted that the scope for judgement and interpretation is too great to be able to guarantee the patient's autonomy and ensure that he or she is the kind of person whom the law grants the option of requesting euthanasia. This variant of the slippery slope argument can be called the practice-oriented slippery slope argument. In the following account, the main emphasis is on the logical slippery slope argument.

a. The logical slippery slope argument

At bottom this argument is about demonstrating that there is a special correlation between three typical components of proposals to legalize euthanasia: (1) the requirement concerning the patient's autonomous decision, (2) the requirement that the patient be suffering unbearably and (3) the requirement that a medical assessment be made to this effect and hence that euthanasia must be indicated medically. The doctor's assessment of whether euthanasia is beneficial to the patient in a specific case means that, logically speaking, pro-euthanasia arguments with the constraints outlined must be pro-euthanasia arguments without the constraints outlined. The conclusion will then be that the key argument actually in favour of euthanasia is not respect for the patient's self-determination but regard for the *benefit* of the patient who, according to the doctor's judgement, is suffering to such a degree that dying is better than continuing to live. Logically, then, euthanasia is a boon for anyone for whom it is indicated, not merely for those capable of requesting it. With time, therefore—so the argument goes—euthanasia will be accepted for patients who are dying and suffering unbearably, even if they are incapable of requesting it.²⁷ A brief account is given below of the steps in the argument that lead to this conclusion.

The first step in the argument is to ascertain that euthanasia is an option for those who are medically assessed to be suffering unbearably and possibly even dying.²⁸ The doctor assesses whether euthanasia is indicated for the individual patient, the point of this assessment being not primarily autonomy. Rather, it must be said that the autonomous request for euthanasia is regarded as a necessary proviso for the doctor to even be able to begin assessing whether the patient is otherwise in a state qualifying him or her for euthanasia according to the provisions set out. The decision of the doctor (and any consulting physician) concerning indication for euthanasia is based on an assessment of whether the patient is suffering unbearably and on whether all other possibilities for alleviating the

²⁷ See e.g. Keown, John (2002), p. 77: "Consequently, the real, rather than the rhetorical, justification for VAE [voluntary active euthanasia] is not the patient's autonomous request *but the doctor's judgment that the request is justified because death would benefit the patient*".

²⁸ It should be noted that it is not crucial to this argument whether the choice of euthanasia acts as a negative or a positive right (see section 3.1.1).

patient's suffering have been exhausted.

The next step in the argument emphasizes that this assessment is reminiscent of the assessment already being made as part of good clinical practice before a doctor omits or interrupts life-prolonging treatment for terminally ill patients who are not legally competent. Similarly, the assessment recalls the deliberations any doctor has to go through before deciding to administer palliative medicine, a side-effect of which is to risk shortening the patient's life, or before deciding to administer palliative sedation.²⁹ Although there may be a difference between the intent of euthanasia and pain-relief therapy at the conclusion of life, most people will surely agree that the doctor's assessment in either case is about the degree of suffering and whether to provide other, less serious therapeutic options that can benefit the patient.

The third and conclusive step in the argument indicates that, in the situation described above, euthanasia without request in dying patients will become just as acceptable as avoiding life-prolonging treatment is today, since the important thing about any medical assessment of the indication for euthanasia is whether euthanasia really is in the patient's interest; and if it patently is no longer in the patient's interest to live (for which reason avoiding life-prolonging treatment is acceptable), euthanasia will also be perceived as being in the patient's interest. The autonomy requirement will therefore recede into the background in cases where the patient is terminally ill and the suffering is so great that living that short while longer will be of no benefit to the patient. An additional opening will perhaps appear when the autonomy requirement in some cases recedes into the background, when unbearable suffering will generally play a greater role as a criterion. But unbearable suffering is difficult to define, so that in the even longer term some people may fear that euthanasia without request will not occur 'only' in the same instances where it is currently good clinical practice for a doctor to avoid life-prolonging treatment for a terminally ill person.

Empirical evidence for the logical slippery slope?

To some extent, euthanasia studies in the Netherlands can be said to

²⁹ For more in-depth treatment of palliative sedation, see *Treating the Dying – The Difficult Decisions*, section 3.4.1. pp 77-80.

provide support for the line of argument described. In 1990 and 1995 the Dutch authorities conducted in-depth studies into how and why euthanasia and other clinical end-of-life decisions are implemented. The study from 1990 (The Rummelink Report)³⁰ showed that doctors in the Netherlands had performed euthanasia in 1,000 cases where the patient was not capable of requesting it. Most cases involved terminally ill patients, where the majority would consider it reasonable to interrupt treatment or possibly administer palliative medicine, with the side-effect of that life being shortened. Indeed, John Keown, one of the foremost advocates of the slippery slope argument, has also stressed that the commission behind the report defended most of the 1,000 cases of unsolicited euthanasia by likening them to palliative treatment. In his book on the slippery slope argument, from 2002, he cites a quotation from the report, showing this:

The ultimate justification for the intervention is in both cases the patient's unbearable suffering. So, medically speaking, there is little difference between these situations [the majority of the 1,000 cases of euthanasia without request] and euthanasia [in the Netherlands 'euthanasia' is consistently used about taking the life of a person at his or her request], because in both cases patients are involved who suffer terribly. The absence of a special request for the termination of life stems partly from the circumstances that the party in question is not (any longer) able to express his will because he is already in the terminal stage, and partly because the demand for an explicit request is not in order when the treatment of pain and symptoms is intensified. The degrading condition the patient is in confronts the doctor with a case of force majeure. According to the Commission, the intervention by the doctor can easily be regarded as an action that is justified by necessity, just like euthanasia.³¹

John Keown also makes a point of highlighting that the 1990 Rummelink Report provides evidence of far more cases of euthanasia without request than the 1,000 mentioned above if cases are included

³⁰ Cf. *Medische beslissingen rond het levenseinde. Rapport van de Commissie onderzoek medische praktijk inzake euthanasie* (1991).

³¹ Taken from the Rummelink Report (Outline Report of the Commission of Inquiry into Medical Practice with regard to Euthanasia) in: Keown, John (2002), p. 117.

where doctors have interrupted or omitted life-prolonging treatment³² and at the same time signalled that their express purpose in so doing was to shorten the patient's life. According to John Keown's reading of the study results, 5,450 patients were administered euthanasia without request if these cases are included. In a questionnaire survey in which doctors are asked to tick various ready-formulated reasons, there may naturally be some uncertainty as to how the individual doctor perceives the ability of such wordings to describe their actual intentions once they had resolved to go ahead. In other words, it is uncertain whether the doctor in all 5,450 cases would insist that the intention was to shorten the patient's life if he or she gave more careful consideration to the matter. But John Keown's reasoning is that, ethically speaking, avoiding life-prolonging treatment with the intention of shortening life must be judged in the same way as euthanasia. On the balance of probabilities, therefore, the extensive occurrence of these actions indicates a slippery slope towards actual euthanasia without request for patients in a similar condition.

Practice-oriented slippery slope

This argument takes as its basis the fact that any regulation and institutionalization of euthanasia will include a number of critical parameters that allow excessive room for interpretation and afford too great a risk of the competences and resources of those taking part (both the person on the receiving end and the one on the performing end) being insufficient to form the basis for so final a decision as euthanasia. The critical points are principally the following four: Firstly, there will always be uncertainty about the patient's diagnosis and prognosis. Albeit perhaps in very few instances, a patient occasionally lives considerably longer and may make a considerably better recovery than predicted by the medical prognosis. Secondly, assessments will vary as to when all the alternatives for relieving the patient's suffering have been exhausted, especially because this depends on the type of suffering (physical or existential suffering?) they are designed to alleviate. Here, in particular, it is a prerequisite that doctors have a high level of knowledge and skill in palliative care

³² The implication here, of course, is that the patients were incapable of controlling their own treatment and that they were in a terminal phase.

provision.³³ Thirdly, the definition of unbearable suffering, as previously mentioned, is largely open to interpretation. How does the patient's subjective evaluation of his or her suffering tally with the medical assessment, and what should count as qualifying a person for euthanasia?³⁴ Fourthly, it can be hard to assess when there is an explicit and sure-fire request for euthanasia from a patient whose powers of self-determination are intact. John Keown has summed up the argument as follows:

Surely, guidelines would end up granting considerable leeway to the opinion of the doctor as to whether the request was voluntary, and to the feelings of the patient as to whether the suffering was unbearable.

John Keown goes on to stress that the necessary confidentiality relationship between the practising doctor and patient regarding such assessments will in itself be a hindrance to successfully maintaining any effective control of euthanasia.

3.5.2 Criticism of slippery slope arguments about euthanasia

Euthanasia without request is ethically defensible in some cases

The most powerful objection to the logical variant of the slippery slope is that it is not at all about a slippery slope from something ethically less dubious to something ethically more dubious. The argument is powerful because it admits the premiss for the logical slippery slope argument: that euthanasia will be exercised chiefly to benefit the patient, and that the patient's ability to request euthanasia cannot therefore be said to be crucial in all cases. Based on this premiss, however, the opposite conclusion is drawn: that, precisely for this reason, it must be legal to exercise euthanasia not only at the patient's request, but also in certain cases where the patient is not in

³³ Dutch experience, for example, shows that doctors choose consulting colleagues to assess assisted suicide cases on the basis of convenience in terms of physical proximity rather than whether the doctor in question possesses expertise in palliative care (see Hendin, Herbert (2002), p. 104).

³⁴ A notorious case from the Netherlands demonstrates the fuzziness of unbearable suffering criteria. A psychiatrist, Dr Chabot, assisted a woman with suicide because she was grieving over her son's death. That grief, according to Chabot, was incurable. Dr Chabot had written to a number of colleagues for their assessment. They all thought it was in order to help the woman accomplish suicide. No one felt it necessary to consult the woman themselves before submitting their assessment (Hendin, Herbert (2002), p. 110).

a position to request euthanasia. The ethical slide described by advocates of the slippery slope argument seems straightforward, of course, if one is of the conviction that euthanasia without request is ethically acceptable in cases logically included in the actual pro-euthanasia argument.³⁵

This conviction bears some relation to a critical attitude towards the sanctity-of-life principle. As described in section 3.2.2, critics of the inviolability of human life perceive the prohibition on killing as a way of safeguarding the value vested in the individual by virtue of being alive. Consequently, the prohibition does not apply if the person whose life is taken attaches no positive value to being alive. According to that person, life cannot be said to have any value per se, only by virtue of the value the individual perceives life to have. Based on this view, it may be felt that a person who has irretrievably lost his or her consciousness no longer has an interest in living. In consequence, the conclusion can be drawn that euthanasia without request and avoiding life-prolonging treatment are both ethically acceptable actions when dealing with this type of patient. Moreover, it may be felt that a supposedly negatively perceived value (unbearable suffering) in incurable and possibly dying patients who are not legally competent justifies euthanasia without request in the same way. Some will therefore feel that euthanasia without request is ethically defensible in severely disabled infants, who may have to go through painful curative treatments in order to obtain what may turn out to be only a brief life with no or severely reduced ability to experience the world, function motorically and assimilate socially. Others will feel that euthanasia without request is also defensible in the case of severely demented people who express unbearable suffering without being capable of requesting euthanasia. In other words, acceptance of euthanasia without request need not tie in with a requirement for the patient to be terminally ill.

³⁵ Cf. Griffiths, John et al. (1998): "I put off for the moment one critical element of the slippery slope argument, namely that the repellent practices that are supposedly bound to follow from legalization of euthanasia are actually repellent. In fact, I think the Dutch case makes plain that on the whole this is not the case. If I am right, then however strong the association between legalization and these other practices might be, the slippery slope argument loses all force because there is nothing to be feared from sliding down it".

Euthanasia is particularly relevant for people who have the ability for self-determination

In a critique of the logical slippery slope argument, one may argue instead from the assumption that the premiss is wrong: The doctor's assessment of the patient's suffering is not the supreme criterion, and self-determination should not be viewed exclusively as the patient's ability to consider and request euthanasia. Instead, it can be asserted that the perceived, limited opportunity a modern health service offers for exerting influence over decisions regarding one's own death is an integral part of the actual suffering for many autonomous patients who are incurably ill or even dying. Against this backdrop it can be argued that euthanasia is an option that makes particular sense for patients with unbearable suffering who are concurrently in a state where their ability for self-determination is intact. By its very nature, euthanasia can be said to be a last resort that should be limited to those who have an altogether special need. Dying people who are suffering but have not decided and are currently unable to decide in favour of euthanasia may not have such a particular need. Their need is for pain relief and palliative care. If the patient has impaired consciousness and is on the brink of death, some will feel that the patient may not care if his or her life is terminated or his or her pain alleviated. Even in this case, however, it will be possible for euthanasia adherents to argue on the basis of the above that euthanasia—given the severity of the means—should only be administered where there is an altogether special need. This special need, it may be asserted, makes the minimum assumption that the patient is suffering unbearably and is simultaneously capable of making an autonomous decision. This precludes any acknowledgement that there is a logical link between the rationale for euthanasia and euthanasia without request.

Appendix

Euthanasia legislation in other countries

The Netherlands³⁶

In 2001 euthanasia was legalized in the Netherlands. However, euthanasia has been practised in the country for years, and Dutch practice has gradually evolved as a result of court rulings. In 1973 a regional court acquitted a doctor who had given a dying woman a lethal dose of morphine after persistently being asked by her to do so. The reason for the acquittal was that the doctor had administered euthanasia in order to avoid severe and incurable suffering. In 1984 the Dutch Supreme Court acquitted a doctor who had administered euthanasia to a 95-year-old woman on her deathbed. The doctor was acquitted because he had acted out of necessity and violated the penal code provision on death-on-demand with a view to discharging a duty to alleviate the patient's suffering. During the years that followed, a practice developed in the Netherlands whereby doctors had to report to the director of public prosecution when they had performed euthanasia. If this authority deemed that the doctor had complied with the specific rules and conditions governing euthanasia and could thus be said to have acted out of necessity, the doctor would not be prosecuted. Until 2001 this practice had not resulted in any actual exception from penal code provisions governing death on request, which in principle was still illegal for everyone. But 2001 saw the introduction of an explicit exception from the general provision on the illegality of killing on request, and under the provisions of the law on euthanasia it is no longer illegal for a doctor. Apart from this formal change, practice was amended in 2001 so that the doctor no longer has to report to the director of public prosecution but to the regional committees that monitor euthanasia in the Netherlands. These committees then assess whether the doctor has adhered to the criteria outlined, and only if that is not so do they report the case to the director of public prosecution.

³⁶ Principal source: De Haan, Jurriaan (2002), pp. 57-75.

According to the Dutch Act on Euthanasia a doctor must comply with the following six "statutory criteria for due care". It should be noted here that the person requesting euthanasia is not required to be the one who is terminally ill. The doctor must:

- a) be satisfied that the patient's request was voluntary and well considered
- b) be satisfied that the patient's suffering was sustained and unbearable
- c) have informed the patient about his/her situation and further prognosis
- d) be satisfied, together with the patient, that there was no reasonable alternative to the situation the patient was in
- e) have consulted at least one other independent physician who has seen the patient and stated his opinion in writing about the current due-care criteria listed in a.-d. above, and
- f) have exercised due care and attention in terminating life or assisting in suicide.³⁷

The law also includes provisions on age limits. If a patient has turned 16 and is no longer able to express his or her wishes, the doctor can perform euthanasia if a written request to this effect is available from the patient and if, prior to the situation, the patient had a reasonable grasp of the situation and his/her interests. If a legally competent patient between the ages of 16 and 18 requests euthanasia, the doctor can perform this after the parents or ward have been involved in the decision-making process, although the latter do not need to give their final consent. Finally, a patient between 12 and 16 can request and have euthanasia performed if the parents or ward consent to the decision to carry out euthanasia or assisted suicide. Apart from these criteria governing entitlement to euthanasia, the Dutch legislation contains a number of provisions on the regional committees mandated to monitor euthanasia and assess on a case-by-case basis whether a doctor's performance of euthanasia falls within the framework of the law. As mentioned, the committees' remit is to assess and approve the doctor's report on euthanasia or, failing that, to pass the case on to the public director of prosecution. The committees have the authority to ask the doctor to supplement his

³⁷ Cf. De Haan, Jurriaan (2002), pp. 57-75.

report with verbal or written information, where necessary for a proper evaluation of the doctor's actions. In addition, the committees can obtain information from the local post-mortem examiner, from the consulting doctor and from the carers involved, where necessary for a proper evaluation of the doctor's actions. The committees make their rulings by a simple majority of votes and must comprise an odd number of members. The members of a committee must always include a legal expert (who is always the chairperson), a doctor and an expert on ethical or philosophical matters. A secretary, who is a legal specialist and plays a consultative role at committee meetings, is attached to a committee.

Belgium

In Belgium euthanasia was legalized in May 2002. The law, the restrictions on entitlement to euthanasia and the framework for its performance are highly reminiscent of the Dutch model described above. There are odd differences worth mentioning, however. In order to have euthanasia performed in Belgium, a person must be suffering from “constant and unbearable physical or mental suffering”.³⁸ Belgian law legitimizes doctors performing euthanasia for patients who are suffering unbearably and are in a “hopeless condition”. As with Dutch law, there is no requirement that the patient be dying, but in Belgium it *has* been added that the unbearable suffering can be physical or mental. Two other noteworthy differences are that the Belgian law, unlike the Dutch one, does not grant entitlement to euthanasia for people who have not reached legal age, and a third physician has to be consulted in cases where no terminal illness is involved.

Switzerland³⁹

Euthanasia is not permitted in Switzerland, but it is permitted to offer help with suicide when that help is given on the basis of altruistic

³⁸ Cf. *Projet de loi, relatif à l'euthanasie, Chapitre II, Art. 3*: “Le médecin qui pratique une euthanasie ne commet pas d'infraction s'il s'est assuré que: [...] - le patient se trouve dans une situation médicale sans issue et fait état d'une souffrance physique ou psychique constante et insupportable qui ne peut être apaisée et qui résulte d'une affection accidentelle ou pathologique grave et incurable.”

³⁹ Principal source: Bosshard, Georg et al. (2002), pp. 527-534.

motives. This is inferred from Section 115 of the Swiss Penal Code, which reads:

Whosoever incites another person to commit suicide or helps him or her to do so from motives of self-interest, will be liable to a maximum of 5 years imprisonment if the suicide is carried out or attempted.⁴⁰

The person being assisted in suicide must ask for such help, and that help must be given in a way that involves the suicide candidate him/herself performing the lethal action (taking a lethal dose of medicine, for instance). There is no requirement that the suicide candidate need already be dying, just as there is no requirement that the person assisting with the suicide be a doctor. Hence, all legally competent citizens of age in Switzerland can ask anyone to lend them assistance with suicide. However, the Swiss administrative tribunal has laid out more restrictive guidelines for cases where a doctor is involved. In such cases there must be: “a medical indication in the sense of a terminal illness with an inevitable progression to death”.⁴¹ These conditions will thus apply when a person wishes to commit suicide in some way that calls for the prescription of medicine. On this point it is worth noting that the physician (unlike a doctor in the Netherlands or Oregon) need not obtain another physician’s evaluation of the patient’s condition. Health staff in the Swiss cantons are obliged to report all deaths from “unnatural causes” immediately, including suicide. These deaths are investigated by the public investigating authority in collaboration with the medical officer. The death statistics do not differentiate between “ordinary” suicide and suicide in which assistance has been involved.

Developments in Switzerland have been swayed by the influence of “right-to-die organizations”. In 1982 the organization “Exit Deutsche Schweiz” was founded, and instead of promoting the legalization of euthanasia it decided to exploit the existing possibility of assisted suicide by offering such help to all severely ill people wishing to die. Since 1990 the association has offered suicide assistance to members of the association suffering from an illness with a “poor prognosis, unbearable suffering or unreasonable

⁴⁰ Cf. Bosshard, Georg et al. (2002), p. 530.

⁴¹ Cf. Bosshard, Georg et al. (2002), p. 530.

disablement".⁴² This takes the form of ingesting a lethal dose of barbiturates, prescribed by the doctor with the express intention of enabling the patient to terminate his or her life. In recent years Swiss MPs have attempted—so far, to no avail—to implement restrictions in this area; this includes prohibiting doctors from lending assistance with suicide and preventing citizens from other countries being able to travel to Switzerland to obtain help with suicide. In Switzerland, contrary to practice in Oregon, it is not forbidden to provide suicide assistance using gastric tubes or an infusion as long as the final action is performed by the actual person.⁴³ This fact, together with the Swiss authorities' tolerance of associations systematizing assisted suicide, means that Swiss practice comes close to providing the same options as euthanasia in the Netherlands. Swiss regulation of "help to die" is more restrictive than in the Netherlands, on the one hand, because no scope is provided for euthanasia as such. On the other hand, Swiss law is more open because it contains the fewest restrictive conditions on administering help with suicide.⁴⁴

Oregon, USA

The State of Oregon made it legal in 1994 for physicians to provide help with suicide, whereas it is still illegal to perform euthanasia. The law was adopted by referendum, with 51 percent of votes in favour of the law and 49 percent against. Unlike Switzerland, only physicians may offer help with suicide, and in Oregon this practice has been regulated by an independent law called "The Oregon Death With Dignity Act".⁴⁵ Under this law a legally competent, adult patient residing in Oregon⁴⁶ can ask a physician for help with suicide if he or

⁴² Cf. Bosshard, Georg et al. (2002), p. 529.

⁴³ Cf. Bosshard, Georg et al. (2002), p. 230: "At first widely unnoticed by the general public, Exit began in 1997 to help people who wished to die but had difficulties in swallowing, to prepare lethal infusions or even to help with the introduction of such substances into gastric tubes. These cases have been classed—and thus tolerated—by the investigating authorities as assisted suicide, since the final step causing death was actually carried out by the person wanting to die."

⁴⁴ Cf. Bosshard, Georg et al. (2002), p. 530.

⁴⁵ Cf. <http://www.leg.state.or.us/ors/127.html>. The above outline is based on the wording of the law to which this link points.

⁴⁶ The law provides for different, valid ways of documenting residency in Oregon, incl.: possession of an Oregon driving licence, the right to vote in Oregon, ownership of property in Oregon.

she is suffering from a terminal disease. The Act defines terminal disease as one that is incurable and irreversible, and will produce death within six months. The patient must voice his/her wish twice verbally (the second time being no later than 15 days after the first) and once in writing. The written request must be signed by two witnesses, one of whom is 'disinterested'; that is to say that he or she is not a relative of the patient, has no entitlement to any portion of the estate of the patient under any will or by operation of law, and has no connection with the healthcare facility where the patient is receiving treatment. The witnesses sign to endorse that, in their view, the patient is legally competent ('capable'), acting voluntarily and is not being coerced. In addition, a consulting physician is required to examine the patient and confirm that the patient is suffering from a terminal disease, is legally competent and has granted informed consent. If the consulting or the attending physician suspects that the patient is suffering from a psychiatric or psychological disorder or depression, the patient must be examined for such. Until any such suspicion has been disproved, it is illegal for a physician to provide help with suicide.

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End of life

This publication consists of a series of three publications in which the Danish Council of Ethics has focused on ethical challenges and problems at the end of life.

It is the translation of three reports previously published in Danish. However, we are pleased to present the three

reports, *“Spiritual Care for the Dying”*,

“Treating the Dying – The Difficult Decisions”,

and *“Euthanasia – Legalizing Killing on Request?”*,

to a still wider audience, as the topics are universal.

The three reports were prepared and published successively, from 2002 to 2003, but should be seen as conceptually coherent. The three Danish publications are therefore being published as one in English.

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