

ORGAN DONATION – Ethical deliberations and recommendations

Summary

In this report the Danish Council of Ethics presents the Council members' recommendations on organ donation. There are recommendations from the Council concerning the relatives' situation at the deathbed. The Council then tables recommendations as to the rules of consent that should apply to organ donation, as well as recommendations as to whether or not there should be a duty to adopt a position on organ donation. Finally, the Council presents different fundamental approaches to the question of the purpose of the information provided on organ donation. The report further includes organ donation practice as at 2008: legal considerations, treatment conditions and ethical deliberations.

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Preface

Transplantation medicine has undergone striking development since a kidney from a living donor was successfully transplanted for the first time in the USA in 1954—a development which on the one hand has led to an understandable desire to apply the technology to improving the odds of survival and the quality of life for very sick people, but on the other hand has produced an

increasing need for organs and has thus spawned a number of ethical dilemmas concerning organ procurement methods. In Denmark many people live with severely impaired quality of life or even die while on the waiting list to receive a new organ^[1]. This has increased the demand for both living and dead donors. The situation is the same in many other countries.

Doctors and patients would like to reduce the shortage of human organs, but also politicians, international organizations and society as such expend resources on trying to optimize this form of treatment. The vast majority of the population take a positive view of organ donation. In Denmark, where organs are harvested predominantly from dead donors, only a smallish proportion of the population has nevertheless registered as potential donors with the Danish Donor Registry. The purpose of a campaign conducted in 2008 was to get more people to make up their minds about organ donation. This campaign resulted in more than 70,000 new donors registering with the Donor Registry, bringing the total up to 575,000.

Coordination of transplantation procedures has also been improved in recent years. In 2008 the Danish Centre for Organ Donation was set up for the purpose of optimizing the utilization of those organs suitable for transplantation. The aim of the Centre is to contribute to solving current problems of an organizational nature. Other important questions have also been debated in 2008—including the question of introducing presumed consent for organ donation, and the role of the relatives and the problems involved with trading in organs. For many people organ donation is a personal and sensitive area that raises questions of an ethical nature, such as the right to self-determination over the body, feelings and rituals around death and the onset of death, consideration for relatives, humanity and solidarity. In practice organ donation involves a different experience and perception of the death process on the part of the relatives, since the function of the body and breathing cease in the brain-dead person during a transplant, and thus not at a time when the relatives can be nearby.

The Danish Council of Ethics wishes to contribute to shedding light on these ethical dilemmas. It is the Council's hope that the politicians will view the report as a useful tool for making decisions in the field and that more potential donors can be helped to clarify their attitude to organ donation.

The report has been reviewed and approved by the Danish Council of Ethics at meetings in September, October and November 2008 based on a draft from a working party on the Council consisting of Gunna Christiansen (chairman), Elisabeth Dons Christensen and Thomas G. Jensen. The Council and the working party wish to thank a number of people for having made their knowledge available for the work along the way. These are: Helle Haubro Andersen, general manager of the Danish Centre for Organ Donation, Lone Bøgh, a nurse at the Danish Centre for Organ Donation, Ib Gaarde-Nissen, chairman of the Transplantation Group, Bjørn Knudsen, Head of Section, National Board of Health, Denmark, Dr Michael Kosteljanetz, consultant at the Department of Neurosurgery at Rigshospitalet, the National University Hospital, Dr Lars Ilkjær, senior physician at the Department of Thoracic and Cardiovascular Surgery at Aarhus University Hospital in Skejby, Dr Steffen Ellebæk Petersen, consultant at the Department of Urology, Skejby, Dr Martin Iversen, consultant at the Department of Cardiology, Division of Lung Transplantation, Rigshospitalet, Dr Jesper Hjortdal, consultant at the Department of Ophthalmology, Aarhus University Hospital and Inger Palfelt, nurse (coordinator) at Rigshospitalet.

Ulla Hybel, LL.M, PhD, of the Danish Council of Ethics' Secretariat has been project manager for the working party and together with Thomas Laursen, MA, has compiled the manuscript on the basis of the discussions on the working party and the Council.

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[1] See Appendix 3 on waiting lists.

Resumé

In this report the Danish Council of Ethics presents the Council members' recommendations on organ donation. There are recommendations from the Council concerning the relatives' situation at the deathbed. The Council then tables recommendations as to the rules of consent that should apply to organ donation, as well as recommendations as to whether or not there should be a duty to adopt a position on organ donation. Finally, the Council presents different fundamental approaches to the question of the purpose of the information provided on organ donation. The report further includes organ donation practice as at 2008: legal considerations, treatment conditions and ethical deliberations. This resumé is a digest



of the report, with the emphasis on the Council's recommendations.

Donation of organs from living donors – including trading in organs – is not discussed in the report, just as circumstances surrounding health-care staff and the organizational domain are touched upon only briefly. More recent initiatives are described in the report, however, such as the establishment of the Danish Centre for Organ Donation.

The purpose of the report

In this report the Danish Council of Ethics presents its recommendations regarding what the politicians should do in order to put a sound framework in place around organ donation.

The aim is to offer some suggestions as to how society can accommodate the needs of people with failing organs for healthy organs in an ethically defensible way, among other things by creating a proper framework for the relatives.

The Council of Ethics' members do not agree as to what framework is actually ethically reasonable. For example, some of the Council's members think that presumed consent should be introduced for organ donation, while others think that informed consent should be maintained in its present form.

That means that the Council of Ethics' recommendations do not point in a particular direction. Instead it can be seen as a thoroughly argued chart or catalogue of the Council members' views as to which social frameworks should exist for organ donation. This can hopefully act as a beneficial platform for reflection and decision-making by politicians and general-interest readers.

Organ donation as a practice in the health services involves difficult ethical considerations. This is primarily due to the dependency that exists between the recipient's need for organs and another person's death. Organ donation frameworks which are good from an ethical point of view, therefore, must entail making proper allowance for the interests of both the donors and the recipients of organs. People with an illness-related need have an interest in ensuring that it is possible to perform organ transplants, and consequently that organs are available. But it is important for everyone in society that the dead body be treated with respect and dignity. To us it is significant to allow relatives a human setting in which to say their goodbyes to their next-of-kin, and important that potential organ donors—that is to say, all citizens over the age of 18—should enjoy an encounter with the public sector that offers the relevant degree of respect for their outlook on life, with respect for the fact that people may have their doubts and that it can be fundamentally difficult to make a decision on organ donation.

In other words, the problem of few organs should be resolved in as far as it is possible to resolve it, without other weighty considerations being trodden under foot on the way to achieving that solution. The Danish Council of Ethics' recommendations are descriptions of different routes towards better ethical frameworks for organ donation.

Organ donation in Denmark as at 2008

Nowadays it is possible to remove organs like kidneys, heart, lungs and liver from one person and transfer them to another person, where the organ can resume its function. The report describes which conditions are usually precursors to the need for a new organ, the waiting time and the patient's condition and prognosis after completion of a transplant. Organs can be donated from both living and dead people. As mentioned, the report discusses organ donation from dead donors only. In Denmark organs from brain-dead people can be used for transplants.

There are two equal-ranking death criteria according to Danish law:
Cardiac death is defined as "irreversible cessation of breathing and heart activity".
Brain death is defined as "irreversible cessation of all brain function".

Between 100 and 200 people a year are declared brain-dead in Denmark. Of these, 60-80 actually become organ donors. On average 3-4 other people can receive organs from one donor if permission for such has been granted, and on this basis some 250 transplants a year are carried out in Denmark.

A transplant is performed in several phases. If, during the course of a particular disease or injury, doctors ascertain that the patient's brain has suffered irremediable damage, organ donation then becomes an issue.

Under current Danish law, explicit consent is required for organ donation, primarily from a deceased person, even prior to the onset of death. If the deceased him/herself has not taken a position on organ donation, it is up to the relatives whether consent will be granted for donation of the deceased's organs.

For the relatives the situation is a difficult one. A person close to them has died suddenly, while at the same time they are faced with the possibility that something is going to be done with the deceased's body that is not common practice by the generally familiar norms surrounding the process of death and burial. Culturally speaking, the relatives are accustomed to viewing death as something definitive and the dead body as something that has great emotional significance solely for those who are still alive and have known the deceased. Now that they are faced with relating to and, in many situations, deciding in favour of organ donation, they are launched headlong into a completely different way of looking at the dead body: it presents itself as a material object also, containing resources in the form of healthy organs which can be of vital importance to other people. In tandem with the grief experienced by the relatives, doubts can arise as to which actions are reconcilable with dignified treatment of the deceased. The deceased have no chance of returning to life—of that there is no doubt. Nevertheless, the process involves so many special considerations more reminiscent of providing care for and watching over a dying person that this can be transposed onto the relatives' experience of the situation. The health-care staff initiate different treatments which are normally associated with treating a living person, but are carried out here because the organs need to be kept healthy. In addition, the brain-dead person is warm, breathing and thus more reminiscent of a living or dying person – not a completely dead person.

If consent for organ donation is granted, blood samples will be used, among other things, to check whether the donor's organs are healthy and functioning properly. The donor will then be examined by two doctors, one of whom is a specialist in brain disease. If it is ascertained during this examination that the patient is brain-dead, dedicated operating staff from one or more of the country's transplant centres will be called in (depending on the organs to be transplanted). After the operation the donor will be brought back to the family on the hospital ward.

The donated organ will then be transported to the centre where the transplant is to take place. The recipient of the donated organ will have been contacted beforehand and prepped for an operation. Following a transplant operation the vast majority of patients with a new organ return to an existence resembling the one they had before they fell ill. They will, however, be dependent on immunosuppressive medicine, which has certain side-effects.

Overview of the number of transplants performed in Denmark in 2007 and waiting list status as at end-2007

Number of (brain-) dead donors in 2007: 72
(62.5% of these donated several organs)

	Kidneys	Livers	Hearts	Lungs
Transplants (from cadaveric donors)	115	43	29	33
Additions to waiting lists	201	40	23	28
Number who died while on waiting list	36	2	3	9
Number of people on waiting list	385	21	14	32

The Council's recommendations

In its report the Danish Council of Ethics focuses on four main topics:

- A. How to create proper frameworks for relatives' leave-taking?
- B. Which rules to apply to the citizen's consent to act as an organ donor in the event of brain death?
- C. How are the public authorities to inform the citizen and support the citizen's decision for or against organ donation?
- D. How can it be ensured that citizens are familiar and comfortable with the peculiar circumstances of the death process brought about by organ donation?

A. Frameworks for relatives' leave-taking

All members of the Council of Ethics recommend implementing measures to foster a great degree of reassurance, respect and dignity in the highly difficult situation in which the relatives find themselves when one of their next-of-kin has been diagnosed as brain-dead and may possibly have to donate organs. The sorrowful and emotionally chaotic situation is further complicated by the fact that the relatives are often those who have to make a decision on possible organ donation.

Reassurance, respect and dignity can be instilled quite adequately with frameworks that take the nature of ritual. The Council recommends that the authorities strongly endeavour to develop and disseminate the practice and ritualistic measures that

already exist by way of local initiatives at hospitals in Denmark. This may, for example, be a more distinct ritual marking of the time of death, a subsequent letter of thanks from the hospital to the relatives and, in addition, measures to ensure that information and dialogue with the relatives are characterized by professionalism and sympathy.

The Council's members also feel that discussing changes to the rules of consent for organ donation should necessarily be accompanied by some discussion of the lack of popular understanding and acceptance of the brain death criterion and, more particularly, the circumstances surrounding the kind of death to which this criterion can give rise. The Council recommends that Danish Parliament take the initiative to scrutinize the problems surrounding the death criterion and leave-taking rituals, and produce proposals for modifying practice at the country's hospitals and transplant centres.

One member (1) of the Council does not think it makes sense to take a stance on changing consent rules until some investigation has been conducted into the conflicts between the brain death criterion and the perception of leave-taking—and measures have been taken to change practice.

B. Consent

Informed consent for organ donation should be retained

A majority (9) of the Council of Ethics' members think that the present regulation of organ donation should be maintained. Thus, explicit consent from the deceased or from the relatives should continue to be available if organ donation is to be able to be carried out.

Informed consent caters best for the doubters and those who do not wish to be organ donors. The members mentioned think that the public authorities should work on the basis that people are in two minds and respect the fact that they may have good reason to be in two minds. Informed consent further promotes active stance-taking and thus creates a likelihood of those who are close talking to one another about organ donation well ahead of time.

Presumed consent should be introduced for organ donation

A minority (7) of the Council of Ethics' members recommend introducing an opt-out system or so-called "presumed consent" regarding organ donation in Denmark. In future, they feel, it should be the case that organs may be removed from the brain-dead for use in organ donation unless the person, while alive, has declined to act as an organ donor. The members mentioned advocate presumed consent because organ donation is basically regarded as a self-evidently value-based preference, and because this system is expected to be able to result in a greater number of people being potential organ donors.

C. Stance-taking and information

Compulsory stance-taking on organ donation should be introduced

A majority (10) of the Council of Ethics' members recommend that organ donation be regulated so that, in future, all citizens should be required to take a stance on whether or not they wish to be organ donors. Previously, there has been no requirement in the legislation that every citizen should take a stance on organ donation. The members mentioned think that such a requirement should be expressed in the legislation in future, but on the condition that this requirement must not be encumbered by any form of sanction if it is not met. Based on an expectation that the vast majority in Danish society acknowledge organ donation to be an essentially collective affair, the members mentioned feel that solidarity regarding organ donation can be promoted by outrightly encouraging citizens to adopt a stance.

Compulsory stance-taking on organ donation should not be introduced

A minority (7) of the Council of Ethics' members do not think compulsory stance-taking should be introduced for organ donation. For these members it is important that the individual citizen should not feel obliged to consider and take a position on life-and-death topics and values that the person in question would otherwise have had greater freedom to be in two minds about and relegate to the realm of the uncertain or the undecided. Moreover, any requirement on the part of the public authorities to take up a position can result in people taking that decision rashly and, to an excessive degree, glossing over the all-important conversation with the next-of-kin.

Recommendations regarding information on organ donation

A minority (7) of the Council of Ethics' members do not think the authorities should disseminate information with a particular outcome in prospect. That applies irrespective of whether the intent is to get many to adopt a position or whether the intent is to get many to say 'yes'. Information campaigns on the topic should not be conducted, but objectively descriptive information should be available on the subject when the citizen applies to register his or her decision, if any. The actual citizen must thus be able to decide whether the exchange of organs is even a topic for inclusion in his or her personal deliberations about life and death.

A majority (9) of the Council of Ethics' members feel that society is obliged to stimulate debate and decision-making about organ donation on an informed basis. The members mentioned think that part of any democracy with active participation as its ideal includes confronting citizens with an expectation that they take a stance on subjects of essential importance to the

collective life of the community. Conversely, no call to adopt a stance must contain recommendations as to what the citizen should ultimately decide in favour of, but respect the fact that the citizen may be in two minds or may have good reason to say no.

One of the Council of Ethics' members recommends that information campaigns initiated by government authorities make it their objective to persuade as many people as possible that saying 'yes' to organ donation is a good choice. It must be clearly and distinctly communicated that organ donation is a blessing, an invaluable social benefit for many severely ill people and hence an act which, in ethical terms, is altogether preferable to saying 'no' to being an organ donor, objectively speaking. Any such call must underpin the fact that organ transplantation is an ethical benefit that is made available in society, and that it is up to the individual to decide whether or not to contribute to generating this ethical benefit by registering as an organ donor him/herself.

D. Recommendation concerning information about the brain death criterion

The Council of Ethics recommends that the public authorities plan for the issues arising from the discrepancy between the brain death criterion and the culturally rooted expectation surrounding the death process by arranging for these topics to be made the subject of thorough public information and debate in society.

Firstly, there is still a need for factual information as to what is comprised by the brain death criterion. Secondly, there is an imbalance between people's naturally or culturally rooted expectations of the death process and the definition of the onset of death, as entailed by the brain death criterion. This manifests itself partly in the seeming difficulty involved in talking about "the dead person's heart beating" or "the corpse being wheeled in to the operating table", when speaking about a brain-dead person. The Council of Ethics calls for debate and reflection on these topics to be set in motion in elementary schools, among other fora, and at post-compulsory education level.

Chapter 1 Introduction

This report deals with the donation and transplantation of organs. An organ is defined as a unit in the body with a special function, usually constructed from several different types of tissue. A human being only has one of some organs, and the organ's function can be crucial to maintaining life.

Nowadays it is possible to remove organs like kidneys, heart, lungs and liver from one person and transfer them to another person, where they can resume their function. Among other things, developments in transplant surgery and medicine to inhibit the body's rejection of foreign organs have made this form of treatment possible.

1.1 Mapping an ethical problem

Donation and transplantation of organs has developed into an established form of treatment in the Danish health services. In the vast majority of cases organ donation is now a relationship between a deceased person who has healthy organs to "donate" and a living person who has a health-related need to receive a healthy organ. This is due to the very limited possibilities that exist for living people to gift their organs to others, as Danish law stipulates that intervention in a living donor's body can be performed "without any obvious risk to the person". There is no question, therefore, of transplanting the heart, liver and lungs while the donor is alive. Most people have two kidneys, however, in which case it is possible to donate one kidney within the framework of the law. The same applies in cases where there is scope for transplanting parts of the organ.

Although the rate of kidney donation from living donors seems to have been on the increase in recent years, it is primarily the donation of organs from dead—more specifically, brain-dead—people that is involved when faced with the decision as to which methods can reasonably be used to meet severely ill people's need to receive healthy organs. In point of fact, this report is an ethical deliberation on the measures that can reasonably be wished for from society, public authorities and individual citizens with a view to meeting ill people's need to receive healthy organs from brain-dead people. It is essential to involve three 'parties' in order to evaluate what can reasonably be done, ethically, to provide for the need to treat severely ill people by means of transplantation: the three parties are the brain-dead potential organ donor, the organ donor's relatives and the person or persons whose health stands to benefit from receiving organs from the brain-dead person.



1.2 What justifies the ethical relevance of organ donation?

Ethical deliberations must start when the question of the reasonableness of taking healthy organs out of dead people's bodies even becomes relevant. This is subject to agreeing that it cannot be considered ethically legitimate to perform such an intervention on the dead person's body at the drop of a hat and for no purpose. The purpose, as mentioned, is to allow transplantation to be used to meet vital needs on the part of severely ill people.

These are people with serious and life-threatening organ failure and, as in any other situation where people are suffering distress, the situation demands immediate care and help. The starting point for ethical reflections on organ donation is thus a self-evident ethical benefit: it is good to help others in distress. But equally obviously, the possibility of lending considerable help to people in distress is precisely what makes it relevant to consider harvesting organs from dead people's bodies and using them for new purposes. It suggests that, basically, it is ethically controversial to undertake that type of intervention on the body of a person freshly deceased, because providing this help involves having first decided whether other weighty and complicated considerations can be made properly in tandem with providing that help—consideration, for example, for the deceased's wishes concerning organ donation while he or she was alive; consideration for the relatives having reasonable conditions for taking leave of their nearest and dearest, for example; and the question of which interventions we as a society in general can reconcile with our view of treating the deceased's body in a respectful and dignified manner, for example.

A good end does not justify any means whatsoever, and it is no simple matter for everyone to decide whether organ donation as a form of treatment in the health services is actually a means legitimized by the end of helping people with severe and life-threatening organ failure. Over the years the public debate on organ donation has moved well away from this original starting point. Rather, the main problem currently being debated among the public and in the political system is the so-called "organ shortage". That is to say, the fact that more healthy organs are needed than can be provided by the present organ donation system.

1.3 Is the need for healthy organs an ethical problem?

There are waiting lists in the health services for treatment involving transplantation. The waiting lists contain people who have severe and life-threatening organ failure, with many of them waiting for a very long time or never managing to receive a healthy organ from an organ donor. These are people who have a serious health-related need for help and care from their fellow human beings and the society around them. Viewed in the light of current practice, in which organ transplantation will be the best form of treatment available from the patient's perspective, it is equally certain that being included on a waiting list may be felt to be an extra misfortune, knowing that more organs might well be available. But whereas the patient's need for help and treatment is a corollary of their illness, it is fair to say that the gap between health-dependent "demand" and the actual "supply" of suitable organs for transplantation is a phenomenon created by society. In other words, it is not a God-given thing that organ donation is a form of treatment that can be expected in the health services. The patient's possibility of inclusion on an organ transplant waiting list and his or her perception that there is a shortage of organs being donated not only presupposes that organ transplantation is technologically possible; it also presupposes that a choice has been made in social development terms—including politically and medically—that organ donation from brain-dead subjects is a good and viable route to helping people with severe diseases. If a shortage of organs is to be seen as an ethical problem, it is conditional on at least regarding this choice as well founded to some extent. That is to say that the so-called "organ shortage" is not just a result of seriously ill people's needs, it is also the consequence of a decision on the part of society that organ donation is an ethical benefit and, moreover, a treatment that must be offered as part of the public health services. Without this decision there would be no scope for transplanting organs from brain-dead people and hence the concept of organ shortage would make no sense.

Thus the actual development in legislation and practice governing organ donation is already based on a normative choice, having already judged that the beneficent value of organ donation outweighs the ethically controversial aspect of taking organs from the bodies of the deceased—always providing that the organ donor is brain-dead and that they themselves or their relatives have given their undertaking. In 2008 the Danish Council of Ethics is tasked with giving recommendations as to what can be done by society—in ethically reasonable terms—to narrow the gap between patients' need for healthy organs and the number of suitable organs available.

As shown by the above, it is important in this regard to highlight the fact that, logically, this 'disconnect' between the need for treatment and available organs may be thought not to pose an ethical problem. There is both a "strong" and a "milder" way of disputing that organ shortage in that sense poses an ethical problem. Having said that, the point of both variants is to deny that it is possible to speak of an ethical mismatch between organ "supply" and "demand". Neither variant necessarily invalidates the premiss that the situation of those with ailing organs calls for help and care, and that they are thus in a situation that is ethically charged.

The strong variant of the view that organ shortage does not pose an ethical problem will argue that organ donation should not even have been introduced as a treatment that a patient can be expected to have performed "on the national health". That may be the conclusion if organ donation is felt to be extremely compatible with, say, the above-mentioned consideration of treating the deceased's body with dignity and regard for allowing the relatives to take proper leave of their loved ones. It may be thought that organ donation creates overly great difficulties in these respects, and that the beneficent purpose of helping those with ailing organs fails to outweigh the detrimental effect that follows from organ donation as provision of a social service. The

milder variant of the view that the organ shortage per se does not pose an ethical problem acknowledges that the introduction of organ donation as treatment in the health services is ethically well founded, but society and the authorities do not have the lawful credentials to attempt to procure more donors than those registering as organ donors of their own accord. One cannot speak of a shortage of organs, therefore, even though there are patients whose need to receive a healthy organ is not being met.

1.4 The Council of Ethics' task

In this report the Council of Ethics will provide recommendations as to what can—with ethical reasonableness—be done by society to narrow the gap between patients' need for healthy organs and the number of suitable organs available. As mentioned above, one of the answers to this question may be that it is not ethically reasonable to do more than what is already being done to source organ donors. And the answer may even be that, viewed from an ethical standpoint, it was a mistake to even introduce organ donation as a treatment in the health services. The Council of Ethics sees it as its task to compile a thorough analysis of the ethical advantages and drawbacks of particular ways of meeting the need for increased organ donation. In this analysis the central parties are, as mentioned, the organ donor, his or her relatives and those patients in need of transplantation. This ethical analysis thus covers the entire basis for organ donation. Consequently, the analysis will not result merely in an evaluation of any future measures relating to organ donation; it will naturally also include an ethical evaluation of the practice already put in place and based on particular normative prerequisites, which cannot be taken as self-evident.

But irrespective of the position adopted vis-à-vis organ donation as a practice in the Danish health services, it must be noted that the need for organ transplantation from brain-dead people constitutes *de facto* an altogether special ethical problem, which calls for reflection regarding some solution. The solutions will vary, depending how the different considerations are weighted. It may be thought, for instance, that the crucial issue is that of taking organs from a person who is brain-dead but to the relatives appears more like a dying than a completely dead person. If weighted very highly, this consideration alone can lead to misgivings about even having such an organ donation practice in the health services. Conversely, though, it can also lead to attaching importance to a willingness to provide decent management of the relatives' difficult situation so that they can have proper leave-taking facilities attached to the setting and circumstances surrounding organ donation.

1.5 Organ donation as a separate ethical issue in the health services

The treatment of organ-impaired patients involves complicated and weighty regard for a number of other citizens outside of the health services. It is this factor which makes organ donation a peculiarly distinctive and complicated ethical problem of treatment in the health services.

Firstly, organ shortage is not just a matter of economics, organization and medical technology. Above all, the fact is that organ-impaired people have a greater chance of receiving healthy organs as a result of others' willingness to be organ donors. The agonizing prospect of being on the waiting list for an organ transplant can rightly be felt to be a relatively major, tragically needless ill if the lack of organs is partly due to other people failing to register their wish to be an organ donor. And in particular, that applies unequivocally if the lack of registration is not due to actual aversion but merely indicative of a person having omitted to register, for whatever reason.

Secondly, organ transplantation differs from all other medical treatments in that it presupposes that an organ can be transferred from a specific person who has just been declared brain-dead to another specific person who, as a result, can live his or her life better and longer than would otherwise have been possible. That means that the potential donors' and their relatives' attitude and outlook on life become out-and-out relevant and decisive to whether severely ill people can have their vital need to receive healthy organs met.

In the process, it has become a condition that organs from the dead body hold some significance for people other than those who were close to the deceased. The functioning organs now form part of a completely different context than previously: they are not just part of the deceased's body. Nowadays the organs are a sometimes vital medical resource for other people in society. It is a fundamental ethical problem if patients die without having received the best possible treatment available, which might have cured them or given them a longer life with satisfactory quality of life in health terms. When this happens, it is equally tragic, of course, whether it involves a person in need of a healthy organ, a cancer patient or someone else altogether. But organ donation differs in that the patients' fellow citizens – their philosophy of life and their ability to take a stance– are so directly and tangibly crucial to whether the best possible medical treatment (organ transplantation) is actually available to the individual patient.

Where the individual citizen is directly involved, it means there are also limits to what we as a society can do to procure more organs. Viewed in isolation, the availability of organs from brain-dead subjects is an undesirable situation. A person has died either because of illness or because of an accident. Naturally, it would be altogether unacceptable if, for reasons of organ transplant therapy, society were either to promote or to omit to prevent such diseases or accidents occurring. Another type of constraint is presumably that there are limits to what the individual citizen can be obligated to do, even if he or she registers as an organ donor. For example, it can hardly be reasonable that potential donors should be obligated by considerations of a possible transplantation to adopt or adhere to a healthy lifestyle in order for their organs to be in as good a state as possible.

Then again, surely it is only reasonable to ask what society *can* be permitted to do in order to meet organ-impaired people's need for healthy organs better? In this report the Council of Ethics will develop this question and supply some answers in the form of well-argued recommendations for the political system.

1.6 Delimitation

Living donors

Donation of organs from living donors is not discussed in this report. The special ethical deliberations concerning living donors (e.g. the reasons for donation, the relation between donor and recipient, consequences of donation etc.) have been described previously in the Council of Ethics' 1999 report: "Living donors. A report on kidney and marrow bone donation"^[2].

Organ trading

Recent years have seen an increased focus on trading in organs, especially from people living in the poorer parts of the world. Every year a number of Danes travel to a different country to buy a new kidney. According to the National Board of Health, Denmark, the number is about four people a year^[3]. Internationally^[4], there is general agreement that trading in organs is fundamentally unethical, and consequently it is illegal in most countries by far. The Council takes the view that such a solution to the need for more organs is not open to discussion: organ trading is an unethical solution. The Council is aware that there are serious discussions in progress as to whether trading in organs can be ethically defensible in situations where the donor cannot be said to be under unreasonable financial or social pressure^[5]. In this report the Council of Ethics does not enter into that discussion, because whatever the circumstances, the very severe current problems with organ trading are ascertainably occurring in a reality where the donors are pressurized by dire poverty, with the money going to middlemen and the donors' state of health subsequently ending with them often in a more hopeless situation than before.

Furthermore, it should be added that organ trading is an independent ethical problem that needs to be considered in partial or total isolation from the issue of the need for organs in Denmark. The shortage of organs can incentivize some Danes to buy organs from living people who are suffering the distress of poverty in other countries. But in the Council's view this fact should not lead to a discussion linking the organ trade with waiting lists, as this may lead to a person who opts to say no to becoming an organ donor in Denmark indirectly being able to perceive him/herself as jointly guilty for the existence of a flourishing organ trafficking trade in the world at large. On the contrary, the Council of Ethics thinks that the responsibility rests fairly and squarely with the person who chooses to make use of this—in the Council's conviction—unethical procedure.

Training and organization

One effective means of shortening the waiting lists, in many people's view, would be to modify the motivation, attitudes and habits of health-care staff in relation to organ donation. One of the chief causes of the lack of organ donation is often cited as the failure to identify possible donors. In the next chapter, therefore, a brief description will be given of factors in the health service structure and staff that may have an inhibitory effect on optimal procurement and use of suitable organs for donation. And the chapter will briefly outline the measures taken in recent years to confront these problems – including the establishment of a Danish Centre for Organ Donation. However, identifying and providing deeper insight into the importance and interaction of these factors is outside the purview of this report framework, which focuses on the ethical aspects of the donors' and recipients' situation. Nevertheless, it is clear that scope for creating a more efficient climate and dismantling any barriers that exist on the part of the health-care staff are also important aspects of the discussion about waiting lists.

^[2] Currently available only in Danish.

^[3] According to WHO 50% of all kidney transplants in the world in 2000 are estimated to have living donors, and 10% of all transplants are estimated to have been brokered via trafficking.

^[4] See, inter alia, the Council of Europe's Convention of 4 April 1997 for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Article 21, and the Declaration of Istanbul on Organ Trafficking and Transplant Tourism, 2008.

^[5] E.g. Taylor, J.S., 2007.

Chapter 2 Organ donation and transplantation – from donor to recipient

Section 1 of this chapter describes the development of transplantation medicine from the

end of World War II to the present. Section 2 describes the organ recipients' pathological situation, and light is shed on the number of organs available for transplantation. Section 3 then discusses factors that may affect this. Finally, section 4 describes a transplant pathway from the point of identifying a potential organ donor until the organ has been implanted in another person.

2.1 The underlying history

During World War II the need to develop new methods of treating wounds, fractures and burns was compounded. At that point it was known that skin could be transplanted from one spot to another on a person, but it was also known that using grafts or transplants from one person to another^[6] was not a serviceable method, owing to the fact that living tissue transplanted from one individual to another was rejected.

From the outset, rejection problems were one of the greatest challenges associated with organ transplantation. By nature, living organisms react to foreign tissue or organs by rejecting them. The so-called immunocompetent cells in the organism form an antibody to foreign tissue and organs, penetrate the tissues and destroy them. If transplanted tissue is compatible with the organism, it will be able to heal without difficulty and remain fit for purpose. This is seen when transplanting tissue from one point to another on the same person, and when transplanting tissue from one identical twin to another. If, on the other hand, transplanted tissue is alien to the organism, the immunocompetent cells in the organism will react to the transplanted tissue. The intensity of the reaction will depend how different the transferred tissue is, but left untreated, at any rate, it will lead to the transplanted tissue being rejected after a shorter or longer period of time.

The first successful kidney transplant took place in Boston, USA, in 1954. The transfer was made between two identical twins. That increased the chances of the organ not being rejected as a foreign body, since identical twins have the same genetically determined tissue type. In 1962 the first kidney transplant in the world was performed, with the patient surviving longer, and with the kidney not coming from an identical twin.

In the beginning it was attempted to suppress the organ recipient's immune defences by means of X-ray radiation and by removing antibody-producing tissue like the spleen and the thymus. In the early 1960s American doctors introduced chemical substances to inhibit the body's immune response. This form of treatment was easier to control and less dangerous for those patients who were already weakened, and in Denmark too it subsequently became possible to start transplanting kidneys. It should be noted that chronic dialysis was not a possibility at that time, and patients' only chance was a kidney transplant, therefore. Gradually, it was also learned how to tissue-type and thereby ensure a better match between donor and recipient, as it was possible to ascertain early on that the number and intensity of the rejection periods could be reduced if donor and recipient had the same or nearly the same tissue type. The first Danish kidney transplant took place on 18 April 1964 at Aarhus District General Hospital. At the same time, it was the first transplant ever in Denmark of one of the large organs: a 33-year-old woman was given a kidney from a recently deceased young man. However, the woman only lived for 17 days after the transplant. Of the four other transplants that year, three were successful and two of the patients survived for longer. The world's first successful heart transplant was carried out in 1967 by the South African doctor Christian Barnard. The patient lived for 18 days with the new heart. It was only with the advent of more specific immunosuppressants like cyclosporin in the 1980s that it became possible to perform heart, liver and lung transplants on a greater scale. Following the introduction of the brain death criterion in 1990, it became possible to transplant heart, liver and lungs in Denmark, where the first heart transplant took place in October 1990 (see table of number of transplants performed in Denmark in 2007 on page 42).

Nowadays recipients of a donor organ are still dependent on being given medicine to suppress their immune defences and prevent rejection. In the majority of cases this treatment lasts a lifetime and has to be used with great care and caution, as it has very severe side-effects. Inhibition of the immune defences results in increased susceptibility to infectious diseases. Other side-effects of immunosuppressants can be high blood pressure, bone disease and development of cancer, e.g. malignant tumours in the lymphatic organs or skin cancer. Despite this, immunosuppressants offer the prospect of longevity combined with good quality of life for many patients. These patients have few enough alternatives open to them. A patient with kidney failure can be treated with dialysis, but a patient with severe liver or heart disease has no similar options.

2.2 Waiting for an organ

The possibility of performing a transplant operation currently depends first and foremost on the availability of a healthy organ from another person.

The vast majority of patients with a new organ return to an existence that resembles the one they had before they fell ill. Children and young people return to schooling and training. Most of those who had work before they became ill return to their job^[7]. However, the waiting time for those on a waiting list to receive a new organ can be long^[8]. As of 1 July 2008 a total of 612 people in Denmark were listed as waiting for a transplant. When an organ is cleared for transplanting, a medical



assessment decides who from the waiting list is to receive the new organ. Donor and recipient must match for blood type, height and weight, and in the case of kidneys some degree of tissue-type match is aimed for. If there are several possible recipients for the organ, the one with the greatest need will typically be the one offered the organ. The general state of the sick person at the time of the transplant has a great bearing on the success of the transplant. In 2007 50 patients on the waiting list died before they managed to receive the organ they needed (kidney, heart, liver or lungs).

Denmark is a participant in a Nordic organ exchange and transplantation organization (Scandiatransplant). This collaboration was initiated in 1969 and originally acted as a collaborative organization for kidney transplant centres and tissue-typing laboratories in the Nordic countries. Scandiatransplant kept a register of all patients waiting for a new kidney with information about tissue type and other medical factors of importance to the transplantation process. When a spare kidney became available, the donor's tissue type was compared with Scandiatransplant's register and the decision as to where to use the kidney taken in accordance with the rules of exchange agreed. It was due to this collaboration, among other things, that the Nordic countries had some of the world's highest kidney transplant rates in the 1970s, with Denmark leading the world with something approaching 30 transplants per thousand inhabitants a year^[9].

A striking development in improving the immunosuppressive agents to prevent rejection has since led to a reduction in the need to exchange kidneys to some extent. The way the collaboration in Scandiatransplant now works is that if a donated organ cannot be used in the country to which the donor belongs, the organ is offered to the other countries in the collaboration following a list that works "by turns". Denmark receives more organs from the other countries in the Nordic collaboration than it supplies. From 2000 to 2005 Denmark thus received 33 hearts from the rest of the Nordic region, while 11 hearts were supplied.

In addition to this, the Danish transplant centres have some collaboration with UK-Transplant and Eurotransplant.

2.2.1 Kidneys

Most organ transplants are performed using kidneys. The kidneys maintain the body's salt and water balance and eliminate a number of waste substances from the body. The indication for a kidney transplant is chronic kidney failure. The background for kidney failure can be congenital malformations or hereditary disease, inflammation, intoxication, infections or raised blood pressure. The patient's kidney problems are often due to sustained diabetes, but in a number of cases it is not possible to find the cause of kidney failure. Chronic kidney failure can be treated either with dialysis (Greek: separation), which cleanses the blood, or with transplantation. A dialysis patient spends 15-20 hours a week on treatment.

Kidneys

160-170 kidneys a year are transplanted in Denmark. Of these, 40 or so are donated by the living relatives of a renally insufficient person. The difference between the need for kidneys and the kidneys available is great. In 2007^[10] 115 kidney transplants from deceased donors and 56 from living donors were performed in Denmark. 201 new patients were added to the waiting list during 2007. The total number of patients waiting for a new kidney in Denmark at end-2007 was 548 (of these, 163 were "inactive", that is to say temporarily taken off the list because of infection or some other interim illness). 36 patients died in 2007 while on the waiting list. On a yearly basis, the need for kidneys is estimated to be 300-350. Nephrotic patients are the group with the longest waiting lists.

After the operation

The success of the transplant depends on tissue compatibility with the donor organ, but the effect of the treatment also depends on whether the donor kidney comes from a living or a deceased donor and whether the recipient has previously been given a kidney (the more transplants are done, the poorer the result). Another essential factor, of course, is the recipient's overall health status – whether it is an isolated kidney disease or whether the patient is also diseased in other places in the organism.

A major risk associated with transplantation is loss of the transplanted organ. The reason for the loss may be due to the body's rejection response, damage to the transplanted kidney, infections, side-effects of aftercare or flaring-up of the disease that underlay the original kidney failure.

After a kidney transplant the implanted kidney functions in approximately 93% after the first year^[11]. The quality of life for most kidney transplantees is considerably improved in relation to those patients who are put on lifelong dialysis. Many kidney transplantees can virtually live a life like anyone else without severe restrictions in either a physical or a social respect. The average lifetime for kidney transplantees is longer than for dialysis patients. The financial costs of lifelong dialysis are much greater than for transplantation and aftercare. The saving per transplanted kidney in the following years has been calculated as

DKK 1-2 m.

2.2.2 Livers

For a patient with liver disease a new liver can be the only possibility of survival. The liver plays an important part in the metabolism and in the conversion of many substances toxic to the body. The primary indication for liver transplantation is advanced cirrhosis of the liver, which entails large parts of the liver's cells dying and being replaced by scar tissue. The cause of this is usually protracted inflammation of the liver. Cancer, metabolic disorders and long-term severe alcohol abuse can also destroy the liver. Acute liver failure can result from intoxications or viral infections.

Livers

Between 35 and 40 livers are transplanted annually in Denmark. The number of liver transplants in 2007 was 43. During 2007 40 patients went on the waiting list, and at end- 2007 a total of 21 patients were waiting for a new liver. 2 patients on the waiting list died in 2007. During the waiting period, patients are on a diet and receive medical treatment to relieve the symptoms. Some patients become very ill and have to be admitted to intensive care.

After the operation

The underlying disease and the patient's clinical condition before the operation have a bearing on the success of a liver transplant. Four years after a liver transplant some 80% of patients are alive. Patients given a new liver experience a considerable improvement in their quality of life, measured both objectively by the physical functions and more subjectively by their mental state and enjoyment of social activities.

2.2.3 Hearts

A new heart is the only option when the patient can no longer be treated with an operation or medication. The central function of the heart is to pump blood and thus nutrients and oxygen to every single cell in the body. Heart transplants are primarily indicated for different forms of serious heart failure. This can be due to congenital malformations, disease of the heart valves or weakening of the heart muscle. The most common cause of impaired heart function is arteriosclerosis, or hardening of the heart's coronary arteries. Reduced heart function leads to severe impairment of the patient's physical activity owing to an inadequate supply of oxygen and nutrients to the body's cells. Both physically and mentally, this state is highly strenuous.

Hearts

In 2007 29 heart transplants were performed in Denmark. The number of heart transplants is on the decline. This is due both to the lack of hearts for transplanting and to the fact that the indication for a heart transplant has changed in keeping with new, improved methods of treating heart disease. During 2007 23 new patients were admitted to the heart transplant waiting list. At end-2007 14 people were on the waiting list. 3 patients from the waiting list died in 2007. Many on the heart transplant list wait for months, either at home or at hospital.

After the operation

An important requirement is that the respective donor and recipient are roughly the same body size. During the initial post-transplant period the survival rate is determined primarily by rejection responses and the risk of infections. In the long run complications can arise in the form of raised blood pressure, diabetes, disturbances of the lipid metabolism and occurrence of different forms of cancer. In Denmark 90% of heart transplantees are alive four years after the heart transplant. Heart patients experience a great improvement in their quality of life, albeit still with certain restrictions on their day-to-day activities. As the heart has not only physical but also symbolic importance, there is a great focus on the psychological state of the heart transplantee.

2.2.4 Lungs

Each and every cell in the body requires a constant supply of oxygen to survive. The primary function of the lungs is to absorb oxygen into the blood through respiration and to liberate carbon dioxide, which is formed during the energy-producing combustion of nutrients. A lung transplant is indicated in the case of a number of severe functional disturbances of the lung structure or pleural cavity, which may lead to untreatable lung failure. Approximately half the patients who have new lungs

transplanted have oversized lungs (emphysema). One of the causes of this condition may be the shortage of a protein (alpha-1-antitrypsin) which protects the lung tissue, and if this protein is missing, the lung tissue can be destroyed. Also, a number of lung diseases, e.g. cystic fibrosis, can destroy the lung tissue, and this disease is also a common cause of lung transplant. In some cases, combined transplantation of heart and lungs is necessary.

Lungs

In 2007 33 lung transplants were performed in Denmark (including 11 double and 22 single-lung procedures). 28 people were admitted to the waiting list during 2007. At end-2007 32 patients were on the waiting list to receive new lungs. 9 patients from the waiting list died in 2007. During the first three quarters of this year 8 lung transplants were performed. During the waiting period patients are admitted for ongoing check-ups and have to be hospitalized on an emergency basis if they contract more severe diseases like influenza or pneumonia. Most are on constant treatment with oxygen, and some are so poorly that they require hospitalization.

After the operation

As with a heart transplant, it is important that donor and recipient are roughly the same body size. The operation may involve transplanting both lungs and heart, both lungs or – in most cases – one new lung. The risk of infection after the operation is high, as the large surface of the lungs makes them very susceptible to infection and the natural cough reflex will have been lost after losing nerve connections to the transplanted organ. In recent years one-year survival has been over 90% and five-year survival approx. 70%. Chronic rejection of the transplanted lungs often occurs after about two years, and that is the most frequent cause of mortality in lung transplantees during the subsequent course. Chronic rejection manifests itself in the form of increasing constriction of the small airways (bronchioles) and respiratory distress due to this. After 10 years most patients will have some mild to severe degree of chronic rejection. Patients waiting for a lung transplant have a long and painful course with severely reduced physical activity. After a lung transplant the patients' health-related quality of life in general is significantly increased, and their life expectancy is much longer than without a transplant. Although a considerable improvement in their quality of life does take place, many lung transplantees still experience certain restrictions, both mentally and physically.

2.2.5 Corneas

The cornea is the transparent membrane on the front of the eye. In order for the eye to see a sharp image, the cornea must curve regularly and be clear. Even small changes to the shape of the cornea produce a drastic reduction in eyesight, and the cornea's transparency is essential to normal vision. Different forms of damage and disease can lead to haziness of the cornea, and thus impair the sight. In advanced cases of corneal opacity a corneal transplant can be the only way to regain the sight. Other reasons for performing a corneal transplant are painful corneal disorders and diseases with spontaneous perforation of the cornea. In such cases an acute corneal transplant is more often than not the only possibility for saving the eye. Today it is not possible to use synthetic materials for a new cornea. A prerequisite for a corneal transplant, therefore, is the availability of live corneal tissue.

Corneas

Corneas are regarded as tissue, not organs. Consequently, the activities of the Danish Cornea Bank have to meet the safety and quality requirements set out by the Danish Tissue Act. The same requirements are made of consent for donation of corneas as for heart, liver, lungs and kidneys. That is to say that consent must be available from either the deceased him/herself or from the relatives. Many organ donors opt out of donating corneas (of those registered with the Danish Donor Registry with restricted permission, 64% have declined to donate their corneas). Some 200 corneal transplants are performed a year. The waiting time for a corneal transplant has risen during recent years from a few months up to two years. In cases with a high risk of rejection response it used to be attempted to achieve tissue type compatibility between donor and recipient. Owing to the shortage of donor corneas, this option is no longer offered in Denmark.

Annually, some 400 Danish patients need a new cornea. The intake of corneas to the Cornea Bank is on the decline, and since 2003 it has not been possible for the Cornea Bank to meet the demand for corneas. During the first quarter of 2008 there were 3 donations (a total of 6 corneas); at the moment, therefore, the influx of Danish corneas is only sufficient to maintain emergency readiness. So in order to be able to treat Danish patients with non-acute, yet still disabling corneal disorders, a number of Danish eye departments have imported tissue from the USA, the Netherlands, Finland and the Czech Republic in recent years. The procedure for corneal transplants is quite different to the one for other forms of organ transplantation. The cornea

contains no blood vessels, which means that it will not readily perish, even if the heart stops. A cornea can thus be taken out for up to 5 days after cardiac death. The corneas are often removed in connection with a post-mortem, and after harvesting the cornea is taken to the Danish Cornea Bank, located at Aarhus Hospital. The Cornea Bank is then responsible for continued storage, quality control and delivery to hospitals for the purpose of corneal transplants. Donor corneas are stored in a special growth medium, allowing the timing of the corneal transplant to be planned.

After the operation

There are seldom complications after a successful corneal transplant. The most frequent complication is “rejection response” by the new cornea, causing it to become hazy and lustreless. Other rare complications are inflammation, bleeding or detachment of the retina. After months the vast majority of transplantees will be able to obtain reading sight in the eye and have adequate vision to retain their driving licence, for example. A donor cornea does not last for ever, but if the original eye disease is halted, a donor cornea can remain clear and good for viewing for more than 30 years. It is possible to repeat a corneal transplant in the event of the first transplanted cornea becoming hazy.

2.3 Organs available

Number transplanted and number on waiting list in 2007^[12]

Kidneys:	171 transplanted (incl. 56 from living donors) and 548 on waiting list.
Livers:	43 transplanted and 21 on waiting list.
Hearts:	29 transplanted and 14 on waiting list.
Lungs:	33 transplanted and 32 on waiting list.

Organ donations in Europe

The concept of “donor rate” is used when it is wished to compare the figures for organ donation in the European countries. The donor rate expresses the number of organ donors per million inhabitants in the relevant country. In 2007 Denmark had a donor rate of 13.16 per million inhabitants, placing it in the bottom half. The four countries in 2007 with the highest donor rate in Europe were Spain (34.3), Belgium (28.15), France (25.3) and Portugal (23.9). The overview of donor rates in Europe has been reprinted as Appendix 1 to this report.

However, as regards the comparability of the information, the National Board of Health, Denmark^[13], states that the number of donors is calculated differently in the individual countries. Some countries, for example, include found donors – whether or not donations are involved (e.g. because the organs cannot be used for a variety of reasons), while other countries such as Denmark only count a donor once there is at least one donated organ. Comparing the European countries’ legislation on consent, the latest listing from the National Board of Health^[14] shows that, under their respective legislation, some 28 countries require consent for donation from the deceased donor. There is a difference in the way the consent requirement is articulated:

- Under the legislation in 7 countries, consent is required from the deceased’s next-of-kin; in one country consent from the deceased’s next-of-kin is required in accordance with guidelines.
- Under the legislation in 7 countries there is presumed consent, while at the same time the consent of the deceased’s next-of-kin is required if the deceased’s wishes are not known.
- Under the legislation in 7 countries there is presumed consent, while at the same time the consent of the deceased’s next-of-kin is required.
- Under the legislation in 7 countries there is presumed consent, without requiring consent from the deceased’s next-of-kin.

Denmark is the only one of the Scandinavian countries not to have any form of presumed consent. At the same time, Denmark has the lowest donor rate, but does not differ crucially from the other Nordic countries’ donor rates. Nor, according to the National Board of Health, Denmark, is it possible to find a clear-cut link between donor rate and legislation on consent. Countries with presumed consent do not all have high donor rates, and not all those with high donor rates have presumed consent. There can also be big differences in the way adopted laws and rules are practised. Although a country has presumed consent, practice may very well be that a transplant is only performed if accepted by the relatives.

Between 100 and 200 people a year are declared brain-dead in Denmark. Of these, 60-80 actually become organ donors. With the aid of organs from these 60-80 donors some 250 transplants are performed in Denmark annually. That means that Denmark is in top when it comes to the number of transplant operations in relation to donors. From one organ donor an average of 3-4 other people can receive organs.

There is no upper age limit for donating organs. With age, however, varying degrees of arteriosclerosis occur in different organs, and the brain-dead person's general state of health before the accident or illness in question also has a bearing. It is rare for hearts from donors over 55-60 years to be usable, but livers or kidneys from 70 to 80-year-olds are suitable in a good deal of cases. In Denmark successful kidney transplants have been seen from donors up to the age of 85.

In 2006 the National Board of Health, Denmark, had a survey conducted into the Danish population's view of organ donation. In the survey 87% of the population voiced a positive view of organ donation (as against 30% in 1995) and 78% said they would be happy to donate an organ themselves.

From treating patients with very severe heart or lung disorders it is also known that nearly all patients take a very positive view of transplantation, and that it is very rare for patients to dismiss transplantation as treatment. The question that may be asked in this same context, therefore, is what factors lead to the Danes' positive view of organ donation failing to be reflected in a higher donor rate?

2.3.1 Influencing the donor rate

In 2000-2002 a project designed to study transplant conditions in the four former counties of North Denmark Region (North Jutland, Viborg, Ringkøbing and Aarhus counties) was conducted at the University of Aarhus Hospital^[15]. The point of the survey was to map professional willingness in terms of organ donation among staff on the intensive care wards. The point was also to assess the number of possible organ donors in the four counties, how the potential was exploited, and what causes there were for the lack of organ donation in cases where a medically suited organ donor was available. The survey concluded that North Denmark Region had an organ donor potential of the same magnitude as other countries, where the actual donation rate is significantly greater, however. The rate for identifying possible donors (detection rate) corresponded to 78% calculated over one year. The rate was calculated across 157 patients who died of intracranial abnormalities. On first sight 74% of these patients were deemed suitable for donation from a medical point of view, though subsequent examination of records revealed an additional 21 potential donors where the relatives had not been asked. Donation was carried through in a total of 25%. The lower donation rate, according to the survey, was due particularly to donation being rejected by the relatives in well over 50% of the cases.

The dialogue with the relatives

As mentioned above, the survey showed that the main reason for a medically suitable organ not being used for transplantation is the relatives' rejection of organ donation. According to the legislation, if no prior consent from the deceased is available it is up to the relatives to decide. If the deceased and/or the relatives have not consented, organs may not be removed. The deceased may also have indicated that organ donation is conditional on the relatives' acceptance, which must be respected. A more recent survey conducted in 2006 for the National Board of Health, Denmark (referred to above, page 43), shows that the growing positive view of organ donation on the part of the population has not resulted in any actual rise in the donor rate, meaning the proportion of relatives who accept organ donation when the deceased him/herself has not made any decision. It is still the case that some 50% say yes and 50% say no. Conversely, the decision is virtually never altered once the deceased has expressed his/her view in advance.

The conversation concerning the possibility of organ donation can be crucial to whether the relatives say yes or no. At some intensive care units this task is performed by specially trained doctors or nurses. Courses are currently on offer to staff faced with the difficult conversation with the relatives – the so-called EDHEP courses (European Donation Hospital Educational Programme), a concept in which actors and psychologists train doctors and nurses in the difficult conversation with relatives about organ donation.

Key people

Another prime reason for the low donor rate, according to the survey in North Denmark Region, was the staff's circumstances. Patients whose state is so serious as to potentially warrant the brain death diagnosis will usually be found at one of the country's intensive care wards. This ward submits details of potential donor registration to the Transplant Centre.

Overview of transplant centres in Denmark:

- A centre at Rigshospitalet, the National University Hospital, and Herlev Hospital performs heart, kidney, lung and liver transplants.
- A centre at the University of Aarhus Hospital, Skejby, performs heart and kidney transplants.
- A centre at Odense University Hospital performs kidney transplants.

The centres in Copenhagen and Aarhus are staffed by coordinators around the clock.

Only rarely is any procedure for organ donation laid down in many intensive care wards. Owing to the staff's lack of experience, awareness of a potential donor and implementation of a donor procedure can be perceived as a very difficult task. In order to heighten awareness around organ donation, most intensive care wards have now appointed key individuals among the staff employed at either the anaesthesia department or the critical-care ward.

The key people's function, according to the National Board of Health's recommendations from 1998^[16], is to ensure that local knowledge about organ donation is kept up to date among health-care staff. The key figures act as resource people, who are in a position to instruct and guide other health-care staff in the procedures and interests connected with organ donation and transplantation.

At the time the Danish Centre for Organ Donation was set up at end-2007 a working party was formed under the Centre, its mandate being to produce recommendations for reviewing the function description for such key people.

Economics

Organ harvesting is financed by the ward to which the donor has been admitted. It has been stated in the debate that the financial onus imposed on the ward in the form of increased resourcing can be a contributory cause in some potential organ donors failing to be identified and reported by the ward. The increase in resourcing can include extra staff to care for donors and operating facilities.

In connection with the political negotiations in 2007 on the Danish Centre for Organ Donation, it was agreed to introduce pecuniary compensation for the hospital saddled with extra expense in connection with a possible donor.

Professional self-knowledge

The staff on the intensive care wards naturally view it as their primary assignment to alleviate suffering and save lives. Since none of this is any longer a possibility for a potential donor, it may be that the transplantation option is assigned lower priority than other treatment tasks relating to patients who have the potential to survive. These patients are more real and more present for the doctors and nurses than an unknown organ recipient connected only indirectly to work on the ward. Moreover, there is a dearth of intensive care places in Denmark, and for a period of 24 or 48 hours, therefore, donors will monopolize a place on the ward, which can result in a patient in need of intensive treatment having to be transported to another hospital with spare capacity.

2.3.2 Danish Centre for Organ Donation

At the end of 2007 the Danish Centre for Organ Donation was established. The Centre's seminal tasks are to be involved in optimizing utilization of the available organ potential to enhance and assure the quality of initiatives aimed both at relatives and at the staff involved, and to ensure coordination of organ donation initiatives in Denmark^[17].

The Centre is based on the existing structures in the field of organ donation and transplantation. These are the existing key figures in the anaesthesia and intensive care departments and the three existing transplant coordinator functions at the University of Aarhus Hospital, Skejby, Odense University Hospital and Rigshospitalet, respectively. The Centre's secretariat is located in conjunction with the University of Aarhus Hospital, Skejby. In addition, a steering group has been formed for the Centre with the participation of central actors in the field.

The Centre's core assignments are not only to ensure that the health-professional staff coming into contact with organ donation are given the requisite training but also to monitor activities related to organ donation and follow up this information. The Centre must also ensure that hospital wards where organ donation can take place have the chance to draw on the resources of experienced doctors and nurses in an organ donation team. That team must support the assignments which the individual ward itself considers there to be a need for assistance with.

Organ donation team

As mentioned above, the plan is to allow hospital wards to tap into resources from experienced health professionals configured in an organ donation team. The crews on the team, together with the transplant coordinators at the centres, are to form part of a network so that the individual crews can stand in for one another. The Centre's function is to take care of recruiting and organizing the organ donation team, which will be attached to the three transplant coordinator functions, and to consolidate the key-person function at the hospitals. The Centre is responsible for ensuring that these networks will work.

In the Danish Ministry of Health's proposal to create a national organ donation centre the Ministry suggests setting up an organ donation team that works together in crews comprising a doctor and a nurse – wherever possible consisting of experienced doctors and nurses from potential donor departments, neuromedicine and neurosurgery or suchlike, employed on a part-time basis. The team must be able to be called in by the departments to attend to the specialist assignments in connection with organ donation, including arranging specialist medical assistance in carrying out the brain death test, conduct conversations with relatives and subsequent contact with the relatives, assuming they wish for this, and oversee contact with the transplant coordinators on organ harvesting. The team's assignments in each individual case can be agreed between the donor ward, the

hospital's key person and the team, as there may be a difference in the help needed by the individual wards in any donor situation. The proposed model has not yet been implemented, since for the time being it has been decided to trial different models of organizing the organ donation team.

As mentioned above, the Centre has a steering group attached, consisting of representatives from Danish Regions, the three transplant coordinator functions, the Danish Transplantation Society, the Danish Neurosurgical Society, the Danish Society of Anaesthesiology and Intensive Care Medicine, the Danish Kidney Association, the Danish Heart Foundation, the Danish Lung Association and the National Board of Health, Denmark (chairmanship).

2.4 The transplant process – from donor to recipient

A transplant is effected in three phases. However, the procedure is not quite the same at the three transplant centres, and a specific sequence can differ from the outlined below, depending on the individual donor departments' need for support.

2.4.1 Phase 1 – the donor

If the doctors ascertain during a particular course of illness or injury that the patient's brain has been irreparably damaged and the brain death diagnosis may be applicable, the question of organ donation becomes a relevant possibility. The first thing is for a doctor from the intensive care ward to contact one of the country's three transplant centres. In Aarhus and Copenhagen these are staffed around the clock by employed coordinators (trained nurses) and in Odense the consultant on call in the department of vascular surgery is contacted.

The on-call coordinator at the transplant centre checks whether the patient is registered with the Danish Donor Registry. If the patient has consented to organ donation or if the patient has not been registered, the relatives will be asked for a consultation. During this conversation with staff from the intensive care ward, the relatives will be told about the possibility of organ donation. When a person is brain-dead, the body's natural regulation of blood pressure and metabolism does not work, nor is there any breathing. With the aid of a respirator and medicine the heart and breathing can be kept going for hours or up to a few days after brain death. In this short space of time organ donation can be of relevance (see more about brain death in Chapter 3).

The donor's circulation is stabilized if consent is given for transplantation, and blood samples are taken with a view to evaluating the function of the organs to be transplanted. The staff on the ward where the donor is based are briefed on these measures by the transplant centre coordinator.

The donor ward then has the possibility of receiving help to have the brain death diagnosis made by calling in a neurospecialist (neurologist or neurosurgeon) if the hospital itself does not have such specialists available. After completing the examination for brain death (see Chapter 3) the transplant centre or centres (because there is often more than one organ that can be transplanted) are notified that transplantation is a possibility. The donor is subsequently examined for viral infections such as hepatitis and HIV. When the samples from the donor have been analyzed, it is decided which organs can be used for donation. The next step is to call in the team from the transplant centre, who will harvest the organ. One operating team is dispatched for each organ donated. These teams consist of a number of specialists with experience in this type of operation.

The donor's family then takes leave of the donor, who is trolleyed to the operating room. The donor is anaesthetized during the operation as there may otherwise be a risk of reflex-conditioned movements during the operation. The organ (or organs) are then removed from the donor and the wound (or wounds) sewn up. Removing a donor organ is a difficult surgical operation, as it has to be carried out in the space of a short time and simultaneously requires a painstaking procedure. After the operation the donor is washed and taken back to the ward to the relatives, where leave-taking can continue.

2.4.2 Phase 2 – the donated organ

The next phase includes storage and transportation of the relevant organ. Some organs can stand a longer time without blood circulation than others. The heart is the organ most sensitive to any change in environment, and in a transplantation context the objective is to keep the storage time for a donor heart to under four hours. Once harvested, the organ is stored in a sterile plastic receptacle or plastic bag submersed in a sterile bucket of water. The bucket is placed in a cool-bag with ice, and the organ is kept chilled at a temperature of around 4 degrees Celsius. The cool-bag is then transported (flown, in some cases) to the centre where the transplant is to take place.

2.4.3 Phase 3 – the recipient

The third phase is transferral to the recipient. When the possibility of organ donation is reported, the recipient of the organ has to be identified. The person matching the donated organ – that is to say by blood type, height, weight and, in the case of kidneys, tissue compatibility also—will be offered the organ. If there are a number of possible recipients who are a match for the organ, the organ is offered to the patient who is most ill. If there is no suitable recipient for the relevant organ here in Denmark, the organ is offered to the other countries in the transplantation network (described on pages 34-35). Once the organ recipient has been identified, the person is contacted by the transplant centre; in the case of heart and lung patients, by

the mobile phone supplied to everyone on the heart and lung transplant waiting list. The patient arrives as quickly as possible at the centre where the transplant is to be performed and is prepped for operating. The patient is examined for possible infectious conditions, match samples are taken and, among other things, water and electrolyte balance carefully assessed.

Transplanting the new organ requires practice and skill on the surgeon's part, as a successful transplant operation requires all structures to be connected meticulously. After the transplant the coordinator from the transplant centre contacts the hospital where the donor died. This hospital ward then contacts the relatives and offers them a consultation session about the procedure and how the transplant went, as well as how the transplanted organs are performing. The donor ward is contacted again by the coordinator after 6-8 weeks and told how the organ recipient is feeling. At the University of Aarhus Hospital the hospital management then sends a letter of thanks to all donor relatives. There is anonymity on the part of both the donor and the recipient of the organ.

[6] Bundegaard, Eva. 1999.

[7] National Board of Health, Denmark, 2001.

[8] The information about the different diseases has been sourced primarily from articles taken from the Danish medical journal *Ugeskrift for Læger*, the Transplant Group's homepage www.transplantation.dk and Kemp et al., 2003. The medical specialists mentioned in the preface have all been kind enough to comment on the relevant sections.

[9] Bak-Jensen, 2005.

[10] The figures from 2007 are taken from Scandiatransplant's calculations, see www.scandiatransplant.org.

[11] These percentages by kidney, heart and liver transplant, respectively, can be seen at the National Board of Health, Denmark, 2001.

[12] Source: Scandiatransplant. See also Appendix 3.

[13] Danish Ministry of Health and Prevention. 2007.

[14] Danish Ministry of Health and Prevention. 2007.

[15] Bøgh and Madsen. 2004.

[16] National Board of Health, Denmark, 1998.

[17] The information in this section is taken primarily from the Danish Ministry of Health, 21 May 2007, and from the Organ Donation Centre's homepage (www.organdonation.rm.dk)

Chapter 3 Death criteria – brain and cardiac death

All the body's organs inevitably begin to perish from the moment the blood circulation stops and the cells are not supplied with nutrients and oxygen. As a result of the organs' incipient decomposition, transplants with organs from dead people will invariably have to be carried out under pressure of time. The point at which a person has actually died, therefore, is a central question in this context.

Since 1990 it has been possible in Denmark to declare a person dead when there is reliable evidence of severe and lasting damage to the brain, causing the patient's circulation to cease irreversibly under all circumstances, regardless of whatever technical aids are available [18]. Organs can subsequently be removed from a donor's body while still maintaining the blood circulation by artificial means, giving a considerably better transplant outcome. What is more, this provides the possibility of transplanting organs that are highly sensitive to even a brief interruption to the blood supply.

Understanding and acceptance of the brain death criterion

Brain death indicates that a person is dead, not because unconsciousness is attributable to the brain, but because the brain function is a necessary prerequisite to maintaining the vital function of the organism. The perception of the onset of death in the case of brain death is different to that in the case of cardiac death, when the body changes almost instantly to the state associated with dead people: breathing stops, the body cools off and the colour of the skin pales. If, on the other hand, the deceased person has been declared brain-dead, the body will still feel warm, and the skin will be its normal colour. Although the relatives have reliable medical information that death has set in, they have to overcome the mental barrier that is deep-rooted in human nature: that as long as the heart is beating and



there is breathing, there is life, and thus hope. Furthermore, although specific bodily states can be cited that involve the onset of death in specialist medical terms, people have different views of what it means to be dead, and how body and soul belong together. Being dead is not just a concept in medical science, but also an existential concept, and recognition of the brain death criterion is largely dependent on emotional and experiential aspects.

It took more than 20 years from the emergence of the debate on the brain death criterion until the criterion had been introduced as an official death criterion in Denmark. During this period it was difficult to find a groundswell of popular support for the brain death criterion. As early as 1984 the National Board of Health formed a committee tasked with providing background knowledge and producing deliberations that could prepare the way for a policy decision on the subject. In 1987 the Danish Council of Ethics was created, and in 1988 the Council published a report on the death criterion, in which a majority of the Council recommended retaining the cardiac death criterion. This majority of the Council thought that retaining the cardiac death criterion was perfectly consistent with organ donation. The majority recommended that the time of death should still be the cessation of the heart function, but with the aid of a respirator it should be possible to artificially defer the death process for up to a maximum of 48 hours *“with the purpose of removing organs for transplantation subject to the person in question having given his or her consent (registered as a donor)”*.^[19] The aim of this recommendation was to ensure that it was still possible to apply one death criterion that was in tune with the popularly rooted view of the onset of death while at the same time being able to cater for the need for organ donation.

At that time the majority of the Council of Ethics based its recommendation partly on the fact that it would be hard for the relatives to understand whether the brain-dead person was dead or dying. Therefore, the majority chose to recommend a solution in which the legislation and the death criterion support the relatives' immediate perception of a person's death, as typical of the norm: that a person is in a death process when the heart is still beating. The price for this would then be to acknowledge that organs are taken from people who have given consent for the organs to be removed while they are not yet dead, in a legal sense, but terminally ill (after certification has established that the brain function has irreversibly ceased). This, conversely, was the price which a minority on the Council of Ethics were unable to agree to pay, for which reason this minority recommended introducing the brain death criterion: *“The minority finds that introducing the diagnosis of brain death as the death criterion is a clear prerequisite for society being able to ask young people to decide whether or not they wish to be organ donors. No one declaring themselves willing to donate organs in the event of death must be in any doubt that organs will only be removed after the onset of death has been ascertained in the form of ceased brain function”*.

Since the introduction of the brain death criterion in 1990, ongoing surveys of the population's knowledge of the brain death criterion have been conducted by various parties – not least the National Board of Health, Denmark. In 1988 and again in 1989 the Council of Ethics compiled a questionnaire survey in association with what was then the Danish National Institute of Social Research. Here 1,571 representatively selected Danes were asked about their knowledge of the brain death criterion and organ donation. This was at a time when the brain death criterion had not been introduced, but there was a prominent public debate as to whether it ought to be introduced. The survey showed that 80% of those questioned knew what it would take to be declared brain-dead. Yet a sizable proportion nevertheless misunderstood the possible consequences of brain death: *“When 9% think that the brain-dead person may possibly awake and 64% think that the body can carry on living for months without treatment despite the complete destruction of the brain, it may be due to the difficulty laypeople still have in distinguishing brain death from states in which large parts of the brain have been destroyed but the prerequisites for declaring brain death are not present”*.^[20]

Other questionnaire surveys have since documented that there is still a substantial proportion of the population that is not fully informed as to what brain death entails. Most recently a survey conducted for the National Board of Health in 2006^[21] has shown that, compared with 2001, there are noticeably more people who think they know sufficient about the brain death criterion. Nevertheless, the concept of brain death is not understood correctly by approximately a third of the population. In 2006 19 % agreed with the statement that “there are examples of a brain-dead person coming back to life”. Every fifth person, therefore, erroneously believes that the brain-dead can return to life. Uncertainty in relation to the onset of death can affect the will of the population to become organ donors—and particularly uncertainty on the part of the relatives can assume crucial importance for whether a medically suited organ is released for transplantation. Understanding and acceptance of the brain death criterion are often pivotal, therefore, to the decision on organ donation – both in the sense of what organ donation entails and in the taking of a concrete stance on donation. The one thing where the population's knowledge is scanty, what it means to be brain-dead—possibly confusing this with coma—can deter many from being willing to donate their own or their relatives' organs. Stories are rife in the media about people waking up from a coma, and relatives may therefore be afraid that they are “killing their loved ones”.

The Danish Council of Ethics' and the National Board of Health's surveys can be used to show that there is a persistent problem in understanding the purely factual aspect of the brain death concept and the brain death criterion. But the surveys say nothing about the population's attitudes towards the brain death criterion and their emotional response to the new supplementary definition of the onset of death. However, a questionnaire^[22] has been conducted with approx. 1,000 upper secondary school pupils taking part in 1992 and 1996, respectively, identifying the respondents' views on the death process inter alia. Against the backdrop of the eighties' debate on the brain death criterion, the respondents (school pupils over 18) are presented with the following question: “Is a brain-dead person dying or dead?”. In 1996 61% replied that they thought of the brain-dead person as dead, while 39% replied that they thought of the brain-dead person as dying. In other words, over a third of the young school students in 1996 are unable to reconcile themselves to the fact that brain-dead is “completely dead”,

replying instead that they would have to be termed dying, if anything. Concerning the young people's reasoning, the author of the survey states the following: *“To a great extent, the reasons used by the young people are the same as those used in the public debate prior to the introduction of the brain death criterion and in the public debate on permission to donate. A large part of the young people who express the view that a brain-dead person is dying are actually predicating that view on the language and pondering on the difficulties raised in trying to say that “the dead person’s heart is beating”. The linguistic difficulties inherent in the actual expression indicate that the very act of speaking about “the dead person’s heartbeat” is unnatural”. Furthermore, the author says later: “Young people are generally quick to assimilate new words and concepts in technological development, but apparently they have not embraced the new concept of ‘brain death’ to any sweeping extent, in the sense on which the law was based”^[23].*

The problematic issue in this context, therefore, is also that this new way of relating to death is not in keeping with the culturally rooted notions and expectations concerning the onset of death. This, in the Council of Ethics' opinion, is a problem across the board in facilitating and orchestrating organ donation, and one which the public is not at liberty to ignore.

Saying goodbye

For the relatives it can be particularly difficult to experience the death process in a person who is brain-dead. If the relatives have not genuinely accepted that brain death is “proper death” or if they have not been prepared for the consequences brain death and subsequent transplantation can have for saying goodbye to the dead person—this can result in the leave-taking process being perceived as undignified or out-and-out shocking. Having entertained thoughts about death and especially leave-taking beforehand, then—both oneself and possibly together with one's family—is important when deciding to be an organ donor. For close relatives, the way in which they are present and experience leave-taking can be of great importance to the way they work through their grief afterwards.

Before the introduction of the brain death criterion the procedure of organ harvesting was more or less the same as today: relatives had to take leave of the donor while the heart was still beating. In the operating room the respirator was then turned off, and once the patient's heart stopped, artificial heart massage would be given until the kidneys had been removed. Not even with contemporary specialist know-how is it possible to perform successful transplants with organs harvested quite a time after the heart has stopped beating. If the respirator is switched off on the ward, therefore, it will be practically impossible to get the donor into the operating room and operated on quickly enough for the kidneys to be of any use in transplantation.

In principle the relatives can be present in the operating room when the respirator is turned off, but then have to vacate the room immediately after cardiac arrest. In medical circles such a procedure is not considered consistent with a dignified and calm leave-taking for the relatives. Another possibility is that, applying the brain death criterion, it is possible to harvest the kidneys following the standard procedure of a nephrectomy, and in some cases maintain the donor's circulation, so that in principle the donor can be returned to the ward for leave-taking with the relatives, where the respirator is then turned off. In that case the relatives are informed that there is no guaranteeing that the brain-dead person's unstable circulation can be maintained. Only the kidneys can be removed by means of such a procedure.

In practice, then, transplantation is ruled out if the presence of the relatives is imperative when the function of the body ceases and respiration stops. This applies regardless of which death criterion is used.

People have different views of how leave-taking should be done. Some relatives prefer to say their goodbyes before the deceased is trolleyed into the operating room, while others wish to wait until the deceased is returned. Some relatives feel it is agonizing to have to wait for treatment to be able to be stopped in order to preserve the organs in the best possible state, their relatives having “already suffered enough”. Others see it as extra time they can spend together with their dear ones, and feel relieved not to be further involved in the decision as to when to turn off the respirator. How to create a setting suited to dignified leave-taking with the deceased once permission has been granted for organ donation is discussed in greater detail in Chapter 4. Death as an existential concept and the relatives' perception of the death process will also be discussed in Chapter 4.

In the following sections light is shed on the scientific-medical aspect of death—what it means to be cardiac or brain dead, and the methods used to make this diagnosis. The legislative take on the time of death is also discussed.

3.1 The onset of death

The Danish Health Act, Section 176

A person's death can be ascertained upon the irreversible cessation of breathing and heart activity or upon the irreversible cessation of all brain function.

The vast majority of people die because the heart stops beating and breathing halts. If breathing and heart activity have ceased irreversibly, the patient can be declared dead. This is called the cardiac death criterion. With cardiac death the brain

stops functioning after a few minutes and the organs (liver and kidneys etc.) start to degenerate because the blood circulation stops.

The concept of “non-heartbeating donor” denotes, among others, acute admissions who, owing to severe illness, haemorrhaging or traumas, develop irreversible cardiac arrest. These patients are sometimes referred to in the English-language literature as “uncontrolled non-heartbeating donors”. By taking fast action, the organs in the body can be preserved by rinsing and cooling (kidneys and lungs mainly) and, after quickly obtaining permission from the relatives, the organs can subsequently be harvested. The transplant results are acceptable, but hardly as good as those from brain-dead donors. Such a procedure requires major emergency readiness, and a legal problem can arise in relation to the legislative requirement that transplant interventions must not be performed by the doctors who have treated the deceased during his or her final illness or ascertained the person’s death.

The concept also includes patients who develop cardiac arrest after the respirator has been switched off. Such donors are called “controlled non-heartbeating donors”. These can be patients who are clinically brain-dead but where, for different reasons, clinical cardiac arrest is used as the actual death criterion after having stopped the respirator (the situation in Denmark pre-1990). They can also be severely neurologically ill patients who have been in a long-term coma (but are not brain-dead, therefore), where further treatment is deemed futile and it is therefore chosen to switch off the respirator, with clinical cardiac arrest as a result.

Since 1990 transplants from non-heartbeating donors have not been performed in Denmark. Prior to 1990 kidney donation was always undertaken on patients who were actually brain-dead, as diagnosed by means of “four vessel angiography”, demonstrating that there was no circulation in the brain. So precisely the same patient group are now donors as prior to 1990. Only the actual death diagnosis and harvesting operation are different.

In some cases it is the brain that dies first. The brain’s cells are highly sensitive to oxygen starvation. If circulation of the oxygenated blood ceases after cardiac arrest, the brain will cease to function more or less immediately (consciousness is lost) and perish before any other organ. The damage is irreversible, because brain cells cannot be re-formed. The patient can therefore be declared brain-dead, whether or not the heart re-starts with the help of technical aids. The brain contains centres both in the cerebral cortex, which is the seat of conscious mental life in the broadest sense, and in the brainstem, which ensures circulation of the oxygenated blood in an organism by regulating the breathing and heart. Destruction of the brain can be due to cerebral haemorrhaging, accidents involving severe brain injuries, widespread brain tumours or meningitis etc. There is no chance of “reawakening” once brain-dead. The heart and lungs can be kept going on a respirator. The heart will stop beating after a few days, however, even though the brain-dead person is hooked up to the respirator. Brain death, according to the National Board of Health’s guidelines, is only present in “unconscious, unresponsive and non-respiratory patients, where breathing and heart circulation function are artificially maintained in a respirator”^[24].

Between 100 and 200 people are declared brain-dead annually in Denmark. The number of brain-dead is declining, which is particularly due to a fall-off in the number of patients with diseases leading to brain death.

3.2 Legislation on death

Technological developments in respirators at the beginning of the 1950s provided scope for keeping a patient’s heart and breathing going artificially. In some cases it was possible to detect that the function of the brain had been definitively destroyed, which gave rise to ethical deliberations about the artificial prolongation of the death process in progress. Even for a number of years before the kidney transplants it had been practice on the neurosurgical wards to turn off the respirator in the case of patients with such severe injuries to the brain that there was no prospect of them ever returning to consciousness^[25].

With the start of kidney transplants in the early sixties, however, the discussion about the frontier between life and death flared up in the public debate. The direct cause of the debate was a dispute between the staff involved at Aarhus District General Hospital. Amongst other things, it was alleged that kidneys were in some cases being removed before the heart had stopped beating; and that kidneys were being removed without the relatives’ knowledge. As a result of the dispute, for a period of time—until the Transplantation Act of 1967 was passed—there was a freeze on the use of kidneys from deceased donors.

As a result of the problems in the transplant field, the then Minister of Justice, K. Axel Nielsen, formed a committee in 1966, mandated to consider the problems of a legislative nature thrown up by the transplants. These were, for one thing, the question of the deceased’s and the next-of-kin’s stance on transplantation, and for another, the short space of time available after the onset of death if the kidneys were to be usable for transplantation. In 1967 the first law on removal of human tissue etc. was passed. The committee set up had discussed whether an official death criterion should be established in law so as to fix when death had set in. This was not wished for, however, as it was regarded as being a purely medical question, one not suited to being laid down in law. However, in the explanatory notes it was stated that spontaneous cessation of breathing, spontaneous cessation of heart activity, and total and irreversible termination of all brain activity were all considered necessary criteria^[26]. This meant that organs could only be removed for transplantation purposes once breathing and heart function had desisted. Once the brain was deemed to have stopped functioning, respirator treatment was halted; then, after the heart had stopped beating, the kidneys could be removed for transplanting.

In 1988 the debate on the introduction of the brain death criterion flared up again. Among other things the background was a desire for the medical profession to be able to transplant hearts, lungs and livers itself, instead of sending Danish patients for treatment in countries that had introduced the brain death criterion. At this time Denmark was the only Western European country not to have introduced a brain death criterion. According to the minister's^[27] comments on the 1990 Act^[28] at the time of tabling the bill with the Danish Parliament, an important reason for introducing the brain death criterion was that it was considered most correct to have the Act reflect practice already current: that the doctors could switch off the respirator when all brain function had stopped irretrievably. At that point in time developments in the world of medical science had resulted in the irreversible cessation of all brain function now being diagnosable with complete certainty. Moreover, according to the comments, kidney transplants could enjoy optimal conditions and organ recipients would thus obtain a better and more viable kidney.

Following lengthy public debate, in 1989 it was possible to garner a parliamentary majority of 91 to pass the bill to introduce brain death as a supplementary independent death criterion in Danish law. The Act came into force in 1990, since when it has been possible to declare a patient dead when all brain activity has ceased, with breathing and heart activity still being maintained with technical aids.

3.3 Ascertaining death

3.3.1 Certainty

The Danish Act of 1871 on the Medical Examination of Bodies^[29] contained a provision that the body of a person who had died in bed was not to be taken out of the bed until 6 hours had elapsed. The rationale behind this rule was to lay down a “safety margin” after the time of death before the body was dealt with or disposed of in some way. The most frequent occurrence at this time was for death to take place in the home and regularly in places where it was difficult or impossible to summon a doctor quickly. It was often those present, therefore, who judged that death had set in.

The six-hour rule was rescinded for transplantation purposes in connection with the adoption of the 1967 Act. For the purpose of transplants it was felt that a “safety factor could more satisfactorily be incorporated” by passing a regulation that tissue procurement was not to be undertaken by the physician who had treated the deceased during his or her final illness. The policy paper behind the 1967 Act stated that “*from a medical ethics point of view, the treatment of a patient—including, more particularly, the extent of endeavours set in train to establish whether vital life functions that have apparently ceased might nevertheless denote a state that is, despite everything, reversible—may, a priori and as a matter of course, be determined solely by whether the treatment can even be assumed to serve any further purpose for the person in question, and will never be able to be curtailed for the sake of another patient’s transplant needs*”.^[30]

A provision was subsequently inserted to the effect that there must be two different doctors, each of whom has full responsibility for his or her patient, so as also to impress on the world at large that the two interests can never be mixed up. This applies particularly to the doctors on the hospital ward treating the potential organ donor. These doctors must have no interest whatsoever other than treating and trying to save the life of their patient—regardless of whether that patient may be a potential organ donor. The provision referred to will now be found in the Danish Health Act:

The Health Act, Section 54

...

Subs. 2. Interventions under Section 53 must not be performed by those doctors who have treated the deceased during his or her final illness or have ascertained the person’s death.

The temporal safety factors still exist in part. Thus, the National Board of Health recommends that at least six hours should elapse from loss of consciousness and cessation of spontaneous respiration before making the diagnosis of brain death^[31].

3.3.2 Ascertaining brain death

A patient being examined to see whether brain death has set in will always be in a respirator, since a brain-dead person is no longer able to breathe of his or her own accord. A person can be declared brain-dead when two doctors have conducted a special examination^[32]. One must be the doctor who has been treating the patient during the final phase of the illness, the other a specialist in neurosurgery, neuromedicine or clinical neurophysiology.

The examination must show whether there are reflexes in the brainstem, which is the part of the brain to stop functioning last. There are checks to see whether the patient responds to the effect of pain, lighting and irritation of the eyes, and irrigation of the auditory canals with cold water; also, whether there is any gagging or coughing reflex on irritation of the pharynx and trachea, and whether the patient can breathe autonomously without the aid of a respirator. The patient must not react to any

single part of the examination. After at least an hour the examination is repeated. Only then may the patient be declared dead.

Additional safety checks around diagnosis are the requirements that the patient's brain lesion be known, structural in nature, unresponsive to treatment and established as fatal. The cause of the brain disorder can either have been explained by visible lesions or be clear from special examinations such as CT or MR scans. If these requirements have not been met, supplementary examinations are required in order to establish the brain death diagnosis. This can be examinations for cerebral circulation (whether there is blood flow in the brain) or an EEG (electroencephalogram).

Other, possibly just contributory, cases of consciousness and non-responsiveness must be excluded. This applies to e.g. intoxication, influence of anaesthetics, muscle-paralyzing drugs, sedatives or anti-convulsants. Similarly, the diagnosis is excluded in the case of low blood pressure and a body temperature below 35 degrees Celsius as well as any disease that can bring about unconsciousness.

If the examination has been conducted and brain death ascertained, this time is the official time of death. The onset of death must only be ascertained once. If the person has been declared brain-dead, therefore, this is also the time of death in relation to all other legislation (inheritance legislation, insurance legislation etc.). According to the Act, no duty exists for the doctors to initiate and complete the examinations needed to be able to ascertain the onset of death as soon as possible. According to the notes to the 1990 Act, maintaining the pump function of the heart once brain death has been ascertained must be done in keeping with general medical principles. However, in the notes to the Act it was presupposed that artificial sustenance of respiratory and cardiac activity may only be done if there is a specific patient who can have the new organ implanted as quickly as possible.

Inspection of the body and issuing of a death certificate may not take place until the deceased's body shows clear signs of the onset of death. This is referred to as the sure late signs of death, which are either rigor mortis, livores or putrefaction (cadaverositas). These signs of death set in at varying times after the heart has stopped beating. Until inspection of the body has been completed and a death certificate issued, the body may not be placed in a coffin or taken to a chapel of rest or a mortuary.

[18] This normally happens within a few days, though instances have (rarely) been seen in which the brain-dead person lay for weeks or months.

[19] Danish Council of Ethics, 1988.

[20] Danish Council of Ethics' 1990 annual report.

[21] National Board of Health, Denmark, 2007.

[22] Zøllner. 1999.

[23] Zøllner. 1999.

[24] Executive Order No. 1,249 of 6 December 2006 on ascertainment of death in the event of irreversible cessation of all brain function, Section 1.

[25] The historical information has been taken primarily from Bundegaard, Eva. 1999.

[26] Policy report no. 454. 1967, p. 21.

[27] Then Minister of Justice, Hans Engell.

[28] Danish Bill No. L149, Official Report of Parliamentary Proceedings, 1989-90, col. 3, 796-97.

[29] *Translator's note*: Given the date of the original Danish Act, however, the British equivalent would probably have been the Anatomy Act, which also governed the use of cadavers for medical research etc.

[30] Policy paper. 1967, p. 22.

[31] Danish Executive Order on ascertainment of death etc., Section 4, subs. 3.

[32] The examinations required to ascertain the brain death diagnosis are set out in Executive Order No. 1,249 of 6 December 2006 on ascertainment of death in the event of irreversible cessation of all brain function.

Chapter 4 The need for organs – what can be done?

On 1 July 2008 there were a total of 612 people on the waiting list in Denmark needing a new organ. In this chapter discussion is given over to some of the measures that have been mentioned in the debate as possible means of shortening such waiting lists. The

seminal question for the Danish Council of Ethics in this chapter is which ethical dilemmas the measures mentioned can be predicted to raise and which ethical deliberations will have to be made when evaluating the different procedures.

Section 1 touches very briefly on how research is currently being done into possible ways of replacing organs with technical equipment or possibly even organs from animals. Within recent years, moreover, there has been research into producing organs via stem cells from the person him/herself. Section 2 sheds light on regulating organ donation. Among other things, a closer look is taken at a person's options for making known their attitude to organ donation before this situation even arises, if ever. The guidelines provided by the law, where the deceased's attitude to organ donation is not known, are then outlined. Section 3 discusses fundamental ethical aspects of organ donation as a social arrangement.

4.1 Other techniques

The development of artificial organs started in the 1950s. Some of the main problems have been—and still are—that in order for an artificial organ to be able to fully replace organ transplantation, it has to be so small that it can be implanted in a human body, it has to be virtually maintenance-free and it has to function with great stability. It is no good having a heart that runs out of battery. The artificial hearts developed can help the patient for up to several years in some cases. However, they are still only a temporary solution, until transplantation becomes possible. Artificial kidneys and lungs have also been developed but are not yet at a stage where patients can get around passably.

Xenotransplantation (from the Greek *xénos*: guest or stranger) is used as an expression for the transfer of living cells, tissue or organs from animals to people. If organ transplantation could be based on breeding donor animals, the problem of waiting might be solvable. During the past 40-50 years many attempts have been made to overcome the immunological and physiological barriers between humans and animals. The most serious problem today with the development of this method of treatment is the fear of transferring severe diseases from animals to people—in particular, the risk of transmitting some virally mediated infection that may develop into epidemics has led to more subdued enthusiasm for this kind of treatment.

As described in Chapter 1, recipients of a donor organ are currently dependent on receiving medicine that prevents rejection. This treatment lasts for life and has certain side-effects, just as the treatment increases the risk of contracting other diseases. If, instead, the diseased organ is replaced with a new organ cultured from stem cells from the actual person, there will be no such rejection responses in the body, and the life-long medication can therefore be dispensed with. This form of treatment is still at the experimental stage only today.

The conclusion is that research in such alternative treatment methods still has not come far enough to offer any genuine alternative to substituting an organ from another person at the moment.

4.2 Regulating organ donation

Discussions about ownership of the body and its component parts after death have not taken up especially much space in the debate in the western part of the world. A government system, stipulating that it is a social duty to donate one's organs after death, would possibly remedy the current problems. Advocates of such a system may state that dead bodies and body parts cannot be owned by anyone, and that dead people are none the worse for the consequences of enforced organ donation. But the notion of such a system is extremely alien to the western way of thinking.

Over time, one consistent feature in this field has been that *the deceased's own view* of organ donation has been in focus.

4.2.1 Disclosure by the deceased

Wherever feasible, the deceased's own attitude to organ donation must be clarified. Under the 1967 Act the deceased's acceptance of organ donation should be available in written form. Under the current regulations in the Danish Health Act a written disclosure from the deceased is primary, but a verbal disclosure is also considered sufficient. A disclosure from the deceased – verbal or written – against organ donation must be respected.

Danish Health Act, Section 53

Subs. 1. From a person who has died at or been admitted dead to a hospital or similar institution, tissue and other biological material can be removed for the treatment of disease or bodily injury in another person in accordance with the rules of subs. 2-4.



Subs. 2. Such action may be taken if, after reaching 18 years of age, the deceased has made a provision to this effect in writing. The same applies if the person has advocated such an intervention verbally. If the deceased has made a provision to this effect in writing, relatives of the deceased cannot oppose the intervention unless the deceased has determined that the decision has been given subject to the acceptance of the relatives.

...

So there is no stipulation about the form of the deceased's disclosure. People in Denmark can act in three ways when it comes to taking a stance on organ donation:

- They can inform their relatives of their views
- A donor card can be completed and kept on their person
- They can register with the Danish Donor Registry.

About informing one's relatives

Where organ donation has been talked about in the family in the event of a sudden death, the relatives' disclosure of the deceased's attitude to organ donation is altogether sufficient to meet the requirements of the law.

The National Board of Health's 2006 survey of the Danish population's attitude to organ donation shows that relatives are less informed about people's attitude in 2006 than was the case in 2001 (in 2001 47% had talked to their relatives, while the figure was only 36% in 2006). The Board of Health interprets this as a possible sign that now, more than previously, the decision to become a donor is being made individually.

In 2006 a Eurobarometer survey on organ donation and transplantation was conducted among the EU member states^[33]. Among other things, the populations were asked whether these topics had been discussed within the family. The survey showed that approx. 41% of European citizens had already discussed the issue of organ donation and transplantation with their families. The Netherlands came highest at 75%, then Sweden at 66%, with Denmark coming third at 58%.

About completing a donor card

In Denmark a donor card can be obtained at pharmacies and libraries, as well as the GP's clinic and other places. It can be completed and kept on the actual person, in a wallet or purse etc., as appropriate. It offers the same disclosure options as registration with the Danish Donor Registry.

In the above-mentioned Eurobarometer survey the EU citizens were also asked about their attitude to donor cards. The survey showed that around 81% are in favour of such a card, while 19% are against the idea. Sweden scores highest with 95% and Denmark comes in fourth at 89%.

However, the survey also showed that having a donor card is still relatively rare. Only 12% of citizens in the EU have a donor card. The Netherlands come top at 44%, then Sweden at 30%, with Denmark coming fifth at 25%.

About registering with the Donor Registry

In 1990 the Danish Donor Registry was set up. Since 2001 it has been possible to register with the Donor Registry with different forms of disclosure:

- Full permission
I hereby grant full permission for all my organs to be used for transplantation after my death
- Relatives' acceptance
My full permission requires my relatives' acceptance
- Limited permission
I hereby grant limited permission for those organs which I have ticked to be used for transplantation after my death (hearts, lungs, liver, pancreas, kidneys, corneas, intestines, skin).
- Relatives' acceptance
My limited permission requires my relatives' acceptance

Prohibition

I oppose the use of my organs for transplantation after my death.

From 2009 it will also be possible to register with “Don’t know”.

Since 2005 it has been possible to enrol for the register via the Internet at www.sundhed.dk. Most registrations are done this way (75-80%). As at 1 September 2008 a total of 589,672 Danes had registered with the Donor Registry – including approx. 7% with a prohibition on transplantation.

The physical site of the Donor Registry is at Rigshospitalet, the National University Hospital. The transplant centres and other hospital departments have access to the register (via a password).

Information can be obtained about registration options, including in a donor folder available from GPs as well as libraries and pharmacies.

Overall, the National Board of Health’s surveys show that some 50% of the Danish population have disclosed their view in one or more of the ways mentioned (during the 2006 survey 36% disclosed that they had spoken to their relatives, 21% had completed a donor card and 12% had registered with the Donor Registry).

Campaigns, among other things, have been taken into service to get the Danes to take a position on organ donation. A campaign can be defined as “a drive to obtain a particular result”. In the spring of 2008 a new campaign was launched, in which the Danes were confronted with a call to take a stance on organ donation—a decision that involves thoughts about disease, sickness, suffering, death and other deep-seated emotions.

During the National Board of Health’s 2006 survey of the population’s attitude towards organ donation, 31% expressed the view that they lack information about organ donation. Asked where they would prefer to have this information from, in that case, 42% replied that they would most like to have the information from their “own GP” and, as the second-highest source indicated, 34% replied “from the health sector”. The third-highest channel of information mentioned is “campaign material” (32%).

When sent a new health card (a form of health insurance card), Danes are now receiving a folder with information on organ donation and a registration form for the Donor Registry.

In April 2008 Danish Parliament tabled a: *Bill for a parliamentary resolution on registration of over 18’s views on donating their own organs*^[34]. Under the bill the government is encouraged to introduce a standard, whereby anyone who has turned 18 and is of age is asked to state their personal point of view with regard to the question of organ donation. This point of view is noted in the Donor Registry and must be able to be changed by the individual at any time. According to the motion, it can be done in such a way that everyone who has turned 18 and is of age must have an opportunity to answer and sign a form the first time the person is going, say, to have a new driver’s licence or passport, or going to attend his or her GP’s. The wording of the motion was amended in some respects during the hearing in Danish parliament. The word “duty” was thus changed to “have the option of” and the word “shall” changed to “can”. Complete with amended wording, the motion was adopted on the second hearing on 12 June 2008. This thus obligates the government to work to introduce such a system.

Limitations on organ donation

A limit of 18 years of age currently applies to people’s own, independent stance on organ donation.

Individuals under 18 are still in the custody of their parents. It follows from the Danish Act on Parental Responsibility that for people under 18 years of age, the parents must care for the child and make decisions regarding the child’s personal circumstances based on the child’s needs and interests. Since the first law in this field, the age limit for self-determination as far as organ donation is concerned has followed the general age of majority. In 1967 the age of majority was 21; today it is 18, as mentioned. This is expressly set out in Section 53 of the Danish Health Act, which regulates transplantation from deceased people:

Danish Health Act, Section 53

...

Subs. 2. The intervention may be performed if the deceased has made written provision to such effect after reaching the age of 18. The same shall apply if the person has committed him/herself to such an intervention verbally.

...

Subs. 4. If the deceased is under 18, the intervention may only be performed if the legal custodian has given consent for the intervention.

A further limitation is the prohibition in law on offering or receiving payment or any other financial gain for the removal or transfer of tissue for therapeutic purposes. Similarly, it is a punishable offence to be complicit in transplantation in the knowledge that such payment has been given or received.

Danish Health Act, Section 268

.....

Subs. 2. Anyone offering or receiving payment or other financial gain for the removal or transfer of tissue and other biological material for therapeutic purposes as set out in Section 52 or Section 53 shall be punished with a fine. The same shall apply to anyone involved in the performance of such an intervention knowing payment has been given or received as set out in item 1.

Can the relatives undo the deceased's decision?

A perennial discussion has been the extent to which an organ donation disclosure from a deceased person is binding. This problem has related primarily to the relatives and any wishes they may have about reversing the deceased's wish for organ donation.

Regarding this "issue" the committee behind the 1967 Act stated that the purpose of the legislation was not to establish a duty to abide by the deceased's wish, but primarily to establish that if the deceased had consented to the intervention, this would be legal. The committee did, however, express the view that the relatives had a duty to satisfy the deceased's wishes if there was a need that could thereby be met.

In the explanatory notes to the 1990 Act this was not discussed as such. However, it was stipulated that *"in accordance with practice to date and medical-ethical principles, doctors will refrain from performing transplantation in cases where the deceased has spoken in favour of such an intervention but the relatives are opposed to transplantation"*.

2000 saw the start of a debate as to the reasonableness of this practice, the real-term result of which was that the relatives had a kind of right of veto. As a consequence of the debate, a passage was inserted in the Act that permission for organ removal can be granted on condition that the relatives also accept the intervention. If such "conditional" permission has not been given, the relatives cannot oppose this, under the law.

The notes on the bill emphasized that force would not be used in dealings with relatives opposed to a deceased person's written provision. By the same token, it was stipulated that there would be no repercussions for staff if it was not wished to perform donation on account of the relatives' opposition. In practice the relatives are always notified before any transplantation is actually carried out. According to the National Board of Health, Denmark, it virtually never happens that the relatives oppose the deceased's wishes.

If the deceased has expressed an aversion to transplantation, it must not be done—not even with the consent of the relatives, where available.

Danish Health Act, Section 53

....

Subs. 2. The intervention may be performed if the deceased has made written provision to this effect after reaching 18 years of age. The same shall apply if the person has committed him/herself to such an intervention verbally. If the deceased has made a written provision to this effect, relatives of the deceased cannot oppose the intervention unless the deceased has determined that the decision has been given subject to the relatives' acceptance...

4.2.2 When the deceased's wishes are not known

As outlined above, it is a requirement in Denmark that explicit consent be available for organ donation. That is not so in all

countries. A number, including the other Nordic countries, have a scheme based on presumed consent. Presumed consent means that there is a basic assumption that all citizens are willing to become organ donors. Direct consent for organ donation is not necessary, therefore, in order for transplantation to take place. It is possible to rebut this supposition. Anyone not wishing to be an organ donor when they die has to arrange for their wishes to be registered with the authorities.

One thing common to those legal systems based on explicit consent and those that have presumed consent for organ donation is that they foreground the wishes of the deceased. If, prior to the onset of death, the deceased has expressed a wish to be a donor—be it verbally or in writing—transplantation may take place. Conversely, if the deceased has voiced his or her opposition to organ donation, the intervention may not take place.

The difference in the two kinds of consent comes to the fore primarily in the situation where the deceased's wishes are not known. If the law requires explicit consent in this situation, there is scope for the relatives to provide this consent. If the relatives take a passive view or if it is not possible to contact the relatives (or if there *are* no relatives), transplantation will be out of the question. Under the various countries' legislation there can be a difference in the competence the relatives have under any particular scheme involving presumed consent. Some countries presuppose the relatives' acceptance, while others give the relatives right of veto, and it might therefore be said that the actual difference between the two arrangements is not particularly great in such cases.

If the deceased's attitude towards organ donation is not known, under current Danish law transplantation can only be performed if the relatives explicitly give consent for such. Any consent from the deceased's next-of-kin for organ donation must be based on information from a doctor:

- a. That death has occurred or is imminent.
- b. That there is a possibility of organ donation.
- c. Which tissue and other biomaterial (organs) it is intended to remove with a view to performing a transplant.
- d. That the closest relatives have a channel for disclosing either that they oppose the intervention or that they do not wish to take a position, with the effect that the intervention may not be undertaken ^[35].

If the relatives are not contactable, the intervention must not take place. If no disclosure from the deceased is available, and if the deceased leaves no next-of-kin, a transplant operation may not be performed either. If the deceased is under 18, the legal custodian must consent before an intervention can take place.

As mentioned in Chapter 2, about half of relatives reject donation. The National Board of Health's surveys show that the proportion of Danes that would be willing to donate relatives' organs is lower than when it involves the population being willing to donate their own organs. Nevertheless, when asked during a general survey, 72% of the population are willing to donate their spouse's organs on death. In practice the figures show that only around half of relatives agree to donation when the actual deceased has not taken a stance on the matter.

The deceased's "next-of-kin" – demarcation and competence

The deceased's closest relatives thus play an important part in the question of organ donation. Only half a million or so of Denmark's population of about 5.5 million have registered with the Donor Registry. It is not known how many have filled out a donor card, but the overall attitude towards organ donation is unknown for approximately half the population.

According to the notes to the 1990 Act the expression "the deceased's next-of-kin" ... "at any rate includes spouse or cohabitee, direct descendants and, depending on the particular circumstances, siblings. Adopted children will generally and foster-children regularly be covered by the rule. According to circumstances—and more particularly when the deceased leaves no spouse, cohabitee or children, the provision may include relatives to whom the deceased was closely attached, or closely related by marriage."

Within the health field a wider notion of kinship is normally used. Thus, in matters of treating a permanently incompetent patient, close friends or carers can also be included by the concept – particularly when there are no relatives. When it comes to organ donation, there must be some familial link with the deceased. If the deceased has no family, transplanting cannot go ahead.

In the particular case in hand it is sufficient for consent to have been granted by one of the people belonging to the circle of the deceased's closest relatives. In the notes on the law it is stressed that consent for transplantation cannot be assumed to be available if just one of the people from the circle of the deceased's closest relatives speaks out against the intervention (or revokes the consent) before the intervention has been performed. That is to say that regardless of whether the deceased's spouse has consented to it, resistance to organ donation from e.g. one of the adult children will result in transplantation not being feasible.

4.3 The ethics of organ donation – an overview

4.3.1 Organ donation as a special ethical matter

As mentioned earlier, organ transplantation differs from all other medical treatments because it presupposes that an organ can be transferred from a specific person, who has just been declared brain-dead, to another specific person, who can consequently live his or her life better and longer than would otherwise have been possible. That means that the potential donor's and their relatives' outlook and philosophy of life become directly relevant and crucial to whether severely ill people can have their vital need to receive healthy organs fulfilled. By implication, therefore, the stage is already set for the ethical discussion on organ donation.

4.3.2 Right of disposal over one's own body

There is a simple way of increasing the availability of organs from brain-dead people. Compulsory organ donation can simply be introduced in cases where a person has been diagnosed brain-dead due to an accident or illness. There are key voices in the bioethical debate that do put forward such a view. In short, the line of argument is that the organs will perish anyway. According to advocates of compulsory organ donation, the resource involved is finite, and in that case it has only symbolic value for the deceased and his or her relatives. By contrast, organs from brain-dead people represent a highly valuable resource for severely ill people, and advocates of compulsory organ donation advocate siding, politically, with those in serious need of healthy organs. But what about the relatives at the deathbed? Based on a philosophy of compulsory organ donation, it can be asserted that it is positively an advantage for the relatives not to be saddled with the burden of decision-making, and that compulsory organ donation is reconcilable with respectful rituals, good information and proper care for the relatives at the deathbed.

Compulsory organ donation is an extreme solution, in the sense that it assigns no weighting at all to regard for a donor's self-determination and the relatives' influence. The fact that the scheme has relatively few adherents in the public debate and is absent from the domestic debate, in particular, is undoubtedly due to a broad-based and deep-rooted view that every single person owns his or her body and should him/herself have extensive influence over how the dead body should be treated.

That self-determination also has a vital psychological importance in the context of organ donation. That is clear, in that the relatives of brain-dead people find it far easier to grant consent for organ donation if they actually know or have some impression of the way the deceased felt about the matter when alive. For most people it is bound to feel intuitively right that this must be the way of things. Knowing how the deceased felt must afford them a sense of security.

Nonetheless, in an ethical analysis, it can be instructive to scrutinize this intuition in a critical vein. Firstly, then, it must be assumed that most people are convinced that the body and the organs perish after death. Secondly, without doubt, the relatives know perfectly well that the deceased cannot, for that very reason, be said to have any relevant interest in what happens to the person's organs. This is in contrast to the fact that, here and now, organs from the deceased can be of absolutely essential help to one or more severely ill people. The relatives are in an emotionally difficult situation, in which they need to come to terms with the fact that their loved one is dead. And yet, against the backdrop above, it may well come as a surprise that what tips the scales to such an extent is constituted by the relatives' knowledge or lack of knowledge as to what the deceased would actually have wished for him/herself. After all, they already know that the organs perish, and they know that their decision is of crucial significance to one or more people in need of a healthy organ. Yet about half of all relatives in this situation say no, and a large part of them would presumably have said yes if they had known for sure that the deceased him/herself had wished to be an organ donor.

By looking at the situation from the relatives' angle, it may be possible to discern why the value of the right of disposal over one's own body is apparently so inevitable in the discussion about what can legitimize organ donation. What normative obstacles or constraints are the reason for relatives, to a relatively large extent, opting out of the beneficent contribution of organ donation, because they do not have sufficient knowledge as to what the deceased would have chosen to do, one may well ask? If the relatives do agree to organ donation, they will implicitly have to accustom themselves to an image of the human body that at any rate is not normal from an everyday perspective: that organs in the body are valuable objects that can be moved and serve a useful purpose elsewhere than in the original body. If, moreover, the relatives do not know the deceased's view, this perspective on the body as a resource will be intensified, in a sense, because the body's object-like nature becomes more pronounced when the relatives cannot satisfy themselves that there is an innate connection between organ donation and the deceased's own views on such while alive. Such external regard for the deceased is clearly in glaring contrast and is altogether inconsistent with the way the relatives naturally view the deceased: for them, the deceased is a person they have lost, and on the face of it they relate to the deceased through feelings and memories linked to a life-story of which they themselves have been part. The deceased is a dead person, and presumably it is hard for the relatives not to view what is happening to the deceased's body as something that is actually happening to this person, regardless of the fact that the person is dead.

The very same is the case perhaps for most living people, who imagine their body after death and what happens to it. In this way the personal life-story extends beyond the frontier between life and death: what others do with the body after death is relevant to the individual's perception of personal integrity and that person's attitudinal horizons.

4.3.3 Organ donation as a reciprocal obligation

Solidarity is a mainstay of the public debate, as well as the debate taking place among health professionals, bioethicists and

politicians. It is an obvious choice to talk about an obligation in connection with organ donation and transplantation. The notion is that serious thought must be given to becoming an organ donor if it is wished to be able to receive organ transplant treatment oneself in the event of needing it due to an accident or illness. According to this argument the reasonableness of asking people to become organ donors is justified by having to contribute to maintaining the community that is ultimately a possibility condition for being able to be treated using organ transplantation oneself. If this point of view is accepted, failure to register as an organ donor is a little comparable to evading tax: one cannot retain one's respect and personal integrity and still wish to receive benefits from the community (schooling, treatment under the health services etc.) while simultaneously undermining the community's existential capability through one's actions. Of course, the comparison only applies in cases where those who do not wish to be organ donors nevertheless wish to receive organ transplantation treatment, should it become necessary.

The nub of the argument is that organ donation is something people are duty-bound to do as a consequence of themselves wanting to receive organs, should it become relevant. If this argument is supported, organ donation will be logically perceivable as a modern community based on a technological possibility, where donors and recipients of organs engage in the cause together. In the debate on organ donation this representation of donation and transplantation as a community between donors and recipients is often used to support proposals for schemes in which there is presumed consent for organ donation, or schemes in which a correlation is actually established between one's willingness to be an organ donor and one's possibility of receiving organs, should the need arise. In the international bioethical debate the point of view has been espoused with proposals to conduct different initiatives to create a moral community around organ donation as a practice in society. In an American context there have been proposals to award medals to organ donors, just as creating websites in the local communities, where people are listed when they have volunteered as organ donors, has been suggested^[36]. Finally, in the domestic debate, there have also been proposals for schemes entitling donors to priority over non-donors if they get into a situation where they themselves need to receive organs: In the less extreme version it may be that a volunteer edges up the waiting list in relation to non-donors, or in the stronger version it may be that registration as an organ donor is a necessary condition to qualify for consideration as a recipient of organ transplantation treatment. In the Danish debate, some people have also suggested tax breaks for people registering as donors.

But what reservations can one have about an argument that a reciprocal relation exists between the willingness to donate and the legitimacy of receiving organs? The most important reservation here is that organ donation and being a potential organ donor can be said to be "benefits", which means something quite different and has different implications, depending who has to honour performance of the service. Donating organs will be entirely uncontroversial and an easy decision to take for some. It will be one thing if a person is firmly convinced that organ donation can help others while not harming oneself or one's relatives in any essential way. For others the decision will be materially more difficult to make, because they are unsure what they actually think about death and life, and what it means for both oneself, when alive, and the relatives on the deathbed to interfere with the body after death. For still others, organ donation will be out-and-out incompatible with the person's view of life, death and the death process, and for these people it is clear that being registered as an organ donor will be a "bane". This highlights how being an organ donor is an easy matter for some, while for others it would be a difficult matter and hence, in one sense, a greater "performance". Of course, this is due to organ donation having to do with very personal notions of death and life. It is arguably in precise keeping with a democratic welfare society for every man to contribute according to his ability without too much regard for whether those being helped might themselves be in a position to offer that same help too.

But there is also another reservation about viewing organ donation and the possibility of receiving organs as being inextricably linked: by introducing the principle of "having to put something into the kitty in order to get something out" with regard to the exchange of organs, it may be thought to represent an intensification of an objectifying or commodifying view of human nature. It may be thought that this principle too widely presupposes that the hands-on market value of organ donation can be measured. This, as it were, further involves capitalizing on the individual person's philosophy of life and reflections about one's own attitude to the role of death for life.

4.3.4 The relatives

Regard for the relatives is central to the debate on organ donation. However, there are two different ways in which the relatives play a part. Firstly, the relatives are relevant because the whole situation around the deathbed is important for the relatives, above all. They are the ones grieving and needing to take leave of their nearest and dearest. Secondly, the relatives play a part because, in practice, they are often the ones to make the decision, on behalf of the deceased, of whether organ donation can be performed. This is because, under current legislation, relatives make a decision on behalf of the deceased, where no decision was made by the deceased. The relatives also have a similar role in many other countries where the legislation differs. For example, it is often the case that relatives also have decision-making powers in countries where presumed consent prevails, and where the deceased has not said "no" to organ donation.

Regard for the relatives' grief and leave-taking

One aspect of the relatives' role, as mentioned, is that the relatives are the ones who are grieving and need proper conditions at the deathbed. There can be different views concerning the weighting that should be given to regard for the relatives' leave-taking by contrast with the regard that can be accommodated by performing organ donation and thus making a difference to severely ill people. But presumably, no one will dispute the fact that regard for the relatives' emotional leave-taking situation is

a relevant consideration to be made.

At any rate, there are three different sets of circumstances in connection with brain death and organ donation that can be potentially difficult for the relatives to handle:

- Brain death is often the result of sudden events, such as cerebral haemorrhaging or a road traffic accident.
- Time is a decisive factor with organ donation as a form of treatment. The decision whether to remove organs must be taken as quickly as possible after the patient has been declared brain-dead.
- Organ donation entails maintaining the heart and circulation until the time of operation using advanced medical technology. For the relatives, especially, this means that the deceased can be more reminiscent of a dying person, because the heart is still beating and the body's temperature can be almost the same temperature as a living person's.

These circumstances mean that relatives of a brain-dead person are confronted with conditions to which they are not accustomed, in the sense that leave-taking from the deceased will take place in a way that differs from typical notions of the death process and the deathbed for which each individual person has prepared him/herself to expect. In particular, it presumably poses a challenge for relatives that they have to take their leave of the deceased while the person's heart is still beating. The difficulties become clear when considering which words to use of the brain-dead person awaiting removal of organs and possibly also pending the relatives' decision on this. The brain-dead person is dead in the legal and medical sense, but owing to the imminent organ donation the respiration and heart are kept going, just as various other medical treatments are initiated with the intention of ensuring that the organs are suitable for transplantation. For the relatives, as for everyone else, it is difficult to find the right words to use about the deceased in this phase. Is the brain-dead person entirely dead or is he/she perceived mostly as dying? Is it reasonable to talk about it being a corpse that is being rolled into the operating room to have the organs removed? Patently, there is a stark clash here between different horizons of experience and different linguistic usage. For the relatives it is a person, a person who has just died. Many relatives will undoubtedly even perceive the brain-dead person more as a dying person than a completely dead person. For them it is of crucial importance that the deceased – or in their eyes, perhaps, the dying person – should not give the appearance of an entirely deceased body, or what we call a cadaver. Conversely, the doctors and staff in attendance will, to some extent perhaps, find it easier to view the situation as parallel to one in which both heart and brain have ceased to function, and in which the body also appears like a corpse in sensory terms too.

Relatives as decision-makers

Apart from being the ones to grieve, the relatives also play a major part, as mentioned, because in most familiar organ donation schemes they influence the decision as to whether organs can be taken from the deceased person. In Denmark, as mentioned previously, the relatives have decision-making capacity in two situations: if the brain-dead person's will is not known or cannot be ascertained, or if the brain-dead person has recorded that organ donation may take place on condition that the relatives give their undertaking.

The relatives' role as decision-makers is complicated by the fact that two completely different rationales are conceivable as to why it is relevant for the relatives to take the decision. On the one hand it may be felt that the relatives should take the decision, because they know the deceased's philosophy of life and attitudes best. In that case their decision can be viewed as genuinely vicarious: their role as decision-makers is to imagine what the deceased's decision would have been. On the other hand it may be felt that the relatives should have the right to take the decision because, next in-line after the deceased they have the greatest interest in the situation. In that case their decision is not actually vicarious. Instead, it hinges on a thought that the legitimacy of removing organs from the deceased can stem from two sources: From the deceased's undertaking or from the relatives' undertaking. This incorporates a hierarchy which means that the deceased's undertaking is the most important, but where this is not available, it opens up the possibility of the relatives taking the decision instead.

It is important to distinguish the two different possible rationales for the legitimacy of the relatives' decision-making capacity, because it is important when it comes to deciding whether the relatives' scope for deciding for or against organ donation should out-trump other considerations—whether it be regard for the deceased's express will or regard for the fact that organs can be harvested to benefit severely ill people. A stance on these dilemmas will be relevant, for example, in two different situations: in situations where the relatives are opposed to organ donation, even though the deceased has voiced a wish to be an organ donor. By contrast, the deliberation about severely ill people is relevant in situations where relatives decline, even though no “no” is available from the deceased and, more especially, if this situation is envisaged under presumed consent.

It virtually never happens that relatives oppose organ donation in cases where the deceased has wished to be an organ donor. Under the present rules, it is also the case that the relatives do not have the right to reverse the deceased's decision. In practice, however, it will presumably be the case that the staff in attendance will not want to carry out organ removal if the relatives are actively opposed to the intervention being performed. Current practice and legislation are thus based quite clearly on the removal of organs being legitimated by the deceased having consented to the intervention. In any case, any reluctance on the part of the relatives cannot, in principle, cancel out the deceased's decision. From this it can be concluded that the regard for the relatives' view of the situation and possibility of reconciling themselves with the procedure does not, in principle at any rate, weigh as heavily as the deceased's explicit views. Yet at the same time the legislation has clearly attempted to make allowance for this situation, in as far as it is possible to make one's commitment to organ donation conditional on the relatives giving their approval as well. In so doing, all citizens have been given the opportunity to decide for themselves

whether regard for the relatives' own opportunity to reconcile themselves to the situation should enjoy crucial weight. It is perfectly clear here that the deceased him/herself has made his/her views known, for which reason there can be no talk of a vicarious decision on the relatives' part. Instead, it may be said that the deceased has simultaneously made known that the relatives must have a right to decide themselves whether they can reconcile their leave-taking with the various procedures and consequences of organ donation.

The other situation in which deliberation on regard for the relatives' scope for deciding becomes particularly relevant is, as mentioned, when the relatives say "no", and there is neither approval nor rejection on the part of the deceased. The question here is how relatives' scope for making a decision is to be weighted against regard for the fact that severely ill people can be treated with the organs taken from the deceased. Under the present informed consent, organ donation in these cases depends on the relatives agreeing. Active approval is required, and in this situation it is most logical to view the relatives' consent as vicarious as such, whatever motives the relatives may have in their own minds as the background to the decision. But the question becomes more open if the same situation is envisaged under presumed consent (where the deceased can be regarded as an organ donor if he or she has not actively said "no"). Should the relatives have an opportunity to make the decision in this situation, and if so, with what reasoning?

Firstly, it must be said that presumed consent, albeit amid rather a lot of uncertainty (see Chapter 5), rests on a notion that the deceased advocated organ donation to some extent when alive. If the relatives are granted co-determination in this situation, for example, it may be perceived as an extra safeguard in the form of a vicarious decision based on the relatives having known the deceased and being able to confirm or deny that the deceased would advocate donating his or her organs. This then requires the ability to be more or less sure that the relatives are in fact actually reconstructing the decision that the deceased would probably have taken. In this case it is the deceased's self-determination and hence impression of having some influence over what happens to the body after death that must be weighed against regard for the fact that severely ill people can be treated with organ transplantation. Conversely, it may be felt that the relatives are being granted co-determination, above all, because they have a vested interest in the situation and therefore ought to be able to decide whether organ donation should take place in cases where no specific consent is available from the deceased. In this case it is the relatives' opportunity to have what, for them, is a satisfactory leave-taking from the deceased that must be weighed up against the regard for helping severely ill people.

It is quite possible to advocate informed consent and by the same token be sceptical about the relatives' possibility of reconstructing the deceased's attitude towards organ donation. The consequence here is that a decision by the relatives on behalf of the deceased is not acceptable unless the deceased has come out in favour of organ donation, which is further conditional on the relatives' undertaking. However, from an argumentational point of view, the relatives' scope for making that decision can be upheld despite any possible scepticism about the eventuality of a vicarious decision. Instead, the stress can be placed on the relatives having been given the right to decide in favour of organ donation because, next in-line after the organ donor him/herself—who has not decided—they are the ones with an essential interest in the situation. Regardless of which rationale it is wished to cite for the relatives' decision-making capacity, the relatives further find themselves subject to being placed in a situation where they have to make a decision while at the same time being powerfully influenced by the whole situation emotionally. The examples above show that, and they also show that determining precisely what role and weight to assign to the relatives' scope for making the decision about organ donation is no simple matter.

[33] http://ec.Europe.eu/public-opinion/archives/ebs/ebs_272d_en.pdf

[34] B 100, 2007-08, 2nd session.

[35] These requirements are set out in the National Board of Health, Denmark's, guidelines on consent for transplantation from deceased people.

[36] Etzioni. 2003.

Chapter 5 Weighing up presumed versus informed consent in ethical terms

Today we have informed consent for organ donation. As a result, while alive, the organ donor must have expressed a positive view of organ donation if organs are to be removed from the dead body. Under the present rules, however, the relatives can grant consent for organ donation even though no consent is available from the deceased. As mentioned previously, only a minority of the Danish population have pre-registered as organ donors, though in opinion polls a majority are in favour of organ donation. That is one of the reasons why many people argue that so-called presumed consent should be introduced for



organ donation instead.

With presumed consent for organ donation, all citizens can be considered organ donors as a starting point. As a result, the actual citizen has to arrange to disclose their resistance to acting as an organ donor if they want to avoid their organs being removed and transplanted in the event of being declared brain-dead due to an illness or accident. That is why presumed consent is also called an “opt-out” model: anyone not wishing to be an organ donor and thus wanting to “deregister” from the scheme must notify the authorities to that effect. If, on the other hand, they are happy to be an organ donor, there is no need to do anything. Presumed consent provides scope for several different ways of “deregistering” from the scheme: there will often be a central register where the citizen has to register his or her views. But just as commonly, the relatives can act as witnesses to the deceased’s views. If the relatives claim the deceased did not wish to act as an organ donor, it has decisive force, though there is no central registration by the deceased him/herself.

Presumed consent for organ donation is a possible alternative to the informed consent current in Denmark. It is an alternative that other countries have introduced, including the other Nordic countries, and the organ donation debate features presumed consent as one of the possible ways to remedy the problem of long waiting lists. In Denmark, as also in several other countries (including Germany and the USA), opinion polls show massive support for organ donation, though this is nevertheless not matched by the number of people volunteering as organ donors. From such surveys it can be concluded that among the population in countries with informed consent, there are many people who do not form part of the organ donor pool, purely because they do not register their positive views on acting as an organ donor. This is one of the background factors against which some people argue for the introduction of presumed consent. However, it should be mentioned that there is no certainty that presumed consent will lead to more organs that can be transplanted. Sweden, for example, does not have a substantially higher donor rate than Denmark, though Sweden has presumed consent for organ donation. But some surveys show that countries with presumed consent have a slightly higher donor rate on average than countries with informed consent. ^[37]

The success of a presumed consent scheme will be linked to the line taken by the relatives in those situations where their nearest and dearest have not taken a stance but are regarded as a potential organ donor because they have not opted out of the scheme. Furthermore, whether only a very small minority will, as the opinion polls indicate, actually register as “no” sayers will be crucial. Perhaps, on the contrary, more people will say “no” to organ donation under presumed consent than indicated by the number of people expressing an aversion to organ donation in polls and surveys. This may be due to the fact that one can certainly reply in the affirmative when asked in a non-committal poll but will reply in the negative when asked to take a binding stance on organ donation after thinking the matter through properly.

Is presumed consent for organ donation an ethically acceptable or even an ethically better way for society to handle organ donation? There are three problem complexes in particular that are relevant to any deliberation of this question.

Firstly: With presumed consent it is not a requirement of the actual system that a potential organ donor (all citizens) adopt an active and positive stance on being an organ donor. If the success criterion for the scheme is primarily to create a larger pool of potential organ donors, it makes no difference with presumed consent whether the individual citizen reflects and takes a position on the subject: for both those who do adopt a positive stance and those who are not in the slightest bit concerned about the matter will be potential organ donors. Is it, ethically speaking, good or bad to have a system that does not presuppose per se that potential organ donors have taken an active stance on organ donation? And what consequences will the system’s lack of stance-taking stipulations have for the way conversations and decisions relating to organ donation are held among people and their closest ones? This problem complex will be treated in section 5.1.

Secondly: How is regard for the donors’ self-determination and stance-taking weighted in presumed consent compared with informed consent? Both informed and presumed consent rely on voluntariness, since both models exclude citizens being compelled to act as organ donors. But what ethical implications are involved when presumed consent hinges on a supposition that the deceased would actually be happy to be an organ donor because he has not registered his disinclination to act as an organ donor? This problem complex will be treated in section 5.2.

Thirdly: Do the public authorities influence the individual citizen with an axiological preference when organ donation is regulated with presumed consent? Can or should presumed consent be thought of as a signal that being an organ donor is “the norm” or the morally preferable thing? This problem complex will be treated in section 5.3.

5.1 Consequences for the individual’s and the relatives’ decision-making process

5.1.1 The relatives' situation at the deathbed

The relatives of a potential organ donor often play a central part as decision-makers on behalf of the deceased. In tandem with their shock and sorrow, relatives are plunged into a situation that is rendered difficult by a series of externalities.

Firstly, brain death is often the result of sudden events like intense brain haemorrhaging or road traffic accidents. In such cases there has been no lengthy course of illness during which the relatives and the sick person were able to talk together about death and possibly also about the sick person's attitude to organ donation.

Secondly, time is of the essence in the case of organ donation as a form of treatment: the decision to harvest organs must be taken as quickly as possible after the patient has been declared brain-dead. This is intended to ensure that the organ can be transplanted and have a good medical effect on the recipient.

Thirdly, organ donation entails the heart and the circulation being maintained with sophisticated medical technology. That means that the relatives' leave-taking from the deceased is made different to normal. The initial leave-taking is done in the hospital ward, where the dead person's heart is still beating and the blood is coursing around the body. That is to say that, despite the state of being brain-dead, the patient may give the appearance of a person who is merely unconscious or asleep: for the heart is beating, the body may be almost the same temperature as a living body and breathing is functional. It is not difficult to see that this scenario can subject the relatives to severe emotional pressure, even though their intellectual reasoning also makes them perfectly aware that their dear one will never return to life again^[38]. After the initial leave-taking the patient is taken to an operating ward, where the organ is excised. The operating wound is then sewn up, making the body look whole and intact. This process can take up to 12 hours, and only after this can the relatives take their second leave of the deceased. The actual operation on the deceased between the two leave-taking sessions prevents the relatives from witnessing the moment when the brain-dead person's heart stops beating and the brain-dead person expires.

5.1.2 Presumed consent does not support social dialogue and decision-making processes

The National Board of Health, Denmark, and different organ donation campaigns practise advocacy for families and friends talking together about organ donation and making up their minds at a juncture when they do not yet find themselves in the role of a relative or an organ donor. As mentioned, a positive disclosure about organ donation is very rarely overturned by the relatives, whereas the relatives say no to organ donation in about half of cases where the brain-dead person's views are not expressly known. These figures alone indicate that, despite everything, the very difficult situation is made relatively easier for the relatives to handle if the deceased's views on organ donation are known^[39]. That is to say, it becomes easier for the relatives to perform their role as decision-makers.

Consideration should be given to the impact a presumed consent scheme will have on motivation and on the setting for conversations about organ donation between people who are close. After all, in one way presumed consent is designed to render conscious stance-taking superfluous. The problems of modern democracies with a shortage of organs for severely ill people are often due, in many people's opinion, to too few people actively taking a stance on and registering their views centrally or informing their relatives about their views. Adherents of presumed consent often argue on the basis of the following reasoning: if schemes with informed consent are not able to generate a high number of potential donors, some scheme must be introduced whereby those who have not taken an active stance are potential organ donors on a par with those agreeing to organ donation under informed consent. That needs to be done for the sake of the severely ill people currently waiting in vain to have a healthy organ transplanted. In keeping with this philosophy, presumed consent creates a larger pool of potential donors.

Presumed consent has precisely this effect because it makes the system independent of any positive disclosure by the citizen. If presumed consent were to be introduced in Denmark today, without altering anything else about the system, a drastic increase in potential donors could be expected. But it would possibly still result in approximately half of all relatives still saying "no" to organ donation in cases where there is no specific registration nonetheless. This assumption will hold water as long as the relatives' knowledge about the deceased's own attitude to organ donation is chiefly what makes it relatively easier for them to say "yes" to organ donation^[40].

In its logic a system with informed consent is more of an incentive for conversations within the family and other social contexts, because a concrete positive disclosure "calls for" deliberations and discussions. Furthermore, the statistics would seem to suggest that knowing about a positive registration by the deceased is of great importance per se to whether the relatives opt for donation. This presumably applies irrespective of whether organ donation was a topic of discussion in the family or whether the deceased merely took an individual decision without communicating it while alive. It is debatable whether it would be just as reassuring for the relatives in those situations under presumed consent where the brain-dead person is acting as an organ donor, merely because that person has failed to register a "no" to organ donation while alive.

5.1.3 Two solutions: More stance-taking or less

In terms of the interaction between the donor and the donor's relatives, presumed consent may be thought to have an Achilles'

heel: in itself, the system does not invite conversations between people about organ donation and the situation at the deathbed, and it is doubtful whether the system takes into account the loyalty relatives will feel for the donor's express or well-known views. The relatives are placed in a greater state of doubt if the patient is an organ donor exclusively as a result of not having registered a "no" to organ donation. It is a state of doubt that can be compared with the state which the relatives have been put in under the present informed consent in cases where they are asked to take a stance because the patient himself did not register as an organ donor while alive.

There are several different ways in which it can be envisaged mending the Achilles' heel mentioned in connection with presumed consent. In 2007 the German Ethics Council proposed a model with presumed consent that will be supplemented with systematic calls by the public authorities to the citizen to actually take a stance on and register his or her views (positive or negative) with a central organ donor register. The German Ethics Council concludes that, ethically speaking, this mixture of a stance-taking system and a presumed consent system is the best way of accommodating two interests: Firstly, that a favourable disposition to donating organs after one's death is actually the best thing, ethically; but secondly, that organs from the dead body are a generous gift which ought to be something the actual individual decides to donate.

The solution model from the German Ethics Council thus attaches importance to taking a proactive and reflected stance on the part of the citizen, while presumed consent will ultimately apply to the remaining group who fail to enrol with the register despite the systematic calls on the part of the public authorities. As its premiss the solution model from the German Ethics Council takes the fact that organ donation and the situation at the deathbed are topics which it is highly desirable for society to have citizens reflect on, discuss together and adopt a position on. At the same time, the German Ethics Council legitimizes presumed consent with something more than the mere supposition that most people are actually supporters of organ donation. Indeed, they say that once the authorities have done everything to get citizens to adopt a position, presumed consent is then the most reasonable, because the choice about becoming an organ donor is, objectively and ethically, the best choice to make (regardless of the fact that there must be freedom for everyone not to make this ethically better choice, as everyone can have subjective and acceptable reasons for not wanting to make that choice). The German Ethics Council therefore attempts to marry an ideal of stance-taking with the gentle and, to their minds, justified, axiomatic pressure inherent in having presumed consent. But other contributors to the bioethical debate stress, instead, that it is most reasonable for the relatives to be exempt from adopting a position on organ donation. The idea is that presumed consent will make it more of a regular practice to allow brain-dead patients to function as organ donors. If everyone in society gets used to this being the norm, it will also be easier for the relatives to find peace in the peculiar circumstances associated with an organ donor's death process. This is based on the argument that the difficult thing for the relatives, in particular, is having to take up a position^[41]. In this way, to a greater extent than informed consent, presumed consent eliminates the decision-making burden on relatives' shoulders. They need not view themselves as vicarious decision-makers for the brain-dead person, as the public sector has already decided for them: if the deceased person has not actively said "no", the government decision that organ donation is the best thing will be the clinching factor. For the relatives, greater calm may be associated with the situation being a given and not requiring any decision of them as to what should happen. To a greater extent, then, presumed consent can be said to make organ donation a circumstance or condition within a technologically highly developed society, where a democratic community has made a normative choice that organ donation is a boon in ethical terms.

5.2 Forms of consent and self-determination

5.2.1 Presumed consent legitimized on the basis of the organ donor's views

Presumed consent is different to informed consent, because decisions to take away organs hinge on conjecture about what the brain-dead person would have wanted if he or she had had the opportunity to take a stance. But inherent in the concept of "presumed consent" is primarily the organ donor's positive approach to being an organ donor, which legitimizes the organs being removed. In that sense, removal of organs is legitimized by the organ donor's attitude and consent, regardless of the fact if this consent is explicit or merely presumed. It is an important point that presumed consent is also based on an ideal that the organ donor's attitude to donating organs is what ultimately legitimizes the possibility of taking out the organs and transplanting them to another person.

Logically speaking, though, the requirement can be restricted somewhat, to the content of the presumed consent: It may be thought that the possibility of saying "no" to being an organ donor primarily legitimizes the use of the "not no-sayers" organs in the event of their being declared brain-dead due to an illness or accident. In other words, our supposition about what the individual organ donor would have decided in the particular situation in hand is not that crucial. The crucial legitimization is thus that the person involved has had the chance to say "no". The two reasons for legitimization are connected, however; for surely, the simpler the channels for the individual citizen to say "no" to organ donation in a system with presumed consent, the more reasonable it will be to assume that the citizen actually advocates being an organ donor, unless he or she has registered a "no". It is never possible to be sure how much the individual person has reflected on the subject, how conscious the decision is, or how much the individual has involved his closest ones in conversations on the topic and in the decision. But it does seem logical that the likelihood of "genuine" donors (i.e. donors who, to some extent, have actually adopted a positive stance on organ donation) will increase in step with the level of information about presumed consent and the possibility of "deregistering" from the scheme.

In the current debate on organ donation and presumed consent, what are considered to be the potential organ donors' actual

opinions about donating organs do count. Opinion polls show greater support for organ donation than the number of people who actually adopt a position and volunteer with the organ donation registers as organ donors. It can therefore be argued that presumed consent will create a more reliable picture of what most people would actually decide in favour of, if faced with the choice. The logic is that there are two gains: for one, a larger pool of organ donors is obtained and, for another, there are more of those actually wishing to be potential organ donors who do register as such.

5.2.2 Presumed consent as a pragmatic solution

Where the current scheme of informed consent takes a “no” to organ donation as its basis, the above line of argument underscores the fact that a popular, tacit “yes” via the legislation can be said to express a genuine attitude on the part of those citizens who do not register their opposition to donating organs. Here presumed consent is seen as being compatible with an ideal that organ donation takes place against a backdrop of an actual stance adopted by the organ donor. Part of the line of thought is that the decision to remove organs from the brain-dead person derives its legitimacy, in the final analysis, from the fact that the organ donor “would agree” that the intervention should be performed.

All things being equal, however, presumed consent is likely to give rise to less personal stance-taking than informed consent, except on the part of those who have already made their minds up and have deep-seated objections to ending up acting as organ donors. Inherent in the logic of presumed consent is the fact that the individual can avoid confronting the topic and at the same time preserve the feeling that there is still no “need” to take a stance on a personal level and in dialogue with one’s relatives. And anyway, the matter is already done and dusted, since all citizens are automatically organ donors, and that is the status a person will have regardless of how much or how little they actually think about the matter and talk to their nearest and dearest about it. This is unsatisfactory for those with a very vigorous requirement that a “yes” to organ donation has to be something reflective of citizens’ personal decision and attitude.

But it is also possible to argue in favour of presumed consent on the basis of a less demanding ideal about attitude shaping and self-determination. It may be thought that self-determination consists exclusively of permitting citizens to opt out of the scheme at any time. But here self-determination is exclusively a formal safeguard to ensure that no one, legally speaking, is forced to be an organ donor in the event of brain death. Such argumentation does not weight personal stance-taking and attitude shaping particularly highly.

Presumed consent can be linked to this less demanding ideal of self-determination, and ethical legitimization of such can draw on two different arguments:

Presumed consent, firstly, can be supported with a line of argument that is less dependent on whether presumed consent can be said to reduce the organ shortage on a balance of probabilities. It may be thought that presumed consent is a better solution for regulating organ donation than informed consent, irrespective of whether the scheme leads to more organ donations. Arguments in favour of this can be that organ donation is basically regarded as a self-evident value-based preference, which is the norm, while opposition to being an organ donor is regarded as an acceptable exception. Based on this logic it can be considered reasonable that those who do not wish to act as organ donors should be the ones to actively deregister. Willingness to be an organ donor can be seen as something that is part of our present cultural background and therefore follows on from the common perception of the body’s status after the onset of death—a perception that is both straightforward and taken for granted: i.e. that after death the body decays, and the dead person himself cannot have any interest in whether the organs perish together with the rest of the corpse or whether they are transplanted to a living person’s body. Furthermore, this normative preference may arguably be said to be so fundamental to a modern society that it is not something the individual needs to take an explicit stance on.

Secondly, it may be thought that self-determination in the form of stance-taking and personal attitude shaping is a benefit worth aspiring to, while more formal self-determination in the form of freedom from coercion is an immutable requirement of any democratic organ donation scheme. On that basis it can be argued that it is quite possible to relax the requirements that consent should rest on stance-taking and attitude shaping, when what is actually at stake is regard for sick people on a waiting list. It is worth remarking that the validity of such a justification for presumed consent depends on factual matters, to wit the question of whether presumed consent contributes to remedying the lack of organs, based on experience, because the argument goes that regard for a benefit, i.e. more treatment of illness with organ donation, in this case weighs more heavily than regard for another accepted benefit, namely self-determination in the form of personal stance-taking.

5.2.3 Should people basically be organ donors?

In the ethical debate on organ donation, the discussion is whether presumed and informed consent are uniform agreements with the populace, in the sense that one agreement does not presuppose more than the other. Quite intuitively, many will certainly feel that presumed consent presupposes something (that one is an organ donor until “proven to the contrary”), whereas informed consent is attitudinally neutral and does not presuppose a particular outcome prior to the individual’s decision. But some claim that on closer inspection this view is wrong, because informed consent presupposes just as much as presumed consent; for informed consent presupposes that we are not organ donors. Informed and presumed consent are thus agreements of the same kind that merely radiate from two opposing assumptions: informed consent basically assumes that citizens are not organ donors and thus places the “no-sayers” in an advantageous situation because they need not take any

additional action in order to have their wishes fulfilled; presumed consent assumes as a starting point that citizens are organ donors and thus makes it easier for those who wish to donate organs because they need take no further action in order to be potential organ donors.

Irrespective of whether or not presumed and informed consent are uniform agreements, it can be noted that the decision-making onus with informed consent rests with those who would like to donate their organs, while the reverse is the case with presumed consent: Here the decision-making burden lies with those who do not want to donate their organs.

But when it comes to making an ethical comparison of the two schemes with regard to their respective position on values like self-determination and stance-taking, it is not the groups actually registering as organ donors or non-organ donors which it is most important to look at. On the contrary, it is the schemes' different way of accommodating two other groups that is most interesting for ethical analysis. One group are the yes and no-sayers that do not declare their stance. The other group is those who are in doubt whether they want to be organ donors.

Apart from the two groups mentioned, the organ recipients—i.e. people with severe injuries or chronic diseases—are an altogether central group to embrace in the ethical deliberations, of course. But this group will not be treated independently below, because the regard for life and a better life for this group of people is the actual point of departure for even discussing whether presumed consent can be introduced with the purpose of better accommodating the need for healthy organs. In one pan of the scales is regard for this group of people, while in the other pan regard for citizens' scope for self-determination and stance-taking on organ donation has to be placed. It is also important that—given medical-technological standards and the individual's rights in the Danish health services—every single person in present-day Denmark is at once a citizen with the possibility of becoming an organ donor, in principle, and is a citizen who can end up in a situation where receiving an organ from another citizen can save that person's life or considerably increase her or his quality of life.

5.2.4 When “yes” or “no” are not registered

Under the current scheme of informed consent there will be a group of people who actually wish to be organ donors, but merely fail to join the register and thus be included in the pool of potential organ donors. For the sake of simplicity this group can be called “false no-sayers”, as they will be treated by the system as people from whom organs cannot be taken, whereas they actually did wish to be organ donors while alive.

Conversely, under presumed consent there will be a group of people who will be thought of and dealt with as organ donors because they have failed to disclose their resistance to such. This group can be called “false yes-sayers”, since they will be thought of by the system as organ donors, whereas they actually did not wish to be organ donors even while alive.

Having two groups of “false no-sayers” under informed consent and “false yes-sayers” under presumed consent cannot be avoided, as it is scarcely practicable to have an information and registration system in which all citizens have taken a stance. However, if the opinion polls concerning organ donation are to be relied upon, the group of “false yes-sayers” under presumed consent will be rather smaller than the group of “false no-sayers” under informed consent. That is the only inference possible from the fact that 86% of the population takes a positive view of organ donation, while only 7% of the population do not wish to be organ donors. Any ethical deliberation must ask to what extent it is most acceptable to live with a relatively large group of “false no-sayers” or a relatively small group of “false yes-sayers”.

One parameter in assessing this depends on how great a value is ascribed to the fact that people who are alive must be able to have a feeling of certainty about influencing what happens to their body after death. If this is ascribed relatively great value, there will be grounds for misgivings about having even small groups of “false yes-sayers”, i.e. people who suffer brain death and become organ donors against their will.

The certain feeling of having an influence over what happens to the body after death is a value that can be important to the individual, irrespective of whether or not the individual has religious convictions about life carrying on after death. The value of having influence over interventions on one's own body after death is about a person, while alive, being able to preserve the feeling of being a person who has a right to bodily integrity or, in a popular sense, “owning” his or her own body.

Nevertheless, it may be thought more acceptable to live with a number of people becoming organ donors against their will than to live with relatively more people ultimately failing to act as potential organ donors, although they would like to. This may be because the regard for giving organ recipients a better quality of life, and in some cases saving their life, is weighted higher than the regard for the citizens' intact impression that the body belongs to themselves.

5.2.5 The doubters

What is the plight of those people who are in doubt whether they want to be organ donors—under presumed and informed consent, respectively—and is it reasonable or unreasonable, ethically speaking, that an organ donation system should concede space for legitimizing doubt?

It seems obvious that doubters or people who are simply reticent about deciding on organ donation are best off under the present scheme of informed consent. Hence, it can also be said that informed consent, to a greater extent than presumed

consent, creates a legitimate basis for indecisiveness or non-decision. Informed consent entails people not being organ donors as a point of departure. Therefore, doubt or the lack of inclination or volition to make a decision has no consequences, not even if the public authorities encourage citizens to take a stance at regular intervals, say. Under presumed consent the consequence of doubt or reluctance to take a decision, on the other hand, is that a person will de facto be viewed as an organ donor.

Doubt or lack of willingness to confront oneself about taking a stance on the subject, you might say, is conceded space under informed consent, whereas in reality these human approaches to the problem of organ donation are disallowed in a system with presumed consent. The question, then, is what is to be preferred, ethically? The answer will depend on the degree to which organ donation is felt, by the community, to be a matter on which each individual citizen can be expected to take a stance and thus, at some point, relinquish their doubts. However, it can be argued that presumed consent also supports the possibility of refraining from taking a view on the topic. But then, as an “unconcerned” person, one merely has to be prepared to recognize that one of the implied consequences of death in modern society is potential organ donation in the event of brain death.

5.3 Organ donation as a value-based preference

5.3.1 Organ donation as a matter of course?

Self-determination as a principle plays a part in the way presumed consent is legitimized. Presumed consent is portrayed as a pragmatic solution to a serious medical resource shortage that costs sick people on waiting lists their lives. At the same time, importance is attached to opinion polls, which are used to document that presumed consent will be more in keeping with the wishes of the majority than the present scheme, which requires active registration to become an organ donor. That is to say that presumed consent is thought to be actual consent, because most people would probably choose to be organ donors if faced with the choice.

As mentioned previously, surveys show that relatives find it considerably easier to decide in favour of organ donation if they know the deceased's views. That in itself shows that for most people it is a fairly firmly rooted notion that having influence over what happens to our body after death is meaningful and that the deceased's views while alive are entitled to a form of respect. In one survey of relatives' experiences of organ donation, a relative says that it was good to get a letter of thanks from the hospital that had transplanted the organ to the recipient.^[42] For the relative, it was an acknowledgement that organ donation is not a “matter of course”, as he puts it.

But it can actually be argued that organ donation should be more of a matter of course than it is under informed consent. Some people in the bioethical debate advocate organ donation not being voluntary at all in actual fact. Instead, the public authorities ought to be able to dispose willy-nilly over organs from the brain-dead for use in patients with a serious need for healthy organs. This attitude is often based on a criticism of our conception that we own our body and can determine what should happen to it after death. Advocates of compulsory organ donation will say, instead, that when alive, we as living people are so closely connected to our bodies that we have a very vital interest in ensuring that our bodies are not damaged or injured: damage to the body is damage to the person. This circumstance alters radically when the person passes away. Then the deceased no longer has any interest in what happens to the body. The deceased is not the one who can sustain injury from intervention on the dead body – on the contrary, only for those who are still alive, particularly the next-of-kin, is the deceased body indissolubly linked with the person who was alive a short while ago. But embracing this philosophy, regard for the relatives cannot include the relatives being allowed to be deputy decision-makers, since regard for improving and saving others' life without injury to the deceased is the decisive factor. Under compulsory organ donation regard for the relatives can consist solely of information, solicitous contact and respectful treatment of the dying person and dead patient.

Presumed consent is not compulsory organ donation. But since presumed consent is all about the public authorities having defined the citizen as an organ donor beforehand, perhaps the scheme does share a basic value set with compulsory organ donation to a greater extent than informed consent. This should be understood in the sense that presumed consent is more indicative that the community has decided that being an organ donor is a benefit worth aspiring to and striving for, in ethical terms, and something which, all things being equal, citizens must be expected to contribute to. Although, ultimately, it is attempted to legitimize presumed consent on the basis of the organ donor's self-determination, it may be more honest to say that presumed consent, more so than informed consent, allows regard for treatment of severely ill people to trump regard for the organ donor's self-determination and stance-taking. This is due to the fact that the actual term “presumed consent” turns on a rather flimsy concept of stance-taking. The question, then, is to what extent it makes sense to talk about “consent” when a brain-dead patient becomes an organ donor because he has not registered a “no” to organ donation.

At any rate, there are three reasons why talking about “consent” in that situation can be misleading. Firstly, it is unsure whether it is possible to more or less “guess” with certainty that everyone who says “yes” in opinion polls would actually volunteer as organ donors too, if they genuinely had to take a stance. For example, there are presumably a number who are split down the middle but who, owing to the political correctness of answering “yes”, register as potential organ donors in opinion polls, where their view is not binding. Secondly, to a far greater extent than with informed consent, the level of information about the possibility of saying no will be crucial to the extent to which it is possible to bank on a specific organ donor actually having taken a stance and having implicitly “consented” to being an organ donor. Thirdly, it may be thought that the possibility of saying no, even under the best possible conditions and with the best possible level of information, cannot be said to be enough

to constitute consent.

One may well agree that “consent” is a misleading term, and at the same time be an adherent of the scheme for which presumed consent is a name. That would only require admitting that self-determination in the form of the organ donor’s stance is a value that is trumped, in part, by regard for the severely ill. Anyone who agrees with this can more appropriately call presumed consent an opt-out scheme that is also in keeping with one of several international designations: an “opt-out” model. Because those that have deregistered can be said with certainty to have made a choice. Thus—accepting the above misgivings—it must honestly be said that there is no way of knowing whether the rest have made a choice. The reasonableness of taking organs from people who have not said no under a presumed consent scheme thus builds not on their presumed view, but on three other premises: They have, firstly, had the opportunity to say no; secondly, the deceased is not harmed by taking organs that would perish anyway; and thirdly, the organs are a vital resource for severely ill people.

5.3.2 Organ donation as part of citizens’ communality of shared values?

Organ donation is a modern technology. The new technology creates possibilities of vital interest for those of our fellow human beings who, owing to illness or accident, are in a highly undesirable situation. The new possibilities are becoming part and parcel of the therapeutic standard being implemented in the health services, to which citizens have a certain right of access if made relevant by their health situation. The new technologically engendered possibilities, therefore, also create new obligations and hence ethical dilemmas that were not relevant before the technology was introduced.

In the case of organ donation the development of medicine to inhibit the body’s rejection of foreign organs, among other things, has led to organs from deceased people turning into a relevant resource for other living people. It is the development of this medicine that results in our even grasping the meaning of a concept like “organ shortage”. Of course, for hundreds of years, the deceased body has been a resource for the furtherance of anatomy, biology and medical science; but with organ donation the beneficial effect becomes far more tangible, in that a concrete living person can benefit hugely from having the organ implanted into his or her body. And this is only feasible if other people agree to their organs being used to this end in the event of their being befallen by brain death.

It is only reasonable, therefore, to ask whether medical advances have added urgency to making organ donation a relevant part of the reciprocal moral relations that define our very communality in a modern welfare society such as the Danish one. Presumed consent is a more powerful signal that organ donation is actually a communal and very pressing matter. As an opt-out model, presumed consent can be said to provide less free scope for doubters or those who simply do not find it reasonable, as a person, to have to take a stance on something of the nature of organ donation. These people are given some latitude, albeit narrow, because their persistent doubt or unwillingness to take a stance will ultimately be interpreted as a “yes” to organ donation—and their doubt or unwillingness will therefore be disallowed in a sense. If organ transplants for needy people are thought to be a sufficiently weighty consideration to justify the state using an opt-out model to implicitly make propaganda in aid of organ donation, then there is good reason to advocate an opt-out model. Particularly based on the more powerful signal inherent in the model, this may even be considered preferable, purely from a principled point of view, despite not perhaps resulting de facto in more, accessible organs from the brain-dead. Voluntariness is not always a given where participation in societal benefits is concerned. There are examples of participation being compulsory in activities deemed useful by the community: this applies, for instance, to schooling and compulsory military service.

Conversely, preference must be given to informed consent if relatively more weight is placed on organ donation having to be a personal decision, and if great value is ascribed to the fact that the organ donor is gifting his or her organ on the basis of well-considered altruism, not pressure from society’s value standards. Furthermore, the desire behind embracing this point of view may be to cherish the fact that every citizen should feel welcome to form his or her own views and outlook concerning life and death without the consequence of invoking disapproval on the part of society.

[37] Alberto et al., 2006.

[38] Haddow, 2005.

[39] Haddow, 2005, p. 14.

[40] Farsides, 2000.

[41] Inter alia, Farsides, 2000, p. 4.

[42] Bøgh, 2006, p. 26.

Chapter 6 The Danish Council of Ethics' recommendations on organ donation

In the Council of Ethics' opinion the inadequate supply of organs available compared to those needed for transplantation poses a considerable challenge which severely ill people have to live with each and every day. In some cases organ donation is life saving, and in others, for example kidney patients on dialysis, organ donation brings with it a major improvement to the patients' living conditions and scope for self-development.

Technological development has led to the transplantation of healthy organs from brain-dead people to people in need of a new kidney, a new heart, a new lung or a new liver having become standard treatment in the health services. It is understandable, therefore, if citizens expect this treatment to be made available as widely as possible as and where the treatment is relevant. Although this expectation only makes sense against a backdrop of relatively new medical technology, it rests on fundamental basic values in society, which have to do with caring for our fellow humans' lives.

The problem with the paucity of organs should therefore be resolved to whatever extent it is resolvable without riding roughshod over other weighty considerations on the way to the solution. The problem with organ donation consists of the often direct dependency between the recipient's need for organs and another person's death. The difficulty with organ donation, moreover, is that some view needs to be taken on what represents respectful treatment of the dead person's body. It is a basic principle of a civilized society that a person's dead body be treated with respect. This respect reflects the concept of dignity that surrounds humankind in all its affairs. Knowing that one's own body will be treated with respect, also after death, provides a sense of security and comfort.

The weighting of the various considerations is important to the kind of organ donation regulation that can be advocated, logically speaking. In addition, this balanced deliberation is relevant to the way in which it will be considered reasonable to inform the population and compile information about organ donation.

Below, recommendations from the Council concerning the relatives' situation at the deathbed will be presented first. The Council will then present recommendations as to which consent rules should apply to organ donation, and recommendations on whether or not it should be a duty to take a stance on organ donation. Finally, the Council presents different approaches-in-principle to the question of the intended purpose of information about organ donation.

6.1 Recommendations on the relatives' situation at the deathbed

It is important for the health services and society to take in hand the relatives' difficult situation at the deathbed, both for the sake of the relatives themselves and for the sake of accommodating, as far as possible, the need for more organs. There is something to suggest that more relatives will agree to organ donation if it is possible to feel more comfortable about the highly dramatic situation that being the relative of a brain-dead person is, with the doctors asking whether organs can be taken from the brain-dead person.

Firstly, then, there is substantial consideration for the relatives themselves and their feelings in a situation which, for the vast majority of people, will assume the nature of an existential crisis—as it will be when a closely-related person is suddenly dead while the relatives are simultaneously confronted with the possibility that something is going to be done with the deceased's body that is not common practice in connection with the generally familiar norms for the procedure surrounding death and burial. At the same time as grief, doubt can arise on the part of the relatives as to which acts can be reconciled with dignified treatment of the deceased. What is more, the brain-dead person, in an immediately sensory and experience-based perspective, is located somewhere between life and death: the brain-dead person is breathing, the colour of the skin is unchanged and the body is warm.

The Danish Council of Ethics finds it crucially important to take this experiential perspective as the starting point when a healthcare professional or general planner faces having to decide how to configure care for the relatives and the framework around it.

6.1.1 There should be a ritual framework for organ donation

All members of the Danish Council of Ethics recommend implementing measures to promote a great degree of security, respect and dignity in the very difficult situation in which the relatives find themselves. A Danish study into the relatives' situation summarizes this challenge by calling it a "meaningful burden". The Council of Ethics feels it will be useful to create different frameworks around the process, intended precisely to support an experience of the situation as a meaningful burden that does not fling the relatives headlong into emotional chaos. These may well be frameworks that have the nature of ritual. The Council of Ethics recommends that a great effort be made by the authorities to develop and disseminate the practice and ritual-like



initiatives that already exist as local initiatives at different hospitals in Denmark. This might be, for example:

- More distinct ritual marking of the time of death
- Many relatives—in the midst of their grieving—have a surprising ability to empathize and a form of sympathy for the potential recipient and his or her relatives. This can be backed up by a letter of thanks from the hospital, information about the “fate” of the organs or by the person officiating at the funeral service offering to mention the organ donation in their speech. This can be a ritual of transition, which with time can create a framework for relatives perceiving themselves as “co-donors” of something that is not taken as read.
- There should be great professionalism and compassion in the information provided and in the conversation with the relatives during which they are asked to consider organ donation.

Line of argument

In the case of organ donation, at any rate, there are two central emotional challenges for the relatives:

Firstly, the process from brain death to the removal of organs is perceived as being muddled and protracted. The medical examination used to ascertain brain death is the basis for declaring the person dead. There is no doubt that, after this point, the person has no chance of coming back to life. Nevertheless, there are many special factors involved in the process, more reminiscent of providing care and holding a vigil for a dying person, and this can be conveyed to the relatives’ (and possibly also the attending staff’s) experience of the situation. The health-care staff initiate different treatments normally associated with treating a living person, but carried out here because the organs need to be kept healthy. In addition, the brain-dead person is warm, breathing and thus more reminiscent of a living or dying person – not an entirely dead one. Finally, the process contains several different stages at which some form of leave-taking can be relevant, most obviously perhaps when the brain-dead person is trolleyed into the operating room; but it might also be when the brain death diagnosis has been made, when the decision about organ donation is made or when the dead person returns from the operating room and the ordinary burial ceremony can get under way.

Secondly, the relatives are confronted with a situation where customary notions of death are brought into play and put to the test. Culturally speaking, the relatives are accustomed to viewing death as something definitive and the dead body as something exclusively of great emotional significance to those who are still alive and have known the deceased. In that regard the dead body is simply identical with the person, who is just no longer alive. When they now have to take a stance on and, in many situations, decide in favour of organ donation, they find themselves plunged into a basically different way of looking at the dead body: Parts of the deceased’s body can improve or maybe even save a life for other people, who within a very short space of time can possibly have a healthy organ transplanted as a result of the relatives agreeing to the organ donation. An obvious idea of beneficence blends into this existentially uncertain situation with an unaccustomed view of the deceased’s body, which cannot be viewed exclusively as a whole entity now, but also offers itself up as a tangible object that contains resources in the form of healthy organs that may be of vital importance to other people.

6.1.2 Changes in organ donation guidelines need to be discussed in the context of correcting former practice

The Danish Council of Ethics’ members think that discussing the change in consent rules associated with organ donation should necessarily be accompanied by discussion of the lack of popular appreciation and acceptance of the brain death criterion and, not least, the conditions of death to which this criterion can give rise. Eighteen years after the brain death criterion was embodied in law, there is still great confusion as to what it basically entails. The hope of a meaningful and dignified leave-taking between a dying person and his or her relatives has existential significance for many Danes. And it is precisely the conflict between this hope and the consequences of the brain death criterion which explains why so many people display reluctance when asked for their consent for donation.

The Council recommends that Danish Parliament take the initiative to scrutinize the problems surrounding the death criteria and leave-taking rituals, and to come up with proposals for changing practice at the country’s hospitals and transplant centres.

For instance, consideration should be given to the possibility of altering the death criterion so as to make it more comprehensible to the general public without complicating organ donation and transplantation in legal terms in the process. Equally important is to think through and discuss with different groups how new leave-taking rituals for organ donors can be implemented with broad-based popular backing. The Council is launching these initiatives partly on the basis of the deliberations and recommendations which it already published in the report on the brain death criterion in 1988 (see p. 54).

6.2 Recommendations on forms of consent for organ donation

6.2.1 Changes in consent rules for organ donation need to be discussed after correcting former practice

A member of the Danish Council of Ethics (Klavs Birkholm) thinks it makes no sense to take a stance on the change in consent rules before the investigation referred to in 6.1.2 into the conflicts between the brain death criterion and the experience of leave-taking has been conducted—and measures to alter practice have been implemented.

6.2.2 Informed consent for organ donation should be retained

A majority (9) of the Council of Ethics' members (Jon Andersen, Birte Boelt, Niels Jørgen Cappelørn, Elisabeth Dons Christensen, Lotte Hvas, Peder Mouritzen, Birthe Skaarup, Karin Verland and Peter Øhrstrøm) think that the present regulation of organ donation should be retained. Thus explicit consent should still be available from the deceased or from the person's relatives if organ donation is to be able to be conducted. As a working basis, the deceased's wishes must be adhered to, but in practice it should still be the case that organ donation is not performed if the relatives actively oppose such organ donation in cases where the deceased wished to be an organ donor.

Line of argument

The members mentioned think that transplanting organs must entail supreme willingness on the part of others to donate organs. It is important to cherish citizens' certainty that they have the freedom to dispose over their own bodies and the freedom to make up their own minds what topics they want to include in their private deliberations about their outlook on life and the role of death in their view of life.

Actively taking a position on organ donation is altogether central. The value of active stance-taking can be measured by comparing it with a model proposed by some bioethical debaters, the gist of which is that there is simply no choice: all citizens are potential organ donors. Such disregard for the individual's right to decide whether he or she wants to be an organ donor would be seriously damaging to people's feeling of "owning" their own body and, more particularly, to their freedom to hold certain outlooks on life, which have consequences in terms of the actions to which people can reconcile themselves. In practice the value of active stance-taking manifests itself clearly in those situations where it is up to the relatives to decide whether or not organ donation is to be performed. Studies show that relatives find it easiest to take the decision if they know the deceased's views, or if they know his/her view of life so well that they feel they know what the deceased's attitude to organ donation would have been. This, according to the members, shows that there is a very clear connection, not least for the relatives, between on the one hand the deceased person, his/her philosophy of life and his/her wishes, and on the other hand the legitimacy of undertaking organ donation.

Furthermore, informed consent caters best for the doubters and those who do not wish to be organ donors. The members mentioned think the public authorities should base their actions on the fact that people have doubts, and respect that they can have good reason to be in two minds. The most correct thing, therefore, ethically speaking, is for organ donation to require informed consent.

Informed consent should also be retained out of consideration for the relatives' situation at the deathbed. In accordance with the views of the members mentioned, informed consent is the regulation that best supports active stance-taking and hence creates a likelihood that people who are close to one another will talk to one another about organ donation well ahead of time. For the relatives, knowing what the deceased thought about organ donation when alive makes a vital difference.

For individuals to be able to forge their own philosophy of life with themselves and their nearest and dearest is a great asset. In the view of the members mentioned this asset is so central and inexorable that even to begin with it is warped to weigh up this asset against regard for helping severely ill people. This is also due to the fact that, as a result of presumed consent, citizens will have their identity as registered organ donors 'frozen' unless they themselves actively do something to opt out.

The members cited think these signals are fundamentally wrong ones to send in a liberal democracy, where conditions for attitudinal pluralism and influence over one's own body should be maximized. The members mentioned therefore feel that organ donation should be regarded as a treatment for which the optimum availability of organs is identical to that brought about by having citizens in society decide voluntarily and of their own accord that they want to be organ donors.

6.2.3 Presumed consent should be introduced for organ donation

A minority (7) of the Danish Council of Ethics' members (Peder Agger, Gunna Christiansen, Thomas G. Jensen, Lene Jensen, Rikke Bagger Jørgensen, Morten Kvist and Elsebeth Gerner Nielsen) think an opt-out scheme or so-called "presumed consent" should be introduced for organ donation in Denmark. At the moment, when an organ is to be harvested from a brain-dead person, it is a condition that the person him/herself has granted explicit consent while alive, or that the relatives of the brain-dead person agree to organ donation being performed. The Council members mentioned feel that in future it should be the case that organs can be harvested from the brain-dead person for use in organ donation unless the person said no, when alive, to acting as an organ donor. Anyone must be able to register his or her opt-out in a central register as with the current register for organ donors. But this would simply involve registering people who have opted out of being organ donors. Furthermore, the system must respect any opt-out communicated to the relatives by exclusively verbal means.

Formally speaking, the deceased's omission to say no to organ donation should be interpreted by the system to mean that the deceased, when alive, wished to act as an organ donor. The relatives should not be faced with a choice, but they should be told delicately and in depth that the brain-dead person is now an organ donor. Practice, however, should still be that no doctor forcefully imposes the removal of organs from a brain-dead person if the relatives actively signify their aversion to this.

Line of argument

The members cited advocate presumed consent because, at bottom, organ donation is regarded as a preference of values that is taken for granted, and because this scheme is expected to be able to result in a greater number of people who are potentially organ donors. The members consider it likely that in practice this will lead to more of those who are declared brain-dead every year actually ending up acting as organ donors. Whether it pans out that way, however, depends on the relatives' reaction to the information that the deceased did not say "no" to being an organ donor and that it is therefore permissible for the doctors to remove organs for use in transplantation. This is due to the following:

With an opt-out scheme the public community is signalling that it is basically fair to assume that citizens are happy to donate their organs. But in practice, apart from this change in signal value, the proposed opt-out model will primarily have the effect of some relatives, who would previously have been presented with a choice, now being presented instead with information that, under the rules, the deceased is an organ donor. Under the present regulations, studies show that approximately half the relatives say no in those cases where the deceased did not sign up to the register for organ donors while alive. The gain will be limited if the same proportion of relatives in a presumed-consent situation are going to react by opposing the performance of organ donation. However, the members mentioned think there is good reason to assume that this is not going to be the case: for many relatives, not being placed in a situation where they have to make that choice, as they are now, will be a relief in the midst of their grief. Psychologically, as a relative, having to come to terms with the peculiar circumstances associated with brain death and organ donation is a substantially different situation to being simultaneously confronted with a choice. What is more, it presumably takes a more definite line of resistance to organ donation to oppose a legitimate organ donation rather than the parallel situation, where the relatives are the ones given the task of taking the decision on behalf of the deceased.

Presumed consent, then, is also an advantage for the relatives, who are relieved of the duty of reaching a difficult choice in a situation already characterized by shock and sorrow. In so doing, they themselves, as well as the health-care staff around them, can concentrate their resources on crafting the special circumstances at the deathbed and organ removal into a carefully considerate and comforting situation, in which the relatives are given a fine setting for saying goodbye to their loved one. Other than this, as stated, the main point is that the opt-out or presumed consent scheme is an advantage for those who have a vital need for healthy organs.

For the members mentioned the rationale for introducing an opt-out scheme is first and foremost a pragmatic solution with the intention of achieving a better situation for the severely ill people who have to wait every day to receive a healthy organ. But in addition to that, the members mentioned feel that an opt-out scheme is a better solution ethically than current regulation of organ donation – not only because of the foreseeably higher number of organ donors, but also because an opt-out or presumed consent scheme encapsulates a desirable signal value that becoming an organ donor is an ethical benefit and an ethical norm in our society.

There are several reasons why that signal value is desirable and in itself makes the opt-out scheme preferable, ethically, to other forms of regulation: Firstly, making organ donation into a natural or relatively matter-of-fact event within the citizen's collective horizon of values is an ethical benefit. An opt-out scheme is standard-setting: it will help accustom citizens to the idea that organs from the deceased body are in some cases of immense value to particular other people suffering from severe diseases, and that issues relating to the deceased's body are not, therefore, unambivalently each individual's "own business". It is perfectly fitting for society as a normative community to signal that organ donation is an ethical benefit on which everyone can be expected to take a position. It is a signal that the choice to become an organ donor is an unequivocally good choice, ethically speaking. At the same time, though, the scheme respects the fact that anyone may have their reasons for not being able to make this choice, in which case it is possible to opt out of the scheme without losing anything, either in the form of rights or respect.

The members mentioned think that the opt-out scheme thus accommodates attitudinal pluralism to a reasonable extent—after all, those who are dead set against becoming organ donors can say "no", without further ado. Conversely, the opt-out scheme places certain pressure on those who are in two minds and cannot take that leap to resolve themselves either in favour of or against organ donation. Here the community is signalling to the individual that such doubt (or just the failure to take up a position) has the same outcome as an undertaking, thereby benefiting those in need of a healthy organ.

6.3 Recommendations regarding compulsory stance-taking

6.3.1 Compulsory stance-taking on organ donation should be introduced

A majority (10) of the Danish Council of Ethics' members (Peder Agger, Niels Jørgen Cappelørn, Gunna Christiansen, Thomas G. Jensen, Lene Jensen, Rikke Bagger Jørgensen, Peder Mouritzen, Elsebeth Gerner Nielsen, Birthe Skaarup and Karin Verland) think that organ donation should be regulated so that in future all citizens are required to take a stance on whether or not they want to be organ donors.

When sending out health cards, the authorities send out an information folder on organ donation, encouraging citizens to take a stance and inform their relatives of their decision.

But previously there has been no out-and-out requirement in the legislation that every citizen should take a stance on organ

donation. The members mentioned think that such a requirement should be expressed in the legislation in future, but on condition that such a requirement must not be encumbered by any form of sanction if it is not honoured. The members mentioned are of the opinion that it is both reasonable and desirable for all citizens to be made directly aware, to a greater extent than is currently done, that taking a stance on organ donation is something which is expected of them.

In the legislation, however, it is important to promote practice that allows for the fact that the organ donation decision is not perceived as something done under unreasonable pressure. Furthermore, it is important to make it clear to everyone that citizens can reverse their decision at any time in the event of a change of heart.

In June 2008 the Danish Parliament adopted a draft resolution urging the government to “introduce a standard whereby all people who have turned 18 and are of age are asked to state their personal standpoint as regards the question of organ donation” (see page 72). In the motion the MPs suggest that, in practice, this can be done when the person who has turned 18 wants to get or renew a driving licence, when he or she attends the GP, or when he or she is due for a (new) passport. The members mentioned by the Council of Ethics consider these proposals to be good, fundamentally.

The argument in favour of compulsory stance-taking

The members mentioned by the Council of Ethics advocate compulsory stance-taking on organ donation because organ donation is an important social issue that all citizens should take a stance on. Organ donation is an essential and vital benefit, and all citizens can find themselves in a situation where the transplantation of a healthy organ will mean the difference between life and death for that person or between good and poor quality of life. For this reason among others, it is important to display solidarity in connection with organ donation, and based on an expectation that the vast majority of members of Danish society acknowledge that organ donation is an essentially collective affair, the members mentioned think that such solidarity can be promoted by directly encouraging citizens to take a stance.

Conversely, the members mentioned are of the clear opinion that it is crucially reassuring for citizens to know that they have influence over what will happen to their body after death, and that it is thus an essential value that should be cherished. That means that everyone should be entirely free to say no to organ donation without it having any consequences at all for them.

The members mentioned think that compulsory stance-taking will contribute to more people getting around to talking to their nearest and dearest about organ donation in good time as well as getting around to taking a stance. This in itself is an additional reason to introduce compulsory stance-taking, partly because, as repeatedly mentioned in this report, it is known that relatives find it easier to make a decision about organ donation if they know the deceased’s attitude.

6.3.2 Compulsory stance-taking should not be introduced

A minority (7) of the Council of Ethics’ members (Jon Andersen, Klavs Birkholm, Birte Boelt, Elisabeth Dons Christensen, Lotte Hvas, Morten Kvist and Peter Øhrstrøm) do not think compulsory stance-taking on organ donation should be introduced.

The argument against compulsory stance-taking

The members mentioned are against the introduction of compulsory stance-taking as described in 6.3.1. For the individual, taking a stance can be important, but this stance-taking should not be made compulsory and assume the nature of a duty because it is important that public authorities should not exert too much pressure in terms of demanding a stance from individual people; because that may result in the individual feeling obligated to consider and take a position on life-and-death topics and values which the person in question would otherwise have had greater freedom to doubt and relegate to the realm of the uncertain or the undecided.

Furthermore, the members mentioned feel that the introduction of compulsory stance-taking can lead to people ending up taking a stance on organ donation too quickly and too superficially. It is important that any decision about organ donation be taken on the basis of a conversation with one’s nearest and dearest at a time when people are prepared and have the necessary time to talk about organ donation. The members mentioned think that a requirement by the public authorities to take a stance—e.g. when issuing driving licences – can result in the decision being rushed and in people largely skipping the all-important conversation with their next-of-kin.

6.4 Recommendations on organ donation information and campaigns

Public information to citizens about organ donation is a necessary tool if organ transplantation is to function satisfactorily as a therapy in the health services. That applies regardless of the form of organ donation regulation advocated. The lowest common denominator for all the schemes – informed consent, presumed consent and compulsory stance-taking – is to require a minimum of knowledge about what organ donation is and the ways in which, as a citizen, one can register as an organ donor.

All members of the Danish Council of Ethics acknowledge that information about organ donation from the government and the central authorities is indispensable. But there are essential ethical deliberations associated with the question as to the objective and hence also the scope and style of communication such information should have. Below, the Council of Ethics’ members set out their different views.

6.4.1 Public information should inform the citizen without encouraging stance-taking

A minority (7) of the Council of Ethics' members (Jon Andersen, Klavs Birkholm, Birte Boelt, Elisabeth Dons Christensen, Lotte Hvas, Morten Kvist and Peter Øhrstrøm) do not think information from public authorities should signal an expectation on the part of society that the individual should take a stance on organ donation. Information on organ donation, on the other hand, should exclusively be a basis for the individual citizen's informed consent in choosing whether or not they wish to be an organ donor. The members do not think the authorities should disseminate information with a particular outcome in prospect. That applies irrespective of whether the intent is to get many to adopt a position or whether the intent is to get many to say "yes". The members mentioned think that taking a stance on organ donation involves very private deliberations on one's personal philosophy of life. By staging campaigns that encourage people to take a stance, the authorities are communicating that the individual citizen's reflections on views of life are key to the number of organs available for organ transplantation. The authorities are further deciding for the citizen that he or she should actually consider his or her approach to organ donation.

In so doing, people are already placed within a commodified context, where there is basically a "demand for parts of the citizen's body", although the citizen has not decided whether the exchange of organs is even a topic that should be included in his or her personal deliberations on life and death. Information campaigns on the topic as such should not be conducted, but it should be the case that objectively descriptive information is available on the subject when the citizen does get in touch to register whatever decision he or she may have made, if ever. It is that type of information that already exists in the form of folders, donor cards and websites like www.sundhed.dk ^[43], where it is possible to register as an organ donor. The information is intended to form the basis for informed consent on a par with other types of information in the health services, for example concerning involvement in medical trials and suchlike.

Some of the members mentioned (Klavs Birkholm, Lotte Hvas and Morten Kvist) think many of the information campaigns to date may be felt to have been conducted with a view to convincing people to say "yes" to organ donation, even if they have been formally "neutral". So it is not enough to decide whether the purpose of a campaign is to be neutral or recommendatory; an essential part is bound up in the style of communication.

6.4.2 Public information should encourage stance-taking

A majority (9) of the Council's members (Peder Agger, Niels Jørgen Cappelørn, Gunna Christiansen, Lene Jensen, Rikke Bagger Jørgensen, Peder Mouritzen, Elsebeth Gerner Nielsen, Birthe Skaarup and Karin Verland) think society is duty-bound to stimulate debate and encourage taking a stance on organ donation on an informed basis. The members mentioned think that part of a democracy with active participation as an ideal is to meet citizens with an expectation that they should take a stance on topics of essential importance to the collective life of society. Therefore, citizens cannot be said to have a right to be left untouched by communications on the subject from public authorities. The relation between potential donors and recipients of organs must not include a duty to be a donor; this is due to the weighty consideration that the individual should be able to shape his or her philosophy of life freely on death and on the relationship with his/her own body without being prompted by public authorities to think or do something particular. There can be no obligation to donate organs, and therefore the members mentioned also feel it would be unsuitable propaganda if communications from the authorities recommended saying "yes" to being an organ donor. Instead, centrally controlled communications from the authorities must align themselves with the fact that citizens should be expected to take an active stance on organ donation. Similarly, it is expedient for that information to contain the message that it is a good idea to talk to one's nearest and dearest about organ donation. Conversely, a call to take a stance may not contain recommendations about which side the citizen must come down on but respect the fact that the citizen can be in doubt or have good reason to say no.

6.4.3 Public information should encourage a "yes" to organ donation

One of the Council's members (Thomas G. Jensen) thinks that information campaigns instigated by government authorities ought to take as their objective the job of persuading as many as possible that a "yes" to organ donation is a good choice. It is perfectly reasonable that such information is value-laden and encourages citizens to take a particular stance. The reasonableness of this is due to the clear benefit to people of having more organ donors, and hence to the collective community as a whole. The important thing is that there will be the possibility of more organ transplants while at the same time the one from whom the organs are taken suffers no harm.

The government authorities do not need to be neutral, therefore, and profess that it is up to the individual to decide whether organ donation is a topic that is worthwhile engaging in, or that the individual him/herself decides whether or not organ donation is a social benefit. It must be communicated clearly and distinctly that organ donation is a social benefit for the invaluable good of many severely ill people, and hence an action that is altogether preferable, objectively, in the ethical sense to saying "no" to being an organ donor. This is entirely consistent with simultaneously signalling that it is not ethically unacceptable to say "no".

That is to say that organ transplantation is an ethical benefit that is made available in society, and it is down to the individual to decide whether he or she wants to play a contributory part in generating this ethical benefit by registering as an organ donor. In

providing citizens with information on organ donation, it must be clearly indicated that the personal decision for or against acting as a potential organ donor is a free decision that will be accepted, regardless of whether the outcome is “yes” or “no”. But, equally clearly, it must be accompanied by a recommendation to say “yes”. Organ donation is an ethically beneficent act, and in the opinion of the member mentioned it is legitimate for the public to recommend this act, given that no one under any circumstances is obliged to perform ethically beneficent acts if they run counter to the person’s conscience or personal ethical limits.

6.5 Recommendation regarding information about the brain death criterion

The Danish Council of Ethics recommends that the public authorities anticipate problems concerning the discrepancy between the brain death criterion and the culturally rooted expectation surrounding the death process by ensuring that these topics are made the subject of in-depth information and debate in society^[44].

There are substantial grounds why the public agencies should make great efforts to provide information and initiate debate and reflection on the emotional and existential relationship with the onset of death as well as the new conditions governing that relationship. Firstly, there is still a constant need for factual information about what the brain death criterion comprises. Secondly, there is an imbalance between people’s natural or culturally rooted expectations of the death process and subsequently the definition of the onset of death entailed by the brain death criterion. This imbalance is reflected partly in the difficulty in talking about the “dead person’s heart beating”, or “the corpse being wheeled onto the operating table” when speaking of a brain-dead person. The Council of Ethics would urge that debate and reflection on these topics, amongst others, be initiated in lower and upper secondary schools. Young people receive their knowledge about the brain death criterion to a greater extent through the media than through teaching contexts^[45]. But the Council feels that it is crucially important for these topics to be debated in qualified settings, with the time and peace of mind to plumb the depths. It is important to insist that thorough reflection on modern treatment techniques and the death process cannot be meaningfully fostered in “fast” media. Schools and teaching that encourages debate are a far more suitable context for this type of knowledge dissemination and mutual reflection on values and feelings.

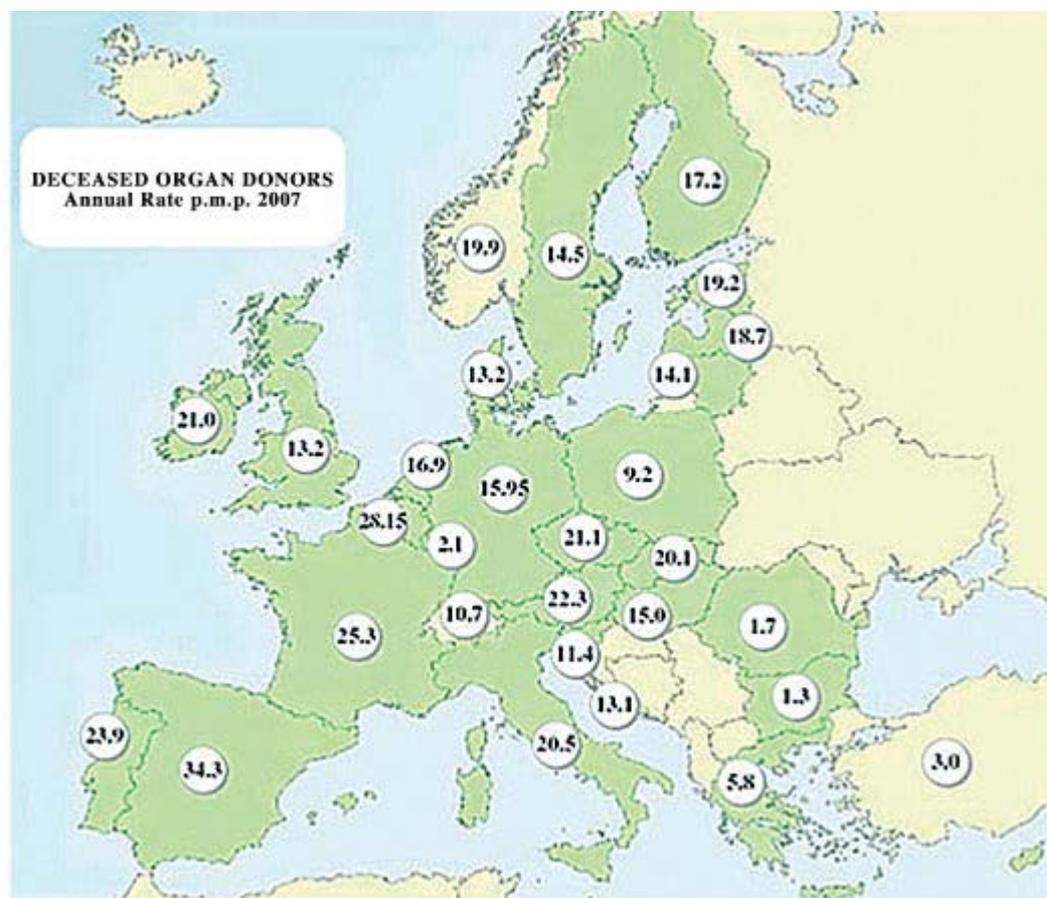
^[43] *Translator’s note:* “www.sundhed.dk is the official Danish eHealth portal for the public Danish healthcare services (*sundhed* means health in Danish). For the first time, the public Danish healthcare services have been brought together on the Internet by Sundhed.dk. This makes it possible for patients, their families and healthcare professionals alike to access information and to communicate with each other.” (Taken verbatim from the English section of the site.)

^[44] In Chapter 3, pp. 53-57, you can read more about the brain death criterion, the popular understanding of it and the Council of Ethics’ recommendations from 1988 on the brain death criterion.

^[45] Zøllner, 1999.

Appendix 1 – Organ donors in Europe in 2007

The number of organ donors in Europe in 2007, per million inhabitants (p.m.p)



Source: [Newsletter Transplant, 13 \(1\)](#)

Lande	Organ donors per million inhabitants in 2007
Spain	34,3
Belgium	28,15
France	25,3
Portugal	23,9
Austria	22,3
The Czech Republic	21,1
Ireland	21,0
Italy	20,5
Slovakia	20,1
Norway	19,9
Estonia	19,2
Latvia	18,7
Finland	17,2
Netherlands	16,9
Germany	15,95
Hungary	15,0
Sweden	14,5
Lithuania	14,1
England	13,2
Denmark	13,2
Switzerland	10,7
Poland	9,2
Greece	5,8
Luxemburg	2,1
Rumania	1,7
Bulgaria	1,3

Source: <http://www.organdonation.dk/statistik/statistik+europa>

Appendix 2 – Overview of donor registrations, 1991-2008

At 1 September 2008 a total of 589.672 Danes had registered with the Danish Donor Registry

År	JAN	FEB	MARTS	APRIL	MAJ	JUNI	JULI	AUG	SEP	OKT	NOV	DEC	I alt
2008	2438	2438	4650	2783	11114	29274	25102	5491	2589	0	0	0	85879
2007	2454	2077	2034	1576	3281	9683	4852	4644	4574	4192	2214	2961	44542
2006	2870	2332	3155	1923	2437	1448	1728	2946	2152	2213	1626	1127	25957
2005	1734	1755	1404	1584	2363	3673	1117	2460	3070	2064	3404	3545	28173
2004	3246	3068	3017	2186	2450	2344	1489	2193	2248	2089	1441	1477	27248
2003	3834	3095	3545	2347	2538	1875	2387	1773	1284	1867	2796	1867	29208
2002	1715	2368	2185	2463	3011	1498	2220	1996	51141	56845	14454	6153	146049
2001	2220	2510	6150	3721	4941	3280	1557	2830	1625	2198	1606	848	33486
2000	800	708	2303	2218	2629	3268	1346	3390	2643	3628	2583	1502	27018
1999	1494	1164	1192	739	655	669	634	540	510	788	822	460	9667
1998	1529	1262	1013	2516	3309	2230	1291	1549	1117	937	1388	857	18998
1997	1442	1110	954	971	720	299	409	1064	603	1727	1323	464	11086
1996	5790	4936	3906	2481	1750	1030	1409	1145	1761	2244	2555	1654	30661
1995	1183	1980	2018	1246	1138	961	744	902	879	1085	1471	4103	17710
1994	2225	1540	1076	674	802	959	835	1352	1710	1077	1523	850	14623
1993	1691	1347	1549	1080	1015	1563	1035	1019	1712	2761	1941	1453	18166
1992	1572	1637	3368	1693	1589	1589	1742	1969	1481	1699	1569	1636	21544
1991	0	4644	3829	3194	2266	1852	2194	1225	1903	2523	2564	1636	27830

Source: www.transplantation.dk/fakta/opdaterede-tal/test

Appendix 3 – Waiting lists, 2007 – Denmark, Finland, Norway and Sweden

SCANDIATRANSPLANT

WAITING LIST (WL) 2007 AND TRANSPLANT CENTRES

COUNTRY	DENMARK	FINLAND	NORWAY	SWEDEN
	Absolute No.	Absolute No.	Absolute No.	Absolute No.
KIDNEY				
Nº OF KIDNEY TRANSPLANT CENTRES:	4	1	1	4
Patients admitted to the waiting list during 2007	201	196	158	347
Patients awaiting for a transplant by 2007, 31 st D.	385	252	195	338
Patients dead while on the WL during 2007	36	12	18	21
ESRD on dialysis treatment during 2007				
LIVER				
Nº OF LIVER TRANSPLANT CENTRES:	1	1	1	3
Patients admitted to the waiting list during 2007	40	55	68	143
Patients awaiting for a transplant by 2007, 31 st D.	21	7	12	40
Patients dead while on the WL during 2007	2	1	0	7
HEART				
Nº OF HEART TRANSPLANT CENTRES:	2	1	1	3
Patients admitted to the waiting list during 2007	23	16	31	44
Patients awaiting for a transplant by 2007, 31 st D.	14	5	5	22
Patients dead while on the WL during 2007	3	1	2	1

LUNG				
Nº OF LUNG TRANSPLANT CENTRES:	1	1	1	2
Patients admitted to the waiting list during 2007	28	11	32	26
Patients awaiting for a transplant by 2007, 31 st D.	32	0	42	24
Patients dead while on the WL during 2007	9	1	6	2
PANCREAS				
Nº OF PANCREAS TRANSPLANT CENTRES:	0	0	1	3
Patients admitted to the waiting list during 2007			18	13
Patients awaiting for a transplant by 2007, 31 st D.			17	24
Patients dead while on the WL during 2007			1	0
SMALL BOWEL Nº OF SMALL BOWEL TRANSPLANT CENTRES:				
Patients admitted to the waiting list during 2007	0	0	0	1
Patients awaiting for a transplant by 2007, 31 st D.				
Patients dead while on the WL during 2007				

Source: http://www.scandiatransplant.org/tx_newsletter2007.htm

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