Farewell to non-commitment

Decision systems for organ donation from an ethical viewpoint

Govert den Hartogh

Monitoring Report Ethics and Health 2008

Centre for Ethics and Health
Farewell to non-commitment. Decision systems for organ donation from an ethical viewpoint
Published by the Centre for Ethics and Health
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This publication may be cited as follows:
The Hague: Centre for Ethics and Health, 2008

This publication can be downloaded via www.ceg.nl / www.rvz.net
To the Minister of Health, Welfare and Sport

Dear Minister,

A great deal of hard work is being carried out by various parties on the Organ Donation Master Plan. The Centre for Ethics and Health (CEG) recently analysed all the ethical aspects of financial incentives for organ donation. We take pleasure in enclosing another study herewith for your perusal. This study is devoted to the ethical aspects of the registration systems from which you wish to make a choice.

Ethically speaking, which system for allowing citizens to decide on post-mortem organ donation would be preferable? Professor G.A. den Hartogh, professor of ethics at the University of Amsterdam, answers this question in Farewell to non-commitment. He also discusses living organ donation and making use of incentives to encourage organ donation.

On 14 February last, the Council for Public Health and Health Care (RVZ) determined its position regarding the findings in this study. You will find Den Hartogh’s main conclusions and the Council’s position stated below.

**Ethical analysis of the present system**

Our present registration system is based on the moral principle that donation should be a spontaneous and altruistic gift. People can register that they want to be a donor, that they do not want to, or that they prefer to leave the decision to their next of kin. But they are also free not to register any decision; in that case the decision automatically reverts to their next of kin. In such circumstances their special position is taken into account; after all, donation can be an additional burden for them during a period of intense grief.
This means that the ethos of donating and the right to self-determination, including being free to do nothing and thus to leave the decision to the next of kin, are important factors in the present system. However, Den Hartogh puts forward a number of serious objections to this moral basis in his analysis and argues that other ethical principles are more applicable.

Firstly, the present system implies that self-determination plays a central role, although this is only true when someone registers. People who do not register as donors are presumed to concur in the decision being taken by their next of kin, but it is by no means certain that this presumption is correct. Under the present situation, it is a very real possibility that people are not aware that they have delegated their decision. The right to self-determination would require that consent must not only be presumed.

Another of Den Hartogh’s objections to the present system is that there is too much freedom of choice. There are moral reasons why it should theoretically be normal for people to donate as long as they have not expressed wishes to the contrary. After all, donation is a form of help to people in dire straits and may also be regarded as a reasonable contribution towards mutually beneficial cooperation. This also emerges from the fact that almost everyone would like to be entitled to a donated organ, should the need arise.

According to Den Hartogh, these reasons show that donation should not be regarded as a disinterested contribution to a good cause, but as a form of social solidarity. This should naturally not mean that the burden imposed on the next of kin by donation should no longer be taken seriously, and for this reason, the option of delegating the decision on donation to them must emphatically remain in place. In such an event, however, this choice would have to be explicitly recorded.

**Ethical analysis of three alternatives**

Besides the present system of consent, Den Hartogh has studied a further three options: the no-objection system (where people are automatically donors unless they lodge a notice of objection), the compulsory-choice system (where the government requires all citizens to fill in the donor form), and the Active Donor Registration System (ADR). Under the ADR system, as under the present system, people can register that they want to be a donor, that they do not want to, or that they prefer to leave the decision to their next of kin. They are registered as donors if they fail to return the registration form and are informed of this in advance and afterwards.

What is Den Hartogh’s opinion of these three alternatives? Based on the right to self-determination, the same objections as those to the present system can be raised against the no-objection system that is applied in other countries: presuming consent is not sufficient. These objections are overcome in the ADR system. If people do not register but are informed of the consequences of their choice, this means that tacit consent has been given.
The compulsory-choice system is entirely in keeping with the right to self-determination. Den Hartogh, however, indicates a preference for the ADR system because this system is more consistent with the moral idea of donating as a civic duty or a mutually beneficial service. In addition, he is of the opinion that the supply of post-mortem organs will be greater under this system.

**Ethical analysis of incentives for living organ donation**

Living organ donation has become of almost equal importance as post-mortem organ donation, particularly with regard to kidneys. There is a large degree of consensus on the decision system for living organ donation, although the use of financial incentives is more controversial.

Van Dijk and Hilhorst put forward a proposal for remuneration in the CEG’s recently published monitoring report *Financial incentives for organ donation*. Den Hartogh agrees with them that the ethical objections generally raised to such proposals are not decisive, although he does feel that doctors must have a good reason for subjecting healthy people to stressful surgery. Such good reasons may include a special relationship between donor and recipient, but not a financial interest on the part of the donor.

**Position taken by the Council**

What is the Council’s position in all this? Like Den Hartogh, the Council feels that the present system leaves a lot to be desired, ethically speaking, as does the no-objection system. The Council also agrees with the ethical analysis of the other two registration systems: the active donor registration system preferred by Den Hartogh and the compulsory-choice system.

The Council, however, does not attach any recommendation to this. It does not express any preference for one of these two systems, nor does it give a verdict on the existence of a moral obligation to donate organs. After all, information on the effectiveness of the systems (in which international experiences are of importance) and public support are also necessary in order to give a balanced opinion. You will be informed about this through other channels during the run-up to the Organ Donation Master Plan.

There is a widespread sense of the importance of this Master Plan. We are confident that the CEG will contribute to the formation of opinions on the complex, sensitive and urgent organ donation issue with this ethical study and with the monitoring report published at an earlier date.

Yours faithfully,

Rien Meijerink 
President, RVZ

Pieter Vos 
General Secretary, RVZ
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The Centre for Ethics and Health (CEG) commissioned me to write this study. The Centre in turn was asked by the Organ Donation Coordination Group to assign this task in connection with the preparation of the Organ Donation Master Plan, which the Coordination Group will submit to the Minister of Health, Welfare and Sport in the spring of 2008.

More than four years ago I wrote a similar study for the Rathenau Institute. Of course, both texts overlap to a certain extent, although I discussed some issues in more detail in Donation or contribution? In this study my aim was to review all major arguments contained in the literature, giving special attention to the literature published during the last five years. During this period I also changed my views in some respects: in particular, I now feel that a no-objection system need not infringe the right to self-determination, provided that it meets a number of requirements. And the Active Donor Registration System (ADR system) does indeed meet these requirements. This time I have assumed that the major facts concerning organ donation and transplantation are known: the number of organs donated, the length of the waiting list, the average waiting period for an organ (for this data, please see the Dutch Transplant Foundation’s Annual Report for 2007) and the advantages, inconveniences and risks of transplantation.

I would like to thank Alies Struijs for her helpful and efficient assistance, Mike Bos and Andries Hoitsma for their comprehensive answers to a number of factual questions, Gert Olthuis for compiling the list of literature, and the CEG forum for a lively discussion on the draft text. And my very special thanks to André Krom, who supported me in my research as he did four years ago, this time at the request of the CEG. He furnished me with almost all the literature I consulted, cleared up a number of factual issues, compiled the glossary, and gave me extremely detailed and useful comments on the style and content of the first draft of this text.

The master plan will undoubtedly reignite the debate on decision systems for organ donation. I hope that this time arguments will play a decisive role in the debate.

Govert den Hartogh
Summary

Discussions on post-mortem organ donation usually centre on four decision systems: the consent system, the classic no-objection system, the compulsory-choice system and the Active Donor Registration System (ADR system). Within these systems, citizens can choose one or more options: whether they wish to be donors, whether they object to this, or whether they (explicitly) leave the decision to their next of kin.

The most important difference between these systems lies in their choice of default. Default is what happens if people do not make a choice. Under the consent system, default means no removal of organs, while the default in the classic no-objection system and the ADR system is ‘donation’. Theoretically, there is no default in a system in which citizens are obliged to make a choice: each choice is made explicitly.

This study discusses the aforementioned decision systems on the basis of four moral principles. Until now, organ donation in the Netherlands has mainly been examined from the point of view of the right to self-determination (1) and the idea that organ donation must be a gift (2). Two obligations are also stated in international literature: organ donation is regarded as a duty to render assistance in a serious emergency (3), or as a contribution to a social benefit which is to everyone’s advantage and to which everyone should contribute accordingly (4).

The discussion results in two remarkable conclusions. It is equally difficult from all starting points to find any justification for the role of the next of kin in the Organ Donation Act: the fact that they are allowed to decide if the deceased themselves have not made any choice. And the ADR system is the only one that is fully compatible with all four starting points.

Self-determination

In the Netherlands, if people do not make a decision on organ donation themselves, their next of kin are the ones who decide. All in all, therefore, the Netherlands has a no-objection system rather than a consent system. Or, to be precise, it has a ‘no-objection-to-delegation’ system, which means that the decision system contained in the Organ Donation Act does not comply with the right to self-determination. This right, which is
interpreted as the right to have control over one's own body, is only respected if consent is actually asked and given. Generally speaking, consent is merely presumed in no-objection systems.

In some circumstances, not objecting may be construed as tacit consent: if the law or common practice has good reason to interpret silence in this way, if the person involved is aware of this and if he can lodge an objection in a simple manner at any time he likes. In such cases, tacit consent is true and full consent. Although the ADR system is a no-objection system, it entirely fulfils the conditions as stated. For this reason, the ADR system is fully compatible with the right to self-determination, provided there is good reason to make donation the default. This will be discussed in more detail later on.

From the point of view of the right to self-determination, no fault can be found with the compulsory-choice system. The fact that citizens are obliged to fill in the donor form does not infringe their rights over their own bodies. It is a minor restriction of their personal freedom, but this is fully justified by the social interest of organ transplants. In the compulsory-choice system, citizens have complete freedom regarding which choice they make: they can choose donation, refusal, or (explicitly) leaving the choice to their relatives.

However, sanctions are necessary in order to induce everyone to make a choice, although the weaker the sanctions, the less people will be likely to make a choice. If the sanctions are serious, this might unfortunately result in many citizens registering objections as a protest.

The ADR system, too, can always fall back on a registered decision by the individual in question, in which the right to self-determination is likewise respected. But in this case, no sanctions are necessary, which means there is less fear of protest votes.

Organ donation as a freely-given gift
The view that donation should be a gift freely given for the sake of the recipient's interests has always been an important moral starting point. According to this view, it is commendable to give, but not reprehensible to refrain from doing so. The ideal of giving freely is attractive in all respects. If it can be achieved without a great many problems, such as in the case of blood donation, the ideal of giving freely may be regarded as a moral attainment. But we are meanwhile forced to conclude that an appeal to people's spontaneous willingness to give results in a structurally insufficient supply of organs, which means that a further appraisal is inevitable. What should have priority in an emergency: the interests of the next of kin or charitable interests? If organs are scarce, the ideal of giving freely must yield to less non-committal opinions on organ donation.
Organ donation as an obligation
In international literature, organ donation is sometimes regarded as a moral duty, and this can be interpreted in two ways. The first of these is classically expressed by Thomas Aquinas: it is the duty of each individual to help anyone whose life is in danger (or who is in similar dire straits) if this individual is in a unique position to provide such help and if this help merely requires him to make a relatively modest sacrifice. Since post-mortem organ donation fulfils all three conditions, this justifies making donation the default and choosing a variant of the no-objection system.

According to a second interpretation, we can regard organ donation as a social benefit which is to everyone’s advantage and to which therefore everyone must contribute. Surveys show that if the worst comes to the worst, almost everyone would like to qualify for a donor organ. Those who are not prepared to contribute after their death only increase the shortage of organs, thereby shifting the burdens attached to this – consciously or unconsciously – on to others, including living donors.

For this reason, it would be a good beginning to include a question on the donor form as to whether the person would like to qualify for an organ themselves if the need should arise. One alternative is only giving organs to patients who have registered in good time as donors. Some people feel that this would contravene one of the basic principles of health care: that this care must be given where it is needed. However, we only apply this principle because we have taken another way of ensuring that the means of providing care are available, i.e. by making everyone legally obliged to pay premiums. A system in which care is given where it is needed and the means are obtained from voluntary contributions is unthinkable, particularly if these means turn out to be insufficient.

It is admittedly a tough measure to fully exclude people who are not registered donors. One middle course would be to only give registered donors priority on the waiting list, thereby emphasising that it is reasonable to contribute to a system from which everyone can benefit.

Solidarity
Both conceptions of personal obligation provide sound arguments in favour of abolishing non-commitment. Organ donation should no longer be regarded as a gift, but as a ‘normal’ contribution to a collective effort to alleviate a dire need: in short, it is a form of solidarity.

Under normal circumstances, citizens can fulfill their solidarity obligations by contributing their possessions or by working. But in the case of organ donation, the contribution in question is one’s own (dead) body, which is why we can postulate that despite the fact that a moral duty exists, everyone must be able to choose whether they will fulfil this
duty. However, the existence of this obligation does provide a cogent reason for making donation the default. Since there is a considerable difference between a decision concerning our living bodies and one which merely concerns our dead bodies, nobody objects to the public prosecutor ordering an autopsy without asking permission. Fortunately, however, we do not need to go as far as that in order to do justice to solidarity obligations: under the ADR system, donation is chosen as the default without any infringement of the right to self-determination.

Even without appealing to solidarity obligations, there is a reason for making donation the default. The fact that society has a legitimate interest in increasing the number of available post-mortem organs is sufficient. Since the introduction of the Organ Donation Act, legislation on this point has been halting between two opinions.

**The position of the next of kin**

Looking at the situation from the four moral principles, the right of the next of kin to decide on donation is only defensible if the deceased has *explicitly* left the decision to them. In most countries, however, the next of kin also have this right (at least in practice) if the deceased has not expressed a personal choice. The strongest justification for this is that generally speaking, the next of kin have a greater interest in the decision than the deceased themselves. The interests of patients waiting for an organ are admittedly even greater, but giving priority to the next of kin is defensible due to their special relationship with the deceased. That is why donation should still remain a gift: if not from the donor, then from the next of kin.

However, this argument is problematic for two reasons. To start with, legitimate partiality should not be carried to the extent that people whose lives are in danger are abandoned to their fate. And secondly, if the next of kin were given the right to decide, this would also enable them to overrule the deceased’s explicit consent. This is generally rejected in the Netherlands and has therefore been precluded by the Organ Donation Act since 2006.

**Rewards**

Besides the debate on legal systems, there is a great deal of international discussion going on with regard to (financial) rewards for organ donation, such as a contribution towards the cost of funerals or cremations. This would not involve the payment of a market price, but would rather be a token of appreciation which would also have an encouraging effect. Two objections to this proposal are normally put forward. The first objection claims that this would adversely affect the altruistic nature of the ‘gift’ of organs, although the question is whether this is actually true. After all, we do not consider the altruistic nature of donations to charity to be undermined by the fact that they are tax-deductible. Moreover, the question here, too, is which issue should be given priority: maintaining the purity of altruistic motives or alleviating existing need.
The second objection to any form of reward is that, by turning dead bodies or bodily parts into ‘merchandise’, we are showing a lack of respect for such dead bodies and therefore – by association – for people. However, it is not certain that organs actually do have this symbolic value in our society: this differs from person to person and from organ to organ. A cautious government policy would then seem to be indicated in which health insurers are given the choice of rewarding the next of kin, and the next of kin are given the choice whether to accept.

**Choosing one of two options**

If the right to self-determination were the sole deciding factor in our choice, we might consider implementing the compulsory-choice system. This can easily be combined with priority for donors on the waiting list, which would only make the consequences for others of the choices one makes apparent. It can easily be combined with a reward system as well.

Nevertheless, those who acknowledge that there are compelling moral reasons in favour of donation will naturally want to make donation the default and therefore choose a variation of the no-objection system, preferably the ADR system. In order to place more emphasis on the obligatory nature of the decision, the obvious solution would be to give registered donors priority on the waiting list in this case too. A reward system, on the other hand, would not be logical: one does not reward people for doing what they ought to do.

It is important that the choice of one of these options is made clearly and consistently, because the way in which society regards donation has an effect on the choices people make. That is why the prevailing idea of a ‘donation to charity’ should consistently be replaced by ‘a free choice with consequences attached’ or ‘a contribution to solidarity in society’.

**Defaults make a difference**

Recent insight into the way in which people make decisions indicates that the choice of defaults is of immense significance. In that case, the legal default must constitute more than a dead letter. International comparisons show that there are countries with a no-objection system where the return is (even) lower than in the Netherlands, given the potential number of donors. However, this comparison also suggests that the countries with the best results are countries with a no-objection system. This is probably due to the fact that the legal system in the second group of countries prescribes a different approach to the next of kin. If the deceased has not registered any objection, the next of kin are not asked an open question. In such cases, conversations are based on an assumption of donation. If the next of kin object, the hospital authorities will try and remove these objections and only respect them if the next of kin continue to maintain
their objections. The way in which the next of kin can be approached is determined by the decision system.

When amending the default, it is of essential importance that hospitals are encouraged to hold talks with the next of kin of registered donors on the basis of this assumption. There is good reason to believe that the percentage of refusals on the part of next of kin will then decrease considerably.

**Living donation**

There is far-reaching consensus on the ‘decision system’ for living donation. Living donation is only possible on the basis of a voluntary and well-considered decision to do so on the part of the donor. After all, the right to determine what happens to one’s own body is an extremely important factor with regard to living bodies.

This need not deter the government from appreciating and facilitating living donations, which means first and foremost that the compensation scheme for loss of income should be a generous one. It also means that the government should enable transplant centres to mediate where necessary when seeking donors.

The crucial question in the case of living donation is what would justify doctors in carrying out stressful surgery on people who have no personal health interest in such surgery, and who even run certain risks. After all, such surgery turns healthy people into patients. Some people claim that the consent of the individual concerned is sufficient, while others maintain that the donor’s interests in a wider sense can justify the operation. However, there is a third opinion, and this is the most convincing: the justification for doctors lies in the special relationship between donor and recipient which gives them a specific responsibility towards one another.

If we regard the matter in this light, living organ donation to unknown persons is a problem. To justify this, we would have to acknowledge that the donor is able to assume specific responsibility for people in distress as a result of a ‘vocation’, and in that case, the donor would have to take the full initiative. This precludes such donors from selecting a particular recipient or group of recipients to whom they wish to donate their organs, since they do not have a specific responsibility towards that particular recipient (or recipients).

**Should living donations be financially rewarded?**

The most controversial issue is the option of rewarding living donors. For example, the authorities could take over the costs of compulsory health insurance for such donors during their lifetimes. In this context, the appeal to the symbolic value of the human body gains ground among the objections to ‘commercialisation’, since this is more apparent in the case of (parts of) living bodies than of dead bodies. Moreover, there would no longer be any justification for doctors to cooperate with donors acting primarily out of financial
motives. Cutting into a living body is entirely different if the donor feels a special duty of care for the recipient then if the ‘donor’ would like to be exempted from paying health care premiums.

The proposal to exempt living donors from payment of health care premiums assumes that living donations which are already taking place will continue to the same degree and from the same motives. This is unlikely, however: donors may also withdraw if others offer their organs. This means, however, that we cannot know in advance what sum would be sufficient to obtain the desired supply: this would be determined entirely by the market.

The matrix below shows how the different decision systems for organ donation should be evaluated using the four moral principles discussed. The matrix also indicates whether these principles provide scope for the next of kin’s right to decide in cases where the deceased has not registered any choice with regard to donation, for financial incentives, or for giving priority to registered donors on the waiting list.

<table>
<thead>
<tr>
<th>Decision systems</th>
<th>Right to self-determination</th>
<th>Ideal of the gift</th>
<th>Duty to help those in need</th>
<th>Social benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present consent system</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>No objection</td>
<td>-</td>
<td>-</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Compulsory choice</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Active Donor Registration (ADR)</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

| Others                     |                            |                   |                             |                |
| Role of the next of kin in the case of non-registration | -                           | -                 | -                           | -              |
| Financial incentives       | +                           | -                 | -                           | -              |
| Priority on the waiting list | +                           | -                 | -                           | +              |
In a supplemental report I will discuss several other variations on the decision-making systems covered in the main text.

1. **One proposal is a variation on the current system in which it is possible to record consent for donation but not a decline of consent. If no consent is found in the donor register, the next of kin decide.**

   What are we to make of this system? While it may be possible to continue to set out a decision to decline consent in a binding statement of will, this still deliberately makes it difficult for an individual to preclude the removal of his or her organs. This is the crux of this system. As such, the system does not respect the right to make decisions over one’s own body, that right evidently being subordinate to the interests of the next of kin. But in that case, it is not at all clear why consent should then suddenly be assigned a major, and perhaps even decisive, significance. This cannot be based on the right of self-determination, being that the system sets aside this right in favour of the interests of the next of kin. But neither can it be based on the interests of organ recipients, because if so this would involve securing organs even when the deceased has made no decision on the question. In short, this system cannot support any coherent justification.

2. **A proposal has been made to add the following option to the present range of choices on the donor form: “I cannot make a decision at this time; ask me again later.”**

   This proposal suggests that there should be more choice. But until a full-fledged mandatory choice system is introduced, anyone can always postpone the decision, and the option to not make a tacit decision is simply not there. If the idea is to make an urgent appeal to people to make some sort of decision in the short term, this would be better stated explicitly as such. Additionally, a repeat mailing would have to be sent to everyone who has not explicitly made a choice.

The other proposals are variants on the ADR system.

3. **The first suggestion is to remind the populace at regular intervals that they can change their registration, possibly through annual information campaigns, or by explicitly pointing out this option to people applying for or requesting governmental documents such as a passport, driving license or certificate of good behaviour.**

   Implementation of this proposal will have a number of different effects, and whether the net result would be an increase in the number of registered donors is unclear. What can be said is that this proposal would have two welcome effects.

   Whatever pains are taken in the ADR system to inform people of the impact of not returning the donor form, there will always be people with whom this information
does not sink in, and regular reminders will help to minimise this number. A reminder mailing to anyone who does not respond is still the most effective remedy for this issue.

A second positive effect is that even if tacit consent constitutes genuine, full consent, many people will still consider it as a sort of “inferior” consent. The more that people reflect on their status at regular intervals and make a deliberate decision to either change or not change their status, the more this will increase the perceived value of the tacit consent, and accordingly, the perceived legitimacy of the ADR system.

4. Some, including the Royal Dutch Medical Association (KNMG), have proposed making a distinction in the donor register for the ADR system between consent explicitly given and tacit consent. This information would then have to be passed on to the next of kin. There are a number of problems with this recommendation. Introduction of the ADR system is justified in part because the system creates the conditions under which tacit consent can constitute genuine and full consent. Recording two types of permission implicitly acknowledges that tacit consent is consent that is “inferior” by nature. Consent, however, is a category that does not allow gradations: either you consent or you don’t; you can’t do it half-way.

Making the distinction avoids the “dilution” effect that explicit permission would be exposed to (see section 16). But tacit consent actually promotes this effect, and there is no reason to assume that the net result of the two effects would come out positive.

5. It would, though, be meaningful to distinguish between the two types of consent if different legal effects were attached to them. Some have proposed interpreting the failure to return the donor form as follows: “I consent to the removal of my organs, so long as my next of kin allow it.” If that is the case, then this option should also be included on the donor form as an explicit choice.

Where exactly does this leave the next of kin? This cannot allow the person in question to leave a free choice to his next of kin that he does not wish to have any influence on himself. Nor can the intention be that the next of kin can state that the deceased actually felt differently than what his tacit registration implies: under the ADR system, the individual is personally responsible for ensuring that his registration is an accurate reflection of his wishes. This means that the correct interpretation of the "yes, unless" formula must be: “I give consent for the donation of my organs unless it becomes apparent that my next of kin have overriding concerns against it.” Ideally, then, this formulation should also be used on the donor form.
In terms of the right of self-determination, the addition of an extra option can only be welcomed, all the more so because this option will presumably be the choice of a large portion of the population. But does this really do sufficient justice to the interests of organ recipients? As an expression of the standard that donation is desirable from a moral perspective, the “orthodox” ADR system should be viewed as preferable.

That said, this variant does still retain the most significant advantages of the ADR system. Specifically, there remains a style of approach to the next of kin by which donation and decline of consent are not presented as choices of equal value, but that donation is the basic premise that should only be departed from in the case of "overriding concerns." Additionally, looking at today's Netherlands this interpretation of tacit consent by the population in general and by the next of kin in particular may be easier to accept.
1. Four moral principles

Dutch government policy on donation differs widely with regard to post-mortem or living donation. In the case of living donation, the government’s role is limited to facilitating this, while in the case of post-mortem donation it strives to achieve the greatest possible number of organs available for transplant. However, the Netherlands has never contemplated introducing a conscription system in which all post-mortem organs suitable for transplant are simply confiscated by the government. This means that the government depends on cooperation from its citizens, either as potential donors or as their next of kin. What appeal can it make to these citizens?

Two views on this have dominated the debate on organ donation in the Netherlands right from the start. According to one view, the government should limit itself to supplying citizens with the relevant information, after which people are entirely at liberty to choose one of the options for registration: donation, refusal or delegation. Citizens derive this freedom of choice from their specific right to decide what happens to their own bodies, even after death. According to the second view, the decision to donate organs should be an act of charity, and in this case, too, the citizens themselves are the only ones to decide whether this motive appeals to them. The dominance of both these views has resulted in a large degree of consensus in the Netherlands (Trappenburg 1993): the removal of organs after death is only permissible on condition that explicit consent has been given, either by the deceased, or possibly by his next of kin if he has left the decision to them.

However, two other moral principles have been advanced in the international debate from the beginning, which have also been advocated in the Netherlands from time to time. One of these principles – the third one in my overview – is as follows: if a fellow human being is in mortal danger, or in similar dire straits, anyone who is in a unique position to provide aid should be expected to do so, provided a relatively minor effort is required to this end. Finally, the fourth principle regards organ donation as a social benefit that is to everyone’s advantage, certainly in the event that people require organs themselves, but also before that: one should be able to rely on organs being available if the worst comes to the worst. And in view of this, everyone should be expected to make a reasonable contribution to maintaining this system. This kind of reasonable *quid pro quo* can only be achieved in one way: an explicit willingness to donate organs.

My task in this study is to give an overview and an evaluation of the arguments in favour of and against various decision systems for organ donation. To this end, I will first deal with each of these four principles separately in the sections on post-mortem donation, and determine for each principle which decision system is preferable on the basis of the

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1 This was one of the objectives of the Organ Donation Act (1998).
relevant principle. I have mainly limited myself to the decision systems currently under discussion in the Netherlands: the present (‘non-absolute’\(^2\)) consent system, the compulsory-choice system, the classic no-objection system and the Active Donor Registration System (ADR system). Under the ADR system, everyone attaining a certain age (18 or under) is explicitly invited to register a choice of donation, refusal or delegation. Those who do not respond are registered as donors, which is why it is called a no-objection system. The individuals concerned receive confirmation of this and may alter their status at any time they wish. In the compulsory-choice system, all citizens must explicitly make a choice upon attaining a certain age, although they are free to choose between donation, refusal or delegation.

I will successively be discussing the right to self-determination (sections 2-4), the view of donations as a ‘gift’ or a spontaneous act of charity (sections 5-6), the duty to help those in dire straits (section 7), and the duty to contribute to a collective provision to everyone’s mutual benefit (sections 8-9). In section 9 I also discuss the idea of giving priority to registered donors when allocating organs.

After drawing a number of preliminary conclusions on the pros and cons of the different decision systems in section 10, I will then confront the four principles with one another (sections 11-12). Are they compatible, or do we have to choose between them, and if so, what choice should we make? Following this, I will discuss two topics separately: first, the question of whether the next of kin should be granted a decision right that is not derived from the deceased’s right (section 13), and secondly, the thorny issue of the admissibility of financial incentives (section 14). In section 15 I debate the question of which decision system is to be preferred, thereby taking all factors into account. In section 16 I round off the discussion on post-mortem donation by examining what the results achieved mean in practice. Will the choice of the recommended decision system make a difference in the supply of post-mortem organs?

Next, I address the question of living donations. It is an undisputed fact that donors can only decide in favour of living donation if they have complete freedom to do so. Although consensus has largely been reached on the question of who exactly can be a donor, one matter for discussion in this regard still deserves to be addressed (sections 17-18). And finally, we come to the most controversial issue of all: the question whether it would be acceptable to introduce financial incentives in the case of living donations as well (section 19).

\(^2\) Non-absolute because others besides the individual in question may also decide on organ donation.
2. The right to self-determination

It is misleading to refer to 'the' right to self-determination, since this suggests that the right to make decisions concerning one's own body is no more than part of a general right to freedom. Although this right to freedom does exist, we would do better to call it a 'presumption of freedom': people are at liberty to do what they like, as long as there is no valid reason for prohibiting this or obstructing their actions. However, my right to decide over my own body is much more specific and powerful than this vague presumption: it arises from the special tie existing between me and my body, even after my death.³ If I subsequently refer to 'the right to self-determination', I mean this specific authority to take decisions regarding my own living or dead body, and I shall explicitly make a distinction between the presumption of freedom and the right to self-determination. This is important in order to be able to assess a number of current arguments in the debate: that the no-objection system would adversely affect 'the right to self-determination' because it forces people who do not want to become donors to fill in a form, or that the compulsory-choice system conflicts with this same right, since this would also involve the right not to have to make a choice.

In essence, the right to decide over one's own body is a shield right, not a claim right: it prohibits others from doing anything to people's bodies without their permission, but does not give people the authority to demand positive efforts on the part of others (Wilkinson 2007).⁴ One may make a choice between burial and cremation - simply because there are very few possible uses for a dead body which do not cause harm to others - and claim that this wish be honoured. However, if people choose to donate their bodies to science, science is not obliged to accept this donation.

Starting from the right to self-determination, how should we assess the different decision systems, starting with the one that is presently in force? This system is known as a non-absolute consent system. The current view is that, starting from the right to self-determination, all consent systems are preferable to all no-objection systems, including the ADR system. However, classifications can easily throw us off the scent. Perhaps a non-absolute consent system is not a consent system at all, in the same way that counterfeit money is not real money, and potential donors are not actual donors.

In order to distinguish decision systems from each other, we must ask what happens if the deceased does not take any decision on donation before his death. I shall refer to

³ Under Dutch law, the right to decide on what is done with one’s mortal remains is interpreted as part of the right to physical integrity recognised under Art. 11 of the Dutch Constitution. Wilkinson 2007 gives reasons for doubting this interpretation, as well as an alternative interpretation of the basis of the law. It is portrayed as a negative right to freedom (shield right) in both interpretations.

⁴ The terms 'shield right' and 'claim right' denote a negative and a positive right respectively. A negative right demands that others refrain from performing certain actions, while a positive right demands that such actions be performed.
this as ‘default’. Typical of a consent system is that organs may not be removed without explicit permission. Therefore, default means the refusal to donate, and there is no reason for any separate registration of refusals. Besides the option of donating, citizens may also have the option of delegating this decision to their next of kin or to a specific person. In that case, the person or persons so delegated may take the decision for reasons of their own. They are not obliged to decide in the spirit of the deceased, since the deceased had every opportunity of deciding himself before his death if he had considered this decision to be important.

Under the present system, citizens also have the option of registering their objection to donation. The aim of the legislator is to have as many citizens as possible explicitly choose one of the three options: donation, refusal or delegation. But what if they fail to do so even then, as the majority of the Dutch population (about 55%) do at present? In such cases the legislator indicates the next of kin as reserve decision makers who still have to make the choice between donation and refusal. But what right do the next of kin have to make this choice? After all, they do not have the special tie with the deceased’s body which gives the right to self-determination its significance? But what the next of kin do have is a legitimate interest in what happens to the deceased’s body. For this reason, they should be properly informed and counselled and it might constitute a reason for deciding against the removal of organs if the next of kin have insurmountable objections to this. But in that case, this is done out of consideration, not because they have any right to decide.

It is often suggested that the next of kin have the right to decide on behalf of the deceased, and therefore that they are actually obliged to decide in accordance with the deceased’s spirit: this is also the implicit supposition in the Organ Donation Act. In the Explanatory Memorandum and the Memorandum of Reply, the legislator at the time relied upon there being a much greater willingness in society to donate organs than was explicitly recorded. If there is no explicit consent, this willingness could still be expressed by giving the next of kin the right to still assent to the removal of organs. When making this decision, therefore, the next of kin would be expected to validate the deceased’s own willingness to donate his organs, and in that case, they would not only be delegates, but also representatives. The legislator apparently used this interpretation to try and do justice to the right to self-determination: since the individual concerned has not decided personally, others will have to decide on his behalf. The same also applies in situations where a decision on an individual’s medical treatment must be taken without the person concerned being able to give personal consent.

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5 Consulting the register is successful in 38% of the cases: 2006 Donor Register Annual Report. However, the percentage of Dutch citizens of full age included in the register is about 45%.

6 This is also the prevailing opinion among the public regarding the role of the next of kin (Farsides 2000, with references). The German Transplantation Act (1997) explicitly states that the next of kin have this representative task. And in France and Spain, if ‘no objection’ is registered, the law requires the next of kin to be asked whether the deceased had any objection.
There are, however, two differences to this kind of situation which make this construction a problematic one from the point of view of the right to self-determination. The first difference is as follows: if someone loses consciousness as a result of an accident, he is not capable of taking the necessary decision at any moment whatsoever. But with regard to donation, the government itself urges everyone to make their own choice and not to leave it to others by sending the donor form to people and making it continually available. For this reason, there is no need at all for any additional representative: because the party concerned has had every opportunity to choose donation and has not done so, refusal still ought to be the default. Since refusal was a separate option which the party concerned did not choose either, we are forced to conclude, in the second place, that there were reasons why he did not study the choice more closely, or was incapable of making a decision. These reasons could be lack of interest, or reluctance to think about the end of his own life. Although he was asked to make a choice, he was unable or unwilling to do so. But in that case – all things considered – it would be an impossible task for his representatives to make the decision in his spirit. Since his spirit was too indifferent or too ambivalent to be capable of arriving at a decision, how could a decision in this spirit be formulated? From the point of view of the right to self-determination, therefore, a representative figure is problematic in two senses: the deceased did not feel the need to delegate the task to anyone, and the task itself is impossible to perform. In many cases, the family’s refusal appears to be founded on the conviction that it would not be seemly to donate the deceased’s organs without his explicit consent (Eaton 1998). And that is exactly the position that the legislator himself did not wish to adopt.

Of course, the legislator only deviated from the absolute consent system because it would predictably result in too few organs. That is the reason why he gave the next of kin the opportunity to donate in the event that the deceased had not made any decision, otherwise the 55% of potential donors who are not registered would be entirely lost. In order to be able to reconcile this policy aim with the right to self-determination, the legislator took refuge in fictitious representation. This structure is unconvincing and has a counterproductive effect. In actual fact, it means that leaving the decision to the next of kin is the default which thereby invites people to choose that option. This means that many people do so as soon as taking the decision becomes too difficult or too much trouble. And for most next of kin, the default then still lies in refusal. This infringes the right to self-determination in order to increase the supply, which eventually is still only achieved to an extremely limited extent.

\[7\] In two surveys conducted in 1998 and 2001, Don Quichot/NTS 2001 found this view in 26% and 14% of the cases respectively.

\[8\] This also turned out to be the case if the next of kin are unable to agree: no donation takes place. The same happens when the inconvenience caused by circumstances is too much for the family. (Siminoff et al. 2007) They seemed to regard “no” as a nondecision. (Sanner 2007)
The discovery that the default is not refusal but delegation for citizens who have to decide whether or not to register has led to the conclusion that an ‘non-absolute’ consent system does indeed belong in the same category as counterfeit money (Nys 2004): as a matter of fact, it is not a consent system but a no-objection system, or to be precise, a no-objection-to-delegation system. Those who do nothing are presumed to have left their decisions regarding donation to others who have to decide on their behalf. From the point of view of the right to self-determination, a further drawback to this system is the prevailing objection to no-objection systems: the presumption is fictitious to a greater or lesser degree. Not everyone is aware that they are delegating the decision to their next of kin if they fail to fill in a donor form, and not many people are aware that these next of kin are expected to decide in the spirit of the deceased. Moreover, although determining what the deceased would have wished is of fundamental importance to most next of kin when making the decision, this is not invariably the sole or the decisive consideration (Sque & Payne 1996, Farsides 2000, Siminoff et al. 2007, Sque & Payne 2007).

3. Presumed and tacit consent

In a no-objection system, donation is the default. This system is also known as the ‘presumed-consent system’, notably in English-speaking countries. Under this nomenclature the system is interpreted as a realisation of the right to self-determination. We will see presently that it can also, or can rather, be interpreted as an effect of other relevant moral views. However, if the system has to be justified from the point of view of the right to self-determination, this is indeed only possible by presuming consent, even if such consent has not been explicitly given.

As I have indicated, the prevailing objection to this presumption is that it is largely fictitious. (Veatch 1991, Veatch & Pitt 1995, Fabre 1998, Erin & Harris 1999, Veatch 2000; 171, Dennis et al. 2002, Nys 2004, CEJA report 2005, Spital & Taylor 2007). Many citizens in countries which have introduced the no-objection system do not know that they are presumed to be donors, or what they have to do to avoid being donors. Although this presumption means that these people would give the necessary consent, even if they did know all this and were explicitly asked for their consent, it is unfounded. The fact that people express themselves in surveys as being warmly in favour of transplant surgery emphatically does not mean that they themselves are willing to

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9 In Sque & Payne’s 2007 survey, 6 out of the 26 next of kin asked refused donation, although they said that the deceased would have wished to donate his organs. The major reason for their refusal was their need to protect the deceased’s body.

10 Veatch & Pitt 1995 argue that with the exception of Colombia, not a single law containing a no-objection system makes any explicit mention of presumed consent. However, it does not automatically follow from this that such laws cannot be justified by this presumption either.

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assume the role of donor without hesitation. This clearly emerges from a comparison of Dutch registration figures with the results of surveys.\textsuperscript{12} It is unlikely that the 55% of Dutch citizens whose names do not appear in the Donor Register have consciously chosen to delegate the decision to their families.

A second objection to the imputation of presumed consent is that presumed consent simply is not consent. We are not complying with the right to self-determination if we know that someone \textit{would} give his consent if he were asked; we are only complying with this right if he actually does consent. And this is even more the case if there is nothing to prevent us from asking him for his consent. However, even in situations where it is impossible to do so, such as if a patient is lying in a coma, taking his ‘presumed wish’\textsuperscript{13} (Harris 2003) as a starting point is problematic. What it actually comes down to is that we should act in the patient’s interests, and we can only determine what his interests are by adopting his viewpoint and evaluating the situation in the light of his priorities. But this does not exercise his right to self-determination.\textsuperscript{14}

Here we encounter a frequent misunderstanding with regard to the right to self-determination (see e.g. Savulescu 2003). For example, this misunderstanding emerges from the view that we should consult the next of kin about donation because they would presumably be the best informed on the deceased’s most recent preferences, while his decision to register as a donor might have been made many years ago. But people only exercise their right to self-determination by making a legally valid decision. It makes no difference if their preferences change afterwards, as long as they do not express these in a new decision. After all, we do not ask next of kin whether the deceased may possibly have changed his mind after drawing up his will.\textsuperscript{15} Nor, incidentally, do we ask this question if the deceased has registered his refusal to donate organs.

From both these objections, it follows that the removal of organs in cases where no objections have been registered is in a certain sense involuntary under the standard no-objection system. However, it would be going too far to say that the removal of organs is therefore compulsory, especially in cases where the individual in question is in fact familiar with the law. After all, one cannot claim that someone has been forced to join the

\textsuperscript{12} Approximately 90% consider organ donation to be a good thing, generally speaking (Verzijden & Schothorst 2003, Friele & De Jong 2007).

\textsuperscript{13} The question asked in such cases is therefore not what the individual in question would actually have chosen, given our knowledge of his psychological idiosyncrasies, prejudices, lack of willpower etcetera, but what would have been the most reasonable choice for him to make in view of his standards and values and the information available.

\textsuperscript{14} Dupuis 1987 rightly states that people have no right to self-determination under this system: they can only claim it if desired.

\textsuperscript{15} It is therefore incorrect to state along with Veatch & Pitt 1995 that if people make no will, they are not indicating that they concur with the statutory default arrangement for their estates: they \textit{unfortunately have not been able to secure their own preferences}. 
army if this person is able to evade this duty by issuing a declaration without any further explanation.\textsuperscript{16}

The ADR system is a no-objection system, although the interesting point here is that the ADR system, generally speaking, meets the objections to no-objection systems to a considerable degree. After all, everyone is expressly invited to choose one of three options for registration: donation, refusal and delegation. If people do not respond to this invitation, they are explicitly informed that they are now officially registered as donors, and that they may alter this status at any time they wish. The only people who would then be able to argue that they are not aware of their status or do not accept it, are those who are incapable of reading the letters or filling in the form.\textsuperscript{17}

The supposition that people choose donation can only remain fictitious with regard to this latter category. If we evaluate this from the point of view of the right to self-determination, this is a serious inadequacy, although it is important to establish that problems of this nature do not only arise under no-objection systems (Jacob 2006). The absolute consent system suffers from a similar deficiency: people who cannot read or write, or who do not speak any of the languages in which the invitation to register is written, are simply not in a position to register as donors, even if they would unhesitatingly choose this option if they realised they were able to. Although their shield right concerning their own bodies is not affected by this\textsuperscript{18}, they are not given the opportunity of fully exercising this right.

The ADR procedure prevents the vast majority of the population from being unaware that they are presumed to have no objections. This overcomes the first point of criticism of the no-objection system as we have known it up to now. But the second point of criticism is obviated as well. The ADR system not only involves presumed consent, but also tacit consent. There are many ways in which consent may be given: at an auction, for instance, raising one’s little finger is sufficient. What is regarded as consent is a matter of convention, although it can also be regulated by law. There are innumerable situations in society in which the law or custom attributes the meaning of consent to ‘keeping silence’ (Hartkamp 1985: 115, Van Dunné 2001: 90, Nys 2004). For example, this very week the ABN AMRO Bank informed me that they would not be sending me any more financial statements from now on unless I were explicitly to inform them that I wished to continue receiving them. If the government repeatedly informs me that I am registered as

\textsuperscript{16} Naturally, an important factor in this regard is how difficult it is to depart from the default of consent to donation. This is exceptionally simple under the ADR system, although in Belgium a declaration of refusal must be made in the presence of an official at the town hall. Only a bare 2\% of the population actually do this.

\textsuperscript{17} Fortunately, many of these people receive systematic help from others in order to enable them to function in society.

\textsuperscript{18} As Cohen 1992 suggests, cf. Spital 1999. Again, this suggestion is based on the interpretation of the right to self-determination as a right to be treated in accordance with personal preferences instead of personal decisions.
a donor unless I explicitly choose a different option, I may be assumed to have given tacit consent to this unless I inform them to the contrary. This definitely applies if the law gives this meaning to my silence.

I recently read a letter to the editor comparing a government that introduces a no-objection system to a vendor who sends people all kinds of unsolicited goods and demands that they either pay for them or send them back (cf. Kluge 2000). Why not compare such a government to a customer who orders goods on the Internet, pays for them with a credit card, and subsequently expects to receive the goods ordered or get his money back? The difference is that there is no law or convention in existence that takes ‘keeping silence’ in the former case to mean consent to the transaction, and that the vendor is therefore unable to derive any confidence that I am willing to pay for the goods from the sole fact that I do not return these goods. Moreover, the introduction of any such law or convention would be undesirable, for obvious reasons.

Another objection to the choice of donation as the default is that the government would force me to spend a few minutes of my valuable time filling in the donor form. This alone would conflict with my ‘right to self-determination’ (Dickens 1997). But the ‘right’ referred to here does not differ from the presumption of freedom, and the social importance of donation is more than sufficient to overrule this presumption. Even ABN AMRO’s interest in limiting its costs is enough in this regard, and even the government itself still demands ‘corvées’ for matters of less importance (Grapperhaus 1993).

An interesting point about the objection is that the fact that it takes up people’s time to register as donors is apparently not considered to be an objection to a consent system. This is in spite of the fact that we should be able to assume that even now, there will be more people willing to donate than those that refuse, so consent systems therefore take up more of citizens’ time on balance than no-objection systems. What this expresses is the realisation that there is a ‘natural’ way in which to exercise the right to self-determination: by acting and not by omitting. This means that the government must have good reasons for transferring the default from refusal to donation, and these reasons cannot themselves be derived from the right to self-determination. The follow-up to this study should make it clear whether we are able to find such reasons.

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19 The author informs us that although he is now registered as a donor, he intends to lodge an objection for that reason if a no-objection system is introduced.

20 If the ADR system were introduced, 30% and 17% of the population would register as donors and as objectors respectively, while 20% would not return the donor form, thereby giving tacit consent (Friele & Kerssens 2004). In a recent opinion poll conducted by Een Vandaag, 25% said they would lodge an objection on the introduction of a no-objection system, and 56% would acquiesce in being registered as donors (www.eenvandaag.nl/docs/opiniepanel/nierdonatie/uitslagorgaandonatie.pdf). The ADR system was obviously not explained properly to the respondents.
The most obvious reason would be that, morally speaking, donation and refusal are not equal options. Many people find this view problematic, since they feel that their right to self-determination is already affected when this is pointed out to them. However, the fact that an individual has the right to make a certain decision does not mean that each choice he makes is equally sound; rather, it means that his choice remains in effect, even if this choice is wrong.

In any event, we should remember here that the present system, too, is not only based on the right to self-determination. As we already saw, this mainly emerges from the fact that the system confers a position on the next of kin which cannot be deduced from this right. If the right to self-determination were the sole relevant moral view, donation and refusal would be fully equal options, and the government would not be allowed to encourage citizens to become donors. In that case, the absolute consent system would be the only acceptable alternative. Nevertheless, the government does make it clear that it prefers citizens to choose donation rather than refusal.\(^{21}\) Although this preference does not follow on from the right to self-determination, it does not conflict with it either. If increasing the supply is a legitimate policy aim and the ADR system promises to result in this, the fact that the ADR system does not infringe the right to self-determination in any way is sufficient, even though this is not the justification behind it (Leenen 1981: 136, Akveld 1987, Kokkedee 1992).\(^{22}\)

Assuming that there are good reasons for making donation the default, we may conclude that the ADR system entirely respects the right to self-determination in view of the fact that tacit consent is true and full consent, as opposed to the prevailing ‘non-absolute consent system’ in which no consent from the individual concerned is required.\(^ {23}\)

### 4. Should default be abolished?

We could also consider introducing the compulsory-choice system in order to counterbalance the deficiencies in the non-absolute consent system (Katz 1984, Veatch & Pitt 1995, Spital 1996). Under this system, the government imposes an obligation on all citizens to fill in the donor form. Theoretically, there is no default under this system: each choice is explicitly made. If we compare it to the non-absolute consent system, the option of presumed delegation – and certainly the privileged position of this option as a default – ceases to exist. Moreover, refusal no longer holds this privileged position of

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\(^{21}\) According to the Further Memorandum of Reply accompanying the Amendment to the Organ Donation Act (Dutch Senate 2005-2006, 29 494 F), information on organ donation must be given ‘concisely, but obviously in favour of donation’. See also section 16 on hospitals’ obligation to arrive at a ‘minimum’ number of refusals from families.

\(^{22}\) It is especially significant that the pioneer of Dutch health law, H.J.J. Leenen, adopted a similar position because he attached such a fundamental importance to the right to self-determination.

\(^{23}\) This specific objection could be removed by an ADR system in which non-registration is interpreted as delegation. But there would have to be good reasons for this default in that case, see section 13.
default in comparison with the absolute consent system. In principle, this would prevent people who are unwilling to consider their attitude towards donation, or who are unable to adopt an attitude, from accidentally refusing, as it were. (However, they can always decide to make their choice by tossing a coin).

There are various reasons in favour of the compulsory-choice system. Of especial importance is the prevention of delegating the burden of making the decision to the family; generally speaking, this is in the interests of the next of kin themselves, who are already faced with the monumental task of coming to terms with the (often sudden) death of a relative. But it is mainly of importance because that particular moment is pre-eminently unsuitable for taking such decisions. Another advantage to the (consistently-enforced) system is that it prevents all the delays which arise when the next of kin are consulted.

However, there are a number of systems that relieve the family of the task of deciding. Of these systems, the compulsory-choice system appears attractive, primarily because it does full justice to the right to self-determination. From the point of view of this right, the system is completely equivalent to the absolute consent system, and in addition, it encourages people to exercise this right autonomously by systematically asking themselves what they actually want. In the care sector and other welfare services, the right to self-determination and the ideal of autonomy often clash because care providers not only give their clients the opportunity to take a well-balanced decision if required, but demand that they do so. Although ‘forcing people to be autonomous’ is a peculiar form of paternalism, in this case coercion is not justified by the interests of the individual concerned but by the interests of those suffering from kidney, heart, lung and liver diseases. So we cannot call it paternalism.

Nevertheless, some argue that the compulsory choice system clashes with the right to self-determination because it allegedly deprives people of the right not to make a choice (Prottas 1995, Siminoff et al. 1995, Klassen & Klassen 1996, cf. also the Further Memorandum of Reply attached to the Organ Donation Act (Parliamentary Papers II 1993/1994, 22 358, no. 13: 24)). This objection is untenable for a number of reasons. First of all, this is once again not a reference to the right to self-determination in the specific sense of the right to decide what happens to one’s own body; it merely refers to the presumption of freedom. After all, the system is blamed for depriving people of their freedom to refrain from making a choice, although this accusation is not correct either. Even under the present system, a choice is always made, either explicitly or by default

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24 Sometimes, however, the option of choosing donation can help the family in this, see note 36.
25 Many next of kin feel this decision is simply too difficult and decide to refuse donation for that reason alone, see note 7.
26 ‘The essential ethical advantage of required response is its undiluted loyalty to the value of individual autonomy.’ (Dennis et al. 1994)
(in favour of delegation), and the same applies to all other systems. Conversely, the freedom from the obligation to think about it is not removed under the compulsory-choice system, since citizens always have the option of tossing a coin to decide. Although it is true that the purpose of the compulsory-choice system is to make people think about donation, this is not even contrary to the presumption of freedom. Incidentally, the interests of people with organ failure would be more than sufficient to overrule this presumption. One would have to make the value of freedom very absolute in order to feel that one cannot even oblige people to think over the opportunities they have for helping fellow citizens in dire straits. This also applies to the sole obligation that the compulsory-choice system actually does impose on people: filling in the donor form and sending it back, postage paid.

From the point of view of the right to self-determination, nothing can be said against the compulsory-choice system, apart from the fact that this system does not provide illiterate persons with a realistic option for making a choice either. Despite this, the system has not yet been permanently implemented in any country whatsoever, even though it has been under discussion for 30 years (Veatch 1976). It has not been implemented in any of the US states, even though the right to self-determination in the USA has always been at least as inviolable as it has in the debate in the Netherlands. The reason for this is simple: the fear that the system will have a counterproductive effect.

If all citizens were to fulfil their obligation to register, this would result in an anticipated increase in all three registration categories: donation, delegation and refusal. Suppose that these additional registrations are distributed among the three categories in the same way as at present. In such an event, more than 60% of the 55% of Dutch citizens not included in the Donor Register would be registered as willing to donate. This compares favourably to the current situation, in which the family consents to donation in only about 35% of the cases where potential donors are not included in the Donor Register.27 This would increase the total number of donations by almost 15%. However, this forecast is based on extremely uncertain assumptions. Will everyone who is capable of doing so actually fulfil their obligation to register? This will depend on the sanctions imposed on non-fulfilment of this obligation, which places us in a dilemma. If such sanctions are merely symbolic or are entirely lacking, this will limit the effect of the obligation to make a choice, so there will therefore still have to be a default: donation, refusal or delegation. However, as soon as the sanctions are substantial enough to make registration more or less unavoidable, there will be a considerable chance that people who only register as a result of the sanctions display their intrinsic opposition by registering an objection. This effect might be even stronger if the sanction chosen is of an arbitrary nature which citizens are unable to associate with the type of transgression they have committed: for instance, if they cannot obtain driving licences, passports, benefits or tax rebates without

27 See note 117 on the percentage of family refusals in 2007.
first registering as donors. But even if effective sanctions are imposed, there will always be people who do not register, people who do not drive a car or who do not travel abroad. In any case there will certainly be illiterate persons, so a default will have to be established anyway. If the default remains presumed delegation, this will limit the deficiencies in the present system at the very most, but it will not eliminate them.

Incidentally, should delegation not remain one of the options in the compulsory-choice system? People might prefer this option, and it would be inconsistent for the government to refrain from expressing a preference for consent or objection on the one hand, while on the other hand restricting citizens’ right to self-determination by depriving them of this option. However, if people who are not registered at present allow themselves to be compelled to make a choice, either as a result of sanctions or not, most of these people will be the ones who are unable or unwilling to decide now. As far as they are concerned, delegation will still be the most popular option, which they will explicitly choose as they currently do by default. There is no reason to expect less family refusals in this category than is currently the case. All in all, it is doubtful whether the compulsory-choice system will result in more donations (Childress 2001, Chouhan & Draper 2003).

Up to now, the system has only been tested in two US states: Virginia and Texas. The results were disastrous: only 31% registered as donors in Virginia, and in Texas, almost 80% refused (Klassen & Klassen 1996, Siminoff & Mercer 2001, Kolber 2003, 2005 CEJA report). Due to this fact, both these states have meanwhile abandoned the system. This kind of precedent does not tell us much because a great deal depends on the way in which the system is introduced and fleshed out: the information given to the public, the options offered and the sanctions imposed. In Texas, people had to take the decision while waiting to renew their driving licences at the office allocated for this purpose. Many of these people were confronted with the issue for the first time in their lives, they were not given the option of delegating their decisions, and the computer interpreted ‘I don’t know’ as ‘No’ (Herz 1999). Nonetheless, these results are far from encouraging.

Like the ADR system, a compulsory-choice system requires making considerable investments in the provision of information, since an obligation to choose can only be imposed on people who have been given the means of making a sensible choice. Although those in favour of the system expect an improvement in the ratio between registered consent and registered objection to result from these efforts to provide

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28 With regard to such sanctions, we could also ask whether they should be not considered as a form of détournement de pouvoir in which powers are used for a different purpose than the one for which they are intended.

29 Explicitly pointing out in the information accompanying the registration form that choosing donation or objection would relieve the next of kin of this decision may increase the number of such choices made. We may infer from research that this increase would be realistic, but not considerable (Cleiren & Van Zoelen 1999, cf. Friele et al. 2006).
information alone, this expectation has not been unequivocally confirmed by research (Smits et al. 2005, Reubsaet et al. 2005, Friele et al. 2007).

The aim of the compulsory-choice system is to encourage people to decide themselves instead of allowing their next of kin to make this decision. This aim can also be pursued in other ways, such as the alternative ADR system in which the refusal to donate constitutes the default. Presumed delegation would therefore no longer be available as an escape route, while those who have difficulty in making a choice would be informed that they are registered as refusers. This would at least serve to confront all citizens at a certain point with the question ‘do I really want this?’ The same effect would be achieved under the standard ADR system where people who do not return the donor form are notified that they are registered as donors. In both cases people are confronted with a ‘definite’ choice which they can still revoke at any time they wish. From the point of view of the right to self-determination, it hardly makes any difference what ‘definite choice’ people make, only a special reason is required for making donation the default. From the point of view of increasing the supply of organs, however, the difference between both versions of the ADR system can be considerable, which is one reason for giving preference to the standard ADR system.

Both versions of the ADR system can be regarded as realistic forms of the compulsory-choice system: realistic because they acknowledge that establishing a default is inevitable. Like the compulsory-choice system, they only assign the task and the right to decide to the next of kin if the deceased himself has entrusted this task to them. Since the next of kin usually prefer to adhere to the deceased’s decision if this is known, this relieves them of a task which is an additional burden at a moment when they already have a great deal to contend with, in a way to which they can generally reconcile themselves (Spital 1996).

My conclusion to date is that if we exclusively take the right to self-determination into account, the ADR version of the absolute consent system and the compulsory-choice system tie for first place. However, the ADR version of the no-objection system is equally compatible with the right to self-determination, provided merely that a good reason is given as to why silence may be considered to be consent. This reason must be derived from considerations separate from the right to self-determination, although these considerations have already been presupposed in current government policy, which is aimed at increasing the supply of post-mortem organs. From the point of view of the

30 In both surveys, a secondary school educational programme (which is now widely available) resulted in a greater willingness to register, but only in a relatively minor increase in the percentage of intended registrations as donors (from 43% to 51% and from 47% to 54% respectively). Smits et al. suspect that better results could be achieved if information is followed by discussions with the family members.

31 Chouhan & Draper 2003 argue that an acceptable system must set actual consent as a requirement, although it can nevertheless adopt as its starting point the fact that there are generally more cogent reasons for donation than for refusal. In that case, they propose a combination of the compulsory-choice system and the ‘Spanish’
right to self-determination, all other versions of the no-objection system are problematic because they are not based on actual decisions but on presumed ones. They are problematic because they allow people’s organs to be removed without their permission, not because they specifically restrict citizens’ freedom. After all, there need hardly be any question of this if it is not difficult to register a status other than default.

This problematic nature is also true of the now prevailing ‘non-absolute consent system’, which on reflection should be regarded as a no-objection-to-delegation system because it chooses delegation to the next of kin as the default. This system also permits the removal of organs without the actual consent of the individual concerned. It is justified by suggesting that the next of kin represent the deceased, although this is problematic for two reasons: firstly, why should someone be represented if he has had every opportunity to make a decision himself? And secondly, how can one assert someone’s wishes if he himself was unable or unwilling to determine these wishes?

5. The ideal of the gift

A second starting point that has dominated the debate on organ donation right from the start, both internationally and in the Netherlands, is the idea that donation, as the word suggests, should be a gift. A ‘gift’ is rather a vague notion, and although we continually come across phrases such as ‘donation is a gift, therefore ...’, it is often difficult to reconstruct an argument from this ‘therefore’. I also must admit that the literature I have perused on donation as a gift very seldom attempts to remove this uncertainty. To start with, then, I shall try and give this starting point as clear and plausible an interpretation as possible.

The notion of a ‘gift’ should be construed as a metaphor. Although people are only able to give what is theirs, the tie between an individual and his body cannot adequately be described in terms of ownership. This gift also differs from standard gifts because it is not unconditionally given: donation can only be effected in very exceptional cases where people’s organs are suitable for transplant after their death. (Lauritzen et al. 2001) The purpose of the ‘donation’ metaphor is to express something about the nature of this conditional disposition.

A link is often established between the notions of ‘gift’ and ‘altruism’. Literature and social debate claim time and again that a gift ‘is’ an expression of spontaneous brotherly approach to the family. The ADR system is a much more consistent realisation of this combination of compulsory choice and a preferential option.

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32 Legally speaking, therefore, a dead body is ‘res nullius’, ‘ownerless property’. The right to dispose of such bodies is a non-proprietary personality right (Kokkedee 1992: 37, Leenen 1994: 52-53). Incidentally, transfers of property to beneficiaries are not normally regarded as gifts either.

33 In which it is automatically presumed that this disposal implies more than consent so that next of kin and doctors are bound to cooperate in effectuating it, see section 3 and section 13.
love, but this is empirically incorrect. Gifts are given for all kinds of reasons – arousing jealousy, for instance – but the commonest reason is that social standards demand that gifts be given. Some examples of this include the presents people take along when they visit friends, presents for birthdays and holidays, flowers given to speakers or performing artists (who then have to cart them home), or employees’ Christmas hampers. There is a special relationship between giver and recipient in all these cases, and this relationship determines what kind of gift would suit a particular occasion, as well as the giver’s and the recipient’s reactions (“Oh, you shouldn’t have done that.” “Please don’t mention it.”) (Murray 1987, Gerrand 1994).

In his classic book *L’ Essai sur le Don* (1923), the anthropologist Marcel Mauss analyses this practice of giving gifts as a form of indirect reciprocity: since giving gifts is part of a normalised practice, all givers know that they will receive something in return in due course, e.g. on the occasion of their own birthdays (see also Komter 2003). The reciprocity is indirect because the gift is not given on condition of an immediate *quid pro quo*. The conception of ‘altruism’ is sometimes used so broadly that it only signifies this independence from an immediate *quid pro quo*. Strictly speaking, however, an altruistic gift is a gift which is given with the sole purpose of promoting the recipient’s welfare. If we bypass the metaphor, we can say that people donate their organs in order to help people in dire straits (patients with defective organs), which is the sole reason for their decision.

One of the greatest uncertainties when using the gift metaphor is this to-ing and fro-ing between more and less rigid meanings of ‘altruism’. There are all kinds of additional options between both these extremes (independence of an immediate *quid pro quo* and being entirely motivated by the recipient’s interests). The interests of people who are close to one another are usually so intertwined that they cannot be promoted independently of one another. People whose lives partly revolve around their partners or children help themselves by helping them. Altruism can be mixed with self-interest in other ways, too; for example, altruists may derive an increased sense of self-esteem or status from their actions. In an ideal situation, these advantages are like bonuses: those who are not primarily motivated by the recipient’s needs do not really have the right to congratulate themselves on their altruism. However, considerations of status in particular can not only support altruism, but also repress it. And then there are other motives which can neither be regarded as altruism (strictly speaking) nor as self-interest, such as considerations of gratitude or justice.

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34 This is also the essential feature of the legal concept of ‘gift’.
35 Altruism is strictly defined in Titmuss 1970’s renowned conclusion stating that blood donation is based on altruism, although it is so widely defined in the data on which the conclusion is based that it also includes ‘reciprocity’ and ‘sense of duty’ (Rapport & Maggs 2002).
A second important connotation of the metaphor is the voluntary nature of the gift (Eijk 1996). This once more conflicts with Mauss’s analysis, and the conflict cannot be mitigated on this point. Moreover, it is frequently assumed that no moral obligations are at issue when using the terms ‘charity’ and ‘altruism’ in connection with organ donation. Although it is laudable to donate organs from charitable motives, it is not reprehensible to refrain from doing so. In ethics, this is known as a ‘supererogatory act’: a fine gesture, or a meritorious deed. A classic example of this is donating money to a good cause. It is better to regard organ donation, as interpreted in the ethos of the gift, as a form of charity than as the giving of a gift (Gerrand 1994).

Now, how can this metaphor be used in arguments on decision systems? It is often maintained that ‘donation should be a gift’, but this can be interpreted in two ways: as the formulation of a standard or of an ideal. According to the standard, the system must guarantee that donation is always a gift. If ‘gift’ should be taken to mean an ‘altruistic gift’ in the strict sense of the word, this would be an impossible demand. There is no system in existence which can prevent people from donating for all kinds of diverging reasons: from gratitude or from a sense of guilt, to get a mention in the newspapers or to go to heaven.

If we adhere to the starting point of the gift as a standard, the notion of ‘altruism’ may only be interpreted in the widest possible sense. This sets two requirements for the decision system: first, that the gift is not given on condition of an immediate *quid pro quo*, and second, that the system may not assume that people who object to donation are moral failures.

The weakness of this interpretation is that it is not clear what these requirements are based on. Why may there be no immediate *quid pro quo*, or no moral duty to donate organs? This only becomes clear if we interpret ‘donation must be a gift’ as expressing an ideal or an ethos. It is a good thing if people help one another if they are in need; it is a good thing if they do this (partly) from solicitude concerning the need itself and not (only) in order to benefit personally. And it is also a good thing if they do so spontaneously and not because society expects it from them. Although the legislator cannot guarantee that this ideal is always achieved, he can propagate the ideal as an ideal. Furthermore, the government can make a modest contribution to achieving the ideal, mainly by adhering to the two specific requirements: no immediate *quid pro quo* and no obligation to donate organs.

6. The ideal of the gift’s perspective

Looking at it from the point of view of the ethos of the gift, how should we judge different decision systems? We are first faced with the problem of lending significance to the
family’s role in the present (non-absolute) consent system. The only situation in which this role is comprehensible is if the deceased has explicitly delegated the decision to his family. He is then saying, ‘Your feelings about this are very important to me, like how you regard the infringement of the bereavement process caused by the donation procedure. In that case I would like you to decide yourselves.’ The next of kin can then decide to give the gift that the deceased himself did not give.

However, for reasons of which we are already aware, it is difficult to understand how the next of kin, as the deceased’s representatives, can donate something on his behalf that he himself was unable or unwilling to donate during his lifetime. It is like the parents of a child that refuses to part with a favourite toy secretly including this toy in the present the child is giving a friend for his birthday.

The radical solution to this problem would be to grant a power of disposition to the next of kin which does not derive from the deceased’s. But what should this power be based on? We could assume that the real giver invariably is not the individual himself but his family, although in that case, consent should be obtained from the family and not from the individual before his death as well. How can we defend the fact that the family only has the right to decide whether or not to donate organs if the deceased himself has not made this choice? This does not appear to be a simple matter at first sight, since the dead body does not form part of the estate to be inherited by the beneficiaries. This issue deserves to be discussed more thoroughly and I shall be doing this in section 13. For the time being, I conclude that from the point of view of the ideal of the gift, it is difficult to defend the next of kin’s position in the non-absolute consent system.

Looking at it from the ideal of the gift, there can be no objection to the compulsory-choice system. The ADR system is to be preferred out of all the variations on the no-objection system because the gift is indeed given by tacit consent under this system, without merely presuming that the individual concerned would have given it if asked to do so. However, proponents of the ethos of the gift often express a strong abhorrence of all forms of the no-objection system, including the ADR system. There are two reasons why they do this: firstly, that under such systems people become donors who by no means answer the description of the ideal giver: people who are so indifferent to all the interests at stake that they cannot be bothered to lift a finger, and people who grapple with the issue to such an extent that they are not able to make an explicit choice in favour of donation. And secondly, those who support the ideal of the gift are opposed to no-objection systems because by making donation the default, the legislator is implicitly

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36 The most common reason for next of kin to consent to donation may possibly be the feeling that the death of their loved one has not then been entirely in vain. Although this is not ‘pure’ altruism, no ‘immediate quid pro quo’ is involved either. For this reason, it does fit in with a broad interpretation of the ethos of the gift.

37 At least, they do in the Netherlands. No conflict between the no-objection system and the ideal of the gift is experienced in countries with this system.
assuming that donation is ‘normal’, something one can theoretically expect from everyone.

I will only be able to give a definitive opinion on these objections after weighing up the ethos of the gift against other moral principles. However, there is still something to be said about them even now, when we are still only thinking in terms of this ethos itself. Like the right to self-determination, the ethos of the gift has dominated opinions on organ donation right from the very beginning. We are meanwhile forced to conclude that an appeal to spontaneous and voluntary altruism fails to even approximately meet the demand for organs for transplantation, and a deep-rooted tension is revealing itself under these circumstances. Supporters of the ideal want two things to happen: that fellow human beings in dire straits receive aid, and that this aid is given through actions arising as much as possible from concern about the situation. Given the present scarcity of organs, these two aims conflict with one another and supporters of the ideal will therefore have to reconsider them. They can either adhere to the aim of allowing the light of unselfish helpfulness to shine forth as much as possible, or they can accept measures to alleviate the need as efficiently as possible, even if this does dim the glow of the ideal to a certain extent.

The first thing that should be said about this consideration is that altruism is only truly laudable if the altruist makes a sacrifice to help others; it becomes more commendable in proportion to the magnitude of the sacrifice. Descriptions of the ideal of the gift frequently stress the value of the gift as ‘the gift of life’, although this refers to the value as far as the recipient is concerned. With regard to the value as far as the giver is concerned, many people attach no personal importance whatsoever to what happens to their organs after their death, provided that these organs are treated with respect. They are sometimes aware that their next of kin support their wish to donate organs and will not voice any objections at all to their removal. There is no question of any sacrifice in such cases. This type of altruism is similar to the altruism shown by a motorist seeing a fellow driver whose car has run out of petrol standing at the roadside and taking him to the nearest petrol station, which he has to pass anyway. It is rather excessive to praise this to the skies, and a true altruist will be the first one to feel a trifle embarrassed by such praise.

The question is, should those who support the ethos of the gift accept this kind of gift, which does not involve any real sacrifice? For a long time, there were objections to accepting patients suffering from haemochromatosis as blood donors, and even now their blood is still used only for research purposes and for manufacturing medicines, at least in the Netherlands. Blood has to be regularly taken from these patients for medical reasons anyway, so this is not done for altruistic reasons. However, these patients may feel considerable appreciation if their blood is not wasted, and this is an altruistic
motive. Would it not be more logical to regard the fact that no sacrifice is required from them to act from these motives, as a fortunate incidental circumstance? If we exclude these donors on the grounds that they are not altruistic enough, we would also have to let new opportunities for reducing the burden of organ donation go unused instead of being pleased with them. Valuing the willingness to make sacrifices is quite a different matter to organising society in such a way as to invoke this social capital to the maximum limit (Pennings 2005).

The whole point is that altruists themselves will fully agree with this, since those who give priority to maintaining the glory of giving are demonstrating that they love charity, or the semblance of charity, rather than their fellow human beings. Surely the ultimate goal is more important than the way in which it is achieved. This dilemma determines the attitude towards no-objection systems that must be adopted from the point of view of the ethos of the gift. The altruistic content of all donations taken together will certainly be greater if the only people admitted as donors are those who have explicitly registered as such, than if donors are also accepted whose attitude to donation is ambivalent, but not quite ambivalent enough to depart from the default (donation) in the framework of a no-objection system. However, the number of donations will be less in the first instance. Those who see the value of the gift through the eyes of the recipient will not readily give priority to the first consideration.

My conclusion is this: for those who are only willing to regard the entire issue from the point of view of the ethos of the gift, the order of priority depends on their own position in this dilemma. If the yield of organs did not count, these people – like their associates who think exclusively from the viewpoint of the right to self-determination – would give preference to the absolute-consent system or the compulsory-choice system. The present non-absolute-consent system would be dropped, or at least, that was my provisional conclusion. After all, in 50% of cases under this system, the gift is given by people who cannot give because they are not authorised to do so (as already stated, I will be returning to this issue in section 13). Supporters of the ethos of the gift would give preference to the ADR system above all other no-objection systems because real and not merely implied gifts are given under this system. However, they would not be so appreciative of the fact that this system – more so than the absolute-consent system – admits people as donors who do not score very well in the altruist test. And they would purse their lips at the implicit assumption that giving is normal, since they would like to continue regarding giving as something special.

People who disseminate the view that giving is something special, a gesture of moral heroism, should however not be surprised if the majority of the population abandon the idea. But supporters of the ethos of the gift should find this very fact disturbing, since

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38 That is why it is hurtful to treat them as second-rate donors.
their fundamental concern is eliminating the need. Given a situation of permanent serious scarcity, therefore, they will have to be prepared to consider steps which will achieve the ideal less fully, while being all the more effective in achieving the ultimate goal it presupposes. I will discuss the situation in which they then find themselves in section 12.

7. Types of Samaritans

Imagine that you come across someone on a deserted road who has had an accident and urgently requires medical aid. You have your mobile phone with you: all you have to do is ring the emergency number. Failure to do so is regarded as disgraceful, and is even punishable if the victim is in danger of his life, although it carries a maximum penalty of only three months in the Netherlands (five years in France).39

What characterises a situation in which this kind of moral duty to help those in need exists (Feinberg 1984: ch. 4, Gutmann 2002)? First and foremost, that the victim is in dire straits and urgently requires help.40 Secondly, that you, as a passer-by, are in a unique position to provide this (first) aid.41 If you behave like the priest or the Levite in the Bible and drive on, there may not be a Samaritan who comes along before it is too late. The situation becomes somewhat more complicated if there are several people who can all give the necessary help, or if several people are able to make a useful contribution, but there is no unique way of deciding what specific contribution can be expected from everyone. I will be returning to this later. Thirdly, the help required of you demands very little effort: even if you were obliged to incur further expense by personally taking the victim to hospital, for instance, this would not be too much to ask of you. The additional expense would still be very slight in comparison with the interests of the victim that you would be serving.

These requirements can be found in a passage in which Thomas Aquinas addresses the question of whether giving a gift is always a supererogatory act, as is assumed in the ethos of the gift. “Those who fail to give a gift are in danger of committing a mortal sin: from the recipient’s point of view, if a clear and urgent need becomes apparent (the first

39 Most states in the USA do not have any such legal ‘duty of easy rescue’, although the moral duty is fairly generally recognised, except among libertarians. John Locke, to whom libertarians are fond of referring, expressly states that anyone failing to help a fellow human being in danger of his life through no fault of his own is actually guilty of murder. The moral duty has legal significance everywhere, including the USA, e.g. with regard to liability of emergency service providers.

40 Even if the person concerned only has his own carelessness to thank for the danger? And even if this carelessness arises from the assumption that help will be given anyway if the need arises? The second problem (‘moral hazard’) is the most difficult, but it does not occur in the case of organ donation (Schwindt & Vining 1998).

41 This requirement is more inclined to be fulfilled in the case of ‘close strangers’ than of ‘distant strangers’, although, incidentally, there is no reason why distance should be relevant. If the requirement of a unique position were not set, even modest obligations to give help where needed would swallow up our entire existence. This is known as the problem of the moral black hole; this problem is avoided by collective organisation of the aid.
characteristic) and no helper appears (the second characteristic) and from the giver's point of view, if he can spare that which is not necessary to him in view of his present situation... (the third characteristic)." (Quotation from Schenderling 2003).

Can these characteristics be found in post-mortem donation? Receiving an organ is a matter of life and death for patients waiting for a donor heart or liver. Although dialysis is an alternative in the case of kidney failure, this procedure does not sufficiently remove waste products, and the patient consequently feels increasingly ill and increasingly less able to take part in useful activities. Moreover, there is an increased risk of life-threatening infections and cardiac problems. Life expectation after transplantation is considerably greater (Wolfe 1999), and if we add the serious burden of dialysis to the list, it becomes quite clear that transplantation is a type of aid to people in dire straits for these patients as well, despite the fact that transplantation also involves problems and risks.

Are donors in a unique position to provide aid? Not in the first instance, since other donors would also be able to help the same patient. But if there is an efficient allocation system operating within a certain region, such as Eurotransplant, a recipient can be identified for each organ that becomes available at a certain point in time. Therefore, everyone who bequeaths usable organs after their death is in a unique position to help specific individuals, thereby taking into consideration the fact that one donor can sometimes help four or more patients.

The third characteristic poses more of a problem. What burdens are imposed on people by regarding them as potential donors? To start with, there is only a very small chance (approximately 0.4%) of people actually being able to be donors after their death. Some people are afraid that doctors will not do all in their power to save their lives if they expect to be able to harvest their organs, but this fear is unfounded. Most people are not personally very interested in what happens to their organs after their death, since these organs – to quote Thomas – are no longer of any use to them. Some people feel it is important that their dead body remains intact for a while, although this wish can only be fulfilled for a few days at the most. Almost everyone would like their bodies to be treated with respect after their death, but there is absolutely no question of any lack of respect when removing organs for transplantation. Finally, there is one category of people who have articulate or less articulate religious objections to the removal of organs. Insofar as these people are orthodox Christians, Muslims or Jews, these objections are based on ignorance, and it is an important task for the clergy to dispose of these misunderstandings (Cantarovich et al. 2007).42 Most religious objections arise from strictly individual convictions, which is typical of religious practice nowadays.

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42 These authors have established a ‘disastrously low level of knowledge of religious precepts’ among the better-educated part of the population in three European and two South American countries.
Nevertheless, such objections can weigh so heavily that our third characteristic – relatively few costs for the help required – is not complied with.\(^{43}\)

In order to evaluate these costs, we should not only examine the deceased’s interests but also those of his next of kin (see also section 13), since the interests of people who share their lives with one another are so intertwined that costs incurred by the next of kin can also be regarded as posthumous costs incurred by the deceased. For the next of kin, the removal of organs means a certain intrusion in the bereavement process, and sometimes there is additional time involved in the preliminary acts necessary for organ transplantation. The question of donation usually arises in situations where the family are stricken by the sudden demise of a loved one, and these incidental ‘costs’ are far from trivial under circumstances which are already extremely onerous. Nevertheless, they may be regarded as relatively limited in relation to the interests of the recipients. It has also emerged from research that the donation procedure does not result in permanent psychological problems for the next of kin (Cleiren & van Zoelen 1998, Cleiren & van Zoelen 2002\(^{44}\)).

All things considered, it can be argued that post-mortem donation also complies with the third characteristic of a situation where there is a duty to help those in need, and thereby with all the characteristics (Menzel 1992, Gutmann 2002, Glannon 2003, Hacker 2004, Hester 2006, Howard 2007).\(^{45}\) There is one exception to this in any event, which is in the case of grave religious objections. What are the consequences of this with respect to the desired decision system?

If the duty is enforceable, this leads us to conscription. For this reason, it is not surprising that an increasing number of authors have spoken out in favour of a conscription system to combat the continuing scarcity of donor organs (Dukeminier & Sanders 1968, Harris 1983, Jonsen 1988, Rakowski 1991: 170, Hoerster 1998, Knoeppfler 2000, Harris 2003, Spital & Taylor 2007).\(^{46}\) Advocates and opponents of a conscription system often believe that the system presumes that the state, or society, has a right of ownership to dead bodies (Knottenbelt 1970, Farsides 2000, Kluge 2000, Emson 2003)\(^{47}\), although there is no need for this presumption. It is entirely normal that

\(^{43}\) In the light of this third characteristic, the fact that haemochromatosis patients are excluded from regular blood donation because blood has to be taken from them at regular intervals anyway (see section 6) is especially curious. Surely it would rather be a reason to prefer these donors.

\(^{44}\) ‘Participating in an organ donation procedure neither hinders, nor furthers, the process of grief afterwards.’ (Cleiren & van Zoelen 2002: 845)

\(^{45}\) Childress 2001 also arrives at this conclusion, in which he sees an ‘overlapping consensus’ between religious traditions and progressive morals. Strangely enough, he does not link this to the conclusion that default should lie in donation, cf. also Etzioni 2003, discussed in section 12.

\(^{46}\) Until recently, Spital was one of the main advocates of the compulsory-choice system. One of his arguments is that ‘the cadaver ... has no autonomy and cannot be harmed’ (Jonsen 1988). Although this is true, it does not mean that the person who was once alive cannot be harmed after his death by e.g. defaming him or failing to carry out his last will (Feinberg 1984, chapter 2).

\(^{47}\) ‘(T)he human body can only legitimately be regarded as on extended loan from the biomass to the individual...’. (Emson). The fact that the state does not own the organs removed is already proved by the fact
affairs falling within our power of disposition carry burdens and obligations with them. For example, citizens generally regard being liable for tax as a compulsory contribution to the duties of the state, to be defrayed from their own resources. Only one or two economists consider gross income as public property that merely flows through private funds for administrative reasons.

If a conscription system were introduced, an exception should be made for people with conscientious objections, in particular objections of a religious nature. The reason for this is that as far as these people are concerned, the third characteristic of a situation demanding an obligation to help people in need is not met, i.e. that the costs incurred are relatively limited. This immediately creates the problem of how to differentiate between genuine conscientious objections and refusals that can be represented as conscientious objections. A conscription system would not be feasible unless we are prepared to implement an extremely strict test regimen to check this.

Another consideration which can lead to the same conclusion is that a difference of opinion may exist among reasonable people with respect to the question of whether the third characteristic is really complied with, i.e. not only whether the recipient’s interests are considerable but also whether the costs for the giver – and especially for his next of kin – are relatively limited.\(^{48}\)

If, for the above reasons, we decide against regarding the duty to help as enforceable, this still leaves us with a serious moral duty. We can even mitigate the moral claim a little further, drop the notion of ‘duty’ and just maintain it as a morally desirable action, provided that the moral weight of the claim is greater than that of a supererogatory act. In that case, donation is not a minor act of moral heroism: it is assuming one’s responsibilities towards others. If we follow this line, we can defend making donation the default; organ donation is ‘normal’, although we are entirely free to refrain from donating.

This brings us to the no-objection system (English & Sommerville 2003, Savulescu 2003). Under this system, ‘no objection’ is not interpreted as ‘presumed consent’, i.e. as a realisation of the right to self-determination. The purpose of the system is to do justice to the moral weight of the claim to help others in an emergency without resorting to coercion. Those opposed to the system sometimes see little or no difference between the no-objection system and the conscription system (Veatch 1995). True, both systems – with the exception of the ADR variant of the no-objection system – allow infringements of the right to self-determination. However, the no-objection system allows people to evade their duty quite simply, so there is no question of coercion. The fact that people

\(^{48}\text{A third possible reason for not regarding the duty as enforceable is that not only people’s money or work are impounded but also their bodies, albeit merely their dead bodies (Gutmann 2002). See section 8 for details.}\)
have to take the initiative themselves in order to evade their duty is not unreasonable, since it shows that they have a serious reason for doing so.

Looking at it from the point of view of help in an emergency, the ADR variant of a no-objection system does not have any particular advantages or disadvantages. The only factors in favour of this variant are the general consideration that government actions should be as transparent as possible, and that imposing burdens on citizens of which they are unaware is therefore undesirable. If we allow people to object to donation, we will also have to accept delegation to the next of kin, since people may then regard the burden that donation lays upon their families as being too heavy. In that event, it is reasonable to also permit them to leave this consideration to their families. However, the default lies in donation and not in delegation. Taken from the starting point of our duty to help others in need, the role of the next of kin under the present system is incomprehensible.

8. Organ transplant as a social benefit

Why is it necessary to impose taxes, and why are public services not financed by voluntary contributions? The standard answer is that the state bears responsibility for the production of public amenities. When a dyke is built, for example, everyone in the area protected by the dyke keeps their feet dry, regardless of whether they helped to pay for the construction or not. Since it is impossible to demand an admission fee for the use of public amenities, economists conclude that rational benefit-maximising individuals will not voluntarily contribute to the production of these amenities. It is not necessary for these individuals to deplete their own bank accounts if other landholders make a sufficient contribution, since they will benefit from the dyke anyway. And of course there is no point in paying by oneself if the others do not pay either. The production of public amenities is a Prisoner’s Dilemma, and the solution to this problem has already been proposed by Thomas Hobbes: coercion by the state.

This line of reasoning invites argument on a number of points. If everyone’s sole ambition is to maximise their own benefits, this means that the state itself consists of such individuals, so it can only be coincidence if it turns out to be to their advantage to use coercive measures in order to produce public amenities. Moreover, socio-psychological research shows that people are actually not only interested in maximising their own benefits; they are theoretically quite willing to make a reasonable contribution to cooperative efforts that are to their mutual advantage, on one condition: that they can count on others contributing, too. And this is often a bone of contention. In a classic survey into tax ethics, citizens can choose between three descriptions of tax payment: "I’m making a contribution", "I’m giving something up" and "something is being taken away from me". During a recent repeat of this survey in the Netherlands, 79% of the MPs
and as many as 59% of the tax consultants chose "I'm making a contribution", although only 15% of these thought that the majority of other Dutch citizens would make the same choice (Stevens 1997). But this is nevertheless the case: during a previous survey, 66% of all Dutch citizens chose "I'm making a contribution" (Hessing 1987).

Coercion by the state is necessary under these circumstances: not in order to ensure that it is in everyone’s interests to discharge their tax liabilities, but to give everyone a guarantee that a sufficient number of other citizens are doing so as well.49

Incidentally, most of the amenities produced under the auspices of the state are not public amenities in a strict sense, even if these actually exist. Education, medical care, legal aid and even legal proceedings could quite easily be distributed through the market and could therefore be produced for the market as well. We do not like this idea because it would mean that obtaining these services would depend on people’s purchasing power. In some cases this problem could be addressed by allowing the market to provide the necessary insurances, since people who are unable to pay for a long stay in hospital would possibly be able to insure themselves against the costs of such a stay. But this still leaves us with two problems: insurance premiums for individuals will differ according to their risk profile, and we consider this to be unfair. In that case, we would have to be prepared to withhold legal aid and life-saving care from individuals who have not voluntarily insured themselves against such risks, at the very moment when they do require them. And we feel that this is going too far. But this still gives rise to the problem associated with the production of actual public amenities, i.e. providing people who are willing to make a contribution with the guarantee that they will not become victims of their own willingness. That is why we implement a compulsory premium in relevant insurance packages, which also ensures that everyone has equal access to the insured aid.

Coercion by the state has the same moral basis in all these cases: everyone should be expected to make a fair contribution to a cooperative effort to their mutual advantage. Theoretically speaking, this duty is enforceable: citizens should not have to accept the fact that others are taking advantage of their efforts for free. Moreover, it is indeed necessary to enforce the fulfilment of this duty, otherwise citizens who are willing to make a fair contribution themselves will become victims of their own good nature. If this guarantee is not given, it is no longer fair to expect them to pay themselves.50

For that matter, the state also holds itself responsible for facilities which do not benefit everyone, if only in the shape of an insurance against the risk of possible future

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49 Incidentally, this was the very function that Hobbes envisaged for the state.
50 The principle of fairness only creates obligations for those who are personally entitled to a reasonable share in the benefits of cooperative enterprise. It is doubtful whether everyone has this entitlement in the USA, for example (Verheijde et al. 2007, Pennings 2007, but cf. Hanto 2007).
contingencies. An example of this is the care of people born with a serious mental handicap: this type of facility does not rely on voluntary contributions either. The relevant moral principle here is the duty to help people in need which I discussed in the preceding section. There is admittedly one condition for the existence of this duty that has not initially been fulfilled in such cases: nobody is in a ‘unique position’ to provide the necessary help. If the state did not exist, this would mean that such help would not be enforceable: it would have to be left to everyone to decide themselves to which persons they are willing to give such help, and to what degree. This is the situation in the case of serious disasters in far-off countries, where help depends on compassion and charity – not in the shape of supererogatory acts and moral heroism, but of what are traditionally referred to in ethics as ‘imperfect obligations’. Although none of the people who find themselves in dire straits have a specific claim to other people’s help, never lifting a finger to try and alleviate others’ distress is in fact reprehensible. There is no question of any absolute non-commitment (O’Neill 1996).

Uncoordinated efforts of this kind fail seriously as far as efficiency is concerned; it is the state’s task to coordinate these efforts. This task means distributing the aid itself, as well as the contributions needed for such aid, as fairly as possible and will ensure that each citizen will once more be in a ‘unique position’ to make a certain contribution towards a certain objective. Once this coordination has been achieved, not evading the contribution asked is once again a question of fairness. In this case, the principle of fairness presupposes the more fundamental duty to help those in dire straits.

Therefore, there are two types of collective activity: cooperation for mutual benefit and organised aid for those in need. However, not all collective activities can be unequivocally put under one of these two headings. There are also collective efforts which benefit all participants, but not equally, and where the disadvantages are not distributed in proportion to the advantage enjoyed. This means that some participants give a certain degree of ‘help’ to others. Examples of this include the aforesaid health insurance where premiums are independent of the risk profile, or the construction of dykes, which is also contributed to by people living in regions well above sea level. The moral motive required in such situations is a mixture of fairness and altruism, which we could refer to as ‘solidarity’. One shows solidarity with the people with whom one works. Cooperation is aimed at the production of goods that benefit everyone. But people who show solidarity with others are not only interested in the advantages to themselves, but also in the advantages to those they work with. That is why they accept the fact that contributions to cooperative efforts are distributed according to people’s means and not purely according to profit.

The contribution required is usually a financial one. This is preferable, since it gives individuals maximum freedom to decide themselves what efforts they wish to make in
order to discharge their obligations. It also ensures that all benefits of the distribution of labour are achieved when bringing about the desired provision.

However, a financial contribution is not always possible, and in that case, we have no problems asking for contributions in kind. All citizens are required to sweep the snow off the pavement in front of their houses (although they can always ask the neighbours to perform this office for them), all citizens can be called upon to appear as witnesses in court cases, and they can also be called up for jury service in other countries. We have already seen that anyone failing to help a fellow human being in danger of his life is liable to a maximum of three months' imprisonment. Vaccination may be compulsory for epidemiological reasons, while national military service was compulsory in the Netherlands not so long ago, and compulsory community service may be introduced in the near future.

A number of criteria for legitimate state tasks follow on from this brief dissertation. If genuine public commodities are involved, the value of the commodity (or a package of such commodities) must compensate the costs of the contribution for all citizens who have to make this contribution. If the commodities involved can theoretically be produced and appropriated through the market as well, they must be essential to alleviating needs that are sufficiently urgent to justify a call for solidarity. For instance, in a decent society, it is unacceptable if no foster family is available for children who have to be removed from their own homes because their parents have abused or neglected them, ‘because the government has to make cutbacks’.

When considering different kinds of government activities, it is possible to debate the question of whether such activities comply with these criteria. Why should local authorities be saddled with the task of supplementing football clubs’ deficiencies so that they can continue to recruit players whose salaries they cannot actually afford? Why should disability insurance be a collective responsibility? No such doubts arise in the case of organ donation. Organ transplantation is unreservedly a form of help to those in urgent need, and the contribution asked of everyone is a modest one, if only because the chances of people ever actually becoming donors are so slight.

If organ donation solely involved helping people in dire straits, this would fulfil all the conditions for regarding it as a social obligation. There is no comparable need in our society where we leave its alleviation to voluntary contributions. However, it is not only a question of helping those in need; it is definitely a question of cooperation for mutual benefit (R.C. Hessing 1984, Dupuis 1987, D.J. Hessing 1993, Koene 2002, Siegal & Bonnie 2006). After all, everyone runs the risk of suffering serious organ failure at some stage, and we know from experience that almost 100% of the Dutch population would like to be eligible for a donor organ in such a situation, regardless of all the more or less fundamental reasons which have possibly prevented them from registering as donors. Admittedly, the risks are not distributed entirely equally among the population, but
nobody is able to fully rule out these risks through their own actions, or insure themselves against them on the market. If there is a reasonable waiting period, everyone can benefit from the assurance that help will be available if the worst comes to the worst. This is therefore the hybrid of cooperation for mutual benefit and coordinated help for those in dire straits that I have already discussed in the foregoing. And that is why an appeal to solidarity is made rather than an appeal to fairness.

One argument that is sometimes used against this line of reasoning is that nobody thinks of donation in such terms. This is not entirely true: an important factor for those very people who register as donors is the fact that they themselves may have to rely on someone else's organs one day. The problem is that many others are unable to see this connection. One important step in the right direction would be to make the following question the first question on the donor form:

- In the case of serious organ failure, would you like to be eligible for organ transplantation yourself?

Therefore, there are two decisive reasons for regarding donation as a duty. Those who register an objection to donation, or who leave the decision to their next of kin (with the considerable risk that they will refuse donation), are consciously or unconsciously (probably the latter) co-responsible for the distress experienced by people waiting for a donor organ. And the sacrifice required is not so great as to prevent us from asking it. For those who consider that the sacrifice is too great, the second argument applies all the more: as long as they have not expressly ruled out the possibility of receiving a donor organ at some stage, they are freely benefiting, consciously or unconsciously, from the efforts of people who are willing to undergo that sacrifice.

Theoretically it is an enforceable duty based on making an appeal to moral motives such as fairness and solidarity, although coercion is desirable in order to provide those motivated by this appeal with the assurance that others are also making a fair contribution. If we consider a conscription system to be undesirable for the reasons I discussed in section 7, the least we can do is to make donation the default and therefore implement a no-objection system (Siegal & Bonnie 2006).

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51 This is an important consideration for 50% of the people who want to donate their organs, and a consideration that counts for 36% of these people (Verzijden & Schothorst 2003).
52 This was proposed by Evelien Tonkens in the parliamentary debate resulting from the Second Evaluation in 2004.
53 For both these reasons, the moral duty to donate organs follows from Kant's categorical imperative. From a Kantian perspective, it is defensible that the duty to help those in need is also based in the last instance on considerations of reciprocity, since each human being may encounter circumstances in which he has to rely on help from others (Loewy 1996).
9. Priority on the waiting list?

However, there is still the possibility that people will evade making a fair contribution, despite the fact that they would like to receive an organ transplant if necessary (then, in any case). Instead of coercion, there is an alternative solution to this problem: limiting the allocation of organs to registered donors, or at any rate giving them priority on the waiting list by giving them a number of additional points according to the Wujciak-Opelz model\(^{54}\) (Lederberg 1967, Hessing 1984, Peters 1988, Kleinman & Lowy 1989, Kittur et al. 1991, Muyskens 1992, Kahan 1992, Jarvis 1995, Breyer & Kliemt 1995, Gubernatis 1997, Schwindt & Vining 1998, Eaton 1998, Gubernatis & Kliemt 2000, Tabarrok 2002, Steinberg 2004, Nadel & Nadel 2005, Giles 2005, Murphy & Veatch 2006, Landry 2006).\(^{55}\)

The main objection to this proposal is that it is diametrically opposed to a legally-enshrined fundamental principle of health care: such care should be given exclusively in accordance with need, not with merit (Gillon 1995, Schenderling 2003, Buijsen 2004, Siegal & Bonnie 2006). This principle has also ensured that up to now, the government has rejected proposals for taking into account the degree in which patients are personally responsible for the state of their health when providing care. Even if such patients are relying on a scarce commodity and could have avoided this situation, this is not taken into consideration when evaluating their claims to care. The patients’ state of health is the sole consideration.

How should we assess this objection? First of all, it should be noted that one form of scarcity is not the same as another. The help required to repair the consequences of an unhealthy lifestyle would not necessarily be given at the expense of other help: it is a question of weighing it up against other spending options. But the number of post-

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\(^{54}\) This system has been in force in Singapore since 1987, in combination with a no-objection system (for non-Muslims) and a consent system (for Muslims). Apparently, however, only a limited number of the population, especially of the Muslim population, are aware of this (Nadel & Nadel 2005, note 97). Living donors should also be awarded at least the same number of bonus points. The United Network for Organ Sharing in the United States has pursued this policy since 2005. One of the frequently-cited practical objections is that people who are unable to be donors, such as children and those infected with HIV, would be excluded from receiving organs or bonus points (Van Dijk & Hilhorst 2007: 18), although an express stipulation could be made for these groups that they would be eligible for organs or bonus points (Steinberg 2004). The same also applies to patients in mortal danger (Gubernatis 1997). Nadel & Nadel 2005: 314-319 cite a number of other problems attaching to implementation and propose solutions to these problems, cf. also Veatch 2004. My own suggestion would be to award bonus points automatically to everyone below a certain age (e.g. 22), while requiring older persons to have been registered as donors for a given length of time at least (e.g. 5 years) before being entitled to bonus points.

\(^{55}\) Some of these authors are in favour of giving people who register as donors the choice of giving priority to registered donors and to make the number of bonus points to be distributed among them depend on the number of people who make this choice, cf. Den Hartogh 2003: chapter 18. Another restriction I proposed there is to use bonus points exclusively for distributing the additional organs which this system would yield compared to the present situation, so that nobody loses out by it.
mortem organs available at a certain point in time is a hard fact. There is admittedly room for manoeuvre in the supply of living donor organs that partly depends on the length of the waiting list for post-mortem organs. But this means that those who refuse to donate organs not only shift the burden on to other post-mortem donors but also on to living donors, for whom the burden is considerably heavier (MacDonald 1997). This makes it all the more harrowing if they would subsequently like to be eligible for an organ themselves.

People like these – and this is the most important point – not only contribute to the scarcity by their claims to care, such as patients with an unhealthy lifestyle, but first and foremost by siding with those who have decided not to contribute to the supply of available organs. We can afford to provide care wherever it is needed, even regardless of how this need arose, because there is a compulsory insurance system to cover the costs of such care. ‘Each according to his need’ can only apply under a system in which the availability of resources for meeting the existing needs is guaranteed in a suitable way. After all, these resources do not grow on trees. Nobody would consider the idea of basing claims to care on the need for such care and subsequently financing the costs of this care from voluntary contributions. Those wishing to adhere to the principle of need with regard to the allocation of organs must be consistent and introduce general compulsory donation (Spital & Taylor 2007).

The principle of distribution according to need presupposes that it is important to meet such a need. Those who adhere to distribution according to need, even if this results in the inability to meet needs, are guilty of a kind of fetishism comparable to that practised by advocates of the ideal of the gift who love charity more than their fellow human beings (Hilhorst 2004, Wilkinson 2003).

Incidentally, compulsory health insurance does not cover all health care. The remainder is not distributed solely according to need, but is exclusively available to people who contribute to the costs of this additional care through supplementary insurance. The only agency that collects resources by calling for voluntary contributions and distributes them according to need is the blood bank, although the supply of blood to date has been sufficient to meet the demand.

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56 That is why donation is not only a question of fairness towards other donors, but also (and primarily) towards recipients who are donors themselves. For this reason, I feel it is unfair to make the number of bonus points depend on the number of donors who themselves attach importance to reciprocity, cf. previous note.

57 The Biomedical Treaty only permits medical criteria to be applied when allocating organs. However, a strict interpretation of this stipulation would also prohibit Eurotransplant from using origin from a certain country as a criterion in order to prevent participating countries from becoming net organ exporters. This actually results in individuals being awarded bonus points for their compatriots’ willingness to donate. The same also applies to using regional donation figures as a criterion. (This could be abolished on the introduction of the individual priority scheme (Gubernatis 1997)). Incidentally, even the waiting period is not a medical criterion, strictly speaking.

58 This does not alter the fact that voluntary blood donors sometimes have trouble with the profiteering attitude displayed by the remainder of the population.
If a person who has not fulfilled his insurance obligations requires health care, he is not entitled to such care, although this does not mean that we just abandon him to his fate even if he were to die. In this case, too, we would not have to exchange the principle of need in its entirety for the logic of insurance. More particularly, we would not have to fully exclude people who are not registered as donors from transplantation; we would merely be able to withhold bonus points from them which we do allocate to registered donors. And there is a second reason for limiting ourselves to this course of action: we are talking about a social benefit, a cooperative enterprise for mutual benefit and for alleviating distress, to which everyone is expected to make a fair contribution. This is quite a different matter than buying oneself into a cooperation that administers scarce organs. Therefore, priority on the waiting list should not be primarily regarded as an incentive to recruit donor registrations, although a slight side effect of this nature would not be unwelcome. The main point is to make it emphatically clear to all citizens that they are being asked to contribute to a social benefit that will also be to their advantage.

A final reason for giving preference to priority on the waiting list rather than exclusion from this list is due to the fact that although this social benefit is to everyone’s advantage, regardless of their genetic constitution and lifestyle, not everyone derives equal advantage from it. If we are going to link contribution to benefit, full and general exclusion of non-contributors would therefore be going too far. If our main objective is to express the fact that it is fair to expect a contribution, even if the benefit attached is not only a form of cooperation for mutual benefit but also a form of coordinated emergency aid, we have no need to aim at the full coordination of contributions and benefits.

A second frequently-voiced objection to the proposal to give registered donors priority on the waiting list is that objections to donation may genuinely be prompted by motives that weigh heavily for the individuals involved. These should not be lumped together with pure indifference and conscious parasitism and as such, they do not deserve to be penalised (Ravelingien & Krom 2004, List 2004, Mackor 2004). The example that is often cited is that of religious objections against donation. This is a characteristic example: after all, people who sincerely believe that the premature loss of an organ would be deleterious to their next stage of reincarnation should be the last ones to expect others to lose organs too, and would therefore not consider themselves entitled to receive organs. Such people do not regard the loss of this entitlement as a penalty but as the

59 Incidentally, one should not attach too much importance to the effectiveness of an appeal to people’s self-interest. For most 18-year-olds, the possibility of organ failure is so far in the future that they will not attach very much importance to insuring themselves against it at present.

60 This may be the reason why, out of all systems that introduce incentives for donation, priority on the waiting list still encounters the least objections from the public: 41% of Americans (Spital 2005) and 44% of Dutch (www.eenvandaag.nl/docs/opiniepanel/nierdonatie/uitslagorgaandonatie.pdf).

61 For this reason alone, it can be argued that priority on the waiting list is compatible with Article 2 of the Organ Donation Act: “Consent to the removal of an organ, granted with the object of receiving compensation for this removal … shall be void.”
consequence of their viewpoints. Even people who are deterred from donation by vague fears must surely be aware that these indefinable dangers also threaten the individuals from whom they wish to receive donor organs (Den Hartogh 2004b). Those who refer to ‘penalties’ and ‘rewards’ with regard to the allocation of bonus points are assuming that the ‘normal’ distribution is according to need, so that each deviation from this requires special justification. In a cooperative enterprise, however, ‘normal’ distribution is determined by coordinating claims to contributions. If refusers do not lose more than a part of their claims, they are therefore being reprieved instead of penalised.

A third objection is that the bonus point plan is based on too limited a notion of relevant contributions. A criminal sentenced to life imprisonment who is a registered donor is awarded bonus points, while an individual who has served society in all kinds of ways, but who refuses to register as a donor in order to spare his family’s feelings, is not awarded any such points (Burdick et al. 1993, Biller-Andorno 2004, Hackler 2004). This objection largely derives its oratorical power from the foregoing. If we leave out any connotations of rewards and penalties, we see that organ transplantation cannot be anything other than an independent social benefit that cannot be mingled with other collective efforts on behalf of the public good. The reason is that this benefit depends on contributions in the shape of organs that cannot be exchanged for other contributions such as money. As a comparison, let us imagine that a remote village is threatened by imminent flooding, which makes dyke surveillance imperative. Everyone in the village over a certain age has to participate in order to make this surveillance effective. If one person refuses to cooperate and the dyke subsequently bursts at the very point where this person should have been standing, he can hardly use the argument that he had already done so much for the community as an excuse.

Looking at it from the point of view of fairness, we have a moral duty to contribute, not only to a system of cooperation for mutual benefit, but also to a system of organised emergency aid and therefore to obtaining post-mortem organs for transplantation as a hybrid between the two. Although there are reasons for allowing people to evade this duty, this must have consequences for their own claims to organs. These considerations give rise to a preference for a no-objection system supplemented by a priority scheme for registered donors (Loewy 1996, Eaton 1998, Robertson 2004).

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63 For the same reason, it is also incorrect to say that a regulation demanding additional contributions from people whose need for care is due to their own lifestyle ‘penalises’ such people. They are only prevented from shifting the consequences of their personal choices on to others.
64 That is why it is disputable that the bonus points regulation is ruled out by the ban on rewards in the European Biomedical Treaty.
10. Preliminary conclusions

A number of remarkable conclusions can be drawn from this overview of the various moral perspectives.

It is difficult to find a sound justification of the present non-absolute consent system. Although this is an attempt to compensate for the limited yield from an absolute consent system, it departs from the essential characteristic of a consent system, i.e. that the default lies in refusal. The default is shifted to delegating the decision to the next of kin, and none of the moral principles we have discussed have given us a good reason to do exactly this. Nor is the situation improved by the fact that the next of kin are also expected to cope with the unnecessary and often impossible task of deciding in the deceased’s own spirit. For the time being, we may conclude that although the next of kin are entitled to have their interests taken into consideration, they cannot claim any authority to decide on these grounds. We will consider whether this conclusion can still be revised in section 13.

The compulsory-choice system would overcome these objections. Assessing it from the point of view of the right to self-determination and the ethos of the gift, it is equivalent to the absolute consent system, or at least in its ideal form, where no default is necessary. One problem, however, is that this ideal form is not feasible, so a default still has to be chosen. And the more serious the attempts made to allow everyone to make a choice, the more chances there will be of people refusing in protest.

The default in the no-objection system lies in donation. Generally speaking, this can only be defended from the view that donation may theoretically be expected of everyone on the basis of charity, fairness, or the cross between fairness and charity which I have called solidarity. In that case, donation is regarded as an (imperfect) obligation, or as morally desirable behaviour at the very least. From the point of view of the right to self-determination and the ethos of the gift, however, the no-objection system generally only presumes consent, and presumed consent is not true consent. Consent must be given and not presumed.

Perhaps the most important conclusion up to now is that the ADR system is quite different. From the point of view of duty, the ADR system shares the advantages attached to the no-objection system, and it adds the advantage of maximum transparency. Apart from the important exception of functional illiterates, however, the ADR system involves tacit consent, not merely presumed consent. That is why the ADR system is theoretically compatible with the right to self-determination and the ethos of the gift, provided that a reason is given for interpreting silence as consent and thereby making donation the default. This reason cannot be derived from the right to self-determination; it must be found elsewhere, such as in the duty to help those in dire
straits and/or obligations of fairness or solidarity. I will be considering whether any other options exist in section 15. However, the fact that justifying the default cannot be derived from the right to self-determination does not mean that it would conflict with the right to self-determination, even if this justification were derived from a moral duty.

A certain tension does arise with respect to the ideal of the gift, since this ideal regards the act of donation as supererogatory.

From the point of view of duty, default should lie in donation; this is the most minimal interpretation of the morally privileged status of donation which can be imagined. In this perspective, the absolute consent system is too non-committal, and the same applies to the compulsory-choice system.

Finally, priority on the waiting list for registered donors can be defended on the basis of the fairness principle. Benefits and burdens should be shared equally in a cooperative enterprise for mutual benefit. As in the case of general health care, this can only be effected in two ways: by making contributions compulsory or by making claims depend on contributions.

11. The right to self-determination in the balance

Freedom rights can be deployed on a number of fronts, and this also applies to the right to decide what happens to one’s own body. In the first place, in order to avoid paternalism: restricting people’s freedom in order to promote their interests. This is irrelevant in the context of organ donation. In the second place, freedom rights provide us with weapons against moralism: restricting freedom in order to safeguard decent behaviour, even if behaviour which is considered indecent does not harm anyone. Theoretically, freedom rights permit ‘victimless wrongdoing’ (Feinberg 1988). Considered in this light, it is especially remarkable that up to now, all champions of the right to self-determination in the Dutch debate on organ donation have acquiesced without a murmur in the requirement that donation may only be carried out ‘free of charge’. As we will see later on, it is entirely possible to set up a system of rewards for donation in such a way that it will not harm anyone. The only possible reason for this restriction of freedom is therefore a moral one. And it is not too difficult to identify these reasons: they are all based on the ethos of the gift, which means that we encounter here a drastic restriction of the right to self-determination for the sake of this ethos. I will be discussing which view should be given priority in this conflict in section 14.

65 This also applies if the benefits are not the same for everyone and the burdens are not distributed in proportion to the profits.
The third front on which claims to freedom can be deployed concerns other people’s interests. In contrast to the other two fronts, however, it is obvious that such claims do not apply absolutely on this front. In general, only the presumption of freedom applies to this point with regard to all kinds of behaviour: it is allowed on condition that other people’s interests do not provide sufficient reason to prohibit it. Incidentally, this presumption is unusually strong when it comes to decisions on one’s own body; this is due to the close relationship between people and their bodies. The presumption is the most easily overruled in the case of behaviour which is harmful to others. For these reasons, the scope for people to decide what happens to their bodies after death is, ultimately, extremely limited: they can decide whether they wish to have them buried or cremated, or donate them to science. And that is all.

It is generally assumed that it is easier to justify the prohibition of behaviour which causes immediate damage to others than to make behaviour compulsory that prevents the same amount of damage resulting from other primary causes. Although negative obligations are considered to weigh more heavily than positive ones, nobody can deny the existence of positive obligations, and hardly anyone disputes the fact that these obligations can be enforceable and may therefore lead to the restriction of freedom.

Although ‘making no objections’ cannot generally be regarded as exercising the right to self-determination, there is no question of any coercion in a no-objection system. If it is our duty to do something and we can evade it simply by saying that we do not accept this duty, we cannot claim that we are being forced to do so. However, it is not true either that we are automatically doing it of our own free will. That is clear if we did not know that we had this duty and/or that we could evade it so easily, but it follows on from the fact that nobody asked for our consent. And this problem continues to exist if our families have a right of veto, even if they are expected to use it in our spirit. This is the only point on which the no-objection system actually restricts the freedom that the right to self-determination gives us; it is all that remains of this system’s ‘infringement’ of the right to self-determination, which is always so emphatically claimed. Can this restriction be justified? If there is a duty to help others in dire straits and/or obligations of fairness or solidarity regarding participation in cooperative efforts to the general good, these are certainly of sufficient weight to legitimate significant restrictions on our freedom. However, this would then be on condition that the government makes an adequate effort to inform citizens about the system, and that citizens can be expected to take the trouble to assimilate this information. Citizenship is not free, and people can then no longer use the excuse that they did not know they had the right to refuse. Consent has not been given, but does not need to be given either.

66 Under the compulsory-choice system, the duty to help others in need also justifies a restriction of freedom, although this restriction is only a very trivial one.
Under the ADR system, the government fulfils its duty to provide information as completely as possible. Silence is interpreted as consent: those who keep silence exercise their right to self-determination. I have already pointed out that a residual problem will continue to exist because one group of citizens is not capable of acquainting themselves with the relevant information. However, I should add here that this is a much wider problem. It should not prevent us from regarding the political community as an alliance consisting of actively participating citizens who are aware of their personal responsibilities and who assume these responsibilities.

Apart from this residual problem, we can conclude that, in general, a no-objection system only limits people’s right to decide what happens to their own bodies to a very slight extent, that this limitation is eminently defensible, and that the ADR variant of this system does not even include this minor restriction. Those who do not choose refusal or delegation under this variant may be presumed to give tacit consent for donation. Since this is true and full consent, there is no reason to state in the Donor Register that such consent was given tacitly. The reason for requesting explicit consent in the first instance is not that this kind of consent would have greater authority; the question is only put in this way in order to encourage people to think seriously about it.

How can we account for the feeling that the moral appeal implied under a no-objection system is fundamentally in conflict with the right to self-determination? There are two reasons for this. We often feel that our freedom is being infringed if others point out our moral obligations to us. But the fact that we have the right to make a certain decision does not mean that each choice we make is equally correct; on the contrary, we do not need any right to make the correct choice. What this right actually means is that nobody can prevent us from taking a decision and carrying it out, even if it is the wrong decision. In the same way, the right to freedom of speech allows us to express untrue and even reprehensible opinions.

Apart from the misunderstanding that all moral appeals restrict our freedom, the idea of a fundamental conflict between the no-objection system and the right to self-determination may also be connected with the exceptional nature of this specific freedom right, which does not concern the disposal of time, work or resources but our own bodies. It could be argued that this right takes up far more space than other freedom rights, also when confronted with other people’s major interests. In that case, not only coercion but any form of pressure would be fundamentally wrong.

We would indeed be justified in objecting for these reasons if the government were to promote living donation by putting moral pressure on potential donors. But would this objection also hold true for post-mortem donation? After all, our relationship with our

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67 John Stuart Mill disputes this misunderstanding on the very first page of ‘On Liberty’.
living bodies is a great deal more intimate than that with our dead bodies, if only because we and our dead bodies cannot be in the same place at the same time. Be that as it may, we have no problems whatsoever in linking negative obligations with dealing with dead bodies. However, there is at least one positive obligation that nobody objects to: a dead body may be impounded for autopsy in connection with a preliminary inquiry, and no consent from the deceased or his next of kin is required for this. It is difficult to maintain that the importance of such an inquiry is of a higher order than the interests of patients waiting for a transplant.

It is impossible to register an objection to autopsy before death, and the next of kin cannot prevent an autopsy either from being carried out if the public prosecutor deems it necessary. We cannot draw too many conclusions from this because there are still all kinds of relevant differences between donation and an autopsy. An autopsy may be in the deceased’s posthumous interests, or its objective may be to verify a suspicion of foul play that is in the interest of the bereaved. So the analogy leaves the question open whether we should regard a positive obligation to donate as enforceable or not. I have already cited a number of arguments for not doing so. We can now add the consideration that the demand we make on people by claiming part of their bodies stands out strongly in comparison with other demands such as those made on their property or their work, even if it only concerns their dead bodies. I shall not offer an opinion on whether this consideration is decisive.

12. The ideal of the gift in the balance

We may expect more conflicts to arise between the ideal of the gift and the other principles. The main point under discussion in this respect is the morally privileged status of donation as a duty, or at least as morally desirable behaviour, and not merely behaviour in the category of ‘it’s nice if you do it, but it’s no problem if you don’t’.

We could agree that it is a valuable thing if people decide to register as donors with the primary aim of helping those in need. We do not have to regard this decision as heroic, since the sacrifice that may have to be made is too small in most cases, as is the likelihood of it being made. It is also important to establish that no system whatsoever, not even the conscription system, makes it impossible for people to act from this motive, in the same way that prohibiting murder and theft cannot make it impossible to spare others’ lives and property from an inner conviction.

We can also agree that a system that expresses the value of a gift is morally attractive. Society is enriched by fields that are not dominated by market transactions or government duress. ‘The market is a zone of the city, not the whole of the city.’ (Michael
Walzer). If there was no question of continuing serious scarcity, we could discount the less attractive aspects of a system based on the ideal of the gift.

But this scarcity exists. I have already pointed out in section 6 that this fact causes tension in the ethos of the gift. What should be our first consideration: the value of the gift or the value of giving, the interests of one’s fellow human beings or the interests of charity? What is the meaning of altruism, if not the alleviation of need? But in that case, it surely cannot be the altruist’s intention to maintain existing needs as an opportunity for him to practise his virtue.

This should be a reason for critically examining the ideal of the gift once again. To start with, then, it is important to remember that it is an ideal and not a standard. ‘Donation is a gift’ or ‘should be a gift’ is a misleading way of saying ‘it is desirable that donation be a gift’. An ideal should be adjusted at the very least if it is achieved at the expense of other values and certainly if the values in question are inherent to the ideal itself. Idealism should not cause too many victims.

Moreover, I have already suggested that there are less attractive aspects to the ideal of the gift. Appealing to this ideal is strongly reminiscent of the resistance that accompanied the introduction of the welfare state for a considerable time from the end of the nineteenth century onwards: all charity would be lost if no more appeals were made to it. Perhaps giving is a pleasant thing, but it is less pleasant to receive and it is particularly unpleasant to have to depend on gifts.68 ‘From charity to right’ describes a rival moral view that is at least equally attractive.

All things considered, there is a great deal to be said in favour of this rival view. It is generally accepted that we have a duty to help those in dire straits under the circumstances already described by Thomas: if the emergency is a serious one, if we are in a unique position to provide the necessary help, and if the effort required from us is relatively limited. The shortage of organs would seem to fulfil all the conditions for the existence of this duty. I have already pointed out that advocates of the ideal of the gift often stress the value of this gift by using terms such as ‘the gift of life’. But the greater the significance of the aid, the more self-evident the giving of this aid becomes, even if it involves making certain sacrifices. Nor can it be denied that each and every one of us may some day have to rely on similar help from others, and that it is morally problematic to claim help which one is unwilling to give oneself. It is actually a curious thing that we refuse to admit in this particular case that it concerns a gesture which people really ought to be able to expect from one another, while we accept innumerable, less urgent duties of citizenship every day without demur. We regard organ donation as an act of

68 One of the reasons why relatively few living donors invoked the compensation scheme for loss of income that the Dutch Kidney Foundation implemented on behalf of the Ministry of Health, Welfare and Sport is that people disliked the idea of receiving money from a charitable institution (Prismant 2006)!
charity, but we would not dream of financing health insurance, police protection or water purification purely from voluntary contributions.

I am not objecting to the ideal of the gift placing the emphasis on altruistic motives. On the contrary, what I have referred to as fairness and solidarity are themselves forms of altruism in a broad sense: they are motives that focus on the interests of the person asking for help. What I consider to be problematic is the idea that altruistic actions are regarded as supererogatory in this context: they are commendable to perform, but failure to perform them is not reprehensible. Advocates of the ideal of the gift sometimes seem to think that charity can only be supererogatory, and that the concept ‘charity is a duty’ is intrinsically contradictory. Charity is then regarded in the same way as gratitude. If we do not actually feel grateful, there is no value attached to thanking our benefactors and giving them a present: they would refuse to accept it if they could see into our hearts. Although it is true that helping others as a result of spontaneous solicitude for their plight deserves more appreciation than if this help were given from a sense of duty, it is always better to act from a sense of duty than not to act at all. But the fact that it is better to act spontaneously in accordance with one’s duty than to act from a sense of duty by no means precludes the fact that there is certainly a duty that requires this action. ‘Love thy neighbour as thyself’ is the second commandment in the Bible and is equal to the first commandment. It is not a non-committal desideratum. Throughout the centuries, Christian ethics have therefore never had any problems in acknowledging the duties to our neighbours. We have already seen that Thomas Aquinas considered failure to help people in dire straits to be a mortal sin.

Why do we find it so difficult to speak to people about becoming donors? This may be connected with the special nature of what we are asking people to do. We fulfil most of our civic duties by drawing on our possessions and sometimes our labour. But donation concerns part of our bodies that can be of use to others, and this fact makes us feel uncomfortable, or in the words of some people, ‘the human body is not just a bag full of organs’ (cf. Nagel & Mayer 2003, Van Reusel & Schotsmans 2006). A dead body must be treated with respect as well because it is a symbolic reference to the living person who already deserved the respect of an aim in itself. And even though this respect is merely derivative, instrumental use for random purposes cannot be reconciled with it. For instance, we would raise objections to putting dead bodies in cars for traffic safety tests and letting them crash into all kinds of obstacles.

Cantarovich et al. 2007 have established that in five of the countries they studied, the majority of the population regard donation as a ‘gift’, but also as an individual responsibility towards the community. This is more the case in South American countries (Argentina and Brazil) than in European countries (Austria, France and Italy).

This also applies to gratitude in most cases. Moreover, it can be reprehensible not to feel gratitude as well, and this applies equally to charity.
But why should this provide an argument against organ donation as a duty and not against donation as a free gift? Or people ought to feel that treating a body without respect is not that bad, as long as the individual concerned (or his family?) has agreed to it. Therefore, no objections could be made to the aforesaid traffic safety tests, provided that the only bodies used are those of people who consented to this use during their lifetimes.

One possible response to this objection is that the idea of donation as a duty is based on the argument that recipients have a greater interest in the organs than donors or their families, and that only the instrumental value of the organs is taken into account when weighing up these interests. However, each and every one of us regards what we call the ‘instrumental value’ in this instance, which is considered to be of a lower order, as the fundamental value that our organs have for us: we would not be able to survive if our organs did not function properly. That is why we are willing to undergo ‘repairs’ if we are ill, without complaining that our bodily perception is being put on a commercial footing. What is more, our bodies and their parts have a supplementary symbolic significance for us merely because they are so essential to our existence. So how could this conflict with this symbolic significance if these same organs take on the same function for somebody else?

Our assessment of ‘instrumental use’ apparently depends on the aim of this use. An exhibition of anonymous dead bodies found abandoned in China was recently held in the Beurs van Berlage (in which obviously neither the deceased individuals nor their families were asked to consent to the exhibiting of their bodies). Opinions differ as to whether this kind of exhibition is in good taste, but if the point at issue is saving the life of a fellow human being, it simply cannot be lacking in respect to use part of a dead body for this purpose. On the contrary, this act erects a small anonymous monument to the deceased donor. People who disagree are sacrificing the underlying fundamental value to a symbolic value to which this same symbolic value refers (Feinberg 1985: 75).

Those who feel that even moral appeals are not compatible with the symbolic value of the human body certainly ought to object to legal obligations, especially the possibility of confiscating bodies for autopsy. The body is not a box of exhibits.

The ideal of the gift dominates people’s ideas on organ donation, even among those who maintain that the right to self-determination is all that matters as far as they are concerned. However, the strongest adherents of this vision can be found in Christian Democrat circles, despite the fact that a less non-committal view would fit in very well with their ideological background. Solidarity would be the focal point of such a vision.

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71 It is therefore incorrect to say that the ‘solidarity value’ of the dead body outweighs its desecration (Van Reusel & Schotsmans 2006). There is no question of any desecration.
72 Incidentally, the no-objection system does not place any obstacles whatever in the way of such people.
instead of altruism. A gift presumes a relationship between one giver and one recipient, but solidarity unites citizens in a joint effort to realise a shared interest. A ‘gift’ in this sense is an individualistic notion and solidarity a community-oriented one.

The American sociologist Amitai Etzioni has written an interesting article describing this kind of alternative approach and correctly specifying it as communitarianist (Etzioni 2003). The essence of this approach is that people are invited to regard organ donation as their social responsibility, as something that can be expected of all citizens, just like contributing to good causes, voluntary care for family and friends, and an environmentally aware attitude towards energy and refuse. The government, in communications with the citizens, assumes donation to be the norm. In the light of this, Etzioni proposes a new wording for donor forms whose explicit aim is to induce citizens to donate their organs. “Saving a life is of the highest moral order; there is no greater moral duty than helping to avert a death or great human suffering when one can do so readily and without costs or risk to self. We are sure you agree that the decent, upstanding thing to do is to reach out to others when less is asked of you than making a donation of money or time, which many – surely including you – so generously give when they are able to.”

Strangely enough, Etzioni rejects presumed consent because although it would theoretically do justice to individual autonomy, it would actually be coercive or at least high-handed in practice. We have already seen that there is no question of coercion in a no-objection system, while the ADR variant of this system goes even further by fully respecting the right to self-determination. Proclaiming donation to be the norm on the one hand while maintaining refusal as the default on the other seems to me to be contradictory. And talking of high-handedness, his wording of the donor form could be a bit more subtle, too. It is also interesting that Etzioni announces in his text that the names of all those who register as donors will be published on a website unless they indicate that they would rather remain anonymous. A no-objection procedure is apparently no longer coercive or high-handed on this point all of a sudden.

What Etzioni makes completely clear is that the debate cannot be limited to the desirability of amending the legal decision system. What we basically need is a change of paradigm from gift to solidarity. This change cannot be effected by a legislative amendment alone and it can only be a gradual process lasting for many years. But a change of decision system may be an essential step in this process (Cantarovich 2002, Childress 2006, Van Veen 2007).
13. A gift from the next of kin?

When discussing the four moral principles, we saw that none of these principles, taken separately, was able to justify the task that the present non-absolute consent system assigns to the next of kin: making the decision if the deceased has not done so himself. However, I have promised to return to the position of the next of kin once more in connection with assessing these views. Next of kin in most countries do indeed have the right to decide, even in many countries with a no-objection system; in some cases this right is conferred on them by law.\textsuperscript{73} In France, for instance, the law does not recognise this right, although it is nevertheless granted to the next of kin in practice. And most people are in agreement with this, certainly in the Netherlands.

What should an argument in favour of this right for the next of kin comprise?\textsuperscript{74} To start with, this argument could point out that donation usually demands a greater sacrifice from the next of kin than from the donor. They see their loved one taken in to the operating theatre while he does not yet look as if he is dead, and have to wait until he returns in the shape of a real dead body. Sometimes they have to wait for this during the time that artificial respiration is continued until brain death has been confirmed. And they subsequently have to live with the memory of the whole course of events. “The true gift comes from the family” (Siminoff & Chillag 1999, Lauritzen et al. 2001). The question is whether this interpretation does sufficient justice to the point of view of the next of kin themselves. Generally speaking, their main concern is what the deceased would have wished. And even if they then still consciously decide otherwise, they do not usually do this because they are giving priority to their own interests, but, for example, because they want to protect the deceased’s body and thereby his ‘person’ in a certain sense (Sque & Payne 2007). Insofar as the next of kin are able and willing to bear responsibility for the decision, therefore, they mainly focus on the deceased’s interests as they see them at that moment.

This does not alter the fact that the deceased’s interests are also \textit{their} interests. It would seriously encumber their bereavement and grief process if they felt afterwards that they had failed their loved one at such a crucial moment. However, this is counteracted by the interests of patients receiving donor organs, and it cannot be denied that these interests are greater. But it is not only a question of who has the greater interests: the next of kin have special ties with the deceased that also entailed (during his lifetime) special mutual care and responsibility for one another’s needs. This special relationship gave those involved the right to concern themselves more with each other’s interests than with those of anonymous strangers. It could be argued that such a special relationship still has this

\textsuperscript{73} In Sweden, for instance, although this is known as an ‘non-absolute no-objection system’.

\textsuperscript{74} This argument is rarely found in the literature. Authors who assume a right for the family to decide that is not derived from the deceased’s right to decide do not usually give reasons for this (such as Boddington 1998). The argument I am discussing is briefly outlined in Engberts 2006.
significance, which is why it is proper to give the next of kin priority over potential recipients of the deceased's organs. They are being asked to make a sacrifice, and they are the ones to decide whether or not they wish to make this sacrifice.

How should we assess this argument? Both of the premises on which it is based are indisputable: the next of kin have a genuine interest in the decision on donation, and they (usually) have a special relationship with the deceased. And it is also true to say that this special relationship has a moral significance. In his *Enquiry concerning Political Justice* (1793), William Godwin, the founding father of utilitarianism and anarchism, discusses the dilemma facing us if we are only able to rescue one person from a house on fire: either Archbishop Fénelon (a philosopher who was greatly admired by Godwin), or his chambermaid, who also happens to be our wife, mother or benefactress. According to Godwin, it is a requirement of 'pure, unadulterated justice' to save the philosopher: “What magic is there in the pronoun ‘my’, to overturn the decisions of everlasting truth? My wife or my mother may be a fool or a prostitute, malicious, lying or dishonest. If they be, of what consequence is it that they are mine?” However, anyone able to subscribe in this way to an abstract principle is not capable of forming close relationships. Therefore, morally speaking, there is nothing against our giving particular care and attention to people with whom we have a special relationship; on the contrary, if we did not do this we would demonstrate that we have no sense of the true significance of this relationship. The simple pronoun ‘my’ does indeed contain moral strength.

But is this a sufficient reason for allowing the next of kin to decide? If we take another good look at the duty to help others in an emergency as described by Thomas Aquinas, we see that the giver’s interests and those of the recipient are not simply weighed up against one another. The recipient has to be in dire straits, while the giver should only be required to make a relatively limited sacrifice. In other words, the giver may multiply his own interests and those of the people with whom he has a special relationship by a given factor before he weighs up these interests against the recipient’s needs. The moral significance of the pronoun ‘my’ is therefore already included in the criteria for the existence of a duty to help others in an emergency.

Does this also apply to the obligations of fairness and solidarity? That depends on the nature of the collaborative arrangement within which these obligations apply. Special care relationships are not taken into account in forms of cooperation for mutual benefit in which contributions and profits are directly coordinated. Those who contribute less have fewer rights: the reasons why they contribute less are not important. The situation is different in solidarity communities where the burdens are distributed according to

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75 This should not be interpreted as criticism of utilitarianism in general; utilitarians are able to acknowledge the importance of special relationships and make allowances for them.

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Farewell to non-commitment 64
capacity. When determining this capacity, special duties of care may be taken into account (as the tax authorities do). So the significance of the pronoun ‘my’ is acknowledged here as well, although the multiplication factor that justifies this pronoun is not unlimited in this case either.\(^{76}\) We cannot evade our duty to participate in dyke surveillance during a gale on the grounds that the gale also poses a threat to our bicycle sheds or those of our neighbours.

Even if proprietary rights to dead bodies were to pass to family members through inheritance, the duties we have discussed would still be attached to these rights. In the foregoing, I have stated reasons why the moral duty to donate organs after death should possibly not be regarded as enforceable. In that case, we would have the right to refuse donation despite the fact that this decision is morally liable to criticism. However, the same cannot apply to our next of kin. Even if we had the right to set aside our duty for the sake of their interests, it does not follow that they also have the right to set aside our duty for the sake of their own interests. After all, unlike us, they have to derive their right from the exceptional protection that their rights would deserve.

The next of kin’s right to decide under the present system is sometimes defended with the argument that those who do not take any decision will want their next of kin to do so (on their behalf?). We have already seen in section 2 that this conclusion is premature. What the argument we are now examining really entails is that people who do not register any objection actually \textit{ought} to leave the decision to their next of kin. The next of kin would be entitled to this position because a greater sacrifice is required from them than from the deceased himself?\(^{77}\) But if that were the case, the next of kin should also be entitled to veto the deceased’s own decision to register as a donor. This kind of double veto exists in countries such as Britain. However, it is fairly widely accepted, and in the Netherlands, the Organ Donation Act has stated since 2006 that choosing donation not only means that consent has been given for donation, but also that the next of kin must respect this consent.\(^{78}\) (For the USA, cf. Farsides 2000: 104, with further references; for the Netherlands, cf. Friele & Kershens 2004\(^{79}\)). In that event, the next of kin cannot invoke the special relationship they had with the deceased. This means that they cannot directly derive any right to decide from this special relationship, since they would then be able to exercise this right with respect to the deceased, too. If the special.

\(^{76}\) Probably more limited than in the case of the duty to help others in an emergency.

\(^{77}\) The next of kin also have the right to demand an autopsy. However, there are considerable differences between this decision and a decision on donation, which makes it difficult to regard this as a precedent. For instance, the deceased is unable to take any binding decisions on an autopsy before his death, not even in the form of a veto. In the case of autopsy, therefore, there is every reason to assign the task of representing the deceased’s interests to the next of kin after his death.

\(^{78}\) Why can the next of kin not overrule this choice? One reason could be that we do not want to burden the family with the choice (May et al. 2000), although this already assumes that there are no imperative reasons for putting this burden on the family anyway.

\(^{79}\) 40% of the next of kin concur with their consent not being asked if the deceased is a registered donor.
relationship does have any significance, this is only because the deceased conferred this significance on it before his death.

But the deceased must have explicitly done so. If the next of kin are only entitled to the right to decide after the deceased has conferred this right on them, default cannot lie in delegation. There is one more argument in favour of this definition of the default that I would like to discuss, primarily because it sheds an interesting light on the meaning of default as such. Choosing the default is of immense importance in contract law. Marie Jacob has pointed out that the default in contract law is often determined in such a way as to protect the interests of the party with the weakest negotiating position. After all, if the other party wants to depart from the default, he will be obliged to open explicit negotiations in this respect, which will invariably involve additional costs (Jacob 2006). Jacob is of the opinion that in the case of organ donation, the patients in need of help have the strongest negotiating position, but she entirely disregards the position of the family in the issue. In practice, default all over the world lies in delegation or donation, and for this reason, the question of which party’s negotiating position should be strengthened relates to next of kin and patients. Of these two parties, patients waiting for an organ are clearly in the weaker position. All they can do is wait and see which way the decision will go, whereas the next of kin can make their voices heard there and then. As long as their relative is still alive, they are entitled to information on his treatment. If this relative is not a registered donor, their permission already has to be obtained in the case of ‘preliminary work’. Furthermore, the next of kin are in such a difficult situation anyway that we dislike the idea of confronting them with the additional burden of asking them to consent to donation. Given the situation, it is almost in bad taste to point out their moral duties to them, whether or not such duties exist. In many cases, the doctors who ask for their consent have just had to relinquish their efforts to save their partner or child, and feel jointly responsible for ensuring that the family are able to come to terms with this death as much as possible. All these circumstances contribute towards giving their interests the weight they deserve.

So we see here how we can recommend transferring the default to ‘donation’, without invoking the moral desirability of donation. If we ask ourselves how the interests of all parties concerned are weighed up in the decision-making process, we see that patients waiting for an organ run the most risk of insufficient justice being done to their interests.

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[^80]: In this context, ‘default’ means the parties’ obligations if they have not explicitly concluded any agreements in this regard.
[^81]: Jacob’s argument is that patients are supported by the institutional power of the hospitals, but this is by no means automatically the case. Be that as it may, the transplant specialists are never the ones who ask the next of kin to consent to donation.
[^82]: As well as with all the relevant information that may be confusing, such as the concept of ‘brain death’.
[^83]: Streat’s 2004 plea in favour of the family’s right primarily shows how an intensivist experiences the situation: the person who registered as a donor is dead, potential organ recipients are far away and he is confronted with the family and their grief. An additional factor is that it is the next of kin who influence public opinion by recounting their experiences, and who can also cause a scandal in the media by so doing.
This also emerges from the results of the process, and is an adequate reason for choosing the default in such a way as to strengthen their position.

I conclude that authorising the next of kin to decide within their own right is indefensible, especially if a duty to donate is acknowledged, but also if both the deceased's consent and objection are binding for the next of kin. The fact that next of kin are granted the right to decide in so many countries, sometimes contrary to the statutory regulations, is not based on an adequate moral justification but on the sole fact of their presence on the scene and the special consideration for their circumstances required at that moment (May et al. 2000, Bucklin 2002).

Even if there were a reason for allowing the next of kin to decide if the deceased himself has not registered any decision, this does not mean that we should deliberately keep this option open. The whole idea that we not only ask the next of kin for a gift simply because we have no choice, but also that we make a point of seeking the opportunity to be able to do so, is rather dubious. It is preferable to refrain from asking people for help in an emergency if these people themselves are in dire straits: this is not fair to either the givers or the recipients.84 (Spital 1996). For this reason alone, the fact that we can always fall back on the deceased's own decision under the compulsory choice system or the ADR system is to be applauded. An additional advantage to these systems is that they do not offer any scope for a 'gift from the next of kin'85, as there is no reason whatsoever for creating this scope.

14. Fair pay for a fair job?

I now come to the final issue concerning post-mortem donation: would it be a good idea to introduce financial incentives to encourage donor registration or consent from the next of kin for organ removal? In a recent study, Van Dijk and Hilhorst give an overview of the options for fleshing out this idea. In their view, the most realistic option is paying a certain sum to the next of kin; this sum could be earmarked if desired for contributing to the costs of the funeral or cremation and would be about 2,500 euros.86 I will limit myself to this option because all the relevant fundamental considerations can then be examined.87

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84 According to research by Sque & Payne 2007, 41% of the next of kin decide to refuse consent to donation because the circumstances have already put such a strain on them that they are unable seriously to consider the request for consent.
85 If the next of kin did have the right to decide, we would have to seek serious options for allowing them to exercise this right at a different time as much as possible. One such option would be a registration system where people could record their views on this in advance.
86 The Monuta funeral insurance company offers a discount of 150 euros on the costs of donors' burial.
87 Rewarding those who register as donors is not a good idea because it may decrease the value of registration in the eyes of the next of kin.
We could ask ourselves for whom exactly this incentive is intended: the donor or his next of kin. This depends on the decision system and possibly on the level of registration. Under the Organ Donation Act system, it would primarily be the next of kin. This is problematic under such a system because the next of kin are expected to decide in the deceased’s spirit, not on the basis of their own interests. If we reject the view that the next of kin have independent decision-making power that does not derive from the deceased’s right, this objection applies to all systems where the next of kin have a decisive role, which they do not have under the compulsory choice system or the ADR system. So the proposal to introduce a reward presumes one of these systems. But even then, there will still be a certain degree of friction as long as we keep the option open of abandoning organ removal as a result of continuing opposition from the next of kin. After all, we do this out of consideration for their feelings, and it would be unseemly even to create the impression of wanting to buy off this opposition.

This proposal immediately disposes of one standard objection to ‘commercialisation’: that it would lead to the ‘exploitation’ of socio-economically weaker members of society, or that the burden of donation would be unilaterally shifted on to these people. There can hardly be any question of this with regard to the amount stated. The fact that this kind of proposal has encountered considerable opposition from society up to now is mainly due to the dominance of the ethos of the gift. Both aspects of this ethos, which I have distinguished in section 5, are of importance here: accentuation of the value of altruism and of the specific significance of the human body.

First of all, altruism: there is naturally no question of altruism if the individuals concerned or their next of kin decide to donate organs in order to claim the reward. But as a gift, donation is an ideal and not the norm: the government cannot force people to donate from certain motives only, all they can do is propagate the ideal and encourage its realisation. There is no valid reason why people who currently donate from altruistic motives would no longer do so if a reward were introduced; this would merely create a potential additional motive. No realistic interpretation whatsoever of the ethos of the gift could include the objection that altruism is being mixed with other motives. That is why nobody objects to the tax-deductibility of donations to good causes, which nevertheless rewards the giving of gifts and thereby makes it more attractive.

This reward on the part of the tax authorities may be seen as a token of appreciation for the altruism displayed, and any reward for organ donation should preferably be regarded in the same way. We need not conceal the fact that we anticipate a stimulating effect on

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88 This would be no different if the money were intended for an altruistic purpose. The ideal of the gift demands that the gift itself may not be given on condition of a *quid pro quo*.

89 This would be different if market prices were paid, see section 19. And I consider it not unlikely that people who are currently registered as donors will lodge an objection in order to protest against the introduction of rewards.
people’s willingness to donate as a result. The amount of the reward should serve to express the fact that such rewards supplement the appeal to altruism rather than replace it, and this message can be reinforced by earmarking rewards for a purpose that is appropriately connected with contact with the deceased’s mortal remains. In that event, the message is that donation is appreciated and encouraged, not bought.

We will have to wait and see whether the measure will be generally construed in this way. The existing opposition to all forms of reward indicates that this is widely regarded as being in conflict with ‘the nature of donation as an act of charity’. Insofar as this conflict exists, how should we assess it? A consideration that I have already put forward applies once more to this point. If an appeal to altruism does not result in enough donations to meet the present need, it is the altruists who should ask themselves how their fellow citizens can be more effectively helped. And if this means that they are less able to fully achieve the ideal of the gift, then so be it. This ideal will have to be weighed up against other values, especially against the very value which constitutes the foundation of the ideal: helping those in dire straits.

From the point of view of the ethos of the gift, however, we can formulate a second objection to a reward system. I argued in the previous section that the removal of organs for transplantation does not affect the respect due to the deceased. But will this respect remain intact if the immediate aim is to pocket a certain sum of money instead of helping people whose lives and health depend on a transplant?

This objection, too, does not do sufficient justice to the proposal to offer a fixed and relatively modest reward. After all, this proposal does not entail paying vendors the market value of the goods for sale. However, let us imagine that this were actually the case: would this condemn the proposal? There are diverging views in our society regarding the symbolic significance of a large number of matters, and this also applies to the human body. Moreover, there is a difference between speaking of the whole body or merely certain of its parts, and in the latter case, which parts. For some people, the deceased’s heart has a special meaning, while for others this is his brain. There is also a substantial difference between references to a dead body or a living one. The nature of the transaction also makes a difference: whether people are giving away their kidneys free, for a fixed reward, or for the market price. And the ultimate objective of the transaction definitely makes a difference, too. Even if those Chinese corpses’ families had given their consent for the exhibition in return for payment, we would be more likely to object to this than to payments for organ donation.

Matters that have an associative significance or symbolic value within a society are not a natural fact of life but a question of convention. In our society, the symbolic significance

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90 For reasons such as these, even registered donors make exceptions, and many people will hesitate to permit the transplantation of faces, hands or genitals.

91 Wilkinson 2000: p. 198 is too eager to deny this, cf. also Van Dijk and Hilhorst 2007: pp. 28-29.
of a kidney (belonging to a dead person) is not such an obvious fact that we are generally able to say that the granting of exchange value shows a lack of respect and should therefore be banned. A satisfactory principle for political ethics in such situations is to let people follow their own opinions. The government itself may then be expected to show restraint, particularly if large numbers of citizens hold objections. But in that case, we should note on the one hand that the proposal in favour of a fixed reward does not reduce the value of the organs in question to the monetary value of the reward, and that it can also be interpreted as a token of appreciation for donations. And on the other hand, we should note that an emergency may constitute a reason to shelve certain scruples. If we have to choose between a symbolic value and the ‘true’ value of the object symbolised by this value, we have no choice but to join Feinberg in choosing the second one. If introducing a reward were the sole option, or the most promising one, for substantially increasing the supply of post-mortem organs, we would seriously have to consider it for this very reason.\footnote{This also applies to those who feel in principle that donation is a moral duty. Such people are likewise guilty of a kind of fetishism if they attach more importance to social recognition of this duty than to the realisation of what this duty requires.}

Although I have hitherto only looked at the proposal from the point of view of the ideal of the gift, the other three moral principles also merit an examination. From the point of view of the right to self-determination, giving people this additional option can only be welcomed. I have already expressed astonishment at the fact that even the most staunch adherents of the right to self-determination have so tamely acquiesced in restrictions on their freedom for ‘moralistic’ reasons.

The other principles involve more problems. If donation were linked to a reward, the government would be confirming that donation is the most socially acceptable conduct, which gives rise to two questions. Firstly, are the efforts that citizens are required to make so great that they should remain purely optional for this very reason? And secondly, do citizens themselves gain such a considerable advantage from others’ efforts that we are justified in asking them to make a fair contribution themselves? I have contended that the answer to the first question is ‘no’ and the answer to the second question is ‘yes’. But in that case, people should in principle be expected to donate organs, even though it is made so easy for them to avoid doing so. Moreover, it would be strange to reward people for conduct that is expected of them.

This also makes it understandable why the tax-deductibility of gifts is bound to a threshold of 1% of the contribution base. The ethos of the gift assumes that giving is supererogatory, but this is actually incorrect. It is only correct to say that people are free to decide to what causes they wish to give, which is why none of the potential recipients...
have any right to the gift.93 This does not alter the fact that it is perfectly normal for people to donate modest sums to good causes; rewarding them for this would create the wrong impression. Only those who do more than others deserve special recognition.

But if incentives help, should we not introduce them anyway? If there is one thing we have definitely learnt from the history of the debate on donation, it is the importance of the way in which people conceptualise organ donation, and for this reason, creating conflicting impressions is not desirable. If we follow Etzioni’s views and regard donation henceforth as a form of solidarity that citizens theoretically owe one another, we should not simultaneously transmit the message that donation is an act deserving special recognition and therefore a reward. In essence, this would again make refusal the default, with all the associated consequences.

This is a fundamental consideration, but at the same time it is a consideration of effectiveness. Introducing a reward system is not without risks. (Arnold et al. 2002, Van Dijk & Hilhorst 2007: 20, Pennings 2007).

15. Conclusion: at the crossroads

The Organ Donation Act system is bankrupt: there is absolutely no justification whatsoever for making delegation to the next of kin the default, and this deficit is not even compensated by an adequate yield. In the light of all the facts, we have a choice of two alternatives. We could choose the first alternative on the basis of the conviction that there are compelling moral reasons for donating organs, and that for this reason, the choice for donation should be made less non-committal. This would first mean changing over to a no-objection system, preferably the ADR system, which would make donation the default and thereby propagate the message that donation is the socially preferable choice. In actual fact, the government has already been disseminating this message for many years by explicitly setting itself the policy objective of obtaining more post-mortem organs. The time has come to act more consistently in this regard. Since non-registration under the ADR system may be considered as tacit yet true and full consent, the right to self-determination is not impaired in any way whatsoever. And there is therefore no reason to differentiate between explicitly given and tacit consent in the register, let alone attaching to it any consequences for the next of kin’s right to decide. If the deceased is a registered donor, talks with the family should be based on the assumption that he is a donor.

In particular, continuing along these lines should mean laying full emphasis on considerations of fairness and solidarity. This could first be achieved by explicitly

93 In ethics, this kind of duty without any corresponding rights is traditionally known as an imperfect obligation. One of its characteristics is the bearer of the duty’s scope for assessment concerning the further substantiation of this duty, although the option of doing nothing is not included in this scope.
including a question on the donor form asking whether the person concerned would like to receive an organ if necessary, and subsequently by introducing priority for registered donors on the waiting list.

If we choose the second alternative, no assumption is made of anything resembling a moral ‘duty’ to donate organs. In this case, the principles of the policy remain the same as those in the Organ Donation Act: the right to self-determination and the government’s task to do its utmost to meet the need for organs. The compulsory-choice system, which theoretically has no default, provides a satisfactory substantiation of these principles. We could then consider rewarding donation, although this would actually make refusal the default again. Incidentally, bonus points for registered donors would fit in very well with this approach, too: this merely expresses the fact that those who make an autonomous choice must be prepared to accept the consequences of such a choice. If we choose this second alternative, we would still have every reason to make donation less non-committal.

It would be nice if the choice of one of these two alternatives could be made consistently and clear-sightedly. In order to achieve permanent improvements in the long term, the prevailing idea of donation as a spontaneous gift to a good cause would have to be replaced by the idea of a free choice with consequences attached, or a contribution to a solidary community. This will be the easiest to achieve if these ideas are not continually competing with one another.

This consideration can itself be an important factor in the choice of a decision system. I argued in section 4 that the ADR system achieves all the aims of the compulsory-choice system without any sanctions having to be introduced. In the preceding section, I indicated that – even apart from a moral duty to donate organs – there are reasons for making donation the default. The fact that the government has legitimately set itself the task of encouraging an increase in the supply of post-mortem organs actually is already an adequate reason. These views advocate also giving preference to an ADR system rather than a compulsory-choice system if the second alternative is chosen. However, it cannot be denied that the ADR system implicitly creates the impression that choosing donation is morally preferable.

Which of these two alternatives should we choose? My readers will not be surprised to hear that I prefer the first alternative. This preference is based on fundamental considerations as well as considerations of effectiveness, which are basically no less important. With regard to the fundamental reasons, I shall be brief: donation is indeed morally desirable behaviour. With regard to effectiveness, I shall first examine the second alternative and then the first one.
In cases where the decision is explicitly or tacitly left to the family – i.e. about 55% of the Dutch population – donation is refused in two-thirds of these cases. If the compulsory-choice system were introduced and the 55% were forced to make a choice, the ratio between consent and refusal is expected to be considerably more favourable. This expectation is based on the fact that the majority of the Dutch people – albeit a shrinking majority – generally hold positive views on donation. For exactly the same reason, the government expected the majority of the population to register as donors when the Organ Donation Act was introduced, or at least expected more people to register than those who actually did so. The explanation is that the abstract view of donation as such only constitutes one single factor that people take into account when considering whether or not to become donors. Other such factors include doubts about brain death, uncertainties about religious standards, concern about the family’s bereavement process, and so on. Since it is difficult to weigh up all these heterogeneous considerations, this creates a deadlock in decision-making. Up to now, people have reacted by postponing registration and eventually abandoning it, but if this is no longer possible, refusal is the most probable reaction (‘I can always change my mind’). After all, ‘not acting’ is the natural default, whether the system includes any default or not: people seek positive reasons in favour of donation, not in favour of refusal. An additional factor is the problem of the sanctions, which we discussed in section 4: the more effective the coercion to make a choice, the more resistance this will cause, and people will express this resistance by refusing as a matter of course. This effect will also apply to people who hitherto decided against registering because they did not want to think about the end of their own lives, or because they were indifferent to the entire issue. The effect is intensified if such coercion is exercised at inopportune moments, such as when obtaining passports or driving licences, although it is difficult to devise equally effective forms of coercion.

In addition, there are also risks attached to financial rewards (and to bonus points): these are inherent to all system changes. Even now, there are people who are threatening to revoke their donor registrations if a no-objection system is introduced, apparently because they feel that the government no longer appreciates their charity. There is probably a level of reward in existence that would be sufficient to result in a significant increase in the number of donations. But it is not certain at present which level this would be, partly because rewards would emphatically make refusal the default again. And the options for increasing the supply are limited by the donor potential (Gutmann 1991). The higher the reward offered, the heavier the fundamental objections will weigh from the point of view of the gift, which can persuade more troubled parties to drop out. All this could result in a spiral of registering and cancellation.

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94 See note 117.
95 Cf. note 18.
96 Despite the fact that it would theoretically be possible to eliminate the scarcity completely without resorting to living donations, cf. Kaserman 2006.
16. The significance of defaults

Although there are also risks attached to adopting a no-objection system, these do not seem to be too great in the preferred variant of the ADR system (Friele en Kerssens 2004). But is it realistic to expect this system to result in an increase in the supply of organs? The prevailing opinion among experts a few years ago was that the nature of the default was immaterial, since the family are ultimately and universally the ones who decide (Veatch 1991, Van Dijk 2002).

This opinion is supported by the (neo)classical economic theory. This theory states that the choice people make is determined by their preferences: it makes no difference whether they have to achieve this by confirming or denying a default. However, more recent insights into the way in which people actually make decisions, most of which have developed within the Tversky and Kahnemann school, have led to completely different views on the significance of defaults. Preferences are not only an input in the decision-making process; they are also partly formed within this process. First of all, the context within which the decision has to be taken plays an important part in this. People who would choose donation for themselves after a period of quiet reflection beforehand may very well decide to refuse if they have to make this choice as next of kin at the moment they hear that their beloved partner or child has died. This may be the case even if they have reason to believe that the deceased held the same opinions as they do. (This is one cogent reason for bringing decision-making on organ donation forward as much as possible). Secondly, preferences for certain options apparently depend on the way in which these options are conceptualised, and defaults are an essential element in this (Johnson & Goldstein 2003, Johnson & Goldstein 2004). A classic example is the difference in their choice of chemotherapy between people who have been told that they have a 50% chance of dying or people who have been told that they have a 50% chance of survival. The second group more frequently decides in favour of chemotherapy. The first group focuses on potential deterioration, while the second group concentrates on potential improvement; people consider it more important to avoid loss than to gain an equally large profit.

The default indicates what the ‘usual’ decision is, thereby determining where the onus of proof lies in order to depart from it. People only take a positive decision if they have a clear reason for deviating from the status quo. In principle, this is not unreasonable because there are generally less costs attached to maintaining the status quo than to

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97 See however Van Dijk 2004, with a more pessimistic estimation of the ‘dilution effect’, which we will be discussing below.
98 The default plays a part in this as well, see note 8.
99 The authors give some interesting examples of the effect of defaults on people’s choices of insurances and savings schemes.
departing from it. If the default lies in refusal or delegation, it is not surprising that less than half of the population choose donation. This is all the more true because there are so many people who do not want to think about the choice or who remain ambivalent; none of these people have a decisive reason for abandoning the default.

If this explains the significance of defaults, the question still arises as to whether the ADR system is compatible with the right to self-determination as I claimed in section 3. If we make donation the default, does this not mean that we are manipulating people who are not actually able to make a positive choice in favour of donation, into the role of donors? The crux of this argument lies in the word ‘actually’: it suggests that people ‘actually’ adopt a position to which their ultimate registration does not do justice. However, the message is here that the position people adopt is not fixed at the start of the decision-making process, but is determined by this process: there are no fixed preferences that deviate from their decision. And that is also why only their decisions should count, not their presumed preferences.

Incidentally, if this argument were to hold good, it would argue equally well against a consent system or a no-objection system. It would be just as problematic to make vacillators refusers as it would be to make them donors.

If defaults did not make any difference, we could expect to find approximately the same number of people who are registered donors in countries with a consent system and those with a no-objection system. In actual fact, of the countries with a consent system, the Netherlands has by far the greatest number of people registered as donors (about 30% of the entire population), while Sweden has the lowest percentage of registered donors among the countries with a no-objection system (about 85%). Although the fact that people in countries with a no-objection system are not always aware of their status definitely plays a part in this, it only explains part of the difference at the most.

Of course, the core question is the effect that this difference in status will ultimately have on the yield of donor organs. This is primarily determined by the meaning that the next of kin attach to this status, which in turn partly depends on what information this status gives them on the deceased’s views and decisions. But another part of it depends on the significance of defaults.

In the Netherlands, the opinion that the choice of default makes no difference has been vigorously propagated in the reports accompanying the Second and Third Evaluation of the Organ Donation Act (Friele et al. 2004, Friele et al. 2007). For this reason, it would be useful to assess these evaluations on this point. The evidence contained in these reports is based on three types of study results.\(^{100}\)

\(^{100}\) For more comprehensive considerations, see Den Hartogh 2004a and Den Hartogh 2005.
First: The Netherlands Institute for Health Services Research (NIVEL) carried out an international comparison for the Second Evaluation. If we look at the numbers of donations effected per million inhabitants, we immediately perceive that the countries in Europe with the highest numbers all have a no-objection system (Dutch Health Council 2003: 50). This, however, could be explained by the fact that these countries have a higher donor potential due to larger numbers of fatal casualties caused by brain haemorrhages and accidents, especially road accidents. In the light of this, Coppen et al. compared three countries with a (so-called) consent system with seven countries with a no-objection system, based on the donor potential in each country. They concluded that no systematic difference existed.

However, we could question this conclusion on a number of points. For instance, the far from unfavourable position occupied by the three countries with a consent system is entirely due to the Netherlands occupying third place. But we only hold third place because Coppen included the NHB (non-heart-beating) donors in the total number of our post-mortem donors. NHB donation is carried out on a far larger scale in the Netherlands than elsewhere, and although some of the NHB donors might also be HB (heart-beating) donors and would possibly become HB donors elsewhere, this is certainly not true of all NHB donors. We can therefore conclude that the Netherlands has partially compensated an extremely unfavourable position resulting from its (in itself wonderful, of course) low donor potential by specialising in NHB donation. However, if the Netherlands drops a couple of places, the top half of the ranking list will be exclusively occupied by countries with a no-objection system (Den Hartogh 2004a).

One thing that would really be useful to help us determine the effect of the choice of default is a comparison of the percentages of family refusals for each country. Strangely enough, this has never been systematically investigated, although there is a distinct impression that these percentages are indeed much lower in countries with a no-objection system at the top of the ranking list than in the Netherlands.\textsuperscript{101}

The results of a number of other international comparative studies have meanwhile become known (Gimbel et al. 2003, Johnson & Goldstein 2003, Johnson & Goldstein 2004, Roels et al. 2004\textsuperscript{102}; Mossialos et al. 2008). It seems we are forced to conclude that the no-objection system provides better prospects than the (non-absolute) consent system. The study conducted by Abadie & Gay is especially significant; it compares 29

\textsuperscript{101} The percentage in Spain was 20% in 2003, see: www.msc.es/Diseno/informacionProfesional/profesional_trasplantes.htm. A percentage of 15-20% has been reported for Belgium, see www.demaakbaremens.org/download/MeerLezen-Orgaandonatie2.pdf.

\textsuperscript{102} These authors have calculated a procurement efficiency index for 14 countries. Austria and Spain head the list and the Netherlands occupies twelfth place. The difference with Coppen et al. is partly explained by the fact that Roels does not limit himself to the 1-64 age category among CVA patients in his calculation of the donor potential.
countries, taking not only donor potential but also cultural factors into account. They conclude that if the effect of all such differentiating factors is neutralised, the yield in countries with no-objection systems will be 25-30% higher than in countries with a consent system. Since these kinds of comparisons are extraordinarily complex, the results should be regarded with the necessary caution. Nevertheless, they weigh more heavily because the recent insights into the significance of defaults give rise to anticipation of this kind of difference.

**Second:** Another method of determining the significance of defaults is holding a survey among the public, in which a representative random section of the population are asked what they would do if the law were changed. A survey conducted by NIVEL for the Second Evaluation showed practically no differences in anticipated yields under the present system and under a no-objection system. However, at the Minister’s request, NIVEL carried out a supplementary study in 2004 into the effects of implementing the ADR system (Friele & Kerssens 2004). This was repeated in 2007 (Friele & De Jong 2007). The respondents in the random survey were asked whether they would fill in the registration form, which choice they would make, and whether they would respect their relatives’ registered status if they were confronted with it as a next of kin. The result in 2004 was that the number of donations would increase from 214 to 272 annually. However, the researchers were of the opinion that this result was a flattering one. In particular, they anticipated that more people would register an objection or would delegate the decision to their families if the system really were implemented.

But the effect of the default is not empirically determined in this way; it is postulated *a priori*. And this is done in a way that is diametrically opposed to what we have meanwhile learnt about the effect of defaults. What this type of study confirms over and over again is notably that people attribute more decisiveness to themselves than they actually show. In 2004 as well as in 2007, no less than 80% of the respondents said that they would fill in the form if the ADR system were introduced: this is an utterly improbable percentage. But the corrections that the researchers proposed in 2004 merely served to increase this percentage for the categories of refusal and delegation (Den Hartogh 2005). The researchers themselves have meanwhile realised this and are now assuming that 50% of the Dutch population will actively register. Despite the fact that the responses in the second survey were far less favourable than in the first one, they still found a slight increase in the number of donors upon the introduction of the ADR system (from 201 to 215 donors).

A second question is how the next of kin will react when they are told that the deceased was a registered donor. If it is unclear whether this registration is based on explicit or

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103 In that case, only 12% of the Dutch population would be registered as donors because they did not fill in the form.
tacit consent, it is likely that the next of kin will be less inclined to respect this status than at present. Although registered consent is currently respected by the next of kin in 92% of cases, only 62% of the respondents in the latest NIVEL survey say they will actually abide by this consent if the deceased is registered as a donor under an ADR system. But here it is assumed that the deceased’s registered status only serves as relevant information for his next of kin. If, on the other hand, there is not only a change in the law but also in the approach to the next of kin, the dilution effect need not occur to the same degree. And that is where profit can be gained.

Third: But in that case, is there any point in changing the law if this profit can be gained from the approach to the next of kin?

The Third Evaluation Report contains an account of a study examining the relationship between the law and the actual situation in a number of countries. The results confirm what we already knew: in many countries with a no-objection system, the family are approached in a way that does not correspond to the statutory regulations. In particular, the family are still asked an open question about consent if the potential donor has not registered an objection, even if the law does not provide any scope for this. In France, for instance, the law has stipulated since 1976 that in the absence of any living will on the part of the deceased, the next of kin are only asked what he himself would have wished, although in practice, the next of kin are almost invariably asked to make a free decision (Nowenstein 2008). The researchers conclude from data such as this that the law makes no difference because doctors simply adhere to their own standards anyway.

They do, however, admit that the approach to the next of kin in Austria and Belgium fits in better with the statutory regulations in force there. The family are informed that the deceased did not register any objections, and the removal of organs is usually only abandoned if the family explicitly opposes and continues to oppose it. The report does not include Spain in this category because families in Spain are actually asked for their consent, despite the fact that under Spanish law, the next of kin may only be asked if they are aware of any objections on the part of the deceased (Matesanz 2001). However, it is generally known that Spanish families are approached with the specific aim of obtaining consent one way or the other (Matesanz 2003).

Spain, Austria and Belgium are nevertheless some of the countries with the highest supply of post-mortem organs and – to all appearances – the lowest percentage of

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104 The Royal Dutch Medical Association (KNMG), among others, recommends maintaining the difference between explicit and tacit consent in the register. However, this would give families the impression that tacit consent is not true consent, which might increase the dilution effect.

105 From her account, it emerges that the French government transmits conflicting signals in its policy. But in that case, it is going too far for her to conclude that governments are basically powerless against the informal standards prevailing in practice.

106 Matesanz also incorrectly concludes that the law is irrelevant.
refusals from the family. Therefore, the correct conclusion seems to be that success depends on two essential conditions: a statutory no-objection system and an approach to the family that fits in with this system.\textsuperscript{107}

We could contest this by saying that the ‘correct’ approach to the family is enough in itself, also without having to amend the law. This may emerge from a considerable increase in the number of donations in a region in the United States where the approach has been altered but the law has not.\textsuperscript{108} In the Netherlands, too, some hospitals have far better results than others (Jansen et al. 2004, Van Dijk & Krom 2004), and it seems reasonable to suppose that this is due to differences in the way the family is approached.\textsuperscript{109} (Cleiren & Van Zoelen 2002). If all hospitals employed the best practices, there would be no need to change the law (Van Dijk & Krom 2004).

This view does not consider it a problem if the legislator turns a blind eye while common practice develops autonomously.\textsuperscript{110} But if the deceased’s name does not appear on the Donor Register, the Organ Donation Act does not provide any legal scope for an approach to the family other than asking them an open question. If the legislator welcomes an approach that focuses on donation, he should make a start by creating legal scope for this.

This is even more true in view of the fact that the government itself is already promoting this other approach by pursuing a targeted policy. Since 2006, donor recruitment has no longer been an obligation for hospitals to fulfil to the best of their ability; it has become a delivery commitment. This means that institutions have to ensure that donor recognition is as effective as possible and the number of refusals by families is ‘kept to a minimum’ (Letter from the Minister of Health, Welfare and Sport dated 28 April 2006, House of Representatives: 2005-2006, 28 140, no. 31). But if the next of kin have just as much right to refuse as to consent, reducing the number of refusals cannot be a policy aim. This resembles Vladimir Putin’s idea of democracy, where everyone is free to vote for the party of their choice provided that the United Russia party obtains a majority. Both objectives of the Organ Donation Act (see section 1) have come into open conflict with one another as a result, and this conflict can only be resolved by changing over to a system in which donation is the default.

\textsuperscript{107} Research has confirmed that it makes a major difference if the approach to the next of kin is neutral or pro-donation (Sanner 2007).

\textsuperscript{108} Delaware and parts of Pennsylvania and New Jersey. For a detailed account of the recommended presumptive approach, see Zink & Wertstein 2006. It is remarkable that the authors do not see any tension between this approach and a decision system that makes refusal the default. Incidentally, it seems likely to me that the extremely directive approach as described by the authors would be counterproductive in the Netherlands, see note 111. This does not alter the fact that the principles are defensible.

\textsuperscript{109} However, Friele et al. 2006 mainly attribute the differences between hospitals to differences in the causes of death. After accounting for this factor, only 7 of the 80 hospitals researched significantly deviated (downwards) from the rest.

\textsuperscript{110} Naturally, discrepancies between the law and practice in itself is something that the legislator cannot ignore.
It is therefore of considerable practical importance to do this. It will bring about an essential change in the context within which talks with the next of kin are held, at least in cases where the deceased has not specifically delegated the decision to them. With regard to such cases, the law should stipulate that the family be informed of the intended removal of organs. Even if doctors are still willing to refrain from removing any organs for reasons of consideration if the family continue to oppose it, it would legitimize conducting the talks with the purpose of achieving organ removal, to which the donor himself gave his essential consent. In almost all cases, this objective can be reached in a way that takes account of the next of kin’s legitimate interests and respects their close relationship with the deceased, so that they can reconcile themselves to the state of affairs now as well as in hindsight (Blok 2005).

But is it a good idea to allow the same people to hold these talks with the family as the ones who have done so up to now? There is a risk that the talks will then be conducted in the same manner. The donor recruitment pilot experiment with requesters in the Rotterdam area in 2004 did not result in a significant decrease in the number of refusals by families because requesters were used to ask the family about donation in only one out of every three cases. In Spain, on the other hand, the question on donation is asked by special donation officials, which seems to be the main explanation for the success achieved in that country (Matesanz 2003).

Some important steps have already been taken. In order to ascertain whether the institutions are fulfilling their delivery commitment, each potential donor is examined to see whether donation has actually been effected and if not, why not. This information is registered for each hospital, which makes it possible to offer supplementary training or assistance if the number of refusals by families remains too high. Although performance-related pay is not recommended (Van Dijk & Hilhorst 2007), this data can also play a part when assessing the question whether a given institution’s donor programme is adequate and whether it qualifies for full compensation. Institutions can then consider using trained requesters themselves.

Expectations should naturally be limited, even in the best cases. A waiting list that has taken many years to build up cannot be reduced to reasonable proportions in a couple of

111 Practice alone will show which approach has the best results in this regard. It is very well possible that talks should to start off by ‘informing the family of the intended removal of organs’, that the persons initiating the conversation should not take too directive an attitude and should refrain from primarily making an appeal to moral motives. A respectful and sympathetic approach is essential (Blok 2005, Friele et al. 2007: p. 111) and moreover, it is required in itself as well.  
112 See the glossary.  
113 “Compulsory deployment turned out to be unfeasible, and in most cases the doctors said they wished to ask the question themselves.”  
114 There are also fundamental reasons for giving preference to talks being conducted by people other than the doctor who attended the deceased. Be that as it may, it is of the utmost importance that the question of donation is not mentioned during the same interview in which the family are informed of their relative’s death (Cleiren & Van Zoelen 2002).
years, while a change in attitude towards donation can only establish itself gradually. The way in which the donor potential develops is of crucial importance in this respect, especially the question of whether further improvements are possible in the treatment of subarachnoidal haemorrhages caused by CVA.\textsuperscript{115} It is also important to know whether the possibilities of NHB donation have been exhausted, particularly in cases where NHB donation could just as well (and therefore possibly better) have been HB donation.\textsuperscript{116} If we examine the entire donor recruitment chain, we see that considerable improvements have been achieved in many fields during the past years, especially in the field of donor recognition. The number of transplants using post-mortem organs raised considerably in 2007, and the waiting list was reduced. As far as that goes, the ‘flanking policy’ adopted after the Second Evaluation may be described as successful, although the number of refusals by families has remained more or less constant.\textsuperscript{117} This problem persists even after having done everything possible under the present system to increase the supply of organs. The only solutions to this problem are a different decision system and a corresponding change in the approach to the next of kin.

17. Living donation: outstanding issues

I have hitherto dealt solely with post-mortem donation. Although living donation has meanwhile become an almost equally important source of organs, especially with regard to kidneys, I will be devoting less attention to this. The reason is that there is a large degree of consensus on the ‘decision system’ for living donation: potential donors themselves make a voluntary and well-considered decision. This is due to the special bond we have with our (living) bodies, which makes the right to decide what happens to our own bodies one of the most fundamental freedom rights: it is an important element of the basic human right to physical integrity.

There are nevertheless some misunderstandings about the conditions governing voluntariness (Den Hartogh 2008). For instance, some people imply that donating organs from a sense of duty is a breach of voluntariness. It is true that in general unseemly to remind potential living donors of their duty, not because it would jeopardise the voluntary nature of their decision, but because a possible duty can only arise from their special relationship with the recipients. It is up to them to assess the nature and

\textsuperscript{115} According to information obtained through mediation by A. Hoitsma, this treatment has improved during the past years (by ‘coiling’), although this mainly concerns patients with relatively favourable prospects. Nowadays, patients with brain death cannot be reanimated by coiling either, at least not at present.

\textsuperscript{116} On average, organs from HB donation are of better quality. A recent programme to replace NHB donation by HB donation wherever possible appears to be successful in view of the donation figures for 2007. This programme is currently being evaluated.

\textsuperscript{117} A drop from 70% to 65% in 2007 put us back at the 2005 level. For a number of years, this percentage has been calculated on the basis of the MSO computer program, which increases its reliability. The figure for 2007 is based on nationwide aggregation of the MSO data at all IC departments (information from the Dutch Transplant Foundation). Jansen et al. 2007 found a percentage of 59% of refusals by families in the MSO data for 2001-2004 at 30 hospitals.
significance of this relationship. Parents of young children may be an exception to this rule because they themselves have assumed a special responsibility for these children by begetting them.

Although consensus on living donation is widespread, it is not comprehensive. There are two points that are currently being debated: first of all, the question of who would qualify as donor, or to be more precise, which combinations of donor and recipient we consider to be acceptable. The second point under discussion is the most controversial of all issues concerning organ donation: the acceptability of payment for living donation.

When living donation was first introduced, it was only permissible between blood relations for immunological reasons. Since these reasons no longer apply, it is generally accepted that other persons with a close relationship to one another – such as partners, non-related family members and friends – can help each other through donation. There have been a few people right from the start who offered to donate one of their kidneys to an unknown patient to be selected from the waiting list. Anonymous donors such as these were initially regarded with deep suspicion because there were some doubts as to their sanity. And this is one of the innumerable paradoxes in the debate on donation: once we have found the perfect altruistic donor, we think he must be mad. Anonymous donation has meanwhile become an accepted phenomenon, albeit a rare one (Dutch Health Council 2003: 139-140). However, another possibility is that anonymous donors may wish to donate their kidneys to a specific person only, such as a Dutch celebrity or a child who has been in the news. These donors may also wish to give their kidneys to members of a special category such as children, Muslims, non-Muslims and so on. Although the Minister of Health, Welfare and Sport authorised earmarked anonymous donations in 2004, these donations are not accepted by any Dutch transplantation centre as far as we know.

Sometimes people are willing to donate to partners, friends or relatives, but do not qualify for such donations due to different blood groups. One solution to this could be to find another donor-receiver couple with the same problem, only with the opposite blood group apportionment. This is known as paired donor exchange and is accepted without question in the Netherlands, unlike the USA or Germany. This is another remarkable fact, since in this case the organs are clearly not donated ‘free of charge’, but in order to receive a quid pro quo in the shape of another organ, which is contrary to the paradigm of the gift. Perhaps it is not immediately noticeable because the ultimate aim of the transaction is still an altruistic one, although the same can be said of many transactions on the market. Most goods purchased on the market are probably intended for use by people other than the buyers themselves, which explains why the shops are busiest in December.

118 Usually AB and BA respectively.
If this option does not provide a solution, candidate donors could also consider donating their kidneys to the waiting list, on condition that the intended recipient then receives the first suitable kidney that becomes available to the waiting list. In a recent report (Dutch Health Council 2007; cf. Den Hartogh, forthcoming publication), the Dutch Health Council rejected this living donor list exchange (LDLE). The main reason for this is that this kind of exchange with the waiting list contravenes an elementary requirement of procedural justice: equal treatment for equal persons. Under a system where goods are distributed on the basis of certain relevant criteria, we cannot permit some individuals to secure priority for themselves by virtue of actions that have nothing to do with these criteria. In this case, the objection to ‘jumping the queue’ weighs all the more heavily, since although the total supply of kidneys for the waiting list is increased, this is at the expense of one category of patients: those with blood group 0, who have the longest waiting time anyway. The rejection of this system has meanwhile been endorsed by the Minister of Health, Welfare and Sport, and I have nothing to add to the Health Council’s line of reasoning.

On balance, the only option out of all the above that deserves a separate discussion is earmarked anonymous donation.\footnote{Another important question is whether the options for organ donation by children should be extended. This question is too complex to discuss within the framework of this study, however.} I shall naturally devote the necessary attention to the question of rewards as well.

18. \textit{Primum non nocere}\footnote{Volenti non fit iniuria. When deciding to authorise earmarked anonymous donation (see section 17), the Minister of Health, Welfare and Sport invoked the right to self-determination, thus implicitly invoking the volenti principle, which states that any act to which we have consented cannot wrong us.}\footnote{Volenti non fit iniuria. When deciding to authorise earmarked anonymous donation (see section 17), the Minister of Health, Welfare and Sport invoked the right to self-determination, thus implicitly invoking the volenti principle, which states that any act to which we have consented cannot wrong us.}

With regard to both remaining issues on my agenda, it is important first of all to raise the question of why living donation should be admissible at all. The removal of a kidney from a healthy individual does not involve any major risks for this individual, either during the operation or – as far as we are aware – in the long term. Nevertheless, surgical intervention is not entirely risk-free (4 or 5 deaths out of every 10,000 operations), nor is it without considerable inconvenience. For this reason, it is absolutely imperative that the donor is fully informed and voluntarily acquiesces in the removal of the organ. In addition, this involves medical intervention that turns a healthy person into a patient instead of vice versa, which is all the more reason why consent is essential and the criteria for assessing the voluntariness of this consent must be stringent.

Although obtaining consent is vital, is it sufficient? Does it justify doctors’ violation of the old rule of \textit{primum non nocere} (first, do no harm)? Some authors feel that it does (Harris 1992, Veatch 2000, Steiner & Gert 2000). They have to invoke the \textit{volenti} principle, which states that any act to which we have consented cannot wrong us.\footnote{Volenti non fit iniuria. When deciding to authorise earmarked anonymous donation (see section 17), the Minister of Health, Welfare and Sport invoked the right to self-determination, thus implicitly invoking the volenti principle, which states that any act to which we have consented cannot wrong us.} But consent is
not generally accepted as being sufficient justification for violating the most fundamental human rights such as the right to life, liberty and physical integrity. We would consider it legally and morally unacceptable to imprison someone permanently, even if he has given his consent to this in the presence of witnesses. Terminating someone’s life at his own request is generally regarded as a crime, even in a country like the Netherlands where some exceptions to this prohibition exist. With regard to physical integrity, we accept consent as a justification of minor infringements of this right, but not for major infringements such as amputations. We are only able to establish the boundary between major and minor infringements in a fairly arbitrary manner, and the European Court of Human Rights has left this decision to the discretion of national legislators.\textsuperscript{121}

In addition, professional medical acts can actually never be justified only by invoking the \textit{volenti} principle. To quote the Medical Treatment Contracts Act (WGBO), doctors must comply with professional standards and treat patients with due medical care, which expresses standard medical ethics on this point. If doctors involve a patient in a medical experiment involving certain risks, it is not enough that the patient has consented to the experiment if it damages his health: the experiment also has to serve an important medical purpose, the risks and inconveniences attached to the experiment must be in proportion to this purpose, and they must always be limited. We could ask ourselves whether even the undisputed and considerable interests of organ recipients are sufficient to justify burdening donors with the risks and inconveniences attached to a nephrectomy, even if these donors have given their consent. Would we allow an experiment involving similar risks and inconveniences to be carried out?

I readily admit that this is a borderline case on which reasonable people may hold differing opinions. Be that as it may, we can conclude that it would be nice if we could find an additional justification for living donation. That would at least serve to increase our faith in the correctness of this act: this is all the more so when discussing transplants of parts of the liver and lungs instead of kidneys, since the risks and inconveniences involved are greater in such cases.

One proposed additional justification is as follows: A number of authors contend that a nephrectomy is ultimately justified by the interests of the donors themselves (Sauder & Parker 2001, Spital 2004), provided that we look at donors’ interests in the widest possible sense and do not limit ourselves to the interests of their health. This proposal, too, contains some paradoxical aspects. If the sole aspect that justifies organ removal is the donors’ interests, how can we simultaneously expect them to donate organs from primarily altruistic motives? In actual fact, donors’ motives will usually be even more

\textsuperscript{121} Laskey, Jaggard and Brown vs the UK, 19/2/1997: member states are entitled to decide at their own discretion.
mixed with regard to living donation than to post-mortem donation (Lamanna 1997, Lennerling et al. 2004). In the case of people who have intimate relationships with one another, increased well-being of the one often automatically means increased well-being of the other. They may be able to undertake new, interesting activities together after transplantation, go on holidays, and so on. If the health of the one improves, this soon means less duties of care for the other. The interests of people who feel responsible for each other’s well-being, and who regard this responsibility as a central and meaningful element in their lives, are even more closely interwoven. If someone’s dearest wish was to have a child, nothing can be more important to them than to see that child survive and recuperate.

So we see that donation indeed frequent involves benefits to the donor. Despite this, I feel that the proposed justification is too easy, since it ultimately does insufficient justice to the tremendous diversity of possible motives for donation. As I have already pointed out, a sense of duty may constitute a significant motive for some donors (and even for some parents), and it is surely going too far to say that it is in people’s own interests to be able to fulfil their duty. But is this a reason for refusing such donations? If donations can only be justified by the donors’ own interests, it would not be sufficient for us to assess the voluntariness of the decision to donate either. We would then have to explore the donor’s motives more thoroughly than we consider seemly.

One last objection to this proposal is that it does not do justice to donors’ own viewpoints. After all, they do not say to the transplantation team: ‘Please remove my kidney because I am sure it will do me so much good.’ They are more likely to say: ‘Please let me do what I feel I have to do, whatever the reason may be.’ It is this request that invites a positive response, whether their motives are altruistic or egoistic, and whether they are based on a specific sense of responsibility or a general sense of duty.

In this case, the one principal fact that justifies us in acceding to a potential donor’s request is that he has a special care relationship with the intended recipient. In his book *Transplantation Ethics*, Robert Veatch claims that the well-considered consent given by an adult of sound mind is not merely an essential condition but also a sufficient one to accept him as a donor (Veatch 2000). But he then goes on to discuss the option of ‘donation’ by legally incapable persons, particularly young children. He contends that if a young child is able to be of tremendous help to another family member by doing something or undergoing something which only involves minor risks and inconvenience for the child, it may be regarded as that child’s duty to give this help. He cites the

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122 It has even been suggested that donors benefit from the opportunity given to them to perform an altruistic act (Levinsky 2000: Maeckelbergh & Verkerk 2006). During the development of US law, the psychological advantages for donors did indeed constitute the reason why living donation is no longer regarded as assault (Russell & Jacob 1993, Crouch & Elliott 1999).

123 In the case of benefits such as increased self-respect, we could also ask ourselves whether donors could not achieve this in a less burdensome and perilous manner (Steinberg 2004).
example of a nine-month-old child that can donate bone marrow to its sister who is suffering from leukaemia.\textsuperscript{124} He considers it disputable whether kidney donation should be included in this category (donation of a lobe of the liver would be out of the question).

But if this is at least conceivable, consent need not have the exclusive significance for the justification of living donation that Veatch wants to attribute to it, since it would then seem reasonable to suppose that parents definitely have a duty to donate a kidney to their child if necessary (Glannon & Ross 2002). After all, parents are jointly responsible for their child’s existence: that is why they bear greater responsibility for their child’s welfare than brothers and sisters do, who have not chosen each other. Of course, this is not an enforceable duty: free consent is still essential. But it is only essential and not sufficient; the parents’ duty of care substantially contributes towards justifying the decision to respond to the offer of donation.

As I have said, we should not assume beforehand that other friends and relatives have this kind of special responsibility; it is up to them to decide whether this is the case (English 1979). But if our relationship with a kidney patient is an incentive for us to consent to donation, we may assume that this kind of special care fits in with the nature and significance of this relationship. And this may justify the transplantation team performing a nephrectomy, even if this is harmful to the donor.

If this analysis holds water, our initial doubts about accepting anonymous donation were not that incomprehensible, although we did not give the right reasons (Henderson & Landolt 2003). If we are unwilling to base our opinions on the *volenti* principle, it is not clearly admissible to subject anonymous donors to intrusive surgery such as a nephrectomy. If we still feel it is admissible, it may be because these people have taken on a special responsibility to contribute towards alleviating this specific need in the world. We could use the word ‘vocation’ to describe it. In such cases, it is essential that they register as donors entirely on their own initiative. This distinguishes their consent from the consent given by participants in a medical experiment who have been invited to take part. However, for this to qualify as a ‘vocation’ in this sense, there must be a serious scarcity of organs. If sufficient organs were available, we would have to reject anonymous donation (in the same way as we would have to reject living donation if there were a sufficient supply of post-mortem organs, despite the considerably superior quality of living donor organs).

These considerations do not automatically apply to earmarked anonymous donation, and in particular to donation to one specific person. We cannot assume a special duty of care on the basis of a ‘relationship’ with someone who does not even know we exist.

\textsuperscript{124} Under the Organ Donation Act, this is probably the only case where obtaining tissue from a person considered to be legally incapable might be acceptable.
special relationship cannot be merely imaginary (Ankeny 2001). And since this person’s need is no greater than anyone else’s, we cannot have a preference for him on the grounds of a special vocation. Moreover, if this kind of specific earmarked donation were permitted, it might persuade potential recipients to make appeals for such donations. This would entail a kind of legal inequality because not everyone has the same degree of access to the media.

Another objection to anonymous donation to specific individuals is that it results in certain people on the waiting list receiving ‘preferential treatment’ in the same way as LDLE does. The normal allocation criteria are not applied irrespective of persons (Ankeny 2001, Dutch Health Council 2003: 138, Zink et al. 2005, Hanto 2007). Of course, this is equally true of living donation to acquaintances. The difference is that we are able to approve and even appreciate favouritism between people who are close, which is the only reason why we accept that living donation to acquaintances bypasses the waiting list.

The situation is more complicated with regard to anonymous donations focusing on specific categories of people. Some of these categories appear to be innocuous: people who feel it is their vocation to do something about the general shortage of organs are just as likely to feel it is their vocation to do something about the shortage of organs for transplantation in children. Other categories are more problematic, in particular exclusions from one’s favourite category. It is doubtful whether it is possible to draw up general rules with the desired level of fine-tuning, which may be a valid reason for abandoning the introduction of earmarked anonymous donation.

This line of reasoning could be countered with the argument that paired donor exchange should also be regarded as problematic, since there is no question of a special care relationship between the donor and the recipient. Both donors only donate a kidney to a specific recipient in order to receive a kidney in return. However, this description of the situation probably does not do justice to the way in which those involved experience it. They both share the problem that they need a donation but cannot obtain one directly; this shared problem involves a certain solidarity that may be taken into account. This interpretation is supported by the surprising degree in which donors who are able to help a related recipient are nonetheless willing to participate in a donor exchange. There should therefore be room for this kind of asymmetrical donor exchange.

125 That is why a defence like Hilhorst’s of earmarked anonymous donation on the grounds of the moral significance of special relationships is unconvincing (Hilhorst 2005, Hilhorst et al. 2005).
126 If the public consider the system unfair for reasons such as these, this may indirectly have a negative effect on the supply of organs. For this reason, Pennings 2007 rightly states that if an organ is lost due to the non-acceptance of an earmarked offer, the responsibility lies with the person who earmarked the offer.
127 Is it therefore unjust to donate an earmarked gift in the case of famine or a tsunami? No, because there is no coordinated allocation system for the entire affected area in such cases.
128 31% according to Kranenburg 2007, chapter 8.
If the only factor that can release doctors from their duty to do no harm is a special care relationship between donors and recipients, the closeness of this relationship must obviously be in proportion to the extent of the damage. So perhaps we should only allow parents, partners and extremely close friends to donate a liver lobe, and certainly not accept any anonymous donations of this type.\textsuperscript{129}

19. Rewards for living donation?

As with post-mortem donation, I shall limit myself to one specific proposal when discussing rewards for living donation. This proposal involves paying a fixed sum to each living donor (unless these donors refuse payment, of course), which could be effected through mediation by the Dutch Transplant Foundation, for instance.\textsuperscript{130} This is attractive from the point of view of cutting costs because there would be no more costs for dialysis (this naturally does not apply to other organs such as livers and lungs). To give us some idea of the reward, Hoitsma suggests 50,000 euros (Hoitsma 2007), while Van Dijk and Hilhorst propose exempting donors from paying compulsory health insurance premiums for the rest of their lives (Van Dijk & Hilhorst 2007).

There is no question of a real ‘market’ in living organs in this proposal (cf. Erin & Harris 2003), since there is only one demander and the suppliers receive a fixed reward instead of the market price. This approach therefore disposes of all kinds of alleged adverse effects of a market in organs, such as an inadequate check on the voluntariness of the suppliers or possible ‘exploitation’ of the socio-economically weaker members of society.\textsuperscript{131} We already encountered the main objections to this proposal when examining the question of rewarding post-mortem donations: they are the impairment of the altruistic nature of donations and treating bodies as merchandise. Since both these objections can be countered with the same arguments I put forward when discussing rewards for post-mortem donations, I will not repeat them. The objection on the grounds of the desirability of altruism is even less convincing in this context because the diversity of possible motives for living donation is so great anyway, including motives of legitimate self-interest. Paired donor exchange actually involves a real exchange transaction: donors give the organ to recipients because they receive something in return. Conversely, the objection to treating an object with a practical value as an object with an exchange value carries more weight rather than less in this context. After all, the associative link between an individual and parts of his body is indisputably greater during his lifetime than after his death. There is therefore a widespread view that the ‘sale’ of

\textsuperscript{129} As advocated in Consensus Statement 2000.
\textsuperscript{130} By limiting myself to this proposal, I am also disregarding the complicated international aspect of the issue. For an overview of data on the existing international trade in organs, see Shimazono 2007.
\textsuperscript{131} Specified by the Dutch Health Council 2003; pp. 142-144.
organs demonstrates the sellers' lack of respect for their own bodies. Nevertheless, the question is whether the conventional assessment of the symbolic value attaching to living kidneys, livers and lungs is sufficiently unambiguous to prohibit rewards for this sole reason.

But there are two other objections to the proposal that we can put forward; these objections have hitherto received less attention in the literature. In the preceding section I raised some questions on the proposition that a donor’s consent alone is sufficient to justify the removal of his organs by a transplant surgeon. Of course, the fact that the donor gives his consent for the sake of financial gain does not resolve the problem. This is the first objection.

The objection is of a different nature than the classic arguments that we have just examined. The reason for a ban on rewards is not a ‘moralistic’ one: behaviour that does not harm anyone will not be condemned as indecent. And this has the following consequence: when an individual qualifies as a donor on the grounds of his relationship with the recipient, the government or the transplantation team do not have to assume the task of interfering in the transaction between donor and recipient. Nobody has to determine whether the gold necklace that the recipient gives to the donor is merely a spontaneous token of gratitude after the event. After all, the law does not prohibit couples either from arranging their household or sexual affairs on the basis of payment.

How heavily should this objection weigh? In the preceding section I admitted that reasonable people may differ in their opinions on the question of whether the recipient’s need together with the donor’s consent are sufficient to justify the removal of organs. Moreover, in this case we are talking about a medical professional moral standard, and these standards are not absolute. The legislator may have good reasons for making certain exceptions to it, and extreme scarcity of organs could be one of them.

But in that case, the legislator would have to have reason to suppose that this scarcity can be effectively tackled by authorising a reward system. And this brings me to my second objection to the proposal to entitle living donors to a fixed reward. This proposal assumes that the ‘new’ donors who will be attracted by the reward will all be additional donors who will supplement the existing supply instead of replacing it. I consider this to be questionable. For the most part, the increase in the number of living donors during the past years seems to be a consequence of the lengthening of the waiting list and waiting periods. This is also fairly obvious: the better the chances of obtaining a post-

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132 According to Van Dijk and Hilhorst 2007: 29, conferring monetary value on an object does not mean that the value of this object is reduced to a monetary one. They point to the option of financial compensation for the loss of a human life. However, the assessment is still different if the right to allow a human life to be lost is purchased for a certain sum.

133 In Germany, a committee has to decide whether an offer of donation is voluntary and well-considered. A survey held among committee members showed that only 33% of them feel they are capable of determining whether the offer contravenes the prohibition on rewards (Sievers & Neitzke 2006).
mortem organ after a reasonable waiting period, the more inclined potential donors as well as potential recipients will be to wait for this. If, therefore, the waiting period shortens due to an influx of new donors, there is a real chance that other friends and relatives who are currently willing to donate will drop out.

In that case, the institution responsible for paying the reward will be faced with the choice of either accepting the loss or increasing the reward. But the latter option is a decisive step towards a genuine market system, where the price is determined by the ratio between supply and demand. And this will again have new consequences: what it actually means is that the nature of living donation (and post-mortem donation as well, in fact) will undergo a fundamental change. If someone donates a kidney to his partner, relative or friend, the result of this will no longer be that someone else has received additional help; it will be that the Dutch Transplant Foundation is being aided and abetted to keep the price at its present level (or even reducing it, if the donor refuses to accept the reward). It is very well possible that people who are not very keen on the idea of a reward anyway will decide against making a gesture that in fact will then only have that significance (Singer 1977, Dworkin 1988). There will therefore be fewer donations for the reasons that currently induce people to donate organs, and more donations from financial motives. Whether or not we deplore this for intrinsic reasons, it will make it impossible to predict which price level will result in the desired substantial increase of the supply. It would certainly be too simplistic to assume that each additional 50,000 euros will actually result in an additional kidney.

More donations for financial gain will certainly mean more anonymous donations. And this serves to emphasise my first problem: is all this reconcilable with the professional standard of \textit{primum non nocere}? Clearly, the answer must be ‘no’, especially for liver and lung donations. But on the other hand, it would be strange to reward kidney donations while not rewarding the greater sacrifice of donating liver and lung lobes.

The line of reasoning in this section does not lead to a categorical rejection of the proposal for a reward, or at any rate as long as it is limited to kidneys. It was with reservations that I presented my argument that the removal of a kidney is not solely justified by the consent of the individual concerned, and this is therefore definitely not the case if financial gain is the object. And although it is true that we cannot predict the price level at which the measure will be effective, it is nevertheless probable that this level will be an acceptable one in view of the net profit gained in years of health (and therefore not only in view of the costs saved on dialysis).

\footnote{In that case it is no longer plausible to propose rewards as a token of appreciation or a ‘generous compensation’. This would give more weight to the objection that the symbolic value of the living body is violated.}

\footnote{That is why it is improbable that implementation of the proposal will prevent Dutch people living abroad from buying organs.}
However, I do believe that rewarding donation can only be a last resort that should only be considered if all other options have been tried and have failed. The argument concerning the symbolic value of (living) parts of the human body is also an important factor in this. The very fact that this is such an important factor for many people should give it a certain weight for others who feel less strongly about it. I shall disregard the considerable and possibly insurmountable legal obstacles that will have to be overcome in order to implement a system of rewards.

What other options do we have for encouraging living donation? There are still several gaps in the existing regulations for compensating loss of income, and these gaps should be repaired. The law could provide a more generous definition of the costs that qualify for compensation, and it should be completely clear to donors what they are entitled to and where they can claim it. If involving a number of institutions in the compensation regulations is inevitable, one of these institutions should play a coordinating, referring and mediating role.

Another important question is whether transplantation centres should assume the task of mediating between patients and potential donors, if wished. Patients often worry about the risks of a refusal, or find it humiliating to have to ask a favour for which they do not really have anything to offer in return (Lamanna 1997, Kranenburg 2007: chapters 3, 4). Moreover, if they were approached by professionals, potential donors should receive reliable information on the risks and inconveniences of donation right from the very first contact. For this reason, the government could consider financing such centres to enable them to take on this counselling role.

This would mean that the government would relinquish the neutral attitude it has hitherto adopted with regard to living donation. I pointed out at the beginning of this study that the government's attitude to post-mortem donation is entirely different to its attitude towards living donation. Despite the fact that encouraging post-mortem donation is an explicit policy aim, the government limits itself to enabling living donations to take place without donors suffering financial damage.

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136 Enumerated in Prismant 2006. Insurers do not always fulfil their legal obligations, particularly with regard to reimbursing travel expenses. The costs of medical examinations prior to organ removal are not always insured. It is not clear whether donors (notably liver donors) are sometimes faced with premium increases for health care insurance. Be that as it may, additional premium costs may arise as a result of no-claim or excess regulations. Lost pay insurances are limited to a maximum for employees and are not generally taken out by self-employed persons. In such cases, an arrangement for compensation introduced by the Ministry of Health and administered by the Dutch Kidney Foundation could be invoked until quite recently, although 60% of the donors fail to do this, probably mostly because they were unaware of the existence of this arrangement. The agreements concluded between the government and insurers, intended to replace the arrangement, have apparently failed to resolve the problems.
We can now establish that this difference in attitude is not without cause. Post-mortem donation is something that citizens in principle may expect from one another, if only because each and every one of us may have to rely on a donor organ at some stage during our lives. Living donation, on the other hand, is certainly not a civic duty, and whether it is a personal duty depends entirely on the nature of the relationship between the donor and the recipient. Nobody has the right to determine the nature of this relationship on their behalf or to attach any consequences to it.

But if they have determined the nature of the relationship themselves and attach the consequence of donation to it, this fact is of importance as far as medical intervention is concerned, since it gives transplant surgeons the right to do something that doctors should usually avoid doing. In this sense, the relationship between the donor and the recipient is not entirely a personal matter. And in that case, it is not reprehensible for the government to adopt a favourable attitude to such relationships instead of a neutral one, in the same way as it does with regard to informal care. I feel it would be going too far to say that the government should ‘encourage’ living donation (Hilhorst et al. 2007), although it could very well show appreciation of the care that is reflected by it, and contribute towards ensuring that the existing willingness is given the opportunity to be expressed (Hilhorst 2005).

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137 The authors do point out the dangers of being too directive (cf. Steiner & Gert 2004). Judging the people who act as counsellors by the number of donations that they help to bring about should be avoided.
Variations on decision systems

Supplementary report
Variations on decision systems

The preparations for the Master Plan naturally included a lively debate among the parties concerned on the most desirable decision system, during which several variations on the systems discussed in this study were proposed. One of these suggestions was to register consent only and no refusals in the Donor Register, while another suggestion was to add a new option to the donor form, stating: ‘I am unable to make a choice at present: please ask me again at a later date’. The remaining proposals concerned the ADR system: firstly, citizens could be reminded at regular intervals that they are allowed to change their status in the Donor Register, and secondly, the Donor Register could differentiate between consent explicitly given and consent tacitly given. Finally, one suggestion was to grant the right of veto to the next of kin in the case of tacit consent. This supplementary report takes a closer look at these variations.

Variation I: registering consent only

First of all, I would like to examine a system that may be regarded as a variation on the current one. As I explained in the main text (section 2), the major feature of the present system is that the default lies in delegating the decision to the next of kin. If citizens do not explicitly register a choice with regard to donation, their families will be the ones to decide. This feature is retained in the variation I am going to describe, which I shall call Variation I. Under the present system, everyone can avoid the default by stating in the Donor Register that they do or do not wish to make their organs and tissues available for transplantation. Variation I only retains the option of registering as a donor; refusals are not registered.

This would more or less mean a return to the system that was in existence before the introduction of the Organ Donation Act in 1998. At that time, citizens could fill in a donor codicil in order to make it clear that they consented to donation, and if no codicil was

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138 The decision can also be explicitly entrusted to the next of kin or to a specific person. It does not make much difference whether or not this element is retained in the system we are going to discuss.

139 What should be done about the refusals that are currently registered? If these registrations are deleted, all those concerned should be individually informed of this at the very least. However, the option of registration has given refusers a guarantee that cannot simply be revoked.
found among the deceased’s effects, the next of kin were asked to make a decision. This
type of system is still in existence in Ireland and some Swiss cantons, and the situation
in the USA is also comparable to a certain extent.\textsuperscript{140} On the other hand, one of the
objectives in countries where national registers have been introduced was usually to give
people the official option of preventing the removal of their organs if so wished (cf. for
France: Nowenstein 2008).

Variation I still has to be fleshed out a little more on a number of points before we are in
a position to assess the system. Although this system makes it impossible for citizens to
register refusals to donate in the Donor Register, it is of course still possible to record
refusals in their wills. Would the next of kin be able to overrule this decision? This seems
extremely unlikely.\textsuperscript{141} Another question is whether the decision to consent to donation
would be binding for the family as well. Although this has now been laid down in the
Organ Donation Act through a change in the law in 2006, does this have to remain so if
Variation I is introduced? The answer to this question will depend on the reasons in
favour of implementing this system. There are two such reasons, although they point in
different directions. The first reason is obviously in order to obtain more post-mortem
organs. At present, about 12\% of Dutch citizens are registered as refusers in the Donor
Register, which means that their organs can never be used anyway. If, on the other
hand, the decision is made by the next of kin, this decision is positive in one-third of the
cases. If refusals are no longer registered, this might then result in 4\% more donors; this
percentage might increase still further if the number of refusals on the part of the family
could be reduced by approaching them in a different manner.

Some faults can be found with this calculation of the anticipated results, however. It may
possibly be too optimistic to assume that the percentage that applies to the entire
category of refusals by the next of kin will also be achieved in cases where people have
currently registered a refusal. To start with, the most determined refusers will then carry
a will around with them, while the next of kin of this category will be more than usually

\textsuperscript{140} In the USA, there are a number of options for people to make their decisions on donation known. Some of
these options allow citizens to register refusal as well as consent. For instance, there is a national wills register
where citizens can also register their decisions (both positive and negative) on donation, and most states
provide the option of ticking a box marked ‘Yes’ or ‘No’ on their driving licence. But other forms of registration
only permit people to register a positive decision. This applies to the national register of a private organisation,
known as Live Bank, in which two million people are currently registered as donors. There are similar registers in
almost all states. And finally, everyone can download a donor card where only consent to donation can be
registered as well. Incidentally, none of these decisions were completely binding up till quite recently. According
to the Organ Procurement Organisations (OPOs) guidelines, the next of kin were always asked to make the final
decision; in some cases even if a refusal was registered. Most states have meanwhile passed laws permitting
the OPOs to bypass the next of kin in the case of explicit consent, although very few OPOs have subsequently
recorded this in their guidelines (Mesich-Brant & Grossback 2005). All in all, we may conclude that it is usually
easier to register consent than refusal in the USA, and it is gradually becoming more difficult for the next of kin
to overrule such consent.

\textsuperscript{141} This would be difficult to reconcile with Article 11 of the Dutch Constitution in its usual interpretation. The
Additional Protocol to the 2002 Biomedical Treaty on Organ Transplantation (which, incidentally, has not been
ratified by the Netherlands) further stipulates that no organs are to be removed if the deceased objected at an
earlier date (Akveld & Buijsen 2008).
aware of the deceased’s preferences and will act in accordance with these preferences. This makes it unlikely that we can actually expect an increase of at least 4% in the number of donors.

The second motive for considering Variation I is the view that it is generally desirable to involve the next of kin in the decision-making process. Apart from one or two individuals with conscientious objections, usually of a religious nature, it surely cannot be of extreme importance to people what happens to their bodies after their death, provided that this is done with respect. But the family have a genuine interest in this regard, and they have to live with the memory of the sequence of events.

It is obvious that the first motive (increasing the supply of organs) is one reason for maintaining the existing stipulation in the Organ Donation Act, while the second motive (giving the next of kin more of a say) might be one reason for granting a veto on a positive decision on donation to the next of kin.

In the main text I devoted a separate section (13) to the role of the next of kin, in which I concluded that this role can only be justified if the deceased explicitly assigned it to them in his will before his death. If this is correct, the wish to increase the supply of organs will have to persuade us to make organ removal the default, instead of a decision by the next of kin. However, I will now put this conclusion in parentheses and ascertain whether we can arrive at a consistent justification of Variation I if we are in favour of a greater role for the next of kin.

**Variation I and the right to self-determination**

How does Variation I relate to the right to self-determination, interpreted as the specific right to decide what happens to our own bodies both before and after death? In section 1 we saw that this right is a shield right: other people are only allowed to do things to our bodies if we ourselves have consented to this. This requirement loses its significance if people are not allowed to refuse, or if they have to leave the decision to someone else. To compare: the right to physical integrity cannot mean that we have the right to consent to sexual contacts but are not permitted to refuse such contacts (or only by notarial deed). Consent would no longer have any meaning in that case.

I am now assuming that it will still be possible in Variation I to refuse donation by expressly making a will to this effect, thereby binding others (including the next of kin) to this will. If this were not possible, Variation I would be comparable (from the perspective of the right to self-determination) with a conscription system, in which post-mortem organs are automatically available for transplantation. In that case, the only difference with a conscription system is that others can still prevent the deceased’s organs from being removed, although the deceased himself cannot do so. However, the existence of
the sole option for refusal is insufficient to protect the right to self-determination. To this end, we would have to be able to deduce from the fact that the deceased did not carry his will on his person, that he agreed to the decision being taken by his next of kin. But this assumption contains a number of weak points which I have discussed in connection with the notion of presumed consent (section 3): it is unlikely that everyone will be aware of the fact that people can record a refusal in their wills, while ‘opting out’ is not made so simple that we can speak of tacit consent. The first problem could largely be resolved by pointing out the option of drawing up a will when sending the donor form to people. But this makes it all the more obvious that the second problem has been consciously created. Citizens will wonder why they cannot simply record their refusal in the Donor Register, and the answer is that this would be too easy. And that is the whole crux of the system: we are assuming that citizens would not register a refusal if they had this option, but we do not give them this option, just to be on the safe side.

It is doubtless correct to suppose that most people would be perfectly content to leave the decision to their families. If they reject donation, they ought to be able to depend on their families doing the same (this was the reason why some questions arise concerning the anticipated positive effect on the supply of organs). But there will also be people who do not trust their families on this issue; the nice thing about a right is that it also protects the choices of individuals who differ from the majority. Moreover, there will be some people who choose refusal despite the fact that they are in doubt, simply because they wish to spare their families the additional burden of having to make the decision.

So we cannot maintain that Variation I does justice to the right to self-determination. This is quite a big step, in view of the role that this right has played in the Dutch debate; this was one of the reasons for including Article 11 (on the inviolability of the human body) in the Dutch Constitution, and one of the two moral principles in the Organ Donation Act. But we may have overestimated the right to self-determination. In section 11 I argued that if we had to choose between this right and the duty to help those in dire need (which choice we are fortunately not obliged to make), this duty would take precedence. We could also adopt the viewpoint that the interests of the next of kin should carry the most weight, not those of the patients on the waiting list.

**Variation I and the recipients’ interests**

But in that case, how can we justify the special weight given to consent to donation in Variation I? We cannot assume this from the desire to do justice to the will of the individual concerned, since we would then have to attach equal importance to a negative decision and a positive one. The reason obviously lies in the other motive in favour of

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142 A third problem is that a will provides less security than registration in the Donor Register, even if the will is always carried on one’s person, since the Donor Register must always be consulted before any organs are removed.
the system: the wish to increase the supply of post-mortem organs. That is the reason why we want a decision on donation to be valid regardless of any objections on the part of the family, or at least to serve as a starting-point when approaching them, even though they still have the right of veto if they continue to oppose organ removal. But the weight this gives to the patients’ interests would then have to apply right down the line and would therefore also apply if the deceased did not make a decision before his death. After all, this weight is not derived from his decision to donate. We apparently feel that we are doing insufficient justice to patients’ interests if weighing up these interests is simply left to the next of kin. But in that case we should do something about it in all cases, not only in cases where the deceased has given his consent.

If we are willing to put the right to self-determination into perspective for the sake of the family’s interests, we cannot let it depend on the will of the individual concerned whether the next of kin’s interests should yield to that of the patients in some cases. In that case, we only have two alternatives: a system that leaves weighing up patients’ interests entirely up to the family (an open decision by the next of kin), or a system in which the organs are automatically removed unless the family continue to oppose this. This would therefore be a consent system and a no-objection system respectively, in which only the next of kin are taken into account with regard to consent as well as to objection. I am assuming that an explicit will drawn up by the deceased remains binding in both cases, and certainly in the case of refusal. However, there would be no point in maintaining the Donor Register in either case, since refusals would no longer be entered there, and consent for the removal of organs has no legal consequences in the alternatives stated.

My conclusion is therefore: No, we cannot find any cohesive justification for Variation I, not even if we subscribe to both the motives giving rise to this proposal. If the right to self-determination is relevant, we should take refusals more seriously, and if it is irrelevant, we cannot attach the same importance to consent as this system attaches to it.

**Please ask me again at a later date**

Another proposal put forward was to add a new option to the existing ones on the donor form as follows: ‘I am unable to make a choice at present: please ask me again at a later date’. The first argument in favour of this proposal is that people have the right to postpone making a choice if they have not yet formed any definite views on the issue when they are confronted with the donor form. At the same time, it would create the

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143 This might be different if we take ‘the will of the individual concerned’ to mean his preferences instead of his decision, see section 3. In that case we could weigh up his preferences together with the patients’ interests, and we could then say that – in view of the fact that the patients’ interests are obvious – the scales tip in favour of donation as soon as either the individual concerned or his family express a preference for it. Incidentally, I feel it would be only fair to explicitly consider these pros and cons in such cases as well, and therefore to register such individuals’ refusal as well as their consent.
impression that citizens are theoretically obliged to make a choice. Those who select the additional option would then be committing themselves in a moral sense to having arrived at a decision when the choice is once more presented to them.

In actual fact, this is a watered-down version of the compulsory choice system. And it has, incidentally, been considerably watered down, because the only appeal is a moral appeal to make a choice, and even this is done in a rather implicit manner. Surely this moral appeal ought to be explicitly phrased on the donor form at the very least, although it is doubtful whether including this option would subsequently have any further added value. This would not give citizens the right to postpone making an explicit choice, since they also have this right at present, provided that no fully-fledged compulsory choice system has been implemented. Nor does this give them the right to postpone their choice at all, however, because if they do not make an explicit choice, they will make an implicit choice as they do now: this choice is refusal, donation or delegating the decision to the next of kin, depending on the decision system implemented. The addition of a ‘please ask me again at a later date’ option does not provide an answer to the central issue of the default.

The question is whether people who choose this option will actually feel obliged to make a decision within the foreseeable future. However, emphatically focusing attention on an option that already exists anyway might encourage people to choose this option if they have even a shadow of a doubt, which would achieve the opposite effect to the one envisaged.

And finally, in the face of so much uncertainty regarding the message that is being propagated as well as the results that will be obtained, it is extremely dubious whether it is worth the considerable expense involved to approach those who choose this option a second time. And is it really our purpose to exclude everyone who still fails to fill in the donor form from this second mailing? Presumably not, but in that case, ‘please ask me again at a later date’ contains an empty promise. Be that as it may, the question will be still be asked once again, even if we do not ask for it to be asked.

Reminding people of the registration option

I shall now examine a few of the proposed variations on the ADR system as discussed in the main text. First of all, one of the suggestions was to remind all citizens at regular intervals that they can always change their registration status. This could be done by running information campaigns every year, or by explicitly pointing out this option to
people applying for official documents such as passports, driving licences or certificates of good behaviour.¹⁴⁴

One important objective of these efforts would be to reduce the number of people who are registered as donors but who are not aware of the fact. This category of people could include those who have meanwhile learnt to speak Dutch sufficiently well, or illiterate persons who have had the system explained to them orally on television, or who are given the necessary assistance this time in receiving an explanation of the situation. All effects of this nature are welcome because they justify the interpretation of failing to return the donor form as an act of tacit consent for more people.¹⁴⁵ That is why it would really be even more important to send reminders once every few years to all those registered as donors on the basis of tacit consent, since a campaign of this nature would address the major target group more precisely and more fully. This would involve a great deal of expense, however.

Another effect might be that people make an explicit choice instead of tacitly consenting. Since a number of these people will then opt for refusal or delegation, this effect will include a net decrease in the number of registered donors. And a third effect could be that people once more realise that they can alter their registration status and do so as a result, or consciously refrain from doing so. They will then avail themselves of the opportunity to verify their own registered status online as well, although it is impossible to say whether all this will lead to an increase in the number of registered donors.

Unlike the first effect, the second and third effects do not have any significance with regard to the legitimacy of the registration. If people have made a voluntary choice, tacitly or otherwise, they can be held to this choice whether or not they subject it to consideration later on.¹⁴⁶ After all, we do not continually remind people who have made a will at some stage that they can always alter this will. However, the perception of legitimacy can definitely be enlarged. Even though tacit consent is true and full consent, many people will nevertheless regard it as an inferior kind of consent.¹⁴⁷ The more people who keep themselves regularly informed of their status, and who consciously

¹⁴⁴ Why would it be better not to do this when sending out tax forms? This would perhaps give too strong an impression that it is a burden that people can easily rid themselves of.

¹⁴⁵ I would like to underline once more that the category of ‘inaccessibles’ cannot be as large as some people assume, simply because such individuals cannot function even marginally in our society. I would also like to emphasise that the government cannot avoid presuming citizens’ approachability when interacting with them at all kinds of levels. The state cannot function either if it is based on the assumption that citizens are inaccessible.

¹⁴⁶ One recurring phenomenon in all the opinion polls is that a larger percentage of respondents say they have registered as donors than those who have actually done so. This discrepancy can include up to 22% of the population! (Taels & van Raaij 2008). It seems likely that a considerable number of these people genuinely believe that they really have made a socially desirable choice, which would be a good reason to send round reminders under the present system. However, this specific reason no longer applies under the ADR system, because in that case, the individuals concerned will in fact tacitly choose donation.

¹⁴⁷ In a recent opinion poll, almost 50% of the respondents differentiated between explicit and tacit consent (Friele & de Jong 2007).
make use of the option of changing this status (or consciously refrain from doing so), the greater the increase in the perceived value of tacit consent will indubitably be.

Even if this does not result in more registered donors, it can help to combat a possibly undesirable effect of introducing the ADR system, which we already encountered in section 16. Since consent under this system can be based on not returning the donor form, it is quite possible that the next of kin will attach less value to registered consent, which they currently respect in more than 90% of cases. The greater the perceived legitimacy of tacit consent, the more negligible this dilution effect will be. But even if we take this into consideration as well, it is uncertain whether the net effect of regular reminders concerning the registration option will have a positive effect on the supply of post-mortem organs.

The following reasons for adopting this system still remain in spite of the above: (1) the first-named effect, i.e. a decline in the number of positive registrations of which the individual concerned was not aware at the time of registration, and (2) increased acceptance of the ‘silence lends consent’ principle. Other reasons include the general value of transparency (everyone knows what is going on and no organs are ‘secretly removed’) and actively involving citizens in their decisions on donation.

**Distinguishing between explicit and tacit consent**

In section 3 of the main text I contended that under the ADR system, tacit consent may be considered to be true and full consent because the individuals concerned are informed on several occasions about their status, as well as about the simple way in which they can change this status. For this reason, I argued, no distinction between explicit and tacit consent should be made in the Donor Register either. In that case, the option of explicit consent only remains in force because this option encourages citizens to reach a clear conclusion by themselves.

During the debate on the second evaluation of the Organ Donation Act in 2004, however, the Royal Dutch Medical Association (KNMG) recommended that this distinction should nonetheless be made (KNMG Annual Report for 2005). One reason for this could be as follows: Although tacit consent may be true and full consent, the fact remains that most citizens do not generally regard it as such. Since families see data entered on the register as indications concerning the deceased’s wishes, they will attach less weight to tacit consent than to explicit consent. If the Donor Register does not make this distinction, they will not think they know exactly what the registered consent is worth. If the Donor Register does make this distinction, this will at least prevent a dilution effect from arising in the case of explicit consent as well.
On the other hand, this does acknowledge that tacit consent is an inferior type of consent. From the point of view of the right to self-determination, this poses a problem, since consent is one of those categories that does not permit of any degrees: we either consent or we do not, there is no such thing as consenting slightly. Therefore, inferior consent is not consent; at the very most, it is presumed consent but it is certainly not tacit consent. If the default lies in removal of the organs, this is no longer compatible with the right to self-determination. The actual effect may be that the next of kin, on hearing that the deceased was registered as a donor because he did not return the donor form, will attach no value whatsoever to this registration and will still make non-removal of the organs the default, as it is at present. This means that the dilution effect may increase within this category. Admittedly, it should be possible to limit the dilution effect to a considerable extent anyway by changing over to a more directive approach to the next of kin, and this changeover is still justified by this variation of the ADR system with its two different options. But there is no reason to expect any net positive effect from this, and in that case, it would be a pity to abandon the interpretation of silence as consent.

**Variation II: a greater role for the next of kin in the case of tacit consent**

Making a distinction between explicit and tacit consent is problematic because this distinction carries an explicit and an implicit message that conflict with one another. The explicit message is: there is no difference between the two types of consent with regard to the legal consequences. The implicit message is: tacit ‘consent’ is not really true consent at all, although this objection will be removed if different legal consequences are attached to each type of consent. In that case, one interesting option would be to interpret failure to return the donor form as follows: I consent to removal of my organs, on condition that my family also consent to this.

Including this ‘yes, on condition that ...’ option as one of the explicit options on the donor form will probably be inevitable. After all, if this option were not included, this would mean that persons currently registered as donors would be denied an option which is open to others, and once people have registered as donors, it would be impossible for them to choose this option afterwards. When introducing this system, all residents will have to be notified in order to point out this new option to them, and most importantly to make it clear to them that non-registration will have a new significance. In that case, the Donor Register should subsequently refrain from distinguishing between a tacit and an explicit choice of the ‘yes, on condition that ...’ option, since the same legal consequences apply to both.

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148 Theoretically, it should be possible to offer people who have already registered the opportunity to choose this option by revoking their registration, but this would probably be difficult to explain.
The idea behind this variation, which I shall refer to as Variation II, is apparently to give the next of kin a legal status in the case of tacit consent which they do not have in the case of explicit consent. But what exactly is this status? I presume it is not the idea that the next of kin should hold the same status as the one under the present system, i.e. they are the ones who make the final decision and are free to choose between consent and refusal for reasons they themselves consider important. In that case, Variation II would be no more than the ADR version of the present system, in which ‘presumed delegation to the next of kin’ is converted into ‘tacit delegation’, because the conditions under which silence can be interpreted in this way have been satisfied.\textsuperscript{149} I am assuming that the consent of the individual concerned, including his tacit consent, does not merely signify that he is paving the way for the actual decision to be made by his next of kin. That would leave us with two possible interpretations of the ‘yes, on condition that …’ concept.

The first of these two possible interpretations is that the next of kin are asked whether the deceased himself had any objections to the removal of his organs, even if he has not demonstrated this by registering. This substantiation of the scope granted to the next of kin for making a decision is based on an incorrect interpretation of ‘consent’, i.e. as a definition of the preferences of the individual concerned rather than an act in the public domain with legal consequences attached (see section 3). We subsequently interpret failure to return the donor form as: ‘I’m consenting right now, but you will have to ask my family whether I will still consent tomorrow’. If citizens are properly informed about their status and the (simple) way in which they can alter this status, we can hold them to their registered status without continually being obliged to ask them whether this status is still in accordance with their wishes. This is their own responsibility.\textsuperscript{150}

A more practical objection to this interpretation of the next of kin’s role is that it is probably too subtle to be able to implement it in practice. This is demonstrated by the situation in other European countries. France and Spain have a statutory no-objection system in which the next of kin have to be asked if they know of any objections on the part of the deceased if he has not registered a decision. Therefore, the role of the next of kin is really only to provide information on this point (Nowenstein 2008). But in actual fact, the family are invariably asked for their consent in both these countries; the difference being that this is an open question in France, while in Spain, the next of kin are asked with an explicit view to obtaining the organs if humanly possible.

And this brings us to the second possible interpretation of the ‘yes, on condition that …’ concept. This interpretation means that the individual concerned has stated the

\begin{footnotesize}
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\item \textsuperscript{149} Strangely enough, this ADR version of tacit delegation enjoys less public support than the existing system (Taels & van Raaij 2008), possibly because the present system was described as a ‘consent system’.
\item \textsuperscript{150} If citizens are reminded more frequently of the possibility of altering their status in the Donor Register, there will be all the less reason to ask the next of kin this question.
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following: ‘I wish to donate my organs in principle. If, however, it transpires that this is too much for my family to bear, I grant them the right to prevent my wishes from being carried out. They themselves may decide whether this burden is ‘too much’ for them’.

In order to demonstrate beyond any possible doubt that this is the correct interpretation of the ‘yes, on condition that ...’ concept, it should be formulated differently, such as e.g.: ‘I consent to the removal of my organs, unless it emerges that my family have strong objections to it’. This way of formulating the concept shows that the consent given by the individual concerned actually has considerable significance.

Is Variation II defensible?

How should we justify Variation II when interpreted in this way? It seems clear that this variation devotes more attention to the interests of the next of kin, compared with the orthodox ADR system that I discussed (and defended) in the main text. We could admittedly ask ourselves whether such attention on the part of the legislator will make a great deal of difference in practice. After all, continuing opposition on the part of the family will doubtlessly always be respected, both in the future and in the case of implementation of any version whatsoever of the ADR system, despite the 2006 amendment to the Organ Donation Act. In that case, however, this is a decision that the doctors responsible take out of consideration; it is not a right that the family is entitled to claim. Those wishing to grant more scope to the family will prefer this scope to be laid down in the law as well.

An important factor here, however, is that this additional scope should be personally granted by the individual concerned, either explicitly or tacitly. Therefore, we are not talking about the next of kin’s personal right that is not derived from the decision right of the individual in question (which I rejected in section 13). From the point of view of the right to self-determination, the fact that another option is being added to the list of available options is to be applauded, the main reason for this being because a large percentage of citizens will probably show a preference for the option in question.151 At the same time, the unconditional consent option will still remain open; this option can be chosen by people who do not want to burden their families with an additional decision.

In that case, the only question that remains is whether this lends sufficient weight to the interests of the patients suffering from organ failure. Does this mean we now have to face weighing up the right to self-determination against the rightful claims of patients on the waiting list? I thought I would be able to avoid this confrontation in the main text! However, this need not necessarily be the case. Most Dutch people have a

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151 66% of the Dutch population feel that the family should be asked for consent under each statutory system (Friele & de Jong 2007).
fundamentally positive attitude towards donation in general, and are also of the opinion that the next of kin should not be excluded from the decision-making process; moreover, most of the others who do not share these opinions are perfectly aware that they are nevertheless held by the majority. That is why we may expect that the interpretation given to ‘tacit consent’ in this variation will not be regarded as artificial. It may possibly be regarded as less artificial than the interpretation of unconditional consent given to it under the orthodox ADR system.\textsuperscript{152} If our expectations are correct here, this variation might serve to counteract the dilution effect regarding tacit consent, which we discussed earlier on.\textsuperscript{153}

Be that as it may, it need not increase. In paragraph 16 I indicated that there are two genuine advantages that may attach to a change in the law towards an ADR system. First of all I referred to the significance of defaults in practical decision-making. By making removal of organs the default, the onus of proof is reversed, as it were: people only depart from the default if they have reasons of overriding importance for doing so (see also Taels & Van Raaij 2008’s interesting dissertation on this). The second advantage is indisputably more important. The ADR system justifies a more directive approach to the next of kin, in which donation and refusal are not presented as options of equal value, but the ‘onus of proof’ does indeed lie in refusal.\textsuperscript{154} Both these advantages are preserved in Variation II. In that case steps should naturally be taken to ensure that the alternative approach to the next of kin is actually put into practice.

A number of people who have automatically registered as donors at present will probably choose the ‘yes, on condition that …’ option (either tacitly or explicitly) if this option becomes available. This in itself could lead to a dilution effect, although it would be counterbalanced by the family possibly adopting a more favourable attitude towards tacit consent. They will be more willing to accept that registration as a donor really does reflect the deceased’s views, and that they may justifiably be expected to take this into account. ‘Non-committal’ tacit consent can therefore cause a decrease in the dilution effect. All things considered, there is little reason to suppose that this version will result in a smaller supply of post-mortem organs in comparison with the orthodox ADR system.

Could it possibly be the Philosopher’s Stone after all?

\textsuperscript{153} This is not the same as inferring a ‘presumption of consent’ from such data on the opinions of the majority, see section 3. Due to this potentially more favourable attitude on the part of the public, this version is preferable to a version in which (a) tacit consent is still automatically regarded as consent to donation, and (b) the explicit ‘yes, on condition that …’ option is added to the existing options, even though this version might fundamentally express the legitimate rights of potential recipients more clearly.

\textsuperscript{154} The number of people who register a refusal because they regard all no-objection systems as a form of ‘coercion’ can also be minimised in this way.

\textsuperscript{154} Known in US literature as the ‘presumptive approach’, cf. section 16, footnote 108: the key to the Spanish model’s success.
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Appendix 1

Glossary

ACTIVE DONOR REGISTRATION SYSTEM (ADR SYSTEM)
A decision system in which citizens aged 18 and over are explicitly asked to register their donation choice. Those who do not respond are registered as donors and informed of this fact. They can always alter their status later on.

BONUS POINTS
Additional points on the waiting list, to be granted to people who are registered donors if they themselves are in need of an organ. This is linked to the duty of fairness.

COMPULSORY CHOICE SYSTEM
A decision system in which all citizens over a certain age have to record an explicit donation choice in the Donor Register, although they are free to choose the option they prefer.

CONSCRIPTION SYSTEM
A decision system in which all post-mortem organs suitable for transplantation are considered to be available for this purpose.

CONSENT SYSTEM
A decision system in which organs may only be removed after death if consent to this removal has been given, either by the deceased himself (absolute version), or by his family (non-absolute version). Also known as an opting-in system.

DEFAULT
This is what happens if people do not register any donation choice, e.g. leaving the family to decide whether to donate the deceased’s organs.

DONOR REGISTER
The register where all citizens of the Netherlands can record whether they wish to make their organs and tissues available for transplantation after their death. It is administered by the Ministry of Health, Welfare and Sport. The decision may also be delegated to the family or to one specific person, and is recorded by filling in the donor form and sending it back. If a potential donor dies, the doctors are obliged to consult the register.

DUTY OF FAIRNESS
A duty that assumes it is reasonable to contribute to social benefits that are to everyone’s advantage. It is the fourth moral principle in this study. See also bonus points.
DUTY TO HELP THOSE IN NEED
The duty to help others in dire need. It applies to people who are in a unique position to help, while the costs of such help are limited in relation to the importance of the help provided. It is the third moral principle in this study.

ETHOS OF THE GIFT
The view that living and/or post-mortem organ donation should be a gift. It may be interpreted as a standard or as an ideal. Giving is supererogatory (q.v.), its motive is charity. It is the second moral principle in this study.

HEART-BEATING DONATION (HB DONATION)
Organ donation by people who have been declared brain dead. These donors are given artificial respiration in order to keep their circulation going.

LIVING DONOR LIST EXCHANGE (LDLE)
A type of organ donation in which a living donor donates an organ to the (post-mortem) waiting list in exchange for a post-mortem organ. It is illegal in the Netherlands. Compare paired donor exchange.

NON-ABSOLUTE CONSENT SYSTEM
A decision system in which others besides the individual concerned – especially the family – can take a decision on donation after this individual’s death. The Netherlands currently has a version of this system, in which the family are only allowed to make the decision if the deceased has delegated this to them, or if his name is not included on the Donor Register.

NON-HEART-BEATING DONATION (NHB DONATION)
Organ donation after cardiac arrest of the patient.

NO-OBJECTION SYSTEM
A decision system in which it is presumed that citizens who do not register any objection to donation wish to be donors after their death. Also known as opting out, presumed consent system or objection system.

PAIRED DONOR EXCHANGE
A type of living donation in which two or more couples with the same problem – the one is willing but unable to donate to the other – are linked up with one another so that the donor in one couple can donate to the recipient in the other couple.

PREPTION OF FREEDOM
The principle that people are free to do as they wish, provided there are no good reasons for prohibiting or impeding such behaviour. Compare right to self-determination.

REQUESTERS
People specially trained to ask families whether they may remove the deceased’s organs.

RIGHT TO SELF-DETERMINATION
(Here), the specific authority to take decisions relating to one’s own dead or living body. It is the first moral principle in this study. Compare presumption of freedom.

SUPEREROGATORY
Commendable to do it, but not reprehensible to refrain from doing it.
Appendix 2

Council for Public Health and Health Care

Composition of the Council for Public Health and Health Care (RVZ)
The work carried out by the Centre for Ethics and Health (CEG)/RVZ falls under the responsibility of the Council for Public Health and Health Care (RVZ). The monitoring report The end of non-commitment. Decision systems for organ donation from an ethical viewpoint was adopted by the RVZ in its meeting on 14 February 2008.

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Composition of the Centre for Ethics and Health Forum (CEG)/RVZ
The Forum was set up in order to provide support for the CEG/RVZ’s monitoring task. The Forum acts as a sounding board group and plays a monitoring, advisory and instigating role when establishing the monitoring report.
MEMBERS
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Appendix 3

Preparations for the monitoring report

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OTHER CONSULTATIONS
Draft texts were discussed in the RVZ Advisory Group (28 January 2008), the CEG Forum (31 January 2008) and the Council Meeting (14 February 2008)
Appendix 4

CEG publications to date

Signalementen

SIGNALERING ETHIEK EN GEZONDHEID 2003:
Raad voor de Volksgezondheid en Zorg
- Eisend gedrag en agressie van zorgvragers
- Drang en informele dwang in de zorg
- Culturele eigenheid en zelfbeschikking van allochtonen zorgvragers
- Zelfbeschikking en eigen verantwoordelijkheid van mensen met een verstandelijke handicap
Gezondheidsraad
- Handelingen met geslachtszellen en embryo's
- Screening van pasgeborenen op aangeboren stofwisselingsziekten
- Geneesmiddelen voor kinderen
- De maakbare mens

SIGNALERING ETHIEK EN GEZONDHEID 2004:
Gezondheidsraad
- 'Vruchtbaarheidsverzekering': medische en niet-medische redenen
- Terminale sedatie
- Bestrijdingsmiddelen, cosmetica, verf: de bescherming van proefpersonen in blootstellingsonderzoek
- Geavanceerde thuiszorgtechnologie: morele vragen bij een ethisch ideaal
Raad voor de Volksgezondheid en Zorg
- Intermezzo
- Geavanceerde thuiszorgtechnologie: meer vragen bij een nieuwe zorg-praktijk
- Mantelzorg, kostenbeheersing en eigen verantwoordelijkheid
- Economisering van zorg en beroepsethiek
**SIGNALERING ETHIEK EN GEZONDHEID 2005:**
*Gezondheidsraad*
- Embryonale stamcellen zonder morele pijn?
- Ethische aspecten van kostenutiliteitsanalyse
- Nu met extra bacteriën! Voedingsmiddelen met gezondheidsclaims

*Gezondheidsraad/Raad voor de Volksgezondheid en Zorg*
- Opsporing verzocht? Screening in de huisartspraktijk

*Raad voor de Volksgezondheid en Zorg*
- Zorgverlener én opsporingsambtenaar?
- Ethiek in zorginstellingen en zorgopleidingen

**SIGNALERING ETHIEK EN GEZONDHEID 2006:**
*Gezondheidsraad/Raad voor de Volksgezondheid en Zorg*
- Vertrouwen in verantwoorde zorg? Effecten van en morele vragen bij het gebruik van prestatie-indicatoren

*Gezondheidsraad*
- Testen van bloeddonors op variant Creutzfeldt-Jakob?

**SIGNALERING ETHIEK EN GEZONDHEID 2007:**
*Gezondheidsraad*
- Overwegingen bij het beëindigen van het leven van pasgeborenen

*Raad voor de Volksgezondheid en Zorg*
- Formalisering van informele zorg. Over de rol van ‘gebruikelijke zorg’ bij toekenning van professionele zorg
- Financiële stimulering van orgaandonatie. Een ethische verkenning
- Passend bewijs. Ethische vragen bij het gebruik van *evidence* in het zorgbeleid

**SIGNALERING ETHIEK EN GEZONDHEID 2008:**
*Raad voor de Volksgezondheid en Zorg*
- Afscheid van de vrijblijvendheid. Beslissystemen voor orgaandonatie in ethisch perspectief.

**Achtergrondstudies**
- Economisering van zorg en beroepsethiek, 2004
- Ethiek in zorgopleidingen en zorginstellingen, 2005

**Verkenningen**
- De vertwijfelde mantelmeeuw, 2004
- Over keuzevrijheid en kiesplicht, 2006

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