BELGIAN ADVISORY COMMITTEE ON
Bioethics

Opinion no. 50 of 9 May 2011 concerning certain ethical aspects of the changes made by the Law of 25 February 2007 to the Law of 13 June 1986 on the removal and transplantation of organs

Request for an Opinion of 12 February 2010
from Mrs L. Onkelinx, Minister of Social Affairs and Public Health
on the removal of organs

Contents

The points 1, 4 and 5 of this opinion have been partially or entirely translated; the points 2 and 3 haven't been translated; these points are available only in French, Dutch or German on the website of the Committee: www.health.belgium.be/bioeth under the headings 'avis' or 'adviezen' or 'Gutachten'.

1. Definition of the subject of the Opinion

[A. – B – C – haven't been translated]

D. Subject of the Opinion, as reformulated by the Committee

On the basis of these factors, the Committee[1] reformulated the issues discussed in this Opinion as follows:

1.a. Is it ethically justified to *remove organs* which will not regenerate, or remove organs when this may have (serious) consequences for the donor, *from living adults who due to their mental state are incapable of expressing their wishes*, provided a person who is legally competent gives his or her consent?

1.b. If the removal would normally have no serious consequences for the donor, or if the organ in question is one which can regenerate, and if the organ is destined to be transplanted to a brother or sister, is it ethically justified to have the option of removing organs from a minor, and more specifically *from a minor who is incapable of expressing his or her wishes due to his or her mental state*, provided the parents or guardian give their consent?

1.c. Is it ethically justified to abolish the possibility for a relative of a deceased person to oppose the removal of an organ by expressing his or her opposition to the doctor (with this opposition still being subordinate to the wishes of the deceased)? This would mean that, *even if the patient is a minor, then in the absence of explicitly stated opposition to the removal of organs after death*, doctors will no longer be *required by law to seek the consent of relatives*, and hence the parents.

[2. Medical aspects: hasn't been translated]

[3. Legal framework: hasn't been translated]

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[1] See Annex 1 to the minutes of the meeting of 24 June 2010 of the Select Committee 2010-3.

4. Ethical considerations

A. *General introductory considerations*

As already mentioned in the chapter on "Medical aspects", living organ donation is becoming more and more widespread.

Although for kidneys, *post mortem* donation has a negative impact on so-called "*graft survival*" (i.e. the length of time that the organ survives after transplantation), and although in industrialised countries mortality and morbidity rates for kidney donors are low, in the case of living liver donors the medical risks are much higher. In addition, many *non-medical* problems may occur, in particular in psychosocial[2] and ethical terms. In the preamble to this chapter on ethical considerations, the Committee wishes to emphasise strongly that organ donation from living donors can cause medical, psychosocial and ethical problems for donors which do not occur, or occur to a lesser extent, in the case of *post mortem* donation.

The reason for this emphasis is that simply noting – as is done in the preparatory documents for the Law of 25 February 2007 – that the supply of transplantable organs from deceased donors is much lower than the demand, and then concluding from this that the shortfall must be covered by organ donation from living donors (whether the donation is from within the family, from friends and acquaintances, from third parties wishing to make an altruistic donation ("Good Samaritan donation") or from third parties wishing to sell their organs), is problematic in a context where policymakers are failing to take action to encourage *post mortem* donation.

The severe shortage of organs available for transplant is undeniable, and has tragic consequences: patients suffering from terminal organ failure die while they are still on the waiting list. The question therefore arises: what solutions can be recommended to address this serious problem? After all, worrying as it is, the problem cannot be approached as a purely economic matter: *ethical limits* have to be taken into account which in a sense go beyond an approach based solely on efficient allocation.

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[2] See for example Erim, Y.; Beckmann, M.; Valentin-Gamazo, C. et al. (2006), "Quality of life and psychiatric complications after adult living donor liver transplantation", *Liver Transplantation* 12, pp. 1782–1790. Trotter, J.F.; Hill-Callahan, M.M.; Gillespie, B.W. et al. (2007), "Severe psychiatric problems in right hepatic lobe donors for living donor liver transplantation", *Transplantation* 83, pp. 1506–1508. Walter, M.; Papachristou, C.; Pascher, A. et al. (2006), "Impaired psychosocial outcome of donors after living donor liver transplantation: A qualitative case study", *Clinical Transplantation* 20(4), pp. 410-415. Walter, M.; Pascher, A.; Papachristou, C. et al. (2005), "Psychological and somatic aspects of living donor liver transplantation: Preoperative assessment and outcome of donors", *Deutsche Medizinische Wochenschrift* 130(30), pp. 1749-1755. Van Hardeveld, E. & Tong, A. (2010), "Psychosocial care of living kidney donors", *Nephrology* 15, pp. S80-S87.

We are increasingly faced with proposals which until very recently would have been regarded – rightly or wrongly – as unacceptable, on the pretext that "the circumstances" (i.e. the shortage of organs) require particular measures to be taken. Such proposals involve, for example, justifying the buying and selling of organs, or even organ trafficking[3]. Other proposals (and the resultant implementation measures) advocate the increasing extension of living organ donation "models" (through crossover donation programmes between several donor-recipient pairs, etc.). Calls are also becoming more frequent for changes to the criteria that organs must meet (age or medical criteria) in order to be transplanted ("extended criteria organs") – something that in practice is anyway occurring more and more often. Within the framework of this Opinion, we will look at the modification of criteria relating not to organs but to *donors*.

In any case, the underlying idea is always the same: the existence of a large gap between supply and demand for organs for transplantation and, therefore, the need to take special measures to fill this gap. Yet the participants in this debate, both in academic publications and at the political level, appear to show less and less interest in situating these "special measures" in a specific ethical framework and in what the limits of such a framework would be, i.e. whether it is appropriate to allow certain types of organ donation only as a last resort, and whether certain types should even be banned outright[4].

Some members take the view that while one of the functions of ethics is to set limits, another function is to encourage new thinking on how to solve the problems encountered. Thus, it would be desirable from an ethical point of view to promote research which would, in certain cases, enable a body part to be treated or regenerated without the removal of organs.

The transplantation of human organs or tissue obviously raises many additional ethical problems when the potential donor is incapable of expressing his or her wishes. Respect for bodily integrity, which is after all a fundamental ethical principle, argues against carrying out physical procedures on individuals who are unable to make decisions and who will not receive any health benefit from those procedures. When the person undergoing a medical procedure is a third party, only the donor's voluntary and informed consent can, in principle, justify infringing his or her bodily integrity. In addition, society has a duty to defend the interests of people who are incapable of expressing their wishes.

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[3] On the issues associated with the commercialisation of human body parts, the Committee refers to its Opinion no. 43 of 10 December 2007.

[4] For a discussion of the setting of these ethical limits, see Ross, L.F. (2006), "The Ethical Limits in Expanding Living Donor Transplantation", *Kennedy Institute of Ethics Journal* 16(2), p. 151.

A categorical refusal to use people who are incapable of expressing their wishes as donors may also raise problems, however, as it may clash with the duty to help people in distress. In some cases, it can be accepted that the benefits to the recipient outweigh the disadvantages to the incapable donor. According to the utilitarian[5] model, the transplant will then be seen as morally desirable, or even morally indicated. From a utilitarian point of view, the absolute pre-eminence of the principle of respect for the individual is thus excessive, especially if the disadvantages for the incapable living donor are minimal and a strict refusal to use this person as a donor would entail severe suffering or even death for the potential recipient.

There may be good grounds to avoid elevating respect for the individual into an absolute principle and under certain circumstances to allow people incapable of expressing their wishes to serve as donors. However, a radically utilitarian legitimation of such transplants carries very real associated dangers. Leaving aside the difficulty of measuring and comparing the utility (i.e. the benefits) of the procedure for the donor and the recipient, abuses cannot be ruled out, and there is a risk of ending up on a slippery slope. Given that people who are incapable of expressing their wishes will not (generally) be able to object to the procedure, they could end up being used as mere resources to serve the interests of a third party, which would infringe their human dignity. In such a scenario, people without capacity would be regarded as easily accessible *organ banks*, or as an obvious solution when capable potential donors prefer not to donate.

This could trigger two harmful developments. Firstly, the social status of people incapable of expressing their wishes (especially people with mental disabilities) might deteriorate to the point where they become second-class citizens who can be exploited. Secondly, there is a risk of the utilitarian argument being generalised to marginally comparable situations, which might for example make the sale of organs from people who have been executed or from financially disadvantaged people something that is no longer morally and socially taboo. Social pressure, or even an obligation, could force certain vulnerable groups in society to serve as paid or unpaid organ donors. The long-term consequences of a precedent where it was decided, for (purely) utilitarian reasons, to use people incapable of expressing their wishes as living donors are certainly unpredictable, but could undermine the moral values upon which the cohesion of our society depends.

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[5] *Utilitarianism* is a school of ethical thinking which is classified as a consequentialist approach. According to *consequentialism*, one’s moral judgement of what action should be taken in a given situation depends *exclusively* on the potential consequences of each possibility. When one has evaluated the likely consequences of each option, that which, overall, will maximise the positive consequences and minimise the negative ones should be chosen. A wide variety of *parameters* may be used to describe a consequence as positive or negative. In utilitarianism, the most influential version of consequentialism, the parameter is "utility". Classic utilitarianism associated this parameter with the notion of *happiness/unhappiness*. In modern versions of utilitarianism, however, the criterion is "*satisfaction of preferences*" (to what extent will option x enable the preferences of those who will probably feel the effects of the action to be satisfied? how does option y do in relation to this parameter? what about z? etc.).

B. Ethical arguments involved

Below we present three examples of doctrines (mainly developed in a U.S. legal context, but clearly of an ethical nature) which can be applied in order to decide whether a living person who is incapable of expressing his or her wishes may be used as a donor: substituted judgment, the best interests standard, and the clear benefit standard.[6]

Substituted judgment

A substituted judgment is made (by a judge, parent or guardian) on the basis of the arguments and considerations which the living person incapable of expressing his or her wishes would probably have used if he or she had been capable. Transplantation is thus permitted if it can be reasonably assumed that the incapable person would have agreed to a transplant in the same situation if able to express his or her wishes. Due to the hypothetical nature of this approach, the substituted judgment must be supplemented by other standards. Both of the doctrines discussed below are examples of such standards.

The best interests standard

In this case, a decision is made (by a judge, parent or guardian) about what the maximum benefit would be for the living person incapable of expressing his or her wishes, or about the minimum harm he or she would suffer. The best interests standard is not based on a substituted compliance with the hypothetical wishes of an incapable living person, but on the principles of beneficence and non-maleficence.

Since under usual circumstances donation is *never* in the best medical interests of the donor, *the benefits can only be of a psychological and emotional nature*. Despite the damage to his or her health, the donor’s well-being can sometimes improve because the donation improves the recipient’s well-being. Specifically, the potential benefits are: a permanent emotional connection with the recipient, the advantage of living in an intact family not afflicted by the loss of one of its members, an increased sense of self-esteem, the avoidance of a traumatic reaction to the death of a close relative, and/or avoiding a possible future sense of guilt.[7]

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[6] On these doctrines, see in particular Cheyette, C. (2000), "Organ harvests from the legally incompetent: An argument against compelled altruism", *Boston Coll. L. Rev.* 41, pp. 465-515.

[7] An interesting review article on liver donation from living donors describes the psychosocial aspects of taking organs from competent donors: "In general, donors have an increased sense of self-esteem after donation and rarely regret their decision to donate. Some psychosomatic disorders have been reported, however, such as diffuse nonspecific abdominal symptoms and pain, sexual dysfunction, anxious depression and overall complaints. A minority of donors exhibit an enhanced perception of distress and low self-esteem before and after surgery, which can easily be overlooked in the preoperative evaluation or during postoperative care. Similarly, it has been

Citing psychological and emotional benefits as a decisive factor may be problematic, however, since the representatives of people incapable of expressing their wishes may have a tendency to interpret flexibly and to exaggerate the psychological benefits in order to justify transplantation. Moreover, the psychological benefits certainly cannot simply be taken as decisive for people without capacity. After all, we know that donors *who are capable of expressing their wishes* are often afraid that the organ will not produce the desired result, or feel intense guilt if the organ fails to produce the hoped-for result, or if the recipient dies. If the organ is rejected, they sometimes regret that the organ was donated pointlessly. In many cases, the relationship between donor and recipient may not improve at all, or may even deteriorate, for example because the donor begins to think of his or her relationship with the recipient in purely therapeutic terms (and hence the relationship starts to depend on how the recipient's state of health progresses after the donation), or because the recipient feels perpetually indebted to the donor.[8] It is therefore not at all obvious or correct to assume that a donor incapable of expressing his or her wishes will experience psychological benefits which will outweigh the disadvantages to his or her health.

The clear benefit standard

According to this doctrine, the decision must be taken (by a judge, parent or guardian) that will clearly produce the maximum benefit for the person incapable of expressing his or her wishes. The reasoning behind this is that the previous two doctrines can be problematic, since the representative/decision-maker may use his or her own subjective values when assessing which values the incapable person would have applied if capable of expressing what he or she wanted, or when weighing up the best interests of the incapable person. In practice, this can lead to the problem of people who are capable of expressing their wishes being too quick to call on someone who is incapable of doing so in order to avoid having to make a donation themselves, or of parents with a seriously ill child jeopardising the interests of another child who is a potential donor.

However, the two doctrines have certain positive aspects that can be combined to form another type of standard: that of clear benefit. The doctrine of substituted judgment assumes that: (a) a normal person would not consent to donation if organs from dead people

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reported that for some donors, the reported return to normalcy took a significant amount of time even when no serious medical complications were experienced. Donors whose recipients do well clinically are themselves more likely to do well psychologically [...]". See Nadalin, S. et al. (2007), "Current trends in live liver donation", *Transplant International* 20, pp. 312-330, p. 324. See also Clemens, K. K.; Thiessen-Philbrook, H.; Parikh, C. R. et al. (2006), "Psychosocial Health of Living Kidney Donors: A Systematic Review", *American Journal of Transplantation* 6(12), pp. 2965-2977. See also Crouch, R.A. & Elliott, C. (1999), "Moral Agency and the Family: The Case of Living Related Organ Transplantation", *Cambridge Quarterly of Healthcare Ethics* 8, pp. 275-287.

[8] See for example Scheper-Hughes, N. (2007), "The Tyranny of the Gift: Sacrificial Violence in Living Donor Transplants", *American Journal of Transplantation* 7, pp. 507-511.

were available or if there were other people who were equally or better suited in medical terms to be living donors; (b) a normal person would not consent to donation unless the donation had a serious chance of saving the life of the recipient; and (c) a normal person would probably not consent to donate if the recipient was not a close relative. The best interests standard looks at the real situation, not a hypothetical situation, and makes an assessment of the potential psychological benefits and the health risks that will lead to the transplant being rejected if it presents an unacceptably high risk to the person incapable of expressing his or her wishes. A *hybrid standard* which combines the advantages of these doctrines to form a clear benefit standard seems to offer the best approach by balancing the principle of respect for the individual with utilitarian considerations in decisions about donation by people incapable of expressing their wishes.

C. Illustrations from American case law

In the United States, the practice of law has led to the development of the *clear benefit standard* (see above) which sometimes authorises these transplants, although under conditions which are much stricter than those applied under Belgian law to organ transplantation from adults incapable of expressing their wishes. To illustrate this, we present below some important judgments given in the United States and the underlying arguments. In the first three cases, the removal of organs was allowed, and in the last two cases it was not.[9]

Strunk v. Strunk In 1969, the Kentucky Court of Appeals decided that, with parental consent, a kidney could be removed from Jerry Strunk, who was mentally disabled, for transplantation into his brother, Tommy Strunk[10]. Tommy Strunk, aged 28, was suffering from terminal renal disease and was dying. Compatibility tests showed that Jerry Strunk, aged 27 but with an IQ of 35 and a mental age of six years, was the only potential match. After a (moral) cost-benefit analysis, the Court concluded that it was in Jerry's best interests to donate a kidney, since Tommy was the primary link that Jerry had with his family, Tommy was the only one able to understand the imperfect language used by Jerry, Tommy would be Jerry's only source of close contact after the death of their parents and Jerry was very fond of Tommy. The Court authorised the removal of the kidney since this posed less of a threat to Jerry's welfare than the loss of his brother[11].

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[9] For a discussion of these cases and other examples from American case law, see Cheyette, C. (2000), "Organ harvests from the legally incompetent: An argument against compelled altruism", *Boston Coll. L. Rev.* 41, pp. 465-515, Section II, "Case law and the applicable legal standards".

[10] Strunk v. Strunk (445 SW 2d 145 – Kentucky Court of Appeals 1969). Consultable at: http://scholar.google.com/scholar_case?case=17344681967852817899&q=%22Strunk+v+Strunk%22&hl=en&as_sdt=4002004 [consulted on 10 September 2010].

[11] *"[...] his well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney"*.

Hart v. Brown In 1972, the Connecticut Supreme Court decided that, with parental consent, a kidney could be taken from Margaret Hart, who was seven years old (and therefore incapable of expressing her wishes), for transplantation into her identical twin Kathleen Hart[12]. Kathleen Hart was suffering from severe kidney disease, had had both her kidneys removed and suffered from very serious blood pressure problems. The Supreme Court held that removal of a kidney was in Margaret's best interest, since she would be happier in a family that remained complete than in a family traumatised by the loss of Kathleen, and above all, because Kathleen's death would be a huge loss for Margaret, who was extremely fond of her sick twin sister. In this case too, the conclusion was that the removal of the kidney was authorised, since the donor's welfare would be more seriously endangered by the loss of the recipient than by the loss of a kidney.

Little v. Little In 1979, the Texas Court of Appeals decided that, with parental consent, a kidney could be taken from Anne Little, a girl aged 14 years who suffered from Down syndrome, for transplantation into her brother Stephen Little.[13] The Court held that it would be in Anne's best interests to donate a kidney since she would gain substantial psychological benefits from her donation, such as improved self-esteem, an enhanced status in the family, a new sense of meaning in her life and possibly transcendental experiences from making a gift of life to another. At the same time, a refusal to allow the transplant would, according to the Court, cause serious psychological harm, given the close relationship between Anne and Stephen, and the fact that Anne was aware that Stephen was ill and that she could help him. A refusal to allow the transplant might traumatise Anne if Stephen died because Anne was prevented from helping him. In this case too, the conclusion was that the removal of the kidney was authorised since the donor would derive more benefits than disadvantages from it.

The Richardson case In 1973, the Louisiana Court of Appeals decided that, although there was parental consent, a kidney could *not* be removed from Roy Allen Richardson, a 17-year-old with Down syndrome and a mental age of three to four years, for transplantation into his 32-year-old sister, Beverly Richardson, who was suffering from severe kidney failure.[14] Roy Allen Richardson seemed to be the best match for Beverly. The assertion that Beverly would assume responsibility for Roy after the death of his parents, and that it was therefore in Roy's best interests to donate a kidney, was rejected as too speculative. Since it had not

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[12] Hart v. Brown (289 A. 2d 386 – Connecticut Supreme Court, 1972).

[13] Little v. Little (576 SW 2d 493 - Texas Court of Civil Appeals, San Antonio, 1979). Consultable at: http://scholar.google.com/scholar_case?case=7643024691450470320&q=%22Little+v+Little%22&hl=en&as_sdt=10000004000004 [consulted on 10 September 2010].

[14] *In re Richardson* (284 So. 2d 185 – Louisiana Court of Appeals, 4th Circuit, 1973). Consultable at: http://scholar.google.com/scholar_case?case=13103975403084622132&q=%22Little+v+Little%22&hl=en&as_sdt=10000004000004 [consulted on 10 September 2010].

been shown that it was in Roy's best interests, the Court decided that he should not be subject to such extensive bodily intrusion. Beverly Richardson died shortly afterwards.

Lausier v. Pescinski In 1975, the Wisconsin Supreme Court ruled that, although his guardian had given consent, a kidney could *not* be removed from Richard Pescinski, a 39-year-old man incapable of expressing his wishes, for transplantation into his sister Elaine Pescinski, aged 38 years.[15] Richard Pescinski was a catatonic schizophrenic with a mental age of 12, without periods of lucidity or any prospect of improvement. Elaine Pescinski, a mother of six children, had contracted a severe kidney disease, and was undergoing dialysis after the removal of both kidneys. She was on the waiting list for organ donation from a deceased donor and her condition was rapidly deteriorating. The Court held that in the absence of consent on the part of the donor, no one had the authority to consent on his behalf to a transplant that would only benefit a third party. In the Court's view, there was no indication that it would be in Richard's best interests to donate a kidney. The doctrine of substituted judgment (by a parent, guardian or judge) ceases to apply, the Court reasoned, if it cannot be demonstrated that the donor who is incapable of expressing his or her wishes will derive more benefits than disadvantages from the procedure. Elaine Pescinski died shortly afterwards.

D. Discussion of the different points of view on the ethical acceptability of removing organs from incapable adults and from minors

Before presenting the views of the Committee members on questions 1.a. and 1.b. (see Chapter 1.D.), the main provisions of current Belgian law, which were discussed in detail in the previous chapter [point 3 hasn't been translated], are recapitulated for each of the two cases. We then set out a list of *factual* and *ethical* questions which the members feel arise from the existing legal provisions, followed by a question relating to *procedure*. Finally, the viewpoints held within the Committee on these issues are discussed.

In general, the Committee believes that, where legislation refers to adults (or minors) who, due to their mental state, are incapable of expressing their wishes, this description can be interpreted as applying to any adult (or minor) with a medically confirmed permanent mental disorder which makes them permanently incapable of controlling their actions. In the Committee's view, others who do not fit these criteria – such as people in a coma or

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[15] Lausier v. Pescinski (226 NW 2d 180, 67 Wis. 2d 4 – Wisconsin Supreme Court, 1975). Consultable at: http://scholar.google.com/scholar_case?case=1947082296372187956&q=%22Little+v+Little%22&hl=en&as_sdt=10000004000004 [consulted on 10 September 2010].

suffering from Alzheimer's disease[16] - are not covered by the legal provisions discussed here, i.e. the provisions of the Law of 13 June 1986, as amended by the Law of 25 February 2007.

1. Removal of organs from incapable adults

When the following **three conditions** are met, Belgian law allows the removal of organs from incapable living adults:

(1) The recipient’s life is in danger;
(2) Posthumous donation cannot provide such a satisfactory result; and
(3) The legal or informal representative appointed by the patient or, if this person is unavailable or does not wish to be involved, the representative appointed in accordance with Art. 14, § 2 of the Law on Patient Rights agrees.

The Committee concludes that, provided these three conditions are met, the removal of organs is allows, *even* if the organs in question are organs which *do not regenerate*, and *even* if their removal may have *serious consequences* for the donor.[17]

These legal provisions raise a host of questions, both factual (on the precise scope of the provisions) and ethical in nature.

Three **factual questions** immediately arise: Must the danger to the recipient’s life be *acute*? How can one *verify* that the second condition (that *post mortem* donation cannot provide such a satisfactory result) is satisfied? And precisely *which* organs are included under "organs which do not regenerate"?

It should also be stressed that:

- As the law does not add any further details about the "recipient", the recipient can clearly be anyone (from a close relative to a distant relative, to a spouse, partner, friend, acquaintance or complete stranger); and
- The law does not impose any restrictions regarding who, in this context, can act as a representative of the patient. (It would therefore be quite possible for the representative and the recipient to be one and the same person - see below.)

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[16] The potential transmission of prion disease is a medical reason for excluding patients suffering from Alzheimer's disease.

[17] Some members, however, favour a literal reading of the law, which states that the removal of organs from an incapacitated adult is possible, but only if this is of organs which *do not regenerate*, and if the removal may have *serious consequences* for the donor. This is the hypothesis of "removal referred to in § 1" provided for under Article 6 § 2 of the Law of 1986".

From an ethical point of view, the current legal provisions are problematic. Measured by the yardstick of the "clear benefit standard" (see above), which some members of the Committee consider to be the appropriate doctrine in this area, Belgian law allows the principle of respect for individual rights to be ignored to an unacceptable degree with regard to potential donors who are incapable adults. According to the doctrine of "clear benefit", transplantation can only be ethically acceptable if it clearly generates more benefits for the incapable adult donor than non-transplantation.

This could not be the case if the transplant exposed the incapable adult to very serious risks to his or her health. In such cases, the potential psychological benefits to the donor can never override the foreseeable drawbacks. Since Belgian law does not list serious consequences for the donor as an exclusion criterion, it allows such transplants to go ahead, provided the three conditions mentioned above are met. Thus, Belgian law actually makes it possible to completely disregard the interests of the incapable adult potential donor.

Even if the incapable adult donor is not exposed to a very serious risk to his or her health, transplantation may be unacceptable from an ethical point of view. This will certainly be the case if the emotional bond between donor and recipient is not sufficiently strong to bring psychological benefits for the donor which clearly override the risks and/or if the donor cannot have any awareness of these benefits (cf. below, 2. Removal of organs from minors). The fact that Belgian law defines the category of "recipients" so vaguely that even people with whom the donor *has no connection at all*, *let alone* a strong emotional bond, qualify, is therefore highly problematic. It means that incapable adults can in principle be used as *organ banks* for complete strangers, without the law being broken. However, this position must be qualified by recalling the existence of certain protective measures. Thus, Article 8*bis* of the Law of 13 June 1986, inserted by the Law of 25 February 2007, states that any removal of an organ from a living person must be subject to *prior multidisciplinary consultation*. This precaution is particularly relevant when the proposed organ removal is from a person who, because of his or her mental state, is unable to express his or her wishes. Moreover, going beyond the legal provisions, practice in this area is also governed by professional codes of conduct and medical ethics, which prevent certain forms of abuse or malpractice.

Even where the health risk is deemed to be low to moderate and a strong emotional bond exists, the use of incapable adult organ donors may raise serious ethical objections. The assessment of such cases should take into account various factors which are often overlooked[18]. Firstly, it should not be assumed too readily that the procedure will only present a very slight risk to the donor's health. Although the risk of medical complications

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[18] See Cheyette, C. (2000), "Organ harvests from the legally incompetent: An argument against compelled altruism", *Boston Coll. L. Rev.* 41, pp. 499-500 and 514.

during kidney donation is now reduced in countries where healthcare is highly developed and widely available (see the chapter on medical aspects), complications can, if they occur, prove extremely serious. Secondly, even if the removal of the kidney goes entirely smoothly, the donor always runs the risk of subsequently requiring medical attention him- or herself should the other kidney fail. Furthermore, in the case of partial liver donation, which is perfectly possible from a legal viewpoint, the risks of mortality and morbidity are significantly higher. It is also important not to lose sight of the fact that unlike a donor capable of expressing his or her wishes, an incapable adult donor will be completely or largely unprepared mentally for the possibility of health problems.[19]

However, the frequent overestimation of the psychological and emotional benefits that the incapable adult donor will derive from his or her enforced altruism is potentially even more problematic than the tendency to minimise the health risks that the donor may incur.[20] As we have already emphasised at length, it is far from self-evident that an incapable adult donor will obtain clear psychological and emotional benefits from helping a recipient with whom there is a strong emotional bond. A survey conducted among capable adult donors somewhat unexpectedly revealed that it is not uncommon for the psychological consequences for the donor to be negative, even if the transplant produces the desired result.[21] In addition, there is a risk that the relationship between the donor and the recipient will be put under great strain, because each party feels constantly responsible for the other party's state of health. We must also bear in mind here the fact that incapable adult donors are unable to feel, or only feel to a much lesser extent, the psychological benefits that some capable adult donors report.[22] Incapable adult donors often lack the highly developed capacity for moral reasoning (due to a lack of the required cognitive capacity) which may lead to an increase in self-esteem in the event of a donation. It is precisely such an increase in self-esteem, which is not dependent on the outcome of the transplant or the risks associated with it, that can protect the *capable* donor from potential adverse psychological effects.

Given that donors experience psychological problems in relation to their donation more often than we imagine, and that most incapable adult donors are unable to feel some of the psychological benefits, it is therefore not at all clear that even where the risk to the donor's health is considered to be low to moderate and there is a strong emotional bond with the

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[19] See Cheyette, C. (2000), *op. cit.*, p. 496.

[20] See Cheyette, C. (2000), *op. cit.*, pp. 475 and 504.

[21] At first sight, this oddly appears to be truer for bone marrow transplants than for kidney transplants. This discrepancy may, however, be explained by the fact that recipients of a bone marrow transplant have a much lower chance of survival, are at greater risk of serious and long-term physical complications and even have a relatively high risk of dying from Graft Versus Host Disease (GVHD), caused by the graft itself.

[22] See Cheyette, C. (2000), *op. cit.*, pp. 505 and 508.

recipient, one can assume that the psychological benefits to the incapable adult donor will automatically counterbalance the risk to his or her health.

These considerations are critically important to the ethical evaluation of Belgian law, because they clearly demonstrate that an objective and informed examination of the advantages and disadvantages for the incapable adult potential donor requires a capacity for discernment which is free from prejudice, and a high level of expertise. Current Belgian law, however, provides no guarantee in this respect. For instance, it imposes no restriction on who may act as the patient's representative. There is a strong chance that a member of the immediate family will act as the legal representative or appointed informal representative. In the obvious situation where the incapable adult is considered as a potential donor precisely because another member of the immediate family urgently needs an organ donation, the representative will be put under tremendous pressure to consent to the transplant.

It may even be the case that the representative and the recipient are one and the same person, so that the personal interests of the incapable person are totally ignored. In such cases, donation by an incapable adult family member may be considered an easy option because it means that the capable family members are left untouched. This is particularly problematic because it is precisely these incapable adults who ought to receive extra protection, not only because they are vulnerable and often unable to defend their own interests, but also because they are not able to be personally responsible in matters of life and death. Since, in this situation, the representative is no longer able to perform his or her protective role impartially, it seems appropriate to provide an additional check through the use of a multidisciplinary committee and/or a judge, as is done in the United States, the Netherlands and France.

The Committee has therefore identified the following **ethical questions** (relating to the criteria that should potentially be specified in the law for ethical reasons):

- In addition to the condition that there should be no compatible deceased donor available, should there be an additional condition that there should be no *capable* living donor available?
- Should the law specify who may be a recipient, and if so, what would be appropriate?
- Should the admissibility of organ removal from an incapable adult depend on the *type of organ* (e.g. in terms of *regenerability,*[23] or in terms of the *severity of the consequences* of removal for the donor, in which case the removal of a kidney might be allowed if all other conditions are met, but not necessarily the removal of the liver)?

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[23] With regard to the regenerability of the liver, see the details given above in chapter 2.B.2.

- Should the law include a criterion relating to the *psychological benefits to the donor*, e.g. stating that removal of organs can only be performed if the death of the person in need of the organ would have a much more negative impact on the donor's welfare than the removal of the organ from his or her body (a criterion which thus requires a very close link between the potential donor and the recipient)?
- If the potential donor still has some decision-making capacity (albeit reduced) – and if he or she can give, to use the jargon of medical ethics, not "*consent*" but "*assent*"[24] – can we conclude that if he or she opposes the procedure (does not give his or her "*assent*"), the removal of organs should not take place?

If, after considering these issues, we arrive at the conclusion that one or more of the criteria (the legal ones and/or those mentioned above) are defensible from an ethical point of view and if, therefore, the removal of organs from incapable adults may *in certain cases* be justified (however slight this justification may be), then the **question of procedure** obviously also arises. i.e. *who should judge whether or not the recommended conditions/criteria have been fulfilled*:

- A doctor? (If so, which doctor?)
- A committee? (Which?)
- A judge? (Which?)
- Some other body?

Some members of the Committee believe that the law should in principle prohibit the removal of organs from mentally incapable living donors. In this view, a person's ability to express his or her willingness and capacity to give consent should be regarded as a prerequisite to acting as a living organ donor. These members believe that the dignity and physical integrity of people incapable of expressing their wishes must not be trampled on by the healthcare sector, even in order to allow more organ removal to take place. The desire to address the ethical and societal problem of lack of organs by jeopardising human dignity is seen as hard to justify.

Other Committee members, however, feel that the removal of organs from incapable living adults may be permitted, but only if most or all of the following conditions – with the clarifications set out above – are satisfied:

- The recipient's life must be in danger;
- Posthumous donation cannot provide a satisfactory result;

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[24] For an explanation of these terms, see point 4.D.2.g below. "Is the child's *assent* necessary?"

- The medical team must do everything possible to identify compatible living donors who are capable, and should only consider using an incapable adult donor as a last resort;
- A psychologist or psychiatrist should carefully consider the impact that the death of the person needing the organ would have on the welfare of the incapable potential donor; the removal of the organ should only be permissible if it appears that the effects on the donor of the recipient’s death would be far worse than the bodily harm caused, implying the existence of a very strong emotional bond between donor and recipient;
- If the incapable potential donor has sufficient capacity to give his or her opinion (assent, not consent), this opinion should be sought, and if he or she is opposed to the removal of the organ, it should not take place;
- The potential donor’s representative – on this point one can refer to the law on patients’ rights and use the "cascade" system which is mentioned there – must agree. This representative, however, may not be the same person as the potential recipient. The potential recipient may also not be a child, parent, spouse or partner of the potential donor’s legal representative;
- An independent multidisciplinary committee (at national level), including, in addition to an expert in internal medicine, an expert in ethics, an expert in psychology and a legal expert, must check that the various conditions are met and provide a reasoned written opinion at short notice; the case should be submitted to this committee by the representative of the incapable potential donor or the doctor; and
- If the opinion given by the committee is positive, the case should be submitted to a justice of the peace for a final decision, under an emergency procedure.

2. Removal of organs from minors

a) The context of the problem

In this area, Belgian law distinguishes between minors who are capable of expressing their wishes and minors who are incapable of expressing their wishes due to their mental state.

If the following **four conditions** are met, Belgian law allows the removal of organs from living minors who **are capable of expressing their wishes**:

(1) The removal of organs must be expected to have no serious consequences for the donor.
(2) The organ in question must be an organ which can regenerate.

(3) The recipient must be a brother or sister of the minor in question.
(4) The potential donor must be at least twelve years old and have previously given his or her consent to the removal of organs; *or* if the potential donor is less than twelve years old, he or she must have the opportunity to give his or her opinion.

In the case of minors ***who are incapable of expressing their wishes due to their mental state***, the law authorises the removal of organs if the first three conditions mentioned above are met, and if the **following condition** is also satisfied:

(4) The parents or guardian of the person in question must give their consent to the removal of organs.

In the case of living donors who are minors, the legislators have thus not deemed it necessary to specify, as a related condition, that the recipient's life must be in danger, that no organ from a deceased person which can provide an equally satisfactory result must be available, and that no compatible living donor with the capacity to consent must be available.

Factual and ethical questions again arise with regard to these provisions of Belgian law.

Two **factual questions** immediately arise: What is meant by "no serious consequences" for the donor, and precisely which organs are included under "organs which can regenerate?"

Where minors are concerned, the Committee has therefore identified the following **ethical questions** (relating to the criteria which should potentially be specified in the law for ethical reasons):

- Should it be a condition that the recipient's *life must be in danger*?
- Should it be a condition that no *deceased donor* must be available?
- Should the condition be added that no *capable* living donor must be available?
- Is the current specification of who can be a *recipient* (the brother or sister of the person in question) defensible from an ethical point of view, or is it too restrictive or too broad?
- Should the admissibility of organ removal from living minors depend on the *type of organ*, or in other words, what interpretation should be given to "organs which can regenerate" and "no serious consequences" for the donor? Is it too restrictive only to allow the removal of an organ which can regenerate, and only if the recipient is a brother or sister of the donor?

- Should the law include a criterion relating to the *psychological benefits to the donor*, e.g. stating that removal of organs can only be performed if the death of the person in need of the organ would have a much more negative impact on the donor's welfare than the removal of the organ from his or her body (a criterion which thus requires a very close link between the potential donor and the recipient)?
- If the potential donor has not reached the age of twelve years but is capable of expressing his or her will and thus giving his or her assent, should the conclusion be, in the event of the potential donor being unwilling to donate, that removal of the organ cannot, by definition, be carried out, regardless of the parents' or guardian's point of view?
- If the donor is at least twelve years old, is it desirable from an ethical perspective to make his or her opinion on the matter decisive?
- In the case of minors who are incapable of expressing their wishes, is it desirable from an ethical perspective for consent or refusal to be the *exclusive* prerogative of the parents or guardian?

If, after considering these issues, we arrive at the conclusion that one or more of the criteria (the legal ones and/or those mentioned above) are defensible from an ethical point of view and if, therefore, the removal of organs from minors (both those who are capable of expressing their wishes and those who are not) may *in certain cases* be justified (however slight this justification may be), then the **question of procedure** obviously also arises. i.e. *who should judge whether or not the recommended conditions/criteria have been fulfilled*:

- A doctor? (If so, which doctor?)
- A committee? (Which?)
- A judge? (Which?)
- Some other body?

The following considerations seem important with regard to this long list of questions.

b) Which organs?

Although it is not an organ within the meaning of the Law of 13 June 1986, it should be noted that bone marrow regenerates within four to six weeks and that its removal involves much less physical risk for the donor than the removal of, for example, a kidney or a liver lobe. However, bone marrow donation does entail some risks: during extraction, the patient must be placed on his or her front, which increases the risk of complications from the anaesthetic, which, moreover, is a general one. A blood transfusion is also commonly given, which increases the risk of infection. However, in general the medical risks to the donor are minimal.[25]

One may also ask, however, whether the current restriction in the law to organs which will regenerate is appropriate. In the case of **removal of a kidney**, the procedure involves a not insignificant risk, since the kidney is not a regenerable organ. However, situations can be imagined where the psychological benefits that donating a kidney would bring the potential minor donor greatly outweighed these non-negligible risks. Assuming that the death of a brother or sister would be a serious blow to both the potential minor donor and his or her family, and taking into account the probability that the potential donor would subsequently be overwhelmed by an enormous sense of guilt, some argue against a total ban on kidney donation by a minor.[26]

They add, however, that in the case of a kidney transplant, additional protective mechanisms must be put in place (in addition to those already stipulated for bone marrow donation), since there is a non-negligible risk of jeopardising the donor's future through medical complications resulting from the donation. The additional conditions proposed are as follows: the category of recipients should be limited to brothers and sisters with whom the potential donor has a genuine bond,[27] who must also be in danger of dying, and to whom no (other) therapeutic option is available; the minor must have reached the age at which considered moral deliberation is possible (at least 12 years); and the minor must give his or her voluntary prior consent. In order to avoid the risk of a conflict of interest, it is also argued that, in such decisions, a "donor advocacy team", i.e. a multidisciplinary team with paediatric expertise, should be called upon to assess the benefits and drawbacks to the potential donor and to check that the minor's consent is truly voluntary.[28] At least on a

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[25] With regard to psychological harm to the donor, it should be noted that many recipients of bone marrow develop a reaction of the graft against the host (GVHD), which can cause serious complications and lead in some cases, to an autoimmune syndrome that destroys all the organs. Obviously, the serious illness or death of the recipient following the transplant may have major psychological consequences for the donor.

[26] See e.g. Friedman Ross, L. (1998), *Children, Families, and Health Care Decision Making*. Oxford: Clarendon Press.

[27] Although the defenders of the "family perspective" might also use (perhaps even more convincingly) the same argument aimed at preventing family breakdown and the harm this would do to the child's welfare in order to defend donation to a father or a mother, the fact is that in the case of a kidney transplant, a child's organ is too small to be transplanted into an adult. In addition, expanding of the category of recipients to fathers and mothers could cause additional problems due to the risk of abuse and exploitation of the child.

[28] See the recommendations of the Committee on Bioethics of the American Academy of Pediatrics, in Friedman Ross, L. et al. (2008), "Minors as living solid-organ donors", *Pediatrics* 122, pp. 454-461, p. 457: *"The Advisory Committee on Organ Transplantation of the US Department of Health and Human Services recommends that all living donors have a donor advocate. The donor advocate's primary obligation is to help donors understand the process and procedures and to protect and promote the interests and well-being of the donor. If the donor is a minor, the donor advocate should have (1) training and education in child development and child psychology, (2) skills in communicating with children and understanding children's verbal and nonverbal*

theoretical level, the removal and transplantation of a kidney may also be considered between identical twins (see the case *Hart v. Brown* outlined earlier).

The donation of a **liver lobe** by a minor entails medical risks to the donor which are too serious to be offset by the potential psychological benefits.

c) Is there a "duty" to donate organs, created by special moral responsibilities within the family?

According to James Dwyer, a psychiatrist, and Elizabeth Vig, a specialist in internal medicine, it is morally acceptable to expect family members, including children, to expose themselves to certain risks and forego certain benefits for the good of the other family members. The responsibility of each family member to the other members thus goes beyond what is generally accepted in an "atomistic" and "individualistic" worldview. According to Dwyer and Vig, the family, as an intimate community, forms a separate moral entity within which the moral boundaries between each member become blurred: for each family member, the objectives of other family members are objectives in themselves and the interests of the other family members must be preserved.[29]

Dwyer and Vig believe that from a moral point of view, we can therefore expect a family member to expose himself or herself to a certain amount of risk for the sake of another member of the same family, However, an appropriate balance must be struck between, on the one hand, the relational bond that unites the people concerned and, on the other hand, the risks to the donor compared with the benefits to the recipient. Accordingly, when the expected benefit is great, we can expect parents to undergo a high-risk procedure, and we can expect siblings to agree to undergo a procedure that involves some risk.[30]

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communication, and (3) working knowledge of transplantation and organ donation. Thus, donor advocacy will usually require partnering of professional colleagues to provide all these skills (an "advocacy team"). Even with an advocacy team, one must realize that the parental request for a child to serve as a donor for a family member may be perceived by the child as a request that cannot be refused. Minors who are evaluated to be donors must be evaluated for maturity and cognitive ability. Before they are allowed to give assent, they must be educated about living donation and counseled at various junctures that it is permissible to say no or to withdraw at any time before the procedure. The child advocacy team should ensure that the degree of emotional intimacy can justify the risks from the perspective of the minor donor, that there are no alternative donors who are adults, and that dialysis is not a realistic possibility for the recipient as a bridge to deceased donor transplantation."

[29] Dwyer J. & Vig E. (1995), "Rethinking transplantation between siblings", *Hastings Center Report* 25(6), pp. 7-12. The electronic version can be consulted at: http://web.ebscohost.com/ehost/detail?sid=21a41864-7302-40d5-a4e4-b57e5e852893%40sessionmgr110&vid=1&hid=107&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#db=heh&AN=9510093415 [consulted on 2 April 2011].

[30] *Ibid.*

Pentz and his co-authors, however, emphasise the following:

> There are limits, even in intimate relationships. Mothers are not allowed to donate hearts to their children, even if they wish to do so.[31]

Dwyer and Vig are aware that their position is regarded as problematic by many people, especially as it conflicts with the "best interests" standard generally used to make decisions about organ transplantation on behalf of people who are not (yet) able to properly express their consent.[32] However, they believe that the best interests standard is extremely problematic because of its egocentric character:

> [Some commentators] have noted that the doctrine of informed consent allows patients to focus on what is best for them and to ignore their responsibilities to family members. [...] But at least the doctrine of informed consent allows patients, if they want, to take directly into account ethical concerns for others. With the idea of best interests the situation is worse. The justification must be made in egocentric terms and does not allow a direct account of ethical concern or responsibility. The justification must show that the procedure benefits the donor and that the benefits to the donor outweigh the risks [...]
>
> If we drop the constraints imposed by the standard approach, we are free to take a more direct approach. We could then ask whether it is morally acceptable to impose a given risk on the donor in order to attempt, with some degree of probability, to save the life of the ill sibling. But even formulating the matter in this way is sure to provoke the most vigorous objections. Some people will object that we are opening the door for certain persons and groups to be used, without their consent, for the benefit of other people. [...]
>
> The objection, however, presents a false choice and may not even lead to the kind of protection that is most needed. Is our choice really limited to two extremes: to a kind of crude utilitarianism where the benefits to A compensate for the harms and risks to B, or to a kind of crude egoism where every decision must aim to benefit the individual person? Instead of choosing between these two extremes, we can try to take into account the ethical import of relationships. Perhaps various family relationships have ethical import that can be brought to bear on cases of tissue transplantation between siblings. To take into account the ethical import of relationships is not to make altruism a general duty. Donating tissue to a sibling is not what we normally think of as altruism.[...].[33]

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[31] Pentz, R.D.; Chan, K.W.; Neumann, J.L.; Champlin, R.E. & Korbling, M. (2004), "Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity", *Cambridge Quarterly of Healthcare Ethics* 13, pp. 149-155, p. 150.

[32] See above, chapter 4.B.

[33] Dwyer & Vig (1995), op.cit.

Lainie Friedman Ross argues from a similar viewpoint. She believes that the best interests standard ignores the unique character of close-knit families and disregards the rights of parents, in the context of close family relationships, to make decisions for the welfare of the entire family, which is not necessarily the same as the best interests of one of the children.[34]

Studies show that some families do actually think of the family from the moral viewpoint described by Dwyer and Vig, and that for many people dealing with the issue of intra-family organ donation, it is almost immediately clear that they will go ahead with the donation, so that the decision requires little thought or discussion.[35] In such cases, there therefore seems to be no informed consent in the sense generally accepted by medical ethics. Can we extrapolate to children, who are not able to give their consent validly (at least until a certain age – see below), the fact that the majority of adults are willing to donate an organ to a family member? It seems problematic to say the least to subject young children who are not old enough to give their consent validly and may even be unable to refuse, to a moral standard that is higher than that which we expect from adults and children who are able to give their consent.

If the risk to the donor is insignificant, there is no problem. However, if the risk is considerable, as in the case of kidney donation under general anaesthetic, some commentators suggest that the best interests standard should be supplemented by the *substituted judgment* standard, which involves anticipating what the child, in light of his or her values, would decide in the same situation if he or she were an adult.[36] According to this view, the child's opinion must be inferred through an empirical examination of what adults generally do *in practice* when faced with the question of whether to donate a kidney to a family member (a brother or sister, for example). Since, as we have already noted, it is almost immediately clear for many people faced with the issue of intra-family organ donation that they will go ahead with the donation, and hence that the decision requires little thought or discussion, some suggest that this reaction can be extended by anticipation to children.[37] However, we may ask why such a generalisation by anticipation should represent sufficient legitimation. After all, some adults do of course still refuse to donate a kidney to a family member (even a close family member), so that by making a generalisation in anticipation, we

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34 Friedman Ross, L. (1998), *Children, Families, and Health Care Decision Making*. Oxford: Clarendon Press. The criterion of intimacy or the close-knit family is essential for Friedman Ross, who would therefore see things differently for families which are not so close-knit.

35 Simmons, R.G.; Marine, S.K. & Simmons, R. (1987), *The Gift of Life: The Effect of Organ Transplantation on Individual, Family, and Society Dynamics*, 2nd ed. New Brunswick, NJ: Transaction, p. 242 and p. 246.

36 See, for example, Fost, N. (1977), "Children as Renal Donors", *New England Journal of Medicine* 296, pp. 363–367.

37 See for example *ibid.*, p. 365.

merely arrive at a *probable* decision that the child would *certainly* make as an adult.[38] The substituted judgment standard is therefore often criticised as being a test which is too subjective and leaves the door wide open to potential abuse.

d) Who can be a recipient?

Various commentators point out that the concept of "family" should not be taken in a strictly biological sense, but should be defined in relational terms. In the *Curran v. Bosze* case, the Supreme Court of Illinois ruled that twins of three-and-a-half years should not undergo testing to determine their compatibility for a potential bone marrow transplant to their twelve-year-old half-brother with leukaemia. The twin brothers lived with their mother (with whom the father of the twelve-year-old boy in need of transplantation had conceived the twins as the result of an extramarital relationship). The mother was opposed to the twins undergoing the tests after receiving advice from medical specialists and parents of bone marrow donors. The father then brought an action in the hope of forcing the mother to allow the twins to undergo testing. However, the court ruled that the twins did not have to undergo the tests, given that there was no strong link between them and their half-brother (who lived with the father and his wife) and that they did not even consider him to be a member of their family.[39]

It is clear that a mechanism needs to be developed to make it easier to determine who is considered to be a family member. A purely biological link is not enough. Should a combination of a biological relationship and a strong relational bond be the only acceptable condition? Or is a strong relational link sufficient in itself? Dwyer and Vig emphasise the following:

> When we speak of family relationships, we have in mind a special kind of social relationship rather than a biological relationship. Consider two examples that illustrate this point. Suppose you have two daughters, one seven and the other five. The seven-year-old is your biological offspring; the five-year-old is adopted. The five-year-old needs a kidney, and neither you nor your spouse is a suitable donor. Suppose - what is very unlikely - that the seven-year-old is a matched donor. Would you allow a transplantation between the two children? A yes answer shows that the social relationship is more important than the biological relationship. But not any social relationship will do. Consider a second example. Suppose you have a seven-year-old daughter who has a friend about the same age. The friend is in need of a kidney. Suppose - what is very

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[38] Sheldon, M. (2004), “Children as Organ Donors: A Persistent Ethical Issue”, *Cambridge Quarterly of Healthcare Ethics* 13, pp. 119-122, p. 120.

[39] *Curran v. Bosze*, 141 Ill. 2d. 473, 566 N. E. 2d. 1319 (1990).

> unlikely - that your daughter is a matched donor. Would you let your daughter serve as a kidney donor? We think most parents would be very hesitant, even if the child got along better with her friend than she did with her sibling.
>
> What makes the moral difference is the family relationship. But membership in a family is not a yes or no matter. It is not even a matter of degree. It is a matter of a variety of qualitative differences. Hence there is a need to consider particular relationships in particular cases.[40]

The blood tie cannot be considered a necessary or sufficient reason to justify organ donation by a minor. On the one hand, there may be a strong desire to donate an organ to an adoptive brother or sister living under the same roof and with whom there is a close-knit relationship, similar to that between partners or spouses who, although they are not linked by a blood tie, sometimes donate organs to one another. On the other hand, some people are completely estranged from their brother, sister or parents, with whom they have not lived for a long time and for whom they no longer have any altruistic feelings.[41] Rosalind Ekman Ladd has the following to say on this subject:

> [W]e may ask if a close family relationship changes the moral landscape. For adults, we can ask if such relationships create special obligations. For children, we may want to phrase the question not in terms of obligations, for children are and should be exempt from many duties that are required of adults. We can ask instead if a close relationship between siblings would be relevant to the acceptability of donation from a minor because it is an indication of the voluntariness of the donor child’s assent.
>
> There is a presumption that it is natural and appropriate to put oneself at risk or suffer serious discomfort to benefit a family member. But we must be cautious about building a moral argument on this basis. A blood or genetic relationship cannot be considered either necessary or sufficient to justify a minor's organ donation. [...][42]

The question therefore arises of whether, in the case of donation of regenerable organs, it is necessary to limit the category of recipients to brother or sister, as required by Belgian law. If the potential minor donor is the only compatible donor for a parent or a significant third party (an immediate family member or even a close friend of the potential donor) whose life is in danger, it is conceivable that the benefits to the donor clearly override the

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[40] Dwyer & Vig (1995), *op.cit.*

[41] Ekman Ladd, R. (2004), “The child as living donor: Parental consent and child assent”, *Cambridge Quarterly of Healthcare Ethics* 13, pp. 143-148, pp. 145-146.

[42] *Ibid.*

disadvantages. Nevertheless, since the risk of conflict of interests (assuming the recipient to be a parent) is real, it is recommended that if an extension of the category of recipients is considered, additional protection should be provided, for example by entrusting the decision to a multidisciplinary committee.

e) The best interests standard and the potential advantages/disadvantages for the donor

From the best interests viewpoint, the potential benefits for the recipient must outweigh the potential disadvantages for the donor. It should first be emphasised that:

> Literature concerning child donors and their feelings after donation is virtually nonexistent.[43]

The potential *benefits* for the donor most often mentioned in the literature, in courts decisions (primarily in the U.S.A.) and in the *Code of Medical Ethics* of the American Medical Association[44], are:

- improved self-esteem resulting from this altruistic act;
- the continued presence of the surviving recipient (brother or sister, for example);
- a higher status in the family; and
- the absence of a possible sense of guilt, if the child were to find out later that he or she could have saved the life of the recipient.

However, some commentators wonder whether children, due to their young age and immaturity, are actually able to perceive these benefits cited by most adult donors. In other words, to what extent are the cited benefits purely speculative? According to Crouch and Elliott, one of the conditions for referring to benefits of a purely psychological nature is that the donor should have reached a sufficient level of cognitive development to be able to recognise the social aspect of the gift, i.e. to be able to understand not only that a kidney will be removed, but also that this procedure is going to help someone (a brother or sister, for example) in a way that few other people, or perhaps no one else, could do.[45]

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[43] Zinner, S. (2004), "Cognitive Development and Pediatric Consent to Organ Donation", Cambridge Quarterly of Healthcare Ethics 13, pp. 125-132, p. 129.

[44] American Medical Association, Council on Ethical and Judicial Affairs. Code of Medical Ethics, Report 56: the use of minors as organ and tissue donors, January 1994, cited in Zinner, S. (2004), *op. cit.*, p. 125.

[45] Crouch, R.A. & Elliott, C. (1999), "Moral agency and the family: the case of living related organ transplantation", *Cambridge Quarterly of Healthcare Ethics* 8(3), pp. 275-287, p. 282.

The key question is at what point the child has sufficient cognitive capacity to understand the precise meaning of the gift and draw psychological benefits from it.[46] In this context, Susan Zinner refers to Jean Piaget's influential theory on the cognitive development of children.[47]

According to Piaget's experimental findings, children aged between two and six years are not capable of abstraction, generalisation or reflection about the future and need very concrete examples. Children aged seven to twelve years, however, can already think abstractly, but often can still only understand an idea if they have already been in contact with it. From the age of thirteen, the minor normally has the ability to use logical thinking to evaluate the risks and benefits of present and future actions. At this stage, minors already show an adult capacity to deal with problems and *may* already be able to give their informed consent, despite their "chronological" age.

The famous study by Weithorn on the question of when children are able to make decisions which are "similar to those of adults" about medical treatment revealed that nine-year-olds do not differ significantly from older children and even adults in their analysis of complex scenarios. It was also found that the reasoning process of children aged fourteen years is not significantly different from that of adults.[48]

This concludes our discussion of which cognitive abilities must exist in order for there to be a real question of psychological benefits to the donor. It should also be noted that there may also be potential psychological *harm* to the donor. In his comments on an opinion issued by the Danish Bioethics Advisory Committee on the donation of tissues and organs by living donors, dated 1999,[49] Søren Holm, a renowned doctor and bioethicist, summarised the results of a literature review carried out by the Danish Committee.[50] From this in-depth study of the literature, the Danish Committee drew four conclusions:

1. The literature on the psychological and social effects of live donation is surprisingly small, and that part of the literature concerned with child donors even smaller.

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[46] Zinner, S. (2004), *op.cit.*, p. 126.

[47] *Ibid.*

[48] Weithorn, L.A. (1983), "Children's capacities to decide about participation in research", *IRB: A Review of Human Subjects Research* 5(2), p. 3.

[49] For the English translation of the conclusions of this opinion (not the full report), see the 1999 Annual Report at www.etiskraad.dk.

[50] Holm, S. (2004), "The Child as Organ and Tissue Donor: Discussions in the Danish Council of Ethics", *Cambridge Quarterly of Healthcare Ethics*, 13, pp. 156-160, p. 157 and the references cited.

2. Giving an organ within a family is not a simple case of gift giving. An organ cannot be transplanted from one family member to another without consequences, often profound in nature, for the family dynamics.

3. Anonymous donation is much less psychologically complicated than family donation.

4. Child donors often feel neglected after donation, because the family's attention is still focused on the recipient.[51]

As organ donation enables a life to be saved, it often has a special impact on the relationship between donor and recipient. In the normal logic of gifts, the gift of an organ should (be able to) be reciprocated later on by a gift of comparable value. If, as in the case of organ donation, this proves very difficult or impossible, this situation can give rise to two problematic consequences: either the donor permanently retains a feeling that the recipient owes him or her something, or the recipient permanently retains a feeling of owing something to the donor. These ongoing obligations can drastically disrupt family relationships and make them problematic.[52]

Other complications in family relationships which are cited in the literature are those which may result from a feeling on the part of the donor child of emotional neglect and lack of attention after the transplantation. In general, the family's attention has been focused for a long time on the patient, so the donor child may already feel neglected before the operation. After the transplantation, the ill member of the family may receive even more attention because he or she is very unwell, and everyone is hoping that the transplant will be successful. Immediately after transplantation, the donor therefore often receives even less attention than before. In many cases, the donor experiences a sense of rejection, or at least the feeling that his or her good deed has not been sufficiently acknowledged.[53]

In addition, Holm refers to another relevant argument raised during the deliberations of the Danish Committee. Often, when a non-regenerable organ (a kidney, for example) is donated by a child, we forget that donating at a young age rules out the possibility of giving this organ in adulthood to another person with whom the child may have an even stronger family bond. We must be aware that family bonds (and obligations) can change and that children, once they are adults and have started their own family, will be even more attached to their

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[51] *Ibid.*

[52] *Ibid.*, referring to Siminoff, L.A. & Chillag, K. (1999), "The fallacy of the 'gift of life'", *Hastings Center Report* 29(6), pp. 34-41. See also Scheper-Hughes, N. (2007), "The Tyranny of the Gift: Sacrificial Violence in Living Donor Transplants", *American Journal of Transplantation* 7, pp. 507-511.

[53] Holm, S. (2004), *op. cit.*, p. 157.

own children (and spouse). If we allow organ donation by children, there is a risk that later in the child's life, he or she will end up in a situation where donating the organ could have saved the life of his or her own child, but is no longer possible. Potential future changes in relational preferences and obligations are rarely, if ever, considered in the rational decision-making process, which gives maximum importance to the expected benefit to the donor.[54]

f) Can altruism be imposed?

In the famous *McFall v. Shimp* case, *Pennsylvania District and County Court* recognised that an adult has the right to refuse to donate an organ, even if the donation could save the life of the potential recipient and even if it involves only a negligible risk to the donor.[55] Robert McFall suffered from a rare and fatal condition for which only a bone marrow transplant offered the slightest hope of survival. His nephew, Robert Shimp, turned out to be the only compatible donor, but he refused to donate his bone marrow, even though he was on excellent terms with McFall. The judge ruled that although "*in the view of the Court, the refusal of the Defendant is morally indefensible*,"[56] Shimp could not be legally forced to undergo a physical procedure for the benefit of another person, because this would violate respect for the individual and it was not possible to determine more accurately where the line should be drawn. In the opinion of the judge, altruism therefore can never be imposed.

Some argue that since adults and people capable of expressing their wishes cannot be forced to donate, minors should also be protected against such an obligation. Holders of this view regard it as unacceptable that minors – who in principle have exactly the same rights as adults, and whose separate legal status is in fact intended to provide *additional* protection – might be subject to an obligation by which adults and people capable of expressing their wishes would not be bound.[57]

Of course it is true that some people who lack (full and complete) decision-making capacity – young children, for example – can be extremely vulnerable to exploitation for the benefit of third parties. However, a *total ban* on organ donation by minors may also prove morally problematic, in particular because in some cases it may run counter to respect for the personal rights of the potential minor donor if he or she has a strong desire to make the donation. *Systematic* application of the principle that the minor would refuse to donate an organ is almost as great a violation of the principle of equality (with adults) as imposing donation on a child. It means that, in contrast with what happens with adults, minors are

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[54] *Ibid.*, pp. 158-159.

[55] McFall v. Shimp, 10 Pa. D. & C.3d (26 July 1978).

[56] *Ibid.*

[57] Dufault, R. (1991), "Bone Marrow Donations by Children : Rethinking the Legal Framework in Light of Curran v. Bosze", *Connecticut Law Review* 24, p. 224. See also Zinner S. (2004), *op. cit.*, p. 129.

denied the opportunity to make a considered choice and are forced against their will to stay on the sidelines.[58]

g) Is the child's assent necessary?

Medical ethics often makes a distinction between the concepts of consent and assent. Susan Zinner defines assent as "Affirmative agreement that does not rise to the level of informed consent".[59] In a statement entitled *Informed consent, parental permission, and assent in pediatric practice*, the Committee on Bioethics of the American Academy of Pediatrics has clearly explained the difference between the two concepts, as well as the reason why assent should, if possible, be preferred to consent by a representative (*proxy consent*) (today commonly known as *parental permission* in this context). This statement dates back to 1985 and since then has been confirmed several times by the Academy, most recently in 2007.[60]

> In attempting to adapt the concept of informed consent to pediatrics, many believe that the child's parents or guardians have the authority or "right" to give consent by proxy. Most parents seek to safeguard the welfare and best interests of their children with regard to health care, and as a result proxy consent has seemed to work reasonably well. However, the concept encompasses many ambiguities. Consent embodies judgments about proposed interventions and, more importantly, consent (literally "to feel or sense with") expresses something for one's self: a person who consents responds based on unique personal beliefs, values, and goals.
>
> Thus "proxy consent" poses serious problems for pediatric health care providers. Such providers have legal and ethical duties to their child patients to render competent medical care based on what the patient needs, not what someone else expresses. [...]
>
> Decision-making involving the health care of older children and adolescents should include, to the greatest extent feasible, the **assent of the patient** as well as the participation of the parents and the physician. Pediatricians should not necessarily treat

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[58] See for example Robertson, J.A. (1976), "Organ Donation by Incompetents and the Substituted Judgment Doctrine", *Columbia Law Review* 76, p. 74: "We may conclude that respect for persons requires that we always presume that [the person] says no to any intrusive procedure. But if, in fact, [the person] would have chosen the procedure, he has been treated unequally in a real sense, because, unlike competents, he has been prevented from realizing his choices". See also Morley, M.T. (2002), "Proxy Consent to Organ Donation by Incompetents", *Yale Law Journal* 111, p. 1218: " [T]he constitutional rights of children and mentally impaired persons ... are violated when the law fails to provide a mechanism through which proxy consent may be tendered for donation of a nonvital organ to an immediate family member."

[59] Zinner, S. (2004), *op. cit.*, p. 127.

[60] See AAP Committee on Bioethics (1995), Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 95(2), pp. 314-317. See also http://aappolicy.aappublications.org/cgi/reprint/pediatrics;95/2/314.pdf [consultation on 3 April 2011].

> children as rational, autonomous decision makers, but they should give serious consideration to each patient's developing capacities for participating in decision-making, including rationality and autonomy. If physicians recognize the importance of **assent**, they empower children to the extent of their capacity. [...]
>
> **Assent** should include at least the following elements:
>
> [...]Telling the patient what he or she can expect [...].
>
> Making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept [...]).[61]

By virtue of the ethical requirement of informed consent in adults, it follows that there is an ethical requirement to try to determine whether the child really wants to make a donation. However, it is often difficult to determine the degree of competence and willingness of the child concerned. According to some commentators, the only way to get a good indication of what the child wants is to assess the strength of the emotional bond between donor and recipient, since if there is a strong bond we can *assume* that the donor will experience a psychological benefit as a result of the transplantation. This reasoning was for example explicitly used by the Supreme Court of the State of Illinois in the case *Curran v. Bosze*.[62]

However, the problem that may arise with regard to the requirement of assent on the part of the child is that a child is always vulnerable to pressure from parents, especially when the parents believe the donation to be the only means of enabling another of their children to survive.[63]

In addition, the question remains of whether a child can make an organ donation if he or she will derive no clear, non-speculative advantage from doing so, and if, as mentioned above, no similar obligation exists for adults. According to Ladd, the child's assent should be seen as the moral equivalent of adult consent, but only if specific additional conditions are met: the parents must have given their prior permission and it should be checked and confirmed that the child understands the scope of the transplantation and has assented voluntarily – a key indication of this being, according to Ladd, the emotional bond between donor and recipient.[64] The following conclusion is reached from this combination of conditions:

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[61] *Ibid.*, pp. 315-316.

[62] Curran *v* Bosze (1990), *op. cit.*

[63] Ekman Ladd, R. (2004), *op. cit.*, p. 145. See also Moutel, G. (2009), *Médecins et Patients. L'exercice de la démocratie sanitaire*, Paris, L'Harmattan, L'éthique en Mouvement collection, p. 93.

[64] *Ibid.*, p. 147.

> If it is the case that a cousin or a friend shares a close siblinglike relationship with a child and the child volunteers, then organ donation might indeed be acceptable. There is still the requirement for parental consent as a safeguard against the exploitation of children as organ donors.[65]

In addition to Ladd, many commentators stress the importance of having the child's assent, on the basis of the ethical principle of respect for the limited autonomy of the child - the same principle as that prioritised by the American Academy of Pediatrics. According to this principle, *even* if the expected benefits for the recipient are substantial, there is *no* moral obligation to go ahead with the donation. Requiring a child who is reluctant to donate an organ anyway would be tantamount to sacrificing the child for the sake of a utilitarian calculation which would infringe his or her personal dignity.[66]

But how should this requirement of assent be applied in practice? The information generally provided to potential organ donors, and which they must understand, includes the following: the condition from which the potential recipient is suffering, the nature and purpose of the proposed transplant, the alternative treatment methods, the prognosis if no transplantation takes place, and the known risks and complications of the transplantation.[67] Studies show that even some adults have difficulty understanding this information enough to be able to give informed consent. Young children can in no way satisfy this requirement. However, from the age of thirteen, minors are able to do so, according to Zinner.[68] She also argues that the risk of the child yielding to possible pressure applied by the parents decreases with age.[69]

Is it permissible to perform organ removal even *against the wishes of the potential minor donor*? Some commentators argue that, although in such a situation the child donor is used as an "instrument" to save the recipient, the donation also indirectly serves the child's own needs, given that the procedure will increase the well-being of the family on which the child's own well-being depends. According to this view – which is clearly based on the concept of family put forward by Dwyer and Vig (see above) – the donor child is also protected against the sense of guilt that one may assume he or she will probably develop later in life if he or she becomes aware of having refused an action which could have saved a

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[65] *Ibid.*

[66] Sells, R.A. (1993), "Consent for organ donation: what are the ethical principles?", *Transplantation Proceedings* 25(1), p. 39.

[67] Merion, R.M. (1996), "How informed is informed consent?", *Transplantation Proceedings* 28(1), p. 24.

[68] Zinner, S. (2004), *op. cit.*, p. 128.

[69] *Ibid.*

life.[70] In this regard, it should be noted that certain cognitive abilities are necessary for the person concerned to be able to develop a sense of guilt. In the case of severe mental retardation (whether the person is a minor or an adult), this argument is obviously inappropriate.

h) What procedure should be used for making the decision?

The main objection to authorising parents/guardians to make decisions on behalf of their child regarding organ donation is the risk of a conflict of interest if their love and hopes for their other child makes them blind to the true extent of the drawbacks to their donor child.

In addition, the few publications on the perception of the benefits and disadvantages of certain medical procedures undergone by children indicate that parents sometimes misjudge their child's values and goals.[71] The question then is to what extent parents' decisions about organ donation correctly reflect the interests of the children concerned. This doubt is deepened further by a study showing that the decisions taken by the authorised representatives of incapable adults reflect the choice of the representative in question, rather than the choice which is in the best interests of the patient.[72]

Given this possibility of an erroneous assessment of the potential child donor's values, and the risk of parental coercion, should another body therefore be involved in the decision-making (a judge or an ethics committee, for example)? Not according to Zinner[73] and Friedman Ross[74]. These authors believe that parents are nonetheless best placed to make a decision, since they will be guided by the best interests of their children and it is acknowledged that they are in the best position to simultaneously assess the values and aims of both the donor and the recipient of the organ. They suggest that the involvement of

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[70] Friedman Ross, L. (1998), *Children, Families, and Health Care Decision Making*. Oxford: Clarendon Press, pp. 114-118: "*To the extent that John's present and future well-being are dependent on his family's well-being, the donation promotes his ends. To the greatest extent feasible, parents ought to respect their child as a partially actualized person, but John's parents can override his dissent in their endeavour to shape him into the person he is becoming. Parents actively shape and steer their child's long-term identity. To this end, John's parents can override his present-day autonomous refusal in order to shape him into the type of person who will come to accept [...] family obligations as integral to his own well-being.*"

[71] Manne, S.; Jacobsen, P. & Redd, W. (1992), "Assessment of acute pediatric pain: do child self-report, parent ratings, and nurse ratings measure the same phenomenon?", *Pain* 48, pp. 45–52, cited by Kent, G. (1996), "Volunteering children for bone marrow donation", *British Medical Journal* 313(7048), p. 49.

[72] See for example Sachs, G.A.; Stocking, C.B.; Stern, R.; Cox, D.M.; Hougham, G. & Sachs, R.S. (1994), "Ethical aspects of dementia research: informed consent and proxy consent", *Clinical Research* 42(3), pp. 403–412.

[73] Zinner, S. (2004), *op. cit.*, pp. 130-131.

[74] Friedman Ross, L. (1997), "Health care decisionmaking by children: is it in their best interest?", *Hastings Center Report* 27(6), p. 44.

an independent third party may be advisable in cases where the parents and the potential child donor disagree.

However, several commentators argue for the systematic involvement of a committee and/or a judge in the decision-making process. The procedure used at the University of Texas M.D. Anderson Cancer Center is an example of the involvement of a multidisciplinary committee in the process of decision-making on bone marrow donation by minors:

> The M.D. Anderson [Cancer Center's] Minor Bone Marrow Donor Policy adopted in 1994 is simple, yet it provides mechanisms for addressing the issues of donation by minors. When a pediatric donor is identified, a separate healthcare team is formed consisting of a social worker, a child life worker, a pediatrician, and, depending on whether bone marrow or stem cells are to be harvested and whether sedation is anticipated, an anesthesiologist and/or an apheresis physician, none of whom are caring for the recipient. The social worker, pediatrician, and anesthesiologist or apheresis physician conduct separate interviews with the intended donor, alone if the child is 6 years or older, to explore the donor's understanding, fears, misconceptions, if any, and willingness to proceed with the donation. If any member of this team has any concerns, a special task force of the Clinical Ethics Committee, designed to have appropriate clinical, psychological, and ethical expertise, meets with the healthcare team to discuss the case. Use of a second healthcare team has the advantage of providing a second opinion, from healthcare providers who are not responsible for the recipient's care, about the appropriateness of the transplant, its benefits, and its burdens. They also provide a safe harbor for the child to dissent. The ethics review is also a mechanism for determining, in unclear cases, who counts as a family member.[75]

i) Conclusions

Some members advocate only allowing the **removal of bone marrow** (since bone marrow is regenerated), and only in certain narrowly defined cases. They are of the opinion that the following **conditions** must be met:

- There must be a strong link (genetic and/or emotional) between the potential donor and potential recipient.

- If the potential donor is at least twelve years old and his or her mental state does not prevent the giving of personal consent, the child must indicate his or her agreement,

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[75] Pentz, RD; Chan, KW; Neumann, JL; Champlin, RE & Korbling, M (2004), “Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity”, *Cambridge Quarterly of Healthcare Ethics* 13, pp. 149-155, p. 152.

and if he or she refuses, the removal may not go ahead. If the child agrees to the donation and the parents refuse, the child's opinion must prevail. Some of the members add that if the potential donor has no genetic link to the potential recipient, the parents (or guardian) of the potential donor must still give their permission, even if the child is over twelve years old, and that in such a case the child's consent is therefore not sufficient.

- If the potential donor has not yet reached the age of twelve, or if his or her mental state prevents the giving of personal consent, the parents (or guardian) must give their permission, but the donor must always be closely involved in the procedure, regardless of age and mental state, and must have the opportunity to give his or her own opinion.

Other members of the Committee believe that in addition to the removal of bone marrow, subject to the above conditions, **the removal of a kidney** from a minor is also permissible in some very exceptional cases, provided the following **conditions** are met:

- The donor and recipient must be identical twins.[76]

- Consent must be given by the donor (if the child is at least twelve years old) or by the parents (or guardian) if the child is less than twelve years old.

Still other members believe that the removal of a kidney from a minor may be permissible in certain exceptional cases, provided the following **conditions** are met:

- The recipient must be a brother or sister with whom the potential donor has a real connection, whose life is in danger and for whom there is no compatible organ available either from a deceased person or a living adult, and no other treatment options.

- The minor must be at least twelve years old.

- The minor must be capable of giving his or her consent and, having received and understood the relevant information, must have given his or her prior and completely

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[76] This is because in such cases the recipient does not need to be given immunosuppressive medication, which considerably reduces the risk of the recipient experiencing medical problems, and increases the probability that the donor will derive psychological benefit. While such cases only occur very rarely, this is not a purely theoretical scenario, as is shown by the case *Brown v. Hart* discussed above in the context of the presentation of American case law.

voluntary consent to the kidney donation. This condition must be verified and confirmed by a *donor advocacy team* with paediatric expertise[77].

- A multidisciplinary committee must agree to the removal of the kidney.

E. Ethical considerations regarding the question of whether the relatives of a deceased person should be able to oppose the removal of organs from the body

The legislators have abolished the possibility for family members of a deceased person to oppose the removal of organs by expressing their opposition to the doctor (with this opposition still being subordinate to the wishes of the deceased). Consequently, *even in the case of minors* and in the absence of explicit opposition to the removal of organs after death, *there is no longer a legal requirement to seek the consent of the family members and hence of the parents*. The question of whether it is ethically justifiable to act without such consent draws attention not only to the special status of *post mortem* organ donation by minors, but also to the system by which *post mortem* organ donation is organised under Belgian law and how the medical sector actually interprets and applies the law in practice. It also raises the question of whether the procedure for *post mortem* minor donors can or should actually be different from the procedure for *post mortem* adult donors.

An important clarification should be made here: because Article 12 of the Law of 19 December 2008 on the acquisition and use of human body material intended for human medical applications or for scientific research purposes refers to the opt-out system as organised by Articles 10 to 14 of the Law of 13 June 1986 on the removal and transplantation of organs, the considerations expressed here relate not just to organs in the sense of a "distinct and vital part of the human body, consisting of different tissues, which maintains its structure, vascularisation and ability to exercise physiological functions in a largely autonomous manner", but more broadly to all human body material, i.e. "any human biological material, including human tissue and cells, gametes, embryos, foetuses and substances extracted from them, regardless of their degree of transformation." *Post-mortem* removal of skin or of the cornea, for example, is therefore also concerned by these considerations.[78]

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[77] See Friedman Ross, L. et al (2008), *op. cit.*

[78] With regard to the procedures referred to by the Law of 19 December 2008 and the regime it establishes, the Committee refers to its future opinion in which it will respond to the other part of the Minister’s request, as indicated in point I.A.

1. What is the current practice in Belgium regarding *post mortem* removal of organs?

As everyone knows, the Belgian system of organ donation is an opt-out system based on the principle of implied agreement, but including the option for the potential donor to either refuse *or* explicitly agree to *post mortem* donation. On the basis of these two principles, the donor's autonomy seems to be respected, but at the same time, account is taken of the principle of solidarity on which organ donation is based. Moreover, the legislation in this way recognises the specific value of maintaining the physical integrity of the person, even *after* death.

In reality it is not particularly simple to determine on purely rational grounds what exactly gives the mortal remains of the deceased their symbolic value. One factor which certainly plays a role is the attention paid to the emotions of family members during the period of mourning following the death, who express their attachment to the deceased by paying respect to the body. In their eyes, a violation of the person's physical integrity may be considered as a "desecration" of the body, *even if it takes place in the context of a medical procedure*. Despite the undeniable role which is therefore played by emotions and subjective feeling, the legislation on organ donation is ultimately based on a deep understanding of the fact that respectful treatment of the deceased implies that even the mortal remains cannot suddenly be reduced to a reservoir of organs or a mass of tissue which can be used without consideration.

The idea that the body of a deceased person also deserves respect and should not be desecrated is not incompatible – quite the reverse, in fact – with the fundamental ethical principle of *solidarity* to which society and the medical sector appeal in the context of regulating organ donation. In the case of organ donation, the organ or organs from the deceased rather seem to be regarded as a gift given after death to another person. It is clear that the principle of solidarity becomes the uppermost consideration, in a way that can positively reinforce the need to symbolically transcend the tragic dimension of the death of a loved one. It is thus no coincidence that parents who lose a child in tragic circumstances (whether shortly after birth or not) often consent to organ donation because they feel that the death of their child will acquire some meaning in this way.

In current medical practice in Belgium, this respect for the body of the deceased is found among other places in the specific interpretation of the amendment to the law on the removal and transplantation of organs introduced by the Law of 25 February 2007. The amended legislation states that in the event of *post mortem* removal of organs, the doctor is in principle no longer required to seek the consent of relatives – the potential donor having either tacitly (through the opt-out system) or explicitly indicated his or her agreement to *post mortem* donation. In clinical practice, however, it seems that in Belgium, the doctors concerned continue to take account of how the close relatives of the deceased react to a formal declaration of intent concerning removal of organs. Current practice is that doctors never go against explicit reservations expressed by the close relatives with regard to organ donation in cases where the deceased person did not explicitly agree to it.

Thus in practice a sort of safety clause is included which goes beyond the legal requirements. The crucial point seems to be the medical sector's desire to keep clinical practice as transparent as possible and to act in a trustworthy manner and with due respect for the sensitivities surrounding potential organ donation. It does not seem desirable for the family of a deceased person to have to deal with the fact that a medical procedure was tacitly carried out on the remains of a loved one without any prior explanation of what was intended, why, and how the deceased person can thus make a *post mortem* gift to the community in a spirit of solidarity. Communication and transparency in this context are consistent with this requirement of solidarity. Moreover, it is in this spirit that Article 12 of the Law of 13 June 1986 states that the removal of organs and the suturing of the body must be carried out with respect for the remains of the deceased, and in such a way as to protect the feelings of the family, and that the remains should be placed in a coffin promptly so that the family can pay their last respects to the deceased as soon as possible.

2. Ethical principals in practice

The balance which currently exists between legislation, solidarity (the ethics of donation) and communication is an example of good clinical practice. The question arises as to what further points can be added, and on the basis of what ethical principles the practice of organ donation can potentially be further refined.

a) General considerations

The opt-out system is thus based on the tacit acceptance of organ donation on the basis of solidarity within civil society, on the assumption that society is *well informed* about the existing legal provisions. But even if this is in fact the case, we find in practice that the medical profession itself has added a further safety clause.

Thus current practice can have the effect of overturning the legal presumption of consent on the part of the potential donor, whether they be an adult or a child, if the family is explicitly opposed to a procedure being carried out on the body of the deceased, since in accordance with good clinical practice, the family is consulted about any removal of organs if the donor never made any declaration on the subject. Such a conversation, or as sometimes occurs in practice, request for authorisation from the family, can thus very concretely lead to plans to remove organs having to be dropped, in the case of both adults and children.

While it is true that doctors go beyond what they are required to do by law, their motivation for doing so is carefully considered. It is obvious that – for all age groups – the slightest suspicion that the body of a deceased person which has been returned by the hospital may have had organs or tissue removed for use in specific therapies on the basis of tacit consent would create a climate of mistrust between the family and the doctors and other caregivers. Organ donation might then become associated to a greater or lesser extent with dubious practices, which however honourable and based on good intentions they might be, would be likely to seriously undermine the spontaneous trust of families in doctors. Moreover, the medical community also seems to be guided here by the principle of respect for the deceased, even with regard to the body (which can no longer be "harmed" in a way that is consciously felt by the person). This "respect for the dead" is in fact a fundamental element of every culture. It therefore goes without saying that the medical community too wishes to act in accordance with such ethical principles.

What is more, existing practice is *also* perfectly consistent with the spirit of the opt-out system in cases where there is *explicit consent* on the part of the donor. Here, the citizen has individually indicated that he or she wishes to contribute to the system on which organ donation is based, and thus concretely manifests his or her solidarity with society. In such a case, the normal communication of information by the medical community to the family is of course sufficient. In such circumstances it seems desirable if not essential for the autonomy and explicit wishes of the deceased to be respected. Here too, however, the provision of information to the family – in case they are unaware of the explicit consent given by their loved one who has just died – about decisions taken in the context of transplantation will inevitably benefit the perceived transparency and willingness to communicate of the medical community as well as showing respect for the deceased person.

b) Removal of organs from minors

With regard to minors, some members believe it is undesirable to act without obtaining parental consent. In these cases, displaying the utmost tact is fully in line with the spirit of "open communication" concerning procedures performed on the deceased. In other words, when the deceased person is a minor, the family should be informed and receive a proper explanation of the procedures that the doctors wish to carry out on the body. The family should be given the opportunity to refuse – in the spirit of current practice in the Belgian medical community.

These members thus see it as desirable, when dealing with potential organ donors who are minors, for the doctor or medical team to inform the family and explicitly ask for their permission to proceed with any removal of organs. The doctor or medical team must then comply with the family's wishes if they refuse to consent on behalf of the deceased minor.

Other members do not distinguish between adults and minors, and where minors are concerned concur with the first position described under c) below.

c) Removal of organs from adults

Since the law formally allows organs to be removed without the family's consent where the donor has not officially expressed any position on the matter, it would be possible to proceed with such a removal without even informing the family. However, it should not be forgotten that medical practice is governed by a code of ethics which explicitly imposes a duty of disclosure of information. This duty of information can also be regarded as implicit in the requirement, expressed by the aforementioned Article 12 of the Law of 13 June 1986, to perform the removal of organs in a manner which shows consideration for the feelings of the family. In any case, current practice is so positive that the Committee unanimously considers that the *communication of information* to the family must be fully maintained when organ removal is carried out in the absence of explicit consent on the part of the donor. As stated earlier, this helps to maintain an optimal balance between the opt-out system and respectful treatment of the family of the deceased, and also ensures a climate of transparency and maximum communication between the medical profession and the family.

Within the Committee, opinions are divided, however, on the question of whether, in addition to *communicating information*, the medical team and doctor(s) in charge should feel bound to act in accordance with any opposition to removal of organs spontaneously expressed by the family and relatives of the deceased.

Some Committee members **(the first position)** hold that, for adult donors whose consent is legally presumed, the medical profession is only bound by *a duty of disclosure of information to the family*. The procedure would therefore be the same here as for potential donors who have explicitly given their consent, and the family would simply receive clear information about why organs are being removed and why this is permitted. It would perhaps also be possible to answer any additional questions from the family, and provide them with support in addressing any emotional issues. However, it would no longer be possible for the family or relatives to withhold permission any organ removal – a scenario which is entirely feasible under the legal provisions establishing the opt-out system.

On the other hand, other members of the Committee **(second position)** take the view that here too, it would be appropriate to maintain existing practice. According to these members, any refusal to allow organ removal expressed by the family or loved ones should therefore be respected. The reason for this position is the risk that the climate of transparency and communication in clinical practice would be jeopardised if there was even the slightest hint of dogmatism or lack of consideration on the part of the medical profession towards the relatives and family. From a strictly ethical point of view too, it is important to maintain a climate of respect and calm around the death, regrettable as a refusal to allow organ donation on behalf of the deceased may seem to the doctors and medical team, and even if the law allows a more proactive approach.

These members also see it as more consistent not to deal with adults any differently from minors in this respect, since the same principle of respect applies to both. Finally, they suggest that introducing the possibility of acting directly against the wishes of the close relatives or family might seriously compromise the practice of good and transparent communication. It could in fact spell the end of the practice of information provision as such. The doctors and caregivers concerned would be able to hide behind the law, which with its opt-out system appears to allow tacit removal of organs without any communication of information or any conversation with relatives whatsoever.

d) Communication of information and the opt-out system

The Committee is therefore unanimously of the view that it is undesirable to depart from good clinical practice, and that *post mortem* organ removal should never be carried out without informing the family beforehand, even if this is permitted by the law*. Acting in a spirit of open communication and transparency creates definite ethical added value.*

Leaving aside the specific question of how potential *post mortem* donors who are minors should be treated and whether or not a distinction should be made between minors and adults, it is desirable to continue to reflect in the future on ways to refine the opt-out system further. As already stated, this system presupposes good communication of information to citizens, who by their "silence" are deemed to be in favour of the organ donation system and the value of solidarity on which it is based.

This does not preclude political leaders, in an equally keen spirit of communication and transparency in the public sphere, from working to inform the population even better and to raise their awareness about the shortage of organs and exactly how members of the public can help alleviate this problem. This may also require some critical reflection on the concept of "presumed consent" (opting out) on which the Belgian system is currently based.

Some members are in favour of the proposal of Govert den Hartogh, who pleads in his report *Farewell to non-commitment*[79] for more active awareness-raising through an active donor registration (ADR) system. However, such a system requires a very carefully designed procedure, by which the authorities clearly explain to all citizens, at a particular moment in their lives, that they must register their wishes (i.e. whether or not they agree to the removal of organs). In such a system, repeated failure to react explicitly to the request to register would be taken as a form of tacit consent. These members felt that such a system would represent a useful modification of the current legislation and would better meet the need for active solidarity in connection with organ transplantation since, as the current legislation already indicates, the opt-out system can promote more active registration. Making the public more aware of the possibility of indicating consent to *post mortem* organ donation, both passively and actively, would definitely contribute to even better practice in organ donation, from both a medical and an ethical perspective.

Other members are not in favour of such measures, as they fear they would lead *de facto* to a return to a system of *opting in*, of which they disapprove.

By way of conclusion, we may quote the Opinion of the **French National Consultative Ethics Committee**, which considers that a *post mortem* "donation" "is based on the possibility of opposing organ removal and not, as has been incorrectly stated, on 'presumed consent'" and suggests that it might be a good idea, "although without changing the current system, to recognise more clearly that what the law allows people to renounce is the expression of a duty to others" since "explaining it to families in this way would avoid making them carry the weight of an alleged "consent" on the part of the deceased"[80].

At a more fundamental level, the French Committee writes in the same Opinion that "the law is not sufficient to regulate the field of bioethics. The legality of a practice is no guarantee that it conforms to morality. Moreover, regulation of a practice does not suffice to remove all the ethical problems arising from its application and does not relieve the actors of the obligation to exercise their personal discernment. In fields where decisions are made about the beginning or end of human life, compliance with the law does not cover all the ethical issues associated with a course of conduct. There are exceptional cases in which a health professional's conscience may lead him or her to break the law, accepting in advance the

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[79] Council for Public Health and Health Care, *Farewell to non-commitment. Decision systems for organ donation from an ethical viewpoint*, 2008, The Hague, Centre for Ethics and Health.

[80] Opinion of the French National Consultative Ethics Committee no. 105 of 9 October 2008, "*Questions for the Estates General on bioethics*". Reference should also be made to two recent books which explore in depth the issues covered by this opinion: P. Steiner, *La transplantation d'organes. Un commerce nouveau entre les êtres humains*, Gallimard, Bibliothèque des sciences humaines, 2010; A. Flückiger (ed.), *Emouvoir et persuader pour promouvoir le don d'organes? L'efficacité entre éthique et droit*, 2010.

consequences of his or her actions. In addition, in a contemporary context in which there are somewhat excessive expectations of the law, which is called upon to extend its intervention into all spheres, the illusion is all too commonly created that passing a law is sufficient to deal with a problem. Emphasising the importance of the law should therefore not lead to an overestimation of its role. The law cannot remove the need for constant progress in ethical thinking."[81]

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[81] *Ibid.*, p. 3.

5. Conclusions and recommendations

The Committee wishes to emphasise strongly from the outset that organ donation from living persons can cause medical, psychosocial and ethical problems for donors which do not arise, or only arise to a lesser extent, in the case of *post mortem* donation.

Question 1.a

Question 1.a was: "Is it ethically justified to *remove organs* which will not regenerate, or remove organs when this may have (serious) consequences for the donor, *from living adults who due to their mental state are incapable of expressing their wishes*, provided a person who is legally competent gives his or her consent?" (see point 1.D., Subject of the Opinion, as reformulated by the Committee).

All members of the Committee reject, from an ethical point of view, the existing legal provisions on the removal of organs from living adults who, due to their mental state, are incapable of expressing their wishes, since such a procedure has been made possible *even when* it exposes the donor to a serious risk to his or her health.

All members of the Committee also stress the importance of Article 8*bis* of the Law of 13 June 1986, inserted by the Law of 25 February 2007, which stipulates that any removal of organs from living persons must be the subject of prior *multidisciplinary consultation*. This precaution is particularly relevant when removal of organs is being considered from persons who, due to their mental state, are incapable of expressing their wishes. The King has the authority to determine the conditions of application of this multidisciplinary consultation, and the Committee believes that an initiative should be taken in this regard.

Beyond these findings, the opinions of the Committee members can be divided into three categories:

A *first group* considers that the only acceptable position from an ethical point of view regarding the removal of organs from living persons incapable of expressing their wishes is a total and unconditional ban. This group believes that a person's ability to express his or her willingness and capacity to give consent should be regarded as a prerequisite to acting as a living organ donor.

In the view of a *second group*, the removal of organs from living adults incapable of expressing their wishes can only be authorised if *all* the conditions listed below are met. In addition to the conditions already set by the legal requirements (i.e. that the recipient's life must be in danger, that *post mortem* donation cannot produce such a satisfactory result, and that the person’s legal representative must give his or her consent), the following should be considered:

- (1) The medical team must do everything possible to identify compatible living donors who are *capable*, and should only consider using an incapable adult donor as a last resort;
- (2) A psychologist or psychiatrist should carefully consider the impact that the death of the person needing the organ would have on the welfare of the potential incapable donor; the removal of the organ should only be permissible if it appears that the effects on the donor of the recipient’s death would be far worse than the bodily harm caused, implying the existence of a very strong emotional bond between donor and recipient;
- (3) If the incapable potential donor has sufficient capacity to give his or her opinion, this opinion should be sought, and if he or she is opposed to the removal of the organ, it should not take place;
- (4) The potential donor’s representative who will give his or her consent may not be the potential recipient. In addition, the potential recipient may not be a child, parent or spouse of the potential donor’s legal representative;
- (5) An independent multidisciplinary committee (at national level), including an expert in internal medicine, a legal expert, an expert in psychology and an expert in ethics, must check that the various conditions are met and provide a reasoned written opinion at short notice; the case should be submitted to this committee by the representative of the incapable potential donor or the doctor; and
- (6) If the opinion given by the committee referred to in the previous paragraph is positive, the case should be submitted to a justice of the peace for a final decision, under an emergency procedure. In the interests of consistency of judicial powers, it seems preferable that if the matter needs to be brought before a magistrate, it should be the justice of the peace; however it is important for him or her to receive proper training in this very special area.

A *third group* is prepared to allow the removal of organs from living adults incapable of expressing their wishes if *the majority, but not necessarily all*, of the above conditions are met. Thus, some members consider that only the extra condition (2) above should be added to those stipulated in the law. Other members believe that the involvement of the independent multidisciplinary committee provides a sufficient guarantee, and that mandatory prior authorisation from a justice of the peace is not required.

Question 1.b

Question **1.b** was as follows: "If the removal would normally have no serious consequences for the donor, or if the organ in question is one which can regenerate, and if the organ is destined to be transplanted to a brother or sister, is it ethically justified to have the option of removing organs from a minor, and more specifically *from a minor who is incapable of expressing his or her wishes due to his or her mental state*, provided the parents or guardian give their consent?

The Committee recalls first of all that, since the Law of 19 December 2008 on the acquisition and use of human biological material intended for human medical applications or scientific research purposes, a problem of legislative consistency exists regarding the removal and transplantation of bone marrow. These matters are addressed in this Opinion, although they are no longer governed by the Law of 13 June 1986, but by that of 19 December 2008, since bone marrow is not an organ in the sense of the Law of 13 June 1986 (in light of the definition introduced into this legislation by the Law of 19 December 2008).

All members of the Committee again stress the particular importance of the prior multidisciplinary consultation provided for in Article 8*bis* of the Law of 13 June 1986, the arrangements for which should be defined by a royal decree.

With regard to allowing or refusing to allow removal of organs from minors, the Committee reached the following conclusions.

Some members advocate only authorising *the removal of bone marrow* (because bone marrow is regenerable), and only in certain narrowly defined cases. They believe that the following *conditions* must be met:

- There must be a strong link (genetic and/or emotional) between the potential donor and the potential recipient.

- If the potential donor is at least twelve years old and his or her mental state does not prevent the giving of consent, he or she must personally indicate consent. If he or she refuses, the removal may not take place; if he or she accepts and the parents refuse, the views of the child should prevail. Some of these members add that if the potential donor has no genetic link with the potential recipient, the potential donor's parents (or guardian) must always give their consent, even if the child is over twelve years, as the consent of the child alone is not sufficient in such a case.

- If the potential donor has not yet reached the age of twelve, or if his or her mental state prevents the giving of consent, the parents (or guardian) must give their permission. However, the donor must always be closely involved in the procedure, whatever his or her age or mental state, and must have the opportunity to give his or her opinion.

Other Committee members believe that in addition to the removal of bone marrow subject to the above conditions, *the removal of a kidney* from a minor is also permissible in certain very exceptional cases, provided the following *conditions* are met:

- The donor and recipient are identical twins, and

- Consent is given by the donor (if the child is at least twelve years old) or by the child's parents (or guardian) if the child is less than twelve years old.

According to still other members, the removal of a kidney from a minor may be permissible in certain exceptional cases, provided the following *conditions* are met:

- The recipient may only be a brother or sister with whom the potential donor has a genuine bond, whose life is in danger, and for whom there is no compatible organ which could be taken from a deceased person or a living adult, and no other therapeutic options.

- The minor must be at least twelve years old.

- The minor must be capable of giving consent and, having received and understood the relevant information, must have given his or her prior and voluntary consent to the kidney donation. This condition must be verified and confirmed by a *donor advocacy team* which is able to draw on paediatric expertise.

- A multidisciplinary committee must agree to the removal of the kidney.

Question 1.c

With regard to the *post mortem* removal of organs, **Question 1.c** was: "Is it ethically justified to abolish the possibility for a relative of a deceased person to oppose the removal of an organ by expressing his or her opposition to the doctor (with this opposition still being subordinate to the wishes of the deceased)? This would mean that, *even if the patient is a minor, then in the absence of explicitly stated opposition to the removal of organs after* *death*, doctors will no longer be *required by law to seek the consent of relatives*, and hence the parents."

All members of the Committee consider that, under *good clinical practice*, where the donor has not made any declaration on the subject, *the family or relatives should at least be informed* of the possibility that organs may be removed. It is not desirable for the family of a deceased person to have to deal with the fact that a medical procedure was tacitly carried out on the remains of a loved one, even though, strictly speaking, the law in its current form allows this. The Committee believes it is essential for the climate of transparency and communication between the medical profession and the next-of-kin to be preserved to the highest degree possible.

All members of the Committee also take the view that if there is explicit prior consent on the part of the donor to the removal of organs, it is enough for the medical team simply to inform the family. In other words, the explicit wishes of the deceased – including minors – must be respected, even if the family objects.

In the absence of explicit authorisation on the part of the deceased for the removal of organs, opinions differ within the Committee as to whether, as well as *informing* the family and relatives, the medical team and doctor(s) responsible must *ask the family for permission to remove the organs* and if applicable, comply with their refusal.

Some *members of the Committee* take the view that the *only obligation that exists is to inform the family*, whether the deceased is an adult or a child. This would mean that the family merely needs to be informed clearly why organs will be removed, and why this act is permitted. There would thus be no need to take account of any opposition on the part of the family or relatives to organ removal. This situation is perfectly possible under the current law.

Other members of the Committee, however, believe that it is preferable to maintain the current practice. They hold that, in the case of both adult and child donors, it is appropriate not only to provide information but also to continue to explicitly seek consent for the removal of organs, and in the event of refusal on the part of the family or relatives, to refrain from such procedures.

Finally, *still other members* make a distinction according to whether the donor is a child or an adult. If the donor is an adult, they believe that the provision of information is sufficient. If the donor is a minor, however, they hold that information should be provided, but parental consent should also be required.

The opinion was prepared in the select commission 2010/3, consisting of:

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Experts interviewed
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The working documents of the select commission 2010/3 – request for opinion, personal contributions of the members, minutes of the meetings, documents consulted – are stored as Annexes 2010/3 at the Committee’s documentation center, where there may be consulted and copied.

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This opinion is available on the website www.health.belgium.be/bioeth under the heading “opinions”.