

# Organ donation after euthanasia; medical, legal and ethical considerations

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## Valorisation addendum



## Valorisation addendum

This chapter will touch upon the return of investment prospects for society from the knowledge gathered during this PhD-trajectory. Creating a practical manual on organ donation after euthanasia has made it possible for dozens of patients to be able to donate their organs, and even more patients on the transplant waiting list to receive an organ. Identifying different aspects of the process of organ donation after euthanasia gave rise to a whole new set of questions and dilemmas, and has changed medical practice. Centralizing the importance of the patient's autonomy, different medical, legal, ethical, political and societal were explored in the studies described in this thesis.

The next paragraphs will elaborate on the societal relevance of the studies performed and the conclusions drawn in the various chapters addressing these aspects.

### Medical considerations

Patients who want to undergo organ donation after euthanasia form and add a new group of donors to the donor pool, which was previously non-existent. A patient who requests organ donation after euthanasia belongs to a very specific patient category: compared to 'regular', existing category of donation after circulatory death, he does not receive life sustaining therapy in the intensive care unit prior to the donation procedure. They often suffer from a neurodegenerative disease, which impairs their quality of life, but does not harm their organs.

Organ donation after euthanasia is however not possible in every person who undergoes euthanasia. Patients who want to undergo organ donation after euthanasia are evaluated in the same way as other organ or tissue donors, on the basis of their current medical records and the preparatory investigations. Based on the findings, different organs might be suitable for donation. To have an indication of how many patients are eligible for organ donation after euthanasia, we used the general criteria to investigate the Belgian euthanasia cases in **chapter 5**.

This has led us to believe that the donated organs can be in at least the same shape as other donations after circulatory death, and perhaps even as donation after brain death. To analyze this assumption, we compared the results of transplanted kidneys after organ donation after euthanasia in **chapter 6**. This study confirmed that we need to proceed performing organ donation after euthanasia, since kidneys donated following euthanasia perform better than kidneys transplanted following donation after circulatory death and nearly as good as kidneys transplanted following donation after brain death. Therefore,

the number of quality adjusted life years (QALY's) was substantially increased. At the same time, this implies a significant reduction of the costs for kidney dialysis.

This thesis describes various medical aspects, namely the criteria a patient must meet in order to be a donor, leading to the conclusion that most patients who undergo euthanasia are not eligible for organ donation, a previous unexplored area of research. Every single donor which is eligible and willing to donate, is however able to improve or save the life of up to six patients. Furthermore, this thesis explores the quality of the kidneys that have been transplanted after organ donation following euthanasia, a research that had not been performed yet.

Drafting the practical manual by Maastricht University Medical Center, together with Erasmus Medical Center Rotterdam, initiated the research. Developing a practical manual was the first step contributing to the initiation of this thesis, which also prompted many other hospitals to think about the practical questions that arise when a patient requests organ donation after euthanasia, and the legal, ethical and organizational thresholds that need to be overcome. As a consequence, these hospitals, their medical professionals, and their board members were prepared when a patient actually submitted a request to donate after euthanasia.

## Legal considerations

In addition to the medical aspects that were elucidated by the studies in this thesis, several legal issues were addressed as well. Even though organ donation after euthanasia had already been performed in Belgium and the Netherlands when starting this thesis, it was nevertheless important to identify the possibilities and challenges of their laws on euthanasia and organ donation. In **chapter 3**, it was demonstrated that legal differences exist, leading to different ways of performing organ donation after euthanasia in different countries. In Belgium, three physicians need to confirm the patient's death before organs can be donated, while in the Netherlands, euthanasia is identified as an unnatural death. These aspects make it necessary to involve additional health care professionals and legal professionals to be able to fulfill all safeguards. It might be better to align both legislations. **Chapter 4** provides an even more detailed overview of the legal aspects of organ donation after euthanasia, with a focus on this procedure in the context of the Medical Treatment Act. To inform lawmakers and policy makers, all possible liability questions were identified and answered.

In addition to the above, when discussing the topic of organ donation after euthanasia at scientific congresses, participants often did not understand why one would perform or

undergo euthanasia, and were concerned about this procedure in minors, since they were aware of the fact that Belgium and the Netherlands allow for euthanasia in children and adolescents. **Chapter 7** discusses that organ donation after euthanasia is possible in minors, from a legal perspective. It is however believed that this will most likely never be performed because of ethical and medical contraindications, like malignancy.

These contraindications however are absent in ‘organ donation euthanasia’ (ODE): anesthetizing patients so their organs can be procured comparable to ‘living donation’, making it possible to increase the quality of these organs. Currently, the laws do not allow for ODE yet, as discussed in **chapter 8**.

### Ethical considerations

Euthanasia is being performed in people who suffer hopelessly and unbearably. Adding organ donation to euthanasia makes it an even more difficult ethical subject, in every possible way. This thesis has identified and discussed several ethical controversies; Should a physician always inform a patient about organ donation after euthanasia? Is it allowed to inform a patient on whether organ recipients have been found? Is it acceptable to let a patient undergo preparatory investigations before he can donate after euthanasia? This has initiated the debate among healthcare professionals, ethicists and lawmakers.

Answers to these questions are not simple, and both result from and contribute to the contemporary social debate. In ten or twenty years, some people will probably have changed their opinions on organ donation after euthanasia, comparable to the societal acceptance of euthanasia itself throughout the years

Specifically the chapters on organ donation after euthanasia in minors and organ donation euthanasia (ODE) have led to critical responses both domestically as internationally, but are essential to be able to adequately address questions pertaining to (younger) patients who want to let their last wish be fulfilled. These items will most likely remain the subject of an ethical discussion in the next decades. This was and remains the core of this thesis: by allowing organ donation after euthanasia, we have made it possible (and will continue to do so in the future) for patients to have their last wish fulfilled.

## Political and societal considerations

The publications in this thesis have increased awareness of organ donation after euthanasia, in both medical and non-medical professionals. Next to attention by the media, it has initiated numerous publications drawing attention to the topic, also fueling the public debate on the topic. The ongoing debate on organ donation, fueled by the issues on organ donation after euthanasia as well as opting out of organ donation in the Netherlands has demonstrated the sensitivity of the subject.

When organ donation after euthanasia was mentioned in the media, it became clear that not every member of society accepts this type of procedure. It is evident that there are opponents of euthanasia, of organ donation, and thus of the combination of these two as well. This does not necessarily have to be the consequence of religious beliefs. It is every person's – and most important every patient's – right to oppose to organ donation after euthanasia. When medical professionals did not want to participate in performing organ donation after euthanasia, their conviction has always to be respected.

Without defending or opposing the new law on organ donation, or being in favor or against organ donation after euthanasia it is necessary that people are aware of the importance of *making* a choice. Thousands of patients on the transplant waiting list rely on other people's altruistic beliefs. In the discussion on organ donation after euthanasia, the suffering of the patient, his relatives on the one hand and the patients on the waiting lists on the other are clearly acknowledged. When performing organ donation after euthanasia, medical professionals who were involved in such procedures have, almost without exception, experienced feelings of relief, gratefulness and appreciation in patients who were able to fulfill their last wish. Despite sadness and grief, the donor as well as his relatives and the recipients were grateful and relieved that something good resulted from a very incomprehensible and frustrating situation.

Apart from the medical, legal and ethical aspects addressed in this thesis, it has had a clear political impact. In the Dutch House of Representatives, parliamentarians have actively inquired about the process of organ donation after euthanasia, and have urged the Minister of Health to create clarity on the possibilities of organ donation after euthanasia. The minister was aware of the drafting of the practical manual, and has thereafter requested the creation of a national Dutch guideline.

## Conclusion

This research has changed the practice of general practitioners and transplant coordinators, who are confronted with the last wish of a patient who will be undergoing euthanasia. More importantly, it has substantially increased the awareness on organ donation after euthanasia among patients, health care professionals and policy makers. This has led to an increased number of patients requesting organ donation after euthanasia. Nearly all hospitals are now prepared to facilitate this combined procedure, and therefore, patients have an opportunity to have their last wish fulfilled.

It is absolutely necessary for politicians and policy makers to think about the future of organ donation after euthanasia, since this research has identified aspects that could be changed in the law to improve the process of organ donation after euthanasia. In case organ donation after euthanasia would be performed more often, this would have a significant impact on the organization of organ transplant and the procurement teams. This could also have potential future financial consequences for the transplant society, and for the use of operating rooms as well as other personnel. At the same time, this would

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