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Make It Plain: Strengthening the Ethical Foundation of First-Person Authorization for Organ Donation

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ABSTRACT

One response to the chronic shortage of organs for transplant in the United States has been the passage of laws establishing first-person authorization for donation of organs, providing legal grounds for the retrieval of organs and tissues from registered donors, even over the objections of their next of kin. The ethical justification for first-person authorization is that it is a matter of respecting the donor's wishes. The objection of some next of kin may be that the donor would not have wished for his or her loved ones to have their preferences overridden, had they considered that possibility. This article examines the basis of the conflict and suggests a remedy grounded in the provision of donor-intent options that have the ability to clarify the donor's wishes.

TRAGEDY

Two related tragedies unfolded in the summer of 2013. The first tragedy was of an all too common kind—a 21-year-old male riding home from work on his bicycle was struck by a car. He suffered major head trauma and was declared brain dead the following day. The second tragedy was of a far less common kind. When the family of the cyclist was informed that he had registered as an organ donor

while applying for his driver's license several months before, they were caught off guard. He hadn't mentioned it to them, and they did not wish for his organs to be removed. Representatives of Lifeline of Ohio, the regional organ procurement organization (OPO), explained that the objections of the family carried no legal force and made clear that they intended to proceed with organ retrieval.

Eventually the case wound up in court, where a judge sided with Lifeline of Ohio, which had argued that the law prevented anyone other than the donor from amending or revoking a person's status as an organ donor. In response, the young man's family argued that he must not have fully understood the choice that he had made. In the end, the family was left feeling anger and frustration, while those involved in organ procurement were left with the emotional burden of knowing that they had forced an outcome on a family who were already experiencing a deep sense of loss and powerlessness.¹

FIRST-PERSON AUTHORIZATION

The staff of the OPO was correct about the law. Ohio, like all other states in the U.S., has adopted a law that establishes first-person authorization (FPA) for organ donation.² This law is based on the revised 2006 Uniform Anatomical Gift Act (UAGA). A greater emphasis on first-person authorization was a major focus of the 2006 UAGA.³ In brief, the pur-

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pose of FPA is to provide legal grounds for OPOs to follow through on organ retrieval from registered donors over the objections of the donor's next of kin; something that occurs in less than 10 percent of cases.⁴

The term "authorization" was intentionally chosen by advocates of FPA to distinguish and distance it from the notion of informed consent.⁵ FPA is understood as a form of simple consent, which does not include an expectation that those who seek consent bear an obligation to provide information or assess the donor's understanding.⁶ Advocates for FPA argue that authorization for postmortem organ donation is more akin to gift giving than it is to agreeing to medical treatment. While informed consent would be required for medical treatment, simple consent is sufficient for giving a gift or making a donation, since we do not ordinarily assume that there is any duty to provide information to those who wish to give us a gift.

Yet it may be argued that we do have an ethical duty to inform people who express a desire to give us a gift if we can reasonably anticipate the kind of conflict with loved ones to which FPA policies have sometimes led. At the least, most would agree that organizations actively requesting gifts (as OPOs do) behave more ethically when they provide information to avoid or mitigate these conflicts. Furthermore, given that it frequently has been argued that FPA is grounded in the ethical principle of respect for a donor's autonomy,⁷ questions may be raised about whether one could be properly described as respecting the autonomy of another while simultaneously maintaining a system in which the meaning of a person's choices are often unclear and sometimes counterintuitive.

There is plenty of evidence that the organ donation system in the U.S. is poorly understood by the general population.⁸ The information provided in printed materials and on websites of OPOs tend to emphasize that there are a number of "myths" and misconceptions that surround organ donation.⁹ Among the misconceptions noted are the belief that many religions frown upon or forbid donation, a fear that physicians will not work as hard to save patients who are registered as organ donors, and the concern that families of donors may have to pay for the cost of organ retrieval. Research indicates that many people are unaware or confused about the number and specific types of organs or tissues that may be used, and about the rights (or lack thereof) of the family.¹⁰ In addition, while OPOs may not consider postmortem organ donation a form of medical treatment that is subject to the requirement of

informed consent, the average person may assume otherwise, given that organ retrieval takes place in a healthcare facility and is performed by trained and licensed healthcare professionals.¹¹ Confusion is also engendered by the inconsistent practices of various OPOs, as some are much more likely to enforce FPA than others.¹²

Still other misunderstandings are plausible and even probable. For instance, some people might assume that if they do not register as a donor, or if they revoke their designation as a donor, it is the same as declaring their wish to not become a donor and that their organs will never be removed for transplant. But to legally establish a means to prevent the retrieval of one's organs and tissues after death, one must create one's own "I do not want to be a donor" document.¹³ The lack of a donor card or absence from a donor registry is not understood as a refusal to donate. It is understood as not making a choice one way or another, leaving it up to one's next of kin to decide whether or not one's organs or tissues will be donated.¹⁴

Likewise, those who have previously agreed to have the donor symbol on their driver's license may believe that asking for the symbol to be removed from a subsequent license is the same as revoking their authorization to donate, but it may not be.¹⁵ Their names may remain on the donor list unless or until they officially revoke their donor designation, following a process laid out under state law. Even when persons do officially revoke their status as a donor they do not become registered as someone who does not want to donate. They are regarded only as persons who have not expressed a preference, and their loved ones will be consulted about donation if there is a possibility of retrieving usable organs or tissues.¹⁶

MAKE IT PLAIN

The ethical justification for FPA for donation is grounded in the principle of respect for autonomy, which affirms the right of self-determination. In plain language, FPA is the assertion that we ought to do what the "donor" wanted. Yet if the donor did not understand the terms of the agreement,¹⁷ or was unaware of other options or how to avail himself or herself of them, then it becomes less certain that donation was what the individual wanted or would have wanted, had he or she understood better or had been more aware of the various options available. As Dale Gardiner has argued, donor registration under such conditions is more like expressing a wish than giving consent. As he notes, we often have

multiple wishes, not all of which are compatible. Unless some attempt is made to examine and weigh one's options, it may not be legitimate to consider a choice to become a donor as the act of an autonomous will.¹⁸ If it is not the act of an autonomous will, then the justification for considering donor registration as a legitimate expression of the right of self-determination is called into question.

In light of the likelihood of various misunderstandings, some have suggested that the informed consent standard be applied.¹⁹ However, implementing a system of informed consent could be problematic in at least two ways.²⁰ First, it could generate extended debate over the nature and extent of the information required for adequate consent, and debate over how, when, and by whom the information should be conveyed. Second, it could be difficult to implement use of the informed consent standard under the current system of donor recruitment without risking a substantial negative impact on the number of persons who would agree to become a registered donor. The negative impact would not necessarily result from the content of the information provided, but from the extra time involved. As it stands, most decisions about becoming an organ donor in the U.S. take place in the context of an application for or renewal of a driver's license, a process most people prefer to keep as brief as possible.²¹ Many might also be discouraged by the extra time it would take if an online registry required them to show they understood key information about donation before it allowed them to register.

There is, however, a way to address the potential for confusion in recruiting donors without requiring the adoption of full informed consent. It is, quite simply, to make the commitment to donate as first-person consent explicit by offering other options, set forth in plain language. In a system in which one may choose between registering as an organ donor, registering a refusal to be an organ donor, or registering a desire to leave the decision up to one's next of kin, FPA would rest on a much stronger ethical foundation.

Such a system is already in place in the Netherlands. In the Netherlands, persons are offered four options:

- I want my organs and tissues to be used for transplantation.
- I do not want my organs and tissues to be used for transplantation.
- I wish to leave the decision to my family and possible partner.
- I am authorizing this [specific] person to make the decision.²²

By offering the option to refuse and the opportunity for individuals to delegate the decision to others,²³ the Dutch system demonstrates a strong commitment to the ethical principle of respect for autonomy.

The implementation in the U.S. of a donor registration system that includes three or more options would require changes to state laws and the creation of registries that record choices other than a simple willingness to be a donor. Yet it would not entail a challenge to the understanding of organ donation as a gift or require more than simple amendments to the existing UAGA. The increased clarity about the meaning of one's choices might also increase trust in OPOs by providing greater transparency, which demonstrates respect for donors as decision makers.²⁴ Above all, while it would not eliminate all objections by next of kin when families are informed that a loved one is a registered organ donor, it should reduce the number and intensity of objections and provide a much more robust ethical foundation for proceeding with organ retrieval over objections by next of kin.

NOTES

1. A. Manning, "Family Loses Fight to Keep Son's Organs from Donation," *Columbus Dispatch*, 12 July 2013.

2. Some recent research has suggested that first-person authorization laws have not actually been effective in increasing the number of organs and tissues donated, perhaps because OPOs seldom take steps to enforce them. K. Callison and A. Levin, "Donor registries, first-person consent legislation, and the supply of deceased organ donors," *Journal of Health Economics* 49 (2016): 70-5.

3. Ohio Revised Code, Title 21: 2108.08, Action by Person Other than the Donor; W.J. Chon et al., "When the Living and the Deceased Cannot Agree on Organ Donation: A Survey of U.S. Organ Procurement Organizations (OPOs)," *American Journal of Transplantation* 14 (2014): 173; National Conference of Commissioners on Uniform State Laws, "Revised Uniform Anatomical Gift Act (2006): Last Revised or Amended in August 2009," http://www.uniformlaws.org/shared/docs/anatomical_gift/uaga_final_aug09.pdf.

4. A family's objection to the wishes of a registered donor should be distinguished from a family's refusal to donate the organs of a potential donor who did not register as a donor. The latter rate is significantly higher. H.M. Traino and L.A. Siminoff, "Attitudes and Acceptance of First Person Authorization: A National Comparison of Donor and Nondonor Families," *Journal of Trauma and Acute Care Surgery* 74, no. 1 (2013): 296; Chon et al., "When the Living and the Deceased," see note 3 above, p. 174; P.A. Stahler et al., "Honoring Patients' Organ Donation Decisions When Family Conflict is Present: Experience From a Single Organ Procurement Organization," *Journal of Trauma and Acute Care Surgery* 77, no. 4 (2014):

557-8. For comparable rates in the U.K., see A. Vincent and L. Logan, "Consent for Organ Donation," *British Journal of Anaesthesia* 108, supp. 1 (2012): i81. Even in those cases in which the family initially objects, the family often concedes in time. Sometimes OPOs respect the wishes of the family even though the law is on the side of the OPO. Objections that end up in court are exceedingly rare. Regardless of how the conflict is handled, however, it is undoubtedly emotionally distressing for all involved. It may also interfere with timely retrieval of organs, allowing some organs to deteriorate. Furthermore, publicity about such conflicts may discourage others from registering as organ donors or persuade those already registered to remove their names from a registry.

5. OPTN/UNOS Organ Procurement Organization Committee, "Report to the Board of Directors," 2014, Richmond, Va., http://optn.transplant.hrsa.gov/converge/committeereports/board_main_opocommittee_11_17_2014_15_3.pdf. Scotland has also chosen "authorization" over "consent" for similar reasons. Vincent and Logan, "Consent for Organ Donation," see note 4 above, p. i80.

6. For a discussion of the difference between informed and simple consent and a compelling argument in favor of requiring informed consent for organ donation, see A.S. Iltis, "Organ Donation, Brain Death and the Family: Valid Informed Consent," *Journal of Law, Medicine and Ethics* 43, no. 2 (2015): 369-82.

7. D. MacKay and A. Robinson, "The ethics of organ donor registration policies: Nudges and respect for autonomy," *American Journal of Bioethics* 16, no. 11 (2016): 3-11; M.B. Gill, "Presumed Consent, Autonomy and Organ Donation," *Journal of Medicine and Philosophy* 29, no. 1 (2004): 55.

8. J.R. Rodrigue et al., "Vascularized Composite Allograft Donation and Transplantation: A Survey of Public Attitudes in the United States," *American Journal of Transplantation* 17, no. 10 (2017): 2689-90.

9. "Busting Myths about Organ Donation," Gift of Life Donor Program, <http://www.donors1.org/learn2/myths/>.

10. Note: Some scholars of ethics argue that organ donation does in fact require informed consent rather than simple consent. Iltis, "Organ Donation," see note 6 above; D. MacKay and A. Robinson, "The Ethics of Organ Donor Registration Policies: Nudges and Respect for Autonomy," *American Journal of Bioethics* 16, no. 11 (2016): 3-12.

11. Traino and Siminoff, "Attitudes and Acceptance of First Person Authorization," see note 4 above, p. 299.

12. Chon et al., "When the Living and the Deceased Cannot Agree on Organ Donation," see note 3 above, pp. 174-5; R. Girlanda, "Deceased organ donation for transplantation: Challenges and opportunities," *World Journal of Transplantation* 6, no. 3 (2016): 457.

13. The sole example of this type of card or statement this author was able to find appears deep in the text of the revised 2006 UAGA, where an ordinary person is highly unlikely to find it: National Conference of Commissioners on Uniform State Laws, "Revised Uniform Anatomical Gift Act," see note 3 above, pp. 1-60. Govert den Hartogh argues that when it is made difficult to register

refusal, one's right to decide about what happens to one's body is "disrespected." G. den Hartogh, "The Role of Relatives in Opt-in Systems of Postmortal Procurement," *Medicine, Health Care and Philosophy* 15 (2012): 195-205, 197.

14. National Conference of Commissioners on Uniform State Laws, "Revised Uniform Anatomical Gift Act," see note 3 above, p. 29.

15. *Ibid.*, 25.

16. As den Hartogh notes, most "opt-in" systems operate in this way, delegating the right to donate to one's next of kin in the event that one does not register as a donor during one's lifetime. den Hartogh, "The Role of Relatives," see note 13 above, p. 197.

17. This was the claim of the family in the opening story, and they may well have been correct.

18. In the case of organ donation, we may wish to become organ donors, but wish even more that our grieving loved ones have their wishes respected. However, if we are not offered a clear and simple way of expressing this stronger wish, those who insist on retrieving organs may end up doing something other than what we actually wanted. D. Gardiner, "An Unethical Marriage—The Human Tissue Act and the UK NHS Donor Register," *Journal of the Intensive Care Society* 8, no. 2 (2007): 42-3. For another perspective on the issue, see MacKay and Robinson, "The Ethics for Organ Donor Registration Policies," see note 10 above, pp. 3-12.

19. Iltis, "Organ Donation," see note 6 above; R. Truog, "Consent for Organ Donation—Balancing Conflicting Ethical Obligations," *New England Journal of Medicine* 358, no. 12 (2008): 1209-11, in the U.S.; Gardiner, "An Unethical Marriage," see note 18 above; M.D.D. Bell, "Emergency Medicine, Organ Donation and the Human Tissue Act," *Emergency Medicine Journal* 23 (2006): 824-7, in the U.K.

20. Members of the Washington State SB 5386 Work Group mention a third: "Restructuring the organ donation laws outside of gift law principles . . . would be a fundamental change that could not be accomplished with a simple statutory amendment to the UAGA. Further, eliminating gift law as the basis for organ donation could have unintended consequences such as undermining the legal foundation that prohibits the buying and selling of organs." J. Reyes et al., "Report to the Washington State Legislature on Strategies for Increasing Organ Donation, Senate Bill 5386," January 2012, http://app.leg.wa.gov/ReportsToTheLegislature/Home/GetPDF?fileName=Organ%20Donation%20Report%20to%20WA%20Legislature_d497ab47-e0f8-48fb-9249-383b1c34a90f.pdf, p. 7.

21. K.P. Whyte et al., "Nudge, Nudge or Shove, Shove—The Right Way for Nudges to Increase the Supply of Donated Cadaver Organs," *American Journal of Bioethics* 12, no. 2 (2012): 32-9, 35.

22. "Options," Donorregister Duidelijkheid en zekerheid door registratie, <https://www.donorregister.nl/english/aboutdonorregistration/options/>. Under the third option, "family and possible partner" refers to relatives listed and prioritized by the law. First priority goes to a spouse or "registered partner." Dutch law allows for those who do not wish to marry to register a formal partnership agreement that conveys certain rights and privileges.

Changes in the Dutch organ procurement system are currently being considered, including a shift from “opt-in” to “opt-out.” “Dutch MPs vote for ‘yes unless’ organ donor register,” *Dutch News.nl*, 27 December 2016, <http://www.dutchnews.nl/news/archives/2016/09/dutch-mps-vote-for-yes-unless-organ-donation-register>.

23. It is ethically permissible and reasonable for individuals to delegate decision making. The decision to delegate is itself an act of autonomy that should not be denied to persons. In the case of organ donation after death, people may feel it is more appropriate for their next of kin to decide because the next of kin will be affected emotionally and have a responsibility to assist those engaged in organ retrieval by providing a health history and other information. It is well established that not all persons wish to make their own decisions, even in the course of regular healthcare. See R.B. Deber et al., “Do people want to be autonomous patients? Preferred roles in treatment decision making in several patient populations,” *Health Expectations* 10 (2007): 248-58.

24. Distrust is a recognized problem. See M.J. Irving et al., “Factors that influence the decision to be an organ donor: A systematic review of the qualitative literature,” *Nephrology Dialysis Transplantation* 27 (2012): 2530-2; “Organ Donation Depends on Trust,” *Lancet* 387 (2016): 2575.