Assistance in Dying and Organ Donation

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MEDICAL ASSISTANCE IN DYING (MAID) AND ORGAN DONATION

Organ donation may be possible for those who choose to receive medical assistance in dying. (1) Organ donation following MAID is offered across Canada, although many patients are surprised to learn that they may be eligible to donate their organs.

WHAT IS MAID? WHO IS ELIGIBLE?

The term "MAID" stands for medical assistance in dying. Canada's original medical assistance in dying legislation was passed in 2016. The initial law included the eligibility requirement that natural death be reasonably foreseeable. Following challenges to the law in 2021, this requirement has now been removed. This broadens the scope of who is eligible for MAID if they wish to have it.

As of March 17, 2021, persons who wish to receive MAID must satisfy the following eligibility criteria: (2)

- Be 18 years of age or older and have decision-making capacity;
- Be eligible for publicly funded health care services;
- Make a voluntary request that is not the result of external pressure;
- Give informed consent to receive MAID, meaning that the person has consented to receiving MAID after they have received all information needed to make this decision;
- Have a serious and incurable illness, disease or disability (excluding a mental illness until March 17, 2023);
 - Mental Illness: Canadians whose <u>only</u> medical condition is a mental illness, and who
 otherwise meet all eligibility criteria, will not be eligible for MAID until March 17, 2023.
 This includes conditions that are primarily within the domain of psychiatry, such as
 depression and personality disorders.
- Be in an advanced state of irreversible decline in capability; and
- Have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable.

MAID AND ORGAN DONATION: CONVERSATIONS AND PROCESSES

MAID and organ donation must be separate conversations. The decision to receive MAID must be made prior to the initiation of any discussions of organ donation by healthcare providers. It is essential to maintain a clear separation between the processes for MAID and for organ donation. (3) This separation is meant to ensure that the decision to seek MAID is not influenced by the potential for organ donation. It is also meant to avoid the possibility that a person may feel pressured to consent to donation to secure approval for MAID. Conversations surrounding organ donation following the decision to seek MAID is complex, as donation will impose restrictions on the process of MAID itself (e.g. it will likely need to take place in hospital in proximity to an operating room, rather than at home; and it will limit the time that friends and family may spend with the person after their death). Therefore, the option of donation following MAID should be offered with sufficient time to engage in the discussion, to make an informed decision, and to incorporate the donation process into the MAID process.

Separation should be maintained between the end-of-life care, donation, and transplant teams. Surgical recovery and transplant teams should not be involved in the patient's end-of-life care or MAID procedure. (4) Society and law makers should be careful to avoid inadvertently creating pressure on patients with respect to their decisions regarding MAID and organ donation. The dead donor rule must always be respected and applied: in other words, the donor must be dead before essential organs can be removed. (5)

Instances of organ donation following the use of MAID are not expected to be common since some of the most common conditions which may lead an individual to seek MAID, such as terminal cancer, rule out the possibility of organ donation. (6) Data from 2018 in the Netherlands showed that organ donation after MAID occurred about 40 times with good results. (7) About 80% of patients in the Netherlands requesting MAID have cancer and are ineligible for organ donation; other general exclusion criteria include serious infections, while specific organ exclusions include kidney disease, pulmonary disease, or liver cirrhosis. (8)

MAID brings new challenges and opportunities for organ donation, but the trust and integrity of the Canadian donation system must be protected.

FIRST PERSON CONSENT

The patient must have the ability to provide first person consent to MAID, as well as to organ donation. (9) The patient should be informed that they may withdraw consent for MAID or donation at any time. Withdrawing consent for organ donation should not affect their consent for, or access to MAID. (10)

The ability of donors to give first person consent for MAID and organ donation creates emotional and moral challenges for healthcare professionals. (11) MAID patients will be competent immediately before death and donation and will therefore be able to give first-person informed consent to donate organs. (12) A donor who can provide first person consent may be considered the "ideal donor" from an ethical perspective, but this may be more emotionally challenging for the organ donation coordinator as they meet the patient/donor in person and have direct personal contact with them, which is not common in other deceased donation situations. Some organ donation coordinators have reported feeling like they lost a friend. Healthcare professionals may experience a greater emotional burden with organ donation following MAID.

MAID AND ORGAN DONATION SUPPORT RESOURCES

Support resources should be available for patients and their families, as well as for health care providers. Patients and families should receive educational materials, work with special trained professionals, have access to support groups, and have the option to be in contact with other families who have gone through MAID and organ donation. Family members may find it helpful to receive grief support, spiritual support, or support from family members with similar experiences. Health care providers and organ donation coordinators should receive special education and training for organ donation following MAID, complete a debrief following the process and receive peer support.

BENEFITS FROM ORGAN DONATION FOLLOWING MAID

After a MAID patient decides to donate their organs, various parties in the process will experience benefits. Donors receive a psychological benefit prior to their death, knowing they will be donating their organs and helping others. The donor also receives the legacy of saving a life. The family members of the donors will similarly experience a "legacy for the family member" and may feel comforted knowing their family member's wish to donate was respected. Family members may further receive a psychological benefit of knowing their family member helped others. The organ recipients and their families receive the medical benefits of organ transplantation.

CONCERNS SURROUNDING ORGAN DONATION FOLLOWING MAID

- Donor motivation for choosing MAID: the primary motivation for a patient choosing MAID should not be organ donation, but rather ending their suffering.
- Balancing concerns about donor coercion, while also respecting patient autonomy. If organ donation is not offered because of the fear of donor coercion, then we are denying the autonomous wish of those who want the legacy of saving a life.
- Patients might find it hard to change their minds and feel pressure to follow through with MAID after deciding to donate their organs.
- Societal pressures: concerns that a patient might consent to organ donation because they did not want to let their MAID provider down (if they perceived the MAID provider to favour donation), or they may feel there is an underlying duty to donate following MAID. Patients may feel that MAID may be in vain if they do not donate their organs.

BARRIERS TO ORGAN DONATION FOLLOWING THE DECISION TO USE MAID

- Increased medicalization of death: when patients agree to donate their organs, there is a need for additional testing related to the organ donation (e.g. bloodwork, additional testing or imaging). This can be a deterrent to opting for organ donation after MAID as many patients do not want to complete additional tests or spend additional time at a hospital.
- Impact on plans for medically assisted death:
 - Location: hospital vs home many MAID patients prefer to die at home rather than a hospital and this may impact their decision to donate their organs;
 - **Timing:** there may be a potential delay in the MAID process to accommodate organ donation.
- Some healthcare providers could refuse to participate in organ donation following MAID as they are opposed to MAID. (13)

ARE ORGAN RECIPIENTS INFORMED THAT THEIR DONORS DIED THROUGH MAID?

Only increased medical risks associated with a particular organ must be disclosed to recipients, such as an increased risk of contracting an infectious disease. Medically irrelevant factors are not disclosed; these are unrelated to increased medical risk and these include: race, religion, or manner of death. They are not disclosed since these factors will not impact the recipient's health and may disclose the donor's identity. (14)

UNCERTAINTY ABOUT DIRECTED DONATION

Directed donation (i.e., directing a patient's organs to a specific recipient) is permitted for living donation, but there are concerns about directed donation following death due to MAID:

- · Concerns about donor coercion or motivation for choosing MAID,
- Concerns surrounding a MAID patient being unable to change their mind about following through with MAID. Organ donation could be seen as a commitment mechanism and the patient may feel like they are unable to change their mind about MAID.

Directed donation following MAID should not be offered or encouraged. (15) However, if a patient insists on directed donation, these instances should be reviewed on a case-by-case basis.

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<u>The Canadian Donation Transplant Research Program</u> (CDTRP) is a national research initiative designed to increase organ and tissue donation in Canada and enhance the survival and quality of life of Canadians who receive transplants.

RESOURCES

- Ontario: Trillium Gift of Life, Donation FAQ, "Is organ and/or tissue donation still an option if I opt for MAID?" - LINK
- Quebec: Organ and Tissue Donation: Eligibility LINK
- Nova Scotia: Medical Assistance in Dying and Donation LINK
- Canadian MAID Legislation LINK
- Health Canada: Information on Access to MAID and How it is Delivered in Canada LINK

REFERENCES

- (1.) Trillium Gift of Life. Is Organ and/or Tissue Donation Still an Option if I Opt for MAID? Frequently Asked Questions https://www.giftoflife.on.ca/en/faq.htm
- (2.) Government of Canada. Changes to eligibility criteria. Canada's New Medical Assistance in Dying Law. https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html#s1
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- (4.) Downar, J. et al. (2019). Deceased Organ and Tissue Donation After Medical Assistance in Dying and Other Conscious and Competent Donors: Guidance for Policy. CMAJ, 191(22) E604–13.
- (5.) See note 4 at 609.
- (6.) Yazdani, S. et al. (2018). Organ Donation and Medical Assistance in Dying: Ethical and Legal Issues Facing Canada. McGill Journal of Law and Health, 11(2), 59–86 at 64.
- (7.) Mulder, J. & Sonneveld, J.P.C., (2018). Organ donation after medical assistance in dying at home. CMAJ, 190(44), e13056 at e1306.
- (8.) See above.
- (9.) See note 4 at e609.
- (10.) See above.
- (11.) See above at e604.
- (12.) See note 6 at 63.
- (13.) Allard, J. et al. (2021). Quebec Healthcare Professionals Perspectives on Organ Donation After Medical Assistance in Dying. (2021) BMC Medical Ethics, 22 1–12 at 4.
- (14.) See note 6 at 81.
- (15.) See note 4 at e607.