

## Letter to the Editor: New Observation

# ALS, MAiD and Tissue Donation: Case Reports from Six Patients' Care Journeys

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In 2016, Medical Assistance in Dying (MAiD) was legalized in Canada. Since they often have few medical comorbidities, persons with amyotrophic lateral sclerosis (ALS) are likely to be eligible for organ donation for transplantation. In Canada, 30 patients had given a total of 74 organs after MAiD by 2020<sup>1</sup> and in the Province of Quebec alone, 182 organs from 82 donors were transplanted after MAiD between 2018 and 2022.<sup>2</sup>

Since their inception in the late 1990s, biobanks have become a cornerstone of modern research.<sup>3</sup> In Canada, a donation to a biobank must be in accordance with the Tri-Council Policy Statement: Ethical Conduct for Human Research Guides, notably through the signature of an informed consent form (ICF) from the participant or the designated person. However, while the procedure to donate organs for transplantation after MAiD is becoming more standardized, it is not the case for donation to research biobanks.

By presenting six PALS journeys through their MAiD request and tissue donation to a biobank located at the CHU de Québec – Université Laval, in Québec City (Table 1), we will describe the challenges inherent to tissue or organ donation for research after MAiD.

Patient 1 was 58 years old when diagnosed with ALS. A few months before MAiD was legalized in Canada, she experienced loss of independence and mentioned wanting to travel to request assisted suicide. In 2019, after significant deterioration, she formally requested MAiD which was scheduled later the same month. She died at 4:30 PM at her long-term care facility, her body was transferred to the hospital and tissue sampled the next morning.

Patient 2 was diagnosed with ALS in 2018. She had a routine encounter with the palliative care team to discuss end of life issues and options, including MAiD. In November of 2019, as her dysarthria progressed and she feared to lose her ability to voice her wishes, another encounter was arranged in January 2020 and MAiD was scheduled for August. In June, she contacted the neuromuscular disease clinic to donate her brain for research. The research coordinators met her and explained all aspects of the biobank ICF. She received MAiD at her home by the end of

August at 3:00 PM. At 7:30 PM, the tissue sampling was performed at the hospital.

Patient 3 was diagnosed with ALS in June 2017. In February 2018, he requested information about MAiD. In October of 2018, he expressed the will to donate his organs and tissues for transplantation and research. He met with the coordinating nurse of the organ donation program. After being informed about the additional tests required to confirm organ donation eligibility and that MAiD would occur in the operating room for transplantation purposes, he agreed and signed an ICF. He received MAiD at 6:30 PM on the day of his choosing. The organs intended for transplantation were sampled 23 minutes after death. The tissues for research were sampled at 9:15 PM.

The next three cases received MAiD in the Saguenay-Lac-Saint-Jean region (Ville de Saguenay), located 206 km from Québec City where the tissues and organs were sent after MAiD.

Patient 4 received MAiD directly at the hospital on a Friday evening. According to the patient's wishes to donate organs for transplantation, they were sampled in the operating room. Tissues for research could only be collected 3 days later, then put in an adequate environment for transportation. The biobank technician noted that the brain tissues were softer and more difficult to manipulate.

Patient 5 received MAiD at the hospital in the evening in May 2019. The local hospital's pathology team sampled the tissues the next morning and sent to Québec City where they were prepared for preservation in the biobank in the afternoon.

Patient 6 wished to donate organs for both transplantation and research purposes. He received MAiD at the hospital on a Monday evening in 2019, and organs for transplantation were subsequently removed. Tissue sampling was done the next day in the pathology department before they were transported to Québec City in the afternoon.

As the number of countries allowing MAiD continues to grow, new challenges regarding the combined procedure of organ and tissue donation after MAiD are brought to light.<sup>4</sup> While organ donation for transplantation has a defined framework (Table 2), tissue and body donations for research purposes is less regulated.<sup>5,6</sup>

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**Table 1.** Details from six amyotrophic lateral sclerosis patients who received Medical Assistance in Dying and donated tissues

Case #	Age	Sex	MAiD Year	Interval Death-Autopsy (Hours)	Tissues collected	Combined with organ donation for transplantation
1	64	F	2019	15.5	Brain, Spinal cord & Skin	No
2	70	F	2020	4	Brain, Spinal cord & Skin	No
3	65	M	2018	2.5	Brain, Spinal cord & Skin	Yes
4	67	M	2019	94.25	Brain, Spinal cord & Skin	Yes
5	70	M	2019	<12	Brain, Spinal cord & Skin	No
6	70	M	2019	17.5	Spinal cord & Skin	Yes

**Table 2.** Legality of organ donation after euthanasia in different countries

Country	Organ Donation after Euthanasia (ODE) Allowed	Cases Reported	Guidelines on Donation for Research after MAiD Available
Australia	Yes	No	No
Belgium	Yes	Yes	
Canada	Yes	Yes	
Colombia	No	No	
Luxembourg	No	No	
New Zealand*	Yes**	No	
United States***	No	No	
Spain	Yes	Yes	
Switzerland	Yes****	No	

\*Human Tissue Act 16-18 (2008).

\*\*Technically legal, but physicians are not compelled to accept donation requests.

\*\*\*MAiD is legal in the states of Oregon, Washington, Vermont, California, Colorado, District of Columbia, Hawaii, Maine, New Jersey.

\*\*\*\*Not banned, but most cantons do not allow MAiD in their hospitals which makes ODE impractical.

Organ donation for transplantation undeniably imposes more constraints for patients who also wish to undergo MAiD. Although some diagnostic tests for donation suitability can be arranged to be done at home,<sup>7</sup> others must be done at the hospital. Having to arrange MAiD in the hospital limits the patient and family's ability to shape this special moment. This being stated, some innovative models of organ donation after euthanasia starting from home have been described based on real world cases.<sup>5</sup> Donation for research imposes fewer constraints. It is often an option for patients who cannot be donors for transplants and allows them to have MAiD at the desired location.

For patients living in rural areas, one challenge is to prevent postponement or delay prior to the organ or tissue retrieval. As shown by patient 4, excessive delays after death can add complexity to an already delicate procedure, potentially compromising the quality of the samples. When retrieval is not possible under 12 hours, the body should be stored at 0–4°C.<sup>8</sup> If the

objective is to isolate living cells for *in vitro* research, reducing the time for retrieval would prevent bacterial contamination. For brain donations, a qualified technician should be available at the local hospital as it is a specialized technique.

In conclusion, organ and tissue donation for research after MAiD is a novel way for patients to contribute to research after death. It should be mentioned to those who show interest in postmortem donation that donation for research and for transplantation are not mutually exclusive. However, guidelines concerning the management of this combined procedure are lacking for clinicians and researchers.

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