

Organ Donation After Cardiac Death in Amyotrophic Lateral Sclerosis

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Patients with amyotrophic lateral sclerosis (ALS) are often told that solid organ donation is not possible following death, although the reasons for exclusion are not evidence based. Because ALS patients typically remain sentient until death, organs may be procured under donation after cardiac death protocols. Anticipating this need, our institution created a process for organ donation in ventilator-dependent ALS patients that was subsequently implemented. To our knowledge, this is the first report of organ donation in a patient with rapidly progressive ventilator-dependent ALS.

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The most common cause of death in amyotrophic lateral sclerosis (ALS) is respiratory failure secondary to neuromuscular weakness.¹ Although patients with ALS do not meet brain death criteria for organ donation, it is still possible for ventilator-dependent patients to donate according to the donation after cardiac death (DCD) protocol. In fact, a recent panel of DCD experts deemed that those with end-stage musculoskeletal disease could be potential DCD donor candidates.² Absolute exclusion criteria for DCD is limited to a history of human immunodeficiency virus infection, malignant cancer outside of the brain, renal failure, and severe systemic infection.³ Despite ALS not being listed as an exclusion, there are no published reports to our knowledge of solid organ donation from patients with this disease.

In all prior DCD cases at our medical center, consent for the procedure has been obtained from the patient's family or other surrogate because the patient lacked medical decision-making capacity. DCD in ALS patients poses the unique circumstance of first-person consent for organ donation surgery, given that cognitive functions are usually spared, allowing patients to retain full capacity to make health care decisions. Here we describe the first published report of organ donation in a

patient with rapidly progressive ventilator-dependent ALS, and report the process we developed and implemented at our medical center.

Prior to the development of this process, DCD for an ALS patient had not occurred at our institution. In anticipating such a request, a committee was formed in 2005 to draft a process that could be followed in the event that an ALS patient wished to be admitted for comfort care, terminal extubation, and organ donation. The process also considered the situation where a ventilator-dependent hospitalized ALS patient requested to become a donor. The committee was composed of a neurointensivist (W.S.S.), a critical care anesthesiologist (M.A.G.), a transplant surgeon (J.R.), and a neurologist specializing in ALS (C.L.-H.). The process was initially presented to our institution's ethics committee, and after discussions with clergy and legal counsel, and external ethics review, a final process was presented to our hospital medical board.

To investigate prior cases of DCD in ALS patients throughout the United States, the director of clinical services of our region's organ procurement organization (OPO) elicited information via a listserv query addressed to directors and coordinators of OPOs around the

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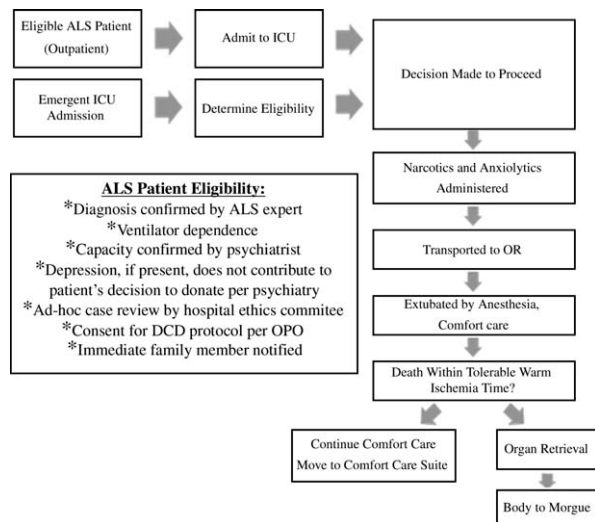


FIGURE: Guideline for donation after cardiac death in patients with amyotrophic lateral sclerosis (ALS). DCD = donation after cardiac death; ICU = intensive care unit; OPO = organ procurement organization; OR = operating room.

country. After initial responses were received, the OPOs were contacted individually to gather additional available information about each case.

The final process approved and implemented at our institution allows organ procurement from eligible patients with ALS from whom artificial support is being withdrawn (Fig).

Our patient was a 40-year-old healthy female nurse employed by our institution who experienced progressive muscle weakness, gait instability, and muscle atrophy. Notably, she had no significant past medical history prior to the onset of these symptoms. She was initially evaluated by a local neurologist, who ruled out multifocal motor neuropathy when there was no clinical improvement with intravenous immunoglobulin, and was subsequently diagnosed with ALS at our medical center in 2008. The diagnosis was confirmed within a few weeks at another institution. The patient's case proved to be rapid, with progression from diagnosis to home ventilator dependence within 1 year, at which point it was predicted by her treating neurologist that she would likely be unable to communicate easily with her family in 6 months time. She and her husband concluded that they would plan for comfort care at that time. Less than 2 months prior to her planned date of ventilator discontinuation, the patient independently approached her neurologist to discuss her desire to be an organ donor. During this meeting the patient was able to actively participate in the conversation by blinking her eyes in response to written statements being read to her using a computer system that recognized eye movements (manufactured by Tobii, Danderyd, Sweden).

In the following month, the patient met with our medical center's ethics committee to review the details of her specific case. She denied any financial considerations in her decision despite the high costs of continuing 24-hour home care. She stated that although she had resources to continue home ventilation for another year, she did not want to live any longer in her ventilator-dependent state. That day the patient also received an independent psychiatric evaluation that confirmed she had decision-making capacity and no psychiatric disease affecting her decision.

On the day prior to her death, the patient was admitted to the neurointensive care unit. Given the novel nature of this process, all people involved in her care including nursing staff and respiratory therapists were offered reassignment if they had personal objections to the patient's care. She provided consent for organ donation to our OPO, the California Transplant Donor Network. An overnight stay allowed the anesthesiologist to gauge the required narcotic doses necessary to prevent air hunger following ventilator removal. The waiting period also provided her an opportunity to reconsider her decision and to meet with close friends and relatives. The following morning the patient was taken to the operating room (OR) with an attending anesthesiologist, an attending neurologist, a medical student, and nursing and OR staff. Prior to removal from the ventilator, the patient received doses of fentanyl and midazolam that were decided upon by the anesthesiologist in consultation with the neurologist. In accordance with established recommendations, the team involved with organ recovery was not present in the room with the patient when the ventilator was discontinued, ensuring that the process of comfort care and dying was decoupled from the organ procurement.⁴ Once disconnected from positive pressure ventilation, the patient passed peacefully in 22 minutes with her husband at her bedside. The neurologist and the patient's husband subsequently left the OR, and after 5 minutes the surgeons entered through a separate doorway and procured organs. Her kidneys were successfully transplanted to a 60-year-old man and a 72-year-old man. Prior to the patient's admission, she emailed the following statement to the attending physician with consent to allow its use in publication or lay press: "I am glad that in spite of my disease, there is still something I can do to help others in a significant way. ALS is preventing me from accomplishing what I wanted to do in my life, but hopefully, my donation will give others a chance to live out their dreams."

Responses to the listserv query addressed to nationwide directors and coordinators of OPOs revealed that

TABLE: Known Cases of Amyotrophic Lateral Sclerosis Patients Donating Organs Following Cardiac Death

US Region	Age, yr	Gender	Duration of Ventilator Dependence	Organs Recovered	Request Donor Initiated?
California ^a	40	F	6 months	Kidneys	Yes
California	30	F	8 months	Kidneys, liver	Yes
New England	51	M	Unknown	Kidneys	On registry prior to diagnosis
Ohio	43	M	6 weeks	Kidneys, liver	Yes
Philadelphia	50	M	2.5 years	Kidneys	Yes
Virginia	40s ^b	M	20 years	Unknown	No
Virginia	54	M	Unknown	Unknown	Yes

^aOur institution.
^bExact age unknown.

other cases of DCD in ALS patients have occurred (Table). An additional 5 cases have reportedly occurred in Florida, New England, and Philadelphia, although further information regarding these cases could not be elicited.

Discussion

To our knowledge this is the first published report of organ donation from a patient with ALS. After ethics committee review and proactive coordination with neurocritical care and our regional OPO, we were able to accommodate a patient who requested organ donation via DCD protocol on an elective basis. Because the patient was in the unique position to provide first-person consent for DCD, the case married an established protocol for DCD with a patient's right to self-determination and autonomy.

In establishing and implementing a process for elective admission for DCD, we identified many unique details that are important to consider, such as the informed consent process, the venue for admission to the hospital, and financial considerations including the source of payment for the admission and the cost of continued home ventilator equipment. In our patient's case, her medical insurance paid for the elective hospital admission and ambulance transport to the hospital, and the OPO paid for the remaining costs. We did not need to address who should pay in the case where private insurance is unavailable, but felt that it is not acceptable for the institution or the OPO to cover the costs of transportation or admission because of conflict of interest. Another request that was not initially anticipated was the presence of the patient's husband in the OR at the time of extubation and death. This request was accom-

modated without any complications and contributed greatly to the comfort of both the patient and her family. At our institution, presence of family at the time of DCD is at the discretion of the attending physician.

This experience was positive on several accounts. Having this process in place ahead of time, our patient was able to benefit from more time to discuss this option with her neurologist, to meet with organ procurement agency counselors, to be assessed by an outpatient psychiatrist, and to partake in an ad hoc ethics consultation. Our patient's wishes were honored, her family was satisfied with the process, and our physicians were confident that all steps were ethically and clinically sound. Additionally, 2 kidney recipients benefited, and her husband was informed of this. Having a detailed process in place allowed us to honor the patient's request much more smoothly.

Potential Conflicts of Interest

SAJ: board membership, *Annals of Neurology* (Associate Editor), *Journal Watch Neurology* (Editor in Chief).

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