West Virginia Network of Ethics Committees
Newsletter

Winter-Spring 2020

A note from the editor: *Many ethics consults involve end-of-life decision making. We explore, explain, and discuss concepts such as withholding vs withdrawing of life sustaining treatments, killing vs allowing to die, active euthanasia vs passive euthanasia, appropriate pain management, and physician aid in dying (PAD)…to name a few. Over the past few years such conversations have become more common as voluntarily stopping eating and drinking (VSED) has emerged as a method by which some people not only chose to end their lives, but sometimes request assistance with in advance directives. Nowhere is this ongoing struggle with decision making at the end of life more clearly reflected than in the growing number of U.S. states that have made PAD legal. At the writing of this newsletter, PAD is legal in nine states and the District of Columbia. In light of this trend, we are pleased to provide you with a thought provoking article written by Amy VanDyke, PhD which traces the journey of how not only PAD but active euthanasia became legal in the Netherlands. Additionally, we have a case detailing the ethical considerations involved in organ donation in general, and donation after cardiac death specifically, provided by Matt Smith, MD. We are grateful to our contributing authors, and as always, we welcome your comments and suggestions for future topics and invite you to share your articles with us.*

Euthanasia and Assisted Suicide for Psychiatric and Dementia Patients in the Netherlands: Is There a Case to be Made for Mission Drift?

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In the Netherlands euthanasia and physician assisted suicide (EAS) were legally sanctioned in the Dutch Termination of Life on Request and Assisted Suicide Act in 2002. The Euthanasia Act (EA), as it is commonly referred to, is available to patients diagnosed with both somatic and psychiatric diseases. Euthanasia can be requested by patient's age twelve and older. Requestors between the ages of 12 and 16 require the permission of their parents. This article reviews the history of euthanasia in the Netherlands including discussion of recent media cases which have caused concern about trends seen is EAS for patients with psychiatric illness and dementia. The use of EAS in these cases has drawn criticism that accepted ethical frameworks and standards are being violated resulting in irrevocable harm. Additionally, evolving Dutch attitudes which may alter the current safeguards of EAS will be discussed.

In This Issue

In an article written by Theo Boer (2018), he discusses what he terms, the three phases of voluntary EAS in the Netherlands. The early period when euthanasia was debated but still illegal (1965-1985), the period where euthanasia was officially tolerated (1985) and gradually legalized in 2002, and the current phase, phase three which began in 2007.

2. That the patient's suffering is unbearable with no prospect of improvement;
3. Had been informed about patient's situation and prospects;
4. Had come to the conclusion with that patient that there is no reasonable alternative in the patient's situation;

"Euthanasia was defined as "intentionally terminating another person's life at the person's request."

The third phase, writes Boer, has seen a threefold rise in EAS requests, inclusion of new pathologies as acceptable reasons for such requests, increasing options to facilitate access including a freestanding end-of-life clinic in the Hague called Levenseinde, and mobile euthanasia teams which have been established to accept, evaluate, and fulfill EAS requests. Early EAS debates made a significant move forward in 1973 in what is known as, the "Postma case." A dying patient repeatedly requested that her daughter, who was also a physician, provide her with euthanasia. After several such requests the daughter helped her mother to end her life. The physician was found guilty of murder, but the sentence, deemed appropriate, was short and suspended. This case provided a vehicle for discussing EAS on the national level (Rietjens, van der Maas, Onwuteaka-Phillipsen, & van der Heide, 2009).

By 1998 a voluntary EAS reporting system with a formal reporting procedure was in use. A review committee consisting of a physician, an attorney, and an ethicist evaluated physician's voluntarily reported cases of EAS and advised the public prosecutor on whether due care obligations had been fulfilled by the physician. Since reporting was not mandatory few reports of EAS were submitted for review.

The due care standard obligated physicians to evaluate and be satisfied in six key areas:

1. That patient's request is voluntary and well considered;
5. Had consulted with at least one other independent physician who must see the patient and give a written opinion on whether the due care criteria set out in (A) through (D) have been fulfilled; and
6. Exercise due medical care and attention in terminating the patient's life or assisting with his suicide

These due care obligations continue to be in use. The Schoonheim case in 1984 was the first euthanasia case to be heard by the Dutch Supreme Court. The case highlighted a physician's moral dilemma in such situations, citing dual obligations to a patient to both relieve suffering and to do no-harm. The patient at the center of this case was a 95-year-old female whose hearing, speech, and eyesight were failing, who was unable to ambulate, and who was reportedly experiencing a loss of dignity as her symptoms progressed. The physician who euthanized this patient was not prosecuted.

Euthanasia and physician assisted suicide were subsequently defined by the State Commission in 1985. Euthanasia was defined as "intentionally terminating another person's life at the person's request." Physician assisted suicide was defined as, "the administration, supply or prescription of drugs with the explicit intention to enable a patient to end his or her life." (Reitjens et al., 2009, page, 272). These definitions remain. In each instance common ethical frameworks are noted; the intention of the physician and the patient as moral agents and decision-making capacity to choose a course of action.

These cases and concurrently evolving frameworks prompted further societal-level discussions about EAS culminating in the EA legislation in 2002. Returning to Theo Boer's analysis of the phases of the Dutch experience with EAS, he points out several criteria which were left out of the final Dutch Act but upon which the original acceptance of Dutch euthanasia was based. He states that the acceptable use of EAS was predicated in part on "the widely shared view that people who are close to their death, who are in severe suffering, and for whom no other relief can be given" should have access to EAS (Boer, 2018). Boers understanding of the program is based on his experience serving a reviewer of EAS cases for many years.

to as "concurrent request" for EAS. A contemporaneous or concurrent request is generally to be acted upon sooner than an AED. (Miller, Dresser, & Kim, 2019; Miller & Kim, 2017) EADs suffer from many of the same ethical concerns/limitations from which other advance directives suffer. Did the patient understand what she was completing at the time she did so? Can the physician interpret the document correctly? Does what the document seems to say meet the present situation?

The cases discussed below highlight emerging ethical concerns which have arisen in the Boer's third phase of the EA law. Several ethically controversial EAS cases which involve patients with psychiatric

"Several ethically controversial EAS cases which involve patients with psychiatric illness or dementia are central to the phase three experience."

The adopted EA law continued to focus on physician obligations for due care and reporting of EAS became mandatory. Previously established due care obligations continued to the set parameters of ethical physician practice and ensure informed and autonomous decision making by the patient. Retrospective review of EAS cases is carried out by Dutch regional euthanasia review committees (RTE). Reviews focus on procedural issues to ensure that due care obligations are met. If due care occurred, the case is not forwarded to the prosecutor. If the committee believes due care obligations are not met the case is sent to the prosecutor for further review. RTE continues to oversee due care obligations. The RTE also now completes and publishes a substantive review of the EAS program every five years (Miller & Kim, 2017)

Patients seeking EAS can do so in two ways. A patient can complete a euthanasia advance directive (EAD) to be used at some future point or a patient can make what is labelled by some authors as a "contemporaneous request" or by other authors referred

illness or dementia are central to the phase three experience. The following cases have met with public scrutiny both in the Netherlands and outside. Additional controversial cases exist; however, these cases will serve as representation of key concerns articulated in this phase of the EA use.

In 2017, international media outlets erroneously reported that a teenager named Noa Pothovan from the city of Arnhem, who suffered from psychiatric illness had been euthanized in accordance with Dutch law. Ms. Pothovan had been the survivor of multiple rapes and suffered from post-traumatic stress disorder. While she had requested euthanasia from the Levenseinde Clinic in the Hague in 2017, her request had been denied. Following the denial of her request, Ms. Pothovan committed suicide from voluntary stopping of eating and drinking (VSED). Ms. Pothovan's death led to controversy internationally because even though the death was the result of VSED, EAS law would have allowed for euthanasia in this case if different physicians would have discerned that the legal standards had been met and due care

had been provided (Symons, X. 2019, June 9 Retrieved from, https://www.bioedge.org/bioethics/dutch-vsed-case-sparks-international-furor-and-ethical-debate/13090).

Several ethical questions remain. Would Ms. Pothovan have had a better death if she had been provided euthanasia or assisted suicide? Is it possible to determine if a patient with a psychiatric dis order is experiencing "unbearable suffering" with no prospect of improvement? Was this young woman's difficult situation wrongly used to highlight a "slippery slope" argument for which there is no validity or does a concerning "slippery slope" truly exist?

Another case, which presents many of the same questions as those present above are found in the case of Ms. Aurelia Brouwers, age 29. Ms. Brouwers became the focus of the media who chronicled her during the two-week period prior to her death. Ms. Brouwers was interviewed as she toured the crematorium where her body would be taken following her death. She talked to the media about choosing her clothing for her funeral and visiting with friends and loved ones in the week. In interviews she stated, "When I was 12, I suffered from depression. And when I was first diagnosed, they told me I had Borderline Personality Disorder," she says. "Other diagnoses followed - attachment disorder, chronic depression, I'm chronically suicidal, I have anxiety, psychoses, and I hear voices" (Presley, L. 2018 August 9, Retrieved from https://www.bbc.com/news/stories-45117163).

Ms. Brouwers originally made the request for euthanasia to her own physicians. When her request was turned down, she made another request to the end-of-life clinic in the Hague. Brouwers did not have a terminal illness though by all accounts, she did have a mental health disability which she reported as causing unbearable suffering. An assessment upon which, the second set of evaluating physicians concurred. Ms. Brouwers was granted her request for EAS. Her death date was January 26, 2018 at 2 PM. Ms. Brouwers sought and was granted euthanasia based on a history of psychiatric illness. Arguably, Ms. Brouwers was not close to death as Boer indicates was the societal thinking about when EAS could rightly be provided. She did articulate that her suffering was, to her unbearable, thus making death preferable to life. From a due care perspective, obligations were found to have been met. Dutch psychiatrists evolving attitudes about the use of EAS for patients with psychiatric illness may reveal another dimension to the moral issue. Onwuteaka-Phillipson et al., (2017) note that requests for psychiatric EAS have steadily increased from 320 in 1995 to 1,100 in 2016.

Despite arguments to be made on both sides, data reveals overall, there is a growing reluctance among a group of Dutch psychiatrist to support EAS requests by psychiatric patients.

While most of these requests have been denied, EAS has been performed on the basis of psychiatric illness. The number of psychiatric EAS completions has gone from zero in 2002 to eighty-three in 2017. An article by Pronk, Evenblij, Wellems, & van de Vathorst (2019) provides an analysis of a small number of psychiatrists attitudes towards EAS. In a first of its kind qualitative study, 17 interviews were undertaken with Dutch psychiatrists to understand their views on supporting or rejecting psychiatric requests for EAS. Results from those interviewed revealed that psychiatrists are "very reluctant to provide EAS, and that their reluctance has only grown over the years" (page 5).

Interviewees expressed concern that the obligation of due care could ever be adequately met in psychiatric EAS requests. They noted, that for many with

psychiatric diseases, suicidality is a symptom of the disease itself and so could never be well-considered. An additional concern was physicians lack of trust that the therapeutic interventions provided to the patient prior to the EAS request were of high quality and appropriate. Specifically mentioned was concern over the "deteriorating Dutch mental health care system" (page 5). Interviewees who supported EAS for psychiatric patients cited issues of fairness and autonomy given the designation that psychiatric disease and somatic disease are similarly defined. Psychiatrists supporting EAS in such cases further expressed an obligation to contribute both to the good life of their patient and thus also to a good end-of life for their patients. Despite arguments to be made on both sides, data reveals overall, there is a growing reluctance among a group of Dutch psychiatrist to support EAS requests by psychiatric patients. The current safeguards of due care may be insufficient given the requirement that the physician be satisfied that there are no remaining alternatives and there is no prospect of improvement. It seems that here, the standard of due care may be more difficult to reach.

A third controversial case involved a patient with dementia. The patient was a woman in her 70s who had manifest memory loss for several years prior to her euthanasia. She was diagnosed as having Alzheimer's disease four years before her death. This patient had prepared AED shortly after her diagnosis. Family reported that the patient had consistently expressed her desire for euthanasia at some point in her disease progression. She also repeatedly expressed fear of being placed in a nursing home for dementia. A few years following diagnosis, this patient revised her original AED and including a statement which read, in part, "I want to make use of the legal right to undergo euthanasia whenever I think the time is right for this…"(Miller et al., 2019).

The patient was cared for at home by her spouse until the last six months of her life when she entered a nursing home. The husband asked that the patient's AED be followed. The geriatrician waited a month to evaluate the suffering of the patient to allow the patient to get used to the new environment. It was determined by the geriatrician in consultation with other physicians that the due care standards for euthanasia had been met. At the time of the planned euthanasia the geriatrician sedated the patient by including medication in the patient's coffee without the patient's knowledge, and later another dose of sedation was provided by injection as the physician believed the first dose was insufficient. An infusion line was then placed. The patient tried to get up during infusion of thiopental. The family present helped to hold the resisting patient in place while the rest of the medication, which would end the patient's life, was delivered. The geriatrician reported all events to the review committee per protocol. While the physician disclosed all events in order to ensure she was being forthright in her report, she was subsequently found to have violated due care in the provision of euthanasia for this patient. The violation was reported as failure to exercise due medical care and attention in terminating the patient's life or assisting with her suicide (Miller et al., 2019). What ultimately occurred in this case has been the source of ethical controversy and debate. Did the resistance of the patient in the moment invalidate the AED? Did the fact that the patient was given a sedative without her knowledge make a difference? Does a patient with an AED ever get to override the document, with or without the presence of decision-making capacity? Seemingly important but unanswered ethical questions in the situation described above.

The family present helped to hold the resisting patient in place while the rest of the medication, which would end the patient's life, was delivered.

In research on EAS for patients with dementia in the

Netherland's (Mangino, Nicolini, de Vries, & Kim, 2019) the authors set out to describe the characteristics of patient who requested and received these services. The research reviewed 75 cases which are publicly available from the Dutch Euthanasia review committees between January 2011 through October 5, 2018. The cases reviewed were noted to be specifically dementia cases.

The authors reported that advance and concurrent requestors of EAS revealed several differences. Alzheimer's disease was the most common dementia diagnosis in both concurrent and advance request cases. Patient's making concurrent requests tended to be older than those requesting by AED. Perhaps unsurprisingly, advance request patients were more likely to have had their diagnosis longer before undergoing euthanasia and were also more likely to have had what the authors referred to as personal experiences with dementia such as having observed a relative suffer with dementia. Fear of nursing home admission was commonly noted in both EAS patients and assisted suicide patients.

The most ethically concerning finding from this study may be that while the assessment of decision-making capacity generally follows a functional model, in these instances in both concurrent and AED requests the authors concluded that the standard framework was being modified, if used at all. They write, "it appears to be either a functional model applied with low threshold (the ability to express a consistent choice, relying on utterances and behaviors) or a model that prioritizes a kind of authenticity criterion (focusing on whether the patient's previously stated wishes are still in effect, despite severe impairments) (Mangino et al., 2019).

The RTE while urging "particular caution" in making decisions about capacity, also seems to accept and recommend that "requestors can be considered to have decision making capacity when they are unable to present supporting arguments" for their request. In these cases, the "utterances of the patient at that point can be assessed in conjunction with earlier or written directives and the patient's behavior or signals." (Mangino et al., 2019, page 10).

This would seem to leave significant room for the subjective interpretation of the physicians evaluating the patient in high stakes medical decisions. It also appears that this stance privileges the AED and past decision making over current capacity. Comparing this process against the use of more typical advance directives, ethics seems to do much the same thing by privileging an advance directive completed by a patient who is assumed to have sufficient decision-making capacity at the time the document was completed. Thus, even if a patient lacks capacity in the present, the wishes of the patient should be followed for end of life decision making. However, a key difference is of course that a patient, even with an advance directive who lacks capacity but who communicates wishes to receive life sustaining interventions previously refused will have them provided. In these instances, the default is to preserve life. In the interpretation of AED however, the default appears to be to ensure the right to euthanasia even when the actions of the patient resist such efforts. Of course, authors have pointed out the question of what truly represents the autonomous wishes of the patient. Is it what the patient claimed in their AED or the situation in which they are currently? Some authors point out the former-self/current-self ethical conundrum and wonder whether the due care standard of unbearable suffering, with no prospect of improvement is met in these situations (Miller et al., 2019). Given the disease trajectory of dementia, at some point patients may no longer have self-awareness and may no longer experience unbearable suffering. Thus, was only part of this due care criterion met, that being no prospect of improvement? From an ethics point of view, one must ask if this is enough to meet this standard?

Boer's article concludes with the statement that, "no society can afford open ended laws when it comes to killing citizens on their request. Given each person's unique and inestimable value, the intentional killing of a human being is and remains an intrinsically problematic act. The killing of deeply unhappy human beings at their request may also have societal consequences" (Boer, 2018 page 10). It seems to this author that Boer's concerns, which I share, along with some Dutch psychiatrists increasing reticence

to use EAS may reflect evolving, though not yet vocalized attitudes from other parts of society. Or, perhaps not. Nonetheless, in the spirit of open societal discourse which led to the EA law, the events of the third phase call for further open dialogue about whether somatic and psychiatric diseases can be measured with the same due care standards or whether mission drift is occurring. Dialogue needs to occur with some urgency because vulnerable individuals good-lives or good-deaths depend on it.

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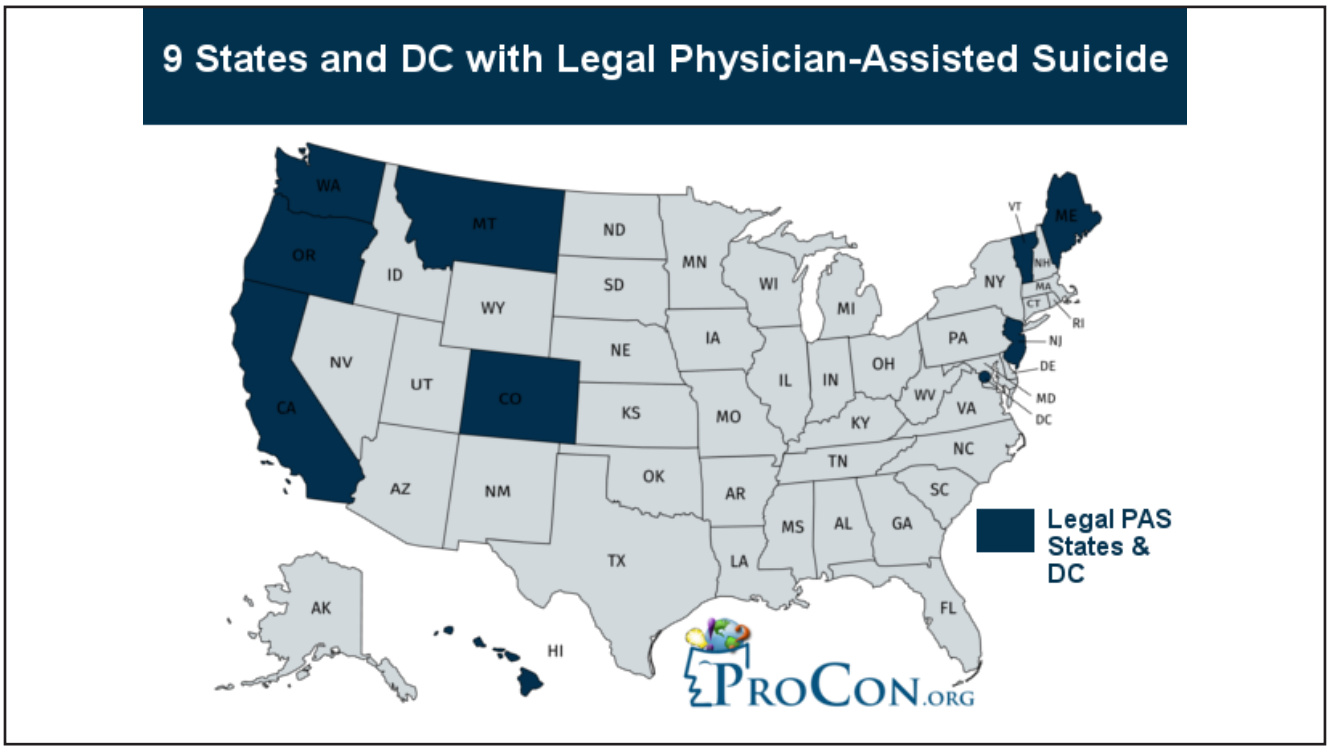

When the Donor isn't Brain Dead: an ethical case analysis

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CASE: **A 54-year-old woman is in the ICU after a large intracranial hemorrhage. The patient has undergone all possible medical and surgical interventions to promote and preserve brain tissue and function. The patient has remained comatose and has required continuous endotracheal support to maintain her airway. The family has requested that the patient have withdrawal of care.** (To Be Continued)

Organ transplantation has been lifesaving for a huge number of patients with end-stage organ damage (e.g. heart, lungs, kidney, etc). Patients that would otherwise die are able to be saved by replacing their diseased and failing organs with those of another person(s). The American Medical Association has stated in a Code of Medical Ethics Opinion 6.1.2 that "increasing the supply of organs available for transplant serves the interest of patient and the public… Physicians should support innovative approaches to increasing the supply of organs… but must balance the obligation with their duty to protect the interests of their individual patients." (https://www.ama-assn.org/delivering-care/ethics/organ-donation-after-cardiac-death)

According to the United States Health Resources and Services Administration, there are over 113,000 people on the transplant waiting list with 20 people dying every day waiting for transplantation with 36,528 transplants occurring in 2018 (https://www.organdonor.gov/statistics-stories/statistics.html). It is obvious from these numbers that the supply of transplantable organs is less than the demand.

The ethical principles that underlie organ procurement dictate that the donation of an organ should not shorten the life of the donor in the efforts to prolong that of the recipient. This has limited living organ donation to a few select organs that are either paired (e.g. kidney) or can remain functional after being sectioned (e.g. liver). The bulk of organ donations are from deceased donors (formerly known as cadaveric donors). A deceased donor's life can not be shortened by donation, because they are already dead. Death can be declared either by cardiac or neurological criteria.

CASE Continued

The organ procurement organization (OPO) is contacted regarding the impending withdrawal of care. The OPO is aware that the patient is not currently dead by neurological criteria nor is likely to progress to it. The OPO approaches the family about the potential for organ donation after cardiac death (DCD). The patient currently has a cough and corneal reflex with extensor response to stimulation. Oxygenation index was obtained and found to be less than 3.

During and after the process of a cardiac death the organs have hypoperfusion, which would lead to damage. The length of time before organs are no longer viable is variable depending on the organ, but typical protocols limit the time from withdrawal of life sustaining treatment (WLST) to cardiac death to 60 minutes or less before organs are viable.

Given that the patient is not nor is likely to be dead by neurological criteria, it is still possible to donate organs after the patient has been declared dead by cardiac criteria. DCD protocols have been devised and implemented to have the patient die via a cardiac death in a controlled setting. WLST in the operating room with the required equipment for organ harvest would limit the time from declaration of death to procurement.

An attempt at DCD would mean that the patient is transported to the OR where the medical team and family are located. The surgical team is typically prepped and ready, but in a separate area. The amount of time required can be from a short few minutes to a few hours (limit depends on local protocols). The dying process can be stressful to the medical teams and family who are present in an operating room in OR apparel while the patient is covered in sterile drapes from the neck down limiting contact with the dying patient. Analgesia is given as necessary, but not in excess to prevent the hastening of death. If cardiac death is not declared in the time allowed for transplantation, the surgery is aborted, and the patient and their family are taken to another hospital area to continue the palliation process.

Because of the potential for a stressful situation without a guarantee for success and to aid in the informed consent process, Rabinstein et all devised the Donation after Cardiac Death – Neurologic (DCD-N) Score, which based on pre-WSLT examination predicts that likelihood that death will occur within 60 minutes (Rabinstein A, et al, *Lancet Neurology* 2012 May; 11(5):414-9.). In the DCD-N Score points are given for each of the following: absent corneal reflex (1 point); absent cough reflex (2 points); extensor or absent motor response (1 point); and oxygenation index >3.0 (1 point). Death within 60 minutes for scores of 0, 1, 2, 3, 4, 5 are 5%, 27%, 29%, 52%, 80%, and 89%.

CASE Conclusion

The patient's DCD-N Score is calculated as 1 (27% chance of death within 60 minutes of WLST). The OPO when discussing the possibility of DCD mentions to the family during consent that there is only a 27% chance of success. The family reports understanding but want any chance to allow the patient to donate even though it was likely to be unsuccessful. DCD is unsuccessful, and the patient expires the next day in the hospital. Family reported understanding and were happy that it was tried even if it was unsuccessful.

Conclusion

Transplantation has been life-giving for patients, but there remain many ethical issues to consider. Working from the principle that the donation should not cause the demise of one patient to benefit one or more others, the Dead Donor rule was devised for many organs. Brain dead patients remain the most viable source for transplantable organs but does not come close to meeting demand. DCD has been implemented to allow for transplantation from patients unlikely to become brain dead. Keys to success are: clinical decisions to withdraw are made by the treating team and the patient representative without consideration of organ procurement; (in my opinion) DCD requires consent even if patient is a designated donor due to the requirements of the WLST process that are different and designation implies after death (e.g. consent is for the process of WLST in the OR, which is nonstandard, not for organ harvest in a designated patient); and the informed consent process should include available data about the success or failure of DCD to help minimize stress related to the WLST process.

CALENDAR OF EVENTS

In light of the pandemic, and uncertainty about when it might be safe to schedule in-person events and reschedule the Spring Seminar, we do not have any in-person conferences, seminars, or workshops scheduled at this time. As such, we would really appreciate your input and requests concerning educational opportunities. What do you want to learn, discuss, or practice? Do you want lectures, case discussions, policy sharing? Or, do you want a break from pandemic planning and would prefer to explore some medical humanities based activities such as a virtual journal or book club? Whatever it is, let us know, and we will do what we can to make distance learning/sharing as interesting and educational as possible. Stay Safe!

Please submit any suggestions to Linda McMillen at lmcmillen@hsc.wvu.edu.

Visit our website at www.wvnec.org for the latest information on future events.

CALLING ALL WRITERS!

We are always looking for interesting ethics topics, cases, and perspectives to share with our WVNEC Newsletter readers. If you would like to contribute by sharing your difficult cases, suggesting an idea for an article, or WRITING an article, please consider doing so. Anyone in a health related field, or who has interacted with the healthcare community, can submit ideas or article to be considered for inclusion in the newsletter. Also, we would like to provide students with an opportunity to have their voices heard in the "Student Corner" section of the newsletter. If you know of or work with a student(s) who may be interested in ethics and would like to write for the newsletter, please encourage them to reach out to us. We'd be delighted to give the future of healthcare a vehicle to share their perspectives. To inquire about any of these opportunities please contact Linda McMillen at 304-293-7618 or lmcmillen@hsc.wvu.edu.

Mission Statement: The West Virginia Network of Ethics Committees assists hospitals, nursing homes, hospices, and home health care agencies to strengthen ethics committees; provides education regarding ethical and legal issues in health care to promote ethically sound decision-making; and helps patients and families to make their end-of-life wishes known.

This is a quarterly publication of the Center for Health Ethics and Law, Robert C. Byrd Health Sciences Center of WVU, for the West Virginia Network of Ethics Committees. Questions, comments, and ideas should be submitted to:

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