



# MID-ATLANTIC ETHICS COMMITTEE

## NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia  
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## INTERPROFESSIONAL ETHICS FORUM FOCUSES ON TRAUMA-INFORMED CARE

Last November, MHECN co-sponsored the Fifth Annual Interprofessional Religion and Ethics Forum at the University of Maryland, Baltimore (UMB) campus, in partnership with the Institute for Jewish Continuity, the UMB Schools of Medicine, Nursing, Pharmacy, and Social Work, and the UMB Graduate School. The focus: exploring mental health from a “trauma-informed care” (TIC) lens. Two core principles in healthcare ethics recognize a healthcare provider’s duty to promote each patient’s well-being (beneficence) and to provide fair access to healthcare resources (justice). A TIC approach



explores ways to meet these duties more effectively for individuals affected by lifetime trauma—particularly childhood trauma. Conference speakers, exploring perspectives across healthcare disciplines and spiritual traditions, provided examples of how issues involving conflict (a common element of many ethics consultations) may be more effectively resolved using a TIC approach.

### A Trauma-Informed approach recognizes three general categories of trauma:

- Big “T” Trauma involves exposure to a violent event such as a natural or man-made disaster, war zone violence, act of terrorism, drug overdose of a loved one, serious car accident, etc.
- Little ‘t’ traumas are smaller-scale events that can trigger big “T” traumas, such as a dog bite or a routine surgery or medical procedure.
- “C” (cumulative) trauma refers to exposures over time that create a chronic traumatic response, such as racism, poverty, homophobia, bullying, child abuse, etc.

The *Mid-Atlantic Ethics Committee Newsletter* is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland Francis King Carey School of Law’s Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

*Diane E. Hoffmann, JD, MS - Editor*

Kaiser Permanente’s landmark “Adverse Childhood Experiences” (ACEs) study initially surveyed over 17 thousand insured Kaiser patients to explore the prevalence of prior trauma and the effects on health outcomes. Findings revealed that trauma exposure profoundly impacts the developing child as well as the emotional and physical health of a human being into adulthood

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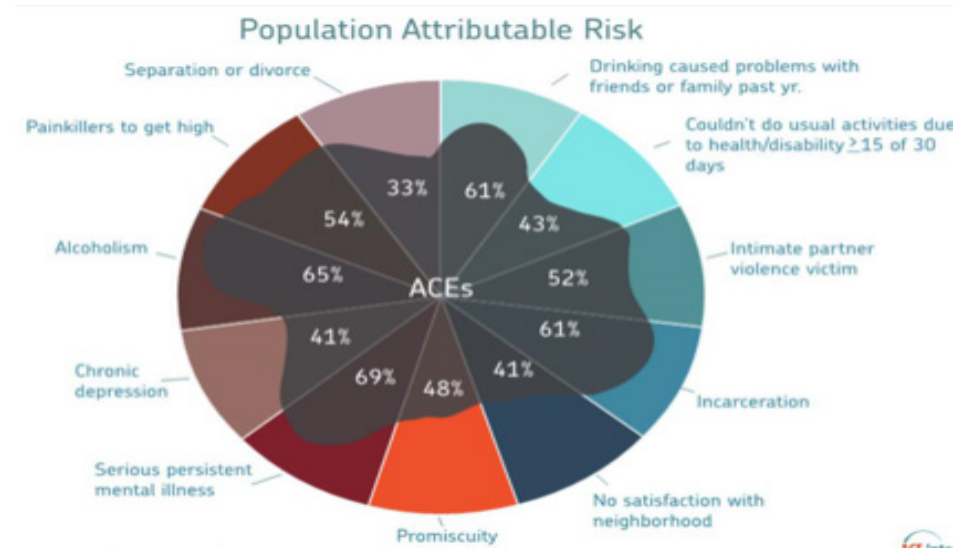
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 is not intended to provide legal  
 advice or opinion and should not be  
 acted upon without consulting an  
 attorney.**

(Felitti, et al., 1998). The original ACEs questionnaire asked ten questions to evaluate childhood exposure to abuse (physical, emotional, social), neglect (physical, emotional), and household dysfunction (including having a household relative with a mental illness, substance use disorder, or who is incarcerated, an absent parent due to death or divorce, or mother who was treated violently). Findings indicated that ACEs are very common (about 2/3 of the original sample had one or more ACEs), and that ACEs significantly increase the risk of having a large variety of physical and mental

health problems later in life. Moreover, the relationship is linear, meaning at the population level, the higher the ACEs score, the more health co-morbidities are found. One study found that individuals with an ACEs score of six or higher had a lifespan reduction of 20 years. This is related to the effects of chronic stress exposure from prior trauma, which overwhelms the nervous system, causing people to lose the capacity to stabilize and regulate themselves. This impacts one's thinking, emotions, behaviors, and physiology in a variety of ways that increases various health risks (see Figure 1).



**Figure 1. Risks associated with ACEs, controlled by gender, age, income, education, and race-ethnicity. ACE Interface ©2016. Percentages indicate the relationship between the listed conditions and ACEs score, e.g., 41% of chronic depression in adulthood is related to ACEs score, controlling for the factors listed above.**

TIC is a “strengths-based framework” that is grounded in an understanding of and responsiveness to the impact of trauma. It emphasizes “physical, psychological, and emotional safety for both providers and survivors” and “creates opportunities for survivors to rebuild a sense of control and empowerment” (Hooper et al., 2010). A TIC approach involves

knowing about ACEs and reducing the likelihood of triggering a trauma-related stress response based on how health care providers (HCPs) or outreach workers interact with patients or clients (the term “patients” below refers to individuals in a helping relationship with an HCP or outreach worker). The emphasis is on discovering and recovering resilience.



## LINDA GRABBE

Emory Professor and Certified Community Resilience Model Teacher Linda Grabbe, PhD, FNP, provided an overview on the topic. Grabbe has honed her skills identifying effects of childhood trauma on physical and mental health throughout the lifespan in her work in primary care and with homeless populations. Potential triggers can include physical touch, personal questions, being in a vulnerable physical position, lack of privacy, power dynamics of a relationship, and gender dynamics. Grabbe recommends practicing “universal precautions” by treating everyone as if they may have experienced trauma. People should be educated about TIC and what it offers. She shared the story of Tonier Cain who had an ACEs score of 10, was homeless for almost 20 years, was addicted to crack cocaine, and had 88 arrests on record and multiple incarcerations and psychiatric hospitalizations. Cain’s life changed when she was exposed to TIC in prison—epitomized by shifting from a perspective of asking “what’s wrong with you?” to “what happened to you?” Now Ms. Cain is a nationally recognized figure on TIC and gives talks around the country (see <https://vimeo.com/10791754>).

Grabbe pointed out that TIC approaches are resiliency-based, an evolution from prior approaches that involved individuals retelling their stories of trauma in order to “de-sensitize” them. That approach ended up re-traumatizing rather than helping. A trauma resiliency model educates affected individuals about how trauma biologically affects the body, teaching them ways to regain emotional control and empower themselves (see TIPS box).

### TRAUMA RESILIENCY TIPS

- Validate individuals’ experiences by actively listening to them.
- If someone discloses a trauma, use an accepting, calm, matter-of-fact, empathic tone. Say, “I’m sorry that happened to you. No one should have to experience that.”
- Don’t probe for details of a trauma history. Only professionals should “screen” for trauma.
- Assess common ways prior trauma is triggered in one’s patient population and explore approaches to avoid this.
- Teach grounding practices (e.g., feel texture of clothing or surface of nearby furniture, take deep breaths, notice smells or sights in nature, lean up against a wall, “if you can name it you can tame it”).
- Offer trauma treatment resources, such as the iChill health & fitness app.

## REBECCA VIVRETTE

Rebecca Vivrette, Assistant Professor in the University of Maryland School of Medicine’s Division of Child and Adolescent Psychiatry and a licensed clinical psychologist with expertise in trauma-focused interventions for children and families, spoke about aligning ethical values while delivering TIC. Many patients seeking care have been mistreated or even re-abused by systems and providers designed to help them. Unfortunately, many providers lack training about TIC. This raises questions about how to fulfill ethical duties of respect for autonomy, justice, beneficence and non-maleficence. For example, the principle of respect for autonomy acknowledges a duty to give voice to the patient and empower him or her to make informed choices. HCPs need to partner with patients by “listening and respecting” more than “blaming, telling, and directing.” This requires a relational approach to healing in which the provider is both emotionally available and self-aware. This sometimes requires admitting one’s mistakes, which can feel uncomfortable but is key to establishing trust.

Finding the right balance between being authentic and maintaining professional boundaries can be challenging when providing TIC. Individuals with complex trauma histories often require more attention from health care providers—for example, due to higher risks for self-injury, substance misuse, risk-taking behavior, domestic violence, and family discord. One common pitfall is to enter into a rescuing-revictimization cycle in which a provider fails to establish healthy boundaries with a pa-



tient and then comes to resent the high caretaking needs of the patient, leading to disruption or early termination of care and repetition of the cycle with another provider.



Vivrette worked through a case study involving a mother of three with a high ACEs score seeking care at an emergency room. Ethical obligations of the health care providers to the patient and the children raise questions about the health care team's primary duties and how to address competing obligations. Providing safe, trustworthy and transparent care that sets patients up for success rather than re-traumatization embodies the ethical principles of beneficence (promoting well-being) and non-maleficence (not harming). The principle of justice involves attending to health disparities and how they impact each case and working to reduce them. Since this work is demanding, clinicians must be aware of their own boundaries and self-care needs. Exposure to others' trauma causing "secondary traumatic stress" is real, and requires self-awareness and healthy organizational systems support.

## INTER-FAITH PERSPECTIVES

An inter-faith panel discussed religious and spiritual approaches to mental health and trauma recov-

ery. Rabbi Shmuel Silber, founder and Dean of the Institute for Jewish Continuity, and also Rabbi of Suburban Orthodox Congregation Toras Chaim in Baltimore, recounted the story of Joseph from the Torah. Joseph was from a large family with tremendous family discord. His many brothers wanted to kill him. Instead, they stripped him of clothing and threw him into a pit. He was sold to an Egyptian and encountered setback after setback, all trau-



As Rabbi Silber summed up:

*"People will think they are damaged goods. Our job is to remind people sometimes the events of life bury us under layers of dirt, but it doesn't mean the wellspring of refreshing holiness and spiritual beauty can't surface. After years and years of having dirt heaped upon you, you can forget about the wellspring buried below. A reservoir of beautiful holy water still courses beneath."*

**Karen Gorden**, practitioner of Nichiren Buddhism and member of Soka Gakkai International (SGI) Baltimore Buddhist Center in Baltimore, shared Buddhist perspectives on TIC. SGI is a Buddhist movement dedicated to peace, culture and education. It seems that more and more people are suffering from a variety of traumas that threaten their core identity. Gorden described relevant Buddhist concepts.

One is transforming karma into mission. Buddhism's concept of karma recognizes that to understand the past, we should look at its effects in the present and, in turn, we should project the causes of the present to understand the future.

Older versions of Buddhism took a more literal view of karma that might view trauma as punishment for a prior transgression. Newer interpretations emphasize deliberately creating the appropriate karma. Did we plan to become ill, addicted, or involved in violence? No. But in this present

matic. Ultimately, Joseph makes a conscious decision to forget his traumas and to view himself as a survivor rather than as a victim. Certainly, this is a poignant topic for Jewish people, many of whom lost family members in the Holocaust. Rabbi Silber recollected his grandmother correcting those who referred to her as a "survivor of war." She didn't want this to define her, rather than her journey of coming to a new country and making a new life for herself and her growing family. Like Joseph, prior trauma and pain fueled self-actualization and growth. Rabbi Silber also evoked the metaphor of digging, borrowing from the patriarch Isaac in the Book of Genesis, who dug wells. Digging is dirty work, it's unappealing. But the well-digger's reward for persistence is finding a magnificent spring of water.

moment, we have an opportunity to make a choice. A negative outcome can be fuel for transformation, when we choose to transform karma into mission. In Buddhism, this awareness and choice is called making a vow. Rather than being passive, we become protagonists of our own lives; we position ourselves for breakthroughs and help others do the same.

Another concept is to acknowledge “treasures of the heart.” In Buddhism, the heart represents the very essence of life itself; it protects, heals, revitalizes, and strengthens our core. Buddhists view life itself as our supreme treasure, and other forms of life support this treasure. We are not defined by our ethnicity or genes but by our oneness with the universe. Buddhists look for transformational practice, a process of fundamental change that SGI refers to as “human revolution.” This creates a culture of resilience. This practice involves “raising one’s gaze beyond one’s restricted, ordinary, everyday world and striving for and dedicating oneself to achieving something more lofty, more profound, more all-embracing” (Ikeda, n.d.).

Such transformational work can



be catalyzed by prior trauma and suffering. Some people may be more privileged than others - but Buddhism views all human beings as fundamentally worthy of respect, and teaches that all people have the capacity to change their life direction. That is why Buddhists believe one must start within. By changing one’s attitudes and ways of thinking and focusing one’s mind, actions, and lives on the highest good, this is the path toward healing and thriving.

As summarized by SGI President Daisaku Ikeda:

*“A human being is a human being. No one is superhuman. For that reason, the most important thing is simply to become the very best human being you can. No matter how you adorn yourself with the trappings of fame, rank, academic credentials, knowledge or wealth, if you are impoverished or bankrupt inside, your life will be barren and empty. What kind of person are you when all those externals have been stripped away, when you stand unadorned except with your own humanity? Human revolution is the challenge to change our life at the very core.”*

**Rev. A. Keith Ethridge** serves as the Associate Director at the Veterans Affairs’ (VA) National Chaplain Center. Rev. Ethridge shared the ways that VA chaplains serve their veteran population, many of whom have experienced trauma from military service. The dramatic increase in suicides among veterans of wars in Afghanistan and Iraq (20 a day, on average) honed Rev. Ethridge’s focus on the intersection between chaplaincy and mental health. Rev. Ethridge helps to train VA chaplains to work as members of the interdisciplinary team to provide a TIC approach. They have focused on post-traumatic stress disorder (PTSD), suicide prevention and awareness, and “moral injury” (e.g., soldiers encountering combat situations where they are told to do something by a superior that conflicts with what their conscience dictates). Rev. Ethridge turned to philosopher and theologian Paul Tillich’s work in exploring the

intersections of spirituality, faith, and mental health. Tillich identified the following spiritual life functions: (1) self-integration (the process by which we come to know who we are in relation to other persons); (2) self-creativity (what we manage to do with the “energy of life,” which might be something as simple as mustering the energy to get out of bed in the morning to meet with the VA chaplain); and (3) self-transcendence (the process of identifying the “ultimate concern” that motivates individuals to find meaning in living). Rev. Ethridge reiterated Christian themes of how to overcome prior trauma that echo themes raised in Rabbi Silber’s and Karen Gorden’s comments—that is, prior trauma can fuel one’s transformation. The old and new testament alike have many accounts of believers who struggled against persecution.

Jesus’ persecution and crucifixion preceding his returning from the

dead embodies this process of rising out of the ashes of trauma and moving toward wholeness.

Conference attendees discussed ways that religious teachings and practices may promote or frustrate the path toward enhanced resilience among individuals with a trauma history. Ultimately, this path is one of self-transcendence, which is as much a spiritual process as it is a journey of physical and mental recovery. It is also a process that requires allies at every level.

For more information about the forum, Click on Conferences on MHECN's website: <https://www.law.umaryland.edu/Programs-and-Impact/Health-Law/MHECN/>.

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# DAX COWART DIES AT 71: REMEMBERING HIS LEGACY



**Dax Cowart** was well-known for his advocacy in protecting patient autonomy. He died on April 28, 2019, at the age of 71, from cancer-related complications. By his own judgment, he lived 46 years longer than he should have. At the age of 25, he was severely burned when his car ignited propane gas from an underground pipeline leak and exploded. Dax (then “Donald”) requested on multiple occasions to be allowed to die, but health care providers declined to comply, even after he was deemed mentally competent to make his own decisions. The blast injuries left him badly burned, blind, and hearing impaired. Most of his hands were amputated, many surgeries were later done to reconstruct portions of his face, and he endured excruciating burn treatments that are now considered barbaric. For example, he was submerged in a bleach solution to disinfect his wounds,

which he described as feeling like “alcohol was being poured over raw flesh,” despite being given morphine before the treatments (Slotnik, 2019). He later married, earned a law degree, and began practicing law. But he consistently maintained that his rights were violated on the many occasions that his pleas to stop treatment were ignored. While he was a frequent speaker on the topic of patient rights, Mr. Cowart maintained that he was not advocating for a patient’s right to die; rather, he was advocating for a patient’s right to choose what happens to his body. It’s fitting to remember the individuals at the center of “cases” that are featured in bioethics literature. Dax’s longtime friend and colleague Bill Winslade (2019) wrote: “I discovered in Dax a remarkable ability not only to communicate his own ideas but also an extraordinary ability to listen and truly hear with almost therapeutic empathy the ideas and feelings of others.” In that spirit, we salute Mr. Cowart’s legacy.

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# CASE PRESENTATION

*One of the regular features of this Newsletter is the presentation of a case considered in an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. We may also change facts to protect confidentiality. Cases and comments should be sent to [MHECN@law.umaryland.edu](mailto:MHECN@law.umaryland.edu).*

## CASE STUDY FROM A MARYLAND HOSPITAL

A 45 year-old woman is admitted to a community hospital after being found unresponsive. Her head computed tomography (CT) reveals she has had a large hemorrhagic stroke, and her neurological assessment reveals her only reflex is that she is still initiating breaths on her own. By the next morning, the Physician's Assistant (PA) notes that the patient is no longer initiating breaths and is appearing brain dead. He calls the attending physician who is off-site for the day at another hospital. The attending asks the PA to proceed with brain death testing with him watching via telemedicine. The hospital brain death policy requires an attending physician to conduct brain death testing, but since the attending is unable to come in person, he decides to have the PA conduct the exam with him watching through a live video feed. Ultimately, the patient is declared brain dead with both the PA and the attending signing off on the brain death checklist. The PA relays the results of the exam to the patient's family. The case is presented to the ethics committee for discussion about ethical standards in such cases.

### Comments from a Health Care Attorney

“Telemedicine” refers to the practice of medicine through the utilization of software and/or technology where the rendering physician is not meeting “in-person” with the patient. The term “telehealth” is used interchangeably with telemedicine, but can be used to refer to a more global scope of remote health care service, such as psychology, nursing, therapy, etc. The case, at issue, however,

relates to the remote delivery of medicine, and therefore that term will be used.

In this scenario, an initial question is whether the attending provider is properly licensed, credentialed and otherwise authorized to provide the brain death service. Telemedicine physicians must be properly licensed, or meet an exception to licensure, under

the laws of the state in which the patient is located. Some states take it a step further and require the physician to also be licensed in the state in which the physician is physically located. In this case, because the attending physician is already in the picture, it is reasonable to assume he or she already satisfies this requirement.

Physicians must also be properly credentialed. Therefore, hospital bylaws should be clear as to requirements applicable to telemedicine physicians. Often times the “telemedicine” related bylaws apply to physicians who only provide telemedicine services and never provide in-person services. To account for situations like the one in this case, the bylaws should contemplate situations where physicians provide both types of services.



Another question to answer is whether the physician established a proper patient relationship under state law before rendering the telemedicine service. Again, the laws of the state in which the patient is located will dictate how a patient relationship is formed and most, if not all states, have regulations specific to how a relationship is formed via telemedicine. Some state laws limit the “modality” that can be used to establish such a relationship. For example, some states require that a patient relationship be established via live interactive communication (or a synchronous modality) and prohibit the establishment of such a relationship via an asynchronous modality; Maryland requires use of live video. Further, and not surprisingly, most if not all states prohibit the establishment of such relationship via email or fax. In this case, the reference to the physician as the “attending physician” suggests a proper patient relationship has already been formed.

The participation of onsite practitioners or other staff, i.e., “telepresenters,” in the context of telemedicine, such as the PA in this case, must be in accordance with applicable state laws. Some state laws or payer requirements such as Medicaid, require the use of a telepresenter in the context of a telemedicine encounter, but most do not. When a telepresenter is involved in the case, the rendering provider must ensure the telepresenter is properly supervised and at the requisite level, i.e., general, direct or personal supervision, each requiring a different degree of physical proximity between the supervising physician and telepre-

sender. Further, the telepresenter’s services must only be in the scope of the telepresenter’s authorized license to practice. In this case, the PA must be properly supervised and the supervised performance of the brain death test must be within the PA’s licensed scope of practice.



State laws often require the provider to obtain certain patient consents or acknowledgements and/or provide disclosures to the patients, specific to telemedicine services. However, in this case, the patient does not have decision making capabilities. Under these circumstances, standard facility policies would apply to consenting and notices, which may allow for the provision of consent by, and disclosures to, next of kin. In Maryland, consent is not required to perform a brain death exam, although some states are formalizing this in legislation.

Finally, to the extent the hospital and/or attending physician wants to bill a payer for the service, payer telemedicine policies must be considered. Medicare only pays for telemedicine services that meet certain requirements related to the provider, patient location, the nature of the technology and type of service. In this case, the at-

tending physician and hospital are qualifying a distant provider (i.e., the PA) at an originating site (in this case, the hospital). An interactive audio and video encounter meets the technology requirement. However, in order to secure Medicare reimbursement, the hospital must be in a physician shortage or rural area and the brain death test must be on the list of approved telemedicine CPT codes. Medicaid programs have similar limitations on the provider, patient setting, modality and service, which vary state by state. With regard to commercial payers, the issue is the existence of payer parity. State parity laws require payers to cover and pay for services rendered via telemedicine, in the same manner as they do when rendered in person. In states without such laws, payers are not required to cover and/or pay for telemedicine in equal measure.

While it is important to be aware of the state telemedicine specific laws, the legal analysis does not end there. Telemedicine is simply the practice of medicine via an alternate platform. Therefore, it is subject to the existing licensure and practice standards, best practices and ethical guidelines. In the future, it is quite possible that the term telemedicine will become antiquated as it will all be accepted as medicine and healthcare with no special “telemedicine considerations.” But until then those state and payer telemedicine specific requirements must be considered.

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## Commentary from the Transplant Community



Telemedicine involves the use of electronic communications in the form of Internet technology, instantly connecting patients and physicians. In the inpatient setting, telemedicine can be used for those admitted to a remote hospital for an acute illness or chronic disorder. Telemedicine has been emerging as a necessary tool to increase access to health care for underserved areas. Some research done by neurologists at the Mayo Clinic shows that diagnosing coma levels are equally achieved by bedside and telemedicine evaluations (Demaerschalk, 2018). It can be an effective and efficient form of health care delivery to overcome barriers of distance and delay in real time.

The Living Legacy Foundation of Maryland's Ethics Committee has had past experience with remote hospitals requiring the use of telemedicine specifically when brain death declaration is necessary. Infrequently, brain death testing has occurred with a physician's assistant (PA) or nurse practitioner (NP) on site at the bedside with the attending physician observing and guiding the brain death testing protocol

via remote access. The protocol is never done in isolation but rather, with a trained attending physician present for each step. In the case of a potential donor, the Organ Procurement Organization (OPO) recovery specialists are usually present to ensure the integrity of the testing and add another "set of eyes." The American Medical Association (AMA) position states that physicians must ensure that they have the information they need to make well-grounded clinical recommendations when they cannot personally conduct a physical examination, such as by having another health care professional at the patient's site conduct the exam (AMA Code of Ethics, 2016). Brain death diagnosis requires experience and training. The American Academy of Neurology (AAN) states that it seems reasonable to require that all physicians making a determination of brain death be intimately familiar with brain death criteria and have demonstrated competence in this complex examination. This would include knowledge of confounding factors such as drug clearance, temperature and acidosis as well as expertise in standardized criteria for an apnea test (Russell, 2019). Each hospital requires a brain death policy and those hospitals using telemedicine should have a separate or imbedded policy that encompasses the range of health care provided through remote access while protecting privacy and confidentiality. Additionally, the AAN recommends appropriate competency of telemedicine physicians in evaluation and management as well as readily

available technological support and informed consent discussions.

In this case study, it is assumed there is a patient/physician relationship soon after admission to the hospital and awareness by the attending of the changes to the patient's condition over time. This relationship is important in determining the necessity for a remotely supervised brain death exam for several reasons. The timing of this exam may necessitate telemedicine. Families are affected by the delay in knowing the accurate condition of their loved one. Potential donation conversations are affected by the testing of brain death. Distance and need for a timely brain death assessment may preclude the attending's ability to be on site for this important diagnosis. The family relationship with the physician and care team establishes the reverence for the grim prognosis and ultimately the diagnosis of death. Telling a family their loved one has died ideally needs to come from a caring attending physician who has established trust and rapport and has borne witness to the brain death testing. In this case the trusted PA reported death to the family with support from the attending. The solemnity of death needs to be respected.

The physician assistant most likely had the necessary rapport with the family to sensitively deliver the sad news. There could be a perception by the family that the attending could not make the time to be at the hospital, hence the need for fully informed discussions to dispel any misperceptions by the family.

Living Legacy Foundation of Maryland's Ethics Committee supports the use of telemedicine for brain death diagnosis when the:

- diagnosis complies with the hospital's policy for brain death declaration
- diagnosis complies with the hospital's policy for telemedicine and declaration of brain death
- use of telemedicine has the appropriate technological support
- need for telemedicine is identified in a timely manner for the diagnosis of brain death
- attending physician is sufficiently trained in brain death declaration
- procedure is done with sensitivity to the family and the death of their loved one.

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## Hot Topics for Healthcare In-House Counsel

On October 11, 2019, the Law & Health Care Program at the University of Maryland Carey School of Law, the American Health Lawyers Association (AHLA), and the American Society for Health Care Risk Management (ASHRM) will cosponsor "Hot Topics for In-House Counsel," a roundtable discussion for in-house counsel at healthcare organizations. The event is intended to provide in-house counsel with an opportunity for informal dialogue on pressing issues facing healthcare organizations and provide the basis for a symposium issue of the *Journal of Health Care Law & Policy*. The planning committee, comprising Maryland Carey Law graduates with experience serving as general counsel at leading healthcare institutions across the country, has identified the following five topics for discussion:

- 1) discrimination by patients and health care providers;
- 2) the challenges of discharge for vulnerable patients, including the practice of medical repatriation;
- 3) new disclosure issues associated with mergers and acquisitions, e.g., cybersecurity;
- 4) opioid use and prescribing concerns in the ER and for admitted patients;
- 5) the challenges for health care institutions presented by the expanding access to medical marijuana in many states.

If you are interested in attending, please contact Diane Hoffmann on or before September 30 at 410-706-7191.

## Accessing Electronic Advance Directive Documents in Maryland Through the CRISP Health Information Exchange

One of the significant problems with advance directive forms is that even if patients have completed one, they may not have given it to their health care provider, the hospital may not have a copy (or be able to find a copy when it's needed), and family members may not know where it is (Fagerlin & Schneider, 1994). In order to address this concern, Maryland policy makers realized the potential benefit of a centralized state repository where individuals can electronically upload a copy of their advance directive on their computer and health care providers can find and retrieve it. [According to a recent GAO study (GAO, 2019), about one-quarter of states have registries—either electronic or paper-based—for completed advance directive forms, POLST forms, or both.] In Maryland, the Chesapeake Regional Information System for our Patients (CRISP) has been charged with expanding access to advance directives by health care providers. This article explains more about the role of CRISP and how it plans to accomplish this task.

### Health Information Exchange and CRISP

Electronic health information exchange (“HIE”) allows doctors, nurses, pharmacists, other health care providers and patients to appropriately access and securely



share a patient’s vital medical information electronically—improving the speed, quality, safety and cost of patient care.<sup>1</sup> HIEs can be established by health systems, networks of payers and providers, and by local jurisdictions or even entire states.

CRISP is an HIE serving Maryland, West Virginia, and the District of Columbia. Incorporated as a non-profit corporation in 2009, that same year CRISP was designated as the Maryland statewide HIE and awarded a \$10 million grant from the Maryland Health Services Cost Review Commission to build connectivity among Maryland Hospitals. Through its 10 years of operation CRISP has built and deployed a range of tools to promote connectivity and interoperability among health care providers and payers in Maryland and the Mid Atlantic.

### Advance Care Planning within the CRISP HIE

An Advance Directive (“AD”), also known as an Advance Care Plan (“ACP”) is a useful, legal way for an individual (or declarant) to direct their medical care, particularly treatment preferences in an emergency or near end of

life. An advance directive can also include the name of a health care agent (or proxy) that can make decisions for a declarant if they are unable to do so themselves. Maryland law permits an advance directive to be in the form of a written or electronic document or a verbal statement made in a video recording. Increasing accessibility to advance directives has generally been a national priority in health care decision making policy to ensure patients receive medical care that is consistent with their values, goals, and preferences. The State of Maryland has prioritized expanding access to electronic advance directives via the State-Designated HIE, CRISP.<sup>2</sup>

In 2014, a **pilot interface** was launched between the MyDirectives.com repository (operated by ADVault, Inc.) and CRISP. Through this proof of concept pilot, CRISP Participating Users (providers) were able to access ACPs stored on the MyDirectives.com registry. While a link to the MyDirectives.com site was included on the home page of the CRISP website, no investment was made in consumer directed marketing by the state or providers. As such, there have been few ACP documents stored on the



MyDirectives.com site during the pilot phase, and health care providers were not informed about the site or told how to access it.

### **Maryland Statute and Regulations Surrounding EADS**

Subsequently, Maryland State law (2016 Chapter 510 and 2017 Chapter 667) required the Maryland Health Care Commission (MHCC) to develop a State Recognition Program for Electronic Advance Directive Services (EADS). The 2017 legislation clarified that the Maryland Department of Health may contract with one or more vendors (i.e., an entity that offers EADS through a web-based application using cloud-based technology), and established an Advance Directives Program Fund to support costs for vendor integrations with CRISP and outreach and education efforts. Maryland regulations (COMAR 10.25.19, effective March 12, 2018), outlined program procedures for State Recognition, a prerequisite for connecting to the State-Designated HIE. Vendor criteria include standards for privacy and security; auditing and compliance; and education, reporting, and technical provisions. In July 2018 the MHCC issued its vendor criteria and application for state designation as an Electronic Advance Directive Service (“EADS”).

To date, one EADS vendor, ADVault, Inc. (developer of MyDirectives.com) applied for State recognition, which was approved by the MHCC in November 2018.



### **Current Status of CRISP-ADVault Integration**

CRISP and ADVault, Inc. executed a Record Locator Agreement in early 2019. This contract provides for the HIE and EADS to construct an “integration,” that is, a crosswalk between the CRISP Clinical Query Portal and MyDirectives, which will let CRISP Participating Users (i.e., credentialed providers and care management staff at organizations that have executed a CRISP Participation Agreement) access to ACP documents stored on the MyDirectives.com site.

Construction of the CRISP-ADVault integration began in April. Completion is targeted for this summer. Upon “go-live”, the integration will provide for CRISP Participating Users to identify patients that have ACP documents stored on ADVault and then access those ACP documents within the ADVault site (MyDirectives.com) via a URL from the CRISP Health Records. Providers will be able to access patient directives through CRISP Health Records Advance Care Planning documents either created by their patient on MyDirectives.com or uploaded by the patient to their MyDirectives.com account (such as Maryland’s template advance directive, 5 Wishes, etc.).

### **Populating the Advance Care Plan Registry**

Upon completion of the EADS integration the important work of populating these electronic services begins. It is incumbent upon health care providers and other advance care planning advisors to educate the public about opportunities to share these documents via electronic advance care planning tools and encourage their use. Several providers and provider coalitions around the state are organizing now to do this.

*Paul Gleichauf  
Account Executive, CRISP  
Columbia, MD*

### **References**

Fagerlin, R. & Schneider, C. (2004). Enough. The failure of the living will. *Hastings Center Report*, 34(2), 30-42.  
GAO (February, 2019). *Advance Care Planning: Selected States’ Efforts to Educate and Address Access Challenges*.

GAO-19-231. Available at <https://www.gao.gov/products/GAO-19-231>.

### **Notes**

1. <https://www.healthit.gov/topic/health-it-and-health-information-exchange-basics/what-hie>
2. [https://mhcc.maryland.gov/mhcc/pages/hit/hit\\_advancedirectives/hit\\_advancedirectives.aspx](https://mhcc.maryland.gov/mhcc/pages/hit/hit_advancedirectives/hit_advancedirectives.aspx)

## Daniel Callahan: In Memoriam

*Adapted and reprinted with permission from The Hastings Center (<https://www.thehastingscenter.org/daniel-callahan-in-memoriam/>).*

Daniel Callahan, a national voice for responsible health and science, who pioneered the field of bioethics, died Tuesday, two days before his 89th birthday. In 1969, Callahan cofounded The Hastings Center with Willard Gaylin. Callahan served as the Center's director from 1969 to 1983, president from 1984 to 1996, and president emeritus, actively publishing numerous essays, until his death.

Upon hearing the news of Dan Callahan's death, one word kept appearing in my thoughts: gratitude. Gratitude for his prodigious thinking, his commitment to listening across difference, his use of accessible language to illuminate complexity, his more than 47 books that advanced the parameters of debate, and his generous mentorship of generations of scholars. Over nearly five decades, Callahan advanced new foundational ideas, offered practical wisdom, influenced international health and science policy, stimulated the creation of the interdisciplinary field of bioethics, and supported its growth across the United States and the world. Perhaps most importantly in this era of polarization and hyper-individualism, he called on us to work together to discuss vying notions



of the good and build solutions to promote human flourishing.

Callahan was motivated by a fundamental wariness of human power. He was deeply struck by the human proclivity for self-deception, especially concerning the potential for irresponsible use of such power in the life sciences and in the realm of biomedical technology. His work demonstrates a deep sense of how fundamental moral sensibility is to our humanness and how vulnerable and naked we would be—and are—in a society of merely self-interested stakeholders engaged in merely instrumental cooperation.

In the mid-20th Century, Callahan recognized that, at precisely the moment when we were entering into a new and unprecedented era of biopower, gaining progressive control over body and world, we might also become tone-deaf and mute on matters having to do with patience and acceptance, community and mutual care, ambiguity, humility, fairness, and steward-

ship. The recent emergence of ever more powerful transformative technologies, like new forms of gene editing which will enable us to change the very nature of the human species and breathtaking advances in artificial intelligence, demonstrate his prescience.

When Callahan began his philosophical career in the 1950s, many philosophers in American universities were doing work in the analytic tradition, far from the public square. At that time, the philosophers who did broach policy questions tended to be deeply skeptical about the value of talking in public about “the good.” Because Callahan thought that philosophy should contribute to the public square, and that robust conversation about “the good” should be an essential part of that contribution, he was, at the start of his career, a rebel among academic philosophers.

The title of one of his most important books, *What Kind of Life: The Limits of Medical Progress*, illustrates one of his central concerns. He thought that modern philosophy, in refusing to ask questions about ends or purposes, had been engaged in a massive over-correction of ancient philosophy's preoccupation with ends. Further, he thought that modern science's focus on how to improve the health of our bodies and increase the length of our lives was deflecting our attention from the equally important humanistic ques-

tion that receives far less attention in our culture: what is a healthier life for? What kind of life do we want to create for ourselves and our children? He was urging us to reaffirm our commitment to the age-old Socratic question about what kind of life would be good. The burgeoning medical-industrial complex was the ideal place to begin asking that question.

Dan Callahan wrote 47 books. Seventeen are solo-authored volumes; nine of these won national prizes. His writings greatly influenced the nature of the doctor-patient relationship, moving medicine away from its paternalistic history to the patient-centered approaches called for today. His work also had a profound impact on our understanding of death and dying, presaging the palliative care movement; on the role of markets in health care policy so relevant to current debates; on the interplay between private and public sector contributions to the U.S. biomedical research enterprise; and on the wise use of numerous emerging biotechnologies. Just two days shy of his 89th birthday, right up to the end of his life, he continued to publish 7 or 8 articles a year, and in 2016 Columbia University Press published *The Five Horsemen of the Modern World*, which explores the social, ethical, economic and political aspects of five critical global challenges: climate change, food, water, chronic illness, and obesity. His body of work brought important accolades beyond the individual book prizes he received: Dan was one of only a few philosophers to be elected to the National Academy of Medicine, and the only philosopher to

have received the National Leadership Award of the American Association for the Advancement of Science.

Callahan anticipated the importance of interdisciplinary study long before it was fashionable. He understood the need for scholars to engage in collaborative discourse to address complex problems that did not respect traditional scholarly boundaries. The breadth of his own abilities allowed him to work well with scholars from a wide range of disciplines and to create an environment at The Hastings Center, where novel synergisms could take place. The interdisciplinarity of his work is also reflected in the fact that his books are widely read among scholars in public policy, political science, economics, sociology, and many other fields.

Dan also chose by design to create work groups composed of people who disagreed with one another, and he helped create traditions of respectful dialogue that aimed – but did not force – consensus. His own scholarship also beautifully illustrates this commitment to exploring commonalities, clarifying differences, and arriving at mutual understanding. His early book on abortion, written with his wife, who was pro-life when he was pro-choice, is an excellent example of his determination to work across boundaries others might fear to span.

Callahan is credited with stimulating the creation of the field of bioethics. Much of this credit comes from having cofounded The Hastings Center in 1969 and estab-

lishing Hastings' two journals, the *Hastings Center Report* and *IRB*, recently relaunched as *Ethics and Human Research*. Callahan was also instrumental in helping other nations build their own capacities, including working closely with universities in Eastern Europe, where there are now well-established institutional homes for this kind of scholarship. In later years, subsequent leaders at Hastings (including my predecessor Tom Murray) did similar institution-building in Asia, by helping to establish the first Asian bioethics center and bioethics journal at the National University of Singapore and building relationships with scholars in China and Japan. During my tenure, Hastings has facilitated the launch of an ethics center at the Chinese University of Hong Kong (CUHK), and with support from a former dedicated board member, built a 10-year fellow exchange between Hastings and CUHK. All these international efforts began with Dan Callahan.

Dan was never content with contributing to academic theory. Throughout his life, he encouraged public deliberation for the purpose of encouraging people to ask better questions about the most significant problems we face. He was unabashed in his willingness to talk about the good life and the good in life: asking troubling questions, insisting that medicine, science, law, and public policy work toward a communitarian vision of a society of free, equal, yet reciprocally engaged persons with a sense of obligation toward one another and a commitment to building a "shared future". [...]



As we grieve the loss of Daniel Callahan, may we be uplifted by the inspiration of this great man. How lucky are we who have worked with and learned from the life Dan so well lived.

*Mildred Z. Solomon  
President, The Hastings Center  
<https://www.thehastingscenter.org/>*

## CALENDAR OF EVENTS

### SEPTEMBER

**5**

Ethical Issues in Uterine Transplantation and Innovative Research in Reproductive Medicine, sponsored by the Cleveland Clinic, Cleveland, OH. Visit: [clevelandclinicmeded.com/live](http://clevelandclinicmeded.com/live).

**27**

The Ethics of Equity, Diversity, Inclusion and Civility: Translating Aspirational Concepts into Professional Practice (2019 Judy Levy Ethics Workshop), sponsored by the Social Work department at Kennedy Krieger Institute, Baltimore, MD. Contact Anitra Swann, [Swann@KennedyKrieger.org](mailto:Swann@KennedyKrieger.org); (410) 298-3549.

## SAVE THE DATE

Sixth Annual Interprofessional, Interfaith Ethics Forum: What the Golden Rule Really Means in Serving the LGBTQ+ Community

**Thursday, November 7, 2019**

**Westminster Hall (UM Carey Law)**

*Discount for MHECN members!*

Check the MHECN website for registration and program information!

## RECURRING EVENTS

Johns Hopkins Berman Institute of Bioethics Seminar Series & Ethics for Lunch series, either at Sheik Zayed Tower Chevy Chase Conference Center (1800 Orleans St.) Room 2117 or Feinstone Hall, E2030, Bloomberg School of Public Health (615 N. Wolfe St.) Baltimore, MD. 12N-1:15PM.

Visit: <http://www.bioethicsinstitute.org/educationtraining-2/seminar-series>

Also visit <http://www.bioethicsinstitute.org/efl> to view topics for the Ethics for Lunch series every third Tuesday from 12:00 to 1:15 pm (Zayed). Co-sponsored by Johns Hopkins' Hospital Ethics Committee & Consultation Service and Berman Institute of Bioethics. CME & lunch provided!

**The Law & Health Care Program  
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*The Maryland Healthcare Ethics Committee Network (MHECN)* is a membership organization, established by the Law and Health Care Program at the University of Maryland Francis King Carey School of Law. The purpose of MHECN is to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. The Network attempts to achieve this goal by:

- Serving as a resource to ethics committees as they investigate ethical dilemmas within their institution and as they strive to assist their institution act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

MHECN appreciates the support of its individual and institutional members. MHECN also welcomes support from affiliate members who provide additional financial support.

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