

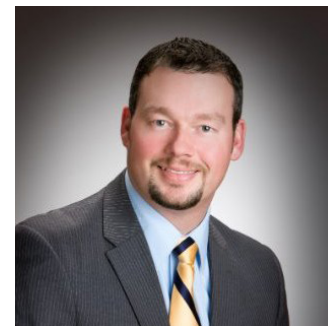


Spring 2018

To Court, Or Not To Court, That is the Question

by Jamie Parker, JD

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A Note from the Editor: During a recent meeting of the WVNEC Advisory Board, it was suggested that many of our articles and cases are written from a hospital based physician's perspective and do not necessarily reflect the ethical issues faced by, and the perspectives of, our multidisciplinary membership who practice in a variety of healthcare settings. With that concern in mind, the next few issues of the newsletter will be dedicated to providing space for representatives from non-physician health related disciplines to provide us with a view of ethical issues through the lenses of their particular disciplines. In this issue a lawyer, a nurse, and a social worker share commonly encountered ethical issues. If you would like to contribute an article or suggest a topic to be addressed in the newsletter, please contact us. As always, our mission is to assist healthcare providers in strengthening ethics committees, to provide education regarding ethical issues in healthcare to promote ethically sound decision making, and to help patients and families to make their end-of-life wishes known.

It is a question that comes up often, sometimes too often in ethics cases. "Can or should I get a court to decide what to do for this patient or my loved one?" When should a health care provider or decision makers utilize the court system to help make end of life care decisions for patients, and when should they not? And, when doing so is it truly in the best interest of the patient, or rather of the person seeking legal help?

Some laws, rules, and regulations appear very clear on their face in particular situations as to when the courts should or even must get involved in a patient's care e.g. emancipation of a minor, and some are much murkier e.g. capacity and competency concerns. However, even when the law permits a physician to seek the guidance of the court, is that really what's in the best interest of the patient ethically speaking? It could appear in some situations to be undermining a patient's autonomy, especially when the patient is choosing an option against the advice of her health care provider, and is not in the provider's mind, "in

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"Improving Patient Care in West Virginia by Promoting Respect and Compassion"

the best interest of their patient.” For example, seeking assisted suicide when there are other treatment options available. This is the dilemma the legal profession faces time and again when faced with the ethical challenges of honoring a patient’s autonomy and beneficence to the greatest extent practicable while also avoiding maleficence or injustice. It is also important to remind ourselves that judges are not typically medical experts, and do not necessarily have formal education in end of life care decision making processes and the complications those may create for the parties involved.

Of course lawyers and judges are bound by our own ethical rules, and by the laws of the state and federal government, but laws and rules don’t always provide a clear-cut solution to every situation. Like medical ethics, legal ethics and the law contain many gray areas that sometimes pose more questions than answers, and can be applied differently depending on the jurisdiction. For example, the components to determine brain death in one state may differ from those in a neighboring state. Another important piece to keep in mind when seeking out the court’s advice, is that once that avenue is pursued, then the court steps in as the final decision maker and you may not like the decision it makes. In this case you may just be left disappointed, or have to spend additional money pursuing an appeal.

Many times a judge is going to rely heavily on the opinions of the healthcare team or those of the family anyhow, so trying to work to an amenable solution outside of court is preferred.

Ethical questions and dilemmas arise often in the realm of end of life care for patients in emergent situations, especially if it involves a minor. Determining whether a minor is mature enough to make their own healthcare decisions is a subjective test that physicians in most situations must make on their own without the help of the court. On the other hand, if the physician’s course of action goes against the express wishes of the parent’s or other decision makers pertaining to their recommended treatment, then the courts will likely get involved.

For example, a 14-year-old patient presents to the ED after a vehicle accident in stable condition. Later, it is discovered she has internal trauma that will require surgery and blood transfusions to keep her alive. However, it has been established that she and her family are practicing Jehovah’s Witnesses’ and do not accept blood products. Her parents are present at the ED and refusing to authorize any transfusion of blood or blood alternatives. For the time being the patient is awake and alert enough to answer all of the physician’s questions regarding the required course of treatment and has capacity to go through the required steps for informed consent. When her parents are absent from the room for a moment she makes a clear and concise statement to the medical team that she does not want to die and wants them to do whatever they need to do to save her life, including blood transfusions. When you inform the parents of her desire, they expressly and vigorously object stating that she is not mentally capable of making those decisions which would potentially have devastating consequences for her faith and with her standing in their community. They state that it would be better for her to die than to receive blood products.

So what should the physicians and care team do? They could make a determination that the patient is a mature minor capable of making her own healthcare decisions and proceed with the surgery and blood transfusions. They could speak to the religious leaders of her community to see if using a blood alternative would be acceptable. They could respect the parent’s wishes and attempt the surgery without any blood products at all. They could seek an ethics consult, or call the legal department and seek counsel. There are a number of possibilities all of which lead to various outcomes and implications for all parties involved. These and other types of cases involving minors and their ability to make their own healthcare decisions are the types of cases that have no clear cut answer and will depend heavily on facts and details, any one of which could completely change the outcome of a potential court decision.

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Conversations at the End-of-Life: The Crucial Role of the RN

by **Dr. Rebecca Smelzer, DNP, MBA, FNP-BC**

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The scenario is familiar. It has occurred many times over my 20 years of bedside practice in Medical/Surgical and Cardiac Intensive Care Units. A patient is admitted from an outlying area, either from home or a long-term care facility. Frequently, the patient has been airlifted from a rural area of our state. Or, the patient may already have endured a lengthy hospital stay, being treated for cancer, respiratory failure, or heart failure. No matter. The patient is now critically ill from heart failure, sepsis, stroke... you fill in the blank. The medical team has made valiant efforts with ventilation, IV vasopressors, antibiotics, perhaps procedures in the cardiac catheterization lab or interventional radiology. But, the picture is bleak.

Here in West Virginia, the family gathers. As I care for the patient, I answer the questions of the family members. They see me not only administering medications and noting vital signs, but wiping their loved one's face and changing their soiled bed linen. They come to trust me, even if our interactions are brief. I hear them speak about their mother or father, grandma or Pap. Stories of love, tears of laughter. Eventually, I hear them agree "Mom would have never wanted this" or "He would have hated to be like this."

What is my duty to these family members who have known and loved and laughed with this person who I have only seen in an ICU bed?

The American Nurses Association Code of Ethics for Nurses states in Provision One "the nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person." Provision Two continues, "The nurse's primary commitment is to the patient, whether an individual, family, group, community, or population." Clearly, I have a duty to see that this patient's wishes are honored.

I engage the family in conversation. I look in the electronic medical record for a Living Will and/or a Medical Power of Attorney (MPOA) designation. I educate the family on the purpose of supportive/palliative care. I ask if anyone has mentioned this option to them yet. I emphasize what supportive/palliative care does; it helps to ease pain and manage difficult symptoms such as shortness of breath or anxiety. I notify the primary medical team that the family would like to discuss goals of care and possibly a supportive/palliative care consult. I encourage the family to think about the wishes of their loved one, even in this emotionally difficult time at end of life.

One valuable resource is the WV Center for End-of-Life Care, which can be accessed by patients, families and healthcare team members at www.wvendlife.org. Advanced care planning documents such as the Living Will, MPOA, DNR card and Physician Orders for Scope of Treatment (POST) are housed here and are easily downloadable. The site also contains educational videos and instructions for completing the forms. Providers can find information about WV Health Care Decisions Act and resources on discussing end-of life and decision making with patients.

As nurses, it is our duty to collaborate with the healthcare team to ensure that patient and family's wishes are communicated and validated. As the team members who spend the most time at the bedside, we frequently are the first to hear the conversations amongst family members that remind us to listen. Nurses need to advocate for families and help them navigate a confusing and overwhelming healthcare

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When Independence Gets in the Way of Safety: A day in the life of a social worker-A Case Study

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Miss Jones, an 86-year-old female, was admitted to home hospice for a recent Cerebrovascular Accident (CVA), which left her paralyzed on her right side. The patient is bed bound and has no support at home other than the hospice staff that comes in daily to care for her Monday through Friday. During a psychosocial assessment it is determined the patient is unrealistic about her emergency evacuation plan and does not appear to appreciate potential safety risks. The patient verbalizes she has “never had a fire and will never have a fire” therefore getting out of the house does not pose to be a concern to her. She also discloses since she is unable to answer the door, she leaves her front door unlocked 24 hours a day so anyone can let themselves in. She states she has “never been robbed and will never be robbed” and in fact leaves a note on the front door indicating the door is unlocked in order for visitors to enter on their own.

The patient has never been married and has no children. The patient has not completed an advance directive. She has some friends who visit her on the weekend but no one is able to be with her around the clock to provide assistance with her activities of daily living (ADLs). The patient is often found to be laying in her own urine and feces with the same food and water at the bedside that was left for her from the day before by meals on wheels. The hospice staff are concerned the patient lacks decision-making capacity. A home visit by a local psychologist is requested to assess for decision-making capacity. Unfortunately, before the psychologist is able to make the home visit the patient falls out of bed injuring her right hip. The patient was not able to call 911 and laid on the floor for 6 hours before her hospice aide arrived. The patient is transported to the hospital via ambulance and admitted to the observation unit. The hospice

social worker requests the patient have a psych consult to assess for decision-making capacity.

As hospice social workers you’re often confronted with how to delicately balance the values of patient autonomy vs beneficence. In this case, the social worker has an ethical obligation to do good for the patient and the patient’s welfare and act on behalf of the patient who clearly is not able to understand the consequences to her decision making. It is not realistic to think a fire is impossible and it is not realistic to think a robbery is impossible. If the patient was deemed incapacitated while she was still residing at her home the hospice team would help identify an adequate health care surrogate and, if needed, make an adult protective services referral.

In this case, the patient ended up in an acute setting which lends itself to better discharge options if the patient is deemed to be incapacitated. If the patient is deemed to be capacitated and is discharged home per the patient’s choice, it is recommended to have the hospice social worker complete an advance directive including a Physician Orders for Scope of Treatment (POST) form for future decision making. A meeting with the medical power of attorney representative and the patient to determine an alternate living arrangement or around the clock care would prevent this from happening again and maintain patient autonomy.



West Virginia Center for End-of-Life Care

UPDATE

Good news! Today I met with leadership at the WVU Health Sciences Center. They are very supportive of the work of the West Virginia Center for End-of-Life Care, and they expressed a commitment to continuing this work for the time being at some level until a more permanent solution to the funding of the Center can be established.

This means that the www.wvendoflife.org website, the phone number (877) 209-8086 and the Registry FAX number (844) 616-1415 will remain operational.

Courtney Dunithan, LGSW, Executive Director, has accepted a new position and her last day at the Center will be March 28th .

Thank you for your support of the Center and for your dedication to ensuring that your patients' wishes are known and respected at the end of life.

Alvin H. Moss, MD
Founding Director

Farewell from Courtney

Courtney Fox Dunithan, MSW, LGSW
Executive Director, WV Center for End-of-Life Care

"Knowledge gained through experience is far superior and many times more useful than bookish knowledge." Mahatma Gandhi



During my time with the WV Center for End-of-Life Care, my knowledge base has drastically expanded. I not only owe gratitude to those I have worked closely with on a daily basis and have helped me lead the Center for the past 21 months but to all the individuals who offered support, a lending hand, guidance, and expertise in times that it was needed. "Thank you" doesn't even cover it! I also hope that I shared knowledge and helped YOU in some sort of capacity. Although I am sad to leave the WV Center for End-of-Life Care, I am excited to return to direct care with individuals. I have accepted a managerial position in the disabilities services field. I will forever be grateful for this experience! Farewell!

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However, once you've determined that communications with the parties involved have reached an impasse it may be necessary to take the step of involving the courts. Judges don't typically want to be a family member's medical decision maker and would much prefer to leave that to healthcare professionals to work out through proper channels and communications with the patient and patient's loved ones if possible. Many times a judge is going to rely heavily on the opinions of the healthcare team or those of the family anyhow, so trying to work to an amenable solution outside of court is preferred.

Respecting a person's autonomy is one of the core values of ethical decision making. If the courts are involved then it likely means the patient's true wishes for their care are in conflict with someone else's idea of what the patient would desire, meaning their autonomy for decision making is either unknown or in dispute by those decision makers. It may seem like an easy choice to ask the court to step in and help decide when these questions arise, but encouraging the parties involved to take every step possible to reach a solution prior to taking that step is the preferred method. Hopefully by doing so, an incapacitated or incompetent person's autonomy can be respected even in the absence of them being able to actively participate in their healthcare decisions, ultimately accomplishing what is truly in the best interest of the patient.

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options such as "Comfort Care" or Do Not Resuscitate (DNR) orders. We may have to be the first to wave the yellow flag, to remind the whole team to slow down and look at the big picture, which includes patient wishes and goals of care.

Nurses, physicians and the entire healthcare team collaborate to provide the best possible care for patients. It can be a challenging time when "full court press" medical care needs to transition to supportive/palliative care. Excellent communication skills, advocacy and compassion must be utilized. The role of the bedside nurse is an integral part of this process.

References:

American Nurses Association (ANA). (2015). Code of ethics for nurses with interpretive statements. Silver Spring, MD: Author.

Over the past few years, with the generous support of a Claude Worthington Benedum Foundation grant, I have been able to meet with representatives from many of the hospital based ethics committees throughout the state. As we collected information about what ethics committees and ethics consultation services look like in the state of WV, we often discussed how ethics committees educate their members and communities. To my surprise, many of our WVNEC members regularly use article from the newsletter to provide ethics committee education. With that in mind, when we don't have a case discussion or an ethics information based feature in the newsletter, we will provide ideas for committee education. As this edition of the newsletter is dedicated to exploring discipline specific ethical perspectives, we offer the following article (with embedded video) for consideration. In response to the opioid problem currently plaguing the country, the article and video discuss an inexpensive and simple program to encourage patients to safely dispose of their unused prescription drugs. The link below has been made publicly available through the American College of Surgeons:

<https://www.facs.org/media/press-releases/2018/opioiddisposal0111>

Calendar of Events

SAVE THE DATE!

May 23, 2018 - 31st Annual May Symposium - This annual one day program will once again be held at Stonewall Resort in Roanoke, WV. Treating patients who have substance use disorders is not new to medicine. However, with rapidly increasing numbers of people becoming addicted to opioids and engaging with the health care system, a new focus has been placed on understanding and treating patients with addiction disorders. There is no demographic which is untouched by addiction, so we will be discussing how addiction affects patients across the life span and the unique ethical issues that arise along the way. Our keynote speaker, Jillian Hardee, PhD, will provide a foundation for the symposium with her presentation on the brain and addiction. Dr. Hardee is an Assistant Professor in the Department of Psychiatry at the University of Michigan and received her PhD in Neuroscience from WVU. Her research seeks to understand the neurobiological factors that are integral to risk for substance use and addiction in adolescents and emerging adults. Registration is limited to the first 100 registrants. Hotel Accommodation: A block of rooms for the night of May 22 has been reserved at Stonewall Resort for conference participants under the Center for Health Ethics and Law. To make reservations, contact the hotel directly at 304-269-7400. Cost: 105.00 for WVNEC members and \$130.00 for Non-members.

WVNEC Noon Webinar Series - The webinar series is in its planning stage. Information on this program will be available in the coming months.

Web Courses Available:

Advance Care Planning: Why, What, and How - Advance care planning refers to a process of conversation between the physician (or other advance practice provider APP) and the patient, preferably with the patient's trusted family member or friend, about the patient's wishes for future medical treatment. This program will provide 1) a sequence of steps for physicians and APPs to create an advance care plan, 2) video demonstrations of advance care planning conversations with patients in good health and those with advanced illness, and 3) information on how to bill for Medicare patients for advance care planning discussions. Cost: \$49.00 per person and includes CE credit.

WVNEC: Completing the POST Form - Advance care planning refers to a process of conversation between the physician (or non-physician professional) and the patient, preferably with the patient's trusted family member or friend, about the patient's wishes for future medical treatment. This program identifies the advantages of POST forms for seriously ill patients, present a step-by-step approach to completing a POST form, and describe how to bill for advance care planning including POST form completion. Cost: \$25.00 per person with CE credit included in the cost.

Visit our website at www.wvnec.org for the latest information on these and other future programs.



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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For more information on these and other future programs, please take a look at “Upcoming Conferences” on our website, www.wvnec.org, or call Linda at 1-877-209-8086.