JOINT COMMISSION ON HEALTH CARE

SUMMARY OF PUBLIC COMMENTS RECEIVED

Development of Life-Sustaining Treatment Guidelines

Comments were received from 13 individuals regarding the policy options and recommendations for the development of life-sustaining treatment guidelines. Comments were submitted by:

- **John Ayres**, General Counsel, Virginia Trial Lawyers Association (VTLA)
- **John/Mary Cannarella**, residents of Virginia
- **Jeff Caruso**, Executive Director, Virginia Catholic Conference
- **Chris Freund**, Vice President, Government Relations and Communications, The Family Foundation of Virginia
- **Maureen Hollowell**, Advocacy Coordinator, Virginia Association of Centers for Independent Living (VACIL)
- **Douglas LeBlanc**, resident of Virgnia
- **Sandra D. Mahanes**, resident of Virginia
- **V. Colleen Miller**, Executive Director, disAbility Law Center of Virginia
- **Thaddeus Pope**, PhD/JD, Director of the Health Law Institute, Professor of Law, Mitchell Hamline School of Law, citizen
- **Teresa Radford**, resident of Virginia
- **R. Brent Rawlings**, Virginia Hospital and Healthcare Association (VHHA)
- **Kurt Schuler**, resident of Virginia
- **Robert M. Veatch**, Professor of Medical Ethics, Georgetown University, resident of Virginia

Policy Option	**Stakeholder position:**	
	In Support	**Other**
1. Take No Action	▪ **John/Mary Cannarella** ▪ **The disAbility Law Center of Virginia** ▪ **VACIL**	
Introduce legislation to amend § 54.1-2990 of the Code of Virginia to:		
2a. (Recommendations #1 and 2) Add requirement for written hospital policies on life-sustaining treatment decision conflict resolution and specify minimum steps to be taken by hospitals in cases of life-sustaining treatment decision	▪ **Ms. Mahanes** ▪ **VHHA**	

Policy Option	Stakeholder position:	
	In Support	Other
conflict (also amend section § 32.1-127 as applicable)		
2b. (Recommendations #3 and 4) Provide qualified permission to physician to cease inappropriate treatment after 14 days and add statement of physician immunity for following requirements	▪ **Ms. Mahanes** ▪ **VHHA**	▪ **Mr. and Mrs. Cannarella:** extend the time provided in the statute from fourteen days to at least thirty ▪ **Mr. Pope:** process safeguards are not sufficient ▪ **Mr. Schuler**: mandate continued provision of requested treatment if transfer is unsuccessful ▪ **Mr. Veatch:** opposes Recommendation #3 ("Provide qualified permission to physician to cease inappropriate treatment after 14 days") ▪ **Virginia Catholic Conference; The Family Foundation of Virginia**: clarify that artificially administered food and water be recognized as ordinary care; concerns about/request clarity in when 14-day window begins ▪ **Virginia Trial Lawyers Association**: opposes Recommendation #4 (statement of physician immunity)
2c. (Recommendation #5) Add stipulation that all actions under this section must conform to federal non-discrimination standards	▪ **Ms. Mahanes**	▪ **VHHA**: provision unnecessary
2d. (Recommendation #6) Revise "life-sustaining care" term and definition	▪ **Ms. Mahanes**	
2e. (Recommendation #7) Eliminate Durable Do Not Resuscitate Orders from applicable documents within § 54.1-2990	▪ **Ms. Mahanes** ▪ **Ms. Radford:** Replace "DNR" with "Allow Natural Death"	
3. (Recommendation #8) Include in the 2017 JCHC work plan that staff form a work group to study health care decisions more broadly, focused on preventing/improving outcomes of	▪ **Ms. Mahanes** ▪ **VHHA**	

Policy Option	Stakeholder position:	
	In Support	**Other**
treatment decision conflict in Virginia, and report back to the JCHC in 2017		

John Ayres, on behalf of the Virginia Trial Lawyers Association, wrote: “VTLA was not invited, and thus did not participate, in any of the working group meetings for the issue over the summer…We do not believe that [recommendation #4 which provides full immunity to healthcare providers from civil, criminal and professionalism/ethics claims] would have received “broad support” from this working group if we had been in the room for the discussion…

The many recommendations provided by the working group do an excellent job of laying the foundation for the “standard of care” to be followed by healthcare providers in these situations. If the healthcare provider follows these standard of care guidelines, then there is nothing to fear because they didn’t do anything wrong/negligent…

Immunity is the equivalent of “special dispensation” or a permanent “stay out of court” card for wrongdoers. It gives them the power to act negligently without regard to public safety or health, with no fear of accountability.”

John/Mary Cannarella wrote: “We do not support the proposals…, which put the lives and well-being of vulnerable and severely disabled patients at risk of being denied treatment due to their physical ability. We also urge that the Commission extend the time provided in the statute from fourteen days to at least thirty, so that a patient or his or her family might have sufficient time to find other caregivers.”

Jeff Caruso, on behalf of the Virginia Catholic Conference, wrote: “We continue to favor strongly the inclusion of language to clearly specify that artificially administered food and water be recognized as ordinary care that is due, in principle, to all people (except in extreme cases when providing it would harm the patient or hasten the patient’s death). If legislation is introduced, we will be especially interested in the presence and clarity of such language… I [also] have concerns about the 14-day clock starting before a second opinion has been rendered and before a medical review committee has also determined the treatment to be inappropriate.”

Chris Freund, on behalf of The Family Foundation, wrote: “1) We would urge that language making it very clear that artificially administered food and water be recognized as ordinary care, with the possible exception of extreme cases when providing it would harm the patient or hasten the patient’s death, be included in any proposed legislation, similar to the Oklahoma statute that deals with this issue…

2) We would urge that there be a very clear denunciation of when the 14 day period begins, preferably after the second opinion has been provided and that the patient's family/surrogate be made aware that the 14 day period in which they must find alternative care has begun…

3) We would urge that language be included that makes it clear to the patient's family/surrogate that they have right to legal representation throughout the process and have legal options outside of the hospital policy.”

Maureen Hollowell, on behalf of the Virginia Association of Centers for Independent Living, wrote:

"The Virginia Association of Centers for Independent Living appreciates the opportunity to have participated in the working group that discussed life-sustaining treatment. The experience reinforces our concerns that existing statute (54.1-2990) could have catastrophic consequences for people with disabilities who are receiving treatment that their physician determines to be no longer medically or ethically appropriate...

This was a study of how physicians could end life sustaining medical treatment when the physician's intent is contrary to the individual's advance directive or decision of their surrogate. This is a not about assisted suicide. Just the opposite – the individual is seeking to live, either by their predetermined directive or decision of their surrogate...

VACIL strongly objects to recommendation #3. Allowing the physician to end treatment in conflict with an advance directive or decision of a legal surrogate is inappropriate. When these two facts are in conflict – 1. physician elects to end treatment and 2. the individual desires the treatment, and the treatment either has to end or has to be provided, ending life should not be the default."

Douglas LeBlanc wrote:

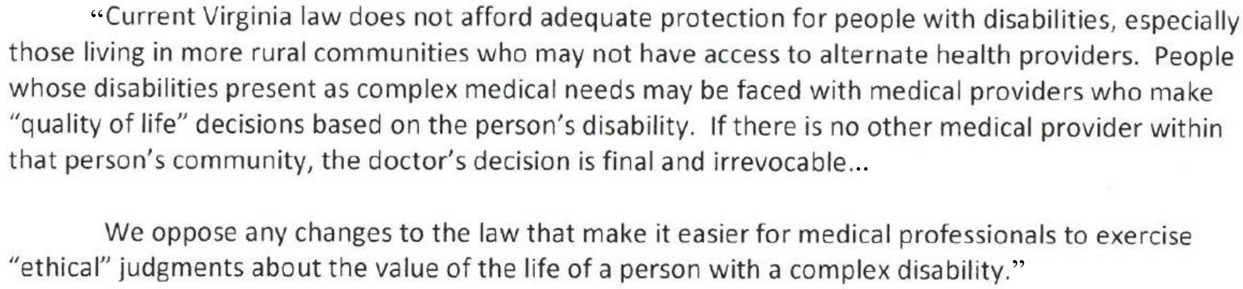
"I write to express my distress that the Commission may give greater power to non-family members in determining whether a person is removed from life-sustaining treatment.

Such a policy would show a deep disregard for our Commonwealth's rich history of freedom, and not least of religious freedom. To compel family members to hand over the ultimate decisions about their loved ones' treatment to a bioethics committee is a heartless gesture, and it will lead to an increased crassness in medical care for people in great need."

Sandra D. Mahanes wrote: "By requiring structured processes and transparency, these actions protect the interests of patients and families while supporting the clinicians who provide care in circumstances involving treatment conflict. Qualified permission to cease that treatment after 14 days also protects both the dignity and comfort of the patient and the moral integrity of the care providers. Stipulating that all actions must conform to federal non-discrimination standards provides additional protection for patients and families, and the other recommendations add clarity to the legislation…

In addition, I support the formation of a work group to study health care decisions more broadly, focused on preventing and improving outcomes of treatment decision conflict in Virginia, as part of the JCHC 2017 work plan. Such a work group could perhaps identify effective practices with the potential to decrease the impact of treatment conflict on patients, families, and health care providers in Virginia."

V. Colleen Miller, on behalf of the disAbility Law Center of Virginia, wrote:



"Current Virginia law does not afford adequate protection for people with disabilities, especially those living in more rural communities who may not have access to alternate health providers. People whose disabilities present as complex medical needs may be faced with medical providers who make "quality of life" decisions based on the person's disability. If there is no other medical provider within that person's community, the doctor's decision is final and irrevocable...

We oppose any changes to the law that make it easier for medical professionals to exercise "ethical" judgments about the value of the life of a person with a complex disability."

Thaddeus Pope, Director of the Health Law Institute, Professor of Law, Mitchell Hamline School of Law, wrote: "The proposed revisions offer legal immunity so long as the treating clinicians wait the 14 day period and follow "key process-focused safeguards." But as now specified, the process safeguards are not sufficient. The ultimate decision maker is the hospital's own "review committee." That committee does not have the requisite neutrality and independence."

Teresa Radford wrote: "I have worked full time as a RN for 35 years in a variety of outpatient, inpatient and home health care settings. For the past 14 years I have had the privilege of working on an acute care unit in a top tier tertiary care hospital in Virginia. One of the most challenging situations I experience is assisting patients and care partners to complete health care planning, especially as it relates to decisions surrounding life sustaining treatments and end of life scenarios. I strongly support efforts to clarify and provide comprehensive guidelines on these difficult topics. I recommend consideration of language revisions to eliminate "DNR" and replace with alternative "Allow Natural Death" which I believe will help transition our health care culture to one that will benefit patients, care partners and health care professionals alike."

R. Brent Rawlings, on behalf of the Virginia Hospital and Healthcare Association, wrote:

"Legislative changes to Va. Code § 54.1-2990 are needed to address the unfortunate circumstances that arise in providing care at the end of life in a way that balances the need to ensure dignity and respect for patients and their families and protect vulnerable individuals, with respect and appreciation for the professional obligations of physicians and nurses. Hospitals are well equipped to provide this balance bringing together a variety of resources in multidisciplinary teams that are specifically trained to assist patients and their families in making decisions to continue or discontinue life sustaining treatments. These are among the most difficult and emotional events for patients, families, physicians, and nurses and a thoughtful approach is needed...

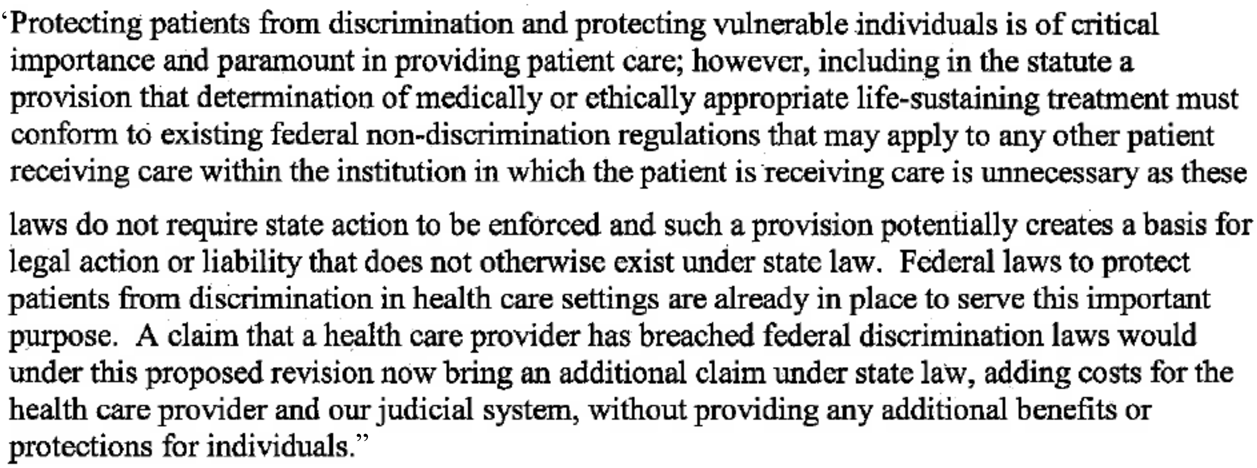
Current law at § 54.1-2990 allows a physician to transfer a patient for whom care has been requested that the physician believes is medically or ethically inappropriate. This provides the opportunity for the patient to continue to receive the requested care from another provider, but in practice, such transfers are not always possible when there is no other physician willing to carry out and accept the obligation to provide the requested treatment...

The legislative changes to § 54.1-2990 included in Recommendation 2 are needed to specify in statute appropriate actions to be taken in these situations where the minimum 14-day time period to effect a patient transfer has expired and a transfer is unable to be effected, but at the same time ensure needed balance to protect patients."

In addition to support for Recommendation #2, "the statute should be revised to clarify that the health care provider is in no way prohibited from performing any tests or procedures necessary to determine what is medically or ethically necessary or appropriate care or treatment. These steps are appropriate to ensure that there is due process in decisions regarding life sustaining treatment and ensure a proper balance between patient and family wishes and the physician's professional obligation...

VHHA supports including immunity from any action in compliance with the statute for persons acting in good faith. This immunity should be broadly crafted to protect all persons potentially involved in the process including committee members, some of whom could be volunteers. The statute should also be revised to specify that the statute does not create a private right of action (such that patients or their families could pursue legal recourse under traditional tort law, not on the basis of strict liability for failure to comply with the statute). Simply relying upon a determination of standard of care under a traditional cause of action for medical malpractice or unprofessional conduct proceedings exposes the health care provider to lawsuits for actions that are permitted by law and provides no assurance that the health care provider will not be hailed into court to defend his or her professional judgment. This again speaks to the need to balance the wishes of the patient and family with the professional obligations of physicians and nurses and undermines the intent of making needed clarifications to the statute. Furthermore, this immunity is necessary to protect other persons involved in the process, such as volunteers and other individuals involved in reviewing physician determinations who have acted in good faith."

Regarding Recommendation #5:



“Protecting patients from discrimination and protecting vulnerable individuals is of critical importance and paramount in providing patient care; however, including in the statute a provision that determination of medically or ethically appropriate life-sustaining treatment must conform to existing federal non-discrimination regulations that may apply to any other patient receiving care within the institution in which the patient is receiving care is unnecessary as these laws do not require state action to be enforced and such a provision potentially creates a basis for legal action or liability that does not otherwise exist under state law. Federal laws to protect patients from discrimination in health care settings are already in place to serve this important purpose. A claim that a health care provider has breached federal discrimination laws would under this proposed revision now bring an additional claim under state law, adding costs for the health care provider and our judicial system, without providing any additional benefits or protections for individuals.”

Kurt Schuler wrote: “I urge that Virginia follow Florida in mandating continued provision of requested treatment if transfer is unsuccessful, and to reject the paths taken by Arkansas, Tennessee, and Texas permitting physicians to refuse to provide treatment if transfer is unsuccessful….

Medical staff should not judge for patients whether the patients' lives are worth living. Except when a patient (or in certain circumstances, his next of kin) has indicated that he wishes to cease life-sustaining treatment or, if unconscious, has an advance directive to that effect, he should not be left to die by withholding life-sustaining care.”

Robert Veatch, Professor of Medical Ethics, Kennedy Institute of Ethics, Georgetown University, wrote: “Recommendation 3 of the proposed law would permit physicians in an ongoing relationship with a patient to refuse to provide desired and effective life-support against the deeply held religious, philosophical, or cultural beliefs of some of the state’s citizens. It would permit a physician to unnecessarily impose death on a patient when the treatment would reasonably be effective in achieving the goal of the patient or surrogate, when no burdens on others are produced, when the patient will not suffer beyond what a competent patient has accepted, and when the provider is a licensed professional with duties imposed by the state to use medical services in the public interest when patients desire those services. Federal case law applied in the Commonwealth of Virginia [Baby K case] has found such treatments are required.”