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My name is Dr. Diana Barnard. Thank you for the opportunity to share my expertise with you regarding Vermont's Medical Aid in Dying Law; Act 39.

My qualifications for being here include being a lifelong Vermonter; all of my post training clinical work has been in Vermont. I was Board Certified in Family Medicine in 1994 and Board Certified in Hospice and Palliative Medicine in 2012. I have practiced medicine for 28 years, 12 of those practicing exclusively with patients and families living with serious illness. I also serve as the Lead Palliative Care Physician at UVMHN-Porter Medical Center and a Hospice Physician for Addison County Home Health and Hospice.

For many years, I was actively involved in the Legislative effort to Pass Act 39. I have been a board Member of Patient Choices Vermont since its inception. I have also been an Advisory Board Member of the leading national organization for medical professionals working with aid in dying, the American Clinicians Academy for Medical Aid in Dying (ACAMAID) since its inception and I actively participate in the ACAMAID list serve and bimonthly educational meetings. I regularly offer clinical education, support and advice to physicians regarding MAID.

The Medical Aid in Dying Numbers:

Statistics show that our numbers are as predicted; they are consistent and there are zero validated reports of abuse. It is common for people to start the process but not complete it for a number of reasons; most commonly either because their quality of life remains acceptable and there is thus no need, or because they have become too ill to be able to participate.

Most people who use MAID suffer with cancer. ALS is next, followed by other neurodegenerative disorders. The Vermont Health Department files a biennial Medical Aid in Dying report to the legislature. The most recent numbers cover July 1, 2019 to June 30, 2021. During that period there were 29 events. Most (#21, 72%) were cancer patients. The next group (#2, 7%) had ALS. Other neurodegenerative diseases accounted for (#2, 7%). Others represented (#2, 7%) of the total.

These numbers mirror the previous annual report, and also correlate with the running total from May 31, 2013 through June 30, 2021. During that eight year span there were 116 events (an average of just under 15 per year). Again, most of these cases were cancer (#89, 77%), with

ALS next (#13, 11%). Other neurodegenerative diseases followed that (#6, 5%) with 'other' at (#8, 7%)

The VDH report confirms that our law is generally working as intended. As with many laws, practical experience often uncovers unintentional problems that need to be addressed.

The issues we need to address with this legislation are:

#### IMMUNITY:

S.74 would provide immunity for pharmacists and others on the team. Offering clear protection from criminal liability to all who participate and correctly follow the Act 39 procedures is vital to having a thoughtful, safeguarded process. Our law unintentionally focused only on immunity for the physicians. We need to update our law to include all other members of the health care team who engage in best practice medical care and follow the legal requirements of the law.

#### TELEMEDICINE:

Medicine is a constantly evolving science. Our law unintentionally did not consider the power of telemedicine as a clinical tool. Since its passage we have learned a lot about the essential role that technology can play in the delivery of timely and high-quality medical care.

Telemedicine has been effectively used in many areas (such as the VA ) for years. In the past two years, telemedicine has been widely and successfully deployed in our state. It has become an accepted part of routine medical care, with physician providers being responsible for using clinical judgement in determining which services can be adequately covered by telemedicine and when a follow up in person visit is needed. Every other state that allows MAID allows the use of telemedicine for the process.

Consider this example of using telemedicine as a tool:

- Prior to the visit, the physician could review of medical records including primary, specialty notes, lab and x-ray test results, clinical course of illness and prognostic data.
- Via telemedicine, the physician could then make personal introductions and get to know the patient, their values, worries, wishes, etc.
- Telemedicine could be used to assess patient supports (family, home health or hospice and other resources) and to assess the patient's understanding of the illness and their capacity to understand and process information.
- As during an in-person appointment, the physician would always be listening for sources of suffering; they would acknowledge and identify any possible therapeutic interventions as well as be listening for a request for MAID and responding to any questions about it.
- The physician would review all of the requirements (including diagnosis, prognosis, age, residency, voluntariness, capacity; as well as being well informed of treatment options and aware of benefits and burdens of different treatment choices) and always remind the patient of their ability to stop the process at any time.

- Telemedicine allows the physician to examine with their ears by listening for quality of voice and what it might indicate about patient weakness, fear, anger or worry. The physician can also listen for clarity of thoughts and content.
- Telemedicine allows the physician to examine with their eyes; assessing the patient's appearance for vitality, strength and effects of advanced illness (fatigue, weight loss, temporal wasting, loose fitting clothes). The physician can look for evidence of respiratory compromise by counting respirations and noting breathing effort, as well as by noting a weak voice, shortness of breath while talking or moving, or use of oxygen. The physician can look for non-verbal signs of pain or distress such as a furrowed brow, grimace, or motor restlessness, and assess the patient's ability to process and respond to questions (capacity, assuring comprehension).
- The physician may have the patient show them via camera any relevant issues such as scars, masses, tubes, abdominal distension. Size and strength of extremities or peripheral edema may also be assessed. The patient can also demonstrate issues of respiratory and mobility effort.
- The physician can continually look and listen for indications that an in-person visit is needed, for instance if the patient can't navigate the technology or if there are communication challenges, patient distress, or if it is difficult to assess patient cognition.
- At the close of the telemedicine visit, the physician would be available for any questions and to plan for the next the follow up visit.
- All of this could be done with the patient in their own home, saving valuable time and energy for what matters most to them in the advanced stages of illness.
- In my experience and professional opinion, telemedicine would allow for a comprehensive evaluation of the patient's condition, understanding and qualifications for moving forward with MAID. When there is any doubt about this ability, clinical judgment will drive the need to have an in-person visit.

#### ACT 39 TIMELINE

Almost all the patients I talk to have a primary goal of wanting to live as long and as well as possible. In the setting of serious illness, treatment can be all-consuming. Many patients and families are focused on therapeutic interventions to treat the underlying illness in order to prolong life.

Most patients also have wishes and goals for how their life comes to an end. Though it can be difficult to talk about openly unless prompted by trained professionals, most people living with terminal illness spend time thinking of their worries for end-of-life care.

As an illness gets more advanced, treatments have less usefulness, people begin to want to plan for the later. Unfortunately, the sad reality is that advanced illness often effects energy for such work. Time is often very short.

Most patients who express interest in MAID have had this interest a long time. However, in my experience and in the experience of the vast number of providers who participate in MAID, we see that patients often wait until very late in their illness to start the MAID process:

- Because providers deferred conversations (“its too soon for that....”)
- Because patients want to be hopeful and focus on how to treat disease.
- Because of challenges in identifying a willing prescriber.

The safeguards of the Act 39 can unintentionally become barriers for desperate patients seeking help. We need to shift the balance of safeguards and barriers. A reminder to the process: A patient must see one MD to discuss their wishes, then see that same MD more than 14 days later to repeat the discussion (more than 14 days often means longer than 15 days when accounting weekends and physician days off). They must also see a consulting MD to discuss their wishes once again. They must place their wishes in writing which requires two signatures from uninterested parties. This creates a lot of time for a patient to carefully consider. For many this time also feels burdensome, and is both physically and emotionally exhausting when energy levels are already low.

In particular, the additional 48 hour delay is an unnecessary additional wait that serves no meaningful clinical benefit. Many other states where MAID is legal have addressed this significant issue, e.g.:

- The 48-hour period makes Vermont’s timeline among the longest.
- NM: No waiting period; still with safeguards of repeated requests, second opinion.
- OR: All waiting periods can be waived if the patient prognosis is short.
- CA: The waiting period between the two prescribing MD visits is now 48 hours.

It is critical to remember that the thoughtful, comprehensive evaluation of a patient’s eligibility and suffering always takes place. Anyone living with a terminal illness likely spends hours, days, weeks, thinking about their death. This is never a decision made lightly. We are therefore requesting elimination of this final 48 hour waiting period.

#### A STORY

Lynn Achee was a woman who lived in Arlington with her husband Tony. Lynn was a competitive athlete. She was the first woman to bicycle to the top of Mt. Washington and the third woman to run to the same summit. She was exceptionally healthy and had no risk factors for the disease she would develop.

In late winter of 2019, she had symptoms of pneumonia and was treated with antibiotics but continued to have a persistent cough. In April of 2020 a CXR, CT scan showed a large mass in Lynn’s lung. A PET scan then showed her to have diffuse metastatic disease.

Lynn responded first with shock, then treatment and planning. She had previous experience with her father who had a prolonged period of decline and suffering in the final phase of his

illness. This had been quite traumatic for Lynn and she knew — confidently — that she did not want to go through that herself.

Lynn's disease was aggressive and her condition declined quickly over just two months. While she was clear in her wishes, and had excellent psychosocial support from her husband Tony and her friends, she still experienced many barriers to her clearly stated wishes. For instance, due to the current additional physician waiver form needed to protect the willing pharmacist from potential liability, she could not identify a willing Act 39 prescriber in her area.

I was contacted and agreed to see Lynn in June, 2020. This necessitated two separate 1 hour and 45 minute drives EACH way to my office. For the second visit, this vibrant competitive athlete begged her husband to get an ambulance so that she could lay down for the trip. I will never forget going out to her car; seeing the mattress Tony had stuffed into the car on top of the reclining front seat to make her as comfortable as possible for the trip.

Despite her advanced illness, Lynn clearly articulated her suffering and her wishes; wanting to live as long as she reasonably could, while having the option to hasten death if needed. She had no firm plans for a date, but clearly wanted the comfort of having the medication if needed.

I reminded them of the additional 48 hour waiting period. I saw her on a Friday and planned to send in the prescription on a Monday. In those few short days, however, Lynn's condition rapidly deteriorated. Over the weekend she felt her quality of life declining and decided to move forward with MAID. Unfortunately, the pace of her decline was such that by Monday her condition had worsened enough to preclude her ability to move forward with the process. Without the additional 48 hour waiting period, Lynn could have had the medications in hand by Friday night and used them when she had wanted.

Both Lynn and her husband Tony were distressed that her consistent, clearly stated wishes could not be honored. She lived an agonizing 11 more days in a condition she dreaded and with her husband Tony caring for her 24/7; watching his beautiful competitive athlete wife face the very terminal suffering she had wanted so desperately to avoid.

Despite his intense grief, Tony was able to articulate his frustration by writing the hospice team, myself, and his insurance company to voice his total distress at how Lynn died. I have a very high bar for the quality of my work. Dying is not easy, and I take pride in my ability to listen deeply to patient's hopes and fears and to offer them the best possible end of life care. In this case, the care I offered was inadequate to truly meet Lynn's needs. I am haunted to this day by this case and committed to addressing the issue.

I talked to Tony again this week; to see how he is moving through his grief and to update him on my efforts to address Lynn's experience. Tony encouraged me to share her story.

Clearly, some of Act 39's safeguards had unintentionally become a barrier to its intended effect to address suffering. I am here today to advocate for addressing the three issues Lynn's case illustrates so that no one else has to face such tragedy.

Thank you for your time and attention to this process. I would be happy to be available for any questions or concerns you may have.

Peace,

Diana Barnard, MD