## GRANITE STATE HOME HEALTH & HOSPICE ASSOCIATION

February 12, 2020

The Honorable Marjorie Smith Chairman, House Judiciary Committee Room 208, Legislative Office Building North State Street Concord, NH 03301

RE: HB 1659, relative to patient-directed care and patient's rights with regard to end of lie decisions

Madam Chairman and Members of the Committee:

The Granite State Home Health and Hospice Association advocates on behalf of New Hampshire's home care, hospice and palliative care providers and people they serve. We are neutral on the concept of HB 1659 as a public policy for the State of New Hampshire. However, we would like to share several observations on this bill.

Our organization believes that all individuals should have access to palliative care and hospice services to manage symptoms, pain and the stress of serious illness. Care is based on the best possible quality of life as each individual defines it. We believe in patient autonomy and we support individual decisions for care at end of life with a goal of comfort, dignity and respect for all.

Death with Dignity or Medical Aid in Dying (MAID) laws may provide an option for some people -- not all -- that could be utilized in conjunction with hospice and palliative care, rather than as an alternative to care. We believe that no one should choose MAID because of a lack of access to effective symptom management, psychosocial and spiritual interventions. Much individual growth and love can occur in the last months of life when symptoms are controlled, and support is present.

State and national statistics from Medicare show that about fifty percent of eligible patients choose hospice care. About one-third of those people are referred for care within the last three weeks of life. Patients and families need honest information about prognosis and a space to have conversations about goals of care earlier in the disease process. Without timely access to care, hospice becomes "brink of death" care rather than a service able to offer the benefits of comfort, emotional counseling and compassionate support from a team of professionals who are experts at relieving distress. We believe that State of NH should do more to educate citizens about hospice and palliative care, including following the requirements of RSA 126-Y, which calls for the creation of a Hospice & Palliative Care Center to be attached to NH DHHS. This law was enacted by SB 259 in 2014, but there was no follow-through.

Our organization convened a group of seasoned hospice and palliative care physicians and nurses to review HB 1659 in detail. Our biggest concern is that this bill promotes fear of suffering by implying throughout the bill that only those who choose MAID can "die in a humane and dignified manner." This bill creates a legal document; we believe that the language should be factual and non-judgmental. Some people may experience severe suffering and unrelenting anguish when they are dying, but with appropriate care, most people will die with their pain and suffering well-controlled.

We also have a few other observations:

- The definition of a "qualified patient" as someone who is "regularly treated in a NH health care facility" creates ambiguity for providers.
- The requirement that any person who is suffering from a psychiatric or psychological disorder, or depression causing impaired judgement, creates a barrier to people who may have gradual neurocognitive decline or even anxiety.
- On page 4, the attending physician must provide the patient with "feasible alternatives, including comfort care, hospice care, palliative care and pain control." Unfortunately, not all physicians are knowledgeable about the scope of these options. We believe that the physician should be obligated to do all in his or her power to relieve the individual's pain and suffering prior to honoring the request, which may include a palliative care or hospice consult, if available
- The medical records documentation requirements on page 5 are not clear. Are these required only of attending and consulting physicians, or from all providers treating the patient?
- Page 7, line 5, Roman II protects providers who choose to participate in MAID, as well as those who do
  not. This could cause confusion in the employer-employee relationship. There may be individual
  providers who choose to participate and are employed by an organization that adopts a policy not to
  participate. This section needs clarification.

Position statements from the American Academy of Hospice and Palliative Medicine (AAHPM) and the National Hospice & Palliative Care Organization (NHPCO) are attached for your consideration.

As hospice and palliative care experts, we believe that compassion is the most important thing we can provide people who are suffering. Compassion includes medical treatments, psychosocial support, spiritual care, and honoring an individual's wishes. If the committee has questions about hospice and palliative care, we would like to be a resource. The Granite State Home Health and Hospice Association will maintain its neutrality on HB 1659.

Respectfully,

Junice McDermott

Director of Hospice and Palliative Care