Summary Report:

*End of Life: What Should We Do for Those Who Are Dying?*

The AUNE Center for Civic Engagement (The Center) facilitated two Deliberative Dialogue Forums with a diverse citizenry to address the issue of End of Life Choices.

This report is the summary of the challenges discussed and the follow-up actions as stated by the Forum participants.

April 2017
The Center for Civic Engagement offered two Deliberative Dialogue Forums addressing the issue of End of Life Choices, asking the question, “What Should We Do for Those Who Are Dying?” The Forum participants were represented by healthcare professionals such as physicians, hospital nurses, hospice nurses and administrators, members of the community who have experienced the difficulty of addressing end-of-life decisions with family and friends, ministers, estate/financial planners and individuals who desire to engage and communicate with others about the issue of death and dying in our culture.

The Forum participants used the Issue Guide (see attachment) as a basis to begin the dialogue of thinking together and listening together for a shared understanding of this important subject and to build capacity for individual and community action.

The Issue Guide presented three different options for discussing this important issue:

1) Maintain Quality of Life: Caregiving efforts should be devoted to keeping patients comfortable and pain free.

2) Preserve Life at All Costs: Do everything we can to prevent death.

3) My Right, My Choice: The same freedoms that we value in choosing how we live ought to be allowed when we die.

The Summary Report addresses the main themes that resulted from
the deliberative dialogue, followed by potential individual and community actions. This Report is by no means inclusive of all of the thoughts, remarks and personal stories that were shared during the Forum. It is an attempt to articulate overall themes representing the dialogue and to provide potential actions as discussed in the Forum.

**IMPORTANT THEMES:**

**Continue End of Life Conversations**

At both Forums, participants emphasized the importance of continuing conversations about death and dying in our communities and remove the negative taboo about talking about death in our culture. It became clear that most families do not know how to have a conversation about death with each other. Participants felt that the value of these conversations are not only important for families and individuals but for the well being of our entire community. Death is something that happens to everyone but it is difficult to talk about comfortably with each other or within the medical profession. As well, access to education and information about end-of-life decisions is limited.

**Actions:**

Engage community members to raise awareness of death and dying choices by working with civic and faith based organizations. Encourage community members to discuss and become more aware of the importance of these conversations with the use of the media, such as television, social media and newspapers. Promote interest in holding conversations about end-of-life choices with community members instead of relying solely on physicians, lawyers and legislators to take
responsibility for these serious and personal decisions. Initiate conversations with children to prepare them as they experience real life end-of-life situations with loved ones.

**Organize friends, neighbors and community groups for discussions similar to ‘death cafes’, ‘Compassion Sabbath’ and/or request the Center for Civic Engagement to facilitate additional deliberative dialogues. Gather family members together and listen to each other as different dying options are discussed.**

*The Value and Significance of Communicating One’s Own End-Of-Life Choice*

The importance of completing an Advanced Care Directive (ACD) became very apparent to participants because of their personal and professional experiences with families who are not prepared to make decisions for loved ones who are facing death and dying. Without an ACD families find themselves in difficult emotional situations or in family disagreements as they try to make the right decisions for their relative. Communicating early with a love one, especially one’s parents as to end-of-life choices is important because their children may not understand and agree with the Advanced Care Directive. It is important to be aware that the ‘quality of life’ definition is unique to each individual and may change as we age.

**Actions**

Meet with all family members, including children when completing an Advanced Care Directive. Standardize an approach by health care institutions to discuss Advanced Care Directives. Prepare an Advanced
Care Directive. **Make it a priority to complete an Advanced Care Directive.** In the Monadnock Region, Jennifer McCalley has offered her assistance to complete an ACD and she can be reached at Jennifer.a.mccalley@hitchock.org or 1-800-730-7577.

**‘Choice’ as an Option**
A growing “death with dignity” movement is reflected in the laws of several states that allow physician-assisted death. Forum participants expressed the importance of a right to die option, having choices including the right to refuse treatment. Traditionally, patients relied on physicians to make decisions for them, the more modern approach is to have patients share in decisions, taking their values into account. Decisions about end of life choices change as we age, we cannot predict how we are going to die hence it is important to listen to each other and honor the change.

**Actions**
Expand the options available at the end of life to include physician assistance in ending our lives when death is inevitable and when suffering makes life unendurable. Move forward from a culture of passive decision making by patients to finding your voice for what you want and what is important for your life. Initiate conversations to differentiate between ‘quality of life’ versus ‘quantity of life’. **Meet with NH State Legislators to discuss the option of legally granting people the freedom to determine when and how they want to die. “Listen”.**

**‘Do No Harm’**
Preserving life at all costs is an option that was discussed. Forty states have made medical aid in dying illegal. Physicians take the Hippocratic Oath, to ‘do no harm’ however some physicians stated that doing no harm may actually cause more harm. Defining ‘quality of life’ is unique for each individual and the more informed people are about their treatment the better they are prepared to make shared decisions with their physician. It is a hard choice to stop treatment and it is important for many patients to know that health care providers will do all that they can to preserve life.

**Actions**

Communicate with a physician, other health care providers and family members about treatment and the consequences in order to make shared decisions. Provide conversations in the community to discuss openly the value of respecting the physician’s oath of ‘do no harm’, the value of human life and an individual’s personal definition for his/her quality of life. **Take a leadership role and personally organize group dialogues inviting friends, healthcare professionals and individuals of different ages to have open conversations about end-of-life choices respecting individual differences in defining the ‘quality of life’ and/or the ‘value of life’**.

**Other Themes:**

Participants discussed different legal constraints that impeded their ability to respect end-of-life decisions, such as, communication with an EMT or other emergency personnel. Also, participants discussed the reality of whether there was equal access to health care and education
regarding death and dying options.

Participants also acknowledged that cost of health care is a necessary point of discussion. Questions such as,’ How do you die with dignity when there are no $’s for your care”? Do we have a responsibility to be proactive with our own health care and lifestyle? “ People are living longer and there are more chronic conditions causing health care to be more expensive.” Medical care presents cost challenges in NH, and specifically care such as hospice care.

**Action**

Continue to discuss these issues with diverse groups of individuals and advocate and keep asking these important questions to further understand the complexities and build capacity for solutions.

**Ongoing Support Available from the Center for Civic Engagement:**
The AUNE Center for Civic Engagement welcomes the opportunity to facilitate and organize additional End of Life Deliberative Dialogue Forums. The Center is also available to facilitate and organize follow-up meetings with individuals to implement actions.

**RESOURCES:**
Books:
Can’t we talk about something more PLEASANT?, by Roz Chast, A Memoir. Published by Bloomsbury in 2014 – suggested by Shawn LaFrance
Some Folk Say, Stories of Life, Death, and Beyond, by Jane Hughes Gignoux (contact Jane)

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See attachment for Issue Guide
See attachment for Participant emails