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Survey shows need for increased palliative care options, awareness in West Virginia communities

The vast majority of West Virginians want to die at home, but most people lack the community resources to help with that process or are unaware of palliative care options close to home.

Using a grant awarded by the Claude Worthington Benedum Foundation with assistance from the West Virginia University Foundation, the West Virginia Center for End-of-Life Care conducted a statewide survey as part of the Community Palliative Care initiative to examine West Virginians' knowledge of and attitudes regarding palliative care. Palliative care is specialized medical care for people with serious illnesses that focuses on providing relief from the symptoms and improving quality of life for both the patient and the family.

The objective of the survey was to gather information on West Virginians' knowledge of advanced illness care and preferences such as how, where and by whom they would prefer to receive such care if the need should arise.

"Results of the survey show that West Virginia has a dramatic gap between the kind of care people want near the end of life and the kind of care people have access to or are aware of," said Courtney Dunithan, executive director of the West Virginia Center for End-of-Life Care. "Our next step is to gather a larger statewide group of stakeholders to create a comprehensive plan to ensure community palliative care is available to all West Virginians who have the interest and need for palliative care services."

Dunithan said the group already includes healthcare professionals from community hospitals, hospices, nursing facilities, administrators involved in patient care. The goal is to

expand that network to include additional representatives from the insurance industry, government agencies, academia and other healthcare experts. Those interested in participating should contact Dunithan at courtney.dunithan@hsc.wvu.edu for more information.

According to the survey, only 23 percent of West Virginians were knowledgeable about community palliative care and the services it has to offer, but if a person has a serious illness 89 percent would at least want to consider the option of community palliative care.

Survey results reveal a number of other interesting facts about West Virginians' attitudes toward serious illnesses and palliative care, including:

- Most (82%) of West Virginians believe it is important for palliative care services to be available in the community for patients with serious illness.
- The top things that matter most to patients when managing a serious illness is being at home and being able to talk to someone about what treatments are available and which ones they do or do not want.
- Nearly three quarters (72%) of West Virginians would rather live a shorter time to avoid pain, suffering, and being put on life support compared to being kept alive as long as possible even if they were experiencing pain and suffering. .

Ensuring residents of the Mountain State have access to community palliative care services is even more vital because the West Virginia Center for End-of-Life Care already offers a nationally recognized registry to ensure people's wishes are respected near the end of life. West Virginia's Physician Orders for Scope of Treatment (POST) program was lauded as a "pioneer" by the New York Times and has been cited in other national publications.

For more information about the Center for End-of-Life Care, call 1-877-209-8086 or visit www.wvendoflife.org.