

From a Family Member to Activist: A Different Nursing Role - End of Life Advocacy

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Sometimes an experience is so monumental that it brings clarity and purpose to life. Supporting her stepfather as he chose to research and then consciously plan his death in his waning days because of his terminal illness, brought together many professional and personal experiences for Lisa Vigil Schattinger, MSN, RN. She realized his peaceful death would be unique and beautiful because it perfectly reflected his values and goals. The option he chose, Medical Aid in Dying (MAID), permitted in his state of Oregon, is not for everyone. His is certainly not the only beautiful death she's seen, but the way that he lived out his life and then died, exactly in keeping with who he was as a person, made it a life-changing event for her.

After returning to her home in Ohio she soon learned that death and dying are viewed by most as difficult topics. And yet, time and again Vigil Schattinger found that people wanted to share their experiences with death when given the opportunity. People not only wanted to work through the hurt and confusion of deaths that did not play out the way they expected, but they wanted a way to take control when thinking about their own end-of-life journey.

Vigil Schattinger did not think of herself as a social activist. Her education and experience had primarily focused on caring for patients and supporting other nurses in their work. However, her personal experience with her family triggered the desire to make a difference for all individuals and their families facing the struggles of a terminal illness.

With this as a mission, Vigil Schattinger founded Ohio End of Life Options,

a nonprofit organization in 2016, and Ohio End of Life Options Political Fund in 2022. These groups are made up of like-minded people whose purpose is to educate Ohioans about the importance of exploring their end-of-life wishes, finding out what options they have for controlling the care they receive at the end of life and advocating for options that are not available to them in Ohio. People normally only talk about these things while in the hospital or while making decisions during a health crisis. By having these discussions outside of healthcare settings, people can take time to communicate their wishes based on personal values, goals, and preferences.

Ohio End of Life Options holds educational sessions about the decisions that can be made ahead of time through documents, such as Advance Directives, and about the value of palliative and hospice care. But as the grass-roots organization has grown under her leadership, Vigil Schattinger developed another new skill not part of her nursing education - political advocacy. This has entailed meeting with state legislators, educating them about policies that affect choices at the end of life, and identifying those who demonstrate an interest in supporting legislative changes. She also helps Ohioans connect with their state legislators to share their deeply personal stories about why the option of MAID legislation would be important.

Vigil Schattinger has seen that end-of-life options are topics that Ohioans are asking about. In agreement with the 2019 ANA Revised Position Statement, The Nurse's Role When a Patient Requests Medical Aid in Dying, she believes that

it is essential that nurses and healthcare providers be knowledgeable about how to have informed discussions with their patients. Ohio does not permit MAID but Vermont and Oregon do and they allow non-residents to travel there, qualify for, and decide to ingest the medication without returning to Ohio. But that entire process is stressful, time-consuming, and expensive for someone who is in declining health due to a terminal illness. For all Ohioans, and particularly for those who want to be able to make plans before the end of their days, it is essential that they understand what care is available to them in Ohio, how that care meets their needs, and how to work toward change in their state if that is what is important to them.

By founding Ohio End of Life Options (<https://ohiooptions.org>) and Ohio End of Life Options Political Fund (<https://ohiooptions.org/politicalfund>), Vigil Schattinger combined professional expertise and knowledge with a personal passion and commitment to work on social change. While policy changes rarely happen quickly, there is a great need for empowering Ohioans to understand and make the decisions they can about their health care. As happened with her, combining a deeply meaningful personal experience with a professional commitment to patient autonomy and well-being can lead nurses down a path that promises to improve the lives and deaths of Ohio citizens. ■

References online:
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