



The Chaplain's Role WHERE AID IN DYING IS LEGAL

By VICKI FARLEY, M.A., M.S., BCC

The practice called physician-assisted death, physician-assisted suicide or physician aid in dying is surrounded by a complex web of emotions. I am a Catholic chaplain in the Northwest, where the states of Washington, Oregon and nearby Montana permit terminally ill adults to obtain prescription drugs with which to end their lives. These laws bring a tangible tension to my ministry in a Catholic health care system's hospice setting, where I find myself in the midst of competing values.

Chaplains want to support the patient, to be with them on life's journey, and this one piece, the ending of one's own life, challenges us on so many levels. The hastening of death goes against the warp and weave of the fabric of what I hold most sacred. I also hold dear the value of free will.

When the "Death with Dignity" laws were being considered, our hospice gathered a team that crafted a policy allowing us to provide care even if our patients and families choose physician aid in dying. Our home services policy affirmed the philosophy that our end-of-life care neither prolongs the dying process nor hastens deaths and that our dying patients and their families will not be abandoned.

Our guidelines and parameters exist to protect our patients, families and our care team. If the patient and family express interest in physician aid in dying, the care team will refer them to their primary care provider. We explain that the team is unable to be in the home at the time patients ingest medication to end life, but we do not abandon them or their families. Making a home visit at the time of death

is part of the service we provide, and we also will refer family and friends to appropriate bereavement support groups.

The chaplain's role is to assist the patient, family and care team in processing the decision and the implications and consequences of choosing to end one's life. To do so involves exploring with the patient the importance of life and death. It requires both a spiritual assessment of the patient and a willingness to gently challenge the driving force behind the patient's decision.

A patient's reasoning often includes these words: pain, control, burden and fear. The spiritual assessment revolves around a sense of meaning, suffering,

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relatedness and hope. As written in the *Ethical and Religious Directives for Catholic Health Care Services*, "the care provided assists those in need to experience their own dig-

nity and value, especially when these are obscured by the burdens of illness or the anxiety of imminent death."

The care team's focus is to make every effort to identify the reasons for a patient's inquiry regarding physician aid in dying. Our interdisciplinary group continues throughout the patient's admission to assess physical symptoms and psychosocial-spiritual concerns the patient has regarding his or her diagnosis. The team needs to plan debriefing times for themselves during the journey with a patient — they shouldn't wait until after the patient's death. It helps to be able to process thoughts and feelings along the way, for it can be intense and emotionally exhausting for the team as they reach out to the patient and family.

We work hard to address the level of physical, emotional and spiritual suffering — their pain. We probe along the lines of: "What would it look like for you to be out of pain?" "What's behind your suffering?" "You seem to be in emotional distress, tell me about it."

Control is a piece of this puzzle. There is so little over which we have control. Control is often a figment of

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our imagination. We think we have control. As we walk with our patients, we begin to explore what control means to them. Is it wanting to be on a specific time schedule? ("I want to be done with life now, because..."). Is it wanting to control the pain, the amount of suffering or who does what to them at any given time?

"Being a burden" flows into the conversation. "I don't want to be a burden on my family." "I don't want to be a burden on society." We make every attempt to involve the family and friends in this conversation. From each person's perspective, what does it look like to be a burden, to bear a burden? Is there another way to look at this, such as giving and receiving a gift? Or sharing life and love for as long as we can? Is lack of self-esteem playing into this? ("I'm not worthy, so I need to get out of the way.")

Fear in this situation is a double-edged sword. Many fear the process of dying and fear not knowing what happens after we die. We ask, what is your greatest fear right now? As you look into the future, what is it that you fear? If you could, how would you alleviate your fear?

WALKING WITH M.C.

In my years as hospice chaplain, I have walked with several patients who have chosen to end their life using physician aid in dying. My role as chaplain is to explore where and how those words — pain, control, burden and fear — intersect the patient's spiritual life. The challenges for me have included sorting out my own feelings regarding the ending of one's life, supporting team members who may not have encountered this situation, being true to myself and being true to my patients and families — respecting their decision. In other words, "I do not have to approve of your decision. I do have to love you."

What is it like, how does it feel, to be a chaplain in such a situation? I will try to paint a word pic-

ture, for it is easier to describe than to explain. I was privileged to walk with M.C. a short distance on his journey. We met twice. Here's my reflection:

FIRST VISIT

M.C. is in a hospital bed in the middle of the living room. His uncle is at the foot of the bed, on the floor in front of the fireplace. Mother is sitting in a chair at the bottom corner of the bed. His sister is on the floor at her mother's feet. I am sitting in a chair next to the head of the bed. The initial greeting from M.C.: "Chaplain, you're here to help my family."

M.C. declares himself an agnostic. He wants his family to have the opportunity to speak their thoughts. The intense atmosphere and family tension are palpable.

I feel that deep within M.C. is a sense of the truthfulness of God. I know this as he tells his mother: "That's where God is, in the inexpressible." He needs ultimate control. Adult life for him has always been lived outside the family norms. He no longer has anything to keep him here. His mother is distressed over his decision. No amount of pleading, sharing and exhorting from his mother changes his mind.

My thoughts as we begin this journey: anxious, tight heart, preciousness of life, walking on holy ground, holding open sacred space. Open hands, bowl of precious energy, leaning forward braced on my knees: giving birth to something with which I personally do not agree. I want to embrace each of them as they, too, struggle.

This is what I see and feel: sacredness of life, sacredness of process, holiness of each person present sharing heart-wrenching love; each heart being torn and offered. What was God doing before I entered this space? Priming hearts to open and spill forth. Where was God in the midst of this encounter? Embracing the whole in tremendous love, warmth of soul, drawing closer, reaching out, opening minds and hearts.

This is what I try to do: hold open the space to allow each person to share his or her thoughts, dreams, hopes, desires, disappointments and losses. The room is overflowing with emotion, cascading over the edges of their sacred bowl. Each family member pours forth love for him. I hold the space open, allowing each person an opportunity to speak. As a care team, we continue to communicate with one another as we provide hospice care. We share what we learn from him in



each visit. I bring each person's interaction with him together to help us draw the larger picture. This soul-searching work is hard on the entire team as we walk with him on his journey.

SECOND VISIT

My second visit is about 10 days later. His sister and I are alone with M.C. His sister is at the head of the bed, out of M.C.'s sight. I am standing next to M.C., touching his arm and hand. His sister moves in and out of the room as she leaves to dry her eyes. M.C. calls to see her.

I want to talk him into living until he dies. Cutting life short means opportunities missed; it means cutting short pain, but also cutting short support, caring and learning.

This is what I see and feel: Ropes twist around each of us, tangling our thoughts. Tautness, fear and immense love surround us as his sister struggles, wanting to "do and say the right thing." I tell her now is the time to say what's in your heart. Openness and a river of love flows between the two as they struggle to make this OK for both of them.

I want to talk him into living until he dies. I want to remind him that people have been dying for thousands of years. Cutting life short means opportunities missed; it means cutting short pain, but also cutting short support, caring and learning. Life. However, I continue to simply hold open the sacred space. M.C. struggles for control. Family is losing.

This is what I do: I support his sister as she stands in the strong current of emotion. I stand behind her, letting her lean into me as she pours out her heart to her brother. I also speak, telling him how much I will miss the wisdom he holds deep within himself.

M.C.'s response is to continue to tell his sister he loves her. He will never forget her. She's been a great sister to him. He's the one choosing to move on, to go ahead.

M.C.'S DEATH

M.C. died two weeks later, after ingesting medications to end his life. Things did not go as planned. He lingered for 36 hours. The family chose not to

have a team member come at the time of death.

I leave a condolence message for the family. There is no further communication from them, and the exhausted care team feels unsettled at the lack of follow-up.

This is what I see and feel: The team reaches out to a black nothingness, a place of deep sadness. Our hearts are patched, torn and patched again. We wanted so much to wrap M.C. in a love that would change his mind. We are heartbroken. The teamwork was incredible. The social worker and I alternated our visits. When a team member felt the need for a joint visit, we would team up. Any time one of us needed to debrief, we'd reach out to the team. Our supervisor kept herself in the loop and provided a holding place for our thoughts and emotions.

This is what I do: I continue to hold open the sacred space that allows each of the team to share and grieve. I share my grief, as well, as we support one another.

SUMMING UP

To honor another's choice, even when it goes against my beliefs and values, is to let go of my issues in response to God's gift of free will. It is a heartrending experience. It is important to remain grounded in the holy and wholeness.

Walking with patients who choose to utilize physician aid in dying provides new understanding of our human heart and mind. My challenge is always to find a way to support patient, family, care team and myself throughout the journey.

Insights I have gained:

- My ministry celebrates the immense depth of the human spirit
- Questioning my beliefs helps define me
- Offering unconditional presence stretches my heart
- Reaching out to others whose decisions differ from mine opens me up to growth
- I believe, along with M.C., "That's where God is, in the inexpressible."

VICKI FARLEY is a board-certified hospice chaplain working in a CHA-affiliated organization in the Northwest.

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