In Sure and Certain Hope

Resources to Assist Pastoral and Theological Approaches to Physician Assisted Dying

THE GENERAL SYNOD *of*
THE ANGLICAN CHURCH OF CANADA

Faith, Worship and Ministry
Task Force on Physician Assisted Dying

FOUR

Pastoral Care*

Pastoral care, in its many forms, involves no more precious mandate than the support and compassion required in the journey with a parishioner at the end-of-life. Care givers hear questions like:

> *"I have looked for God everywhere and can't find him, where is he?"*
> *"why wouldn't God call me home?"*
> *"why am I left to linger so?"*
> *"why must I suffer so ... this is so unbearable"*

These and similar words are often voiced by those who are facing the end of their lives. It matters little whether the source of their pain is physical, psychological, emotional or spiritual suffering. What matters is that for many, the premium challenge of end-of-life is to continue to experience meaning, purpose and control over one's life.

The legality of assisted dying will dramatically reshape the scope and tenure of pastoral care provided to those who face end-of-life concerns. Before the Supreme Court of Canada's 2015 decision, end-of-life concerns were limited largely to questions of treatment, pain control and comfort. Now the 2015 Supreme Court decision places end-of-life care within a new legal and ethical framework that allows for the choice of assisted dying.

Faith communities, through their ministries of spiritual and religious care, will now be

* For purposes of clarity in this section dealing with pastoral care, those living with a mortal illness facing end-of-life challenges are referred to as parishioner. Pastoral care-provider refers to the priest, chaplain, deacon or lay visitor who provides spiritual and religious care to the parishioner and her/his circle of family, friends and care providers.

challenged to clarify their role in the provision of guidance and assistance at this final stage of an individual's life journey.

This presents our church, and those who care for the ill, with two fundamental challenges.

First: pastoral care-providers must discern honestly through prayer and consultation their personal views and values and how they affect their capacity to support patients in decision-making in relation to end-of-life and assisted dying. Can the pastoral caregiver, whatever their personal views, support an authentic request for assisted dying? If not, then the pastoral caregiver must seek out and make available to the parishioner appropriate alternate pastoral resources. The duty of care requires that the church be present in that care. If I determine that I am not the one to be able to provide the best pastoral care in that context, it cannot ensue that the patient is abandoned by the church.

Second: pastoral caregivers must assess the strengths and limitations of available resources that can, or cannot, support the parishioner who seeks assistance with dying. To promise support for a parishioner who seeks assisted death and then to discover there are either limited or non-existent medical resources to make such a request possible, is to create the opportunity for additional emotional distress for the parishioner. Likewise to deny existing resources to a parishioner seeking assisted dying because of the personal beliefs of the pastoral care-provider, (I do not believe in assisted dying and so I will not refer to those who do), is equally harmful to the parishioner.

Our faith tradition holds that all life is sacred. This belief is the foundation of all healing ministries. Support for assisted dying seems antithetical to this belief. And yet, for those who seek assisted dying, exploring fully the questions and implications regarding assisted dying often requires a fundamental and deep examination of the meaning and purpose of life for both the one who is seeking assisted dying and the pastoral care provider. Seeking assisted dying is a reflection of the struggle for a quality of life upheld by a deep and abiding belief in the sacredness of life. It is certainly possibly that life has become too painful, bleak or lonely. Abandonment by community, including church can only contribute to that loneliness. Or maybe life is too limited by illness. Or maybe life is understood as sacred, fully lived, complete and ready to end.

> To "listen" another's soul into a condition of disclosure and discovery may be almost the greatest service that any human being ever performs for another.
>
> –Douglas Steere, Gleanings: A Random Harvest
> author, theologian, philosopher

Narrative methodologies, exploring a person's life story, may provide a framework helpful to both the pastoral care provider and the parishioner as they explore together the deeper meanings of assisted dying. For within one's narrative or life story lies the meaning which may inform the life and death decisions of assisted dying.

Ultimately, it is not the pastoral care givers belief, nor the traditions or dogma of any faith tradition, nor the hopes and desires of family and friends which will determine the choice of assisted-dying. The final choice remains with the parishioner, informed by their own consciencious appropriation of their faith tradition. Family and friends provide the primary community within which the conversations that shape decisions happen. The pastoral care giver's role becomes that of spiritual guide or facilitator. It is the pastoral care-giver who reminds and draws everyone's attention back to the reality that God is present and amongst them sustaining this difficult journey of discernment and choice within God's embrace of love and grace.

The pastoral care giver will be challenged to address the spiritual and religious needs not only of the parishioner who seeks assisted dying, but

of the parishioner's circle of family and friends who will struggle with their loved one as she/he discerns a desire for assisted dying and the care providers themselves, the professional health care providers who will facilitate decisions made. Here the role of the pastoral caregiver is to be present with and give expression to the needs and concerns of all who are involved in the process of assisting another to die.

Resources available to the pastoral care provider or pastor can be found within the rich Christian traditions of sacrament, ritual and the ministry of presence.

> O God of peace,
> who taught us that in returning and rest we shall be saved,
> in quietness and confidence shall be our strength;
> by the might of your Spirit lift us, we pray, to your presence,
> where we may be still and know that you are God;
> through Jesus Christ our Lord. Amen.
> –*Book of Alternative Services, Collect, Ministry to the Sick*

Pastoral Care and Sacramental Liturgy

Our Anglican faith and witness rests within our sacramental traditions that mark the passages of life from birth to death. Our sacramental liturgies for those who are ill or approaching death provide for the lifting up of petitions and questions of faith, the searching for God in our present moments and the reassurance that God is ever present amongst us. As such, our sacramental liturgies can assist those who are dying to find the answers they seek and to experience, even in such difficult times as end of life, God's abiding love.

Pastoral Care and the use of Ritual

Christian ministry, by its very nature, involves ministries of healing which strive for the well-being of the mind, body and spirit. In May 1968, the *Bishop of Toronto's Commission on the Church's Ministry of Healing* noted;

> Health and healing are difficult to define, but health may be described as a condition of satisfactory functioning of the whole organism. The words; health, wholeness and holiness are closely linked in origin. Healing may, therefore, be described as the process by which a living organism, whose functions are disordered, is restored to health or "made whole"; that is to say, returns to complete functioning. In a sense, all healing maybe considered to be Divine. Many aspects of healing are still outside our present knowledge, and this we should honestly and humbly admit.

Rituals have always been an important part of our lives. Rituals give form and symbolic meaning to feelings and events. Rituals provide a container or catalyst that allows for the exploration and expression of whom one understands oneself to be. Rituals assist in the articulation of meaning. Rituals can capture and give expression to the emotions and experiences of separation, transition, healing and celebration, to name but a few of those elements which constitute and give structure to our lives. Rituals can capture the experiences of life and frame them into moments of meaning within which decisions can be made.

It is a commonly held truth of the Christian experience that the healing of a person can be achieved without the blessing of a cure. The Christian ministries of laying on of hands and holy anointing bear testimony to the lived experience that wholeness of person, despite the reality of terminal disease, is possible. These two rituals, which rest upon the healing presence

of God made manifest through the Holy Spirit can become a powerful resource available to the pastoral care giver.

The laying on of hands, holy anointing, guided meditation and structured prayer are but a few of the rituals available to the pastoral care giver which may provide a valuable container or frame within which the parishioner and her/his family, friends and care providers can find resolutions to the difficult questions surrounding assisted dying.

Rituals, designed by the pastoral care giver, using symbols unique to the circumstances of the parishioner can also significantly frame the experience of the parishioner and facilitate resolution of end-of–life questions.

> A young man, dying of AIDS, was surrounded by his family who were conflicted and distraught over his illness, which had revealed his homosexuality, bringing moral judgement upon him which was difficult for the young man to bear. The family's distress over their dying brother and son seemed to crowd out his ability and need to be heard. The chaplain suggested a ritual that might facilitate much needed conversation amongst family members. Using the tradition of the talking stick, the chaplain designed a ritual involving prayer and a candle. The chaplain met with the family in the young man's room, and, after a short prayer and a moment of silence, the chaplain lit the candle. All had agreed that whilst the candle was lit, only the young man could speak. Which he did, addressing each family member separately, mother, father, siblings, sharing his feelings of loss, love and hopes for forgiveness. Once the young man was finished, the chaplain read another prayer appropriate to the setting and extinguished the candle. The family, centered by the candle and prayer and ritual of structured conversation, broke through all of their fears and judgementalism and embraced anew their son and brother. Significant healing took place, health care decisions were made in a collaborative way and planning for the future was made together. Because of this simple ritual, the young man was able to share his feelings, express his love and say his farewells.
>
> –Reverend Canon Douglas Graydon

Pastoral Care and the ministry of presence

Our Christian tradition is in many ways built upon the practice of being present to God. The ministry of presence builds upon this tradition whereby the pastoral care-giver gives oneself over to the other, in this case, the parishioner and their community. It involves active listening skills combined with unconditional regard for the parishioner, family, friends and other care providers. The ministry of presence waits upon the *disclosure of one's soul* (as articulated by Douglas Steere).

It is within such a ministry of presence that the narrative of the person seeking resolution of questions regarding assisted dying arises. With God's good grace, resolution is found within the life story of the parishioner.

Being present to another requires the sacred ability to listen, to speak and to touch. It is within the sacred conversation of being present that one can sometimes discern most clearly the needs, questions and desires of the other. Within the ministry of presence, sacred conversations remind us of our mortality and vulnerability, our sense of self-worth and the beliefs that give shape to the meaning of our lives. To enter into that conversation, to be truly present, the pastoral care-giver must be deeply aware of her/his own values, faith and spirituality. The pastoral care-giver must be willing to share non-judgementally their own stories, experiences and life lessons and must strive to build bridges between the stories told by the

parishioner and the stories / teachings of Christ.

The ministry of presence builds bridges and linkages between the parishioner and their community of care. A ministry of presence empowers truth telling and the making of meaning. A ministry of presence connects life with faith and in as such can facilitate resolution of the challenges of end-of-life care and questions regarding assisted dying.

Self-care

This ministry can be a taxing and stressful one. End of life care requires that the pastoral care giver set aside one's concerns and worries, so as best as possible to enter into the deep listening which will be required within a ministry of presence.The practice of self-care by the care-giver is essential. Self-care resources are readily available and pastoral care givers are encouraged to seek out prayerful support groups and/or spiritual guides to assist them in their ministry. Collegial support—even simply connecting with others who undertake the same or similar ministry—is also critically important.

Reflections

The reflections included here arise from the chaplaincy community of the Diocese of Toronto. The Task Force would recommend that each Diocese access the wisdom and experience of end-of-life stories within their own communities of faith.

I HAD A PATIENT in her mid 40's who had a rare disease that affected all of her digestive organs. Her lungs were filled with liquid and she could not eat without vomiting. She was profoundly unhappy with her quality of life. Doctors generally answered all her questions with "we don't know" and then sent her for more tests and to see more specialists who also did not seem to know. She once asked one doctor if she was dying—the answer she received was "not today." Another doctor told her they did not want to do some possible procedures because of the harm they would cause. The patient was worried that she wasn't able to give all her fears to God— that she kept taking them back again, not wanting to be honest with God. She worried that she wasn't battling hard enough for health, and that made her not a good mother or wife or friend, because she felt that she was only thinking about herself. At least that's how she was owning up to it. When I asked the question, "Can you tell me about your fears?" she said, "I am not ready to die. My children are being forced to grow up. It's my fault. And I won't see it either." In fact, she wasn't thinking about just herself at all, but her thinking was confused and tied up with worry.

Human life is profoundly relational. There are no isolated, self-made individuals. We are made for relationship and find fulfillment in healthy and life-supporting relationships and communities.

My patient was struggling with her place and her life and death in relationship. In the next breath after expressing her worry for her children, she told me, "but for me I want this to end well, if I could choose just for me." I asked her if she was thinking about how that end might look as a choice. She was, in fact, viewing it in terms of choice, and she felt guilty for that. As it was then, it is my work as a pastoral caregiver to have the patient honour her own desires, to help her hear her own judgments. I invited her to talk about her sense of God and God's presence with her in these judgments, and of her values, however she might choose to act upon them. I asked her to ponder the thought that relationships can also be part of dying. It was important

that she allow herself the possibility of choices that give her peace, and in those she could also serve her relationships after her death. My role was to work with her to untie the knots in her thinking, knowing that the moment of death is a time of ending and beginning for those left living. At heart, it was for me to accompany her in making the choice that she saw as possible and best for herself and for those whom she loved. These relationships and sense of self were in the knots she needed untied. And they were all untied by her within her own narrative, never with me telling her what must be done or what was "right."

– The Reverend Joanne Davies, Anglican priest and Ecumenical Chaplain,
Mount Sinai Hospital, Toronto

FOR OVER 20 YEARS I was a chaplain who specialized in end-of-life care. Fifteen of those years were spent within the HIV/AIDS community, mostly at Casey House Hospice in Toronto. During the early days of the AIDS pandemic, young gay men were facing catastrophic illnesses. Many railed against the injustice of facing an early death while also battling the fear, social stigma and judgementalism that HIV/AIDS engendered around the world. Many wanted to die while still in control of their life. Everyone had a very clear understanding of the pain and suffering which awaited them as AIDS destroyed their immune systems and then destroyed their bodies.

Seeking assistance with dying was at times a daily conversation. Most of the men I met had been part of the gay pride movement advocating for the right to live openly and authentically as gay men who wished nothing more than what society offered - that being the right to love and be loved without fear of being judged.

Assisted suicide, (as it was referred to then) was illegal. All that I could promise was a willingness to stay with these men and to seek with them the presence of God who was there amongst and with us.

What arose from that catastrophic world of illness was the creativity of many who embraced their dying as best as they were able. Extraordinary healing took place within that painful place. Young men healed family wounds, expressed deep and abiding love for one another and celebrated their lives with extraordinarily creative funerals.

Within that experience I learned that, for some, assisted dying, if it had been possible, would have been a choice that would uphold the dignity, autonomy and humanity of their lives. Assisted dying would have been the natural extension of ensuring control within their life and therefore would have maintained a sense of quality of life and a recognition of the sacredness of life. I learned that my role as chaplain was primarily to assist them in searching out an answer to the reason for unrelenting suffering and loss of quality of life. For others, assisted dying, if it had been available, would have been an authentic reflection of our God given freedom of will and self-determination which is, I have learned, a fundamental dimension of who we are as created by God.

Our society is now at that place where assisted dying is a reality. For me, as a person of faith, the challenges and questions involved in this reality are deep and nuanced. My ministry as a chaplain has taught me that even within this new reality I know God is with us and amongst us. This for me, is good news indeed.

–The Reverend Canon Douglas Graydon,
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REFERENCES*

American Nurses Association (2013). Euthanasia, Assisted Suicide, and Aid in Dying. Revised Position Statement. April 24, 2013.

Branigan, M. (2015) Desire for hastened death: Exploring the emotions and ethics. *Current Opin Support Palliat Care*, 9 (1): 64-71.

Canadian Nurses Association, Canadian Hospice Palliative Care Association and the Canadian Hospice Palliative Care Nurses Group (2015). Joint Position Statement: The Palliative approach to are and the role of the nurse. Ottawa: Authors.

Catholic Health Alliance of Canada (2012) *Health Ethics Guide*. 3rd ed. Ottawa: Author.

Downie, J. (2012). Downie, J. (2004). *Dying Justice: A case for decriminalizing euthanasia and assisted suicide in Canada.* Toronto: University of Toronto Press.,

Howard, J., Davis F., Pope, C., & Ruzek, S. "Humanizing health care: The implications of technology, centralization, and self-care". *Medical Care* 15 (May 1977):12.

Hudson, PL, Schofiled, P, Kelly, B., Hudson, R., Street, A., et al. (2006). Responding to the desire to die statements from patients with advanced disease: recommendations for health professionals. *Palliative Medicine*, 20: 703-710.

Ohnsorge, K, Gudat, H, and Rehmann-Sutter, C. (2014). Intentions in wishes to die: analysis and a typology—A report of 30 qualitative studies of terminally ill cancer patients in palliative care. *Psycho-Oncology*, 23: 1021-1026.

Stajduhar, K.I. (2011). Chronic illness, palliative care, and the problematic of dying. *Canadian Journal of Nursing Research* 43(3): 7-15.

* Used for definitions of terms