



PALLIATIVE CARE TOOLKIT

A PRACTICAL GUIDE TO SUPPORT LIFE
DURING SERIOUS ILLNESS OR AT LIFE'S END

*Uniting Evangelicals to bless Canada
in the name of Jesus*

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VULNERABLE**

The Evangelical Fellowship of Canada (Alliance évangélique du Canada) is the national association "uniting Evangelicals to bless Canada in the name of Jesus." Since 1964 the EFC has provided a national forum for Evangelicals, fostered ministry partnerships, conducted research on religious and social trends and provided a constructive voice for biblical principles in life and society.

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Introduction

Most of us have thought about the end of life, when it may come and what it may be like. But polls show that few of us are talking about it or planning for life's end, either with family or friends. Fear of death and not wanting to upset families make many Canadians reluctant to discuss end-of-life care.¹

Euthanasia and assisted suicide became legal in Canada in 2016. Death became a topic of conversation, politically and socially. This conversation centred primarily on whether or not individuals should be able to choose the timing and manner of their death. It is a conversation fuelled in part by fears of suffering, death and dying.

But palliative care opens up another side to this conversation by envisioning holistic care for the whole person and their loved ones, alleviating pain and symptoms, and improving quality of life. Palliative care is an approach that truly allows people to die with dignity. Palliative care empowers people, especially those with a life-limiting terminal illness or disability, to live life as fully as possible. They are supported and cared for until the natural end of their lives.

Palliative care particularly resonates with Christians as it embodies the principles taught by our faith: to care for the vulnerable and uphold the sanctity of human life.

Many Christians provide end-of-life care in seniors' residences, long-term care facilities as well as in hospices. Pastoral care is also available within congregations to people in crisis or advanced age, including at the end of life. These opportunities to support one another can be difficult but can also bring rich and potentially beautiful moments.

This toolkit helps equip Canadian Christians to understand what palliative care is, why it matters and to advocate for, support and engage in local palliative care.



Palliative care is an approach that truly allows people to die with dignity.

¹ Harris Decima poll for *The Way Forward*, 2013.



1



UNDERSTANDING PALLIATIVE CARE

The story of palliative care

Dame Cicely Saunders: Founder of the modern hospice movement

It was her belief in the need for excellent end-of-life care that led Dame Cicely Saunders, the founder of what we now call palliative medicine, to become a doctor in the first place. Saunders saw the needs of patients with terminal illnesses and refused to accept the status quo, which was often to tell the patient and their loved ones that there was “nothing more we can do.” Instead, Saunders believed “there is so much more that can be done.”

Saunders trained as a nurse during the Second World War. She went on to care for patients with terminal illness and saw firsthand the need for better pain control. In the late 1950s, Saunders began planning a specialized hospice where the symptoms and pain of patients would be properly managed. When she was told these ideas wouldn't be accepted in medicine unless she became a medical doctor, Saunders headed to medical school and qualified as a doctor in 1957.

Saunders' commitment to the dying and her vision to establish a hospice were grounded in her strong Christian faith. She founded her approach to the dying on the words Jesus spoke to his disciples in the Garden of Gethsemane, “Watch with me.”

“Suffering is only intolerable when nobody cares,” wrote Saunders. “One continually sees that faith in God and his care is made infinitely easier by faith in someone who has shown kindness and sympathy.”²

In 1967 Saunders founded St. Christopher's Hospice in London, England. This hospice pioneered new approaches to controlling pain and symptoms, as well as holistic support for the dying person and their family. Cicely Saunders was awarded the Order of the British Empire in 1979 and given the title of Dame.

“You matter because you are you, and you matter to the end of your life,” Dame Saunders would tell her patients. “We will do all we can not only to help you die peacefully, but also to live until you die.”³



“You matter because you are you, and you matter to the end of your life.”

– DAME CICELY SAUNDERS

1 Saunders, “Watch with Me,” in *Watch with Me: Inspiration for a Life in Hospice Care*, 2nd ed. (Lancaster: Observatory Publications, 2005).
2 Saunders, “Care of the Dying: Mental Distress in the Dying,” *Nursing Times* 72(30) (1976): 1172-74.
3 Saunders, “Care of the Dying - 1. The Problem of Euthanasia,” *Nursing Times* 72(26) (1976): 1003-5.

Dr. Balfour Mount: A Canadian connection to palliative care



“It is possible for the period of terminal illness to be one of achievement, reconciliation and fulfilment for the patient and family.”

— DR. BALFOUR MOUNT

It was an evening of discussion at his church over the book *On Death and Dying* by Elisabeth Kübler-Ross that opened Balfour Mount’s eyes to the experience of terminally ill patients. Mount, a Montreal cancer surgeon, began to realize the care offered to terminally ill patients was woefully inadequate, even at the excellent hospital where he served.

In 1973, Mount made a week-long visit to St. Christopher’s Hospice in London, founded by Dame Cicely Saunders. After seeing the excellent care offered there, he returned to Canada and set up a palliative care unit in Montreal’s Royal Victoria Hospital.

Mount was the first to use the term *palliative care* to describe this kind of care. The word palliative comes from the Latin root *pallium*, which means “to cloak or to hide.” To “palliate” means to mitigate or moderate the intensity, to improve the quality. As Palliative Care McGill notes on their website, “Dr. Mount coined the term ‘palliative care’ to highlight the notion of cloaking or protecting those living with terminal illness, with a focus on quality of life up until the moment of death.”⁴

Mount asserted that a positive, creative attitude toward death and bereavement could make a difference. As he put it, “It is possible for the period of terminal illness to be one of achievement, reconciliation and fulfilment for the patient and family.”⁵

What is palliative care?

The goal of palliative care is to relieve suffering and improve the quality of life. Palliative care offers whole care for the whole person, and can be offered anywhere – at home, hospital or hospice. It is suitable for people of any age and at any stage of a serious illness.

Palliative care provides multi-disciplinary care for a person who has been diagnosed with a progressive, life-limiting disease or who is near death. At its best it also includes care and support for the patient’s caregivers. It provides physical care that relieves pain

⁴ www.mcgill.ca/palliativecare/about-us/history

⁵ Balfour Mount, “The problem of caring for the dying in a general hospital; the palliative care unit as a possible solution,” *CMA Journal*, July 17, 1976.


and symptoms, as well as social, psychological and spiritual care to address issues the patient, family, friends and caregivers are experiencing.

Palliative care does not seek to hasten death, but to promote quality of life. It offers care and alleviation of symptoms, beginning at the time of diagnosis and throughout the rest of the patient's life.

Palliative care is one of the few fields in medicine in which the spiritual aspect of care is recognized and addressed, even celebrated.

According to the World Health Organization's definition, palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- Will enhance quality of life, and may also positively influence the course of illness; and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁶



Palliative care provides multi-disciplinary care for a person who has been diagnosed with a progressive, life-limiting disease or who is near death.

Palliative care answers the question, how do you wish to *live*?

⁶ www.who.int/cancer/palliative/definition/en/

INFOGRAPHIC

Palliative care considers the whole person and responds to four groups of needs

Physical

pain and symptoms

Spiritual

the meaning of life and death,
our relationship to God, peace

Psychological

worries, fear, anger,
sadness

Social

needs of the family, food, work,
housing, relationships



INTERVIEW

Physician opens up about assisted suicide and what palliative care has to offer

Dr. Michael Koke of Kitchener, Ont, is a palliative care physician and general care physician in oncology interviewed in *Canada Watch*, a newsletter of The Evangelical Fellowship of Canada.

Canada Watch: *What would you like Canadians to understand about palliative care?*

Michael Koke: Most people don't understand that with adequate palliative care the majority of people don't want or need physician-assisted suicide. When I hear surveys that say Canadians are okay with assisted suicide, I think part of what Canadians are saying is they don't want to die with pain and suffering. If they understood palliative care could help, they wouldn't be as condoning of assisted suicide.

We also need to talk together about things like advanced directives, end-of-life care – all the topics people don't like to discuss in a culture which glorifies being young as opposed to accepting frailty, aging and dying. But if we have these conversations and work through a clear statement of our wishes for the end of life, there can be a real benefit. It can help to facilitate a natural death that is not hastened by assisted suicide or prolonged with unnecessary treatments.

CW: *How do you think the availability of assisted suicide in Canada might impact your work in palliative care?*

MK: It is gut-wrenching to have a patient you've cared for choose to end their life. And while the law requires that a person who asks for physician-assisted suicide also be informed about alternative ways to relieve their suffering, including palliative care, I'm concerned that palliative care is not well understood and that it's not available consistently nationwide.

CW: *What can we do to encourage palliative care and discourage assisted suicide for families and friends?*

MK: Our starting place needs to be compassion and sensitivity for those who are suffering. But I think it is misdirected compassion



"If Canadians understood palliative care could help, they wouldn't be as condoning of assisted suicide."

– DR. MICHAEL KOKE



to end people's lives rather than providing care and alleviating their suffering.

It surprises me that there's a sizeable number of Christians who think assisted suicide is okay. When we start to dialogue we find that people either haven't really thought about it deeply or are complacently accepting it "because it's the law." When they really wrestle with the implications, people may reconsider. It's about education.

Seeing what the Bible says about this is obviously the most important thing. Churches could focus on death and dying issues in adult Sunday school and in men's and women's groups, in sermons and of course at home. We should be getting people talking about the issues even though it is uncomfortable at first.

Additionally, when a loved one is dying, it's good for the family to know what to expect. Often we are treating the suffering of the family as well as the suffering of the patient. Sometimes it takes

days for a loved one to die, but usually the person is not suffering. If they are getting good palliative care, they are sedated and they are usually quiet and peaceful.

CW: *What is your greatest satisfaction as a palliative care physician?*

MK: Seeing a good death of course and connecting with patients and their families around that. There is a very different feel about a Christian death. Standing on the cusp of eternity with them, it's very beautiful. They are just about to see God.

1

Discussion questions

1. Dame Saunders, founder of the modern hospice movement, believed suffering was particularly hard to bear when no one cares. Does this resonate with you? Why do you think this is true? How does it help us to know that we are loved and we aren't alone when we are suffering?
2. Read Matthew 26:36-46. In this passage Jesus was sorrowful and troubled, praying, "My Father, if it is possible, may this cup be taken from me. Yet not as I will, but as you will." How can we find comfort and strength from Jesus' suffering? What difference do you think it makes to have someone "watch with me"?
3. How does the idea of protecting those living with terminal illness fit within our faith? Or the idea of *living* until one dies? What biblical passages or teaching might relate to these ideas?
4. What makes life worth living for you? Why do you think the people around you might choose to end their lives? What influences those feelings of life being worth living or not?
5. Why is autonomy, or the ability to rule ourselves, so important for Canadians? How does this accord with our faith?

2



How does our faith motivate us to support palliative care?

Our faith calls us to care for those who are vulnerable. Jesus is our model. Not only does Jesus illustrate what it means to love our neighbour with the parable of the Good Samaritan, a story of tangible, compassionate help for a stranger who is hurt and in need – Jesus himself is often portrayed in the Gospels as being moved with compassion when He comes across people who are suffering either physical illness or spiritual oppression. We need only think of Jesus’ response to hearing the news of the death of Lazarus – weeping – to be convinced that suffering and death touched Jesus’ heart deeply.

The Christian response to suffering is care and compassion, upholding the sanctity of every human life and journeying with those who are walking in the shadow of death.

At some point all of us will likely face the suffering of a close relative or loved one nearing the end of their life. It is here that Christian involvement in palliative care can be one of the most important – and perhaps most meaningful – opportunities to “bear the burdens” of others who are unable to bear them on their own. Being involved in palliative care is one way for Christians to testify to the sanctity of life in a culture that so often devalues it.

We can think theologically about issues like palliative care. Life is a gift from God for us to respect and protect through all its stages. Each person’s life is holy, or set apart by God, as a special part of His creation and is enlivened by the breath of His Holy Spirit. All humans have worth and dignity, regardless of age or ability, because they are created by God, loved by God and made in His image (Genesis 1:27).

God calls us to care for those who are vulnerable. Jesus teaches that the sum total of God’s law is to love God and our neighbour. Loving our neighbour is one of the greatest ways to live out our love for God.

In both the Old and New Testaments, the people of Israel and followers of Jesus were expected to care for one another as God’s people, but they were also commanded to care for the foreigners, widows, orphans and poor people in their midst. The parable of the sheep and the goats in Matthew 25:34–36 tells us that when we

“While other worldviews lead us to sit in the midst of life’s joys, foreseeing the coming sorrows, Christianity empowers its people to sit in the midst of this world’s sorrows, tasting the coming joy.”

–TIMOTHY KELLER, *WALKING WITH GOD THROUGH PAIN AND SUFFERING*

“Our traditions instruct that there is meaning and purpose in supporting people at the end of life. Visiting those who are sick, and caring for those who are dying, are core tenets of our respective faiths and reflect our shared values as Canadians. Compassion is a foundational element of Canadian identity, and it is accordingly incumbent on our elected officials at all levels of government to support a robust, well-resourced, national palliative care strategy.”

– INTERFAITH STATEMENT ON
PALLIATIVE CARE, JUNE 16, 2016

serve the vulnerable, we are serving Christ. As Jesus says in this passage: “I was sick and you visited me.”

We are called to protect and cherish human life because God has set humans apart to receive His covenant love (1 John 4:9) and because He has given of Himself in and through His Son Jesus Christ, who came in human vulnerability to demonstrate His love for us (Romans 5:8), even when we were His enemies.

Jesus came to be with us in humility, to take on our frail human flesh and to be a servant (Philippians 2:5-11). Leaving His glory with the Father at a personal cost, Jesus demonstrates what it truly means to care for the vulnerable. Caring for people in their deepest need is a way to love just as we ourselves have been loved (1 John 4:11).

The resurrection of Jesus Christ proves, once and for all, that the physical body matters, that it is part of who we are. Our hope is in bodily resurrection. With palliative care, we care for the body, the heart and the soul of the dying person when they need us the most.

How is palliative care unique?

a. Palliative care makes an important distinction between pain and suffering.

Pain is primarily a physical question, which medical professionals are qualified to assess and treat. But suffering is a broader and much deeper human experience, involving emotional, psychological, spiritual and social dimensions. Suffering is beyond the expertise of traditional medicine alone to address. Palliative medicine treats physical pain but also comes alongside and provides comfort and care to those who are suffering. Palliative care addresses the fullness of human suffering.

b. Palliative care is uniquely able to address suffering.

Palliative care addresses suffering in a way that is compassionate and life-affirming, respects the worth and dignity of each person regardless of their religious or non-religious beliefs, and provides practical, tangible care.

Isolation and stigma often come with incurable illness. Palliative care can provide social, spiritual and psychological support that alleviates loneliness.

c. People who receive a more holistic approach to end-of-life care that both controls pain and addresses suffering are less likely to want to end their lives.

We know from other countries' experience with euthanasia and assisted suicide that fear and despair often fuel a request for hastened death. Many people who are ill or at the end of life are concerned about being a burden – to family and loved ones, caregivers or an overburdened medical system. They may be afraid of pain and suffering, and of what lies ahead. Palliative care supports and encourages them by seeking to meet their social, psychological and spiritual needs.

People who receive palliative care report less pain and less depression. They need fewer hospitalizations and they live three to six months longer than those who do not receive palliative care.¹

d. Palliative care is not only a compassionate response that promotes and improves quality of life, it is also less expensive than acute care.

Seniors are the fastest growing segment of the Canadian population. The coming demographic shift to an aging population increases the urgency of establishing high quality palliative care across the country. With euthanasia and assisted suicide now legal in Canada, many seniors may increasingly feel the pressure not to be a burden on the system and opt to end their lives.

The need for palliative care, however, is not restricted to seniors. The Canadian Cancer Society report indicates a 40 per cent increase in new cancer cases is projected over the next 15 years.² Many of these we know will be terminal cases, thus increasing the urgency for good palliative care for individuals whose cancer is incurable. There are also many other life-limiting, non-terminal conditions beyond cancer (e.g., multiple sclerosis, diabetes, etc.) that often result in the need for extensive care.

This is where palliative care not only attends to the needs of the patient but also makes good economic sense. According to the Canadian Hospice Palliative Care Association, hospital-based



People who receive palliative care report less pain and less depression.

1 "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer." *New England Journal of Medicine*, 2010; 363: 733-742.

2 Canadian Cancer Society, *Right to Care: Palliative care for all Canadians*, 4.

hospice palliative care may save the health-care system thousands of dollars per patient: approximately \$7,000 to \$8,000, compared to more typical acute care.

However, as we have noted with our interfaith partners elsewhere, “While economic figures reveal the significant cost-savings associated with palliative care, our interest in this issue is rooted not in dollars and cents, but in the incalculable worth of every person.”

Establishing accessible, high-quality palliative care for our aging population and for those experiencing terminal illness will improve quality of life and lessen the strain on the health-care system as we navigate this demographic shift.

e. We are living in a new context where people are legally able to ask for their lives to be ended.

The debate over euthanasia and assisted suicide over the last few years has raised the issues of patient suffering and autonomy.

The Evangelical Fellowship of Canada was one of the many groups who raised the need for quality palliative care with the Special Joint Committee on Physician-Assisted Dying. As our brief to this committee stated:

Underlying arguments for assisted dying is the exercise of autonomy, the exercise of choice. But without access to high quality palliative care there is no real choice at the end of life. Without access to quality palliative care, people will be vulnerable to feelings of isolation, despair, to feeling like a burden to family or caregivers, and to the medical system. Assisted death must not be the only choice... We urge the government to establish a national strategy to address the availability of high quality palliative care.³

“...without access to high quality palliative care there is no real choice at the end of life.”

Palliative care offers people the option to live with care and support that alleviates their suffering, so that assisted death is not perceived to be the only or best option.

f. Palliative care recognizes the communal nature of life

Increasingly, Canadians may begin to feel greater pressure to hasten death, either their own or their loved one’s death. But it’s important to also take into account the extent to which a person’s

3 This brief and other resources on Bill C-14 are online at www.TheEFC.ca/C14.

life and death have an impact on the community around them, their family, friends, neighbours and churches.

Death is not only a personal loss to the individual, but a loss to those around the person as well. Palliative care recognizes this loss and sorrow, and offers support for the patient as well as their caregivers and families. It can be a great opportunity for relationships to be mended and to enjoy one another's company in profound, unique and beautiful ways. It is an opportunity for family and community to journey meaningfully alongside loved ones at or near the end of life.

Palliative care by the numbers



96%

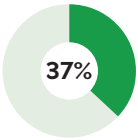
OF CANADIANS SUPPORT PALLIATIVE CARE



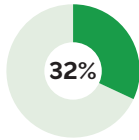
15-30%

OF CANADIANS HAVE ACCESS TO PALLIATIVE CARE

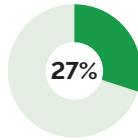
CANADIANS BECOME AWARE OF PALLIATIVE CARE MOST OFTEN THROUGH WORD OF MOUTH, FROM:



FAMILY MEMBERS



THE MEDIA



FRIENDS

OF PEOPLE WHO ENDED THEIR LIVES THROUGH ASSISTED SUICIDE IN OREGON BETWEEN 1998-2016:

91.4%

WERE CONCERNED ABOUT LOSING AUTONOMY (E.G. THE ABILITY TO LIVE AND ACT INDEPENDENTLY)

89.7%

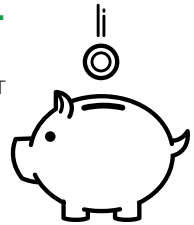
WERE CONCERNED ABOUT BEING LESS ABLE TO ENGAGE IN ACTIVITIES THAT MAKE LIFE ENJOYABLE

42.2%

WERE CONCERNED ABOUT BEING A BURDEN ON FAMILY, FRIENDS AND CAREGIVERS

\$7,000-\$8,000

IS THE AMOUNT THAT PALLIATIVE CARE SAVES PER PATIENT OVER ACUTE CARE



40%

INCREASE IN CANCER PATIENTS PROJECTED IN THE NEXT 15 YEARS

SOURCES: CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION; HARRIS DECIMA; POLL: THE WAY FORWARD, 2013; IPSOS CANADA, PUBLIC AFFAIRS REPORT FOR PALLIATIVE CARE MATTERS: CANADIANS' VIEWS OF PALLIATIVE CARE, SEPTEMBER 1, 2016; CANADIAN CANCER SOCIETY; RIGHT TO CARE: PALLIATIVE CARE FOR ALL CANADIANS, 4; OREGON DEATH WITH DIGNITY ACT, 2016. WWW.OREGON.GOV

2

Discussion questions

1. How do we treat others, knowing that they have been created by God in His image and are loved by Him?
2. How is God's relationship with humans distinctive? What difference does this relationship with God make in how we view our own lives and those of others?
3. Read Matthew 25:31–46. Consider Jesus' words in this parable: "I was sick and you visited me." In what ways might God be calling you or your church to care for those who are sick and vulnerable? How would these actions be a sign of our belief in the Good News of Jesus?
4. How are seniors or people with terminal illness supported in your church or community? Are there stories of good things happening or gaps that need to be met?
5. If isolation, stigma or loneliness are the experiences of people who are terminally ill or nearing the end of life, what can we do to respond as individuals, communities of neighbours and churches, and structurally as a society? Is this a symptom of a larger problem?
6. Is there anything new about our society's fearful denial of dying and loss of control? What do you think is underlying these feelings? How might Christians interact meaningfully and accessibly with those who feel this way?

3



Engaging in public policy

Health care is a shared jurisdiction in Canada. The provinces and territories are primarily responsible for delivering health care. The federal government provides funding to the provinces and territories, and is responsible for providing health care to specific populations, such as Indigenous communities and the Canadian military. The *Canada Health Act* is federal legislation that sets out conditions and criteria for insured health-care services that provinces and territories must fulfil in order to receive federal transfer payments for health. There is no single national palliative care program, and access to palliative care varies considerably across Canada.

Palliative care was widely discussed and its importance underlined during the debates on the legislation that legalized euthanasia and assisted suicide in 2016. In what was otherwise a rigorous and often divisive debate on Bill C-14, the one point on which all parties agreed was that palliative care must be made more widely available to all Canadians.

The Final Report of the External Panel on Options for a Legislative Response to *Carter v. Canada* (in December 2015) found that there is an urgent need for improved access to excellent palliative care. As the Foreword to that report states,

With the advent of physician-assisted death, it has become critically, even urgently, apparent that Canadian society must address its deficiencies in providing quality palliative care. . . . Our country must rise to this challenge, as no Canadian approaching end of life should face the cruel choice between physician-assisted death and living with intolerable, enduring suffering in the absence of compassionate, comprehensive quality care.¹

Canadians with a grievous and irremediable medical condition may now have the ability to end their lives, but not to receive the high-quality palliative care that will alleviate their symptoms, suffering and distress.

There is an urgent need for improved access to excellent palliative care in Canada.

¹ External Panel on Options for a Legislative Response to *Carter v. Canada*, Final Report, 2.

The EFC and the Canadian Conference of Catholic Bishops released a joint declaration on euthanasia and assisted suicide in the fall of 2015. More than 25,000 signatories, including Evangelical, Catholic and Orthodox leaders, and more than 20 Jewish and Muslim leaders from across Canada endorsed the declaration. Among other things, the document called on federal, provincial and territorial legislators to make good-quality home care and palliative care accessible in all jurisdictions.

WWW.EUTHANSIADeCLARATION.CA

During these debates, The Evangelical Fellowship of Canada (EFC) sent a copy of a booklet it published, *Euthanasia + Palliative Care: A Guide for Canadians*, to all MPs and Senators, to facilitate reflection and response on palliative care.

A private member's bill on palliative care introduced by MP Marilyn Gladu in 2016 received all-party support in the House of Commons and became law in December 2017. It requires the development of a palliative care framework, which would increase caregiver support and data collection, and identify education and training needs. The EFC and other faith groups supported Bill C-277 in several letters and submissions to government (see www.TheEFC.ca/c277)

CASE STUDY

Faith groups play part in getting new hospice built

An Initiative to help the dying crossed denominational lines to create something new

Christians and Christian groups played a part in getting a new hospice built in the Chatham-Kent, Ont., area. Paul McPhail is pastor at the Chatham Christian Centre and general secretary of the Independent Assemblies of God International (Canada). He's been a member of the Erie St. Clair LHIN (Local Health Integration Network) advisory committee for a few years and has been around palliative care for some time.

"In 2004 I did over 200 funerals or memorial services," says McPhail. "In 2005 I was elected as the national leader for the Independent Assemblies. Since that time I haven't been able to do as many, but I stayed on the political side. Once you get your feet to the table, you might as well stay there and have a voice."

The community of Chatham-Kent is an hour away from hospices in Windsor, Sarnia and London. Volunteers began to meet in 2011 to talk about setting up a hospice closer to their home. Partnerships were developed with the LHIN, the municipality, the Chatham-Kent

Health Alliance and St. Andrew's Residence, a seniors' facility with ties to St. Andrew's Presbyterian Church in Chatham. Fundraising began in 2013 with a \$3.5 million goal.

"In 11 months we raised \$5.7 million," says McPhail, including "small congregations giving \$5,000 all the way to the Ursuline Sisters giving a \$500,000 donation," he says. "Faith groups have been very supportive of palliative care and hospice."

The ten-bed hospice opened in April 2016. Along with his own involvement in the LHIN, McPhail notes other Christians who are part of the hospice including Chatham-Kent Hospice Foundation executive director Jodi Maroney, and hospice integrated program co-ordinator Michelle O'Rourke, who had been the St. Joseph Roman Catholic parish nurse.

"From small congregations donating through to the entire presbytery in the United Church contributing, we can talk about all of the different groups that have stepped up to support (the hospice)," says McPhail. As a denominational leader, he also sees how the hospice meets The Evangelical Fellowship of Canada's objective of supporting individuals at the end of life.

"This is a quality program and a significant change as far as how families deal with death," he says.

Republished with permission from Robert White, *Faith Today*, Nov/Dec 2017.



Many different groups stepped up to support the hospice.

CASE STUDY

How music tends and heals

Music has a rich and valuable role to play in hospice and palliative care. When we are involved in someone's dying process, music can add richness to this mysterious, often painful, and very often beautiful experience. Music can strengthen relationships and invite presence. It doesn't have to be about having the best voice, or playing an instrument, or having music training. Music care is about *relationship*.

Introducing music into a palliative care relationship can be intimidating for some, although it doesn't need to be. Whether you are a health care provider, family member of a person who is dying, or currently receiving palliative care yourself, music can find its way into the dying process and help make it more meaningful.

Here are three simple ways to use music to strengthen relationships in palliative care:

Ask the question: “What is some music that is significant to you?”

When we ask, “what is a song that has been significant in your life?” we invite a rich opportunity for meaningful storytelling and sharing. Asking a person if they can share a meaningful song with you can create intimacy and emotional closeness very quickly. Listening to these songs together, and sharing stories of songs that are significant to each other, creates an environment of both contemplation and togetherness that can be quite appropriate at the end of life.

Sometimes music can speak the big emotions more effectively, or more comfortably, than words.

Allow space for singing

Singing is a powerful healing tool that humans and other mammals use instinctively. Many of us in North America have unlearned the natural instinct to sing. See what it feels like if you gently sing a lullaby to someone you care for, or a nostalgic children’s song, or a silly song that begets laughter (the best medicine of all). Sing songs that have personal significance – hits from teenage years, children’s songs, hymns that mean something special to the person. Sing quietly, imperfectly, and with care and compassion. If you’re connected to your caring instinct, you won’t go wrong.

Speak through songs

Sometimes music can speak the big emotions more effectively, or more comfortably, than words. Invite your client, loved one or patient to pick songs that express something they would like to say, either to a person or to the world. It can be one song or an entire album. You too can share songs that express something you would like to say to your loved one or client, something words are hard to express. It can be happy, sad, reminiscent, angry, silly, pensive or forlorn; the music can tell a story, speak a prayer, or say I love you. Listen to the recording together, or if you’re a performing musician, play or sing it. You can discuss it after or simply let the music hang in the air and speak for itself.

Music is about relationships. And in end-of-life care, relationships are the most vital lifeline of all.

Excerpt from www.FaithToday.ca/Blog by Sarah Pearson, a music therapist and program development coordinator for the Room 217 Foundation.

CASE STUDY

How I wound up on 100 Huntley St with my golden doodle

It was actually a *Faith Today* article and webinar that indirectly led to my dog Dewey and I embarking on a journey to become a therapy dog team visiting seniors in a residence.

While researching and interviewing for a piece about palliative care and euthanasia — of all things — I started to hear a clear message, especially from Bruce Clemenger, president of The Evangelical Fellowship of Canada. He talked about the need for Canadian Christians to embrace our seniors and make sure we are being the hands and feet of Christ to a portion of our population who are often lonely and sometimes neglected by their families, friends, and perhaps even by an overloaded medical care system.

At the same time, I was feeling a clear call to volunteer my time outside of the church circles in which I normally served. Plus, I have a great big, fluffy, lovable golden doodle who loves nothing more than going from person to person in a room, being cuddled and loved and talked to in warm, adoring voices by whoever is willing and available.

So, Dewey and I applied to become a therapy dog team through St. John Ambulance. We went through the process of evaluation and training, and then a four-week mentoring period with an experienced therapy dog volunteer.

Each week I, my mentor, and Dewey of course, would meet outside the doors of the Port Perry Villa, and have a conversation about things like what side of a wheelchair to approach, how to handle barking if dogs meet up in this otherwise very human environment, and the most important tip for me: to not get in the way. In my nervousness, I had been kneeling down to be eye level with Dewey, so I could reassure him in this unfamiliar setting. My mentor asked me not to do this, to just trust Dewey to do his job.

I did, and things gelled from that moment on. Dewey would spend as much time with each senior as they wanted, being cuddled, scratched and stroked, giving and receiving love and affection. It's been surprising to me, actually, how many seniors permit enthusiastic face licking! I would stand back and hold Dewey's leash loosely



Dewey would spend as much time with each senior as they wanted, being cuddled, scratched and stroked, giving and receiving love and affection.

and trust that all would go well. If the senior wanted to talk to me at all it was to ask a few questions about Dewey, but even more likely to share a story about a dog they once loved. It's very moving to listen to the vivid memories of beloved but long-passed-away pets.

My friend and *100 Huntley St* host and reporter Cheryl Weber caught wind of Dewey's new job and asked if she and a camera crew could come to Port Perry and visit and film Dewey at work. And that's how I ended up on *100 Huntley St* with my golden doodle. Ruff! Ruff!

From www.FaithToday.ca/Blog by Karen Stiller.

3

Discussion questions

1. What does it mean to be a compassionate community where you live? Who needs compassion?
2. In what ways could you, your family or your church show compassion? What are the barriers to becoming a compassionate community? What changes are possible? Where do you think God may be leading in this area?
3. You have read how faith groups in Chatham-Kent, including an evangelical church, helped to support a new hospice in their community. And how Karen Stiller felt she should add a volunteer role outside of her church community. Most of us feel pressed for time. How do you discern where you should be volunteering? How do you decide how to spend your time serving in your church and serving those in need in your broader community?
4. What music brings you comfort? What music would you want to hear towards the end of your life?
5. What do you think of Sarah Pearson's statement, "Relationships are the most vital lifeline of all"?

4



GETTING INVOLVED

What can I do?

Circle of support¹

■ Pray

Pray for those in your community who are vulnerable, living with terminal illness or who are near death. Pray for the caregivers, family and loved ones, medical professionals and practitioners. Pray with patients and caregivers, if appropriate and possible.

■ Learn

- **Find out what palliative care is available in your community.** Is palliative care provided locally in hospital, a long-term care facility or a hospice? Is home care available? Are there gaps in care?
- **Read about issues** facing those at the end of life and supports available. You'll find many in the resources listed in this toolkit.
- **Research and develop** your own advanced care planning (see pages 38-41 for ideas and resources).

■ Discuss/raise awareness

Talk to friends and family about what you're learning. This free booklet has discussion questions suitable for use in small-group conversations.

■ Support

Consider supporting local hospice or palliative care services with your finances. Participate in or plan a fundraising initiative. If you are a professional, you might consider offering legal or accounting support to patients and their families as they navigate the legal and financial complexities surrounding death and dying.

Find out what palliative care is available in your community.

¹ Based on Defend Dignity's Circle of Response model for assisting women who have been exploited.

Could you partner with other churches to fund and provide hospice beds?

■ **Volunteer**

Explore how you might be able to volunteer and partner with existing palliative care, hospice or home care services, as an individual, family or church community. You could offer to help a senior or someone who is ill, their caregivers and family in the following ways:

- **Presence** - Just be there, so that no one feels forgotten and alone, to offer a hand to hold.
- **Conversation** – Regular phone calls, in-person visits, listen, reminisce, read, look at photos, listen to music, read out loud, read a favourite Bible passage, pray with and for the person, talk about wishes/hopes/legacy.
- **Practical, tangible help** – Provide a meal, household maintenance or cleaning, drive to medical appointments or visits to family, do errands, walk the dog.
- **Planning** – It is helpful to plan what advance care you and your loved ones want. Include your wishes, hopes and the kind of legacy you wish to leave for your loved ones.

■ **Innovate**

If you are in an area where services are not readily available, pray, research and consider if your church community might be able to help meet some of the need. Could you partner with other churches to fund and provide hospice beds? Home care? A parish nurse or health-care system navigator? What helps and services could you offer to individuals who are sick or dying?

■ **Advocate**

Call or write your elected representatives, both provincial and federal, to ask for increased support and funding for palliative care

Tips for visiting hospital patients

1. Whenever possible, pull a chair alongside the bed and sit down. This allows eye-level contact, and gives the message you have come to be with them and have time for them.
2. Be sure you are not sitting with a window behind you or the glare of the light can make it hard for the patient to see you.
3. Let the patient share their understanding of their illness and do not ask probing questions about their diagnosis.
4. Be sensitive to the needs of the patient and adjust the length of your visit accordingly. For example, a shorter visit might be best with a post-operative patient.
5. If you pray with the patient, stay for a while afterward to address any personal concerns which may have arisen in the patient's thoughts through prayer, or any emotions that may have surfaced.

Republished with permission from John Vlainic,
Faith Today, Sept/Oct 2012.

What are the conversations we need to have around death, dying and bereavement?

Each of us can consider plans for the future, for ourselves and with our loved ones. Each of us is closer to our life's end than we were yesterday. Planning well for end-of-life care, treatment and death can enable us and our loved ones to live life to the fullest.

The questions below can act as conversation starters as we reflect and discuss plans for the future.

Medical/physical care and legal questions

- Who do I want to make decisions for my medical care, if I'm not able to do so?
- Where do I want to be cared for, e.g., home, nursing home, hospice, hospital?
- What kind of medical care do I want to receive? Are there treatments I would refuse to receive?
- Have I written or reviewed my will recently? How do I want to have my minor children cared for? How do I want to distribute my possessions?
- What would I want at my funeral?

Reflection questions

- What do I want my life's legacy to be?
 - What are five things I'd like to be remembered for?
 - What are five things I want to do before I die?
- What can I be thankful for in this moment?
- What has brought me happiness in life? What is most important to me?
- What is my hope? What brings me through difficult times?
- What is one memory I'd like to recall in my final hours?

Planning well for end-of-life care, treatment and death can enable us and our loved ones to live life to the fullest.

FAQs

What can I say to someone who is dying?

Your primary role will be to provide comfort by listening. You don't need to be profound, provide answers or make a long visit. Treat the person as you normally would. You may want to reminisce or listen to music together. You could bring photos of shared moments in the past to look at together.

Be prepared to sit quietly with the person and meet needs as they arise. Don't feel like you need to entertain. Be aware that the person may not have the energy to engage with you.

If your friend wants to talk, you could ask one of the open-ended questions suggested by Dying Matters (www.dyingmatters.org):

- What would you like to talk about?
- How do you feel about your situation at the moment?
- Is there anything you want us to know...?
- What do you hope for in the next few weeks?

What can I say to someone who has been bereaved?

Do acknowledge their loss by saying something like,

- I'm sorry for your loss.
- I was sorry to hear about...
- I've been thinking of you.

You could also say, "I don't know what to say."

Avoid statements like, "God needed another angel," "Everything happens for a reason" or "I know how you feel." Avoid clichés like "Time is a healer," or verses like "All things work together for good." Even though these statements may be true, like "Your loved one is in a better place," they may not be comforting to the grieving person at that moment.

How can I support caregivers or help someone who's been bereaved?

Keep in contact with them. Be available to listen. Invite them to participate in activities. Keep in mind they may need time before they are interested in accepting. It is better to offer specific, practical help like providing meals or helping with errands and household activities rather than saying, "Let me know if there is any way I can help."

"I thought I could describe a state; make a map of sorrow. Sorrow, however, turns out to be not a state but a process."
 – C.S. LEWIS,
A GRIEF OBSERVED

How long does grieving last?

Each person's experience of grief is unique. Grief can have an impact on all facets of life, emotional, social, physical, intellectual and spiritual.

How can I find out what palliative care services are available in my area?

Check out the Canadian Hospice Palliative Care Association's directory of hospice palliative care services (www.chpca.net/family-caregivers/directory-of-services.aspx) or call their toll-free Hospice Palliative Care Information Line (1-877-203-INFO) to identify hospice and palliative care services near you.

A family doctor, home care nurse or hospital social worker may be able to provide information on palliative care available in your community.

Organizations that are concerned with specific diseases, such as the Canadian Cancer Society or the Alzheimer Society of Canada, may be able to provide information on support and services, as well.

**Canadian
Hospice
Palliative Care
Association:**
1-877-203-INFO
www.chpca.net

Resources

CANADIAN PALLIATIVE CARE SERVICES

Find hospice and palliative care services near you at Canadian Hospice Palliative Care Association's directory of hospice palliative care services: www.chpca.net/family-caregivers/directory-of-services.aspx

BOOKS

- *A Caregiver's Guide: A handbook about end-of-life care*, www.hospicetoronto.ca/caregiver-resources/
- C.S. Lewis, *A Grief Observed* (Faber and Faber, 2013 [1961])
- Timothy Keller, *Walking With God Through Pain and Suffering* (Dutton Publishers, 2013)
- *Facing Death, Discovering Life*, Catholic Health Alliance of Canada (www.chac.ca/resources/index_e.php)

WEBSITES

www.virtualhospice.ca – Canadian Virtual Hospice provides information and support on palliative and end-of-life care, loss and grief, e.g., "Considerations for a Home Death: how

you can prepare to provide care at home" and "Finding meaning and purpose in a health crisis"

- www.advancecareplanning.ca
- www.chpca.net – Canadian Hospice Palliative Care Association
- www.dyingmatters.org
- www.hospiceuk.org/what-we-offer/clinical-and-care-support/family-and-carers
- www.pallium.ca
- www.thepalliativehub.com

4

Discussion questions

1. What do you want your life's legacy to be? Ephesians 5:15-17 calls us to "make the most of every opportunity" (NIV) or to "redeem the time" (KJV). How can you be doing that now?
2. Read and reflect on 1 Chronicles 16:34. What do you have to be thankful for in this moment? How is God good in the present moment? What role does thankfulness play in sustaining us through difficult times?
3. What is my hope? What brings me through difficult times?
4. What is one memory that I'd like to recall in my final hours?
5. What further information do you need or action to take with respect to end of life planning or support for yourself, your family or others?

Conclusion

Palliative care asks the question: how do you want to live? For Christians who believe life is a gift from God and that He calls and enables us to care for the most vulnerable among us, palliative care fits well within our faith's teaching and calling.

Those who suffer need care and companionship. They need to know they are loved and their lives have meaning.

As EFC President Bruce Clemenger and interfaith leaders wrote in a column in the *Hill Times*: "How a country cares for its most vulnerable reflects our national values and priorities. Those approaching the final stage of life are, unquestionably, among our most vulnerable."

Let us be known as Christians by our love, including – and perhaps especially – the love we extend to people with a serious illness and those at the end of life. Let us encourage, comfort and support those who suffer.

Palliative care promotes living life fully, to the end. It alleviates pain, loneliness and depression. It provides support to patients, their caregivers and their families. Palliative care

recognizes the spiritual, social, emotional and physical needs of individuals and their caregivers, and helps to meet those needs. All of this is a natural outworking of our faith.

What is our part to play in ensuring this essential care is available to all Canadians? As we make ourselves available to be the hands and feet of Jesus, we will discover His purpose and blessing.

“While Christianity was able to agree with pagan writers that inordinate attachment to earthly goods can lead to unnecessary pain and grief, it also taught that the answer to this was not to love things less but to love God more than anything else. Only when our greatest love is God, a love that we cannot lose even in death, can we face all things with peace. Grief was not to be eliminated but seasoned and buoyed up with love and hope.”

– TIMOTHY KELLER, *WALKING WITH GOD THROUGH PAIN AND SUFFERING*



Our mission

The Evangelical Fellowship of Canada exists to unite Evangelicals to bless Canada in the name of Jesus.

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*Uniting Evangelicals to bless Canada
in the name of Jesus*



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