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Befriending Death

A Culture in Denial

Growing older is something we avoid discussing in our age-denying culture. The explosion of plastic surgery options and anti-aging products seeks to capture the elusive fountain of youth. Marketing for seniors' residences focuses on youthful energy, portraying couples golfing or ballroom dancing. No matter how much we desire otherwise, that is not the reality for many older adults. It would also be fair to say that we live in a death-denying culture. We even have problems saying the word "death," choosing to use terms like "passing" or "sleeping" instead. We don't like to think about death, let alone talk about it – perhaps for fear it might find us!

Discussing dying is uncomfortable not only for the average person but for most professionals, including doctors, nurses and clergy. No matter how much education we have or how many books we have read, unless we reflect on our feelings and life experiences, it is difficult to integrate our learning. To be fully present to someone who is living with a life-threatening illness, and to summon the courage to raise the questions and hear the answers, we must explore our own understandings and feelings about this awkward subject.

Do you remember playing with a jack-in-the-box when you were a child? Down goes the jester, deep inside – then put a lid on it! Slowly turn the crank as the tension builds and builds,

using an incredible amount of energy to keep it from popping open. Eventually you can't keep the lid on any longer, and the jester is released, exploding violently out of the box.

So it is with the things we would rather not talk about – especially our personal experiences of death and the associated feelings that we tend to bury. Deep in our unconscious mind lurk the questions that often have no answers – ones we have wrestled with and have tried to leave behind. Although these questions may not seem to bother us in our day-to-day living, they can cause physical symptoms including insomnia, aches and pains, headaches or stomach ailments. An inability to focus and a short fuse can also be a sign that something we may not have identified or processed is bothering us.

Our minds and bodies can only compensate for so long before we must name and address these underlying feelings and questions. If they continue to fester, they will cause great physical and psychological distress, much like the tightly wound jack-in-the-box growing closer to exploding open. Taking time to discover the feelings and questions and bring them to the surface is very healthy in the long run.

One of the most successful ways to determine what might lie in the shadows of our heart and mind is to take time to stop and just *be*. Our society is so fast paced. We seldom take time to be still, although we have been programmed as a species to do so regularly. Every living thing needs time to rest so it can be rejuvenated and refreshed. Seeds must lie dormant before they bear fruit. If this step is missed, the plants begin to diminish. If dormancy is prevented, the entire species will die. This rest period, filled with the necessities of nutrition and fertility, is crucial not only for the plant world but for every living thing.

For humans, this time of rest is not simply a convenience or an enjoyable break, but a biological, spiritual and psychological

necessity. Coming to quiet for a period of time, keeping distractions to a minimum and giving ourselves an opportunity to truly rest, think, feel and process can surface issues we weren't aware of. The memories and thoughts that appear may be ones we had forgotten, or we may have believed we had dealt with them long ago. Taking time to process these is important. Another way to allow dormant feelings and experiences to surface is taking time to write or journal. The beauty of writing is that it gives you the ability to see what the issues are and look back at your writing as these issues become more apparent. Some principles of journaling include the following:

- *Prepare before writing* – Quiet yourself and relax; set aside time without distractions to let your thoughts percolate and surface.
- *Find the right place* – A comfortable chair or a spot under a tree; anywhere you can be alone and inspired. Try lighting a candle or beginning with quiet prayer or meditation.
- *Consider the issue of privacy* – Do you want others to read what you have written? What will you do with these journals if anything happens to you, especially if your journal discusses personal issues that may affect the lives of others if your thoughts are revealed?
- *Gently begin to write* – For a beginner, this may take the form of a letter to yourself or to someone else, or perhaps to God. Others find writing in the form of poems or stories helpful.
 - Name how you are feeling and what has been happening in your life; often words and feelings arise that you hadn't realized were present. Successive entries can give you a picture of what is going on and perhaps why you are feeling the way you are.
 - Begin with a question, such as the ones we will explore

throughout this book; reflect on your thoughts and feelings and write them down.

- *Assess your well-being* – How are you feeling about what is surfacing? Are you anxious, afraid, angry, confused, grateful or relieved? Identifying these emotions will give you a sense of what this issue is really doing to your body and mind.

Sometimes writing or journaling can put us in touch with difficult issues and feelings. These may have to be addressed more openly by talking to a close friend, family member or spiritual guide. In some cases it may be best to speak to a doctor or counsellor, especially if there are deep and complicated areas to be dealt with such as enduring grief or painful memories that do not begin to ease even after they are identified and brought into the open.

Writing can be therapeutic for many people in many situations.

Alex was a young girl about 14 years old who was dying of cystic fibrosis, an incurable disease that affects the lungs and leads to an inability to process oxygen. She would often begin coughing violently and be unable to catch her breath, which was hard for the hospital staff to watch.

Staff members were frustrated with Alex's mother, who had her own personal demons. She was often not there to sit with Alex and comfort her during these episodes, when Alex would be crying out for her as she choked for air. Yet this young girl had discovered a way to cope. Besides the wonderful caregivers, her saving grace was her computer.

Alex took solace in being able to write and write and write. Having this "friend" allowed her to put her feelings and frustrations in a place where she could process them

a bit at a time, which helped her immensely through her final days.

If we are to become more comfortable with the subject of death and dying, whether in our personal or our professional life, we must first let go of the fear of talking about it. We do this by reflecting on our own beliefs, biases and experiences. Whether our reflection is done through writing or journalling, through solitude or in discussion with others, it is a key first step in recognizing that it is okay to have many questions and maybe not so many answers. Perhaps our death-denying culture is actually not denying that death exists, but longing for a safe place to ask the questions and face the fears we all have about this unknown but natural stage of life.

REFLECTION QUESTIONS

Journalling is about identifying what you are thinking as well as what you are feeling.

1. What are your initial *thoughts* about journalling?
2. What are your initial *feelings* about journalling?
3. Who do you talk to when you have important personal issues and concerns to work through?
4. Where is your safe place to explore your own questions? (For some people, it is on the Internet or in a library book.)
5. Do you journal already, or spend time in ongoing self-reflection? How is self-reflective practice helpful to you?

Beliefs and Biases

Our beliefs and biases shape how we view things and how we make the numerous choices that affect our daily living. A *belief* is an assumed truth that we use to anchor our understanding of the world around us. A *bias*, on the other hand,

is a prejudice in favour of or against one idea, thing, person or group, compared to another. Sometimes our beliefs are expressed in automatic responses that can quickly shut down communication with others. Our biases can be even more disruptive to communication, as they are often unconscious.

Taking time to reflect on our own beliefs and biases is important. It can be a difficult and unsettling experience to find that they affect our conversations and our therapeutic relationships, yet this discovery can lead to great personal and professional growth. Pema Chodron, a Buddhist nun, wisely reminds us all that “The truth you believe and cling to makes you unavailable to hear anything new.”¹ Learning to recognize our initial reactions to what others say, acknowledge their words in silence, and then reflect and identify the appropriate response allow us to remain authentic but open to other people’s life experience.

Our experiences as well as our learning play a part in developing our beliefs and biases about death and dying. The Life Loss graph exercise in the next section is a tool that can help you express what you may have learned about loss and death through the years. Exploring various scenarios can also help you identify your beliefs and biases in these areas as you are present to someone who is dying.

Imagine meeting for the first time someone who is terminally ill. Your beliefs and biases could initiate a reaction within you to avoid talking about what is happening in case it upsets them, although you know the topic is important to address. Ignoring it can make the person feel isolated and give the message that you are uncomfortable. Yet, you can’t presume that they want to discuss this subject right now – even though you might think it is best to talk about it. Taking the time to sit with them, being totally present and asking if there is anything he or she wants to talk about is a good way to open a conversation

and build trust. Remember that entering into a therapeutic or helpful conversation is done with a conscious intention to be able to keep the focus of the conversation on the other person's needs and not yours.

Or imagine that family members have asked a patient's caregivers not to tell the patient he or she is dying because the family believes the person will not be able to cope with the news. Meanwhile, the dying patient begs the caregivers not to tell the family that he or she is dying for fear they will not be able to cope. In both instances, we observe a noble, primal reflex to protect loved ones from pain and suffering. Yet no matter how hard it is to face the truth, when people withhold information the result is often two separate camps swirling independently in a windstorm of pain and suffering when they could be sharing it together. Both parties need help understanding their own fears and needs. Guiding them to face the truth together will usually provide the best scenario for dealing with the issues that must be addressed to pave the way for a "good death." We must set aside our own beliefs or biases about what we think should be done, and take the time to explore options with the people involved so they can reach their own decision.

Desiree was a nine-year-old girl, full of life and energy, even though she had end-stage leukemia. Her family decided not to tell her she was dying.

During a play therapy session, Desiree drew a plane with all of her family members inside, looking out the windows. When asked where the plane was going, she said it was going to bring her to heaven, and that it was time for her to go. She took the picture to her family and explained the significance of it. Although it was very difficult, her family responded with incredible strength and talked freely about Desiree's dying, because that was

what she wanted. The real turning point for the family, as well as for the palliative care team, was when they noticed that Desiree had drawn herself flying the plane.

Palliative care team members, patients and loved ones all maintain their own personal biases and beliefs. Remaining open, objective and non-judgmental is key. Discussing issues that arise can identify beliefs and biases that surface and can help to explore ways to work with them.

A common bias is misunderstanding the use of medication at end-of-life, particularly strong pain medication. People who are dying may fear they will become addicted and may decide to suffer with the pain rather than increase their dosage. They believe the medication is going to hasten their death and need reassurance that although large doses are needed to control certain types of pain, it is the cancer or the disease causing their death, not the medication. Others believe that allowing physical suffering to continue is a sacrifice that helps prepare them spiritually for their death. It is helpful to explore the physical, emotional, spiritual and psychological dimensions of the person's ideas and beliefs in order to address issues and explore options together.

Bertha was a 93-year-old woman with advanced congestive heart failure who was actively dying. She felt that her physical pain would be the sacrifice that would help her son get to heaven. (He had died of cancer 20 years earlier.)

Bertha's main physical problem was shortness of breath. The palliative care team explained that a small dose of morphine would help to take away the sensation of breathlessness and help her breathe more comfortably. Bertha was adamant that she would not take the morphine. This went on for three painful weeks as her

struggle to breathe escalated. A health care aide decided to sit with Bertha after repositioning her at 3:00 a.m. The aide asked Bertha why it was so important for her not to let the team help her. Bertha shared that a few years before her son died, he left his 20-year marriage and never saw his children. She believed that as a result of his actions, her son never made it to heaven, but through her physical suffering she could make that happen.

The aide asked Bertha if it would be okay to share this information with the team and her family in order to work through it together. Her family knew how much Bertha's faith meant to her. Once they heard what she was doing, they offered to help her by doing works of charity to assist their brother. The chaplain also had an opportunity to talk to Bertha, and they explored gospel stories and the notion that God was loving and forgiving. Bertha eventually allowed the team to administer the morphine, which helped immensely with her comfort and shortness of breath.

Bertha surprised us and lived another six months, all the while continuing to prepare for her death and teaching us important lessons in how to support her.

By being mindful of our beliefs and biases, and being open to change, we can respond to the dying in ways that allow the person to “steer the plane”. When we can keep *their* needs and beliefs as the focus, their experience of dying will not be determined by our unexamined way of being in the world.

REFLECTION QUESTIONS

1. Take some time to consider your own beliefs in the following areas:
 - Dying
 - Grieving
 - Having faith
 - The afterlife
 - Telling the truth
 - Shedding tears
2. Do you have any biases, one way or another, regarding how you address these issues with others?
3. Can you see how your beliefs or biases might affect your ability to be open to others who do not think the same way you do?
4. How might this situation affect the way you care for the dying and their loved ones?
5. Are there steps you might take in preparing yourself to work more objectively with the dying, especially those who do not share your beliefs?
6. If you are accompanying a family member or loved one, do you have beliefs that might affect how you care for them or interact with them? Will these beliefs help your loved one to die well?
7. Do you see the need to seek some help from others in dealing with your beliefs or biases that are surfacing as you walk with the dying?

Our Own Stuff

Our early experiences of grief and loss will shape our response to the death of a loved one, a pet, a job, a relationship, or a dream, hope or desire. Many bereavement specialists report that a person's first two experiences with death can predict how they will respond to death in the future.

John is a 48-year-old man who works in the auto industry in the city where he was raised. He is married and has two children. Two months ago, his father was diagnosed with advanced cancer.

Time was passing quickly, yet John was hesitant about visiting his father or even calling him on the phone. He also refused to talk to his children about their grandfather's illness. John's wife, Sarah, was shocked by his response, although it was obvious that John was suffering. He was starting to miss work and had trouble engaging in activities with his family. Sarah convinced John to see a counsellor at the hospice palliative care facility where his father was a patient.

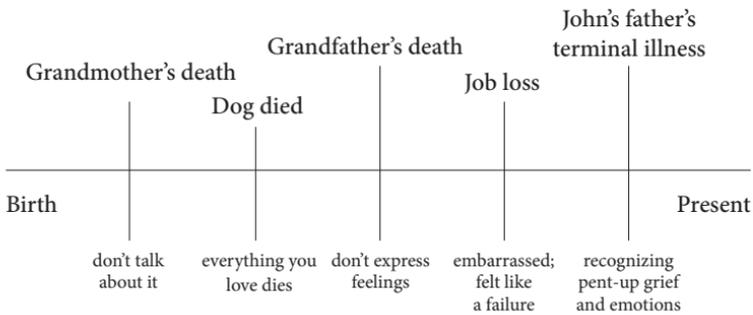
The counsellor had John draw a Life Loss History Graph. In this exercise, a person plots all the losses they have experienced on a line representing the years of their life. They can then reflect on the messages they have internalized, often subconsciously, during those losses.

John's grandmother died when he was eight years old. His parents decided not to bring him to the funeral home visitation or the funeral. When John was twelve, his grandfather died. This was a very complicated relationship, as John's father had been estranged from his own father for over 10 years prior to his death.

After doing this exercise and spending some time reflecting on the messages that he received, John realized that avoidance was the key operating factor in the way he dealt with death. The main messages from the losses in his life were "don't talk" – "don't feel" – "don't trust". John had transferred these past messages into the way he was now coping with his father's illness.

By recognizing this response, John was able to make a conscious choice to address his feelings more openly without judging himself harshly. He could finally focus on facing the truth with his family and his father. They supported one another through the pain and sense of loss they were all experiencing.

John's Life Loss History Graph



Messages from these losses:

- don't talk about death
- don't share your feelings about death
- "be a strong boy"; "suck it up"

Your Life Loss History Graph

Take some time to reflect on your own life and plot your significant losses. It will be helpful to do this exercise in a journal or on a separate piece of paper where you have lots of room to write. Chart your earliest recollection of death or loss: this could be a person, pet, object/thing, move, or other loss. Continue with other losses, such as a loss of a friendship, leaving home, divorce, illness ... The longer the vertical line, the more significant the loss.

Under each loss or event, list a few words that come to mind that remind you of how you felt at the time. Remember

who was there to talk to you about it; how your family members dealt with it; your feelings, support, disappointments, and so on. Think back to how you were told about the loss. What feelings, emotions and patterns do you see? Anger, fear, denial, acceptance, peace? It is very likely you will see that you are using the same patterns to deal with loss today.

There is no right or wrong way to do this exercise, and no one will judge your work. It is simply to help you reflect and identify why you may be dealing with loss in a certain way. If you have an emotional response, don't be afraid to express it. It is okay to cry or to be angry or sad. You may also be grateful or thankful for the support you had during these times and be able to see how you have adjusted to living with the loss.

Recognizing what has been positive and negative in our own journey can help us to be more aware of avoiding the responses and reactions that could be detrimental as we support others who are facing loss and grief.

EXERCISE

1. Plot your own Life Loss History Graph.
2. Be sure to include your feelings and responses.
3. What patterns do you notice developing?
4. How has this history affected how you respond to loss today?

Dying to Know

Understanding some of the terms and concepts used in end-of-life care can be daunting and confusing for anyone – whether you are a health care or spiritual care provider, volunteer, patient or family member. Over the last 50 years, great strides have been made in understanding and supporting people encountering death, dying, grief and bereavement.

Various disciplines continue to explore these areas, including medicine, nursing, psychology, sociology and spirituality. Along with these we find a newer, specialized field of *thanatology*. It encompasses the study of the social and psychological aspects of death and dying and is derived from the Greek word *thanatos*, meaning “death.” Thanatologists study the dying process, the grieving process, and social attitudes towards death, including ritual and memorialization.

The evolution of hospice and palliative care

Dame Cicely Saunders (1918–2005) is credited with the birth of the modern concept of hospice care. She lived in the United Kingdom and studied nursing, social work and eventually medicine. She established St. Christopher’s Hospice in London in 1967. For centuries before this, hospices were often run by religious orders to house the incurably ill, where travellers or the impoverished could go for good care and sanitary conditions. St. Christopher’s was founded on the principles of combining teaching and clinical research, expert pain relief and symptom relief with holistic care to meet the physical, social, psychological and spiritual needs of patients and of their family and friends. It was a place where patients could garden, write, talk, and get their hair done – indeed where they could continue to live as fully, comfortably and actively as possible, until they died. This focus on living as one is dying is the hallmark of hospice and palliative care.

At the same time that Saunders established St. Christopher’s Hospice, Swiss psychiatrist Elisabeth Kübler-Ross began to consider the social responses to terminal illness. Her 1969 bestseller, *On Death and Dying*, greatly influenced how the medical profession responded to the terminally ill. A new field of Clinical Pastoral Education was also developing, and formalized Pastoral Care was being put in place in many settings. Continu-

ing advances in understanding and treating cancer and other diseases, as well as better pain control and symptom management, became key components in the evolution of specialized end-of-life care.

Dr. Balfour Mount is credited with bringing hospice care to Canada, establishing it in the 1970s in Montreal. Because the French word *hospice* translates as “poor house,” in Quebec the term “palliative care” was more widely adopted. “Palliative” comes from the Latin *palliare*, an outer cloak that covered and protected soldiers at war. Thus, palliative care concentrated on covering the symptoms, or reducing their severity, rather than stopping or reversing the progress of the disease or providing a cure. Today, “hospice palliative care” is the nationally accepted term to describe care aimed at relieving suffering and improving quality of life for those with life-threatening illness.

Hospice palliative care is accessed in a variety of ways, depending on the circumstances and the services or resources available in one’s community. A community may have a free-standing hospice that offers resources and education programs to help people understand and cope with dying and bereavement, with outreach teams and visitors to support people in a number of ways. Some hospices include a residential component, with rooms for people to live in as they are closer to death. Often these are set up to look and feel like home, with space for family and friends to share in celebrating the final days of their loved one’s life. Specialized palliative care units in hospitals have been designed to try to accommodate this need as well. This “home away from home” is a cherished place for people to spend their final days when unable to remain in their own dwelling.

Those who wish to die at home are often able to do so with support from community nursing agencies, hospice volunteers and hospice palliative care teams, which can usually be

accessed through their physician or local health care agency. Hospice palliative care teams, whether they are based in the community, in a hospital or in a residential hospice, are multi-disciplinary and can provide a number of important services. The staff usually includes nursing and medical care personnel, as well as chaplains, social workers, support staff, occupational therapists, physiotherapists, dieticians and volunteers. There is sometimes access to therapists who can provide music or art therapy, therapeutic touch, energy therapy, massage and more. They can assist both patients and loved ones during this time of transition, reducing anxiety and assisting those journeying through death and loss. A newer source of support is available in some areas through parish nursing or faith community nursing. Parish nurses are specially trained registered nurses who work within a faith community to promote health, healing and wholeness among its members. Recognizing the interconnectedness of body, mind and spirit, parish nurses promote wellness through health education, advocacy, spiritual support and linking the needs of those they serve to resources in the greater community and in their community of faith. This ecumenical discipline, which is becoming more available, can be a wonderful source of support to the dying and their families.

The key is to find out as much information as possible *early* in the disease process, as so much assistance is available to people long before they are actively dying. Although specialized hospice palliative care support is available in many settings, patients and even medical personnel can be reluctant to access it. Many feel that it's a sign of giving up hope of a cure or giving up on treatment too early if they ask for assistance from the supportive care or hospice palliative care team. Conversely, palliative specialists lament that it always seems too early to contact palliative care – until it's too late! Referring early in the diagnosis can help

the patient and family deal with what is ahead, keeping them comfortable and informed no matter how long it is until the patient's actual death. Often families or medical personnel, or both, are in denial that someone is close to dying, causing them to miss the opportunity for an ample amount of quality time to address end-of-life issues openly and experience a "good death."

Phil, a father of three adult children, worked for a small auto body shop. His wife, Pauline, was after him for a number of months to go to the doctor. He kept complaining of pain on his left side, radiating to his back, and thought he had pulled a muscle at work. Eventually, Pauline noticed his skin turning yellow and convinced him to see the doctor.

Shortly afterwards he was diagnosed with advanced pancreatic cancer. He was offered six weeks of chemotherapy, which was not going to prolong his life, but could have helped his symptoms. After discussing it with his wife, he chose not to take the treatment. He began to have pain and nausea and was finding it harder to do the day-to-day activities he was used to. His local community nursing case manager made a home visit and was able to provide some nursing support and help with managing his medications.

Within a few weeks he began to experience numbness in his legs. A CT scan showed that the cancer had spread to his spine. Emergency palliative radiation was arranged to shrink the tumour and avoid permanent paralysis. He returned home and was given only a few short weeks to live. His wife applied for the compassionate leave program through Employment Insurance, and he was able to secure extra nursing hours through a clause in his life insurance policy.

Although it was difficult to accept that Phil would die so soon, the last few weeks of his life were filled with many special conversations and memories. His wife and family spent lots of quality time with him, and were able to count on the support of good friends and extended family for meals and comfort. The chaplain from the palliative care team spent time offering support and the home care nurses became their fast friends. The volunteer visiting program through their local hospice gave Pauline some respite time and continued to visit through the family's time of bereavement.

Every story and every situation is different. The important thing to note is that it is never too early for someone to talk to a health care provider or loved ones about their wishes and ask about options for end-of-life care, even if death is not imminent. After all, do any of us really know when we are going to die? Medical professionals can estimate the timing in certain cases, but it is always good to be prepared and aware of possibilities. Three times more people die of age-related issues and chronic diseases than cancer. Many serious diseases of the heart, lungs, liver, brain and other organs are also terminal diseases. As a culture, we must become more comfortable recognizing that medicine cannot keep us alive forever.

Intensive Care Units are often not appropriate places to be treating some people who have serious chronic diseases. As a health care system, we must develop more suitable and accessible supportive care systems that involve realistic discussions of expectations and goals of care. We must come to recognize what dying looks like, whether it is from a diagnosis related to cancer, aging or severe chronic illness.

Our society and our health care system often look at dying as a failure of acute care medicine instead of a normal stage of

life. We must all challenge one another to become more comfortable with the reality of our mortality, and choose to celebrate our end-of-life journeys as well and as openly as possible.

REFLECTION QUESTIONS

1. Do you know how to access your local hospice palliative care resources?
2. Is it your experience that death is seen as a normal part of life, or as a failure of acute care medicine?
3. Have you ever been in a situation where the family was in denial about a loved one's imminent death? What happened? Would a particular intervention have led to a better outcome?
4. Have you had an experience of health care providers who seemed to have been in denial or were not forthcoming about the severity of a life-threatening illness? What have you learned from this situation that may help you in the future?

Henri Nouwen and Befriending Death

It seems indeed important that we face death before we are in any real danger of dying and reflect on our mortality before all our conscious and unconscious energy is directed to the struggle to survive. It is important to be prepared for death, very important; but if we start thinking about it only when we are terminally ill, our reflections will not give us the support we need.

Henri Nouwen

In these words, Henri Nouwen gives the definitive reason why all of us must do the inner work of looking at the reality of our mortal lives long before we are told we could be dying. Nouwen serves as a guide as we take death out of the shadows, talk about it and actually befriend it.

Henri J. M. Nouwen, a Roman Catholic priest with a background in psychology, is one of the best loved and most influential spiritual writers of our time. He believed that theology and psychology were intimately connected, a place where the understanding and experiences of the human person met the heart and the soul.

Henri was born in Holland in 1932. He moved to the United States in 1964 to study at the Menninger Institute in Kansas, where he researched this connection of mind and spirit in the new field of Pastoral Counselling and Clinical Pastoral Education (CPE). A colleague invited him to teach at the University of Notre Dame. Eventually, he moved to the divinity school at Yale, where he enjoyed a stellar teaching career, attracting students from a multitude of faith backgrounds. Besides teaching, Henri produced an extensive library of articles and wrote over 40 books on topics such as spirituality, compassion and ministry, and soon became the author everyone was reading. His books were rich with questions and raw with feeling, as he wrote from his own heart, discovering where God could be found in the difficulties and circumstances of everyday life. His works have been widely embraced not only by students and clergy, but by people in the pews, health and pastoral care professionals, and seekers from many backgrounds and cultures.

During his time at Yale, Henri recalls coining the phrase “befriending death” during a discussion with a student who had studied the work of noted psychologist Carl Jung. Jung’s work speaks to the importance of “befriending” such things as your shadow side, your dreams and your unconscious. He believed that we come to maturity by integrating not only the light but also the dark side of our story into our selfhood. Henri realized that befriending death was indeed the basis of all other forms of befriending.

After moving on to teach at Harvard, Henri realized that he no longer felt fulfilled in academia. He began the search for a place to settle where he could feel at home, inside and out. His restlessness led him to spend time in a monastery, then to serve as a missionary in South America, but neither experience seemed to answer the ache in his soul. Eventually he moved to France after meeting Jean Vanier. Vanier, the son of Pauline and Georges Vanier (a former Governor General of Canada), had established a small community he named “L’Arche” (French for “The Ark” – a place of safety), where adults with developmental and physical disabilities lived in community with him and other volunteer caregivers. L’Arche soon grew into an international movement. L’Arche Daybreak, a similar community in Richmond Hill, Ontario, invited Henri to live with them as their pastor. He moved to Canada in 1986.

For the next ten years, Henri called L’Arche Daybreak home. His relationship with Adam, one of the disabled core members whom he cared for, affected him deeply. He wrote a number of books during these years, and continued to teach and travel. In 1996, Henri died suddenly of a heart attack at the age of 64. His loss was a great one in the world of spirituality, yet books continue to be written about him and by him, with editors and authors revising his collections and compiling his unpublished works. Because of his background in spirituality and psychology, Henri had the rare gift of grasping concepts and language that could bridge the sacred and the secular. His works continue to appeal to a wide readership today.

Nouwen took time to reflect on his own mortality and write about it after surviving a near-fatal car accident. *Beyond the Mirror* (1990), and *Our Greatest Gift: A Meditation on Dying and Caring* (1994), were published during this time. Other Nouwen works related to the topic of befriending death were researched

and compiled in Michelle's book, *Befriending Death: Henri Nouwen and a Spirituality of Dying* (2009). Henri's reflections, along with the works of other noted experts, will offer wisdom and insight as we journey through these pages.

The inner life is always a life for others.
When I myself am able to befriend death,
I will be able to help others do the same.

Henri Nouwen

Care and Compassion

The word "care" finds its roots in the Latin word *kara*, which means "lament" – *to grieve, to experience sorrow, to cry out with*. This understanding expresses an invitation to enter into someone else's pain before doing something about it. Yet we usually feel more comfortable providing a service or using our knowledge to bring about a change or a cure rather than meeting others in their pain and then journeying together towards their healing and wholeness. It is easy to look at caring as an attitude of the strong towards the weak, or the powerful towards the powerless; "Let me take care of you. I have some area of expertise to offer that you need."

We use the word "caregiver" to describe someone who is giving care to or caring for someone else. However, true healing can happen only when both parties enter into the relationship equally. Caring is a partnership where one person reveals their pain, brokenness and vulnerability to another. Through a relationship of trust, they work together towards healing and wholeness. Instead of being referred to as a caregiver, a more appropriate term would be "care partner." This type of healing is an invitation to partner in caring with one another. There may be no physical cure to be found, but there can always be care!

In exploring this relationship of care vs. cure, we can look at stories of people with cancer who, upon finishing their chemotherapy, visit the doctor at the cancer clinic only to hear the devastating words “I’m sorry, your treatment has failed and there is nothing else we can do for you.” Yet there is *always* something that can be done! In fact, it is often when there seems to be no more active treatment to offer that true care and compassion are allowed to flourish. Dr. Patrick Vinay, a palliative care physician at Notre-Dame Hospital in Montreal, describes how he has experienced this evolution of cure and care in his own life and practice.

A patient with a new diagnosis of lung cancer comes to the doctor looking for answers. He first enters into a “bubble of power” – looking for the best hospital, the best doctors and the best treatment. He wants to control the monster attacking his body – telling his lung to “heal and win”! But this work of healing is stressful, and his family adds more stress as they remind him to “eat”; “take care of yourself”; “you have to beat this thing”.

The hospital is not as worried about the person as “the lung”; it is an opportunity for science and research to shine. Biology has the answers, so the “sickness of the human person” becomes isolated. This bubble of power wants to be in control of the sickness, and the relationship with the doctor at this point is often episodic.

Eventually, the bubble bursts. The treatment is not leading to a cure, and the doctor’s toolbox is empty. The doctor sees his own impotence now, his own failure and defeat. He realizes that he is not a specialist for them anymore, and yet it is a very poignant moment in his relationship with this patient. Now, they both step into a new bubble – a bubble of powerlessness and

vulnerability. The lab coat comes off and they are two human beings – both equals – facing the mystery of life.

This place is not pleasant. They did not teach us any of this in medical school. It is a place where the doctor has to become his “small self” and the sick person has to now apologize to his family for smoking for forty years. Yet, in that space, between the patient and myself, there is a desire to be present. Beyond words there is a real support of being to being. There is a resonance between us – it is not necessarily religious – but it is very profound.

The cancer is not a priority now. The patient’s capacity is changed from being autonomous to wanting to be in relationship. To some people the situation might look like a shipwreck, fueled by death and hopelessness. Yet, it is at this point that we enter a bubble of meaning – open to real life. One begins to see end-of-life differently. There is an ability to see a new face in the suffering one, despite the pain. They are in need of a climate of humanity now, a fertile earth where they can evolve as a person. It is not about science anymore but relationships.

I believe there is actually no place more spiritual than a hospital. It is here where suffering can become healing; where people can become aware that their identity is shaped by who they are and not what they do. Around every corner is the mystery of life and death. It is important to create a new community in palliative care for people who still need to evolve – to create a “carrying” environment where they can accompany one another.²

The definition of “compassion” is similar to “care”, derived from the Latin words *cum* and *pati*, which together mean “to suffer with”. Compassion asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion and anguish, expressing a full immersion into the condition of being

human. Care and compassion are offered in many ways, by those in formal professions who are paid for their care partnering, or those who accompany others as friends, family members, neighbours, loved ones or volunteers. Dr. Rachel Naomi Remen, a well-known author and physician, writes in her book *Kitchen Table Wisdom* about the type of healing and compassion found in care partnering.

People have been healing each other since the beginning. Long before there were surgeons, psychologists, oncologists, and internists, we were there for each other. The healing of our present woundedness may lie in recognizing and reclaiming the capacity we all have to heal each other, the enormous power in the simplest of human relationships: the strength of a touch, the blessing of forgiveness, the grace of someone else taking you just as you are and finding in you an unsuspected goodness.³

True care and compassion leads to healing and wholeness for both care partners. Take time to reflect on when this has happened in your own life, and discover the true gifts or fruits of these encounters.

REFLECTION QUESTIONS

1. Reflect on a time when you cared for another. What did you give? What did you receive from them?
2. Reflect on a time when you were cared for or needed healing. What did others give you that helped you experience healing and wholeness?

Meaning and Purpose

We are not human beings having a spiritual experience.

We are spiritual beings having a human experience.

Teilhard de Chardin

Holistic care is the attention to health and healing with regards to the whole person, including body, mind and spirit. Someone may be fairly healthy physically, yet have difficulties with their emotional or mental health, or feel empty or unfulfilled spiritually. The desire in providing holistic care is to see the human person as a unique being, filled with their own dignity, gifts and promise, seeking a return to balance or wellness through our partnership of care with them.

The Association of American Medical Colleges developed a definition of spirituality and its link to health that can help us understand this connection:

Spirituality is recognized as a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism and the arts. All of these factors can influence how patients and health-care professionals perceive health and illness and how they interact with one another.⁴

Ponder a few moments on the following statements, and reflect on which ones express your own understanding of spirituality:

- Spirituality is a journey, a discovery, a response to life, a search for ultimate meaning, or deepening relationships.
- Spirituality seeks connection through belief systems and relationships to something beyond or greater than oneself, to find meaning and purpose in one's life.

- My spirituality and religion are so intertwined, they are virtually one and the same.
- Spirituality helps us to look inside ourselves – our heart and soul – to discover our true self.
- We explore our spirituality through our relationships with others, with all of humanity, with the earth/world and all created things and, ultimately, with God – or a transcendent being/life source/energy as understood by various spiritual traditions.

Walking with someone who is dying is a spiritual journey for everyone involved. The English word “spirit” comes from the Latin *spiritus*, meaning “breath.” The word “soul” is derived from the Greek word that refers to “vital breath.” Speaking about the soul of a person refers to their vital breath – that which makes them ultimately unique. There are so many ideas and different understandings concerning the term “spiritual” that it is helpful to clarify how we use it in hospice palliative care. The Canadian Hospice Palliative Care Association uses this definition for spirituality:

An existential construct inclusive of all the ways in which a person makes meaning and organizes his/her sense of self around a personal set of beliefs, values and relationships. This is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual’s spirituality.⁵

Ultimate meaning in life is often tied to *transcendence*, or an awareness of something greater than oneself, something sacred or divine. Having meaning in life gives purpose to living, and leads to the desire to remain in relationship with others, God, ourselves, nature – whatever we hold as sacred or important. Our

values, which include our beliefs and morals, help us to recognize and live out of that which gives us meaning and purpose.

Dr. Christina Puchalski, an internist and expert in spirituality and health, explains that “Spirituality is the thing we all have in common; it is the search for the meaning in a person’s life. It moves us out of ourselves to other concepts, which could be found in religion, nature, or relationships with others, but it is not exclusive to religion.”⁶ Religion, on the other hand, refers to a system of rituals and beliefs within a concept of community. Religion can provide a context for understanding meaning and purpose, as well as suffering, loss, despair, hope, and beliefs regarding God, the afterlife, modes of prayer and ritual, and so on. All of the major religious traditions regard life as sacred, and advocate for compassion and mercy as important human aspirations.

For many people, the development of the spiritual self is closely connected to a particular religious tradition. Others find meaning and purpose through non-religious values, beliefs and practices, including a strong connection to relationships and values outside oneself. Even for those who may not consider themselves particularly religious, a health care encounter can often be a place of meaning, as it raises questions about life, death, suffering, dignity, dependence, fidelity, care, justice, and more. In hospice palliative care, these questions seem particularly poignant.

Spiritual care may be provided in a number of ways. Elements for addressing spiritual care issues are primarily devoted to presence, listening and respectful assistance in helping people to discover their own purpose and meaning in light of their beliefs and values. Although someone may see himself or herself as a spiritually strong person, an environment of suffering will raise many new questions. Accompanying others challenges us to review what spirituality means to us, bringing us face to

face with our own humanity, vulnerability, fears, questions and beliefs.

What is most important to remember is to keep the focus of the spiritual care of the dying person and/or their loved ones on *their* questions and beliefs, not the beliefs of the caregiver. There may be an appropriate time for a mutual sharing of thoughts or ideas, but those who walk with others must remember that their role is never to impose their personal beliefs, but to help the dying person/family to be comfortable exploring their own questions and fears.

This time of painful questioning and reflection during a life-threatening illness can be done alone, but is more helpful with a companion or guide, such as a trusted friend, spiritual advisor, chaplain or member of the care team.

Elizabeth's husband of 24 years was dying of cancer caused by work-related exposure to asbestos. Charlie took pride in his work and could not believe that he was not going to see his two children marry and would not grow old with his wife.

Both Elizabeth and Charlie were questioning the meaning and purpose of life. They had an old friend who was a retired factory worker, a very wise and spiritual person. They asked him to visit with them as they worked through their anger, fear and loss of hope. They talked about everything. This friend suggested that they start journal writing – a process of getting thoughts and feeling out of the head and mind and down on paper in order to surface and address them.

Although Elizabeth and Charlie still felt like they were being robbed of a life together, this guided journey helped them and their family find some peace as they openly discussed the effect the illness was having on their lives.

Generally, a person's spirituality and set of beliefs is very personal and private, but a palliative care situation is an opportune time to respectfully inquire about emotions, fears and questions around living and dying, meaning and purpose. You may have to take the initial first steps in raising the issues as you develop an open and non-judgmental relationship of trust together. They in turn may invite you in to a deeper level of sharing where together you explore their questions, addressing areas such as fear, guilt, shame, reconciliation and loss, so that they might die with some resolution to their questions and a more peaceful heart. To be invited into this journey is very humbling and a precious gift to be held with reverence. Although it may be difficult and painful, it is a time of profound grace, even if all matters are not resolved. Often, it is the one journeying with the dying person who is transformed the most by this sacred encounter.

REFLECTION QUESTIONS

1. Describe your spirituality.
2. Do you adhere to a particular religious tradition?
If so, how has this helped develop your spirituality?
3. What has meaning and purpose for you?
4. How would you describe your "vital breath"?
5. Can you share your spirituality with your loved one(s)?
If not, what is stopping you?

Exploring Spiritual Questions

Exploring spiritual questions can be uncomfortable, yet it is important for providing holistic care. All those who journey with others must be comfortable discussing areas of meaning and purpose and recognizing spiritual distress, although there are times when it is appropriate and necessary to

involve chaplains, spiritual care specialists, clergy and other faith leaders in assisting people to discuss these issues. Unresolved spiritual distress can lead to difficulties in an end-of-life journey, affecting overall wellness and increasing a person's sense of suffering and pain. Feeling lonely or discouraged; asking questions such as "Why is this happening to me?" "How will I be remembered?" "Why is God doing this to me?" or "Where is God now?"; feeling angry, anxious or misunderstood; asking to discuss matters of faith, hope, meaning or purpose – all these are signs that someone may be suffering from spiritual distress.

Esther was an 89-year-old woman who was dying after some extensive surgery for gynecological cancer. Esther's husband had left their marriage many years before, and she had devoted her life to raising their two daughters, working as a nurse and being an active member of her church.

Through the years, Esther had come to learn that her husband had been unfaithful to her, passing on a sexually transmitted disease that, over time led to her cancer. Esther was horrified at this situation, coming from a generation that did not talk about sex or death at all. Ultimately, Esther felt completely abandoned by God and harboured anger at God for allowing this to happen. She felt too much shame about the illness to talk about this with her pastor and felt very alone in this journey.

Eventually, Esther connected with the social worker on the team, Lindy, who allowed her to speak of this distress and go to the depths of her pain without judgment. Lindy explained that she had a right to feel angry at God and encouraged her to explore those feelings so she could ultimately allow them to be set free. The abandonment issue was much more difficult to deal with, but the entire team assured Esther that they would be there for her and not abandon her during this challenging time.

Engaging a spiritual care provider, social worker or other palliative care team member can help to address some of these questions and can offer some relief of the suffering and anguish being expressed. Henri Nouwen talks about spiritual distress and God's will.

We are often tempted to “explain” suffering in terms of “the will of God.” Not only can this evoke anger and frustration, but also it is false. “God's will” is not a label that can be put on unhappy situations. God wants to bring joy not pain, peace not war, healing not suffering. Therefore, instead of declaring anything and everything to be the will of God, we must be willing to ask ourselves where in the midst of our pains and sufferings we can discern the loving presence of God.⁷

Life-threatening illness causes not only the patient but the family to ask questions about the deepest meaning of life. Often people hold the answers to their own questions but need a listening ear and a curious companion to explore them with. Encourage the person to talk about what is bothering them and remain an attentive listener, helping them to identify their fears and beliefs as well as what has helped them in the past. We offer a few helpful hints for engaging in these conversations, although in cases of ongoing distress or unresolved issues it is always good to engage a spiritual care provider or counsellor with expertise in this area.

- Remarks about meaning or meaninglessness might indicate that the person is struggling with issues of feeling significant or worthy of living.
- Comments about feeling isolated or alone may mean the person needs to talk more about his or her relationships with others – in particular, perhaps, those that are strained or incomplete.

- Conversations about loneliness may surface the need to explore forgiveness or reconciliation with others.
- Talk of hopelessness is common at the end of life. Often hope will begin to emerge while exploring feelings and issues together. Assure them that you won't abandon them and have committed yourself to be their care partner in their struggle for meaning.
- A feeling of powerlessness is common, since control over what is happening to the person's body is lost. The person can address this feeling by maintaining even a small sense of control, such as what to watch on television, when to eat or go to bed, or what to do during the day.

Care partners must also explore their own spiritual questions and address their own spiritual needs to stay healthy in a care partnering role. For both of us, our roots in the Catholic Christian tradition play a major role in our spiritual lives and in our service to others. Our faith shapes how we are called to respect the dignity and life of every person, and stresses the importance of pursuing justice, peace and holistic healing. Ongoing study, reflection, reading, spiritual direction, prayer, connection with a faith community, days of retreat/solitude, enjoying nature, making time for rest and exercise – all help to keep our busy lives in balance while nourishing the heart and soul. Praying with others and for others is also a large part of what we have brought to our respective practices and ministries, when prayer has been requested and appropriate. Respecting the needs and beliefs of those we serve comes first, but because we have taken the time to nourish and develop our own spiritual life, we feel comfortable speaking to others about theirs.

In addressing spiritual questions, one of the more common difficult issues seems to come from those care partners who do have some background in a spiritual tradition speaking with

those who do not. Those who believe in God and in an afterlife find comfort and meaning in that understanding, especially as death nears. When faced with a patient, client or family with no traditional faith language, it can be difficult for the care provider to help them make sense of what is happening or find language for looking at a big picture of life. We have found a helpful hint that might be useful in these situations.

For someone with a religious faith background, their expression of meaning and purpose in light of their faith might sound something like this:

We are created by a God who loves us, and are created to bring love, to know love, to give love to others and to love God in return. In doing so, we have hope that we will be in communion with God for eternal life, experiencing everlasting joy and peace.

In speaking with someone who may not have a belief in being in relationship with God, one could still allude to the same framework, inserting the word “love” wherever the word “God” is used. Most faith traditions teach that God is love; believers can therefore make the transition to this language in good conscience and with heart. The new statement might sound like this:

We are created out of love, to live a life of love; to love others, to know love, to give and receive love. We come to know that our love will live on forever in those whose lives we have touched, and that indeed, love is stronger than death.

Many care partners have found this suggestion helpful in engaging others to speak about how love and relationships provide meaning, purpose and a sense of a lasting legacy.

For patients or clients who do have a faith background, encourage them to explore their spiritual questions by inviting

them to reflect on their life of faith: “How has your faith helped you in the past?” “How is your faith helping you now?” Taking steps to reconnect people to their religious tradition or faith community if they have been away for a long time may also be helpful, if someone expresses a desire for this. Exploring spiritual questions with others from one’s own faith tradition may allow for the opportunity to talk about beliefs together, to share prayers, scripture readings, or other rituals and expressions of faith. However, this must only be done when requested or deemed comfortable by the person or their family. It is never appropriate to impose your own beliefs, even if you share a similar religious background.

Feeling comfortable exploring spiritual questions and identifying spiritual distress is important when journeying with those at end-of-life. Seeking comfort from a spiritual tradition, a faith community, a relationship with a loving, forgiving and merciful God, and discovering the gift of love in living and legacy all assist greatly in providing support and easing spiritual distress for the dying and their loved ones.

REFLECTION QUESTIONS

1. Was I truly present, open and non-judgmental in exploring these areas with the person? How?
2. Did I have a sense of sacred energy or grace in our conversation? How so?
3. Am I feeling more comfortable assessing signs of spiritual distress? What learning might I pursue in this area?
4. What were some of my own emotions? Questions? Fears?
5. Are my own spiritual questions surfacing? Are they being addressed? Do I have someone to talk to about this within my own life?
6. Do I need to follow up? Debrief? How could I pursue that?