

Taking Care: words for hospice

A homily by Jane Slemon

May 17, 2015 at the Unitarian Church of Vancouver, BC

© 2015 Unitarian Church of Vancouver

In J.M. Barrie's play, Peter Pan stands upon a rock that protrudes out of the ocean, stranded there by Captain Hook. The cruel gesture is that Peter must watch death approach: as the tide comes in, the dark heads appear, floating around him in a circle so that he faces those rising waters and the teeth of hungry alligators and says, "To die will be an *awfully big* adventure."

Accepting palliative care, when a doctor or home care nurse suggests it, might feel like giving in. It might feel like health care has given up on us. What we are doing is letting go of treatments with the goal of cure and accepting treatments with the goal of comfort. Some of us spend years in the stage of accepting palliative care at home. The word, coined only 40 years ago, is becoming more common, and many people accept a combination of palliative and curative treatments, even in hospice. Hospice—from the word hospitality and its connotations of making space for someone specific to their needs—is a place of accompaniment, a place to be present for someone's last while on earth, accompaniment of body and spirit. Families choose hospice when dying at home proves a little too difficult or if care is too complex. And certainly accepting hospice philosophy can be an emotional and difficult transition. But many who come to hospice are surprised by how full and satisfying those final days, weeks or months can be—how devoid of pain and discomfort, how free from fear or from the tiresome navigation of health care, even how peaceful and joyful it can be. Because I am daily uplifted by people who share with the staff their celebrations and stories, who gather in rooms and laugh, and sing and cry, I wanted to share with my congregation what I have learned, what anticipating our dying times can do to enrich our lives today. I wanted to share with you the notion of dying well. I told a friend of mine about my topic, and she laughed: "Dying well, you mean we have to do *that too*?" Well, I have no idea what will happen to any of us, true, but I do believe in preparing ourselves, as if we will have a little while to contemplate dying, for the sake of those days, sure, but also for the quality of our lives and relationships right now.

The hospice, where I work as Director of Care, is a home with two fireplaces, a dining room, and a piano. I have always loved walking in and seeing the fire glowing. Each single bedroom in our hospice opens its double doors to a great green yard rich with flowers, birds and bulrushes. When I first threw open the curtains for a new resident, Alfred, he said, “take me back there where the horses are” so I wheeled him out there to sit a while, minus the horses, and we listened to the bird sounds, a peregrine falcon perching up on a dead tree over the neighbouring blueberry orchard—and we could imagine horses. Nursing there involves everything from the terrifically “mundane” to the most puzzling and complex “myster[ies]” of physical assessment and the human spirit (Thorne). Without more than rudimentary diagnostics available at hospice (although anything of that nature *is* available if someone needs it from a nearby hospital), nurses combine physical assessment and medical knowledge with what the resident is telling them. Faced with a symptom, the nurse might reason—is this something we can reverse, is it something we want to reverse, is it causing discomfort or is the discomfort just in the family member, does the individual have a value that is affecting what they feel in some negative or positive way? It used to be that caring for the dying was *what you do when there is nothing left to do*, but there is indeed plenty to know and do, plenty that is specific to the human activity of dying. And yet everyone who is dying is doing something they have never done before and something they’ll do in their own unique way.

Every year on my birthday I give myself a word. Throughout the year, I ponder its meanings, watch it find new contexts. From these birthday presents, I have brought six words with me today—words that have become old friends, joists of my philosophy, to help me to talk about Taking Care, and all that hospice has come to mean to me. My words are, **foundation, time, breathe, listen, quiet, and honour.**

1. Foundation

When I was a new nurse and working at an extended care hospital out at UBC, I met such a range of people nearing the ends of their lives, and I noticed a key difference among them. Some seemed beyond the reach of others; they hid their eyes and avoided communication. And others connected with their eyes or their hands. Even if their speech was a nonsensical *word salad*, they communicated with tone of voice and body language, and I felt their trust. So

I pondered how it was that some people were so open at the ends of their lives while others were shut and distant. Did the quality of their dying days have anything to do with the way they had approached their lives? I began to ask them their stories. I was nineteen and building my own **foundation**. I was embarking on that classic decade of confusion, my 20s—confusion about whether I was in the right field of work, whether I'd ever find love and community. I learned pretty quickly that talking about death and dying didn't go over well at parties. And I learned that if I kept my hopes and sorrows inside me, my spirit would dwindle and fold in on itself. To die well—like some of these terrifically old ladies who'd once been professors and activists (goodness, one lady told me she'd been kicked off the trolleybus in the middle of the Burrard street bridge for saying the word “cancer” in public, it was 1948)—to die well meant to live well. It meant taking care not just at the end, but now. It meant taking care to entertain questions that would build **foundation**. I asked myself, Am I challenging myself in good ways? Ways that make my heart beat with a healthy excitement? Do I need to apologize? Should I take responsibility? Palliative care physician Ira Byock says we should contemplate these five things as we near the ends of our lives: *forgive me, I forgive you, thank you, I love you, goodbye*. Well, it's not a bad list for any day of our lives. And what are the more individual questions that speak the goals we give ourselves in this our “one wild and precious life”? (Mary Oliver, “Summer Day”).

2. Time

Time doesn't always heal. Martin Luther King taught us that in his letter from Birmingham Jail when he pointed out that 340 years of slavery didn't end because time passed. And when the injury is to a relationship, **time** is more likely to exacerbate the wound than to heal it. If a silence or a comment we've made causes remorse and “reconciliation doesn't occur on time,” then, as David J Roy says, “remorse has the human spirit all to itself” (“They Touched Hands Again” 2014). While we have breath and voice, we have the means to ask forgiveness of those we've hurt. We can “untie the strands of humanity that have become a tight knot of rage or hatred” releasing spirit and the mind. At the hospice, I have seen emotions tie people up: Keela felt the guilt of leaving her children too soon; Dwayne felt the shame of his addiction; Shelly spoke of her remorse about why her sister was now estranged; others have spoken of confusion, disconnectedness, even frustration with bureaucratic agencies, and their family's

financial worries. Those are emotions that can contribute to what we in palliative care call ***total pain***—a term coined by Cicely Saunders, who was the founder of the hospice movement (she lived until 2005) and who dedicated her life to research that helped us better understand how to comfort or to *palliate* the dying.

Pain is subjective, totally subjective. If Agnes tells me she is in pain, then she is. I can assess her body for physical signs of discomfort; I will watch her face; and I will ask her to describe it, noting whether her words indicate a radiating pain, or the pain of bones, or of pressure on a nerve, which might merit treatment with ice or repositioning, or which might indicate some chemical treatment, Tylenol or morphine, or something to correct a chemical imbalance. But if Agnes is feeling emotional pain, no amount of morphine will help. So if I take time, if I am listening bravely, I can consider whether her discomfort is caused by some unhappiness more difficult to sort out. “Grief is exactly the weight of a sleeping child,” says Ann Michaels. The pain in someone’s belly may be a *please forgive me* that has been left unsaid or said too late. I sat with a dying man once, his adult children in a circle around him, and heard him whisper the words, “all is forgiven,” and his children said not a thing; they were too badly bruised by the past to absolve him. Leonard Cohen tells us, “There ain’t no cure for love.” So too, there isn’t no cure for remorse other than to communicate our feelings early enough. If I am present and attentive when that sort of window opens in a conversation, when a bit of honest language brings in a fresh and healing breeze, then perhaps there is time enough for healing—and then perhaps the days can hold less worry, more togetherness, some peace in the morning light, in view of the astonishing beauty of robins on a wet lawn and a tree moving slowly in a breeze.

3. Breathe

Breathing together we are in quiet conversation. The chest that rises and falls engages me in that simplest of gestures, that natural exchange of gases, connecting organelle and cell to blood stream and lung, to the room and those in the room, and to the air and the birds outside the window. I walk into June’s room and within a minute am breathing at her exact rate, depth and rhythm. June has glioblastoma, brain cancer, and can no longer find her words, but, when she is awake, she and I will sit and converse, body language and tone more meaningful than our words. While she sleeps, I look for any labour in her accessory muscles, and by mirroring

her breathing I feel in my own body for whether she is getting enough oxygen. June is sleeping peacefully.

Next door, Lucy's every breath has a terrible rattle.

"Are you short of breath?" I ask her, and she replies, "Oh no, I'm fine. Is that... a flicker ... I'm seeing ... on the lawn... a fledgling?"

Lucy was wheeled in on a stretcher from the hospital, announcing she was ready to die that very day; she had *said and done* all she needed to *say and do*. But she took in the view from her hospice bed, tasted the food made just for her, and amended her goal—she wanted to live another week. The next day, after experiencing our shower spa and telling the care aide, Lisa, "that! Was! Heaven!" her goal altered again: she wanted to live two weeks and get in another shower. Lucy got what she set her mind to. Her family gathered around her bed, told stories, laughed together and raised their Dixie cups to her. (I officially don't know what was in those Dixie cups.) She was often seen with a grandchild tucked under her wing in bed.

Maurie was strong, a swimmer in her 50s. Cancer brought her to us and her friends and family festooned the room with butterflies and created a schedule, so that someone was always there with her. She declined slowly and became almost unresponsive; yet, she found ways to remain part of the party. When friends talked in the room, she would sometimes smile deep joy in her face. Lisa walked in one day, whistling the tune, "Whistle While you Work" and Maurie pursed her lips, ready to whistle along had she been able to. Because she could hear us, she was with us still, letting us know the voices she knew meant something: her friends sat around and told stories and laughed together and let their tears stream down their faces whenever Maurie cracked a smile. They were keeping Maurie in the circle.

We breathe together, as well, when we share our advance directives, when we let someone know what we want to have happen at the end of our life. I might say, Bob, you are my decision maker; *if the quality of my life no longer affords me joy—joy in sleep, in food, in finding comfort, joy in the accompaniment of people—let me go. And if there's a decision you can make for me, go ahead and make it. And if in doing so something goes wrong, It's okay. Don't worry. If you can't be with me as I go, don't worry. I'm fine.* In sharing this with someone I trust, I am asking him to lean in; breathe with me; help me determine whether I'm comfortable, whether I want to fight this new infection or under the circumstances let it take

me. We who are standing by *breathe with the one who is dying*: we gather all that can be gathered: we listen for the untold story in the room, and we learn from what's said at meetings with the hospice team and the family, so everyone has a chance to speak candidly about whether our goals of care are exactly right for the situation. In 6 months time, families should be able to say, "That was a good death; that was a peaceful passing." So while palliative care begins with the quiet conversation of breathing together, it should also protect our memories and send us along on our way with the knowledge we did all we could have done, for the body, for the heart, for the spirit.

4. Listen

One of the things I love about this church is that we learn about different religions, uncovering the remarkable similarities among them, and we connect the perils of the physical and natural world to the spiritual truths we might find, clearing new philosophical pathways for us to walk along. We talk of practicing an open mind, and we ponder what we might make our own from each new perspective. When a member of our church found she had just months to live, she revealed what had been up to then secret—she said, "there's too little God here." She found another church where she knew no one but where God was spoken of more comfortably. I will never forget the bravery of her decision, nor that our church didn't have what her spirit needed. I admire her will to continue asking questions that let her seek comfort where it could be found. She entertained a brand new spiritual structure; how very Unitarian. At the hospice, the residents bring with them a huge variety of beliefs. In listening, I accept that there are times people find hope in being part of a story, a story as wide as the universe, for as Northrup Frye taught me, that is the divine: we make up stories; "we want to know in part, but we also want to be a part of what we know" (Paul, First Corinthians 13, quoted in "Motive for Metaphor"). In more ways than one, each family speaks a different language, rich in its own meanings and symbols, carrying different values even to things like hot and cold drinks, foods, stoicism, and the colour of blankets. And often people are still developing their own philosophies. Doubts challenge a previously unquestioned idea and sets new questions into motion. And so we enter into the simple act of wondering what "awfully big adventure" waits and we choose which metaphors to live by.

Today, only 50% of Canadians have access to palliative care. We have not yet developed a society that argues for a full complement of palliative caregivers trained specifically to alleviate the suffering of the dying. Suffering, says Elizabeth Kubler Ross, “reminds us of our lack of omnipotence [...] and our own mortality.” In Shakespeare’s play, King Lear suddenly recognizes that people in his kingdom suffer—poor Tom stands before him, nearly naked and shivering in the storm, and Lear suddenly knows he has taken “too little care of this”: He bellows to himself, “Expose thyself to feel what wretches feel, That thou mayst shake the superflux to them, And show the heavens more just.” In the human act of caring for one another, in “shak[ing] the superflux,” that is, the extra coin from our pockets, or the bit of extra time we have to sit with someone—whatever we can give—we take care of those who are suffering and so, miraculously, find the “heavens more just.”

The United Nations Committee on Economic, Social and Cultural Rights presently recognizes palliative care as part of the right to health, but the United Nations doesn’t as yet include “hospice and palliative care” in its list of Sustainable Development Goals for 2015-30. That means if aid for palliative care is needed elsewhere in the world, Canada is likely to hesitate in responding, instead, channeling aid monies to items on the list. I was present in Montreal last September (2014), when Stephen Lewis spoke to the International Palliative Care community about the importance of achieving this addition to the list of goals. In Africa, Lewis told us, women who care for the dying are valued less and are given less support than their own infants—because the well-being of the infant *is* listed on the Sustainable Development Goals. His passionate words gave rise to the Declaration on Palliative Care, a petition we all eagerly signed (and which, btw, you can find at www.palliativecare.ca). If the international community could shift its priorities so that people are given support in the care of the dying, then we would be able to guide people in their work, protect them from disease as they do so, and honour the value of what they already do within the society. And then we could help to change the plight of caregivers, bring a more humane approach to the care of the dying, and indeed *find the heavens more just*.

5. Quiet

The hospice has about 40 trained volunteers, each with his and her particular gift and character. People come to massage hands, to sit, to bring trays, to plant flowers. Our quietest

volunteer is a curly haired terrier called Abby, and Craig is her caretaker and partner. With Craig's help in assessing who might benefit from a visit, Abby knows how to find the perfect spot to curl up on someone's bed, knows how to let an uneventful afternoon become a good snuggle. Responsive as a dancer, Abby teaches us how to be sensitive about when to lead and when to follow.

Last summer, Keela arrived depressed, withdrawn and angry. It wasn't easy at first to approach her. Keela had school-aged children who came with their homework in the evenings, but the family didn't seem at ease with one another. What could they talk about, bewildered and angry in their own ways. When I asked if she wanted to escape to a nearby park, using a wheelchair, she said, "Can we?" At the park, we sat quietly and watched ducks floating or children playing. I would choose a single word, anything—*playground* or *hair* or *cars*—and she would let the word jog a memory from her life. I would guide her through a meditation on the memory and then, as she began to speak, I'd write down what she said, later working with her to find the line breaks and places the words on a page. One of her poems told of when she was three and stood utterly still in a playground because a bee had settled on her foot, and, since she was startled into stillness, her ice-cream dripped down her hand in the hot Trinidad sun. Another poem told of her being 16 and strutting in great determination to the beauty salon with the intention of totally transforming herself; when she looked in the mirror, she was shocked and staring at a pink David Bowie, her lovely long pony tail stolen, thinking, how will I go to school tomorrow? Her family had never heard these stories before, and they wanted more.

In her final weeks, Keela's family spent evenings at the hospice gazebo, talking softly as the sun turned golden and slanted sideways through the yard. The poet in Mary Oliver's "Summer Day," "know[s] how to pay attention, [...] how to kneel down in the grass,/ how to be idle and blessed ," and asks, "Doesn't everything die at last, and too soon?" The speaker shares with us that most essential question: "Tell me, what is it you plan to do with your one wild and precious life?" We don't know if we will die with enough consciousness to think and wonder in the quiet as, like Peter Pan, we feel death approaching. But in preparing our minds, in practicing peacefulness, self-comfort, memory, and mindfulness as we go through this good day, we are doing ourselves that kind favour of preparing nonetheless. We are treating the

mind as if all will be well; we are living with the brave conviction that pain can be controlled and the spirit can be comforted.

6. Honour

Whatever sad situation it is that brings one to hospice may be tragic, but it need not *only* be tragic. People wonder, will I be a burden? No one is a burden, because in dying we give those we love a chance to be with us and witness final and potent days. It is a sacred time. In accompanying someone, body and soul, we experience and express the meanings we carry deep in our hearts. The word honour rings in the air everyday at the hospice, because the word truly describes what people feel to be there: “Honoured to meet you, Sir. “ “It’s an honour to have this chance to sit with you, Mom.”

It was an honour to meet Alan Dawe, UBC Professor of English, who came to us a few weeks before the end of his life. He gently inquired as to whether we could help him to hurry this mortal process. We let him know we couldn’t do anything to shorten his life, but nor would we do anything to prolong it. What we could do was find the right medications, we could omit any medications he didn’t want to take, we could add treatments or adjust his environment—anything that would bring him painlessness or the level of consciousness he desired as nature took its course. Alan was intrigued with those he met at the hospice and found the golden story in everyone. He enjoyed telling stories of his writerly life as he kicked his feet under his quilt. We gazed across the wet November lawn, the light beginning to fade. I recited the poem I knew by heart: “Song,” by Seamus Heaney: “And the moment when the bird sings/ very closes to the music of what happens.” He listened, then, in a whisper, honoured me with his own, first explaining the poetic form of the villanelle with two lines that repeat alternatively until the end when they fold together before the silence: As I listened, time stood still.

A Villanelle by Alan Dawe

The voices coming from my radio
Bring sounds of baseball on the summer air
As we wait another hit by Ichiro.

Out in the courtyard, clumps of daisies glow,
They dominate the afternoon I share
With the voices coming from my radio.

The early innings of the game are slow,
Plays that excite the crowd are rare,
As we wait another hit by Ichiro.

Safe in their cars, my neighbours come and go,
Their destinations could be anywhere.
I stay with the voices coming from my radio.

The “eyes of the day” will soon be gone, I know.
Their glow will fade, then not be there,
As we wait another hit by Ichiro.

Late innings now. The courtyard shadows grow.
The days are passing. Now with few to spare,
I have the voices coming from my radio,
And wait another hit by Ichiro.

(used and reprinted her with permission from Alan and Jonathan Dawe)

It seemed, as he spoke, he had been saving it, like Frederick who has collected the colours of summer and gathered words; for Frederick words were supplies brought into winter to help his friends get through the grey days (re: *Frederick* by Leo Leoni).

In the poem’s images, I witnessed anticipation, a sliver of hope perhaps: not hope to live on forever, but hope that this moment too can be beautiful, meaningful, or simply shared with another person. Alan chose a different sort of leave-taking: he said sweet good-byes to his adult children and then told them to get back on their planes, back to their families, and leave him alone. He preferred his death to be a private affair. Beyond searching for a cure, beyond any struggle associated with navigating health care, Alan’s mind was richly prepared with images and stories. There came the day we wheeled his body down the hall to the van, draped by our Leaving Quilt, one of many quilts made by a local group of volunteers, the whole hospice team standing silently together as the van drove away.

Our silent farewell to Alan Dawe was also a thank you, thank you for trusting us, for letting us take care of you and for letting us honour you at that time of your life.

A year is a long time to live with a single word and see it find so many contexts and meanings. I wonder how many I’ll have gathered for my final poem. Just as every word’s usage lends it

new light and new meaning, so does everyone who comes to hospice bring new meaning to what palliative care is and can be. This week is National Nurse's Week. And I want to tell you, I am honoured to be a nurse, to be involved in people's lives in this way, to be told or even to be a part of their stories, to be the one taking care of mundane things that bring comfort or to be the one to find a creative solution, to be always learning practical knowledge in a field that is just beginning to flourish, and to witness the mystery of each human spirit—bringing meaning to every single day I live and breathe.

Frye, Northrup. "Motive for Metaphor." *The Educated Imagination*. Anansi 1993. Print.

Thorne, S. (2011). "Theoretical issues in nursing." In J. C. Ross-Kerr & M.J. Wood (Eds.), *Canadian nursing: Issues and perspectives* (5th ed.) (pp. 85-104). Toronto: Elsevier. Print.

Roy, David J. "They Touched Hands Again: A meditation on reconciliation." *Journal of Palliative Care*. Autumn 2014. Print.

17 May 2015 Readings:

Song

by Seamus Heaney

A rowan like a lipsticked girl.
Between the by road and the main road
Alders stand off among the rushes
At a wet and dripping distance

There are the mud-flowers of dialect
And the immortelles of perfect pitch
And the moment when the bird sings
Very close to the music of what happens.

from *Field Notes*

The Summer Day by Mary Oliver

Who made the world?
Who made the swan, and the black bear?
Who made the grasshopper?
This grasshopper, I mean the one who has flung herself
out of the grass,
the one who is eating sugar out of my hand,
who is moving her jaws back and forth instead of up and
down-who is gazing around with her enormous and
complicated eyes.
Now she lifts her pale forearms and thoroughly washes
her face.

Now she snaps her wings open, and floats away.
I don't know exactly what a prayer is.
I do know how to pay attention, how to fall down
into the grass, how to kneel down in the grass,
how to be idle and blessed, how to stroll through the fields,
which is what I have been doing all day.
Tell me, what else should I have done?
Doesn't everything die at last, and too soon?
Tell me, what is it you plan to do with your one wild and
precious life?