

Life trumps death

Death is a powerful thing, no doubt about it. Its persistent existence is unavoidable and it shapes our lives and decisions. Despite our best efforts, it continues to be the eventual destination for all of us and for all things that live. Death is a mysterious thing, often defying explanations of meaning and scientifically ambiguous in its border with life. It breaks our hearts, leads us to question our beliefs and can sap our will to live. It scares us to...well, you know. In fairness, death is sometimes also a comfort and relief, a place of rest and a source of peace. But most often, death is a source of fear and pain.

One of the ways that death demonstrates its power is how it dominates our thoughts when someone dies. The fact of the person's death, and many times the manner of the person's death, consumes us and it is difficult to think of anything else. Everywhere we look, we see it. When we try to put our minds elsewhere, sights, sounds, smells, big and little reminders all bring back the harsh reality of the death and the person's absence. In this way death seems alive, refusing to stay buried or stay put as it is our ever-present companion. While we can think of death as stillness, our experience of death can have great vitality and flexibility. Death demands our attention and refuses to be ignored.

Death's domination of our thoughts can especially be a challenge when a death has been unexpected and even more so if the death was violent. We relive our memories or imaginings of the death trying to understand what has occurred and convince ourselves that it was and is real. A car accident, a sudden heart attack, a suicide, a murder. When these occur, it is difficult to think of the person without at the same time thinking of their dying. Of course, this dynamic can be found in any type of death even when we have had opportunities to prepare ourselves for its coming.

Living, as we all do, in death's wake, we learn that death has its limitations. No matter the death-who the person was, how it came about, whether or not we saw it coming-a person's death is exceeded in importance by the person's life. The most important thing about those who have died is not that they have died. The most important thing is that they lived. Life trumps death. This is a truth that is more

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comprehensible with distance from death. The more time goes by, the more we can remember times of living without having them overwhelmed by memories and thoughts of the death. Years, months, weeks, days, hours, minutes or even seconds of living are ultimately more important and valuable than death. Even for babies who never breathe a breath of their own, love, hope and connectedness were present and these are part of life, and thus they, too, trump death.

Death is not small and is far from trivial. Death can stop one from living, but it cannot erase the life lived. That life continues and has life of its own. This truth was illustrated recently in a local elementary classroom. A much-loved teacher had died suddenly with an apparent heart attack. Shocking and unexpected, it was difficult for all who knew her, including her students, to take it in. In the week following the funeral, we had a discussion about the teacher and her death. As I had not known the teacher, after talking about what she was like, I asked the students to each draw me a picture of her. All the pictures expressed something special, but one particularly stood out. In this picture there is a casket, a sun, and some windows, but they are toward the edge of the paper as the figure of a smiling teacher dominates the page. Coming out on both sides of her drawn figure is a "super hero cape" (labeled accordingly) and the artist's picture of himself, much smaller than the teacher, smiling with his hands above his head holding on to the end of the cape. On the shoulders and arms of the teacher are small, smiling, stick-figure children. The impact of the teacher's death and absence is obviously huge, but is it bigger than the positive impact that she made on her students in life? Absolutely not. As sad as her death is, her life is what counted and counts the most. Life, not death, gets to carry children on her shoulders and wear a super hero cape.

Carrying loss

Several times a year I lead the discussion in a training series about pediatric palliative care and the first video that we watch each time is of an African-American grandmother and grandfather telling the story of their granddaughter who died with cancer. As their granddaughter's death comes near, they share about how they decided what things to do to keep their granddaughter comfortable, what medical interventions were not appropriate and how they left the ultimate outcome to God.

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At the end of her explanation the grandmother calmly concludes, "That's how I carry it." It is a heavy burden to care for a granddaughter who dies from cancer and to be confronted with decisions that affect the nature of that dying experience but the grandmother found her way. "That's how I carry it," she says.

Isn't this the challenge for the rest of us, too, finding ways to carry our experiences, good and bad, gifts and losses, with us? We work to make sense of the world around us. Sometimes there are answers and ways to explain what happens and sometimes situations defy explanation—which is an explanation in itself: It's one of those unexplainable things. However we find or don't find sense in our experiences, our challenge is still to find a way to carry them with us.

Now some of us admittedly carry too much. We can do this in different ways. There are times when we have a loss, cradle it in our hands, hold it for a while and then toss it over our shoulder thinking (or pretending) to be finished with it. But it's not finished with us. What we don't realize at the time is that as we toss it over our shoulder it just takes its place on the pile of unfinished business that we carry in the bushel basket on our backs. Some of our baskets have great capacity—lots of space for lots of heavy things and we wonder why we are so tired so much of the time and why our bodies and spirits break down. We are weighted down and in need of finding a way to lighten our burden. We are carrying too much.

Another way we carry too much is to take on what really doesn't belong to us—it's too big for any one person to carry. Guilt is a sneaky and tricky traveling companion continually trying to get us to feel responsible for and carry things which are too big. We can wear ourselves out trying and trying to carry those guilty burdens but it's a setup and we won't succeed. We can only do so much and the grandmother from the video understood that. She understood that some things she could control and some things were out of her control, and that's how she was able to carry it.

There's at least one other perspective of how we carry the losses of our lives. Along with finding a way to make sense of our experiences, sometimes we can find additional strength to do our carrying. David Browning wrote about his experience (*Living with Dying*, 2004) with an unusually insightful and articulate nine-year-old girl who came to him for counseling following the unexpected death of her brother.

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After the girl's grief improved she was ready to end therapy but David was not as he wanted to continue to be of help and assistance in her healing. The girl eventually explained that when they first met she had been like a girl carrying the burden of two buckets but now she had only one bucket to carry. David wanted to help her empty that second bucket, too, but the girl had other ideas. "That's the bucket I need to carry with me as I get older...But it's okay, because I'm feeling better. I'm ready to go ahead with my life now. And you helped me feel strong enough to carry that bucket." And that's how she carried it.

Grief as gratitude

Several years ago at a pediatric oncology social work conference, I had the opportunity to hear Rev. John Claypool speak. Rev. Claypool was a pastor in the Christian tradition (first Baptist and later Episcopal) and he spoke to us about his experience of having a young daughter who eventually died from cancer. I had heard bits and pieces about Rev. Claypool over the years and of his book, *Tracks of a Fellow Struggler*, which is mostly comprised of four sermons that he preached following his daughter's death. In his talk at the conference, Rev. Claypool told of getting up in the night and going to his study to read a number of months after his daughter had died. For some reason, he picked up a German theology book and read one theologian's take on the story of Abraham and Isaac from the book of Genesis in the Hebrew scriptures. Rev. Claypool admitted that like many others in his religious tradition, this had always been a difficult story. In their old age, Abraham and his wife Sarah had finally had a son through whom a great nation was supposed to come. When Isaac had grown into a boy, God came to Abraham and told him to kill Isaac—to sacrifice him on an altar to God. Abraham obeyed but was stopped by God at the last moment as God provided a ram to sacrifice instead. A challenging story which raises hard questions. Grieving his daughter's death and reading a German theologian in the middle of the night, an insight came (was given?) to Rev. Claypool: Instead of focusing only on the loss of his daughter, he could also focus on the blessing of her life. He had had the privilege of knowing her and being her father. This experience had not been lost and it continued with him, was part of him. She was a part of him. In the midst of his grief, as a facet of his grief, he experienced a true and deep sense of gratitude.

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Rev. Claypool's story came back to me recently as my dad sent me a picture in the mail of a young maple tree dressed in orange leaves for the fall. Our family planted that tree last October on my mother's first birthday after her death the August before. On the back of the card my dad included the date and the name of the type tree we had planted: October Glory. In the midst of the missing, I felt gratitude that I had a mother befitting the title and beauty of this tree.

Many of us have had similar experiences after loss where gratitude becomes a significant part of our grief experience. Sometimes it comes suddenly and dramatically. Perhaps more often it comes like other experiences of deepening wisdom, gradually, unconscious at first but eventually accumulating into our awareness. The experience and comfort of grief as gratitude comes from within, not from without—it cannot be imposed by others no matter how well-meaning. In the movie *500 Days of Summer*, the main character, Tom, has experienced a great loss and a friend shares the well-worn phrase, "it is better to have loved and lost than to have never loved at all." Tom stares and with no change of facial expression replies flatly, "Try it."

When gratitude does come, it is a needed solace and reminder that in the midst of loss there are things that remain. Experiences, memories, lessons learned, gifts given, tender and joyful times, affirmations. How wonderful it is to have had an amazing daughter. How good to have had a loving grandmother, a nurturing father, the comfort of a brother or sister, the faithfulness of friend, the affirmation of a spouse and lover. Loss need not, and really cannot, be minimized and it's not an either-or kind of thing. Losses are real as well as the pain that comes with them. Gratitude can be real, too, as well as its sources. When gratitude comes and comforts, it is part of the softening of the edges of grief and for this we can be thankful. A welcome and true experience of thanksgiving.

To wait, to hope

Last spring I spent almost two weeks in Antigua, Guatemala with my daughter and a group of high school Spanish students, their teacher and parent chaperones. The students went to learn more Spanish, be immersed in and exposed to Latin American culture and see another part of the world. Each weekday students and chaperones

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spent the morning in small-group Spanish classes. I was placed with a few other parent chaperones who also had limited knowledge of the Spanish language. Despite our teacher's faithful efforts (she seemed to think we adults came because of a passion to learn Spanish—we came mostly to keep the teenagers out of trouble), I learned little Spanish and even less has stayed with me. My nickname on the trip became "Señor No Se" (Mr. I Don't Know) and my other major use of Spanish was "lo siento" (I am sorry).

While sharing a mutual sense of exasperation with my teacher, there was one high point of our morning classes. One day while reviewing vocabulary and verb conjugations, my teacher read, "Esperar—to wait, to hope." I sat up (at least internally) and asked her to repeat this and clarify which she did and then continued with more vocabulary and verbs (none of which I remember). "To wait, to hope"...the same word with varying levels of meaning, different parts of a common experience, alternative ways of thinking about the same thing. As I've heard more than one pastor say, that'll preach. I learned something after all.

To wait. For a diagnosis, test results, news about whether or not someone will be OK, whether or not someone has died. To wait. For when it will start to feel better, to sleep through the night, for telling the story without tears, for smiles to come along with the memories, for laughing again, for new relationships, for answers to the questions. Who wants to wait for such things? Waiting is not a nice word. For seeming such a passive thing, waiting can be exhausting.

To wait and hope—now that feels different. Even if waiting can feel helpless, *esperar* suggests that it's not hopeless. To wait is to hope and vice versa, to hope is to wait. While waiting suggests passivity, hoping suggests something different. Perhaps situations and people can make us wait, but no situation and no person can decide about our hope. Hoping is up to us.

So as we wait, we hope and as we hope, we wait. What's coming is not here yet. That encouraging news, that brighter day, the strength to get up and try again, that first sense of soft light after a long, long night. This kind of waiting is not easy and this kind of hope is not cheap—waiting can be excruciating and hope is often born out of

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pain. Yet we don't have to experience our griefs as victims. We can choose to wait, we can choose to hope.

We wait and hope for both beginnings and endings. My Guatemalan Spanish teacher was pregnant and I would guess that for her "esperar" was much more than a vocabulary word. Since returning from Guatemala I have learned that esperar can also mean "to expect". Something new is coming, something that can't be rushed, can't be predetermined and in the end is beyond us. So we wait and we hope and sometimes we even expect. Esperamos.

My teacher would be so proud. And so surprised.

Hope won't leave us alone

I've seen the flame of hope among the hopeless

And that was truly the biggest heartbreak of all

That was the straw that broke me open

Bruce Cockburn, singer/songwriter

The Last Night of the World

Hope won't stay away, just won't leave us alone. It's everywhere and in places where we might least expect it.

We have a palliative care program here at Arkansas Children's Hospital. The Palliative Care team follows children who have "life-limiting conditions"-very serious medical conditions which will likely cause them to die before reaching adulthood. Most of the children met don't come close to adulthood as they die within a year or two after the Palliative Care team meets them. Having a child with such a serious medical condition is a nightmare scenario and one of the heavier places in the world that we imagine. In the past three years we asked parents of these children to complete a few selected surveys to help us better understand their needs and concerns. One survey asked about different facets of hope in life and we have seen something extraordinary. Despite the burdens of having a child with an expected shortened life,

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the overwhelming majority of parents reported a strong sense of hopefulness in life on their surveys. Even in such challenging circumstances, it is hard to get rid of hope.

Now hope is a tricky one and can be covert. In difficult times, hope is not always obvious-it can go undercover, sometimes deeply undercover. When we look at life on the surface, we may not see any evidence of hope and doubt that hope survives. It's the discontent that we can see on the surface that lets us know that hope is present somewhere beneath the layers. Discontent comes because we, or at least part of us, believe that things could or should be better. To believe so means that part of us believes that it is possible for things to be better, and when we believe that it is possible that life can be better, we do so because of the presence of hope: hope disguised as discontent. Writer and therapist David Seaburn describes hope as the belief that the story can change. Our life and our story are not going well and the narrative trajectory is discouraging, yet hope says that the ending of the story is not yet written and something good can happen still. We feel discontent-frustration, anger, depression-because we have not yet given up on the possibility of a better outcome. If hope had truly disappeared, then discontent would lose its source.

We sell hope short too often because we think that hope can only take one form. Many times this form is that of a miracle cure or the rescue from death and its consequences. If that number one thing on the list doesn't come to pass or becomes impossible, then the temptation is to believe that hope is lost. Perhaps we lose sight of hope, but hope generally doesn't leave us-hope is not into abandonment. Instead, hope is both a shape shifter and reproduction machine. Hope can and does change form to fit a new reality and hope divides into different forms that can coexist. In a life-threatening situation, we can hope for the miracle cure, more good time if a cure does not come, less suffering, and a peaceful death all at the same time. Hope refuses to be pinned down and locked in.

Sadly, there are situations in which hope can't be found within a person. In these cases, despair and pain have left no room for hope, even in its discontent disguise. It is here where the risk of suicide is present as there may be no tempting thought that life can be better and no space found for hope. Hope is not one to give up, however, and it will find temporary sanctuary in the hearts and minds of others who hold hope for the despairing one. Hope is patient and waits for the first opportunity to fill the

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space left as pain and despair begin to lessen. Until that time, we can hold hope for another. This may be one of the few things we have to offer in this dark place, but holding hope is a powerful thing and not to be taken lightly.

Despite all the loss, illness, trauma and death in the world, most persevere because most have a sense that the last word has not been spoken, the last action not taken, there is more life to live, and maybe... well "maybe" is a sign of hope, and thankfully, hope just won't leave us alone.