We Cope by Coming Together: Chaplaining During Covid

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Erratum
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*Things fall apart; the centre cannot hold.* -William Butler Yeats, *The Second Coming*

When things fall apart, we cope by coming together. Everyone knows that bodily things fall apart when death draws near. On our hospice team, the nurses take the lead with the bodily casualties. The broken skin needs bandaged. The body fluids must be attended to. The pain and breathlessness call out to be eased.

Just as predictably, when dying creeps close, matters of the mind and heart require tending as our centers– our normal ways of keeping ourselves together – begin to lose hold. In hospice, we chaplains and our social work colleagues are specialists in caring for these wounds of spirit and soul. There is no obvious poultice for heartbreak; no prescription to banish fear, grief, uncertainty and loss of control. Because we cannot cure, we humbly walk beside to bear witness. We gently offer guidance shared by those who have walked their way before. We hold out a steadying hand, utter a prayer or blessing. Sing a lullaby. We bravely turn toward pain when some might turn away. We help loved ones to cope by coming together.

Before Covid, dying was already hard, of course. Accompanying loved ones in the face of death – what we do in hospice – wasn’t easy then, either. Yes, before Covid, our team’s work of midwifing the dying and their loved ones – primarily in retirement communities – was not easy. There was no roadmap or timetable. The primary tool in our toolkit was compassion. Things would still fall apart, but we could help families hold one another amidst the falling apart. We could reach out and touch or embrace. We could stand alongside a grieving spouse or child or – God forbid – parent at their loved one’s bedside. We could help them find words or water or the next breath when they could not find them on their own.

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Let me show you a window into this reality as I introduce you to Jack and Yolanda, to Charlie and Marie. Two elderly couples, both women living in nursing homes with end-stage dementia. Before Covid, both of their spouses visited regularly from home. Yolanda lived in more of a no-frills, budget nursing home. Marie lived in a fancier one with more staff and nicer upholstery. Amenities aside, both couples were rich in love and connection, with Jack and Charlie showing up daily with stories and snacks from home that had nothing to do with how much money was in the bank.
Jack’s visits reminded Yolanda that her dementia or amputated leg did not take away his love. He brought baggies of Pringles and Teddy Grahams to feed to his beloved, along with stories from sixty years together, loving a smile back onto Yolanda’s face.

Charlie came each day to the fancy nursing home to spend all afternoon with his wife Marie with advanced dementia. He would wheel her to the cafe in her wheelchair so they could each get a dish of ice cream. Or they’d sit by the window, looking out at the passing cars as he narrated stories of family and neighbors and she listened silently, no longer able to talk. Somehow, despite her silence, it seemed to the passerby that this daily routine reminded Marie to the core of her being that she was loved, that she still belonged. In other words, when dementia robbed these women of their memories – when their bodies and minds forgot how to do the stuff of living – these couples coped by coming together.

Our hospice team helped by affirming Jack and Charlie’s caregiving. By facilitating life review. By assisting with personal care; by preventing and treating bedsores; by collaborating to relieve pain. By educating families about what to expect as death drew nearer.

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Covid seemed to change everything about our caregiving, even for those who did not have Covid. Layers of plastic and nitrile and distance separated skin from skin, eye from eye. At times, we hospice caregivers were not permitted to visit. Even more frequently, family members could not see their dying loved ones face to face.

In early days of Covid, I felt unseen, my toolbox taken from me when the nursing home said only the hospice nurse and aide were essential visitors. Wound care and washing, it seemed, were essential, while seeing, holding, storytelling, connecting – the care of chaplains, and most importantly the love of families, were dispensable. Impossible decisions made in a boardroom or a government office, setting off cascades of heartache.

I struggled with new dimensions of powerlessness in a profession where numbness to death had already crept in. Where guilt over forgetting a soul’s name was common. Where relief over a death when caseloads were too high was felt but only secretly admitted. I also felt disconnected from my tribe. Essential collegial connections were made through layers of PPE or, more commonly, through a laptop screen.

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For Jack and Yolanda, Charlie and Marie, when Covid came to town, all their visits ceased from one day to the next. What remained were silent, lonely afternoons for these husbands and wives. As
days, weeks and months passed, necessity became the mother of invention as families sought some way, any way, to connect. So many tools of compassion and coming together had to be reinvented.

In the summer months, Jack and Yolanda’s daughter once brought her dad to the nursing home so they could drive by in a Covid car parade and wave at Yolanda, who was sitting outside in her wheelchair, lined up with other residents. In early fall, before the weather got cold and the surge hit, they were able to have some visits outdoors with a plexiglass shield keeping them six feet apart. Before Yolanda died this winter, Jack and their daughter were allowed one last visit at her side, holding her hand, allowing her to hear one last time the cadence of their voices as they said “I love you.”

Even though Marie lived in the fancy nursing home, her family didn’t have it as good. As her spring birthday approached, Marie had stopped eating. For her birthday, Charlie brought their sons and grandkids for a window visit. Since she was now too sick to be up in a wheelchair, Marie was wheeled in her hospital bed to the inside of the window. She seemed to stare blankly as her family held up happy birthday signs and sang to her through a cell phone. A few days later, she died, that serenade their only goodbye.

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As a chaplain, I gradually realized that I had to get crafty, finding creative ways to help families cope by coming together. Even in the midst of Covid, I had the privilege of bringing connection between loved ones. Holding the cell phone for Charlie and family at Marie’s birthday window visit. Connecting Jack and Yolanda by speaker phone so Jack could try to get Yolanda to crack a smile with a silly story about a monkey that had always made her laugh. Making porch visits to the home of a daughter, bitterly angry that Covid had taken her mother away from her: no visits allowed. Writing emails to another daughter, who wrote back grieving missives, wondering what she would do when a lifetime of nightly phone calls to her dying mom (and best friend) would soon cease. Comforting son, spouse and daughter as they took turns suiting up like astronauts in PPE to make their single fifteen-minute visit to say goodbye to Mom, only one at a time permitted. Placing a gloved hand in the withering hand of one who could not touch the skin of the one she really wanted to see.

As Covid has progressed through the months, I have witnessed moments of healing connection. When the state saw that loneliness and isolation might kill more quickly than Covid, they allowed Compassionate Care Visits. Smiles returned. Hands were held. Hearts were healed. Precious time was had, allowing for healthier goodbyes, embraces shared, gentleness returned. I had the privilege of witnessing, of accompanying, of soothing, of naming rage and injustice and aching hurt. Of memorializing, of praying, or honoring, of storytelling.
As I grieved and walked with grieving families, even still I gave thanks for work that mattered. For witnessing the sacredness of human love stories. For Zoom miracles when fellow chaplains heard, saw, and honored one another. For the privilege of daily connecting loved ones in this Covid Era, where it becomes clearer than ever that when things fall apart, we cope by coming together.