

Radical Acts of Love

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Preface

Gran was the first person I saw die. I was nineteen years old and she was eighty-one. She was my father's mother and she lived with our family for the last couple of years of her life, in a small cottage attached to the old sandstone house my three siblings and I were raised in, just outside Glasgow. Gran died of oesophageal cancer, more common in those days because of the heavy cigarette-smoking combined with her daily tipples of whisky. I remember following Mum into Gran's bright white bedroom and watching over her shoulder as she washed my grandmother and changed the soiled sheets. I wanted to help her care for Gran but I felt frozen, unsure what to do, even though I had worked in hospitals for two summers by that time. Gran was my kin, not a patient. That made a difference then.

I don't remember being afraid of death, rather just curious about the unusual smells in the room and the fact that she coughed a lot and didn't talk much. Mum made it okay. She didn't seem afraid either, just busy. She had been a nurse too, which must have helped her know what to do. There were no long heartfelt conversations at Gran's bedside, nor long bucket lists of activities to be accomplished. There was just the work of dying – for my gran, the patient, and for my mum, the caregiver.

I learned then that most deaths are natural. Not easy, but not necessarily scary; nor traumatic or over-medicalised; not romantic nor glorified. Death is most often ordinary and manageable, acceptable but deeply sad. The majority of old people, like my grandmother, died at home in those days before it was commonplace to be admitted to a hospital, or hospice, for the last days or weeks of life.

Most people now under sixty have never seen a person die, so have become deeply fearful about death; both their own, and the deaths of their beloved others. They have had no role models to

show them how to care for a dying person, and therefore no confidence in being able to do so. My hope is that the baby boomer cohort who pushed for the return of the midwives to de-medicalise birth will also be instrumental in reclaiming the death process. This book is my contribution to the re-empowering of all of us to take charge of our lives and our deaths, remembering that we know how to die, just as we knew how to come into this world. We also know how to heal, and how to settle our lives as best we can before we die. In my view, this is the greatest gift we could give our loved ones: to be prepared and open and accepting when the time comes for us to leave this world.

My first summer job was at the Glasgow Sick Children's Hospital, working as a nurses' aide on the orthopaedic floor. Frustrated Glaswegian kids with broken bones, strung up on traction, yelled at me to fetch things and made fun of me if I messed up. Even though their demands intimidated me, at sixteen I loved the feeling of being helpful. The following summer I worked in a psychiatric hospital for the elderly where many patients had been hospitalised for thirty or forty years. I remember an ancient, scary woman who shuffled along behind me everywhere I went, and stared at my every move like an owl contemplating her prey. At a young age, I was compelled to try to understand the brokenness of humanity.

When I enrolled at St Andrews University, I planned to study geography. I had always loved maps, and still do, but in my third year I declared a major in psychology. The study of human behaviour trumped my interest in topography. I graduated in 1980 with an MA in Psychology, and the following spring I became a student again, studying nursing at the Royal Infirmary in Edinburgh. I wanted to travel and work at a job that was in demand across countries and cultures, and to find a way to make a difference in the world.

I was twenty-two and had been a student nurse for six months when I was assigned to care for a man in his forties dying of leukaemia. He had just been moved from the main ward, with its fifteen beds down either side, to one of only two private rooms. Standing nervously outside his room that evening, as my heart hammered against my ribcage, I thought about what I would say:

Good evening Mr Stevens, I'm Nurse Brown, here for the night shift.
How are you feeling?

I wasn't sure that my experience with Gran or nursing school had prepared me for this.

I took a deep breath and knocked softly on Mr Stevens' door. A stronger voice than I was expecting said, 'Come in.'

The darkened room enveloped me as I stepped in, my eyes taking a few moments to adjust.

'Hello, you must be my nurse for tonight. Just call me Jack, will you? All this formality – not much use for it at this stage of my life.'

'Good evening. I'm Nurse Brown,' I said. I wasn't allowed to tell patients my first name or call them by theirs, though I always wanted to. His baldness struck me, as did the dark circles under his eyes.

The photograph by Jack's bed caught my eye. A family shot, taken on a windy day somewhere on the coast. The woman's dark hair was blown across most of her face; she had a joy about her. Two children: a boy about eight years old, a cheeky face, a red-head; and a little girl, perhaps five, holding on to a soggy-looking cracker, a shy glance at the camera.

'The summer holidays?' I asked, glad for the opener.

'Just this past summer, on Islay,' Jack replied. 'Bitter wind, but we love it there, been going since Alistair was a baby. Won't be any more of those holidays now, at least not with the four of us.'

'Mmm,' I said, at a loss for words. Tears threatened, but *not now*. I bustled around the room, straightened the pile of paperbacks, folded the *Guardian* and popped a few scrunched tissues into the paper rubbish bag taped to the edge of the tabletop.

'Shall I refill your ice water?' I asked.

'Thanks. The painkillers make me unbelievably thirsty.'

I picked up the Styrofoam cup, glad for the excuse to step out of the room. As I stood at the ice machine, the clatter of the cubes dropping into the empty cup soothed me with its ordinariness.

Although I felt awkward and incompetent to help Jack with his vast sadness and fears about dying, over the next few days he put me at ease by talking openly about his feelings. He described the guilt he felt about leaving his children and his wife, even though

he knew cancer wasn't his fault, and he worried about the pain his death would cause them.

With Jack, I learned that it was not my responsibility to take away his sorrow and worry, but more to offer a soft place of caring for his feelings to land. I found that if I mostly listened and spoke rarely, Jack talked himself through his feelings until he finally ran out of words, and a deep quiet wrapped around us. The space between us seemed to connect us both to something larger, a perspective that I know now, more than thirty years later, can be deeply comforting in those moments when words make little sense.

Jack's openness and vulnerability inspired me to learn more about how people live with dying, and how healthcare professionals can support people better through emotionally and spiritually difficult times. He taught me that a quiet, steady, non-judgemental presence – and a deep faith in the person's ability to find his or her own way to navigate life's end – is the cornerstone of any useful caregiving. It feels to me that this quality of presence originates and emanates from the heart; not the physical organ, but an emotional centre where a particular sensation gathers – perhaps it is love or compassion – generated in response to another's suffering. This connection through suffering can create a feeling of spaciousness or wholeness between two people that I believe is the potential healing space.

The experience with Jack propelled me to seek a deeper understanding of how to create the conditions whereby this wholeness can be evoked. I will always be grateful to him for my initiation into the work that has become central to my life.

A few years later, when I was twenty-six, I wanted to spend a year living and working in a different country, so I went to Canada. A twelve-month stay turned into one of over thirty years. I worked as an oncology nurse in Vancouver for ten years, and it was during that time that both my love for the work and my dissatisfaction with the system within which I practised grew. I became frustrated with a healthcare model that focused more on treating the disease of cancer than the person with the illness. I wanted more time to attend to the heart and the spirit of a person, and their loved ones.

I also became disheartened with a culture that was no longer empowered in its relationship with death. I saw how afraid

healthcare professionals and many oncologists were discussing death with their patients, let alone providing tools to help them address their fears and worries.

In retrospect, I realise I was also struggling to handle the pain of my chosen vocation. I didn't know how to grieve the people I cared for who had died and I didn't know who, or what, to rage at. I felt responsible for what happened to a person, and what didn't happen. I saw cancer as the enemy, and I joined in the fight. Standing up for what we believe in is the daily practice of oncology nurses, but I had yet to learn how to do that *and* keep my heart open.

I wanted to change myself and change the system.

After returning to university and completing my MSc in Nursing, I took a full-time position as a clinical nurse specialist, which allowed me to continue to work directly with patients, families and nurses in a counselling role. I have the utmost respect for nurses who become educators, researchers and administrators, but I knew my career path was to be in direct clinical care. I became more and more interested in the emerging field of integrative medicine – an approach to healing that focuses on the whole person (body, mind and spirit), including all aspects of lifestyle. It emphasises the therapeutic relationship of person and practitioner and makes use of all scientifically supported therapies, both conventional, complementary and alternative.

I studied with Dolores Krieger, a retired nursing professor from NYU, every summer for ten years. She and Dora Kunz, a leader in the Theosophical Society of America, developed Therapeutic Touch, an energy healing technique based on the ancient practice of the 'laying on of hands'. This modality is used for the relief of pain and anxiety, and to ease the dying process. These two women mentored me in this healing practice, which opened me up to what I now understand as my spirituality – a lifelong quest to find meaning, purpose and comfort in the universality of human experience. Without the fear of being engulfed by my own feelings, they taught me how to connect deeply to a person. They helped me to trust the inherent capacity each human has to take responsibility for their healing and happiness.

In 1993 I was inspired by a television series produced by Bill Moyers entitled *Healing and the Mind*. The sixth episode described a

weeklong retreat for people with cancer in Bolinas, California, run by Michael Lerner and Rachel Naomi Remen. I phoned Commonweal the following day and asked how I could learn more about their retreats. They happened to be offering their first workshop two months later to teach healthcare professionals how to run a cancer retreat programme and I registered.

After the Commonweal workshop, I gathered together a team of healthcare professionals who were interested in running cancer retreats, and the following year the Callanish Society was born in Vancouver. As I write this preface, Callanish has run almost one hundred weeklong retreats and has become a thriving centre for families with cancer to heal and strengthen into life, and for some, into death. It is a place dedicated to people who have been irrevocably changed by cancer, offering them retreats and programmes to reconnect to the essentials of life. We are committed to helping people talk about dying with those in their close relationships, to resolve past hurts and traumas, and to prepare themselves to die with peace and acceptance.

I hope *Radical Acts of Love* will give readers an increased understanding of the processes of dying, whether it be around one's own death, or the death of a loved one. Just as we carefully prepare for a birth, so too can we openly and consciously make preparations for dying, and therein provide some comfort and reassurance about what is, after all, a certainty for all of us. My wish is for this book to inspire hope for families who want to live and love as best they can in the period of time between learning of a poor prognosis and the moment of death itself.

The families in this book represent a small sector of the population and hence their experiences cannot be described in any way as universal. I am cognisant that some readers may not find their own experiences with death and dying represented in these stories and for that I am regretful.

I have tried to protect the privacy of the people in these stories by changing identifying features, or writing composite stories. I have sent stories to surviving family members to read for accuracy and comment. These communications have been deeply touching and have reassured me that love most certainly abides.

I have organised the book into four sections. Each one contains four to seven stories which will illuminate the experience of

opening up to death, preparing for it, healing the past, dealing with unfinished business or accepting what is unresolved, making choices about dying on one's own terms, and learning to draw comfort from nature and the universality of death.

My Cree friend Maureen Kennedy told me that in her tradition, elders collect 'teaching stories' from their many years of life experiences.

'There comes a time,' she said, 'when the elders must release those stories into the world. You will know, Janie, when that time comes for you. You have many teaching stories by now, don't you?'

'Thirty years' worth, at least,' I said, nodding my head.

I believe the time for releasing these stories is now.

Preparing for death is a radical act of love for ourselves, and for those close to us who live on after we're gone. My hope is that these stories will reassure you, the reader, by providing a roadmap through one of the most important and least discussed experiences of our lives. May these teaching stories, gifted to me by others, heal, nourish and strengthen your hearts and reveal the terrible beauty inherent in living and dying that is your birthright.

I.

OPENING THE HEART TO DYING

'Peace comes when our hearts are open like the sky, vast as the ocean.'

—JACK KORNFELD

At a retreat I attended a few years ago, Zoketsu Norman Fischer, a Soto Zen priest, offered a teaching that has stayed with me. He described how at the end of our life, when the body loses its functions, the heart continues to have an endless capacity to express and receive love. His statement comforts me, to know that even without a healthy body, we still have a worthy function: to give and receive love, opening our hearts in our living and dying so that our beloveds can be sustained by that love, long after we are gone.

I have learned that it is easier to open my heart in the presence of other people, than to do it on my own. Perhaps being open-hearted about any aspect of our life is dependent on our connection with other people. Maybe it is that very connection, especially in difficult times, that activates our compassion and care towards one another and keeps us from feeling isolated and lonely.

I meet people every day who open their hearts to death, their own or another's; they show us how to remain open to the heartbreaks of life. They encourage us not to close up to pain and loss but to risk opening up to connection.

Opening the Heart to Dying contains five stories about what can happen to your life, and to the lives of those you love, when you open up to your own dying. Each of the five people in these stories made choices about dying that were congruent with the ways they had approached living. By opening their hearts to death, each person became more deeply connected and loving towards themselves and the people they cared about, and consequently more present in life itself.

because it's too hard to manage symptoms at home, but Karen was settled enough, and Kathy and I could administer the pain medications prescribed by her doctor. The home care nurse would also check in every day. I'd stay for as long as necessary to see Karen out of this world and be there to support Kathy.

'Will it be long?' Karen asked me, two days after I arrived. We were sitting at the kitchen table, over what ended up being our last bowl of soup together.

'Probably a week or so, at the most,' I replied. Sometimes there are surprises and people die quicker or slower than one predicts, but when you've seen many people die, your hunches are usually fairly accurate.

'That's good. I'm feeling okay about dying. Made it to sixty-two. Not bad,' she said. Karen had always treated life as an adventure and dying seemed to be no exception.

'I'm more scared of being kept alive than of dying,' she said, gazing out of the window for a few moments. 'Anyway, the place I'm going to *has* to supersede this existence on the earthly plane. I'm not scared. I'm just sad to die, to miss out on being on this beautiful earth with the people I love,' she said, looking at me. I felt a tear run down my cheek. Missing her had already begun to press into me.

'I hope you will at least come back, in some form, to tell us if you were right, that it *is* better over there,' I said.

'I imagine you passing your hand through the veil, like this,' she said, reaching for my hand across the table. 'I'll find you.'

'Wouldn't that be something if we really will be this close?' I said. 'Don't you wish we knew for sure?'

On the morning of 4 January, Karen told us to sing for her. 'Come on, you two minstrels. Get the ukuleles out.' Her voice was weak but the look in her blue eyes was as playful as ever. Over the years, whenever I became too serious she tried to make me lighten up. She never let me get too entrenched in an opinion, teasing me that my attachments to theories had little substance. Life was more of a mystery than a mental construct.

Kathy and I had taken up the ukulele six months before. We liked the idea of playing music, not just listening to it, and we

thought it would help us relax during the tough times at work. Our ukulele teacher had assured us that with just three chords we could play two hundred songs. So far we'd managed five.

'Swing low, sweet chariot,' we sang, fumbling with the chords. 'Coming for to carry me home.'

Karen's eyes were closed, the inkling of a smile stretched across her chapped lips. She didn't have the strength to sing along.

'A band of angels coming after me, coming for to carry me home,' we crooned.

I could hardly believe how small Karen had become. She had always been such a fit, muscular woman, an avid tennis player until her late fifties. She joked about having a left bicep as large as Navratilova's. The weight had fallen off fast since her diagnosis in December, and her arms barely had the strength to lift a glass of water to her mouth.

The desire to eat and drink ceases at a certain point when the body no longer wants sustenance – a sign that death is near – but even with such a tiny body, Karen's presence in the room was enormous; mesmerising, like a harvest moon on a clear night.

'I looked over Jordan and what did I see,' Kathy and I strummed on. 'Coming for to carry me home.'

Karen was asleep, her head lolled to one side and her breath raspy. She slept for a couple of hours after that, and then awoke. Her half-opened eyes darted around the room as though she was tracking something compelling.

'I can only describe the place I go to when I'm half-awake with two words,' she told us: 'Golden love.'

'Golden love,' she repeated, and I felt a rush of reassurance relax my body. Kathy looked at me and smiled. There had been many shared moments of friendship when Karen's wisdom had disarmed us, dissolving any point of view we had thought worth holding on to.

'For years we've wondered what happens when we die? I have news for you,' she murmured. 'It is like we thought, but more, so much more. The great love that we come from is the same love that catches us at the end. It's so beautiful.'

Karen's words were like fragments of truth landing clickety-click into exactly the right place, the only possible configuration. She had always said spirit is the ubiquitous substance out of which

each life arises and passes away; she called this substance consciousness and said it was benevolent and eternal, like love. Some people might name this loving substance God. She didn't. She believed that when the body dies, the energy that animated the physical form merges with consciousness.

I have often wondered whether believing in the continuity of the spirit helps us to feel more at peace about dying. When dying is purely hypothetical, a concept in the mind, believing in an afterlife often reassures people. In my view, when the body is dying, the visceral experience can be frightening, painful and intolerable, or peaceful, comfortable and manageable. Beliefs about the afterlife aren't what make the difference between a difficult or an easeful death, more the degree to which the body's symptoms can be effectively managed, and the more a person has made peace with the emotional experiences of his or her life.

Karen had been unconscious for a couple of hours when I sensed another change. Her breath was shallower and the breaks between breaths lasted several seconds. Her hands and feet were cool and mottled and her lips pale. Death had been lingering in the house for days, but had now moved closer.

'What's happening?' Kathy asked, feeling the shift too.

'We'll stay right here with her,' I replied. Karen's eyelids fluttered, as if dreaming.

'Should we say goodbye?' Kathy asked.

'Do you want some time alone with Karen?'

'No, I just wondered if I should give her permission to go, tell her I'll be okay.' Kathy's face crumpled at the pain of imminent separation.

I moved from the foot of the bed to the head, where Kathy sat, and put my arm around her shoulder.

'We've been saying goodbye to Karen ever since we knew she was going to die,' I said, stroking Kathy's tousled hair. She hadn't slept much, lying on a mattress on the floor by Karen's bed the last two nights.

There's not one moment to say goodbye, but a series of moments through which the ending slowly unfolds.

Kathy leaned her body sideways onto the bed, her head resting on Karen's chest. 'I don't want to say goodbye. We've had such an amazing life together.'

Karen's breath was like a whisper, the out-breath slightly more audible than the in-breath.

'I can't imagine Karen needs permission to go, do you?' I said. 'She always was the boss.'

At this we both laughed, surrendering our attempts to move the situation along.

A dog barked a few houses away. The room was quiet except for every so often when one of us said, 'I love you.' No other words made any sense.

Then the screen door banged against the side of the house and a rush of cold air pushed in on us. The wind had prised open the latch. We had opened the glass door earlier that afternoon so that Karen could feel the fresh air on her skin.

Tears flooded our eyes as we understood that the end was near. Ten seconds of stillness between breaths felt like forever. Another long exhalation, followed by silence – twenty seconds, thirty seconds. I knew to wait. Even after a minute there might be a final breath. And there it was. Karen breathed one more breath in and out, and then her life was over.

I didn't want to move a muscle, as though the stillness in the room told me to wait, not to interfere with a cycle that was still completing in the room. My eyes were magnetised to the stand of poplars outside the window as they responded to a crescendo of wind and the sky that was turning deep pink as the sun dipped below the horizon. Then I noticed Karen's face was softening in tiny increments, the frown line between her eyebrows slowly dissolving and the shape of her mouth shifting. My attention was pulled back and forth between these two happenings: to the elemental world outside the window and to Karen's body, made up of elements too, which were shifting and dissolving in front of our eyes, in what seemed like a necessary dynamic interplay. About an hour later, the momentum in the room had ceased and I noticed a tiny smile had appeared on one side of Karen's mouth, as if to say, 'Yup, it's just as I thought.'