

I.
OPENING THE HEART
TO DYING

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

—JACK KORNFIELD

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

JANIE BROWN

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.

I

KAREN: Golden Love

‘Karen might be dying,’ Kathy said on the phone one evening in early December, out of the blue.

‘What do you mean?’ I said, a wave of nausea rising from my gut. The three of us had been friends for twenty-five years. Eight years after we met, we co-founded the Callanish Society, a charity offering weeklong retreats for people living with cancer.

Kathy’s voice was trembling. ‘This past two weeks we both thought she had the flu, but every day she’s weaker and she hasn’t been off the couch for two days.’

My take-charge nursing voice kicked in. ‘Has she seen a doctor?’

‘You know what she’s like, Janie. She’d rather not see a doctor,’ Kathy said.

JANIE BROWN

This was one of the sticking points in their twenty-three-year common-law relationship. Kathy was a nutritionist and preferred herbal potions over pharmaceuticals, like Karen, but they disagreed about the role of Western medicine in health and healing. Karen told me once how scared she was of doctors and hospitals because her father had died in a cancer hospital, after just one dose of chemotherapy, when she was in her twenties. She told me she believed it was the medicine, and not the cancer, that killed him.

‘Kathy, you need to take her to the hospital,’ I said.

The following morning, Kathy bundled Karen up in blankets and drove the eight miles to their doctor’s office in town. They loved living in the Cariboo region of British Columbia, six hours north of Vancouver, with its big, snowy winters, swathes of grassland dotted with green lakes, and a multitude of wildlife. Kathy and Karen met in the Cariboo in their early twenties, when they both attended a conference held by the Emissaries of Divine Light, an intentional community with seven spiritual centres around the world. Several years after Karen and Kathy moved to live in the Emissary commune in the town of 100 Mile House, British Columbia, they fell in love.

The visit to the hospital confirmed Karen’s liver

RADICAL ACTS OF LOVE

was failing. An ultrasound revealed widespread metastases from breast cancer. We knew what that meant: she likely wouldn't last long. We had worked with people with cancer for eighteen years by then and knew there was no rhyme nor reason for who gets it, what type or stage they are diagnosed with, who lives or dies from it, and how the dying process unfolds for each person. We knew that being a healthcare professional is no guarantee of good health, or an easy death.

By choosing not to consult an oncologist, Karen opted out of having any cancer treatment. She had always been clear and fast in her decision-making, not labouring over questions she already knew the answers to. She said it was all the fire in her astrology chart.

She was one of the few people I'd known to reject treatment without first learning the options. Many people find the reality of 'no treatment' too scary, and would rather adopt a fighting stance, with chemotherapy or radiation being their best weapons. Battling to stay alive made no sense to Karen. She knew her days were numbered and believed that even if treatment lengthened her life by some months, it wouldn't add to its quality. She had seen hundreds of people go through cancer treatment and felt that treatment in her case would just prolong the inevitable

JANIE BROWN

and zap what little physical energy she had. She wanted to feel as well as she could for as long as she could.

Karen chose to die at home with the support of her friends, family, and a local home care team, rather than die in a hospital or hospice. I knew where I needed and wanted to be. On 27 December 2013, I packed my bags for an indefinite amount of time and drove north to support my beloved friends as they conjured up the strength they would need for Karen's parting.

People have cared for dying loved ones at home for centuries, all around the world. Sometimes people need to be in hospital, 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

RADICAL ACTS OF LOVE

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,

JANIE BROWN

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

RADICAL ACTS OF LOVE

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

JANIE BROWN

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.

RADICAL ACTS OF LOVE

‘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

JANIE BROWN

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

RADICAL ACTS OF LOVE

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.'