

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

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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.

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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

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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

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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

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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,

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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

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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

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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.

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'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

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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

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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.'

DANIEL: Memory Box

Daniel stood in the doorway of my counselling room, hand-in-hand with his seven-year-old daughter, Emily.

‘Sorry for the surprise, Janie,’ he said, glancing towards his daughter. ‘Can Em entertain herself in the waiting room while I talk to you?’ He looked at me from inside dark circles of fatigue. ‘Lin came down with a migraine and stayed in bed this morning, and when Emily insisted on coming with me, I didn’t have the heart to say no.’

Preventing the little disappointments was something he could do. He had no control over the big loss that lay ahead for her.

‘My girls don’t know how sick I am,’ Daniel had told me on the phone the week before. ‘It’s better that way, don’t you think?’

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He'd decided not to tell them the latest news from the doctor, that his cancer had come back with a vengeance and he likely had only a few more months to live. Being the father of two daughters aged seven and nine was Daniel's proudest accomplishment.

'We need to have a longer chat about this in person, don't you think? Can you come in for a session?' I had asked.

Two days later he knocked on my door, Emily in tow.

She looked me straight in the eye, with a big smile. She exuded self-confidence, a sign of resilience, a character trait that makes all the difference in the aftermath of a tragedy.

'I'm so happy to finally meet you, Emily. I've heard lots about you.' I stooped down to her height and held out my hand. She took it briefly.

Emily's dark brown hair was cut into a bob with a fringe that fell shy of her wide hazel eyes. She was dressed in multiple shades of pink. Her sneakers were well-worn and the strobe lights in the heels flickered faintly as she headed for one of the comfy chairs. She pulled a colouring book and a zip-lock bag of crayons out of her backpack.

'If you need us, just knock on this door, okay?' I pointed to the door of my counselling room. 'Your daddy and I will be in there talking.'

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She nodded without looking up. She was already colouring the dress of Princess Aurora bright purple.

Daniel took his usual seat on the overstuffed couch with its back to the window. His baldness seemed to highlight the ashen complexion of a man losing his life force, and his baggy sweatsuit attempted to obscure his weight loss.

A large maple tree against a backdrop of blue sky filled my office window behind where Daniel sat. The tree steadied me for conversations that were not often easy.

‘My wife and her parents are relying on me to get better. When I talk about dying, they tell me to stop being so negative. They don’t want to talk about death and believe that talking about it will make it happen. There are beliefs in her culture which I don’t understand. Of course I want to live, but it’s not a reality any more, is it?’ Daniel held my gaze and I inhaled slowly.

In these moments, when someone directly asks if they are dying, there are choices to make in response. Slip beneath the words, shift my eyes away from the gaze, succumb to the instinct to protect, to avoid the pain, to say something else, anything else. *You can beat this cancer. You’re too young to die. Miracles happen, they really do. I know lots of people who’ve defied their prognoses. Michael, the guy you met last time you were here, outlived the doctor’s prediction by two years.* You want to echo a family’s plea that death

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is conquerable, that the sick person just has to find the strength to fight. But in the end, you have to be honest. Death was already present on the couch beside Daniel, coaxing me to speak, and Daniel needed me to respect his capacity to handle the truth. Without respect, there's no dignity.

I exhaled slowly. 'No, it's not looking like you're going to make it, Daniel.'

Daniel's voice was urgent. 'If I'm going to die, then I want it to be as easy as possible for Lin and the kids. They've got to be able to manage without me.' He turned his wedding band around and around on his finger, loose from the weight loss.

'Daniel, I can help you prepare for your death, without either of us giving up hope that surprising things can happen.' Daniel's shoulders dropped an inch or two as he relaxed, and his eyes gave way to tears of relief.

'Thank God. I knew I couldn't figure this out by myself. I just know that pretending I'm *not* going to die isn't going to help anyone,' he said.

The dawning reality that death cannot be avoided has its own rhythm, its own season, and fruitful conversations about dying happen in their right time. I used to think it was my duty as a healthcare professional to guide people towards the fact that death was approaching, even without an invitation

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into the conversation. I'd feel a sudden rush of heat in my body, an upwelling of responsibility. I believed my forthrightness would help the dying person and give them enough time to prepare for what was ahead. I had seen many people run out of time to say goodbye, which often precipitates years of regret for those left behind.

However, over time, I've learned that my agenda, my hurry to open up a conversation, can frighten a person who isn't ready. I've had to cultivate patience, quell the impulse to jump in until the truth has caught up and the psyche has assimilated what the body already knows. Sometimes the mind never catches up, and I have had to learn to accept that, too.

I knew Daniel was ready to talk from the urgency in his voice and the way he leaned forward into our conversation.

'Let's start with the practical stuff,' I said, an easier place to start than the emotional preparation. 'Have you thought about where you might die?' I asked.

'I can't imagine Lin and the kids coping if I die at home, in our bed. She'd be haunted after. What do you think?' he asked.

'Memories of death are not always gruesome. They can be gentle and afterwards people usually speak about the comfort of having the person die at home,' I said.

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Daniel's face was softer. 'My grandpa died in his own bed, now that I think of it, and Grandma seemed to be okay, but Lin believes death is unlucky so I think it would be easier for her if I died in a hospital, or a hospice,' Daniel said.

I explained to Daniel the difference between palliative care units, regular medical units and hospices. Palliative care units (PCUs) and hospices tend to be better staffed than medical units, and have team members who are specialised in end-of-life care. They both have less of an institutional atmosphere. People tend to go to a PCU for symptom management, such as pain or nausea, and then, once that's under control, they can go home again or to a hospice. Most hospices have a policy of only admitting people who have a prognosis of three to six months.

A faint flush of pink had settled in Daniel's cheeks. The knowledge that help was tangible likely brought him some ease and consolation.

'There's a hospice quite near your house. You can bring things from home such as pictures for the walls and your own pillows and bedding. Lin and the kids could be there as much as they want, and they can even sleep over,' I said. Daniel's eyes were locked onto mine.

Memories of countless families I had known flooded my mind. Little Sarah, who was four when

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her mom died in a hospice, brought offerings from home: a flower from the garden, a candy, a storybook. The hurt was evident in her wary glances and the dishevelled state of her mismatched clothes. Matthew, almost sixteen, who slumped in the chair by the window of his dad's hospital room, baseball cap pulled down low, earbuds always in place. He exuded inaccessibility, but he never missed a day of the fifteen-day after-school vigil before his dad died.

Daniel moved himself from the practical to the emotional. 'Is it okay for the kids to see me dying? Would it traumatise them?'

'It depends on whether the process is an easeful one or not. Most times the palliative care team can settle your symptoms, and you'd look to the kids like you were sleeping. It will be very sad for them, but not traumatic.' I was aware of my change in emphasis, from 'would' to 'will', ushering Daniel closer to what was inevitable. He leaned forward slowly to pick up the glass of water on the table and took a couple of gulps. I waited while he took a tissue and wiped his mouth, then dropped the tissue into the wastepaper basket. When he lifted his eyes to mine, I continued.

'In the unusual circumstance there is a symptom that's difficult to control, or something sudden happens, then it is best for kids not to be there. That *would* be traumatic,' I said.

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‘Who decides?’ Daniel asked, with surprising stamina for what had become a lengthy conversation. My thoughts briefly turned to Emily in the waiting room. I felt grateful for her self-reliance that allowed me to talk to her dad without interruption.

‘The team at the hospice will guide you, but it would be good to talk with Lin about this too.’

‘What about after I’ve died? Can the kids see me then?’ Daniel asked.

I reassured Daniel that children usually know whether or not they want to see the person who has died, and how long they want to stay in the room. I recommended that his wife Lin or someone close to the kids should be with them. Kids need to say goodbye just as much as adults do.

‘This might sound like a weird question.’ Daniel paused, then looked at me.

‘It’s okay,’ I said.

‘How am I going to know when I’m dying? Are you living one day, and dying the next?’

‘We live right up until the last breath, really, but there is a time when we enter the final phase of dying which usually lasts from a few hours to a few days. The body doesn’t want food or liquids any more, and the organs naturally shut down. You’ll be asleep more than awake, and you will likely know you are dying,’ I said.

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Daniel leaned back against the cushions of the couch and glanced behind him, out of the window, taking a break from the conversation.

He turned back and I continued. 'When Lin entered the last phase of childbirth, the pushing part, you were there, right? No matter how much determination she had, she couldn't stop what was happening. Your daughters really birthed themselves,' I said.

Daniel's eyes shone at the memory. 'It was amazing to hold each of them for the first time.'

When I told him my belief that just as the body knows how to birth itself, it also knows how to die, I saw the relief soften his face.

'Death will happen when it happens,' he nodded.

I waited to see if there was more, or whether Daniel would close the conversation. He might have used up all his extra energy for the day, and he still had to drive home.

His voice had become subdued. 'I just hate all the pressure to have to will this cancer away with my mind. The stress comes from all those books Lin keeps leaving by my bed, the ones that tell me that my mind is stronger than the cancer. If I could do that, I would have already done it, right? Of course I want to live, but this cancer has got the better of me.' He paused, as though an unbidden thought was pushing up against him. 'This is not my fault is it, Janie, getting cancer?'

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‘Of course it’s not your fault,’ I said, with a vehemence that surprised me. ‘Life deals us this stuff and then we have to handle it, and how we do that affects not just our own life but the lives of all the people we love, into the next generation and the next. If you can find compassion for yourself, Daniel, then your daughters will learn from you. Your dignity and self-respect will accompany them throughout their lives.’ I felt the warmth of emotion build up behind my eyes at the thought of his daughters growing up without this fine man.

Daniel had perked up, sitting taller, as though his hope was being redefined. Instead of hoping for survival, he could hope for continued meaningful moments with his family, for as long as possible.

‘Perhaps we should check on Emily?’ Daniel suggested. I stood up and opened the door to the waiting room. Emily looked up expectantly.

She entered the counselling room and plonked herself down on the couch close to her dad and looked at me with wide eyes.

‘What were you and Daddy talking about?’ she asked.

I looked at Daniel to determine if he wanted to speak. He nodded at me to respond.

‘Your daddy and I were talking about what it’s like to be sick.’

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Emily looked up at her dad. His eyes were moist.

‘Do you know what’s going on with your daddy?’ I asked.

‘Yes, he has cancer, and he’s going to die,’ Emily said, matter-of-factly.

I raised my eyes to the maple outside, to seek brief solace from the heartbreak of the moment, and I noticed the new tender leaves shivering in the April breeze. When I looked at Daniel, a plea for help radiated from his eyes.

I took his cue and responded. ‘It will be very sad for you and your mommy, and for your sister, won’t it, when Daddy dies?’ I said. Choosing to be honest in a situation like this feels like jumping into an abyss.

‘Yes, it will,’ she said. ‘Daddy, I don’t want you to die.’

She looked up at him and Daniel reached out with both arms and drew her in against his frail body. Witnessing the intimacy of father and daughter took me to my own father dying, and to all the daughters and sons who must say goodbye to parents too soon. I felt oddly comforted by remembering my father’s love and the deep ache of my own loss.

Daniel whispered into Emily’s ear. ‘I’ll always love you, Em, no matter whether I’m here or not. Will you remember that?’ Her head acknowledged his question with a slight nod. Daniel continued, ‘I would

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move a mountain or drink the whole ocean or never eat another candy if it meant I could stay here and be your dad.'

'Would you eat Muffy's cat food?' Emily looked up with a mischievous smile.

'I most certainly would,' he said.

Emily smacked her lips together in satisfaction. 'Good.'

I leaned towards her. 'Sometimes it can help to talk about the things you're going to miss when Daddy dies, because they become the happy memories that can help you feel better when you're sad,' I said.

Emily's eyes lit up. 'I'd like to talk about those things.'

'Maybe you and Daddy can make a memory box together? First, you remember all the things you love about Daddy, and then you find something at home or make something to put in the box to remind you of that special memory. We could start talking about the memories today, and then when you go home, perhaps you and Claire can finish the memory box together, with your dad?'

Emily nodded with enthusiasm.

'What is one thing you love about Daddy?' I asked.

Without any hesitation she answered, 'I love Daddy's kisses.' She smiled up at him.

'Of course you do,' I said. 'How do you think we

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could put Daddy's kisses in the memory box, so that you can pull one out when you want to remember?'

'I know,' she said, excitedly. 'I could put Mommy's lipstick on Daddy and then he could kiss pieces of paper and then we could put them in the box.' She giggled.

Daniel and I looked at one another with raised eyebrows. Creativity had wrapped the pain of imminent loss in delight. His kisses would survive long after he was gone.

'Daddy, what do you think? Will you do it?' Emily asked.

'Of course,' Daniel said.

We talked then about other ideas for objects to go in the memory box. Children sometimes choose favourite photographs from vacations or celebrations, or saved letters or cards written from one to the other. Some parents write letters to their children or make audiotapes or videos of them reading favourite stories. Children might pick items of clothing, or jewellery, or objects from nature like shells or rocks collected from a special beach. They might paint and decorate the memory box together.

'Will you bring your memory box to show me next time you come?' I asked Emily. She nodded.

Children need to make preparations, too.

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Lin asked her daughters if they wanted to see their dad after he died and they both said they did. Daniel had been admitted to hospital suddenly one day when his pain had escalated and he died forty-eight hours later, from what the doctor thought was likely a blood clot. Lin thought the girls might want to do something special for their dad, and she left it up to them to decide what they wanted that to be.

Emily asked Lin if she and her sister Claire could take all the petals off the flowers in the vases along the window ledge, and she had agreed. The girls then slowly and carefully pulled the petals off each flower and piled them up on the tray table next to the bed. There were tulips and lilies, anemones and roses, petals of all sizes and colours, and some that still held fragrance. The girls carefully overlapped the petals, one at a time, and shaped them into the words 'WE LOVE YOU DADDY' on top of the white blanket covering Daniel's lifeless body. All the while they did this, they chatted to him, telling him the stories they would never forget.