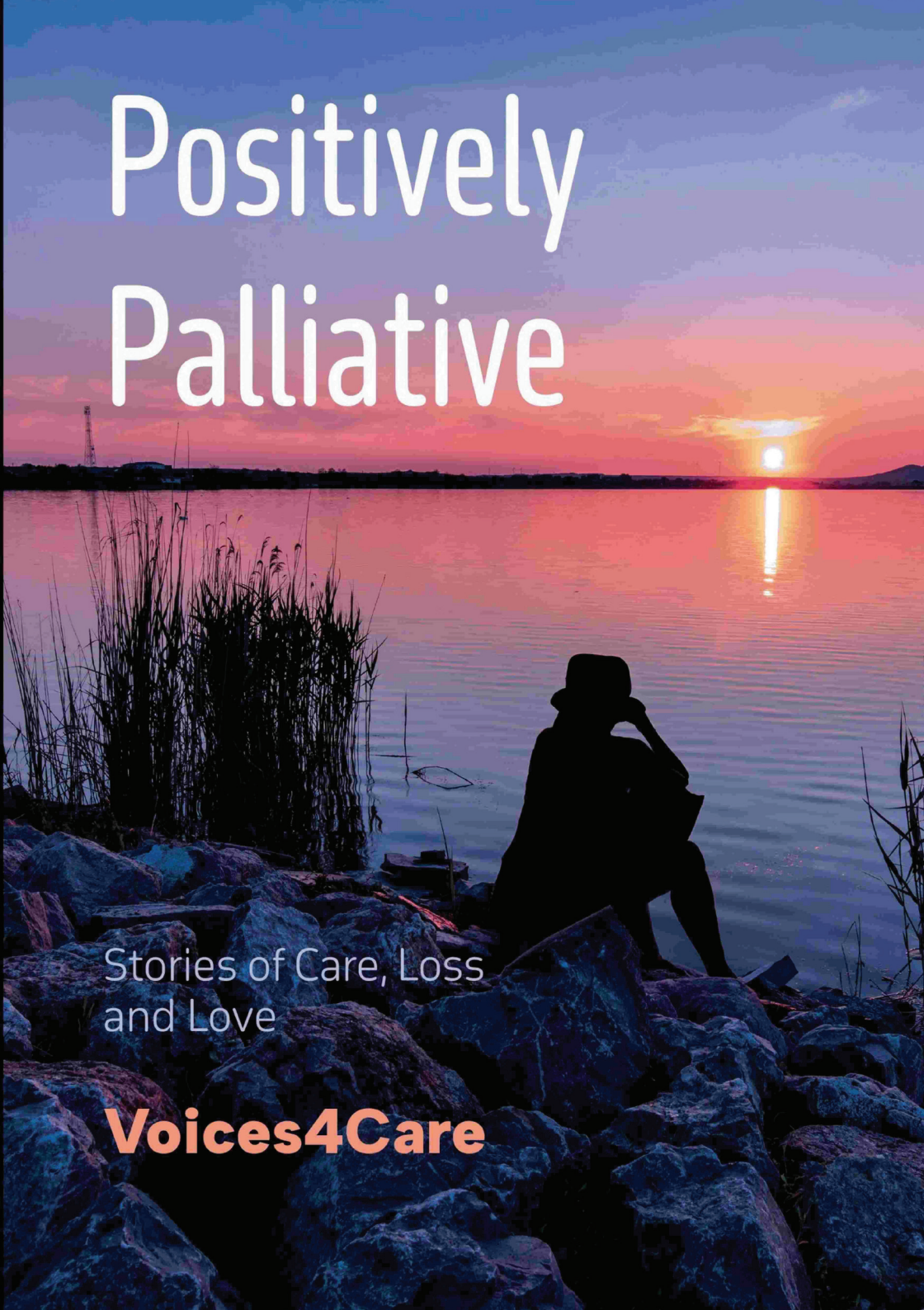
Positively Palliative



Stories of Care, Loss and Love

Voices4Care

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Dedication

To those we love and remember, and
living life to the fullest, one day at a time....

Acknowledgement

The idea for this book came from my former colleague, Clodagh O'Donovan. One day we were chatting away about how lucky we were to be able to interact with the Institute's volunteers, learn about their lives, including their personal experiences of living with a life-limiting condition and stories of carers of loved ones and how enriching it was at a personal level. Then she said, 'imagine if you had a collection of their stories'. And as they say, the rest is history.

We wanted to be able to share these stories of care, loss and love because there is so much humanity in them and it is impossible not to connect with at least one story. Such a treasure needs to be shared with the world. Therefore, the All Ireland Institute of Hospice and Palliative Care, is forever grateful to each and every Voices4Care member (current and former), who bared their souls by sharing their stories, as well as those who worked in the background by editing, providing advice and creating cover ideas. We are honoured that they decided to share their stories with us and allowed us to create a book that commemorates their loved ones. It reminds us to enjoy life one moment at a time, to slow down, while creating awareness about palliative care services, their benefits and how they can improve quality of life.

Furthermore, the All Ireland Institute of Hospice and Palliative Care (AIIHPC) would like to thank Clodagh (for the idea!), the Irish Hospice Foundation for supporting us with launching the book, Orla Kelly for beautifully creating the layout of this book while seamlessly supporting us through the maze of the publishing world, and to the law firm, Pinsent Masons, for providing excellent pro bono advice and support.

Finally, AIIHPC, wishes to thank its funder and 28 member organisations which include universities, hospices, health and social care providers and charities from across the island of Ireland for their essential support and engagement with our work. For anyone not mentioned, please forgive me. Your contribution and service is so appreciated. Thank you!

It has been my privilege and pleasure to work alongside Voices4Care members to produce this book. I thank the Voices4Care members for trusting me with this project; it was a long process and worth every minute of it as it enriched me personally and professionally.

Paula Pinto- Programme Manager – Book project lead for AIIHPC

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I would say palliative care will allow you/ your friend/ your loved one to live as well as they can for the remainder of their life.

Witnessing a loved one's palliative journey changed my life for the better. What at first feels like the worst thing to happen can have positive effects.

I was able to recognise and realise what is important in life: family, love, happiness, and health. As a result, I honed my career, let go of sweating the small stuff, and lived life to the full. Experiences with palliative care can also enhance one's ability to empathise with other humans, and to me the ability to truly empathise with fellow humans is a fundamental part of a functioning society.

Palliative care also gave me the gift of time: to say what needed to be said, to share the love we sometimes hold back, and to be present when it mattered.

—Laura McClintock

Love

Katy Megahey

Love flowers while she walks in beauty every day

Shining bright like a star high in the distance

Her scent keeps lingering on

I hear her whisper in my ear that everything will be alright, holding me tight in her arms

It will be alright, as you are big and strong now

I understand you must go now

Sleep tight, little one, flying like a butterfly

I'll see you in heaven one day

Thank you for making me into a beautiful woman

I'll never stop loving you

Just keep blossoming like a beautiful flower

Our Angel Nurse

Joan Fitzpatrick

After we battled through the night to keep our dying mother from suffering with limited support from the on-call doctor, daylight came. It was Halloween morning, marking the start of winter and dark days. Our mum hated those dark days, and we understood afterwards that she had to depart before they set in. Unexpectedly, there was a ring on the doorbell, and a public health nurse we had never met before told us she had come to dress our mother's raging bed sores. She was a gentle and truly empathetic nurse with a calming presence on us all as we gathered around our mother's bed. The nurse gently moved our mother onto her side to access the wound, and as she did, Mum let out a loud sigh and passed away with all of her seven children holding her.

The following day, and unfortunately too late, we received a call from palliative care to arrange a visit. Although we didn't get the benefit of palliative care for our mother, we believe that our angel nurse was sent to us at the right time to allow us to let go of our mum so she could escape the coming dark days of winter.

I would tell the person it's okay to be afraid, to feel nervous or anxious, but they will be embraced and supported every step of the way in palliative care.

I would encourage them to ask questions and express how they feel. The palliative care staff will be like an extension of your family. They will support your wishes and allow you to live your best and most comfortable life.

—Geraldine Rooney

A Journey Together in Faith

Fiona Colclough

You were strong, stubborn, full of grit and determined to stay alive

A man of great courage, resilience and always open to be revived.

Your life was successful, accomplished and full of the desire to thrive,

But then came the fragility of your body, and the constant battle to survive.

We faced it together timidly, and yet courageously, one step at a time;

With sickness came a gradual, but steady, decline of your body and mind.

A seemingly endless journey of which pain and suffering was the main storyline,

But in the midst of darkness, the truth of life was evolving as the real quest to find.

We searched, explored, waited for the next stage of the journey to unveil,

With unconditional love, great belief and patience, we knew we could prevail.

Both of us entwined in our own circle of trust, never wanting to part

Whilst all the time knowing we were captive to the mercy of your beating heart.

As your body began its relentless descent on a path of clear demise,

One by one, the senses and the organs began to fail, never again to rise,

But your heart beat the strongest and fiercest, like the love of a faithful friend,

Remaining till the last breath, as it should, united, right up to the end.

Now in the grave, fully sealed over, your earthly pilgrimage of suffering and pain is complete,

My journey of loss and grief now symbolised by your ever-present empty seat.

The continuing bonds of our life are yet still unfolding, though in a very different way,

Etched out and carved very carefully, in a knowing Faith that we will meet again someday.

Thanks for the laughs, tears, the darkness and most of all the light.

It has been one heck of a journey taking full toll, to regain new sight.

But now I live in the present moment, not afraid of life to have its say

Because you've crossed the threshold of Faith, found the Truth, and are well on your way.

Dad, Mum and me – a positive story of palliative care

Janet Moffett

In 2012, I retired from a thirty-five-year career as a social worker—fifteen years as a practitioner, then as a manager. During this time, I had real interest in palliative care from the social work perspective, and my role enabled me to promote the development of services.

After my retirement, I continued to follow how those developments were progressing. I was definitely an 'interested member of the public'. I am also a former carer. My ninety-four-year-old father had been diagnosed with prostate cancer in 2009. At his age, he was advised that he would probably die 'with' and not 'of' his cancer. They didn't know my dad! Coming from a long-lived family (his aunt lived to 114 years), he was looking forward to celebrating his one hundredth birthday. Sadly, he didn't quite make it, and despite harassing his poor consultant for every available treatment—barring surgery, which he had to accept was not an option—he began to go downhill rapidly in 2013. We could see that his needs were now palliative. Dad was a lovely, charming man, widely respected and much loved. We—not least my mum—all wanted to do the best for him. He made it very

clear that he wanted to be cared for at home, and she was determined that we would achieve that—not that he ever accepted that he was actually going to die! We had excellent community services from the generalist palliative care team, supplemented by a full care package, until he died in March 2014 in his ninety-ninth year.

I learned hugely from that experience. There were two main lessons. The first was that in supporting carers, while good practical services are vital, equally important is taking time to listen carefully to the carers' concerns, no matter how trivial they seem. Don't make assumptions about their knowledge or understanding. We are an articulate family that includes doctors and other professionals. Maybe we gave the impression that we knew what we were doing, and it did help that we knew our way around the system, but we floundered in some areas. My mum had little experience of death and worried greatly about what the moment would be like. Dad had a growth on his neck, and a couple of weeks before his death, Mum was warned that it could begin to bleed and would be extremely difficult to stop. She was given instructions about how to deal with this (it never happened), but she was terrified, and from then on she needed another family member there every night.

But the other, more positive lesson was that of the value of a 'good death'. With support from our great care team, we persevered, and Dad died very peacefully at home with family by his bedside. My mum, though naturally very sad, and even though Dad didn't make his hundredth birthday, got tremendous satisfaction from knowing she had given him the care he wanted, that she had done her best and had nothing to regret. She lived for a further two years and often repeated how happy she was that he hadn't had to go to hospital or a nursing home. At times the wider family felt Dad was being a bit selfish, as attending to all his needs was hard on Mum, both physically

and emotionally. Clearly, for many people the security of a death in a care setting with the support of professional and support staff is the best option. But there's no doubt that in our case this 'good death' made the grieving and bereavement process much easier not only for Mum but for the whole family.

My story as a carer is a positive one of my father's long life, well lived, which ended in a way most people would choose. Other stories are much less positive, even harrowing. The many heartbreaking stories of people dying alone during the COVID pandemic brought home to all of us just how important it is to be able to give people the end-of-life care they need and deserve. But every story, positive or otherwise, teaches us something that can and should inform the future development of palliative care services.

[Palliative care] gave me a stronger and more positive outlook on life, having come so close to death.

For me, it was the support and encouragement I received from the palliative care team; also, my involvement with Voices4care now gives me a focus to try to help others.

Remember, ask; no question is stupid if you don't know the answer. Be positive.

—John Joyce

My Grieving Heart

Fiona

As I sit with my grief
watching the flames flickering in the hearth,
I am weary.

The void left is so tangible
it is as though a hand reached into my chest
And ripped out a piece of my heart.

The tears and emotions come,
with little notice,
in waves of varying intensity,
from small ripples to giant breakers,
all of which I must learn to surf.

I am engulfed in my pain
as I watch the world around me continue.
And yet at times, it feels so surreal,
as though it hasn't happened.

Why does my mind play tricks on me like this?
Those first beautiful moments upon wakening
when all is well and reality evades me,
offset by long sleepless nights
reliving those last precious breaths.

My only comfort is my belief
that the depth of my grief
is directly proportionate
to the depth of my love for you.

And I pray that the hand that reached into my chest
and took a piece of my heart,
was your hand.
For that piece of my heart
will always belong to you.

Every Day Is a Good Day

John Joyce

'We're the palliative care team.'

Here I was, in hospital for the past five and a half months, hearing those five words. I can still see the three nurses silhouetted in the hospital window. At this stage, I had been through two surgeries and seventy-two radiotherapy sessions. And I was now on chemotherapy.

Looking back, I was fifty-two years of age, healthy, fairly fit, working part-time and caring for my mother, who was a diabetic. I had gone to three doctors to be treated for a recurring cold sore. After a chance meeting with a retired nurse, I was convinced to go again to get another opinion. In this doctor's surgery, I heard the dreaded words 'We think it's cancer.'

This was the start of my cancer journey.

At first it did not seem real—a cold sore cancer. But after a biopsy, it was confirmed as basal cell carcinoma (skin cancer). After the first surgery, my consultant was happy that all the cancer cells had been removed. Life went on as normal. The cancer was forgotten about. Six months later, after a scan and after meeting with the consultant, I was told the cancer was back again.

I was in total shock, as I had no pain or any symptoms. I had another operation to remove the affected area. As it had returned in only six months, the consultant referred me to have radiotherapy.

More scans were done, and then a meeting with the radiotherapy consultant was arranged. The day arrived for the consultation. Nervous of the unknown, I was put at ease by the nurse, who explained how the procedure worked.

Firstly, a mask had to be made of my face to allow for the exact targeting of the cancer cells. I found it difficult as a warm plastic sheet was placed over my face. It failed on the first two attempts, as I felt very claustrophobic. The nurse asked if I would like another nurse to come in and hold my hand. I cannot voice the reassurance of someone just holding my hand.

On the third attempt, there was success—the mask was made.

All this time I had kept it from my mother, telling her the bandages were from getting wisdom teeth out. I drove to Galway each weekday for seven weeks for my radiotherapy sessions. Towards the end I was feeling very tired and physically drained, each day telling my mother lies that I was working.

Again six months passed until I had more scans. Results said there was no change. The cancer was still there. Another thirty-two radiotherapy sessions were suggested, so my daily trips to Galway began again.

This time I was not fit for the daily drive, so it was arranged that I would stay weeknights in the Lodge (Inis Aoibhinn). During the first two weeks, I was feeling very tired and started to lose weight, as I found it difficult to eat. I always felt full. On week three, as I made my way back to the Lodge, I got a call from the radiotherapy department to come back. There I was told that, as my weight had dropped dramatically, I was to be admitted to a hospital ward to have a percutaneous endoscopic gastrostomy fitted (PEG feed).

The nurse said I would have a tube through my nose until the operation to fit the percutaneous endoscopic gastrostomy could

be arranged. I was at a very low point, as my mother had died the previous week. I had to have treatment on the day of her removal and again straight after her burial.

I asked if a doctor I was familiar with in the radiotherapy department would do the procedure. It was agreed, and one doctor could. A nurse laid me down. I was terrified, but the doctor said cough, and the tube was fitted.

I stayed in hospital for five-plus months, with a daily routine of bloods, treatment, and eighteen hours a day on feed, combined with intravenous medicine.

The palliative care team explained that they would alter my pain medicines, etc. I was devastated to hear the words *palliative care*, but in some way reassured. They discussed my feelings and how I felt at their intervention.

As my stay in hospital was coming to an end, I was put on chemo, as the radiotherapy was having no effect on the tumour. This chemo was known to extend life by eight months.

After hospital, I was moved to a nursing home for a four-week stay, again with Palliative Care looking after me. I felt reassured to have this team in place to visit me there. As the four weeks neared an end, my sister agreed to have me stay with her, on condition the palliative care home team would visit me there and she had a phone number to contact them.

I was terribly ill at this time. After two months I had a setback; my face dropped, and my swallow decreased. Back into hospital for another three weeks. My face was treated as Bell's palsy, but later the drop was found to be caused by the tumour pressing on my nerves.

An operation was done to permanently close one of my eyes, and I was left with permanent disfigurement of my face.

Back out to my sister Mary's again, but at this stage I was accepting that this was my life now. The palliative home care team were incredibly supportive when I said I would like to move home to live alone. They helped in all sorts of ways, both practical (bus pass, welfare payments) and the mental aspects of relying on myself. I moved home with the palliative care team as my lifeline, always a phone call away. They continued to call weekly to see if I needed anything.

After four years of them calling, we decided I no longer needed them. It was like losing a friend, and it felt strange for some time.

I am now John Joyce as I am now, not the old John Joyce. This is the new me, and I have to accept the cards I have been dealt. Without palliative care assistance through my journey, I do not think I would have made it through. I would encourage anyone who hears the words *palliative care* to not be afraid, embrace it, and use all its resources and benefits, just as I did.

From fearing the words *palliative care*, I have come to regard it as my saviour. I am still getting PEG feeds every night, and I go for treatment in Galway every two weeks. I hope this will give people courage. I try to get out every day and meet people; it helps me stay positive. Thanks to palliative care, I have a great life for however long it lasts—days, weeks, and hopefully years.

My fondest memory of Tommy is how relaxed he was when he woke up in our house the first morning after six weeks in hospital and another six weeks in Hospice care. He was happy to be home again and meet friends and family when they dropped in to visit.

—Mary White

The Pies of Peace

Memories of my Dad, Paddy Kelly

Linda Cooper

During the Battle of the Bogside in Derry (August 1969), protestors and the army were ensconced in their opposing positions in William Street.

The army were in place at the bottom of the hill and the protestors were at the top of the hill, both amidst the local shops.

The battle raged on between them for three days and nights.

The ones at the top of the hill were holed up beside a local bakery.

The army was situated at the bottom of the hill beside an abandoned lemonade lorry.

Somewhere, in the middle of the mayhem, the battle-worn factions realised there was treasure to be had . . . lemonade and cakes!

It was a hot August day and both sides were tired, hot, and hungry.

Out of the smoke came the shout: 'Hey you down there. We have cakes, and you have drinks. Do you want to trade?'

'Yes,' came the reply.

So both sides sent one forward, carrying their offerings.

They met on neutral ground. Swapped and returned to their side.

For a while peace reigned supreme whilst everyone enjoyed the unexpected treats.

The sun shone and all was good again.

Images of Christmas Day in WW1 1914 floated through my head as Dad told this story in his own inimitable way. A truce of sorts amidst this terrible situation.

Then, obviously, fully replenished. Up went the shout.

'OK, let's go!'

And the battle began again.

My Friend Sharon Jackson

Sonia Patton

I first met Sharon back in 2013 when my hubby and I stayed at her very eclectic B and B in Belfast. From the moment I met her, she was a total firecracker, mad as a hatter, and I knew we would become friends—in fact, that she would become a friend of our family, fondly calling us 'my Pattons'.

Sharon was there throughout my cancer diagnosis in 2014, and she thought nothing of jumping in her car and travelling a two-hundred-mile round trip to help look after me and my family.

My girls were three, five, and fifteen years old at my diagnosis, and Sharon was instrumental in helping my eldest daughter through difficult teenage years. Molly is now twenty-five years old and eternally grateful to Sharon.

During my radiotherapy in October 2014 at the Belfast Cancer Centre, I had to stay in Belfast for the duration. I stayed many nights with Sharon, who fed and looked after me. We completed all sorts of zany arts and crafts and decoupaged lightshades and tables, with great craic and a few naughty glasses of wine thrown into the bargain. It was just the tonic that I needed.

Sharon received her own cancer diagnosis in 2016, with Stage 4 stomach cancer. The prognosis wasn't good; she was given six to

eighteen months. That would not defeat Sharon, and she decided it was time for the bucket list (Sharon preferred to drop the *b* and replace it with another letter!), which involved a variety of 'Mohican' hairstyles from vibrant yellow to deep blue, a few tattoos, and an enviable world tour of beautiful places.

Twelve months came and went, and Sharon put her mind to chronicling her experience, which kept all her friends and family up to date and filled with laughter, hope, and 'sticking two fingers up' to cancer. Sharon was a giver. She loved life, and she went on to volunteer at a local cancer charity and bake cakes for the elderly residents of a care home.

Over the next few years, Sharon encountered many good days, but there were some bad and very dark times too. With the love and support of her family and friends, Sharon went on to set up Soul Sistas, a ladies-only support group to help her and others deal with alcohol problems.

Mid-2021, Sharon's cancer came back with a vengeance. It had metastasised to her bones, and she attended Marie Curie Hospice to help control her pain and medication. Sharon knew that her time was running out, and she set up Sharon's Angels to help support her and assist her family, as her wish was to die at home. We all knew our roles and what days we would be on call.

Right to the very end, Sharon was in control. An unexpected Facebook message to her friends and family read:

Please keep 12th February free . . . pre wake party in mine,
More info to follow. Have a fabulous day.

This was to become the 'wake of all wakes'. Sharon was the 'hostess with the mostest'; she smoked cigars and danced (or as she

said, shuffled), and it was a truly spectacular night. The very next day, I was with her as she was interviewed by Barra Best for the BBC. His article can be read here: *https://www.bbc.co.uk/news/uk-northern-ireland-60367681*

All who attended received a photobook of the night with a personal message from Sharon.

On 28 February 2022, Sharon and I danced the night away at an eighties disco night. It was a precious, lovely night filled with love, laughter, Shirley Bassey tunes, and drag queens. That was the last time I saw her.

On 25 March 2022, another Facebook message read:

> *To all Sharon's friends, this is her family. Sharon sadly passed away peacefully tonight at 10pm. Thank you for all your kind thoughts and wishes over the past few weeks. They were all passed on. As she passed fireworks went off over Belfast. She always said she would go out with a bang.*

God bless, Sharon. You are sorely missed.

Try not to be afraid. We are all on a journey, and even though it's hard to let go of things, it's good to have a choice in how we do it. We are already grieving, but we are not on our own. Be gentle with yourself, and always remember that you are surrounded by abundant love and support.

—Ruth

Our Family Experience

A Cautionary Note

David Hayden

As a prelude, I need to say that I believe in palliative care. For several years I have been an active member of the Voices4Care volunteer group in the All Ireland Institute of Hospice and Palliative Care here in Ireland. It has been a positive experience. My involvement was preceded by several years of experience, going back to the 1980s, when I worked as a voluntary assistant in caring for the elderly in a Dublin religious care home, and a few years later in a hospice palliative care ward in a Catholic hospital in London. These experiences were valuable to me and confirmed my belief in the palliative care model.

Fast forward to 2022, a very hard year for my family. My father, Liam, had been the main carer at home for my mother, Margaret, who had slowly advancing dementia and reduced mobility but generally good health for her eighty-seven years. Dad was adamant about trying to care for Mam, who was very content in her own home. The usual care helps were called upon, with care assistants coming into the home for a few hours several days a week. On one such occasion, Dad went down to the local shop to get some groceries. On the way back, we believe that he may have suffered a stroke in his little car, which

crashed at a roundabout, and he was shortly thereafter pronounced dead. I had gone out to the Ukrainian border with aid to the refugees flooding into Poland, and I received the news out there. My sister (who lives abroad) came immediately to look after our mam, in her home, while the family began the search for a suitable nursing home. She contracted a lung infection, was brought to the local hospital for several weeks, and from there she was moved to the chosen nursing home, where she received excellent care.

Several weeks later, she contracted a serious double infection of the urinary tract, with a slight perforation of the bowel. Again she was hospitalised, this time to a major Dublin hospital. Her condition was serious, but with continued intravenous antibiotic treatment and paracetamol for control of discomfort, Mam pulled around, and was then moved from A&E to an acute surgical ward. There she remained for nearly a week, in which time she made a full recovery from infection, such that she was able to return to the nursing home where she'd been. Since Mam's situation was considered acute, I had been allowed to remain with her at her bedside during her hospital stay.

The cautionary note in this experience is the following:

On the morning of the second or third day of Mam's stay in acute surgical, we found that her intravenous line, supplying the antibiotics and paracetamol, had come undone during the night. Early the next morning, a palliative care nurse visited. She had been aware of Mam's case. Seeing the intravenous line unattached, she made a quick mention that we as family might not want the line reattached and that we might want to formally start a more intense palliative care pathway that would involve removing hydration, etc., and administering the appropriate drugs needed for pain control for the few days without the hydration. I and my family were utterly shocked at the suggestion; Mam was not suffering the pain of cancer, she was responding well to

the intensive antibiotic treatment, and her pain control was merely at the level of paracetamol for relief of discomfort.

While in the acute surgical ward, I did notice that what was being suggested for our mother in terms of palliative care was being applied to several other patients there, but I could only surmise that their cases were different and probably involved terminal cancer, etc.

The 'cautionary' note I raise here in telling our experience raises some questions:

- Can a palliative care regime be invoked too quickly, or without due regard to the full situation of a patient and their family?
- Just because a patient is both very elderly and has been very ill, is this sufficient for a recommendation, or even a suggestion, that a palliative care pathway (remove hydration, etc.), be adopted?

I and my family believe that the questions raised by this experience should be examined and reflected upon by the relevant professionals, caregivers, and patients and the general public.

The journey of caring for people in palliative care changed me, because it taught me to be brave in facing the inevitable and find a reason to transform my life into something more meaningful.

Caregivers are emotionally impacted by watching many people pass away in nursing homes. At the time, I used to feel that life was always fading away, but I decided to value my life even more. Seeing people's last minute so frequently showed me the preciousness of every breath, every smile, every second I have in this world and all the chances I have to make it wonderful. It made me think about how I can get to their age with the sense that I spent my time well in this world.

—Beatriz Gonzaga

Words

Martina Crehan

When I was planning this piece of writing, I struggled with which aspects to focus on. Our story was as ordinary and extraordinary as the story of anyone else who can recount their experiences. Ordinary in that everyone who is plunged into the world of terminal illness faces the same roller coaster of shock, fear, and despair, with the tantalising mirage of hope always a few steps too far ahead. Extraordinary in that we all find our own unique way of navigating that roller coaster and of finding normalcy and—yes—happiness in that process.

As I struggled with my thoughts, I started to look back through some diary notes that I had kept during Don's illness, and I came across one from the eve of his first chemo treatment (which we knew was maintenance focused rather than curative), when he said, 'Tomorrow is the first day of the rest of our life.'

I mentioned this to a friend, who said, 'Oh, how sad that he was thinking that this was all his life was going to be from then on.' And it made me stop and think, because that wasn't what he meant in that statement. He was focusing on the fact that this was the first step in hopefully helping him to reclaim some of his life and that he, and we, were going to live even as he died. It also forced me to stop and think about language, how we interpret words, how we communicate; how we define things like illness, palliative, carer, and even death.

In the phrase attributed to Samuel Beckett, 'Words are all we have,' and so my words here focus on aspects of communication in the journey of care: how we define it, its subjectivity, and the importance of 'finding your tribe' through the stories/support of others. I started to reread those diary entries and my conversations on support forums, and whilst bringing yourself back to the person you were during that time is a slightly surreal experience, I hope that sharing some of those words may help to illustrate my thoughts and reflections.

My husband's name was Don, and on September 28, 2012, at about two p.m., our world as we understood it ended with a diagnosis of oesophageal cancer. We both entered a new world for which we didn't have a road map. We faced bewildering crossroads (which often felt as though they were clouded in fog) in quick succession with no clear idea of what lay at the end of any particular path and with a new language of illness to learn. That world restarted and ended in a myriad of ways as we travelled through the next few months together through tests, that ever-present hope roller coaster, and eventual arrival at a point we had hoped not to reach— treatment would not be curative but aimed at holding back the eventual progression for as long as possible.

Don started chemotherapy and the world shifted again, but this time with changes in our individual as well as joint pathways. Don and Martina, husband and wife, suddenly took on new mantles of "patient" and "carer," and together we had to define what that meant to us. We both, I have to say, struggled with the interpretation of those terms; indeed, Don had an allergic reaction to the idea of his wife as carer, worse than any he might have had to chemo. For him, it had connotations of dependency and a loss of that sense of partnership that defined our relationship. So we talked about it; we talked about having to rewrite the relationship's expectations, how we viewed this

stage as an extension of the love and care we'd exhibited for each other throughout our lives together. The first step for us was the importance of negotiating a comfort level in the changing dynamics of the relationship between carer and loved one, and that subtle shift in language from patient and carer to wife and husband loving and caring for each other, albeit with different levels of need, helped us to find some stability on ever-shifting sands.

In that role of caring, I now had to find ways to cope with my new path. The home become filled with the paraphernalia of illness; I worried about alien concepts like neutropenia; I cleaned incessantly (to those who know me well, the sudden transformation to domesticity was probably more frightening than Don's illness); I faced constant battles in my mind: Do I give up work? Do I continue as normal? Who do I talk to? In many ways, as a carer, you become a channel of communication for others—the second set of ears at every appointment, the fielder of calls and questions from friends and family, the researcher for every crumb of comfort from latest research, the one who sits beside a loved one at every chemo infusion and tries to interpret and preempt every side effect. We were lucky to have a very supportive medical team from a communication perspective, particularly in the form of our general practitioner, who was very mindful of the need for both of us to have a safe space to talk through our worries and concerns. The Oesophageal Cancer Fund and the Irish Cancer Society were really helpful sources of informative support, but there is an instinctual need in those situations to "find your tribe"—those who wear the T-shirt every day. My general practitioner directed me to online forums, and there I found my oasis of conversation and shared knowledge.

This was one of my first posts, regarding chemo:

I know that everyone reacts differently to chemo, but I am already worrying about all the danger signs they tell you to look out for. The box (almost literally!) of medications that we picked up today is daunting enough! We're hoping that the chemo will have an effect on the size of the tumour. Eating has become quite difficult. Some days are fine, but today has been quite bad, with pain and regurgitation after a few mouthfuls. He's lost so much weight already that I'm concerned about his ability to tolerate the chemo. Just another worry to add to the list, I suppose.

What was helpful for me was not just asking questions and venting in this way but also feeing that I could somehow help those a few steps behind us on the journey.

We found that speaking up as quickly as possible was key to this, as not all meds work in the same way for everyone. He has continued to work, travel a little (with consultants permission!), and live life as normally as possible. He does what he can when he can, and rests when he needs to. Physically, it's useful to keep a diary of your side-effects as that helps you to see if there is a pattern, and you know what to expect.

And so the journey continued: chemo, scans, stent insertions; no remission but reaching a stable state; the cliché (because it's true) of one day at a time; watching, waiting, seeing him continue to work as much as he could; and then new stages—progression and reaching the end of the journey.

Since we had the 'no more treatment' discussion, aiming for quality of life over quantity hasn't worked so well as yet. D spent 10 days in hospital as his pain levels from

the mets in his shoulder and the (still a mystery) pain in his groin and upper leg reached uncontrollable levels. He even went to hospital voluntarily on a Sunday—which for D means things are really bad; even his medical team were commenting on it, as they know how much he hates being admitted. They put him on a pain pump for a while, adjusted his pain meds and he had some radiotherapy on his shoulder. His care was excellent, and oncology and palliative care are really coordinating care very well between them.

That forum entry touches on so many things that were vital at that time—honest though never easy conversations about palliative care. There is such a need to have "What matters most to you?" at the centre of that conversation. Don needed that space to understand his prognosis; what his concerns were about what lay ahead; where he wanted to die. And a recognition that that in itself is individual. Although research suggests that most people want to die at home, Don didn't. He didn't want me to have that added stress and to have to see my home afterwards through the lens of those final moments.

But those conversations were crucial for me also. I needed to know that pain could be controlled; I needed to know that, when it was almost too difficult and painful to broach the subject together, there was someone who would listen to our anxieties as individuals and not just me as an extension of Don. A system that would recognise that I was grieving long before the actual death of my husband; that I was struggling with the "right" way to do this and only slowly realising that of course there is no script to be followed. Carers need that space and attention; they need that support and outlet; they need some physical comfort as they sit on chemo wards; they need to know that they are seen and heard, that those in every role in the health professions have been facilitated in learning not just about the physiological elements

of death but the journey of grief before death for both the patient and the patient's loved one.

> *D is coping with all of this superbly. He is calm, accepting of his prognosis, not angry; but I am the one falling to bits. I am finding it so difficult to live without hope, and have spent most of the past 24 hours in tears at one point or another. I don't feel I'm helping him at all. I promised myself I wouldn't cry in front of him, but the flood gates open at the slightest thing. I had convinced myself that he would still be able to enjoy things a bit more—he wanted to make some little trips, etc. While he is still relatively ok, he is very sleepy. He is on a cocktail of pain meds, so could be that, or it could be general decline, but the chances of any gadding about seem to be diminishing by the moment. I feel helpless, hopeless and very, very sad.*

Again, personal definitions of what was happening became important. In the zeitgeist of the moment, Don was "losing his battle" with cancer. In the midst of this seismic event in your life, you are surrounded by the battle metaphor, and that metaphor did not sit well with us. Don was not dying because he didn't fight hard enough or because he wasn't strong enough. Again, I know that so many people find this useful, and we all choose the lingua franca that works for us on an individual level and that helps us make sense of this frightening and erratic existence, but to many people the reluctance to name things what they are stands in the way of honest, vulnerable conversations about fear and anxiety and, yes, death. Don was a man, to paraphrase Cicely Saunders, living whilst dying.

And live he and I did. I found great solace not just in conversations but in the stories of others. There's a lovely narrative by an author called Patrick Dillon about the terminal illness of his wife, called A

Moment of Grace, where he talks about the happiness amidst that dreadful time. And it really resonated with me as I was experiencing that paradox. There was serenity, a grace, and—yes—a happiness during that time. We worked, lived, laughed, even as the curtain began to close, which I would never have believed on that day in 2012.

And so we reached the end. Don died in July 2014 in hospital just before he was about to be moved to hospice. In his own inimitable fashion, he did this in his own way—very quickly and quietly, when I had left the room for a few moments. And I moved from the carer to the widow.

Pablo Neruda

If I die, survive me with such a pure force you make the pallor and the coldness rage;

flash your indelible eyes from south to south, from sun to sun, till your mouth sings like a guitar.

I don't want your laugh or your footsteps to waver; I don't want my legacy of happiness to die . . .

Don certainly left a legacy of happiness for me to attempt to live up to, but the carer journey leaves a legacy too. I had a much shorter journey than many people have, but even that impacts on so many aspects of your life, which linger for quite some time; everything from diet and sleep patterns to concentration levels, aside even from grief, take a toll, which I was certainly unprepared for. But I also focus on the learnings: the vivid richness of small moments of joy; the kindness of strangers; the power to decide how to survive and to live well.

For me, this quote from Haruki Murakami sums up the journey:

> *And once the storm is over, you won't remember how you made it through, how you managed to survive. You won't even be sure, whether the storm is really over. But one thing is certain. When you come out of the storm, you won't be the same person who walked in. That's what this storm's all about.*

The storm certainly changes you, but the impact and in particular the memories of words stay in your mind. I will hear forever the words used when diagnosis and prognosis were communicated; I will hear forever helpful and unhelpful phrasing from medical teams; I will remember the need to have the process of death explained to me and be comforted by the fact that this was communicated in a clear and supportive way by the palliative care team. And finally, I will forever cherish how, even in the non-hospice setting, Don and I were given time and space to share final words of love—because words were all we had.

I would say that how we live and how we die is more important than how long we live or how many days we have left.

Understanding/ acknowledging/ accepting that my memories of my sister are unique to me and no one else has those exact same memories, nor can anyone take them away from me—this gives me comfort. They are mine and they are precious.

I sat with my sister, side by side on the edge of her hospital bed, as we ate two Loop the Loop ice pops, looking out the window at the sunset. Four days later she wanted another one at ten thirty at night, and I left the hospital and ran and ran and ran until I found a shop open that sold them. I then ran and ran and ran all the way back to the hospital, and we shared our last ice pop together. I have a little chat to her every time I have one now. They are and always will be my favourite ice pop.

—Fiona

Humour at a Funeral

Mary Kinhart

After the funeral of a neighbor's mother, we were asked to a local for lunch. I went to use the pub's ladies' room. As I was going to wash my hands, I couldn't help but notice a lady facing into a corner, fighting with something in her hands. After I asked if she was okay, she apologised profusely for having her false teeth out. I laughed so hard that I had to explain myself!

My Pop-Pop would take his dentures out at the table all the time. So, as a little kid, I was used to seeing dentures. And a memory of my mom just needed to be told.

Mom hated her dentures; in her later years, she got very careless with them, often falling asleep with them in her hand—so careless that one of her dogs learned that her dentures tasted good. My sister, Judy, was furious when the dog broke her top denture in half. She had to glue them together. She had done everything to make it more convenient for Mom to put her dentures in a box. Judy is also the one who had to chase down the dog and get the dentures off him.

By this time, the laughter was probably getting loud, as other ladies had come in and we were causing a queue. So we said goodbye and went back our separate ways. There were a few inquisitive looks at the laughing women reentering the sombre pub.

Some time later, a man came over to thank me. He said that he hadn't heard his mother laugh since she'd learned that her (deceased) sister was sick. But she was having a great time telling people about my mom, her dentures, and the dog.

What advice would you give others? Offer reassurance and support.

What helped you through the journey? Talking to hospice staff and friends and praying.

How did the journey change you? Made me more sensitive to others' feelings.

Fondest memory? Sitting chatting about all the good times and remembering special events with family.

—Irene Harbinson

Judy's Hospice

Mary Kinhart

When I walked into the hospital room, I barely recognised my sister, Judy. She was yelling at people to get out of her room. She didn't recognise me, and she got angrier when I put my coat and purse down. When she stopped yelling, I told her that I had been ignoring her all my life; I couldn't change that fast. She shifted a little to look closer and quietly said my childhood nickname: "Patty?" l pulled a chair close and answered her. She didn't seem to believe I was really there until she touched me. I couldn't believe how wasted she looked, her skin hanging between the bones of her forearms. I did my best to remain calm and just talk with Judy. She was quite muddled with pain and medications, talking about people unseen to me. Having gotten used to Mom's bouts of dementia, I just accepted it and tried to work through the conversation regardless of how unreal anything sounded.

It was Weta who had told me that her husband, Ken, was going to buy me a plane ticket to Florida because my sister was very sick. Although Judy and I spoke almost every day, most of the conversations were focused on Mom's care—the pets, money problems, or almost anything besides Judy's health. And since Judy and Mom lived in the St. Petersburg area of Florida and I lived in my current home near Ballina, County Mayo, it was very easy for her to keep details from me. Judy had just recently started to complain about not being able

to do things for herself. That's what first made me think I didn't have the whole story.

During her earlier stay in hospital, a lone male assistant had been unable to sufficiently help Judy walk back to her bed from the shower. She slid to the floor, breaking her left hip in the process. She rang me when that happened. She was in agony. I guess she made them give her her mobile phone before she chased him out of the hospital room.

How was I to help from thousands of miles away? Well, I managed to calm her enough to where she let the nurses back in the room to help her. The worst part was that there was no way to set her hip; that's how badly deteriorated her bones were already. For the remainder of her life, she lived with the pain of that broken hip. That's why we tried to have one of us be with her as much as possible, since her broken hip was often overlooked with staff changes, etc.

The next day, we even got smiles out of Judy when two police officers brought her personal effects to the hospital room to sign over to me. When the officers arrived, Judy was having some interesting visual hallucinations that were making her happy, so I was encouraging her to tell me more about what she was seeing. At least one of the officers was visibly uncomfortable, especially when Judy started describing some beautiful things on his uniform. The men were thorough but hasty in their duties. Of course, these were Judy's belongings, so she was possessive about them. To make life easier, I gave Judy anything she asked for so she could check too. As soon as I signed off on the documents, those officers were gone as quickly as they could leave the room. Apparently, bravery comes in many different forms. When I told Judy that she might have frightened the officers, she wanted me to get them back so she could apologise. I told her that they were too busy and she had no reason to apologise; she had only complimented the man's clothing.

Within a couple of hours of arriving that Monday, I was called out to see the doctors, who needed my approval to move Judy to hospice. I was still obsessed with how my sister was declining so quickly. So I listened to the doctors talk at me but barely understood what was happening. I couldn't even say when they moved Judy to hospice, although Weta and I were at the hospital throughout the whole process. The one thing I insisted upon was allowing Judy to eat and drink if she wanted. I had been told repeatedly that she would choke on anything by mouth. "She has *no* chance of surviving this; why does she have to suffer *more*?" I finally said very forcefully. I told them that I would feed her; no one under their authority needed to do anything but stay out of my way! They relented but again warned me that I could cause her death. That was the closest I came to blowing up at a doctor. How dare they try to control me or my sister so inhumanely when she had no hope of survival. So I could bear more guilt? Because the cancer was killing my sister? NO! The doctors learned that my quiet compliance only went so far. If they expected me to watch my sister cry for a drink, they'd better get the police officers involved fast! I'd prefer that she choke to death with me than suffer anything I could help ease.

I had to override doctors' orders a few times until it was clear that the hospital was going to have to keep sending my sister food and drink. To be fair, I had to be very careful that Judy didn't choke. But I remembered playing with straws as kids; just cover the top and you only get the amount of liquid left in the straw. That's what I did, giving Judy time to taste and swallow the water. The food was more challenging.

Over these few days, my sister had become robot-like. She no longer looked me in the eye or spoke unless she was asked a direct question. I didn't understand much of the process of dying at that

point; I just wanted her to be comfortable. So I offered her tiny bites of food until she said yes and opened her mouth. I found that she liked the egg mayonnaise and chocolate pudding . . . on the same spoon. It was not easy to figure out and it was disgusting, in my opinion, but she was eating it. When I complained about the combination I was feeding her, half a teaspoon at a time, her response shocked me. Still robotic and staring straight ahead, she just said, "Don't knock it till you've tried it." It was the first glimpse of my sister's normal character that I'd seen since I arrived.

Within a couple of days, Judy was moved to hospice. Weta and I followed from the hospital, and the move went as well as we could have expected. Having the hospice doctors and nurses involved was so much easier than working with hospital staff. Once Judy was settled, Weta and I went to the hospice cantina for ourselves. While we had something to drink, we noticed the overwhelming aroma of baking cookies. While our own tummies grumbled, we asked about the cookies being baked before dinnertime. We were kindly welcomed by the receptionist, who told us where the cookies could be found throughout the facility. She also told us that studies had shown that the scent of baking cookies was very comforting to most people. It was the kind of detail I hadn't expected.

When we got back to my sister's room, there was a nervous lady waiting outside for me. Although Judy had improved enough to hold a spoon and try to eat, she couldn't do it on her own. The plate they had brought her was not very appealing anymore, and I had brought some easy-to-eat treats with me. But when I started to remove the tray from in front of Judy, the nervous lady in the hall made her worries clear. Judy started to sob loudly and grab at the plate. To the aide's credit, she watched how I let Judy hold on to the plate until I showed her the other food I had for her and convinced her that she didn't want the old stuff on the plate anymore. It wasn't easy, but as soon as

I could slowly remove the old plate, the aide hid it behind herself and moved back to the doorway to watch the rest of the job of convincing Judy that she wasn't going to be deprived.

The biggest trouble I got into was a few days later when Judy became more conscious and able to read again. She wanted to know what the bracelet reading *DNR* was about. Another dear friend to both of us, Vanessa, was with me that day. As she was a nurse, I thought she would help me out, but she stayed quiet while I got in a world of trouble with Judy for putting the do-not-resuscitate order on her. The fact that her bones were too weak for her to even survive chest compressions was entirely lost. I just had to take that all on the chin and tell Judy that the hospice doctor was considering sending her on to a nursing home, since she was improving so much. As soon as he decided that she was thinking clearly again, she would be free to make her own decisions again.

I spent that Christmas at Weta and Ken's home, between Judy at the hospice and Mom in her nursing home. Pat, my dear husband, somehow managed to keep me from completely falling apart by talking to me every day.

The last few days before I returned to Ireland were spent trying to find a decent nursing home for my sister. Too many of the facilities I visited either had no room for low-income residents, were overcrowded, or were sadly understaffed. At the last minute, a spot opened up at a facility very near Ken and Weta's home. That's where I had them take Judy, so that Weta would be able to visit at her convenience.

A bit over two months later, I returned to Florida to check on Judy and Mom as well as do what I could with their house, vehicle, remaining pets, and storage facility. Breanna, my daughter by mutual decision, and Sara, another dear friend, had helped clear out Judy's truck.

Weta and Venessa worked inside the house to find photographs or anything else they thought would be of any value to me. Before much of the physical problems started, hoarding had already been an issue. So as you may imagine, with the physical decline of Mom and then Judy, everything had gotten much worse.

At home, I was able to think a bit more clearly. I had still been trying to hold on to their possessions for them. When I returned in March 2016, I was getting rid of everything. I became very disenchanted with material possessions, although I could still see the signs of hoarding in myself.

Again, loved friends rallied around me to help. The very loved and loyal pets had been rehomed to neighbours and friends. The house was already in foreclosure, so the bank got it back; the truck was sold to a breaker for parts; and anything that could be of use to others was donated.

I wanted to spend time with my mom and sister, not worry about stuff. So I planned a St. Patrick's Day picnic at my sister's nursing home. This is one of my fondest memories of those times. In spite of all the health problems and challenges all around, Mom and Judy got to spend time together and communicate almost like they had years before. The time passed much too quickly, but it was wonderful and probably the last time I heard either of them laugh.

After returning to Ireland, I did my best to manage their care with the help of friends and a paid carer, Debbie, who did a great job of helping me talk to Mom and giving me updates.

Judy had so many more troubles that I agonised over whether I should have tried so hard to keep her alive before. But she just didn't accept mortality; she asked me not to give up on her. I didn't, but at some point she contracted MRSA. Regardless of the antibiotics or other drugs used, her organs were failing.

Judy survived until the end of November 2016. Vanessa had recently returned to Florida and wanted to see Judy urgently. I had known Vanessa since the early 1990s, and she became friends with my sister and mother not long afterward. Of all the tough times I've known Vanessa to endure, I don't remember seeing her cry as she did when she saw Judy that last day. I know she didn't want me to be more upset, but she said that Judy was losing her fight.

I rang Weta, and Ken brought her up to the hospital. I knew they both wanted to be with her. I had been talking to doctors all day about alternative treatments—any hope. Some doctors do not have a good way of talking with people facing the horrible decision of taking a loved one off life support. After hanging up on that one, I rang Judy's oncologist, a very kind doctor I had met during a couple of appointments I attended with Judy. He took time between patients to talk to me. It wasn't long. I knew he had been using experimental chemotherapy that had shown some positive results earlier, and he agreed but said that it was no longer working against the cancer. "This is probably the time to let her go." I thanked him for trying his best and for taking my phone call.

Once semicomposed again, I called the hospital back to ask if Weta was there. I wanted to talk to someone other than the pushy doctor who had pressured me so much earlier. We discussed how they would treat Judy and what I needed to do for legal reasons. They did not expect Judy to survive long after being taken off the respirator.

I rang Vanessa again. She and Weta were with Judy, trying to soothe her—not an easy task while they were all dressed up to protect themselves from the spread of MRSA. Vanessa had me on video call as she and Weta stepped out while the respirator tubes were removed. When I saw Judy again, a tear slid from her eye as Vanessa and Weta started praying the rosary. I promised Judy that I wasn't giving up on

her; her body couldn't fight cancer and infection anymore. Eventually I joined the prayers, shortly before the phone battery quit.

I had an angiogram the morning of November 29, and that's the day I took my sister off life support. I cried myself to sleep with my husband holding me.

When I woke up almost thirteen hours later, I rang the hospital's hospice desk. I was told Judy would be taken to one of those private rooms if she didn't pass away quickly. The very kind nurse that I spoke with said that Judy was still alive and explained the measures they had taken to ease any discomfort for her. She also told me that Vanessa and Weta were still with her. She asked if I wanted her to wake them. I declined, asking her to just let them know I'd rung.

After hanging up, I meant to pray, but it all came out more like a threat to the fathers who'd died young—first Judy's birth father when she was a baby, and then our daddy when she was twenty-one—for the loss and abandonment I felt. I knew it had hurt Judy even more deeply. I'd lost only one father, but I was angry at both of them. Why was she still holding on for so long? I told her I could not travel to be with her. Why had no one helped her cross over yet? They'd better hope there was no life after death, because if there was, I would find a way to make them regret all the time they had *not* been there for her—not just in life but in death!

I woke Pat punching the wall in anger. I told him about my earlier phone call and how much I doubted my decision.

Vanessa's phone call interrupted my anger. She called to tell me that Judy had passed on. Something between heartbreak and relief overwhelmed me. I donated Judy's body to scientific research, and Weta organised her funeral.

Mary Jude Redgate's earthly remains are now with me, at home here in Ireland. I had planned to bury her in the plot with our mother,

by our father. But between church politics, family politics, and outrageous costs, I don't think she cares. If I die before my husband, he will put their urns with me.

Barely a month after Judy's death, Mom's nursing home rang me to ask if they should take her to hospital. They suspected another stroke but were not certain. It felt selfish, but I couldn't handle losing them both so quickly, so I told them to send her to hospital. Too frequently she presented stroke-like symptoms when she had kidney or bladder infections. Fortunately, it was a UTI that resolved, slowly but surely. Debbie, Mom's carer/companion, did notice some changes. Our phone calls were shorter. Debbie needed to tell me that Mom was making different facial expressions rather than using words to answer my questions or comments.

She did talk again, but not much. I honestly believe she knew Judy was gone. They had always been very close, having lived together their whole lives. Maybe I should have told her about Judy, but I couldn't be with her, and it was not news I could give over the phone. But I do believe she knew.

Mom did fairly well for almost a year before she had another stroke. They sent her to hospital right away, but it was a massive stroke that damaged almost the entire left side of her brain. The doctor caring for Mom and suggesting that I not put her through more tests or procedures was very kind and patient with me. He said he needed help to send me the brain scan showing the damage because he wasn't that good with computers and he didn't know how to send scans, as they were confidential and protected.

The day Mom was taken to hospital, Liz rang me to say she'd check on Mom at the hospital on her way home. Liz was an administrator and retired RN at the nursing home with whom Mom had become good friends. When I next heard from Liz, she was so angry that she

was barely making sense at first. Apparently, Liz had been late leaving work and was caring for her own mother at home, so instead she had stopped at the hospital to check on my mom on the way to work the next morning. She was not remotely happy with the condition in which she found Mom. Not only did she give the staff a piece of her mind, after she cleaned Mom up and made her comfortable, but she told them that she wanted her returned to the nursing home. She was *not* leaving Mom in the hands of strangers who had her stuck at the far end of the hallway away from the nurses' station! When someone challenged her about her identity, she said she was Mom's daughter before storming out to get to work and call me.

If I recall correctly, the hospital rang me before Liz. They were a bit strange on the phone, as I'm guessing their security protocol was also in question, considering how long it took anyone to even question what a stranger was doing to one of their patients. They asked if my mother was to be returned to the nursing home and if I had a sister.

I think there were at least two angels involved in Mom's care that morning—Liz and Judy. Liz was one of the few people Judy trusted with Mom; they were both very good advocates for their charges.

I told them that my sister was absolutely correct—I wanted Mom back at the nursing home, where she knew people. The woman on the phone started to tell me that Mom was not aware of the people around her. Being in no mood to deal with a fool, I simply asked if I needed to get an attorney involved.

Mom was back in her room at the nursing home that same day. The only difference was that I had placed a DNR on her. When I talked to Liz that day, she thought she might have overstepped her boundaries. Not at all! My mother was not exclusive to the children to whom she'd given birth. She was an unofficial mother, advocate, and guardian to many, many children and adults in her lifetime.

When Liz rang me a couple of days later to let me know how Mom was doing, she confirmed what I'd known forever—doctors do not know everything. She said that when she kissed Mom on the forehead before she left, she saw Mom's right hand move just a bit. Mom used to touch Liz's cheek in parting. Tell me again how stroke victims don't know who's around them! They are all individuals, and we don't know everything about any of them except that they are people who deserve respect and kindness.

Not more than about a week after all this, I was meditating, and my mind wandered to Mom. I felt like I could talk to her, so I did. I thanked her for sticking around in that decrepit and painful body so I did not have to bear losing her so soon after Judy. But I knew it was an awful burden for her. I promised to do my best to not fall apart when she passed on. She had given me her best, and I would do my best to pass it on.

I'm not sure how long it was before I got the call to tell me that Mom was gone. The aide who brought her lunch couldn't wake her; she'd passed in her sleep. Liz was heartbroken but relieved, as was I. Mom's body was donated to scientific education. Debbie kindly organised her funeral service.

Mom's remains are also here with me, at home in Ireland. There are only about a third of the ashes in Judy's urn. It makes me wonder if Mom isn't in a classroom somewhere. I think she'd like that.

The journey broke me. I still hear my sister asking me not to give up on her. She was dying from cancer. I did everything I could, but it wasn't enough. I had to give the order to stop life support for her over the phone. I couldn't be with her, but two dear friends stayed with her for thirteen hours while she passed away.

Spirituality saved me from myself. After my sister passed away, my mother got sick again. She was hospitalised for a kidney infection. I begged and prayed for her not to leave me too.

I practised guided meditation until I learned to meditate on my own. It was very challenging but has been priceless. It helped me control many urges to harm myself, but I still had many suicidal thoughts and did cause some self-harm.

My husband made a punching bag for me to give me an outlet for my frustrations. It helped, but I also sought help from counsellors and psychiatrists. I called help lines when I really needed to.

By the time my mother had a massive stroke about nine months later, I was able to place a do-not-resuscitate order on her. Again, I got help from an unexpected source.

An administrator and friend at Mom's nursing home went to visit her in the hospital. She was livid about the state she found my mom in, and after cleaning her up, she demanded that Mom be taken back to the nursing home. Liz rang me when she got to work to tell me what she'd done. I couldn't thank her enough!

When I spoke to the hospital, I confirmed that Liz absolutely spoke for me. I wanted Mom back home, where she was comfortable and people knew her.

I had hired a private caretaker to visit Mom a couple of times a week to check on her and to help me communicate with Mom on the phone. Debbie was lovely and got along well with Mom.

A couple of weeks later, during meditation, I thanked my mother for fighting so hard to stay with me, but I didn't want her to suffer any longer. Later that day, the nursing home rang to tell me that Mom had passed away in her sleep. She was gone when they brought her lunch.

Debbie arrived when they were talking to me. She had become friendly with us and offered to organise Mom's funeral for me. It was simple but beautiful.

—Mary Kinhart

Humour

Fiona

A day without laughter is a day wasted.
—Charlie Chaplin

Have you ever heard the expression *If you don't laugh, you'll cry*? Well, on the palliative journey you will cry—a lot. But you will also laugh. There will be lighthearted moments that will bring some relief and balance to the darker, heavier days.

Don't be afraid of humour. Don't be afraid to share that joke with your loved one. Don't be afraid to laugh when your loved one makes the joke. Don't feel guilty. Enjoy the shared moment. It will become a treasured memory on your grief journey.

My sister was the wittiest person I know. She was just so funny and quick. One of the many happy memories I have was when we were sitting in the waiting room of the oncologist's office and other patients were glancing over at us because we were giggling away to ourselves in the corner. I can imagine they didn't think we had too much to laugh about. My sister had lost her hair at this stage from the chemotherapy. However, to pass the time, we were attempting to complete a crossword together, and neither of us had a clue. So we

were coming up with our own answers and squashing them into the crossword, which meant reconfiguring the other questions, and it got funnier and funnier as we went along.

Several months later, we both unexpectedly gave each other crossword books on Christmas Day, and the laughs continued. This was a moment that only we shared. It was unique to us. It makes me smile when I remember it, and it has certainly been very helpful on my grief journey. Was it appropriate for the pair of us to be giggling in the corner of an oncologist's waiting room? Probably not. Do I regret it? Definitely not.

Fond Memories

While Mom was a science teacher, she had to move her classroom from one building to another. She had a human skeleton which she took great care of moving. She sat him in her car's passenger seat with the seat belt on and strategic padding to keep the skeleton as safe as possible, then slowly drove to the new building. All went well until she got back onto the school property. Then someone driving in the opposite direction apparently was shocked or distracted enough by Mom's skeleton passenger that they drove off the road and onto the baseball field. Nothing was damaged, but explaining the tire tracks on the field was something that amused Mom for years.

—Mary Kinhart

Communication

Fiona

Good communication is the bridge between confusion and clarity.
—Nat Turner

How many of us have been in the situation where we just don't know what to say? Or where we say the 'wrong' thing? Or we don't say anything at all? How many of us have been in the situation where we're out and about and we see someone we know look away or cross the road to avoid us? Or we ourselves have looked away or crossed the road?

Six days before my sister died, I walked into her hospital room and asked, 'How are you?' She shrugged her shoulders, shook her head, and just looked at me. I'll never forget that look. It was a combination of *Did you really just ask me that?* and *How am I supposed to answer that?* It was a pivotal learning moment for me. One of many. Now, when I find myself in similar circumstances, I ask 'How are you feeling today?'

Our use of words and language can make a big difference on a palliative journey for all involved. Words can hurt and harm but also heal and be helpful. Try to be as clear and direct as possible without being harsh or abrasive. In the moment, this can be difficult, as our emotions wash over us like an unexpected wave. It is tempting to avoid using certain words or phrases to soften the reality, but this can cause

confusion. There are seven C's to remember when communicating—clear, cohesive, complete, concise, concrete, courteous, and correct. If you remember all of these, I applaud you. If, like me, you find yourself driving home and berating yourself for saying 'something stupid', don't be hard on yourself. Remember, we are all human, just trying our best.

The phrase *Honesty is the best policy* works well in these situations. If I don't know what to say, then that's exactly what I say: 'I'm sorry, I just don't know what to say.' I've even written it on cards: *There are no words to write—I don't know what to say.* Personally, I have found that people are receptive to the honesty. It is certainly a better solution than looking away or crossing the road, a nonverbal means of communication that can be confusing and hurtful.

Often, we put ourselves under pressure to say something when it's not necessary at all. Eye contact and a soft smile or tilt/nod of the head can convey a thousand words. One of my favourite quotes is:

We have two ears and one mouth so that we can listen
twice as much as we speak.
—Epictetus

Hope and Happiness

John Wall

The word *palliative* conjures up all kinds of images and meanings for the vast majority of us. I'd like to use my own experience to dispel a few of them.

Six years ago I entered a world where words such as *bleak*, *terminal*, and *death* became second nature to me.

Six years later, I'm now living in a world where those words have been replaced by *life*, *hope*, *happiness*.

My diagnosis no longer defines me, and cancer no longer dictates the present nor the bright future that lies ahead.

Like anyone else in a similar boat, I struggled enormously for the first few years. Mortality was never something that I'd ever thought about, especially not my own. Be that as it may, it was staring at me and at that point wanted to take me from this life to the next, wherever that might be. My body and mind had other ideas, though, and slowly began to believe in what might be possible. What if I'd been given a second chance, but this time around with an appreciation for life that I'd once taken completely for granted?

And so began a journey that has brought me here, typing this and looking forward with hope in my heart and finally being able to see beyond the horizon. Let me tell you, the view is amazing!

A single visit to my palliative care consultant was the defining moment. When I was advised to do this at first, I said an emphatic 'No!' to the appointment, believing this would be the beginning of the end for me. Instead, I suffered in silence, but thankfully there came a point where my stubbornness along with my ignorance gave way to curiosity and common sense. That visit ensured an almost immediate transformation in my quality of life, which in turn has enabled me to deal with the physical and mental challenges of living with Stage 4 cancer—successfully living at that.

My advice to anyone reading this is simple: never take your good health for granted, and when something does go wrong, remember there is help out there. All we have to do is ask for it.

Every day is now a good day, and I look forward to each and every one of them, knowing how important they all are.

My mantra is *Carpe diem—seize the moment, seize the day*.

Hope you are able to seize yours.

Thoughts and Memories of Our Dad

Linda Cooper

Dad was born in 1937. He was one good-looking guy. He met and married Mum in 1962 (she died in 1979). He raised seven daughters single-handedly—some going, I tell you, surrounded by women.

He went to the Derry dances in his youth and loved to jive. He played snooker, and his nickname was Cautious Kelly. He could make a snooker match last for hours.

He was at the bogside on Bloody Sunday. He was there when Dana won the Eurovision Song Contest. He met Bill Clinton in 1995 and wrote a poem that was published.

He loved his garden; roses were his favourite. He was a DIY fanatic and lived by the motto *If it moves and it shouldn't, use duct tape. If it should move and it doesn't, use WD-40.*

He believed that Sudocrem was a cure-all.

He was a great storyteller and loved a good laugh. He dressed up at Halloween, Christmas, and parties. He had an encyclopaedic memory and was always up to date with current affairs. Although he was grumpy sometimes—and who isn't?—he was our dad, and we loved him.

In his last days, he was in extreme pain. He asked to die. Every pain, every scream, and every tear tore through our hearts and souls,

never to be forgotten. Both we and the GP promised him he wouldn't be in pain, and we failed him and the system failed us.

Now imagine that he was your loved one.

Dad had a knack of mispronouncing words, often with hilarious consequences.

He often told us when he was running low on his 'stomach tablets', meaning omeprazole. Only he called them *ozmaparole*.

He never seemed to get number-one golfers' names right, so Rory McIlroy became Rory McGrory.

The 'Single Ladies' singer became Bouncy (not Beyoncé).

I don't think we will ever call them anything else now after all this time. It's his legacy to us. ☺

Dad always had trouble sleeping and was used to taking a sleeping tablet sometimes at night. I was visiting him one time, and at about eight p.m., my sister said to him, 'Do you want anything from the kitchen?'

'Give me one of my drinks and a biscuit' was his reply.

My sister brought him in a biscuit and a can of energy drink.

I said, 'Dad, you can't drink that at this time of night. You'll never sleep!'

'Don't worry,' he said. 'I'll take a sleeping tablet.' ☺

Fragments of Time

Liza Clancy

Kevin loved watches. Anyone who knew him knew he loved collecting things—Nike trainers, cars, Beckett books, and watches were up there. He loved analogue over digital when it came to watches, so much so that I often struggled to go to sleep with the ticking sound of a second hand in my ear.

In the hours before he died, Catherine, John, and I sat with Kevin in his room in the Bon Secours in Cork, and time seemed to slow down. We have often spoken of the energy of the room during that time, late at night, when everything was quiet, and it seemed like the universe had put a protective shield around us, stationed at his door. No one came in or out barring the three of us, and the silence was both peaceful and comforting.

We had an unwritten pact between us—he would never be left alone. And so we took turns keeping vigil, an unscripted but effortless choreography as we moved in and out as we needed to. We talked to him, out loud and in our minds. We reassured him that everything was okay and everything was done and he could go whenever he wanted. We played his favourite music—Chopin melodies and the score from *Cinema Paradiso*. Calmness spread over his face, and occasionally he smiled or looked off to something or someone in the distance, as if he could see where he was going next.

I became fixated on his watch. Even though it seemed like time stood still, the second hand moved steadily around, always keeping the same time. As those final moments came around, that second hand measured the space between his breaths, each one coming further and further apart. With each breath came the hope that this would be the final one for him and he could be free, and at the same time the hope that he would continue to take one more. I lost count of how many times I thought he had died, only for him to take one more breath. Time became liquid, and yet the second hand moved always at the same pace, measuring breath after breath until the very last one.

At 12:21, in the early hours of Wednesday morning, 12 February 2020, Kevin died. We sat there, for how long I have no idea, just letting everything sink in and sitting in the stillness of that moment. Once I moved and went to find the medical staff, we knew everything would pick up. So in that moment, suspended in time, we just sat. Everything that needed to be done was now done. Everything that was in our hearts that we wanted to give him had been received.

After a while, I left the room to find a nurse—Aisling. I will always remember her, because Kevin thought she was the prettiest nurse in the hospital and she loved his sense of humour. I will also always remember how, when I told her Kevin was gone, her first words were 'Gone where?' and then her own shock and sadness kicked in.

And then, as it does in moments of chaos, time sped up. Nurses came in, doctors were paged, and Kevin was officially pronounced dead. The standard Irish shock treatment of cups of tea and sandwiches appeared out of thin air. We stepped in and out to make phone calls, thankfully few, as only a handful of people had known that Kevin was sick. The night nurse manager came to visit us—a steadying presence with a dark sense of humour matching our own—to inform us that Kevin wouldn't leave the hospital until the morning, when he would

go to the mortuary, so we were welcome to stay with him as long as we wanted.

Eventually, time settled. Aisling and one of the other nurses came in to tend to Kevin, and Catherine and I were invited to help. Those moments in the immediate aftermath are some of the most precious I have experienced. I have rarely seen such kindness and compassion from two strangers, especially given that Kevin could no longer hear us. They removed all his monitoring equipment, all the while speaking to him and explaining what they were doing. We washed him and changed his bed and settled him back in, all the while laughing about how much he would love four women fussing over him. And I took his watch off his left arm, the second hand still marking time, and I put it on my own.

And then we sat again. Michael arrived, and we drank endless tea, and reminisced, and told stories, and eventually we began to plan his funeral and what we would do and when and where. And in those hours, Kevin's face returned to utter peace as he returned to himself. His ultimate marathon was over, and he could rest.

As morning broke, the noise of the outside world began to filter into our little protected space. We could hear patients stirring, breakfast carts in motion, and visitors arriving. It was time to leave and time for us to rest a while now. The porters arrived to take Kevin to the mortuary, and we made our way to the Bru Columbanus Hostel, an amazing accommodation facility for family of Cork Hospital patients. We phoned the local funeral directors and made arrangements to visit them later that day.

And as the world woke up, I went to sleep with the now comforting ticking sound of a second hand in my ear.

More Than Words

Liza Clancy

'I'm so sorry. I don't know what to say.'

Pure perfection in nine words.

Let's face it . . . when someone is going through a difficult time, whether it's any type of loss or traumatic event, our human instincts kick in. We rush to comfort, to fix, often to minimise, and to do what we can to help. So what do we do when in that moment, there is absolutely nothing that will make things feel better for the other person?

Pain is uncomfortable, both to experience and to witness. And in that lies the problem—it's our own discomfort and pain that we are trying to avoid. If we can do something to make someone feel better, we will, of course, feel better about ourselves. And as humans, we have for so long been trained to use our brains to come up with words that will explain everything and make things okay and fix everything, because then we can just get on with the rest of our lives. I can tell you from experience that in these cases, there are plenty that don't work ('He was very young', 'At least you didn't have kids', and 'Sure you are young—you'll find someone again' being three of my least favourites!), but there are few that do. Trite words for the sake of words are exhausting. Those in the eye of the storm of their grief

become the comforters, the easers of the discomfort of others—as if they didn't have enough on their plate in that moment.

What really worked were those who were happy to sit with me in my pain, in silence, with a hug or a hand squeeze; to let the tears fall when they needed to, to laugh, or just to sit still. Things don't always need to be fixed; sometimes they just need to be. In those nine words was everything that someone needed to say and everything I wanted to hear—the acknowledgement that no words made anything better, and that was okay, because in that moment, I didn't want to and couldn't possibly feel better. And those nine words didn't ask anything of me—I didn't have to comfort, or answer questions, or even respond. Here was someone who was willing to be comfortable with being uncomfortable with me—a gift of pure empathy from one person to another.

So, when you find yourself with someone at a difficult time, choose your words carefully. And most importantly, get comfortable with being uncomfortable, in sitting with them in their pain. The ability to do that is more than words. And sometimes words are just not needed.

But if you are stuck, at least now you have nine.

Last Things

Liza Clancy

As I begin to write the *how I got here* story, which will be done over many different posts, I often come back to the concept of 'last things'. As we move through our lives, we so often mark the 'first things' milestones—first steps, first tooth, first kiss . . . they become part of the fabric of how we remember our time in this life, and we hope that throughout our life we can still get to experience a 'first thing', because they have a special energy about them that will never be repeated no matter how many times we do that thing again.

For me, the loss of my husband, Kevin, turned my thoughts to 'last things'. This photo is the last photo I have of us—in fact, it's probably the last photo taken of Kevin before he died. It was taken on our wedding anniversary; there's a funny story behind it too, but that's for another day. Another memory to add to the 'last things' basket.

Kevin's diagnosis was accidental. He had completed the Malaga Half Marathon in December 2019 and didn't feel well a couple of days later. Still in Spain, he took himself to hospital and got scanned and was told to come home and see a doctor immediately.

A barrage of tests and a week in hospital ensued, and by 9 January 2020, we had the news. It was, as Kevin said to me, 'the worst possible news I could have thought of'—Stage 4 bowel cancer. The prognosis

was two to three years. I remember thinking at the time, *Well, at least that's not a few weeks, but I have a feeling it won't be that long*.

The next few days were a blur of research and visits and decisions around treatment. We had so many conversations about the future and a long list of what-ifs. Kevin wondered if he would ever be able to go running again (he didn't in the end, so Malaga became that 'last thing') and if he would go back to tour guiding and driving (that didn't happen either). We reminisced about the past too, and new stories emerged that I hadn't heard before and added another layer to an amazing human. We made plans to visit friends to break the news to them—Kevin was insistent that beyond the initial small circle of people, everyone needed to be told in person, and that we had time.

They say there's never enough time, and in a way, that's true. No matter how much time you have, you are never prepared—and you would always give anything to have more time with a loved one. That is the powerful energy of love; it draws you to other people, and it's hard to prepare for a day when you still have that love but they have done their 'last thing'. Someone described grief as 'love with nowhere to go', and that sums it up perfectly for me.

In the early hours of 11 February, Kevin was rushed back to hospital, feeling unwell after chemotherapy. By that afternoon, it was clear that things hadn't gone to plan at all, and two to three years was looking more like weeks or months. New options were drawn up, but Kevin, being Kevin, had other ideas. With the peaceful acceptance that he kept throughout, he knew there was only one more 'last thing' to do, and a few hours later, with me, his sister Catherine, and his brother John by his side, he took his very last breath.

I don't remember a huge amount about the subsequent days (more on that in another post), but in the weeks and months that followed, my grief became about last things. The last time we spoke before

unconsciousness took over, his last joke, the last text he had sent me. As the initial fog cleared, more 'last things' memories surfaced, and they still do, three years later. During loss, last things become more of the focus than first things—perhaps because there will never be any more first things.

In a magical way, Kevin's final last thing became a first thing for me—the first time I walked the liminal space between life and death, the first time I witnessed a soul transition, and ultimately the catalyst that set me on my path to celebrancy and doula work.

In the same way that life and death are two sides of the same coin, so first and last can be also. As much as we can't live our lives in fear that every experience could be the 'last thing', I have learned to keep the thought consciously with me. My connections with others and how I walk this path have become more meaningful, because on some level, I understand and accept that any moment could be someone's 'very last thing'. And some day it will be mine.

Our Brian

Marian O 'Mahony

CHAPTER 1
Terminal Diagnosis

'We are talking about a week, maybe two at most. Brian is critically ill,' the consultant said.

In 2001, our family, like every family of teenagers, was busy and active. Three boys and our foster child, Vicky, made sure of that. As parents, John and I enjoyed the energy and enthusiasm of our chaotic, busy home. John, our eldest son, age twenty-two, was coming and going from our home in Cork to his college course in Tralee. Paul, nineteen, had a lovely girlfriend, Valerie, who brought fun and laughter to all our lives. Brian eighteen, was studying hard for his Leaving Cert, and Vicky, age sixteen, was also studying. The washing machine was constantly on, trying to keep up with the football, soccer, and dance clothes as well as school uniforms; the decks were constantly blaring, as the lads loved to create their own music.

'Mum, I've got a pain!' Brian panted, gasping for breath, clutching his chest. This was my first indication that something was seriously

wrong with my normally healthy son. He was six foot tall, dark haired, his brown eyes always dancing with mischief—I thought him so handsome, though I know I'm terribly biased. When we phoned our family doctor, he quickly told us to stop at the nearby pharmacy for aspirin before bringing Brian straight to the hospital.

We were seen more or less straightaway, and when the ECG showed no problems, I began to breathe a sigh of relief. *Well, at least if it's not his heart*, I thought, *we have a chance to sort things out.* I hoped it wasn't anything too serious—perhaps a collapsed lung or something like that. However, the X-rays and blood tests showed nothing unusual. The pain eased, and Brian was discharged at four thirty p.m. No problem was found. The doctors didn't know what was wrong. What a relief—even though there was a question nagging away in the back of my mind.

Over the coming two weeks, however, Brian's pains returned more frequently, in different locations in his body. He was gasping for breath; his body would visibly tremble. He stayed home from school, and his dad, John, checked on him every lunch hour. Dr Dillon organised a number of blood tests. Day after day, nothing showed up. We were very confused and surprised that we did not have a diagnosis, but we were optimistic that the illness would just wear itself out and Brian would get better.

Dr Dillon probed further when there wasn't a diagnosis of a physical illness. He questioned whether or not Brian had problems at school or was experiencing exam pressure. 'No! The pain is real,' I insisted. That finished that discussion, because my doctor believes mothers. He just had to check all the possibilities.

John and I were so concerned that John took a week's holiday from work to be with Brian, feeling he needed the care of a parent. Plans had previously been made for Paul, Brian, and their dad to go to a soccer international in Dublin between Ireland and Denmark

on Wednesday, February 28. However, Brian could not get out of bed that day. As it happened, the match was cancelled because the Lansdowne Road terraces were covered with ice and snow. We were grateful that the match had to be rescheduled. Brian didn't feel he had missed out on anything.

With no improvement in Brian's pain level and no obvious cause for his pain, Dr Dillon made an appointment for him to see a haematologist in the local hospital. Two weeks after that first pain in his chest, Brian had more blood tests. The haematologist said that she hoped Brian had a virus, or perhaps it was glandular fever or Weil's disease, as yet again nothing unusual showed up.

Tests continued every day on an outpatient basis, yet no new information came to light. Brian was quite disabled by pain at this stage. He was losing power in his pain-racked hands, and his legs could not hold him up. He was unable to eat anything. I didn't know what to think or feel. I was mostly numb. Brian seemed so very ill, and yet I could do nothing. I had no idea what was wrong with him or how to help. When would this pain go away?

Then the blood tests began to show some increase in white blood cells, which could mean infection. Brian was admitted to hospital—by now it was mid-March. At this stage, Brian's pain was intense and pretty constant. He couldn't lift his head off the pillow, and he used a straw to take a drink. His body was twisted and racked with pain.

Brian's friends were incredible, though. Mobile phones were relatively new at that time, and his friends kept in constant contact. They chatted away to him like normal and made no big deal of his growing disabilities. In hospital, when he couldn't walk, they grabbed a wheelchair and took him for races up and down the corridor like it was the greatest fun. They wanted to make light of the fact that Brian couldn't walk anymore.

A lumbar puncture was organised. At work, I got my usual phone call from John with the consultant's test results. 'I'm afraid I've got bad news,' he said. 'Brian has leukaemia.'

It was two thirty in the afternoon. That was the time my world stopped turning. 'The good news is that he has an eighty-five percent chance of survival. He's young, has no health problems. He has every chance.' John's voice was matter-of-fact as he tried desperately to make this news sound acceptable. I had secretly nurtured a hope that the symptoms would amount to nothing, that Brian would just get better. This dream was now dashed, replaced with a statistical outcome.

Because of the chemo, Brian would be completely open to infection. He was being moved to an isolation ward and would start chemo immediately. He would, hopefully, be better in six months. But, in the meantime, he would have to stay out of pubs, discos, etc., away from anyplace where there were lots of people, which would expose him to a high risk of infection.

'What's the bad news?' I quietly enquired.

'If they don't cure it, he won't be with us this time next year.'

The world stopped when I heard those words. I put the phone down and tried to arrange my thoughts. What did I know about leukaemia? Nothing. John said something about four types and that Brian's type had a big success rate. I assumed that Brian, being young and otherwise healthy, would be in the eighty-five percent group. There was every reason that he would, no reason at all why he wouldn't.

Oh my God, I thought, Brian was a real social butterfly. How would he cope with staying out of groups? How was I going to help him deal with the isolation he would have to endure for the summer? How could I even get across to him that this was actually important?

My head was spinning. I felt I was a stranger in a strange land. Why had this happened to Brian, of all people? He was such a nice kid. He loved life, loved his friends, and was such fun to be with.

Immediately, word spread at work about Brian. My work colleagues were so concerned and caring. Ever since Brian had been admitted, I'd gone to see him in the hospital every day before work. His dad went in at lunchtime, and I went in again at five p.m. and stayed until John, the children, and friends came after dinner.

I walked away from my desk and headed to the hospital.

I don't really remember a lot about the doctor telling Brian he had leukaemia, only that Brian didn't really mind having a blood disorder, but he didn't want anyone to know he had leukaemia. He didn't want to be 'the leukaemia kid'. He didn't want people feeling sorry for him and talking about him. I agreed to this just for the short term. The doctor explained to me that the chemo would start now and Brian would probably be sterile as a result. There was no time to harvest seeds. This really upset me, as I had always visualised my children having families of their own. Anyway, I'd tell him that later, when he got better. There was time enough to face that cruel blow.

The pain should be gone in a week, we were told. Brian was written up for morphine injections for the pain. Being eighteen, he was technically an adult, so I didn't have any authority to make decisions on his behalf. I was really worried about whether or not I should talk to him about the chemo making him sterile. Was he going to feel later on that I should have understood the implications and prevented such an outcome? I just didn't know. The doctors seemed to be in such a rush, not wanting to wait even a couple of hours, so I just let it go and hoped to God I was doing the right thing.

We moved to the isolation ward, 2D. I'd never been in an isolation ward before. Each patient had an individual outer room with a sink

and a supply of sterile disposable gloves, masks, aprons, and shoe covers. Having washed our hands and gowned up, we went through to Brian's en suite room. His bed was in the centre of this reasonably sized white space. The furnishings were sparse: a chair, locker, and wardrobe. There was a portable television high on the wall. Surprisingly, I also discovered that there was a fridge, which I later found out was donated by the Leukaemia Association, so patients could enjoy a cool drink, as being in isolation means never leaving the room to go to the hospital shop or vending machine.

Brian began a regime of blood transfusions and chemotherapy. I needed to talk to Brian about how we would approach telling people why he was in hospital. We talked about this 'leukaemia' word that he didn't want to admit to. I advised him that he might as well get used to it. If he didn't want sympathy or attention, not telling his friends the truth would not be the best way to go about it. So we agreed that we would tell people now that his sickness had a name—it was leukaemia. We would talk honestly about our situation.

Blood transfusions and chemo continued, but Brian was not pain-free within the week, as we had been told. This did not worry me unduly. Surely the terrible pain would be gone by week two. The doctors thought that Brian's pain could not be as bad as it seemed, so they sent the social worker to talk to him, as though it was all in his mind. I didn't understand how they could possibly imagine that Brian could be pretending to be in such pain, day and night. I felt really angry that Brian was having trouble getting morphine when he was trembling in pain. How could anyone be so blind to the obvious distress and disability that was so plain to see? I felt so helpless and frustrated. I felt like I was suddenly living in a parallel world, which of course I was.

'We don't like giving morphine freely,' a nurse told me.

'It isn't about what you like,' I said, frustration and desperation in my voice. 'It's about keeping Brian out of pain. There is nothing wrong with his head. He has real pain in his body.'

Brian loved soccer and was full of life. It was difficult to see him so disabled. I felt so much compassion for him in this horrendous pain.

He was worried about his hair. Lots of it fell out after the first chemo. Watching my now frail and pain-filled son try to negotiate two IV stands while going to the bathroom—one arm had chemo in one drip and blood in the second, while the other arm had a drip for fluids and other medications—I could not believe we had come to this. Weeks before, we had been planning holidays and so forth. Vicky was due to take part in a fashion show and was all excited about her modelling debut. It was an annual fourth-year event where the students run the fashion show, organise everything, and do their own modelling. The proceeds always go to charity, and this year the charity was the Leukaemia Fund. John had come to the hospital early in the day so I could leave and prepare Vicky. We had makeup, nails, and jewellery to sort out, and we had to make sure there wasn't a hair astray for her strut down the catwalk.

Brian had really enjoyed his experience in the fashion show when he was in fourth year, and he wanted to support Vicky and see her do her thing. He tried so hard to be there on the day. He sat on the side of the hospital bed, grabbed his crutches, and attempted so many times to put his legs under him. But he couldn't. He was exasperated by his weakness, disappointed in himself that he could not force those legs to bear him up. This was one of the very few times that Brian was left alone in the hospital in the evening. We recorded the show for him. He was so proud of Vicky, who put on such a wonderful show. I was torn between my natural pride and joy in Vicky and the searing pain of leaving my child in hospital in such terrible shape.

We could see how concerned the hospital staff were, and we knew that every effort was being made to find a cure. We were advised that the treatment would be delivered on an outpatient basis shortly, once Brian's bloods were okay. It had been expected that he could stay home after a week, but it was more than two weeks before Brian was allowed home, and then it was only for a weekend. We were given prescriptions for pain relief and other medications to help him through, but the pain continued at home. His knees and ankles were red and swollen. He used five pillows, one under each ankle and each knee and one on which to rest his painful and immobile arms. If he turned sideways, he used the pillow between his knees to save them from touching each other.

Brian and I were always very close. When we sat down on the couch, I would practice some metamorphosis with him. This is a healing technique that uses symbols to encourage a positive frame of mind. On other occasions, I would massage his back. We didn't have really deep conversations, as he wasn't a word person. But we had an understanding.

It's so confusing when relationships suddenly change, suddenly turn upside down. I had always enjoyed Brian so much—he was so funny, always lighthearted, and enjoyed people. At nighttime he had often cooked up something to eat for himself—a burger and small pizza in a burger bun, which was one of his favourites. He called it his 'pizza burger,' and he made one for anyone in the house who wanted it. He was carefree and generous, and that didn't really change—he never complained, never worried about himself.

His brothers spent all the time they could with him. John, thoughtful and considerate, had come home from college to be with him. Paul never left his side, and Vicky too, though she had a part-time job in Tesco, spent as much time as she could chatting and caring for him, trying to distract him from his pain.

Now we were worried sick. We were due back in the hospital on Monday.

It was Monday, April 2, my birthday, a day to remember. I took the day off work to bring Brian back to the ward. 'No response,' the consultant said. 'I took a risk last week with very strong chemo because there was no response the previous week. There is no response again. He's a young man. We'll do everything we can. But it doesn't look good.'

Oh God! My mind was racing. Was he telling me that . . . ?

John's words came back to me: *If they don't cure it, he won't be with us this time next year.*

'What do you mean by "it doesn't look good"?' I asked.

'Typically,' the doctor answered, 'before chemo, a patient with Brian's type of leukaemia could expect to live three to four weeks from date of diagnosis.'

This was where the hammer blow came—that Brian now had less than two more weeks to live.

My world just stopped turning. There was no cover-up, no room for misunderstanding in those words. My world seemed to stand right there, suspended in disbelief. Some kind of slow-motion replay was going on in my head. What had he just said—*critical . . . a week . . . no response*?

What in God's name am I going to do? I thought. *Dear God, what is Brian going to do? How are we going to survive this? Brian isn't going to survive this?*

Having a very sick child is one thing; having a child about to die is a totally different space to be in. Disbelief, shock, terror—I can't really tell you how I felt. I was trying to think rather than feel. Somehow thinking of things I should do was a way of keeping my

mind off the chilling fact that Brian was critically ill. I tried to put some boundaries on my situation, to contain it in such a way that I could somehow cope with it.

I remember my most consoling thought at that time came from my common sense. *Other people have survived this*, I reminded myself. *This happens to lots of families, and somehow they make it through.*

I went back to Brian with a smile on my face. 'Everything's okay, love. I'll be back in a while.' I kept it light and carefree, I hoped. Outside the hospital, I phoned John and told him what I had just heard.

My husband, ever the optimist, tried to console me and, without doubt, himself. His voice was thick with desperation. 'But they are trying everything. He's getting more chemo. Please God it will work.'

CHAPTER 2

Enduring Illness

I went across to my regional office nearby and applied for compassionate leave of absence from work. I would be paid for two to three weeks. It looked like this was all the time I was going to need. John and I had a moment to talk together outside the hospital. Mostly we were operating shifts in staying with Brian so that he was never alone, so we had little time to discuss things together. 'Look at all those bastards out there and nothing wrong with them, and our poor Brian who wouldn't hurt a fly, and look what he's going through,' said John, his words spoken straight from the heart.

Our other children had to be told that their brother was not going to survive this illness. Our eldest son, John, was busy working towards his final exams in business studies and also had a part-time job to fund his college expenses. Naturally, he knew about Brian's illness, but we had painted a hopeful picture, because we were hopeful. Now I needed to phone him and explain that the news was much worse than any of us had imagined.

'What can I do?' His first reaction on hearing the terminal diagnosis was to rush home and be with Brian. I thought it a good idea for us to carry on as normal so we wouldn't alarm Brian. So I told John to stay on at college for the moment and to come home only at weekends.

Paul, our middle son, was already keenly aware of how serious the situation was, and Vicky had to know. It was such an unbelievable story to try to tell. I knew they wouldn't really take in the enormity of the words I said. I hadn't truly taken it on board myself. How could I say out loud what I did not even believe deep down? I could not

visualise Brian's dead body. I could not contemplate that our time with Brian was going to be very short.

I did the best I could to say to the children that Brian was not going to make it through this. Those words seemed to take the edge off the reality and were all I could come up with. I doubt I was very convincing. It was all such a whirlwind. A few short weeks ago, Brian had been the tall young man talking about his future, styling his hair this way and that, as teenagers do, with an eye on the girls. But when he was admitted to hospital, he was listed as anorexic because he couldn't eat with the pain and, consequently, had lost a lot of weight.

Pain was still a big issue for Brian, and his knees and ankles were red and swollen. I stayed in his hospital room late into the night and came back early in the morning, but I didn't want to frighten him by staying through the night. It was just so difficult to know how to make the best decisions. All I can tell you is that I tried to weigh things up and do the best I could not to alarm Brian. He had not guessed that he was going to die. It was the furthest thing from his mind, I would say. He was concerned about doing his exams, as he didn't want to be left behind when his friends went on to college.

I didn't wish to worry him by staying overnight, so I waited in the corridor during the night, but not in his room. I could be with him in moments. I went out the door every night saying to him that hopefully he would be feeling a bit better tomorrow. Life was completely different, and I had no experience to fall back on that would help me through. An eighteen-year-old boy does not want his mum fussing. But neither does he want to be alone in pain, needing a drink of water. With Brian being critically ill, I knew that any setback could mean I might need to be with him straightaway, and staying in the corridor seemed like a reasonable solution. So I stayed outside his door all night.

In isolation, he made such a lonely, solitary picture. Being confined to a room is in itself a cruel punishment, and I didn't know what Brian had done to deserve this. There was no question of coming home for the weekend, and the Thursday night of the following week was a nightmare. I never left Brian's side that night. He was in unbelievable pain. 'Rub me, Mummy. Rub my legs. Rub my back,' he pleaded. It was this terrible bone pain. 'It's, like, you know, when you go out in the snow and your hands are freezing. When you come in home and warm them on a heater, they really pain. That's what this pain is like, Mum. I can't handle it!'

'We'll handle it together, love,' I answered, with a great deal more confidence than I felt. I knew my massaging did nothing, but I wished it did. With all my heart I asked God to forget my limitations and just let His love and healing flow down my hands and into my Brian's thin and pain-ridden body, to ease his pain.

But the pain was relentless. Massaging him passed the time on that terrible night. But I didn't want time to pass; I wanted it to stop. The nurse gave him morphine all night. She was so kind. But there was no letting up. If he was going to die, why did he have to suffer as well?

'Brian, let go of the pain, love, let go, let go,' I kept saying. I didn't want him hanging on to life if this was to be his life. I did my best to sound confident and cheerful.

The nurse said she would contact the nearby hospice in the morning. They could prescribe better pain relief than the ward. This was Holy Thursday night. Every moment was lived. Every moment was suffered. We experienced our own Gethsemane. It takes a lot of pain for a mother to wish her child were dead. What to do? What to do? So much has been written about in this world, but I didn't have a manual to guide me down this path.

That was the first time I stayed all night with Brian. The next day he began to wear patches prescribed by the hospice, and the pain became more manageable. Brian had tablets and patches in lieu of injections. With his propensity for bleeding, this was a safer route. I made sure that he was never left alone again. The nurses gave me a foam chair that pulled out flat on the floor so I might sleep next to him. He needed help to turn in the bed; he needed help to have a drink.

Good Friday was another long day of pain. At about five o'clock on Holy Saturday morning, Brian began to bleed. He and I struggled together to reach the bathroom. He sat on the chair in the shower to try to clean himself up. I could tell that Brian was going to pass out from the heavy bleeding. I threw a towel over him to protect his modesty, and the nurse and I both lifted him back to his bed.

Oh God! The electric blood pressure monitor had just made that awful bleeping sound that everyone knows from television programmes like *ER*, when some poor misfortunate's heart has stopped. *Bleeeeeeeeeeep.*

Was this it? I felt panic rising inside me. I didn't wish Brian to suffer anymore, but I wasn't ready—not yet, not now, not this minute. I soothed him. 'Brian, it's okay. You're okay, love. Mum is with you. I'll look after you as I always have.' I prayed silently for a little more time. *Please, one more day. I'll be so grateful for just one more day*, I implored.

I injected all the confidence I could muster into speaking with Brian, wanting him to feel safe, not to be frightened. Silently, I said to myself, *Brian, if you need energy to hang on, you can use mine. I can hold the two of us until you get blood.*

Who knows whether that kind of thought makes any sense or, indeed, any difference? I'm just telling you my natural reaction was to try to reach out and save Brian.

Just then, the nurse said, 'I have a pulse! Send for the house doctor!' Blood and platelets were ordered. Platelets are the clotting agents that prevent bleeding out.

'Should I send for his father?' I asked, hoping for a reassuring answer. Of course, deep down I knew she had to say yes.

'And you might like to send for a priest,' the nurse added.

My heart sank.

When his dad saw Brian, he was so shocked at the terrible sight before him. Brian lay still, silent and unconscious in the bed. He was lifeless and as white as his sheet, the blood drained from his face.

We just stayed close to him. Could we collect the units of blood from wherever they were stored? Could we speed it up in any way? No. It took two hours for the platelets to arrive.

Can you imagine how many seconds are in two hours? At six a.m. on Holy Saturday morning when you know your child could die at any second, can you visualise the torture of waiting that long?

Our local priest heard that a boy from the parish was in hospital and called to see him. Fr Nyhan, a shy, saintly man, arrived in the afternoon and blessed our Brian. How can I describe what it was like to listen to the priest anoint my unconscious child? A part of me was praying with all my heart, and a part of me was silently screaming, *This can't be happening. This is a nightmare. I can't be standing here, like it is a normal thing to do, witnessing the anointing of this most precious gift of my life. I don't want to do this thing. I don't want to be here.*

Vicky and the boys called later in the morning. They were so shocked. We waited until they had woken up to tell them what had happened. Mainly we did this as we didn't want Brian to become alarmed if he woke up and saw everyone around his bed at some ungodly hour on a Saturday morning. Also, I wanted to be kind to my

children and shield them from anything I could. We are a family that just doesn't do drama. We go quiet. We all talk across each other with great enthusiasm on a good day. On a difficult day we say little and really listen to each other.

It was now evident to our children that Brian was seriously ill. John had plans to study over Easter, and he hoped to get an honours degree. But of course his concentration had now gone out the window. It was April 14, Paul's twentieth birthday. This was not how we'd envisioned spending it. We all just sat by the bedside. We didn't really say anything to each other. We didn't want to acknowledge what had happened and exactly where we stood. We were talking about the smaller things, like how long it took to get the platelets and how quickly they might work. When I reflect on it, we're all on the same page when it comes to bigger events—we ask how we can be of help, and then we do what we need to do, quietly and with minimal fuss.

A lovely young lady from the Leukaemia Association called by with an Easter egg and PlayStation game for Brian. She had called in a couple of days earlier telling us that her association visited hospitals at Christmas and Easter to give gifts to leukaemia patients. When she heard about the new PlayStation, she offered to bring him a game.

I looked so wistfully at that chocolate egg, wishing Brian would live to taste a mouthful. In order to respect the privacy of patients, nursing staff don't update every member of cleaning and catering staff on current patient status. Of course, this is correct procedure, but it seemed to underline our pain when someone breezed in and said, 'Will I leave a cup of coffee and a biscuit? He might like it when he wakes up.'

'No, we're okay, thanks,' I answered. It was on the tip of my tongue to explain that I didn't even know if he would wake up.

Late in the evening, Brian opened his eyes, and we were all relieved. We carried on as if nothing had happened and he'd just slept late. He

never asked, and I never mentioned anything about his bleeding out in the shower. I suppose he must have said to himself that he didn't even remember getting back into bed after the shower. How often have we said that when we arrive somewhere? Said to ourselves that we don't remember the details of the journey, as we were preoccupied? It was the weekend, so it made sense that we would all be at his bedside.

Often, when I would walk around in the isolation ward, Brian, who could not move without help, would say, 'Mum, I can't see your face.' That was about the only useful thing I could do—just to be there, to help him feel safe. Otherwise, I spent my time moving pillows as he continuously turned and twisted, trying to find a less painful position, and airing him—it helped to waft the sheet and allow him to feel a breeze on his aching body. I massaged him and smoothed some cream on his face. I took his hands and held them to my face. 'I love you, baby,' I said.

'I love you too, Mum.'

'Thank you for being my baby,' I said to him.

'Thank you for being my mum.'

He just didn't know how hard it was for me. I seldom cried when with him, but when I couldn't stop a tear, I would tell him why. 'You know how much it hurts me to see you in pain, my precious.' And he seemed to believe that.

We decided not to tell Brian he was dying. Didn't see the point when our time was so short. Brian didn't know how much my heart was breaking. His feet looked so perfect. Like every other parent, we had spent a fortune on correctly fitting shoes when Brian was small. He played soccer and football and was a good runner. He was left footed and was forever kicking a ball. But now his feet gave him so much trouble. Even when the door to his room was opened, the movement of air gave him intense pain, especially in his feet.

We spent long days and nights in that one room, in isolation. I remember looking out from the second-floor window of our hospital room at the little patch of bright-blue sky we could see from his bed. It was a beautiful day. There wasn't a cloud to be seen. Brian was lying on his bed with only a sheet over his aching, disabled body. 'We could be on holiday in Spain,' he said. 'You know, the blue sky, no clouds or anything and sleeping with only a sheet on.'

'Indeed we might,' I answered. But I struggled to say the words, knowing I would never sit in the sun with him again. I felt that without my Brian, I was never, ever going to know happiness again for as long as I lived.

There were a number of different issues for Brian. One was around bleeding. When his platelets were low, he was at huge risk of haemorrhage. In fact, that was what we were waiting for—the final haemorrhage. I hoped it would be a brain haemorrhage, as Brian would feel nothing. But it could be a bleed. He could just bleed to death in front of me and there would be nothing I could do, nothing the hospital could do.

I tried desperately to think of what might help. So we got some black towels, so it would be less traumatic for Brian to watch himself bleed to death. Ten minutes should do it, I was told, and he would probably lose consciousness during that time.

How would I manage to help him through that? Would his life flash before him, and would he suddenly be scared and realise he was dying? Could I depend on myself to help him to leave us easily when it was his time?

Brian was becoming anaemic, and blood was constantly being sent for. God bless those people who donate blood. I wish they could see what good they do. When I knew his platelet count was really low, I was terrified. I learned that the staff did not order platelets

until things were quite drastic, as they would lose their effect at some point. They had to gauge and balance all the risks. When platelets were low, it was easy to see the effect on his body: his gums bled, and he had black-and-blue bruise spots all over his body. I knew then his chances of haemorrhage were particularly high. A low blood count from losing all the blood made him exhausted, though this seemed the least of our problems at the time.

There was also the issue of pain. Brian had bone pain. His body visibly trembled, and this was accompanied by deep and merciless panting. How could I bear another minute helplessly watching him try to muster enough energy to stay on top of it and cope with this relentless suffering? I had discovered that when Brian couldn't breathe with the pain, what was happening was actually a progression of the leukaemia. He wasn't getting enough oxygen, hence the panting.

There was nerve damage to his mouth from early on. He had no feeling at all in his lower jaw and lip. He had to devise a way of eating so as not to bite his tongue. It was like eating straight after going to the dentist while still numb, but this was permanent. There was nerve damage to his feet, which caused intense pain. In hospital, the phlebotomist took a blood sample every day, and this was checked to keep track of his blood count.

The hospice team called to visit him every day to monitor the pain and would adjust the prescription to increase the dosage of pain relief drugs or prescribe additional as required. But the pain relief took time to work. Despite all good intentions, there was lots of pain. After some time, anaesthetic tablets were prescribed, and they controlled the nerve pain to Brian's feet. He had nerve damage to his arms, and he lost power in them. My Brian had always been so good with his hands. He was the one who loved to cut the grass and do other odd jobs around the house. He was so meticulous and tidy. If my clothes line was at an angle or a bedhead was loose, Brian came to the rescue with his screwdriver.

All I could do was love him. 'I love my precious Boober,' I said. I'd called him Boober when he was little, because I thought he looked like one of those little Fraggles that he used to watch in *Fraggle Rock* on TV. I sat with him in that hospital room, watching *Star Trek*, *Judge Judy*, and soaps on TV. I slept on the pull-out chair on the floor at night. My mind was racing. *I must be calm when he is dying*, I told myself. *I mustn't cry and make it harder for him to go.*

I'd heard people can hear for twenty minutes after breathing has stopped. So I had to devise a plan—a 'what to do plan', as Brian used to say. The best I could come up with was to say what I'd said to him at home anytime he went out the door to school or elsewhere—'God bless, protect, guard and guide my precious boy.' That way he might, I imagined, feel like I was giving him permission to go on his journey. My mother had similarly blessed me on my journeys. But what about this guard-and-guide bit? What was out there?

Sometimes you hear that this particular journey is not always simple. He had no dead loved ones that he knew who could come to meet him. You often hear that someone you love comes to welcome you. So what to do? I decided I would give Michael the Archangel the job. 'Michael,' I pleaded, 'I give you my most precious possession. I ask you to put your arm around my baby and bring him safely to wherever it is that he is going. Don't leave him go until he is safely home.' And that was all I could do. I had to trust someone if I couldn't do it myself. So I trusted Archangel Michael and I would say, 'God bless, protect,' etc., and that was it. There was so much more I wanted to say. But I couldn't. I knew I mustn't.

I expect you will have this surreal experience of planning a death for a loved one at some point. It's the price one pays for living and loving. The ones you love may travel over before you, and you will want to savour every precious moment of their lives. My dad, whom I adored, died suddenly when I was seventeen years old. I didn't get

to say goodbye. Being with Brian during his terminal illness was my first experience of this.

Day by day we struggled with the platelet count, the anaemia, the searing pain. Each jostled for position to be the most critical factor torturing my child. Every day he had blood tests. To get the results back as quickly as possible to the ward, I brought the sample down to the haematology department, and the staff handed me the results in a few minutes. *Will the blood transfusion have helped*, I wondered anxiously, *or will the chemo have knocked back those immature white cells?* I understood basic information about the results: ideally, the percentage of leukaemia cells should be low. I worried about Brian's platelet count, which should have been 140 to 400. Brian would likely bleed when the platelet count was in the teens, meaning it could happen when his platelet count was14 or 15, for example.

One particular day I glanced down at the results I was handed. Sweet Jesus! Three. Brian's platelet count was three. *Oh no*, I thought. *He's died on his own upstairs. Oh, please, no . . . please, no! Please, not alone; please don't let him die alone.*

Panic set in. Was this it? Was it over? Was the waiting over? Was it happening now?

I sprinted down the corridor, up the main hall, all the time feeling I had failed him, that he had faced his death alone. I took the stairs three steps at a time. 'Excuse me! Excuse me!' I called as I frantically pushed past people.

I ran into the ward and burst into Brian's room, afraid of what I'd see. Brian smiled like all was well in his world.

'Hi, love,' I called, as casually as I could. 'Forgot to drop your results to the nurses' station. Back in a jiffy!' I rushed to the nurses' station, tightly clasping my Brian's death sentence.

Platelets were ordered immediately, and we were in with a chance. Would he last the two hours that it took to treat the blood and transport it? I chatted idly to Brian about this and that when there was so much more I wanted to say. I could not say aloud what was in my breaking heart. I couldn't tell him that I loved him and I was frightened of all that was ahead of us. I couldn't even whisper that life was testing me to the last. Everything was wrong, everything was so very wrong.

Two long hours later the platelets arrived, and my overwhelming panic was relieved, to be replaced by the now customary fear and dread.

Days later, Brian got a throat infection. There was panic, as staff could not bring down his temperature. He couldn't swallow; he couldn't speak. The pain! The hospice staff called every day. He had intravenous antibiotics in one arm and blood and chemo as well, with fluids, of course, on another drip to keep him hydrated. The nutritionist called to see if she could manage to get any calorie-loaded drinks into him to prevent him losing more weight. But he couldn't swallow, even a sip. He hated looking so thin.

I was frightened going to sleep on my foam bed on the floor in case something happened and he wasn't able to call me. I propped his mobile phone in his hands with my name on it; he'd only have to hit the button to ring my phone and wake me. Would he be able to do that—hit the button on the phone—if he took a turn? I had no idea, but I couldn't think of any better plan.

The third antibiotic treatment worked for Brian and his temperature came down, so he was able to speak normally to us again. 'Mummy, when I look in the mirror, it doesn't even look like me,' he said of his gaunt appearance.

As a family, we all put on the performance of our lives. We were happy and cheerful with Brian, chatting idly about who might be

chosen for the next Celtic lineout, how exciting a television show was, or some such nonsense. We could not for a moment allow our faces to show Brian the pain that we were in. How often did life seem like some kind of a dream, living one reality and feeling quite another? I kept asking myself how I was supposed to do this. How does one care for a dying child? Keeping a smile on my face seemed the right thing to do. Yet if I tell you I was smiling while minding my dying child, it seems gross. It was one of the many contradictions that had turned everything upside down and inside out in this new life, which was full of pain, confusion, and terror. I was constantly fearful of what was coming down the tracks, going over and over in my mind how I might master the various challenges.

Brian's arms were quite disabled. He could use his fingers, but he had no power in his hands. He couldn't even open a Coke bottle. He could only twist the top if I had opened it. I had a really strong urge to put a pillow over his face and finish him off myself. I wanted the suffering to end. I know I could never have done such a thing, but I wanted to. Life can be so difficult and confusing. I wanted to do the wrong thing for the right reason. Or was it the right thing for the wrong reason? Was it the right thing to take him out of his misery? Was it wrong to want him alive? I really could not be clear in my head as to what was right and what was wrong. Life is like that, isn't it? Sometimes it asks us to make impossible decisions with no experience or training to guide us.

I was beginning to understand in layman's terms that Brian's problem was that he was producing too many immature white blood cells. These blasts, to give them their proper title, were of no use to him, and they were also crowding out his red cells. This was, essentially, why he was going to die prematurely. His body was making no attempt to reverse that trend, and chemo would only give him so many chances at recovery. His cell count (the percentage of leukaemia or immature

white cells) might be ninety-two percent one day, but then a course of chemo might knock it back to seventy-five percent the next day.

The chemo was having some good effect this time around. This latest session had knocked back the number of immature white cells, blood transfusions had replaced them with working cells, and Brian was a bit stronger. He had made quite a good recovery following his severe throat infection.

John refused to give up on him. 'They're still trying. The next chemo might work,' he said, with hope in his heart.

'I know Brian is critically ill,' I said to a doctor. 'I know he could die at any moment. But what is the best possible scenario?'

'Weeks, rather than months,' she said.

When I told John this, he said, 'But that's only if the chemo doesn't work.'

The next day I approached another doctor on the team. 'We're hearing different stories,' I said to her. 'I keep hearing that he is going to die, and John still believes there is a chance.'

'Why don't you both come in together?' she said.

'Us coming in together to you won't change anything,' I said. 'We just interpret the information differently. We both understand maths. Can you give me a figure for Brian's chance of surviving this? Forty percent? Thirty percent?'

'Less than one percent,' she replied.

There it was—less than one per cent. There was no trying to reinterpret that. Brian's body was still producing large numbers of blasts. Treatments could kill those off. But he was never going to recover, since he was not manufacturing any of the right cells.

It is the human dilemma to have difficulty discerning what the truth is against what we wish to be true. It was really difficult trying to

assimilate this fact when people were saying, 'You must stay positive. Brian won't die. Don't worry.'

I was quite annoyed by the well-meaning *You have to stay positive* stuff that people said to me. It implied that if I was positive enough, my child would live. I now knew that he couldn't and wouldn't. It was a terrible weight to put on my shoulders—that if only I was positive enough, I could turn this thing around.

I now understood that, in a way, this whole journey had nothing to do with me. Whether Brian lived or died, I had no say in it. It would have been easier for me if people had said something like *Be present. Enjoy your time with Brian. We will think of you and pray for you.*

I've learned from that experience to say less to people. In fact, I just usually say, 'I'm sorry,' and if I spend a long time with them, perhaps I repeat, 'I'm so very sorry,' and leave it at that. I don't even say what I'm sorry about, as I don't know where someone is at. It could mean sorry the child is sick, sorry you are so upset, or sorry he's dying, or all of them. Being 'sorry', I've realised, will fit any of the many different spaces one occupies during difficult times.

Brian had such incredible friends. Young people today are just so terrific. Youngsters called to the house and they called to the hospital, gangs of them. They were so attentive, at his beck and call during all his illness, visiting when he was well and fretting when they had to stay away because he was too sick for visitors.

One occasion that stands out in my mind was when one of his friends called to the house to visit Brian. I couldn't help crying when I explained that I had just brought him into the hospital earlier and he was dying, that I had just come home for my nightclothes. I remember this little young lad putting his arms around me without saying a word. I really wish our young lads were more appreciated.

When Brian's friends were with him in the hospital, I would take a break. I might come home, have a shower, and change my clothes. He would phone when the friends were ready to leave. As I went to and from the hospital, I often heard Celine Dion singing 'Think Twice' on the radio, and I was really moved.

Look back before you leave my life
Be sure before you close that door

I too wanted to ask Brian not to leave me, not to do what he was about to do, to tell him that my everything depended on him. She put words on my feelings. I knew, however, that it was not up to me—or indeed Brian, for that matter. Life had its own agenda.

Having been anointed in mid-April, followed by that horrendous throat infection, Brian had about three relatively good weeks around the beginning of May. By this, I mean he could walk a little with the help of the anaesthetic tablets. He was allowed home from hospital. On those Saturday nights we would bring him as far as the door of his favourite pub, and he could manage the few steps to a table inside. He would phone us a while later to collect him, and he would manage the few steps to the car outside the door. What a blessing the mobile phone was in the circumstances that Brian found himself. His friends could phone him anytime, and if he was well enough, he would see them. But he wouldn't let them see him if he wasn't well. He wore long-sleeved T-shirts if his arms had black-and-blue patches from the low platelet count so they would not be upset at the sight of them.

The first time I saw it in writing—*Brian O'Mahony, terminal illness*—was on a statement that I needed to produce to get Brian's medical card. What was I supposed to do with that sentence? Where in my brain was I supposed to park that fact?

We have such wonderful neighbours. At Easter when we were full-time in the hospital with Brian, neighbours came in and cleaned our house. On the evenings that I would get home from the hospital, neighbours, on seeing my car, would phone or call to enquire about Brian. This was another change in my life—people were constantly tracking me. I knew that there was a watch on family members and even friends so enquiries could be made for an update. It felt very supportive on one level, but on another level I felt like I was on some kind of reality show, a very new experience for me.

One evening I needed to rest so badly, having had no sleep the previous nights, that a neighbour offered me a bed in her house for an hour. This would help me avoid doorbells and phones. So thoughtful. Another cut our grass. 'I know Brian always cut the grass,' he kindly said.

But it was hard to find people who would listen to me speak of watching my critically ill child lurch from crisis to crisis. Bishop Buckley visited Brian a few times in hospital. I don't know where he gets the time, but he visits all of his flock in hospital. He is an incredible shepherd.

Fr Nyhan called many times to see Brian when he was at home. He was such a gentleman. To my great embarrassment, at home, Brian struggled onto his crutches and left the room for Fr Nyhan to sit down. Usually visitors of my age group were for me, not him, so Brian didn't seem to take on board that the priest had called to see him in particular. That was Brian. He just ignored the fact that he was critically ill.

Take, for example, the day he got his new chair. Quite early on when Brian was very disabled, I got the idea that a reclining chair would allow him to be in the sitting room when he might otherwise need to lie down in his bed. I bought a chair with a touch control that

would recline it at the touch of a button. I bought it on a Saturday—a very wet Saturday, as I recall. Brian, his dad, and his brothers were all there to help with moving it into the house, and our patio door had been removed to enable them to do so. It cut through me to watch Brian trying to help negotiate the chair through the door. He couldn't straighten his knees and he was completely bent over, not to mention loaded with painkillers. Yet there Brian was, hovering, trying to help.

He showed me how to be in this world. He lived. He ignored his pain and disability as much as he could, as if they were a minor inconvenience to his process of living. Going into hospital, he was mostly in a wheelchair; coming out, he might be on crutches. Sometimes he could walk. Whichever it was, he never complained. As he said to me once, 'God gave this to me.' That was his attitude.

Brian had those good weeks and was home from hospital, though he was still critically ill. Everything in life was now measured in steps, as Brian could manage only a very limited number of them. We tried to keep life as normal as we could, making sure that every event that we organised would involve only a few steps for Brian. When the hospice nurse called, I said, 'Please, can you give him something to get him up out of that bed? It doesn't matter if he dies on his birthday, but, please, help him be able to walk a few steps that day and be well enough to meet his friends.'

So he was put back on steroids. The steroids really helped. Brian managed to get to the pub for a little while on his nineteenth birthday, and all his friends came back to our house to celebrate until about three a.m. They were such incredible young lads. I hope their parents are proud of them. I was.

We organised Brian's medication so that his best time of day would be around eight o'clock at night. That way he could hopefully meet up with the pals. The patches he wore for pain had begun at 25

mg and had now increased to 175 mg. He'd started on the morphine-type tablets at 10 mg every six hours, and now he could be taking 70 mg every ten minutes during his worst times. The anaesthetics were at the highest possible levels, and there were other medications too. Paul bought him a foot bath for his painful feet, but when he tried it, he said he couldn't feel the water or the bubbles. He felt no sensation apart from pain.

When Brian was able to walk to the end of the street, the neighbours were delighted, but I was trying to figure out what to do if he started bleeding at the end of the street. Should I just let him die there? Or should I have someone help me bring him up to the house and let him die at home? I expected that he would be frightened if he had a bleed that wouldn't stop, but he would hate the fuss of strangers around him. I was thinking to myself that most people don't cope well at the sight of blood or death and that the people helping might prove more of a problem than a solution. I feared all sorts of bad things might happen to him even when I'd drop him to a neighbour's house or down to the pub so he could spend a little time with his friends. I'd be thinking that if he had a bleed there, they would call an ambulance, but I'd be terrified that he would die in the ambulance without any of his family with him.

However, I knew that I had to let him go and give him the best life I could. I couldn't project my fears onto him. Anyway, deep down, I knew that Brian would die wherever and whenever he was supposed to die. That was a consolation. I was not in charge. I just needed to get my bit right—I needed to stay strong.

My colleagues at work were fabulous. The constant phone calls the first few days after he was diagnosed were hard on them and on me. I couldn't spend my time with Brian answering phone calls because I needed to project calmness and just simply be with him. So

begging their forgiveness, I asked them if it would be all right to fax them when I got home for my shower at night if there was anything to report. That way everyone would have a firsthand account. Dial-up internet was so slow in those days—an email would have been tedious—and so a brief handwritten note was quicker faxed.

How many ways could they say sorry? They had no more adjectives to use, and I knew the depth of their sincerity. There were constant enquiries and offers of support. A colleague baked the most beautiful double chocolate cake—'to die for' really rang true this time. Brian loved his food, and he enjoyed and appreciated every morsel.

Then there was my family. My mum was a nun in England. Having been widowed for fifteen years, she had decided that after we were reared, she would give her remaining years 'to God', and she joined a convent. She was eighty-three now. I told her how things were, but I tried to save her some of the details to make it a little easier on her. Tony, my brother in Dublin, is two years older than me and is Brian's godfather. He and his wife, Marion, were both so supportive. They called to visit and constantly were a caring presence. Frank, my older brother, lives in Dundalk. He and his wife Mary Rose showed us so much empathy. They really understood what I was going through, and they prayed constantly. John's mother prayed and kept a candle lit in front of her picture of the Blessed Mother. His brothers, Julian, Gene, and Hugh, were constantly enquiring if they could help in any way, as were their wives, Margaret, Mary, and Marie.

Brian's school principal had by now arranged for him to be provided with a scribe for his state exams—a person who would write for him, since he couldn't use his hands. They understood how desperately Brian didn't want to be left behind when his friends went on to college. His favourite subjects were maths and mechanical drawing, and he was hoping to qualify for a course using those skills.

However, we now needed to inform his school that his illness was terminal. Having those conversations—cancelling the scribe, talking to his teachers, who were so nice but shocked, not knowing what to say at the other end of the line—it all felt so unreal, a scene from a film that I would never want to watch.

I kept asking myself what I should be doing. I figured my job was to be a mother; no point in second-guessing the medical staff. I would just keep loving Brian—that's what I was put here to do—but that was not as easy as it sounds. In the morning, when he'd open his mouth and his teeth were covered in congealed blood, I wanted to cry. His gums were bleeding. There were blood blisters and ulcers on his tongue and inside his mouth. There was the ritual of giving Brian four different mouthwashes in a certain order and putting a cream on the ulcers to try to keep infection at bay. He often cut his tongue when he was eating because of the numbness of his lower jaw. The blood on his gums indicated low platelets, which meant his risk of haemorrhage was higher. Then there were the bouts of bone pain where he panted and trembled, fighting for every breath. There was the intense nerve pain—in his feet mostly.

When he was good at home, I tried to bring him out most days if he could manage the few steps for a sandwich. 'That was delicious,' he always said, rubbing his hands together enthusiastically. He was so appreciative. Brian never complained.

I felt very comforted and supported by the wonderful palliative care team in the nearby hospice, 'a service without walls'. They understood that we don't have two distinct populations, the living and the dying; there is only the living. Our lives were enriched by being supported in pain management at home and in hospital, and we knew that hospice care was available if this became necessary. I'd phone the hospice every time Brian's pain got worse at home. By that stage, I

understood which type of pain needed more medication—the bone pain, the nerve damage, or the general pain. Every time I spoke with the nurse, she'd assure me that she would phone me back. Always true to her promise, she would contact the team within a few minutes, and she would phone me to tell me that there had been a prescription called in for collection right away in our local pharmacy that would help relieve Brian's pain.

It was most helpful having someone to talk to about practical things relating to caring for Brian. I remember saying to the public health nurse, who visited every couple of days, 'What am I going to do if Brian can't manage the stairs at all? I hate the thought of him being stuck in his bedroom.' Brian only met his friends downstairs. When he was not able to come down, he would cancel the visit. She showed me that two people could cross their arms and catch each other's hands, making a seat for Brian to sit in. Sitting down, he could put an arm around each person's shoulders, and we could then lift him downstairs. I was so relieved. It was an elegant solution.

I can't explain how I got through each day. It really was only on a moment-by-moment basis. I was so distressed by the extreme pain Brian was suffering. I was so shocked and sickened by his disability, and I was really terrified, waiting, hoping he wouldn't suffer anymore, yet hoping this time would go on forever. I was terrified that I could not endure the torture, the overwhelming grief of watching Brian die—how could I bury him in the dirt or face a day without him?

They say there are no atheists in the war trenches. Feeling on a battlefront myself, under constant bombardment, I certainly called out for help. I believe I was heard, because somehow I got through each day. The last present Brian had given me was a framed picture of 'Footprints in the Sand' to hang on the wall at Christmas time. You might remember how that ends—'The times when you see one set of footprints is when I carried you.' So I guess I was carried.

On the story went, up and down, Brian in and out of the hospital. As we were anxious to have him at home as often as we could, he was in hospital only for the duration of a particular treatment—blood transfusion or chemo. It was physically exhausting, and it was torture for us all. There are no words to describe what it is like to watch the one you love endlessly, relentlessly suffer with no letup, day or night, from this terrible disease. Then there was the Russian roulette with the numbers game, reading the low platelets count or the high white blood cell count. One or other of these crucial figures was always frightening. It was like life had a gun to my head and it went *bang*. But on so many occasions it was like life said *Only joking*, and the blood, platelets or chemo would revive Brian, and we were back on the roller coaster. There was definitely a deadly bullet in this gun, but was this the end? Would he die now, or would the platelets get here in time? Would the chemo have the desired effect and knock back the white cell count? Every few days now there would be bleeding, the platelet count would drop, the white cell count would go up, or some new drama would happen that led to an increase in his pain level.

My boss organised the celebration of a Mass in my workplace to ask for a blessing on our family. The staff canteen had been transformed. An altar was created by draping the humble table with a beautiful cloth, candles, and flowers. There were more flower arrangements on the windows. Retired staff and staff from other locations all joined in prayer for us that evening. I felt so disorientated being in a roomful of concerned and sad people all praying for me and my family. Usually work is a place of business; now I was seeing a whole other side to my colleagues, a very caring, human dimension. I kept experiencing this feeling of having stepped off the edge of the planet into some alternate reality. Where I had been busy a couple of short weeks before with the day-to-day challenges of life, now I was not busy; I was powerless, unequipped in my new role as bystander in the unfolding tragedy.

The public health nurse organised a hospital-type bed for home. The special mattress was a great help in stopping Brian from getting sores. The back of the bed went up, so Brian was able to sleep in the sitting position, which helped enormously when he was finding it difficult to breathe. It also bent up at the knees, so it eliminated the need for the five supporting pillows. She got him a sheepskin, which was soft underneath him, and little sheepskin footie slippers for the cracked hells on his feet. They really helped him. She also advised us to stock up on a supply of nappies, though we didn't need those yet.

The steroids increased Brian's appetite. He was an eating machine. He put on weight and got that bloated steroid look. He retained fluid. Sometimes his previously sticklike legs were like tree trunks. His stomach became so swollen that he couldn't bend over.

Our only focus was on keeping Brian happy. He was very lucky that he was so loved by his dad and his brothers, who shared the same interests. Saturdays were great. The football pools were done. They'd put a bet on the horses, and then there was the golf and the Formula One to watch, as well as the tennis. Vicky and I just did the caring bit, as all this sport was a bit beyond us.

We lurched along in this intense mode of being. On the surface we were like one big happy family, all attentive to Brian's every need. We could have taken out shares in an ice cream company, as we bought so many ice cream bars! But caring for Brian was such a pleasure. He was so appreciative that it was a pleasure to do the least little thing for him. One felt so much compassion for Brian, but never sorry for him. As I keep repeating, he never complained. It is hard to imagine, but he never felt sorry for himself.

We could have received an Oscar nomination for the performance we put on. You would think everything was normal if you were looking on. You would think it was normal for people to smile and joke, to

shop and watch football matches, when a family member is in pain and dying.

I found it really upsetting when I bought carrots, small pizzas, or other favourite foods of Brian's. My mind would race on. I wondered whether or not Brian would get to eat these; would this be the last time I'd be shopping for these items for him? More often than not, I met a neighbour or two while shopping who would ask about Brian, and I would have to talk about all those things that I didn't want to think about. I would listen to well-intentioned advice, grounding me in the reality of my unhappy situation. There was no place to hide, nowhere that I could put my burden down for a minute.

We were now at the end of May, and Brian had to go into hospital again. He bled a lot. There was such a smell from congealed blood, which embarrassed Brian, as he had always been such a spotless young man. We had to squirt air freshener every ten minutes just to stay in his room, yet we all piled in happily every night to watch a video or a match. We could see all the black-and-blue patches under his skin and the blood in his mouth. We knew these facts meant his grasp on life was very tenuous. How many more times could the medical staff revive him?

Transfusions of sixteen units of blood and three units of platelets saw Brian back home again on the Sunday of the holiday weekend. John was home from college in Tralee, and without a job or studies to concentrate on and a social life on hold, he doted on his brother. He offered to make Brian one of the 'pizza burgers' that he liked. Brian, not wanting anyone fussing over him, insisted that he'd make it himself. The only way John could convince him to sit down and relax was to joke that he had been writing down everything he had done for Brian since he got sick, assuring him that he would be ticking them off against the favours Brian would owe him when he got better.

Everyone in the kitchen at the time, especially John himself, found it really difficult not to break down in tears.

A week later we managed to get a family photo taken. We used the excuse that because John had just finished college, he would soon be heading off somewhere to a job and we would need to get a photo of all of us together before he left. We got together in the sitting room, and Valerie took the photos. Brian wasn't very happy to be having his photo taken when he looked so poorly, but I knew they would be the last photos I would ever have of my family. It would be my 'remaining' family after that. Brian didn't understand that John wasn't the one leaving—he himself was the one leaving.

Soon afterwards, Brian got really poorly again, and his sight failed. 'It's like when you come in on a really bright day and can only see shadows,' he explained. But—you've guessed it—he never complained. Low platelet counts always led to haemorrhages; this time it included bleeding behind his eyes. Brian was left in darkness.

He was referred to the ophthalmology department. I was so moved by the young registrar who examined Brian. I could see him fumbling and generally uncomfortable as he told us nothing could be done. He was clearly distressed that he couldn't do more. 'Are my hands clean, Mum?' Brian asked, when he was washing his hands. 'I can't see my hands.'

I'm still so moved when I hear Charlie Landsborough sing 'What Colour Is the Wind?'

What colour is the wind, Daddy?
Is it yellow, red or blue?
When he's playing with my hair, Daddy
Does he do the same to you?
When he's dying, does his colour fade?

Is a gentle breeze a lighter shade?
Just like his friend the sea, the wind feels blue to me
I know each colour, its shape and size
I've seen them all with my daddy's eyes.

Charlie's gentle voice reminds me of a time when our child could see the world only through our eyes. It was hard watching Brian become so disabled. Medical staff were baffled that he had survived all these weeks. Every time he came home, they told me that he would not be coming back to the hospital. Every time he ended up in hospital, they would say he would not be going home again. Yet weeks were passing.

I would stand in front of him and give him my hands. He would try to hang on to them and pull himself into some kind of erect position. Then he would flop into his wheelchair, grab his crutches, or carry on walking if he thought he could. On the stairs I would stand a step below him in case he'd fall. He would hang on to the banister with both hands and try to negotiate each step, one at a time, so slowly, sometimes completely bent over like an old person. He sat on a stool in the shower, and I would sit outside the door in case he needed me.

I was constantly thinking of the future. How could I cope? What would I need to do, and what steps could I take to see that everything was done as well as possible and with the least amount of trauma?

There would be a funeral. How could I organise myself for that day? John already had a black tie; I would need to buy ties for the boys. Oh my God, this would be my first time buying two of something, underlining the fact that from here on, I would have only two boys instead of three.

I needed to buy a black dress for myself. I had spent weeks glancing at dark clothes in the shops and had been unable to go in

and purchase them. But I knew inside that I would not be able to pick out a dress after picking out a coffin. So one day when I saw a black dress inside the door of a small shop, I dashed in. It was a size too big, but I said I would bring it home and alter it myself rather than trying on other things. It was one of the many difficult tasks, bringing home the reality of life for us. Brian came into the kitchen while I was turning up the hem, but, of course, he took no notice of me doing a bit of sewing. Those moments seemed so cruel.

On a Monday at the end of June, Brian got very ill, and he was in terrible pain. The hospice advised us that he was on the highest doses of all medications. The only option was to admit him to the hospice, where a bed had been available for him for some time. They would just open a line and pour constant pain relief into him. His dad asked what I couldn't ask. 'Will he ever come out?'

'No,' they told us.

So, with no increase in medications, we continued to care for Brian at home.

The hospice admits patients between nine and five daily. By six thirty p.m., Brian was pleading to be admitted. I felt so terribly guilty that we hadn't brought him to the hospice earlier; we were just trying to have him at home for every possible minute. John and I agreed that we would have him at the door at nine the following morning.

But as morning came, the pain became more manageable, and we carried on at home.

Later in the day, I brought Brian in as a day patient to the hospital. He was getting no ease, day or night, from a stomach pain, a pain he had not experienced before. He was given various medications, but there wasn't any instant solution. We called in again early on Wednesday; yet again, no remedy was found. However, the pain eased around two thirty p.m. Wednesday afternoon, and Brian got his first

couple of hours' sleep at home in days. His heartbroken dad lay on the bed next to him, calling him 'my old segotia' and telling him how much he loved him, never letting his guard down for a minute, never revealing his feelings of utter desolation. Brian was talking about saving up to go on a holiday next year, his dad saying that would be brilliant, something to look forward to, definitely.

Later on Wednesday, Brian struggled downstairs to his recliner chair in the sitting room. His body seemed to be collapsing. We kept chatting about what we were watching on television so that he might feel he was also involved in watching the programme, even though he couldn't see the picture.

At about five thirty p.m., the bone pain started up again, with Brian panting for breath, his body trembling. This all-consuming pain, this extreme situation, was now commonplace for him. His brother John, who had finished his final exams, was home from college, and Vicky was back from Irish college. So we all poured into the sitting room together. At midnight, Brian began to watch a film. His dad and Vicky had gone to bed. Paul had work in the morning, so he had gone too. I told our son John, who was watching the film along with Brian, that I would get some sleep while it was on and to call me when it was over and I would put Brian to bed.

At half one in the morning, John woke me to say, 'Mum, you sleep on for another bit. I'll get Brian to bed and stay with him a while.' John was so gentle and knew well the ritual of the four different mouthwashes Brian used before he went to sleep to help prevent infections in his bleeding gums. I knew also that his dad had been checking on him, so I fell asleep.

A little over three hours later, at four forty-five a.m., I woke up and went straight in to Brian. 'John, you go on to bed now, love. I'll sit with him,' I said to my eldest. So I sat there, as I did so many

nights, enduring this Chinese torture of watching my child pant for breath and tremble with pain. This pain that had begun at half past five the evening before was still tearing through Brian. I settled into the rhythm of the noisy struggle for each breath.

It took me a moment to notice that there was a difference—there was a rattle also. I'd never been with a dying person, but I'd heard about this 'death rattle'. So what to do?

Nothing. We wanted Brian to die at home. There was no point in calling anyone. Everyone was punch drunk with exhaustion. No one could do anything. This could take a very long time, days even. Better let everyone sleep, I decided. Anyhow, we couldn't alarm Brian by having us all sitting around his bed at five in the morning.

So I just sat there. I sat there with my baby. I listened to his breathing, his death rattle. I wiped away the few sneaky tears that filled my eyes. I had a word with Archangel Michael and reminded him to be close. I trusted him not to let me down. I didn't know what I was supposed to do or how I was supposed to do it—I tried to be in the moment the best that I could and stick to my plan. To carry on like nothing was different so Brian would not be alarmed and remain peaceful.

What else could I do? I was so scared. What if he realised he was dying, leaving all of us? What would dying actually be like for him, or for me?

On the odd occasions that Brian opened his eyes, we smiled at each other. Like I did every day, I rubbed his hands, I touched his face and his hair, and I massaged his aching body. I watched as a yellow flush began in his chest and worked gradually up to his face and then down the rest of his body. Liver failure, I imagined.

I have no words to describe the ache that overwhelmed me. At half past six, my husband, John, woke, and I told him about the change. I

suggested that Paul stay home from work. John agreed with me about Brian's condition, and the two of us just sat with him.

At eight a.m. when the doctor's surgery opened, we phoned for the doctor, who came immediately, giving Brian more morphine and an injection to suppress secretions. Brian couldn't swallow his spit, and that was causing the rattle. The injection helped reduce the secretions, and Brian felt a little more comfortable.

The hospice nurse was asked to call over to Brian, and a prescription was written for more medications for the nurse to administer. John was anxious to have every possible medication available and was waiting at the pharmacy door when it opened for business.

Some weeks before, I had given a list of phone numbers to my friends Anne and John for the various people who should be called when it became necessary. I didn't think that my loved ones or I would benefit from me making this call personally. The time had come for Anne and John to make those calls. So I phoned them and told John that Dr Dillon had confirmed with us that Brian was now dying.

At about a quarter past nine, Brian needed to go to the loo. He sat on the edge of the bed. I stood in front of him and tried to help him up as usual, but his knees kept buckling. 'I'll get you the pigeon,' I said. The 'pigeon' was our local word for the portable urine bottle.

'No, I'll be able to walk,' he insisted. I tried to help him, but I was too small, and he had no power at all in his legs. I shouted for Paul, who was at his side in an instant. We held him under both shoulders.

'My legs won't hold me up for some reason,' Brian said. There was no anger in Brian's voice. He couldn't see. He couldn't walk. These were just circumstances that he noted, and then he ignored them and worked around them.

Paul and I got Brian to the bathroom. Then he began to vomit over the handbasin. 'This is it!' I said to Paul. I suddenly realised that

when I lifted his head, he would be gone. And sure enough, when I lifted up his head and looked into those big hazel eyes, there was no one home. Deathly silence. His eyes were empty. My Brian was gone.

I believed he might still hear me, so I just kept saying, 'I love you forever, baby. I love you forever. God bless, protect, guard, and guide my precious boy.' Again and again I said it. So I was able to keep my silent promise to Brian to send him on his way peacefully, with all my love and blessing. I dared not feel my own emotions, the overwhelming grief and the searing gut pain that engulfed me. I dared not say *Come back, Brian. Don't go, Brian. Don't leave me, Brian*, although it was on the tip of my tongue. I felt the silence in every fibre of my being.

Brian had been gasping loudly for each breath. Then . . . it just stopped.

Exactly that. It stopped.

The sound stopped.

It was replaced by a screaming silence.

A silence that was so shocking I felt it deep down in some primitive place. This silence was overwhelming. Deathly silence.

My son Paul and I picked our precious Brian up by the shoulders and legs and brought him back to his bed. When we laid him down, two more breaths left his body. 'He's breathing, Mum. He's breathing,' Paul said excitedly.

'No, pet, Brian is gone,' I had to reply. I closed my baby's eyes and told him again, 'I love you forever.'

I felt him growing colder and wondered how in God's name I was going to live without him. The sweetest thought in my head was to be gone with Brian. It was like the life was sucked out of me. I couldn't find my voice. I could barely whisper. I actually could not say

the words—I could not say to John and the children that Brian was dead. 'Paul, call the others, and phone your dad,' I whispered. I hated asking Paul to do such a difficult job, but he was so brave and strong and I just didn't have it in me. A twenty-year-old young lad hugging his dead brother is a sight you never want to witness.

Paul woke Vicky and John, and they came straightaway to Brian's bedside. Paul then phoned to tell his dad the terrible news.

My husband was, at this point, just getting into his car outside the local chemist to go to the hospital pharmacy in the hope of getting the new prescription filled there for Brian. I'd vaguely wondered why John had taken so long getting the prescription filled. It transpired that the medicine was not in stock, and he was delayed while they checked other pharmacies.

John came home to his dead child and could only sob from the very depths of his being. Wordless.

We spent a long time as a family with Brian, finding our voices to whisper to him that we loved him. We quietly touched him, feeling his hair that had become thin and wiry, kissing his lips to say goodbye. It was so shocking to get that cold nonresponse. This was a very surreal situation—mum, dad, brothers, and sister around a dead young man in the bed, sunshine pouring through the window. Just quietness. John and I holding it together for the sake of the children. There was no need for words to communicate how we felt. We were shocked and desolate, trying to steady ourselves and hold on to that last bit of warmth as it left our Brian's body.

Eventually, John said we had to call the doctor.

'Why?' I asked.

'For a death certificate,' he pointed out.

CHAPTER 3

Funeral

We phoned he doctor and the priest. It was now about ten thirty a.m. The hospice nurse called around. It was difficult to find the words for her, so I just said, 'Sorry, Brian died. He doesn't need you now.'

She offered to lay Brian out, and she laid him in his bed, hands joined.

The pain is all ours now was my thought. I still couldn't speak of this horror, could not put words to it.

Brian died on the morning of Thursday, June 28. It came to mind that a few short months ago on February 28, when he had been too sick to go to the soccer international in Dublin, we didn't even know what was wrong with him. Little did we know what lay ahead for us all.

We needed to make funeral arrangements. It just followed that we would lay out our Brian at home—have his wake in his own house. It was where he belonged.

We were all in this together, so John phoned the undertaker, who, very sensitive to our situation, came straight out to the house to discuss the arrangements with us. We agreed on the funeral arrangements with him. Brian would be waked at home, the Rosary would be that Thursday night at eight o'clock, the Removal would be at eight o'clock the next night, and the funeral Mass would be held at eleven o'clock on Saturday morning. Following the Mass, Brian would be buried at St. Oliver's Cemetery nearby. We had no trouble agreeing on a casket—the one with the carving of the Last Supper. We had shared everything; we had all eaten together at the table, broken the bread of suffering, and faced death together.

Then we had to pick the clothes in which Brian was to be laid out. All too soon, the undertaker's hearse pulled up outside our front door, and the patio door came out again. Last time we'd needed to take the patio door out, I recalled, we were bringing in that comfortable recliner chair for Brian.

The funeral home staff advised us to stay in the living room while they brought our Brian's body out in the black plastic body bag to the hearse. For the first time, we were alone without our Brian. Despite our broken hearts, there was a sense of peace. We had achieved our goal. Brian had died without the emotional trauma of knowing that he was leaving all his loved ones behind. There had been no fear. He had just slipped away in the bosom of his family.

The next job was getting Brian's room ready. We would lay him out there when the undertakers brought his body back later for his wake. We got some of those fat white church candles in different sizes and a beautifully embroidered white bedspread and pillowcase. With the curtains closed, the candlelight flickered softly and gently. Two magnificent bunches of lilies were sent by different people to the house. The flower arrangements looked lovely at either side of the bed. By his pillow, I placed the silver christening cup with the little duck on it that Brian's uncle Tony had given him. In it was the tag that had swung from his crib in the Bon Secours hospital, announcing his birth:

18/05/1982
Room 106
Male
3.5 kilos

The funeral Mass had to be organised. Together with friends and the organist, we sorted out the details. We used a picture of Brian

from a party he'd attended on the front page and his beloved Celtic and Liverpool crests on the back of his Mass leaflet. It was suggested to me that we should not serve alcohol at the wake, seeing as there were so many young people in mourning. I hadn't thought about it. Of course I needed to consider the youngsters, and decided to serve teas and coffees only.

We showered and cleaned ourselves up for visitors. That black dress that I had altered came out, and a jacket to go over it. The boys put on their black ties. The hearse came back, the patio door was taken out yet again, and our Brian came home.

I was so glad to have him back. He was not really gone from me while I could touch him. He looked so peaceful in his Celtic jersey. His face had been made up, which made him look much better. We also had a sense of peace. We knew he was no longer suffering.

Brian's friends were distracted, inconsolable. Brian had always told them that he was fine, and they had believed him. We were anxious that they be part of everything and feel included. They sat around outside the house, these groups of young people. Later that night, they visited together the places where they used to congregate and play football. They couldn't take it in that 'Mahony' was gone. They were left behind, alone, bereft.

That Thursday was a very long day. From early on, people called and stayed in our front room. Sandwiches, apple tarts, and scones appeared from so many kind hands, and the dining room table was laden with food. It was so unreal, though, bringing someone to the kneelers at the end of the bed so they could pay their last respects to Brian, who was lying in the soft candlelight.

His dad, John, says he found it impossible to describe his emotions during the hours leading up to the Rosary as well as on the day of the Removal with any clarity. Lying in bed that Thursday afternoon and

looking out the window on a very fine day with birds singing and the wind rustling the leaves, he was actually emotionless—numbed. We checked every so often on our boy. There was blood coming from his mouth, so we phoned the funeral home. Staff said they would have to take Brian away and drain fluids. They would have him back for the Rosary. So the hearse and the black bag job had to be done again. There seemed to be little respite from trauma for this body.

So many people called: kind and caring people, family and friends from near and far. Neighbours offered accommodation for visiting relatives; the many kindnesses enveloped and supported us. In a couple of hours, the hearse returned, and Brian was back at home in time for his own Rosary.

Fr Nyhan led the prayers and used his microphone and speakers to reach the throngs filling the garden and spilling out onto the park outside.

After the Rosary, we settled down for the night. Valerie never left our Brian alone. 'Is Brian alone?' she would enquire if she saw someone leave, and she would bound up the stairs to sit with him. Paul also spent a lot of private time with Brian, having his own final conversation with the brother he had cherished so dearly. As did John and Vicky—we all had our final things to sort out with Brian, the things we couldn't say while we were pretending he was going to live.

Brian bled again. I packed his nose with cotton wool, but it was soon soaked. His eyes and mouth bled, and there was a hissing noise.

When he'd been sick, every time we saw blood, we were full of fear—fear that he would bleed to death. This time, it was easy. There was no fear. I wrapped his head in the black towels I had purchased to soak the blood. There were towels on the pillowcase and under his chin to save the shirt until morning. I'd never heard of such a thing happening—everything relating to Brian's illness was new to me.

However, I liked that I could still do something for him—still be his mum—and I wished I could have known more, been more prepared, been less traumatised and shocked by unfolding events.

I was so tired, so physically and emotionally exhausted. I needed to get to bed at a reasonable hour and get some sleep. I was afraid that I would not be able to muster enough strength to face the day ahead. But I owed it to Brian to do what was right by him. There wasn't much sleep in the end, as there was so much to do—tidy the house and have a quiet cup of tea when everyone was gone.

You are probably wondering why I didn't stay up all night with Brian. I was shattered. I was all done in. I knew Brian would not have demanded or expected that of me. I had stayed up round the clock when he needed me. Now he would not begrudge me a little sleep. I needed to dig deep to find energy somewhere to do what was needed for these last days with Brian.

With lots of people in the house at all times, John wanted each day to finish as quickly as possible until the funeral was finally over. He felt a lot of anger, recalling distinctly, when all the crowds had gone, that it was as if the whole world had stopped. For a while he went through a lot of self-pity, and I think it was possibly in the quietness that his grieving really started.

We called the funeral home again the following morning, Friday. The Celtic jersey was blood soaked, as was the pillowcase, despite our best efforts with the towels. So it was back into the black bag again for Brian. Sometime later, the hearse backed up to the door and Brian was home again. His clothes had been washed and dried. As his mum, my first reaction was, 'Did you get the clothes dried properly before they put them back on?' Then I realised that it was never again going to matter to Brian whether his clothes were damp or not. The intrusion of this reality was one of many painful steps on the long journey of reconciling myself to the fact that my child had died.

Brian's body still gave trouble. The bleeding started up again. Packing wasn't enough, so for the third time our Brian went off in a black body bag and the patio door was once again taken out and the hearse pulled up. We were advised that rather than negotiating the stairs to lay Brian out in his bed, it would be better to put Brian's body in his coffin and leave him downstairs. He said something about fluid and the less movement the better, so we sorted out the sitting room to receive Brian's coffin.

The candles, flowers and kneelers were rearranged. The hearse pulled up again. The patio door came out again, and Brian returned in time for his own Removal.

I can't describe adequately what it was like. Young lads stood there in white shirts and black ties, sobbing their hearts out. Boys and girls took turns to come into the front room to say goodbye, lining the garden, making this already tragic scene more heartrending. I wanted so much for everyone to get a chance to complete their journey with Brian and say goodbye in the most appropriate way for them. The words of 'Hail Holy Queen' echoed through the house and out onto the park as Fr Nyhan prayed into his loudspeaker.

Then it was time to close the coffin. We called in the army of white shirts and black ties to say farewell. We lingered in a last touch, a last *I love you*. The lid went down on our Brian forever. The patio door came off one last time as John, Paul, and their dad helped shoulder our precious Brian out of his home and into the hearse. That scene—my children shouldering their brother out the front door, their dad anxiously glancing to see if they were okay while he was balancing the coffin on his own shoulder—it's a picture etched in my mind forever.

We walked behind the hearse to the nearby church. Supporting us were a sea of youngsters, relatives, and a huge crowd of neighbours and friends. We followed Brian as we retraced his footsteps, silently

walking the road that he had travelled every day. As I walked behind my son through throngs of people on this beautiful sunny evening, I recalled how often I had walked these same steps when I was pregnant with Brian, taking him in a buggy to nursery or bringing him to school to visit friends or to sporting events.

The hearse pulled up at the Church of the Real Presence. It's a very apt name for our church, I think, as there is a real presence of good in our community. We were shown so much kindness by people of all beliefs. Again the men in the family picked up their beloved Brian in his coffin and carried him to the altar—the same altar at which he had been baptised, the same altar at which he made his First Holy Communion. This was the same altar where he had served as an altar boy and made his Confirmation. The same bishop was standing there waiting. Fr Nyhan and Bishop Buckley said the Rosary, and then we left our Brian in God's house and reluctantly came home to emptiness. We didn't really want to think about the day ahead. It was enough to live each moment. We stayed busy during the evening planning the details of the prayers and hymns.

Saturday morning came. It was a bright, sunny day. The black limousine brought us to Brian's place of rest—our Church of the Real Presence. Sitting together as a family without Brian really pained us. I was silently urging myself to keep it together, saying to myself, *This is us now; this is our family now. You can cope. Your children need you.*

Fr Nyhan led a beautiful ceremony. The choir began with 'Here I Am, Lord', and Tony, Brian's godfather and uncle, read from the Book of Ecclesiastes:

> *For everything there is a season, and a time for everything under heaven: a time to be born, and a time to die . . . God has made everything beautiful in its time.*

The choir followed that with the biblically based 'On Eagle's Wings':

And He will raise you up on eagle's wings
Bear you on the breath of dawn
Make you shine like the sun
And hold you in the palm of His hand

Julian, Brian's uncle on his dad's side, read from Thessalonians:

We want you to be quite certain, about those who have died, to make sure that you do not grieve about them. So we shall stay with the Lord forever. With such thoughts as these you should comfort one another.

After the Gospel, Fr Nyhan reflected on how Brian had lived the Sermon on the Mount. Despite all that he had suffered, he told us, Brian had rejoiced and been glad. Even when persecuted by his disease, he had always spread lightness and happiness.

Reading her 'Prayer of the Faithful', Vicky recalled how brave Brian had been in his last few months. Friends took turns going to the altar to read their particular 'Prayers of the Faithful': Patrick remembered 'Mahony' for music, sport, and good times; Noel recalled Brian always being ready with a funny comment and wanting a good time, saying he had given him inspiration in sickness and in health. Brian's friend John spoke from the heart: 'I am at a loss today,' he said, 'as I have lost one of the most generous, funny and kind friends I ever had. Rest in peace, Brian.'

At the Presentation of the Gifts, the bread and wine were brought up by the cousins of Brian's own generation. A procession followed, representing the different facets of his character. His beloved football was brought to the altar. Then his number-three Wilton United jersey

was draped on his coffin. There was the team photo from when he was younger in the Street Leagues—in it he was wearing those football gloves that he wouldn't part with, even though he wasn't the goalie. His Bishopstown GAA jersey was draped on the other end of his coffin. There was also the vinyl record, which recalled Brian's love of music and the fun he had mixing on the decks and DJ-ing. Vicky brought up a video, remembering all those family times watching TV together. Valerie, through her tears, brought up the grey top of the tracksuit that she had so carefully chosen for his birthday, a symbol of how much he meant to her. It was then the turn of Jim, the boy next door, who had gone to nursery school with him on that first day. Jim, as a teenager, had played in a band called the Buds, and he had brought his own compilation, which was just about to be cut and which he had dedicated in Brian's memory. It was titled *Boober*, in remembrance of the many times Jim had joked with Brian over the fact that his dad and I called him Boober, from *Fraggle Rock*, as a pet name.

The choir sang 'I Will Never Forget You, My People', and the sign of peace was followed by 'Bind Us Together, Lord'. 'Freely, Freely' was the hymn that accompanied Communion. Brian's very sensitive brother and my eldest, John, read 'When I Leave' as the Reflection after Communion:

> *Family and friends, I am about to leave. My last breath does not say goodbye, for my love for you is truly timeless. I leave myself to your memory with love. I leave my thoughts, my laughter, my dreams to you, whom I have treasured. I give you what no thief can steal, the memories of our moments together, those tender, love-filled moments, the successes we have shared, the hard times that brought us closer together, and the roads we have walked side by*

side. I leave you a solemn promise that after I am home in the bosom of God, I will be present in the Communion of Saints, whenever and wherever you call on me. My spirit will be drawn to you by the magnet of our love. Whenever you are in need, call me. I will come to you, with my arms full of wisdom and light, to open your blocked paths, to untangle your knots, and to be your avenue to God. And all that I take with me as I leave you is your love and the millions of memories of all that we have shared. So fear not, nor grieve at my departure, you, whom I have loved so much, for your roots and mine are forever entwined.

Brian's favourite music was played, and there wasn't a dry eye in the church when U2 gave full voice to 'With or Without You'. We wanted to set Brian free to travel on his journey with our love and best wishes, but we could never give back to Brian all that we had received from him. There was so much that he had brought to all our lives. The men of the family, once again, were called on to carry Brian, in his coffin, slowly down the aisle for the last time, as the choir sang Brian's beloved Liverpool Football Club anthem and originated by Gerry and the Pacemakers:

When you walk through a storm, hold your head up high
And don't be afraid of the dark
At the end of the storm, there's a golden sky
And the sweet, silver song of a lark.
Walk on through the wind, Walk on through the rain
Though your dreams are tossed and blown

I put one of my arms around Vicky and my other arm around Valerie, and the three of us followed the coffin. The army of white shirts and black ties followed the family as the choir continued.

Walk on, walk on, with hope in your heart
And you'll never walk alone
You'll never walk alone
You'll never walk alone

As I watched my son's coffin progress down the aisle through the crowds, I recalled his happy, excited face as he and his friends walked, or rather 'raced', in twos down that same aisle after his First Communion. He had been delighted with his new clothes and shoes and was anxious to spend some of the money burning a hole in his pocket.

We followed the hearse with Brian's coffin in it, and it stopped for a minute at the green at the end of the park where he had spent so much time with his friends, playing football and just hanging out. The little stream gurgled along. The rope hung idly from the tree that leaned across the water. How often had I washed clothes and dried out the runners when the children had fallen into the water? It was all such innocent fun. God, how I wished for those carefree moments back!

'It's so much easier to follow the hearse than it was to follow his wheelchair,' I remarked to my family. Everyone agreed. Brian was out of pain now.

We arrived at St. Oliver's Cemetery and followed the same ritual—the men carrying the coffin, Val, Vick, and me leading the crowd. Silence. You could have heard a pin drop. The air of sadness and respect was palpable.

Our procession wound its way to the open grave. The sun warmed us as it might on any other summer's day. Last prayers were said, and we gave Brian's coffin a final kiss. Brian's dad and brothers did the last thing they could do for him on this earth—they fed the ropes

through their hands, gently lowering our precious Brian into the darkness below.

We took one last, lingering look at the coffin with its shiny brass plate, which simply read *Brian O'Mahony R.I.P.* The green mat of artificial grass was pulled across, and a huge number of wreaths were piled high on top. There was nothing of our Brian to see anymore—nothing to touch, nothing more we could do for the one we loved so dearly and had lost.

Silence. No one moved.

After the longest time, the few people who hadn't shaken our hands came forward to sympathise. The crowd was still loath to move.

Eventually, we left the graveyard, which was still crowded with silent mourners. We had invited all who could to the Tennis Village afterwards for something to eat. It was such a suitable venue. Brian had played so much tennis there with us as a family and with his friends. I could barely say goodbye to the youngsters as I left the Tennis Village, knowing this chapter of life was now closed forever. Nothing could ever again be the same.

CHAPTER 4

Life Goes On

The Tuesday after Brian died, I removed his bed from his room. I asked the boys to keep what clothes were useful to them, and I binned the rest. The boys had shared everything, always. I didn't want anything around that would need sorting later. I didn't want this pain to go on forever. I wanted to do things now while I was 'on a roll', as it were, still partly anaesthetised by shock. I didn't think that it would suit me to divide this pain up into chunks and deal with it bit by bit. It was better to face it all at once, and then things could only get better. I didn't want my life to always look like this, a life with a gaping hole in it.

I made arrangements to return the hospital-type bed, and I also made up my mind to get rid of Brian's own bed out of the house. Even though I felt having the empty bed staring at us would be difficult for the other children, it was heartrending and harrowing to actually remove it.

I went back to work on Wednesday. My head was in a spin, in a whole other world. My body felt wrecked; I'd never expected that grief could have such a physical as well as an emotional impact. On my coffee break in the canteen, I recalled the evening my colleagues invited me to the Mass for Brian when he was seriously ill. Had this nightmare really happened? Could I wake up and find it was all just a very bad dream? Please, could I wake up? Mostly what I felt that day, and for a long time after, was shock and horror. I couldn't believe that in this day and age, anyone could suffer so. I felt like someone released from a concentration camp, shocked from all that I had witnessed. Being part of the whole illness-and-death experience had been nerve-

racking. Every cell in my body had registered the happenings. I could only feel cold, numb.

Staying calm when Brian was bleeding, struggling for every breath, or trembling with pain—that had been a decision. My calmness was a mask. My entire family had to deal with their own sorrows, and I had a responsibility to be strong and lead them. We came through this experience together; we didn't need any unnecessary drama.

I could not get some feelings out of my mind, though—the many times I had felt like there was a gun to Brian's head and the many times when, while alone at home with Brian, I was frightened. Often, I had been absolutely terrified. Was this groan to be Brian's last? I remembered his breathing, so shallow on that morning before his birthday, when I could barely hear life. I'd sent for the doctor, but, of course, there was nothing extra he could do. We just had to sit it out, stay smiling for Brian's sake. The frustration of it all, the horror, the intensity of emotion. I was exhausted, physically as well as emotionally. I had stayed round the clock in the isolation ward, not even coming home for a shower on the really bad days. I had spent weeks at a time confined in a room or sitting next to Brian at home in the bedroom or front room, with no exercise, no proper food, no normality. Moving his pillows, wafting his sheet to ease his pain, giving him sips of water. It was just Brian and me and a boiling pot of emotions.

Shock and horror registered as I came to terms with the violence and relentlessness of this disease on an innocent body. Dark, primordial gut pain had immobilised my feelings.

A couple of times after his death, I thought I could feel Brian's presence behind me, and I worried that I was losing my sanity.

John also returned to work the week after Brian died. Knowing that the brain could only think of one thing at a time, he was glad to have a little distraction from the pain of losing his son. John and I

talked about Brian, the fact that he was so straightforward and to the point. He did nothing by half measures and accepted everything in good faith exactly as it was said.

We talked about silly things, like how Brian would be amazed if you asked him 'What time is it?' when we were all wearing watches. And there was the time Brian answered the phone at home when his dad called enquiring if I was gone in to the city. He asked how I'd gone, and Brian hesitated for a second before replying, as if explaining to a fool, 'Out the front door, I suppose!' John recalled that Brian was an excellent runner and had finished first in the underage section in the marathon. He spoke about Brian the left-footed footballer. I could feel John's pride in Brian, who was sincere and loving, never given to idle remarks.

John had good friends that he spoke to at length about Brian. He accepted that all that had happened was God's will. But the emptiness, the sadness beyond belief, propelled him to Brian's grave every day. He talked with him every morning and night. His good friends, in whom he could confide, really helped him through, helped him to find clarity.

We could feel Brian in every room. In the bathroom, I would remember lifting his head up for the last time. But there too resided the memory of us bathing the three boys together when they were small. I would be soaked to the skin by the time the whole procedure was over, and there would be three shiny faces ready for bed. In the kitchen I remembered how much Brian loved the fry I cook for brunch on Sundays. There was the kitchen stool that he'd fixed. 'It needs a Brian-ing," he said as he fixed the loose top. In the dining room, I recalled Brian really loving his food. How he relished julienned carrots, shiny with butter, when I had the time to chop them small. I remembered how he'd laughed at me when I nearly set fire to the table. I spilled

the brandy as I lit the plum pudding at Christmas, sending the flames running across the table.

There were so many cosy memories in the sitting room. When his coffin ended up in there, I remembered thinking that he would have liked to leave from his favourite room. Brian was always so easy to please, like when I got his new chair.

'You should have left the tag on,' I remembered Brian saying.

'What tag?' I enquired.

'You know, the banner on my chair. It said *The most comfortable chair in the world*, and it really is the most comfortable chair in the world.' Brian appreciated everything so much, and that made all our lives so much easier. John remembered the hours he spent watching him sleeping on that chair, hoping and praying that he would live to see another day.

I smiled as I remembered Brian's graduation. The neighbours called and we all celebrated, opening a bottle of champagne for the gang of youngsters, whom we photographed in front of the fire. That same photograph now graces Brian's memorial card. Another photo that just had to be included in that card was one in which Brian is holding a prize and wearing a sweatshirt with *More Than Equal* written across his chest. How prophetic that turned out to be. The last photo on the front of his memorial card is a happy and proud Brian walking down the ramp, enjoying the fourth-year fashion show.

The music decks sat quietly in the playroom. The boys had spent lots of time creating their own mixes on Paul's decks, but this wasn't a creative time for any of us now. We were all in shock.

One Sunday, John and I felt we had to get out from the house for a minute. We were suffocating in our grief. Our home seemed like a prison, where we had been engulfed in so much torture and pain. We

drove to nearby Kinsale for our lunch. Coming out from the hotel, we noticed a teenage girl on crutches. It was the same place where Brian had eaten the toasted sandwich that he had so enjoyed.

It was just too much for me, and tears welled up. Leaving home, I hadn't thought about Kinsale being the last outing that Brian and I had, but the memories of walking behind Brian dying on his crutches, the agony of it all, came rushing in on top of me.

Pain strikes when you least expect it. It's still difficult when I'm asked, 'Do you have any boys?' I want to answer, *I have three*. But sometimes it's not appropriate to mention a dead child, so I answer *two* when I want to say *three*. It's like I'm sticking a knife into myself. It's almost a physical pain.

I had been having these awful dark feelings, questions, and ideas. What if Brian was being tortured even more on the other side? He had no one to look after him. He didn't know anyone. What was dying like? Was it hard? What did he face ahead of him? Maybe there was no other side? Maybe this was just a story I believed to make my life here more pleasant? Surely he must be so lonely over there—if there was an 'over there'?

Few people wanted to talk about Brian's death when he was sick, and even fewer would talk about it now. For me, it was a crushing loneliness, keeping all these questions to myself. It wasn't that I wanted to grieve—I just wanted to know that Brian was okay. The whole experience was one of love, given and received, of loving and being loved. It was love experienced to a degree that I couldn't have even imagined.

The closest Brian and I had ever come to a philosophical discussion was in the hospital. 'Mum, do you ever fly in your dreams?' he said. 'My friends don't. But I do,' he told me.

'Yes, love. I do, often,' I told him.

'If ever I think about it, I come back to earth. But if I don't think about it, I keep on flying,' he said.

'Next time you're flying, don't look back. Don't look down,' I advised him. 'Keep on flying.'

It was such a surreal conversation. We spoke about lucid dreaming and how, in lucid dreaming, we have a chance to control our actions within the dream.

A few days after the funeral, I got to listen to Jim's CD, *Boober*, up in his own house with his mum and dad. You probably remember from the title of the CD that Jim had dedicated it to Brian. The track that really speaks to me is track 4, 'Steal My Show':

The light's on you
You're the star that they all wanna know
What to do
When you know it's the end of the show
Make it slow
Now you're gone, flying high and as free as a bird

And it's time for me to be by myself
It's time for me to reach and touch someone else I've gotta go
I've gotta go
Alone

The following day, a group of Brian's friends called to our house. 'This is Brian's last mix,' they told me as they handed me a CD. And then they headed off, leaving me to listen to Brian's final creative efforts on my own. It was trance music.

I'm going to tear everything down
And replace it with something new . . .
With God, a world of God . . .
Love and compassion

Did Brian have some inner knowledge of how soon he would meet his God? It was like some out-of-body experience, listening, as it were, to words beyond the grave.

Brian's month's mind was on a Saturday. It's customary to attend Mass and remember the deceased a month or so after the funeral Mass. I decided to read a poem called 'To My Dearest Family', which imagines how one of our loved ones in heaven might speak to us:

To my dearest family and friends
There are some things I'd like to say
But first of all to let you know that I arrived okay.
I'm writing this from Heaven, where I live with God above
Where there are no more tears or sadness, just eternal love.
Please, don't be unhappy just because I'm out of sight
Remember, now, I'm with you every morning, noon and night.
Up here, God gave me a list of things to do
And foremost on that list of mine is to watch and care for you.
That day when I had to leave you, when my life on earth was through
God picked me up and hugged me, and said 'I welcome you.'
I will be there beside you through the days and weeks and years
When you are sad, I'm standing near to wipe away the tears.

But don't be afraid to cry, it does relieve the pain
Remember, there would be no flowers unless there was some rain.
But one thing is for certain, though my life on earth is o'er
I'm closer to you now than I ever was before.
There are rocky roads ahead of you and many hills to climb
But together we can do it, just take one day at a time.
And now I am content, my life has been worthwhile
Knowing as I passed along the way, I helped to make you smile.
When you're walking down the street, and I am on your mind
I'm walking in your footsteps, only half a step behind.
And when you feel that gentle breeze or the wind upon your face
That's me giving you a great big hug, or just a soft embrace.
And I will always love you, from that land way up above
Soon we'll be in touch again—and PS—God sends his love.

After the Mass, we went to the local soccer club for something to eat. Brian had played so much soccer there. On winter nights, the young lads would book an indoor court to play together. He had his first pints there—'raza', or raspberry cordial and water. We'd booked a DJ and had a great night there at John's twenty-first birthday party. Now this venue was linked to an altogether different family occasion.

There have been so many difficult times. The horror and shock of witnessing this cruelty visited on my child has been permanently etched on every cell of my body.

One night I dreamt about Brian. I thought that I was with him and he was well. I was crying and saying to him, 'Oh, Brian! I had this horrible dream that you got really sick.' I was rubbing his shiny soft

hair with tears in my eyes, and he was giving me one of those looks that said *What is she on about?*

When I woke up, there were a couple of moments where the dark pain lifted, and I thought that his illness had been a nightmare and Brian was safe and well. I was so blissfully happy just for a moment. Then reality flooded in, and I knew I had to live in the nightmare.

In one way, it seemed a particular cruelty to bring us so close and then snatch Brian away. I had spent months with him, listening to every breath, helping every movement. I was in tune with every rhythm of his body, and there was just him and me for long stretches of time when his dad and everyone else had work or school or whatever. I spent long, pain-filled nights with him, and frightened, anxious days. Now there was nothing. I had gone from twenty-four-hour Brian-filled days to nothing.

His dad, John, wondered whether Brian could have orchestrated events in his own life. Brian, undoubtedly, had an understanding that his dad might find it difficult to be present on certain occasions. Had Brian managed to orchestrate the timing of his own birth in the Bon Secours hospital so that his dad arrived ten minutes after his birth? And, again, in the case of the timing of his death at home, so that his dad arrived at his bedside minutes after he died?

Smiling, John recalled incidents where Brian would stick solidly to his own point of view. He remembered the many matches he watched Brian play, soccer for Wilton United and GAA for Bishopstown—left footed, as John had noticed from a young age.

I remember walking back to work one lunch hour. I put my hand in my coat pocket and found a piece of paper. I automatically pulled it out to see what it was. *Have a good one, Mahony*, was written on it. The words hit me broadside, and the tears just poured down my face. It was a card that I had found on flowers on Brian's grave, with

a note from the heart. This wish—*Have a good one, Mahony*—was our deepest desire for Brian in his new life.

Shock and horror were very near the surface for all of us. And that's not to mention the sadness at our loss, which was a different issue. I missed Brian so much. It took years for me to be able to remember anything of who he was without disability. I have talked of his courage and bravery facing death, as they amazed me. But really the thing that I remember most about Brian is how funny he was. Brian was always pulling funny faces. He made funny noises and used his own made-up words and was an innocent practical joker.

The world is not the same without Brian. I am not alone in missing him, of course. As a family, we don't talk much about how we feel. We show our feelings more by action than words. To have had a taste of the love and friendship a young adult can give, and then lose him before he has taken more than a few steps in his new life—it's so painful. Not alone have we lost Brian; we each have lost ourselves, lost who we were in a family of six. We have had to reconfigure ourselves as a new entity, a family of five.

Paul, many nights, deeply distressed, was out at Brian's grave at about one thirty in the morning, and he and I would chat for a couple of hours when he came home.

'You know, I really wished I could have been Brian,' he spluttered. 'I was always stronger. I'd go for a header when we were playing soccer when he wouldn't. I wished it could have been me all that time. I wished that I had to suffer all that pain and not Brian. I was stronger. But now I'm glad it wasn't me who died and Brian left to grieve. The pain I have now is worse than anything Brian suffered. I'm glad that I'm suffering this, not Brian. I'm glad that I got the worse pain. I'm glad that it was Brian who died.'

I know that there are no words that can adequately describe the intense pain that we all felt, but these words of Paul give a slight indication of its depth.

John remembered his brother as always being the little 'pet' going for cuddles with me, long after the rest of them were too cool for that. Smiling, John recalled one thing that ran through every aspect of Brian's character—what you might call an unusually logical way of looking at things. He often pointed out the obvious, what everyone else had failed to see.

John recalled times when Brian's 'logic' brought about the very best results. Brian's famous logic, he remembered, was well demonstrated on the Christmas that he and Paul had outgrown Santa but Brian still believed. On Christmas morning, when everybody had finished opening presents from friends and family, several large gifts remained under the tree. These, of course, were Brian's presents from Santa. John looked on as Brian happily opened this extra set of presents.

As Brian opened one of the gifts, he looked across the room at John with a knowing expression on his face. No words were said, and John says he will never know for certain whether Brian's 'belief ' in Santa was a big act that year. One thing is for sure, however; when Brian looked at him, he knew he was getting more presents, and he knew that John knew it too! Logic: Kids who believe in Santa get more presents than those that don't.

John wasn't with his brother when he died but had spent the preceding hours with him. However, it has meant a lot to him that he stayed with Brian on his last night and helped him through it, holding his hand and telling him that he was doing great when he was gasping for breath. He forgot about his own pain and was there for Brian.

Paul recalled all the fun they had in hospital when the crowd of young lads would have their laughs and one would go across the road to Abrakebabra and bring back food, creating a party atmosphere.

Vicky remembered Brian's kindness. How he would sit down with her at homework time and give her a hand with her maths. He was good at maths, and he was good at explaining them too.

His dad and I are glad that we were so close to Brian. At all times we believed him, and knowing him so well, we were convinced he wasn't the kind to imagine a pain. We made our own decision about visitors, allowing his friends to visit. Brian without friends would have been like a fish without water. We were his parents. Our job was to parent him, to provide him with survival tools. We considered his friends his best chance of psychological survival. Rather than limiting the number of youngsters visiting, as was suggested, we limited the relations. Taking care of a young adult, I soon realised that he didn't want visits from well-meaning neighbours or family; he wanted his buddies.

I had the opportunity in his final months to really love Brian unconditionally. The more disabled he was, the more I loved him, and my heart was breaking watching him struggle. This intense experience is forever etched in my body. It's part of who I am now. It's not the child I miss, it's my adult son—taller than me, enthusiastic about music, kind and funny. I miss his laughter. The final hymn at Brian's Anniversary Mass a year later spoke to our feelings:

Wear my name upon your heart
Keep it safe while we're apart
Till we meet in deepest peace
Somewhere again.

I've had a little statue of the Pietà in my bedroom since I was a little child. However, it became abundantly clear to me that while this masterpiece is sculpted in marble, the reality Michelangelo captured was lived in flesh and blood, and, for me, in real life. I remember the morning I lifted a lifeless child back to his bed with the nurse. Brian's heart had stopped, the pulse monitor bleeped that flat sound, but life gradually returned as Brian came back to us. We dodged the bullet that morning. I don't have words to adequately describe that reality—the nurse suggesting I call the priest and phone his dad. I felt sick with pain and fear.

I used to faint at the sight of blood when I was a child. Can you imagine? I didn't know that morning when I would hold Brian's dead body in my arms for real, just as Mary did in the Pietà.

His dad also vividly remembers that morning in the hospital—his feelings of powerlessness, continually asking the nurse if she thought that Brian would pull through, feeling that if there was life, there was hope. He placed it in God's hands; this was the only way he could continue watching his little boy when he was white as a sheet, the life drained out of him. It is an experience he would not wish on anybody.

I'm grateful I was given the chance to be with Brian. I'm glad I could help out. I was blessed that Brian allowed me to be 'love' in his life, grateful that he was gracious enough to allow all of us to be with him without ever a complaint. It was a catastrophic change in Brian's life, from playing soccer and going to school one week to being terminally ill in a wheelchair weeks later. Yet he managed it. He managed it because he accepted it. He did the best he could with it.

My sense of gratitude remains. When I hugged Brian's remaining clothes—I needed to retrieve every last molecule I could smell of my boy—I knew I had a lot to be grateful for. How many people, yearning for the child they cannot have, would gladly settle for nineteen years?

That longing has to be a worse ache. How many people whose children died suddenly or in accidents wish they could have been present when they passed away? How cruel is it for families where children die through suicide or addictions, or have long-term serious illnesses where parents feel helpless? I surely would choose my journey over any of theirs. This I know. I'm sorry if you have been on a journey more difficult than mine.

Love was his gift to us. He told me to accept as he accepted. I felt he was telling me to stay with the overwhelming love, soak it in, live it and breathe it. I accept that Brian had somewhat of a cameo role; he was not present for all the episodes of my life. But look what he brought to our lives. He showed me how to live each day fully and without complaint. He showed how to play the game and not get bogged down. He wasn't interested in winning, just playing.

The morning Brian died was a calm and easy morning from Brian's point of view. The doctor had called me out of Brian's room and said, 'You do know that he is dying.' I returned to Brian's room, and ten minutes later all his energy was used, and Brian left us with no fuss or bother. Living and dying, he moved freely and simply.

I had practiced my goodbye over and over—'God bless, protect, guard, and guide. I love you forever. I love you forever.' I kept telling myself, *You can do it. You can do it. You must do it. You can't let him down. You can smile and you can do it.* And I did. Despite the overwhelming pain we felt, there was a deep feeling of satisfaction, of relief, of getting it right for Brian. It was love that turned the horror of his funeral into a beautiful reflection of 'the life of Brian'. The love of his family, relatives, friends, and neighbours, of work colleagues from my office and John's, of his classmates and of John's, Paul's, and Vicky's classmates—it was like a blanket that enfolded us and kept us safe. This is the Real Presence; this is God in our lives, strong and alive in our community.

At Christmastime we always get a hamper from 'the lads'—never forgotten, always cherished by them—and we in turn are very moved and comforted by their constancy. A blessing on each of them. I know I repeat myself when I say that young people today are wonderful, but it's worth repeating, as our world is safe in their hands.

We will always be drawn to remembering Brian and wanting to be with him again. A photo plate on his headstone has Brian smiling at us, and we have written:

It broke our hearts to lose you.
But you did not go alone.
For part of us went with you,
The day God called you home.

It's consoling for me that this photo plate is often warm to the touch. It faces southwest, so the sun warms it, making it easier to kiss the marble face that looks out at me. When the headstone we ordered for the grave came, the little wooden cross—put up to temporarily mark Brian's burial spot—was no longer needed. So I brought it home. On it is a plaque that reads *Brian O'Mahony, 28th June 2001, Rest In Peace*.

We nestled his cross behind the arch, against the back wall of our back garden. We have a three-foot figurine of a boy right next to it. It's set in a very private spot with the evergreen 'Gold Brian' plant growing right alongside it. I hadn't realised before this that there even was a plant called Gold Brian.

A further plaque that I came across, which means so much to me, peeps out respectfully from behind the figurine and reads:

If the dead can come back to this earth
And flit unseen around those they loved,

I shall always be near you;
In the gladdest days and darkest nights
Always, always,
and if there be a soft breeze upon your cheek
it shall be my breath,
as the cool air fans your throbbing temple,
it shall be my spirit.

Brian is part of us; we are not leaving him behind. Rather, he is part of every barbecue, and he cheers at every score his nieces and nephews accomplish when they're kicking about.

In the meantime, life has moved on for us all. My son Paul is now a social worker with Tusla. He married Valerie, his childhood sweetheart, and they have three beautiful children. They named their eldest boy Brian and also have a daughter, Deirdre, and another son, Kevin.

Vicky is getting on with her life, though she has yet to meet the man of her dreams. Our son John works for HSE. He married Sinéad, a girl from Brian's class in school. They too have three beautiful children, Eve, Liam, and Sam. The birth of the second of their beautiful children, Liam Joseph, was the most wonderful gift on my sixtieth birthday. You see, I always feel quite emotional on my birthday, as I was told Brian was going to die that day. Holy Thursday is another day when I feel acutely aware of the pain of life, because Brian had such a bad night on Holy Thursday. My sixtieth birthday fell on Holy Thursday, so both occasions came together.

But everything changed; my sadness was completely superseded by the joy of birth as my precious fifth grandchild, Liam, was born on that day. When I collected balloons to bring to visit my new grandson, the shopkeeper suggested we put them in a black garbage bag so the strings would not get tangled in transport. On this occasion the black

bag did not symbolise my son being removed from the house but rather celebration.

Liam Joseph was christened on June 28, the fourteenth anniversary of Brian's death. Joseph was Brian's second name.

This is the circle of life. I am so very grateful for all that I have been given. It's true that some people have a shorter life span than others, but they leave sweet memories to cherish.

Love you, Brian.

About All Ireland Institute of Hospice and Palliative Care

Established in 2011, the All Ireland Institute of Hospice and Palliative Care (AIIHPC) is a leading organisation with national and international influence promoting excellence in palliative care. AIIHPC is a collaborative of hospices, universities, health and social care organisations and charities on the island of Ireland. As the palliative care sector's Institute, AIIHPC:

- Involves people with life-limiting conditions, carers and communities in delivery and development
- Works to integrate palliative care across the health and social care system so that people are supported as early as possible
- Supports the development of specialist palliative care services for people who need them

AIIHPC works across research, education, public engagement and policy development with a group of visionary members who recognise the value of working together to improve the palliative care experience and quality of life for people with life-limiting conditions. Together, our members have seen first-hand how this collaboration has led to greater investment in palliative care research, a more coordinated approach to training healthcare professionals and improved engagement with people with life-limiting conditions, carers and the wider public, which is helping to inform future policy across the island of Ireland.