WITH Dying, Death and Wisdom END in an Age of Denial IN MIND

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Introduction

It may seem odd that, after half a lifetime of keeping company with the dying, anyone should wish to spend even more time immersed in telling their stories. It may even seem presumptuous to offer those stories in the hope that readers will choose to accompany dying strangers across the pages. And yet that is what this book sets out to do.

Throughout my career in medicine, it has been clear to me that we bring our own ideas and expectations with us in any encounter with the Big Questions. Whether that is birth, death, love, loss or transformation, everyone frames their experience through the lens of what they already know. The trouble is, whereas birth, love and even bereavement are widely discussed, death itself has become increasingly taboo. Not knowing what to expect, people take their cues instead from vicarious experience: television, films, novels, social media and the news. These sensationalised yet simultaneously trivialised versions of dying and death have replaced what was once everyone’s common experience of observing the dying of people around them, of seeing death often enough to recognise its patterns, to become familiar with life lived well within the limits of decreasing vigour, and even to develop a familiarity with the sequences of the deathbed.

That rich wisdom was lost in the second half of the twentieth century. Better healthcare, new treatments like antibiotics, kidney
dialysis and early chemotherapy, better nutrition, immunisation programmes and other developments radically changed people’s experiences of illness and offered hope of cure, or at least postponement of dying, that was previously impossible. This triggered a behaviour change that saw the sickest people being rushed into hospital for treatment instead of waiting at home to die. Life expectancies increased; many lives were enhanced and lengthened.

Yet these welcome healthcare advances can only remediate us up to a point; beyond the point of saving us to live ‘well enough’ there is a point of futility. Here, technology is deployed in a new deathbed ritual that is a triumph of denial over experience. The death rate remains 100 per cent, and the pattern of the final days, and the way we actually die, are unchanged. What is different is that we have lost the familiarity we once had with that process, and we have lost the vocabulary and etiquette that served us so well in past times, when death was acknowledged to be inevitable. Instead of dying in a dear and familiar room with people we love around us, we now die in ambulances and emergency rooms and intensive care units, our loved ones separated from us by the machinery of life preservation.

This is a book about real events. Everything described really happened to someone, sometime, in the last forty years. To preserve the anonymity of the people described, almost all the names have been changed, along with their jobs, and sometimes their gender or ethnicity. Because these are stories rather than case histories, sometimes the experience of several people is woven into a single individual’s narrative, to allow specific aspects of the journey to be depicted. Many of the situations may seem familiar because, despite our averted gaze, death is unavoidable, and these accounts will have parallels in many people’s own experience.

Because most of my career has been spent working in palliative care, it is inevitable that most of these stories are about people who have had access to palliative care specialists. This generally means that any challenging physical symptoms have been engaged
with and usually reasonably well controlled, and emotional symptoms are being addressed. Palliative care is not solely concerned with dying: excellent symptom management should be accessible to people of all diagnoses at any stage of their illness, when they require it. That is the broad remit of the specialty of palliative medicine. The majority of our patients, however, are in the last months of their lives, and this gives us a particular insight into the way people live when they know that they are dying. It is that part of our experience that I am seeking to convey in these stories: how the dying, like the rest of us, are mainly getting on with living.

In the main, I am offering the reader my eyes and ears, my seat at the bedside, my place in the conversations, and my perspective on events. Where there are lessons for us, these are the gifts of the people whose stories are collected here. Where there are mistakes, they are entirely my own.

It’s time to talk about dying. This is my way of promoting the conversation.
Reading the Label

Medicines usually have a label that says ‘Take as directed.’ This helps us to get the intended benefit from the prescription and to avoid under- or over-dosing. The prescriber should have described what the medicine is for, and agreed a dosing schedule with the patient, who can then choose whether or not to follow the medical advice. The label also often includes a health warning, to ensure that patients know about any potential hazards.

Perhaps it will help you to decide how best to approach this book if I describe what it’s for, and what kind of ‘dosing schedule’ I had in mind. And yes, there is a health warning, too.

This book is a series of stories based on real events, and the intention is to allow the reader to ‘experience’ what happens when people are approaching the ends of their lives: how they cope; how they live; what matters most; how dying evolves; what a deathbed is like; how families react. It’s a tiny glimpse into a phenomenon that is happening somewhere around us every single day. By encountering death many thousands of times, I have come to a view that there is usually little to fear and much to prepare for. Sadly, I regularly meet patients and families who believe the opposite: that death is dreadful, and talking about it or preparing for it will be unbearably sad or frightening.

The purpose of this book is to enable people to become familiar with the process of dying. To achieve this, the stories have been
grouped into themes, beginning with stories that describe the unfolding and evolution of dying and the variety of ways in which people respond to it.

Throughout the book, each story can stand alone to satisfy readers who like to dip in and out at random, but there is a gradual progression from more concrete principles like physical changes, patterns of behaviour or dealing with symptoms, towards more abstract concepts like making sense of human impermanence and how we evaluate, in the end, what has been truly important to us.

Also threaded through the book, but not in any chronological order, is an account of my transition from a naïve and frightened student to an experienced and (relatively) calm physician. My life has been immeasurably enriched by working within clinical teams of skilled colleagues, many of whom feature in these stories. They have supported me and acted as mentors, role models and guides throughout my career, and I am deeply aware that our strength lies in teamwork, which always makes us stronger than the sum of our individual parts.

Health warning: these stories will probably make you think not just about the people in them, but about yourself, your life, your loved ones and your losses. You are likely to be made sad, although the aim is to give you information and food for thought.

At the end of each section there are suggestions of things to think about and, if you can, to talk about with someone you trust. I’ve based these suggestions on current knowledge from clinical research, on ways I have seen people and families coping with serious illness and death, and on the gaps I have encountered that could have been filled to make the last part of life, and the good-byes, so much less challenging.

I’m sorry if you’re made sad, but I hope that you will also feel comforted and inspired. I hope you will be less afraid, and more inclined to plan for and discuss dying. I wrote this book because I hope we can all live better, as well as die better, by keeping the end in mind.
Patterns

Medicine is full of pattern-recognition: the pattern of symptoms that separates tonsillitis from other sore throats, or asthma from other causes of breathlessness; the pattern of behaviour that separates the anxious ‘worried well’ from the stoical yet sick person; the pattern of skin rashes that can indicate urgency and thereby save a life.

There are also patterns in the way a condition evolves. Perhaps the most familiar these days is pregnancy and birth. We know the nine-month pattern of pregnancy: the changing symptoms as morning sickness gives way to heartburn; the early quickening and later slowing of the baby’s movements as the swollen belly constricts activity towards term; the pattern and stages of a normal birth. Watching dying is like watching birth: in both, there are recognisable stages in a progression of changes towards the anticipated outcome. Mainly, both processes can proceed safely without intervention, as any wise midwife knows. In fact, normal birth is probably more uncomfortable than normal dying, yet people have come to associate the idea of dying with pain and indignity that are rarely the case.

In preparing for a birth, pregnant women and their birth partners learn about the stages and progression of labour and delivery; this information helps them to be ready and calm when the events begin to take place. Similarly, discussing what to expect during
dying, and understanding that the process is predictable and usually reasonably comfortable, is of comfort and support to dying people and those who love them. Sadly, wise ‘midwives’ to talk us through the dying process are scarce: in modern healthcare, fewer doctors and nurses have opportunity to witness normal, uncomplicated dying as their practice increasingly entangles technology with terminal care.

The stories in this section describe the patterns of approaching our dying, and how recognising those patterns enables us to ask for, and to offer, help and support.
Unpromising Beginnings

It is inevitable that a career in medicine will involve seeing death. My journey into familiarity with death began with a still-warm body, and continued with the necessity of discussing the deaths of patients with their newly bereaved loved ones. It was a long way from talking about dying with people who were themselves dying, a conversation that would have been discouraged by medical wisdom when I was training, but it was an apprenticeship of sorts, and it taught me to listen. In listening, I began to understand patterns, to notice similarities, to appreciate others’ views about living and dying. I found myself wondering, fascinated, and I found a sense of direction.

I first saw a dead person when I was eighteen. It was my first term at medical school. He was a man who had died of a heart attack on his way to hospital in an ambulance. The paramedics had attempted to resuscitate him, without success, and the emergency department doctor whom I was shadowing was called to certify death in the ambulance, before the crew took the body to the hospital mortuary. It was a gloomy December evening and the wet hospital forecourt shone orange in the streetlamps; the ambulance interior was startlingly bright in comparison. The dead man was in his forties, broad-chested and wide-browed, eyes closed but eyebrows raised, giving an impression of surprise. The doctor shone a light in his eyes, listened over his chest for heart or breath sounds; he examined a print-out of the ECG from the last moments that his heart was beating, then nodded to the crew. They noted the time of this examination as the declared time of death.
They disembarked. I was last out. The man was lying on his back, shirt open, ECG pads on his chest, a drip in his right arm. He looked as though he was asleep. He might just wake up at any moment, surely? Perhaps we should shout in his ear; perhaps we should just give him a vigorous shake; he would surely rouse. ‘Come on!’ the doctor called back to me. ‘Plenty to do for the living. Leave him for the crew.’

I hesitated. Perhaps he’s made a mistake. If I stand here long enough, I’ll see this man take a breath. He doesn’t look dead. He can’t be dead.

Then the doctor noticed my hesitation. He climbed back into the ambulance. ‘First time, eh? OK, use your stethoscope. Put it over his heart.’ I fumbled in the pocket of my white coat (yes, we wore them then) and withdrew the shiny new tool of my trade-to-be, all the tubing tangled around the earpieces. I put the bell of the stethoscope over where the heart should be beating. I could hear the distant voice of one of the crew telling someone he would like sugar in his coffee – but no heart sounds. My observant trainer picked up the end of my stethoscope and rotated it, so that it would pick up noises from the patient and not from the world, and placed it back over the heart. Now there was utter silence. I had never heard silence so solid, nor listened with such focus. And now I noticed that this man looked a little pale. His lips were a deep purple and his tongue was visible, also dusky. Yes, he is dead. Very newly dead. Still working out how to be dead. ‘Thank you,’ I said to the pale man. We left the ambulance and walked through the orange rain back into A&E.

‘You’ll get used to it,’ said the doctor kindly, before he picked up a new chart and carried on with his evening shift. I was perplexed by the stark simplicity, the lack of ceremony. Our next patient was a child with a sweet stuck up her nose.

There were other, less vividly remembered deaths while I was a student, but in the first month after I had qualified, I earned the hospital record for the number of death certificates issued. This was
simply because I was working on a ward that had a lot of people with incurable illnesses, and not due to any personal responsibility for their deaths, please understand. I quickly became on first-name terms with the bereavement officer, a kindly woman who brought around the book of certificates to be signed by the doctor who had declared the patient dead. In just the same way as I had seen in that ambulance five years earlier, I noted the deaths of fourteen people in my first ten days (or perhaps it was the other way round); the bereavement officer quipped that perhaps I should get an award.

What the bereavement officer didn’t see, though, was the massive learning curve I was climbing. Each of those certificates was about a person, and each of those people had family members who needed to be told about the death, and who wanted to know the reasons their loved one had died. In my first month of clinical practice I had twenty conversations with bereaved families. I sat with people while they wept or stared blankly into a future they could barely contemplate; I drank cups of tea-with-sympathy, brewed at Sister’s instruction by one of the experienced auxiliary nurses and carried on a tray (‘With a proper cloth, please!’ ‘Yes, Sister.’) into Sister’s office, which was only entered by doctors with Sister’s personal permission. Bereavement visits were an exception: permission was assumed.

Sometimes I was the second fiddle, listening to a more experienced doctor talking to families about illness, death, why the drugs hadn’t worked, or why an infection had torn the person away just as their leukaemia was responding. The family members nodded bleakly, sipped tea, dripped tears. Sometimes I was the only doctor available if others were in clinics, or it was after hours, and sometimes I brewed the tea-with-sympathy myself, finding the familiar routine a comfort, noticing the details of the flowery, gilded china cups and saucers that Sister provided for these most special visitors, before taking a deep breath and entering the room to give the worst news in the world.

To my surprise, I found these conversations strangely uplifting,
Families were rarely totally unprepared: this was a ward for people who had life-threatening illnesses. During these conversations I would learn so much about the deceased person, things I wished I had known while they were alive. Families told stories about their gifts and talents, their kindnesses and interests, their quirks and peculiarities. These conversations were almost always in the present tense: there was a sense of their loved one still being present in some way, perhaps while the body was still tucked in the same bed, or was being cared for somewhere else in the hospital. And then they would check themselves, correct the tense, and begin to rehearse their steps into the huge loss that was gradually, terribly, declaring itself.

Some time during my first six months I had to tell an elderly man that his wife had died. She had died suddenly, and the cardiac arrest team had been called. As is customary, her husband had been telephoned and asked to come as soon as he could, no further details given. I found him standing on the ward, outside her room, looking at the unfamiliar screen across the door and the sign saying ‘Please do not enter, please see the nursing staff.’ The crash team had departed, and the nurses were occupied with their drugs round. I asked if I could help, and then saw the bewilderment and fear in his eyes.

‘Are you Irene’s husband?’ I asked. He moved his head to say yes, but no sound came out of his mouth.

‘Come with me, and let me explain,’ I said, leading him to Sister’s office and to yet another of those conversations that change people’s lives. I don’t remember the detail of the conversation, but I remember becoming aware that, with the death of his wife, this man now had no remaining family. He seemed frail and lost, and I was concerned that he might need support in his bereavement. Had I been more aware then of the wonderful contribution that can be made by GPs and primary care services, I might simply have asked his permission to let his GP know that his beloved wife had just died, but I was inexperienced and in an unexpected situation: I had discovered him outside his wife’s room while I was in...
the middle of administering the midday intravenous antibiotics for
the ward. I hadn’t prepared myself for a bereavement discussion.

As usual when terminating these sad conversations, I assured him
that I would be happy to talk to him again if he found that he had
further questions as time went by. Although I always said this, and
I truly meant it, families never did come back for more information.
And then I acted on impulse: I gave Irene’s fragile-looking husband
my name and telephone number on a piece of paper. I had never
given out written contact details like this before, and his apparent
indifference as he screwed the scrap of paper into a ball and pocketed
it seemed to indicate that this might not be a helpful contribution.

Three months later I was working at a different hospital, now
as a junior on a surgical ward, when I received a phone call from
the ward sister of my previous ward, she of the tray-with-cloth
and the gilded china. Did I remember that patient called Irene,
she asked. She had had a call from Irene’s husband, and he was
most insistent that he make contact with me. She gave me a
number, and I called him.

‘Oh, thank you for calling me back, doctor. It’s so nice to hear
your voice . . .’ He paused, and I waited, wondering what question
might have occurred to him, hoping I would know enough to
answer it.

‘The thing is . . .’ he paused again. ‘Well, you were so kind to
say I could phone you . . . and I didn’t know who else I could
tell . . . but, well . . . the thing is, I finally threw Irene’s toothbrush
out yesterday. And today it isn’t in the bathroom, and I really feel
she is never coming back . . .’ I could hear his voice breaking with
emotion, and I remembered his bewildered face, back on the ward
the morning she died.

The lesson was coming home to me. Those bereavement conver-
sations are just the beginning, the start of a process that is going
to take a lifetime for people to live alongside in a new way. I
wondered how many others would have called, had I given them
a name and a number in writing. By now I was more aware of
the network of care that is available, and I asked Irene’s husband for permission to contact his GP. I told him I was honoured that he felt he could call me. I told him that I remembered Irene with such fondness, and that I could not begin to imagine his loss.

Towards the end of my first year after qualification, I found myself reflecting on the many deaths I had attended in that year: the youngest, a sixteen-year-old lad with an aggressive and rare bone-marrow cancer; the saddest, a young mum whose infertility treatments may have been responsible for her death from breast cancer just before her precious son’s fifth birthday; the most musical, an elderly lady who asked the ward sister and me to sing ‘Abide With Me’ for her, and who breathed her last just before we ran out of verses; the longest-distance, the homeless man who was reunited with his family and transported the length of England over two days in an ambulance, to die in a hospice near his parents’ home; and the one that got away – my first cardiac arrest call, a middle-aged man who was post-op and stopped breathing, but who responded to our ministrations and walked out of the hospital a well man a week later.

This is when I noticed the pattern of dealing with dying. I am fascinated by the conundrum of death: by the ineffable change from alive to no-longer-alive; by the dignity with which the seriously ill can approach their deaths; by the challenge to be honest yet kind in discussing illness and the possibility of never getting better; by the moments of common humanity at the bedsides of the dying, when I realise that it is a rare privilege to be present and to serve those who are approaching their unmaking. I was discovering that I was not afraid of death; rather, I was in awe of it, and of its impact on our lives. What would happen if we ever ‘found a cure’ for death? Immortality seems in many ways an uninviting option. It is the fact that every day counts us down that makes each one such a gift. There are only two days with fewer than twenty-four hours in each lifetime, sitting like bookends astride our lives: one is celebrated every year, yet it is the other that makes us see living as precious.
French Resistance

Sometimes, things that are right in front of our noses are not truly noticed until someone else calls them to our attention.

Sometimes, courage is about more than choosing a brave course of action. Rather than performing brave deeds, courage may involve living bravely, even as life ebbs. Or it may involve embarking on a conversation that feels very uncomfortable, and yet enables someone to feel accompanied in their darkness, like ‘a good deed in a naughty world’.

Here’s Sabine. She is nearly eighty. She has a distinguished billow of silver-white hair swept into a knotted silk scarf, and she wears a kaftan (the genuine article, from her travels in the Far East in the 1950s) instead of a dressing gown. She is in constant motion in her hospice bed, playing Patience, applying her \textit{maquillage}, moisturising her sparrowesque hands. She drinks her tea black and derides the ‘You call that coffee?’ offered by the beverages trolley. She has a French accent so dense it drapes her speech like an acoustic fog. She is the most mysterious, self-contained creature we have encountered in our newly built hospice.

Sabine has lived in England since 1946, when she married a young British officer her Resistance cell had hidden from Nazi troops for eighteen months. Peter, her British hero, had parachuted into France to support the Resistance. He was a communications specialist, and had helped them to build a radio from, by the sound of it, only eggboxes and a ball of string. I suppose he may also have brought some radio components in his rucksack, but I dare not ask. Forty years later, her accent sounds as though she has just stepped off the boat at Dover, a
new bride with high hopes. ‘Peter was so clever,’ she murmurs. ‘He could do any-sing.’

Peter was very brave. This is not in doubt: Sabine has his photograph and his medals on her bedside table. He died many years ago, after an illness that he bore with characteristic courage. ‘He was never afraid,’ she recalls. ‘He told me always to remember him. And I do, naturellement, I talk to him every day’ – and she indicates the photograph of her handsome husband, resplendent in dress uniform and frozen in monochrome at around forty years of age. ‘Our only sadness was that the Lord did not send us children,’ she reflects. ‘But instead we use our time for great travel and adventures. We were very ’appy.’

Her own medal for courage is pinned to her chest on a black and red ribbon. She tells the nurses that she has only taken to wearing it since she realised that she was dying. ‘It is to remind me that I too can be brave.’

I am a young trainee in the new specialty of palliative medicine. My trainer is the consultant in charge of our new hospice, and Sabine loves to talk to him. From his discussions with her, it emerges that he is bilingual because his father was a Frenchman, and also a Resistance fighter. He occasionally has conversations with Sabine in French. When this happens, she sparkles and moves her hands with animation; the symmetrical Gallic shrugs between them amuse us greatly. Sabine is flirting.

And yet, Sabine is keeping a secret. She, who wears her Resistance Medal and who withstood the terror of the war, is afraid. She knows that widespread bowel cancer has reached her liver and is killing her. She maintains her self-possession when she allows the nurses to manage her colostomy bag. She is graceful when they wheel her to the bathroom and assist her to shower or bathe. But she is afraid that, one day, she may discover that she has pain beyond her ability to endure, and that her courage will fail her. If that should happen, she believes (with a faith based on 1930s French Catholicism mixed with superstition and dread) she
will lose her dignity: she will die in agony. Worse: her loss of courage at the end will prevent her forever from rejoining her beloved husband in the heaven she so devoutly believes in. ‘I will not be worthy,’ she sighs. ‘I do not have the courage that I may require.’

Sabine confesses this deep-seated fear while a nurse is drying those silver tresses after a shower. The nurse and Sabine are looking at each other indirectly, via the mirror. In some way, that dissociation of eye contact, that joint labour at the task in hand, enabled this intimate conversation. The nurse was wise; she knew that reassurance would not help Sabine, and that listening, encouraging, allowing the full depth of her despair and fear to be expressed, was a vital gift at that moment. Once her hair was dressed, her silk scarf in place and Sabine indicated that the audience was over, the nurse asked permission to discuss those important concerns with our leader. Sabine, of course, agreed: in her eyes our leader was almost French. He would understand.

What happened next has lived with me, as if on a cinema reel, for the rest of my career. It formed my future practice; it is writing this book. It has enabled me to watch dying in a way that is informed and prepared; to be calm amidst other people’s storms of fear; and to be confident that the more we understand about the way dying proceeds, the better we will manage it. I didn’t see it coming, but it changed my life.

Our leader requested that the nurse to whom Sabine had confided her fear should accompany him, and added that I might find the conversation interesting. I wondered what he was going to say. I anticipated that he would explain about pain management options, to help Sabine be less worried about her pain getting out of control. I wondered why he wanted me to come along, as I felt I was already quite adept at pain management conversations. Ah, the confidence of the inexperienced . . .

Sabine was delighted to see him. He greeted her in French, and asked her permission to sit down. She sparkled and patted the
bed, indicating where he should sit. The nurse sat in the bedside chair; I grabbed a low stool and squatted down on it, in a position from which I could see Sabine’s face. There were French pleasantries, and then our leader came to the point. ‘Your nurse told me that you have some worries. I am so glad you told her. Would you like to discuss this with me?’

Sabine agreed. Our leader asked whether she would prefer the conversation to be in English or French. ‘En Anglais. Pour les autres,’ she replied, indicating us lesser beings with benevolence. And so he began.

‘You have been worrying about what dying will be like, and whether it will be painful for you?’

‘Yes,’ she replied. I was startled by his direct approach, but Sabine appeared unsurprised.

‘And you have been worrying that your courage may fail?’

Sabine reached for his hand and grasped it. She swallowed, and croaked, ‘Oui.’

‘I wonder whether it would help you if I describe what dying will be like,’ he said, looking straight into her eyes. ‘And I wonder whether you have ever seen anyone die from the illness that you have?’

If he describes what? I heard myself shriek in my head.

Sabine, focused and thoughtful, reminisced that during the war a young woman had died of gunshot wounds in her family’s farmhouse. They had given her drugs that relieved her pain. Soon after, she stopped breathing. Years later, Sabine’s beloved husband had died after a heart attack. He collapsed at home and survived to reach hospital. He died the following day, fully aware that death was approaching.

‘The priest came. Peter said all the prayers with him. He never looked afraid. He told me goodbye was the wrong word, that this was au revoir. Until we see each other again . . .’ Her eyes were brimming, and she blinked her tears onto her cheeks, ignoring them as they ran into her wrinkles.
‘So let’s talk about your illness,’ said our leader. ‘First of all, let’s talk about pain. Has this been a very painful illness so far?’

She shakes her head. He takes up her medication chart, and points out to her that she is taking no regular painkillers, only occasional doses of a drug for colicky pain in her abdomen.

‘If it hasn’t been painful so far, I don’t expect it to suddenly change character and become painful in the future. But if it does, you can be sure we will help you to keep any pain bearable. Can you trust us to do that?’

‘Yes. I trust you.’

He continues, ‘It’s a funny thing that, in many different illnesses that cause people to become weaker, their experience towards the end of life is very similar. I have seen this many times. Shall I tell you what we see? If you want me to stop at any point, you just tell me and I will stop.’

She nods, holding his gaze.

‘Well, the first thing we notice is that people are more tired. Their illness saps their energy. I think you are already noticing that?’

Another nod. She takes his hand again.

‘As time goes by, people become more tired, more weary. They need to sleep more, to boost their energy levels. Have you noticed that if you have a sleep during the day, you feel less weary for a while when you wake up?’

Her posture is changing. She is sitting up straighter. Her eyes are locked on his face. She nods.

‘Well, that tells us that you are following the usual pattern. What we expect to happen from now on is that you will just be progressively more tired, and you will need longer sleeps, and spend less time awake.’

_job done_, I think. _She can expect to be sleepy. Let’s go . . . _But our leader continues talking.

‘As time goes by,’ he says, ‘we find that people begin to spend more time sleeping, and some of that time they are even more
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deeper asleep, they slip into a coma. I mean that they are uncon-
scious. Do you understand? Shall I say it in French?’

‘Non, I understand. Unconscious, coma, oui.’ She shakes his
hand in hers to affirm her understanding.

‘So if people are too deeply unconscious to take their medica-
tions for part of the day, we will find a different way to give those
drugs, to make sure they remain in comfort. Consoler toujours.
Yes?’

_He must be about to stop now_, I think. I am surprised that he
has told her so much. But he continues, his gaze locked onto hers.

‘We see people spending more time asleep, and less time awake.
Sometimes when they appear to be only asleep, they are actually
unconscious, yet when they wake up they tell us they had a good
sleep. It seems we don’t notice that we become unconscious. And
so, at the very end of life, a person is simply unconscious all of
the time. And then their breathing starts to change. Sometimes
deep and slow, sometimes shallow and faster, and then, very gently,
the breathing slows down, and very gently stops. No sudden rush
of pain at the end. No feeling of fading away. No panic. Just very,
very peaceful . . .’

She is leaning towards him. She picks up his hand and draws
it to her lips, and very gently kisses it with great reverence.

‘The important thing to notice is that it’s not the same as falling
asleep,’ he says. ‘In fact, if you are well enough to feel you need
a nap, then you are well enough to wake up again afterwards.
Becoming unconscious doesn’t feel like falling asleep. You won’t
even notice it happening.’

He stops and looks at her. She looks at him. I stare at both of
them. I think my mouth might be open, and I may even be
leaking from my eyes. There is a long silence. Her shoulders relax
and she settles against her pillows. She closes her eyes and gives
a deep, long sigh, then raises his hand, held in both of hers, shakes
it like shaking dice, and gazes at him as she says, simply, ‘Thank
you.’ She closes her eyes. We are, it seems, dismissed.
The nurse, our leader and I walk to the office. Our leader says to me, ‘That is probably the most helpful gift we can ever give to our patients. Few have seen a death. Most imagine dying to be agonising and undignified. We can help them to know that we do not see that, and that they need not fear that their families will see something terrible. I never get used to having that conversation, even though it always ends by a patient knowing more yet being less afraid.’

Then, kindly overlooking my crumpled tissue, he suggests, ‘Shall we have a cup of tea?’

I escape to brew the tea and wipe my tears. I begin to reflect on what I have just seen and heard. I know that he has just described, with enormous skill, exactly what we see as people die, yet I had never considered the pattern before. I am amazed that it is possible to share this amount of information with a patient. I review all my ill-conceived beliefs about what people can bear: beliefs that had just scrolled through my startled and increasingly incredulous consciousness throughout that conversation; beliefs that would have prevented me from having the courage to tell Sabine the whole truth. I feel suddenly excited. Is it really within my gift to offer that peace of mind to people at the ends of their lives?

This book is about my learning to observe the details of that very pattern our leader explained to Sabine all those years ago. In the next thirty years of clinical practice, I found it to be true and accurate. I have used it, now adapted to my own words and phrases, to comfort many hundreds, perhaps even thousands, of patients in the same way that it brought such comfort to Sabine. And now I am writing it down, telling the stories that illustrate that journey of shrinking horizons and final moments, in the hope that the knowledge that was common to all when death took place at home can again be a guide and comfort to people contemplating death. Because in the end, this story is about all of us.
Tiny Dancer

The pattern of decline towards death varies in its trajectory, yet for an individual it follows a relatively even flow, and energy declines initially only year to year, later month to month, and eventually week by week. Towards the very end of life energy levels are less day by day, and this is usually a signal that time is very short. Time to gather. Time to say any important things not yet said.

But sometimes there is an unexpected last rise before the final fall, a kind of swansong. Often this is unexplained, but occasionally there is a clear cause, and sometimes the energy rush is a mixed blessing.

Holly has been dead for thirty years. Yet this morning she is steadily dragging herself out of the recesses of my memory and onto my page. She woke me early; or perhaps it was waking on this misty autumn morning that brought her last day to mind. She twisted and twirled her way into the focus of my consciousness: initially just images like an old silent-movie reel showing disjointed snatches of her pale smile, her pinched nose, her fluttering hand movements. And then her laugh arrived, with the crows outside my window: her barking, rasping laugh, honed by the bitter winds along the industry-riven river, by teenage smoking and premature lung disease. Finally, she drew me from my warm bed and sat me down to tell her story, while mist was still bathing the gardens beneath an autumn dawn.

Thirty years ago, arriving at my first hospice job with several years’ experience of a variety of medical specialties, some training in cancer medicine and a freshly minted postgraduate qualification, I probably saw myself as quite a catch. I know that I was buoyed
up by the discovery that palliative care fitted all my hopes for a medical career: a mixture of teamwork with clinical detective work to find the origins of patients’ symptoms in order to offer the best possible palliation; of attention to the psychological needs and resilience of patients and their families; honesty and truth in the face of advancing disease; and recognition that each patient is a unique, whole person who is the key member of the team looking after them. Working with, rather than doing to: a complete paradigm shift. I had found my tribe.

The leader of this new hospice had been on call for the service without a break until my arrival in early August. Despite this he exuded enthusiasm and warmth, and was gently patient with my questions, my lack of palliative care experience, my youthful self-assurance. It was a wonder to see patients I already knew from the cancer centre, looking so much better than when they had recently been in my care there, now with pain well controlled but brains in full working order. I may have thought highly of myself, but I recognised that these people were far better served by the hospice than they had been by the mainstream cancer services. Perhaps my previous experiences were only a foundation for new knowledge; perhaps I was here not to perform, but to learn. Humility comes slowly to the young.

After my first month of daily rounds to review patients, adjusting their medication to optimise symptom control but minimise side-effects, watching the leader discuss mood and anxieties as well as sleep and bowel habit, attending team meetings that reviewed each patient’s physical, emotional, social and spiritual wellbeing, the leader decided that I was ready to do my own first weekend on call. He would be back-up, and would come in to the hospice each morning to answer any queries and review any particularly tricky challenges, but I would take the calls from the hospice nurses, from GPs and hospital wards, and try to address the problems that arose. I was thrilled.

Holly’s GP rang early on the Saturday afternoon. Holly was
known to the city’s community palliative care nurses, whose office was in the hospice, so he hoped that I might know about her. She was in her late thirties, the mother of two teenagers, and she had advanced cancer of the cervix, now filling her pelvis and pressing on her bladder, bowels and nerves. The specialist nurses had helped the GP to manage her pain, and Holly was now able to get out of bed and sit on the outdoor landing of her flat to smoke and chat with her neighbours. When she developed paralyzing nausea in the previous week, her symptoms were improved greatly by using the right drug to calm the sickness caused as her kidneys failed, as the thin ureter tubes that convey the urine from kidneys to bladder were strangled by her mass of cancer.

Today she had a new problem: no one in her flat had slept all night, because Holly wanted to walk around and chat to everyone. Having hardly walked more than a few steps for weeks, overnight she had suddenly become animated and active, unable to settle to sleep, and she had woken her children and her own mother by playing loud music and attempting to dance to it. The neighbours had been banging on the walls. At first light her mother had called the GP. He found Holly slightly euphoric, flushed and tired, yet still dancing around the flat, hanging onto the furniture.

‘She doesn’t seem to be in pain,’ the GP explained to me, ‘and although she’s over-animated, all her thought content is normal. I don’t think this is psychiatric, but I have no idea what is going on. The family is exhausted. Do you have a bed?’

All our beds were full, but I was intrigued. The GP accepted my offer to visit Holly at home, so I retrieved her notes from the community team office and set off through the receding autumn mist to the area of the city where long terraces of houses run down to the coalyards, ironworks and shipbuilders that line the river’s banks. In places the terraces were interrupted by brutal low-rise blocks of dark brick flats crowned with barbed-wire coils and pierced by darkened doorways hung with cold neon lights in tamper-proof covers. These palaces bore unlikely names: Magnolia
House, Bermuda Court, and my destination, Nightingale Gardens.

I parked my car at the kerbside and sat for a moment, surveying the area. Beside me rose the dark front of Nightingale Gardens. On the ground floor, a bare stone pavement ran from the kerb to the tenement block: not a tree or a blade of grass to garnish these ‘gardens’, which certainly never saw or heard a nightingale. Across the road, a terrace of council-owned houses grinned a toothy smile of white doors and window frames, all identical and recently painted. Some of the tiny front gardens displayed a few remnants of late-summer colour; rusting bed-frames or mangled bicycles adorned others. Several children were playing in the street, a game of catch with a tennis ball played while dodging a group of older boys who were aiming their bikes at the players. Yelps of excitement from the kids, and from a group of enthusiastic dogs in assorted sizes who were trying to join in.

I collected my bag and approached Nightingale Gardens. I needed to find number 55. An archway marked ‘Odds’ led to a dank, chilly concrete tunnel. My breath was visible in the gloomily lit staircase. On the landing, all the door numbers were in the thirties. Up another couple of flights I found the fifties, and halfway along the balcony corridor that overlooked the misty river, and was itself overlooked by cranes rising above the mist like origami giants, number 55. I knocked and waited. Through the window I could hear Marc Bolan telling me that I won’t fool the children of the revolution.

The door was opened by a large woman in her fifties wearing a miner’s donkey jacket. Behind her was a staircase leading to another floor, and beside her the living-room door swung open to reveal a diminutive, pale woman leaning on a table and moving her feet to the T. Rex beat.

‘Shut the door, will you?’ she trilled across to us. ‘It’s cold out there!’

‘Are you the Macmillan nurse?’ the older woman asked me. I explained that I worked with the Macmillan nurses, but that I
was the doctor on call. She beckoned me inside with an arc of her chin, while simultaneously indicating with animated eyebrows that the younger woman was causing her some concern. Then she straightened up, shouted, ‘I’m off to get more ciggies, Holly!’ and left the flat.

Holly looked at me and explained, ‘We smoked ’em all last night. Gaspin’ now!’ Then she invited me in, saying, ‘Wanna cuppa? There was something childlike about Holly, with her tiny frame and her dark hair swept up into a high ponytail. Her skin shone with an alabaster clarity, stretched taut over swollen legs and a pinched face. She seemed to emanate a faintly yellow light, like a fading lightbulb. She was in constant motion, as though driven by an unseen force. Her feet danced while her hands leaned on the table; then she sat down abruptly in one of the upright chairs and began to rub her hands along her arms, along her thighs, along her calves, shuffling her bottom and nodding her head in time to the music. Alice Cooper next: Holly drummed her fingers, then played air guitar, tossing her ponytail to celebrate school being blown to pieces. Throughout, she sang along in a thin contralto embellished by occasional hiccups.

The music stopped with a click that drew my attention to the cassette player on the window ledge. These must be mix tapes she had recorded in her teens. Without the music to give shape to her movements, the choreography broke down and she simply rocked on her chair, rubbing her limbs with her thin hands and tossing her hair like an angry genie. She looked up at me, as though noticing me for the first time, and asked, ‘Got a ciggie?’ When I shook my head she laughed and said, ‘Oops, no, you’re the doctor, aren’t you? You won’t approove of ciggies!’ in a sing-song voice tinged with sarcasm.

‘So, what’s the deal, doc?’ she said next. ‘I feel GREAT today! I wanna sing and dance and get outta this bloody flat!’ Casting her gaze around the room, she sighed heavily. ‘It’s like a pigsty in here. Needs a good cleaning. Amy! AMY!!!’ she moved her gaze...
to the ceiling, brown with cigarette smoke, as though to look at Amy, who was presumably upstairs.

A teenage girl in pyjamas appeared at the living-room door. ‘Mam?’ she asked. ‘Mam, what’s all the noise for?’ Then, catching sight of me, she whispered, ‘Who’s this? Where’s Nan?’

‘Nan’s gone for ciggies. This is the doctor. This place needs cleaning. Get the Hoover over it, will you?’

Amy rolled her teenage eyes, said, ‘Yeah, in a mo,’ and disappeared back up the stairs just as her grandmother reappeared through the front door. Lighting two cigarettes at once, Nan held one out to Holly then stumped through to the kitchen, saying, ‘I’ll get the kettle on. Tea, doctor? Biscuit?’

Seated on the sofa, I watched Holly continue her interminable movements. I recognised this pattern. I just needed a bit more information.

‘Holly, are you feeling restless?’ I asked.

She regarded me solemnly, exhaled her smoke, and then said, ‘Look, are you gonna ask a load of questions? Cos, not to be rude or anything, I’ve already done that with the first doctor. So it’s like this – yes, I can’t lie still, can’t get to sleep, can’t get the tunes out of my head. OK? Got the idea?’

Nan appeared with a tray of mugs filled with tea, a plate of biscuits and thickly sliced fruitcake. I have come to know such hospitality is a custom along the riverside.

‘Holly’s not usually so grumpy,’ said Nan. ‘I think she’s tired. None of us got any sleep last night.’

‘When would you say the restlessness started?’ I asked. The women looked at each other to consider.

‘It’s really since you stopped being so sick,’ said Nan.

Holly agreed. ‘That puking was doing my head in. I couldn’t keep nothing down. But now I don’t feel sick I feel really kind of energetic.’

It seemed bizarre that this waif, glowing with the lemon tinge of kidney failure, her life ebbing like a fading echo, could describe
herself as energetic. I asked her to hold her arms out in front of her and to close her eyes. Her arms twisted and danced before her, and she bounced her legs on the balls of her feet. When I took her hand and slowly flexed her arm at the elbow, I could feel the muscles tensing and releasing as though the joint was moved by cogwheels. Her gaze was unblinking in her doll-like face.

‘When did the sickness stop?’ I asked, although I already knew the answer: the day the nurses gave her a syringe-driver with anti-sickness medication for her kidney failure. The same day the restlessness began. Because the drugs that were stopping her nausea were also giving her this sense of driven restlessness: akathisia, or ‘inability to sit’. She was perceiving the sense of drivenness as ‘kind of energetic’, and it was this that had suddenly caused her to get out of bed and want to move around.

Here’s a dilemma. This young mother is close to the end of her life. Her kidney failure is so severe that many people would be unconscious at this stage, but the drug that has stopped her nausea and vomiting is also causing restlessness and a desire to get out and about. Her legs don’t have the strength to hold her up, and she is in a fifth-floor flat. I don’t want to stop the anti-sickness drug: her nausea would return very quickly. Yet she will exhaust her meagre energy reserves if she keeps pacing and dancing and cannot get some sleep.

There is a drug, an injection, that will reverse this restlessness and ceaseless drive to movement, without losing control of her nausea. We keep it in the hospice, and I can go back to get it. But in the meantime Holly is stir crazy, like a caged animal. How can we assuage her desire to be on the move?

‘Do you have a wheelchair?’ I ask. No, Holly was well enough to get up and down the stairs until two weeks ago. Then the pain kept her indoors. Then when the pain was better she was exhausted by her nausea.

‘Sally downstairs has got a wheelchair,’ chimes a voice from the
doorway. Amy has been listening in. She is dressed now, in black
tights and a neon-yellow T-shirt, stripy yellow-and-black
leg-warmer and an army beret. ‘We can borrow it. Where are
you taking her?’

‘I’m not taking her anywhere. I’m going back to the hospice
to get another medicine to help with this restlessness. But while
she’s so restless and desperate to get out, I wondered if you’d like
to take her out and around the shopping arcade down the road.
Just for a change of scenery.’

Nan looks startled. Amy shouts, ‘I’m going to ask Sally!’ and
leaves. Holly looks grateful at me, and says, ‘Well, I never
expected that! Thanks, doc. They keep mollycoddling me, and
getting out will be brilliant . . .’

After a couple of minutes, Amy taps on the window. She is on
the balcony corridor with a wheelchair and two huge men in black
leather jackets.

‘Tony and Barry will carry her down, and we’ll go round the
shops!’ she exclaims gleefully.

‘Wait – there’s no lift?’ I ask, but there’s no point – the seed
is sown, the wheelchair borrowed, and Nan is already on the phone
to Holly’s sister to arrange to meet her at the shops. And I’m not
about to contradict Tony and Barry, who are Sally Downstairs’s
sons. They are on a mission. And they are massive – only their
enthusiastic smiles are wider than their huge shoulders.

I head back to the hospice, and phone the leader. I describe
the scenario – the petite patient so frail, with advanced kidney
failure; weaker day by day until this sudden flush of ‘false energy’
caused by the anti-sickness drug; my diagnosis of akathisia and
my plan to treat it. After asking a few questions he seems satisfied
by my examination and conclusions. He asks whether I’d like him
to come with me to give the antidote and make the next plans,
and although I want to be able to cope on my own, a mental
picture of the smoke-stained room, the tiny dancing patient and
the gigantic, leather-clad neighbours makes me glad to accept the
offer. He drives to the hospice while the nurses help me to gather the drugs and equipment I will need.

The second trip to the riverside feels different. The mist has cleared away, and the afternoon is lengthening into early evening. Nightingale Gardens is in sunshine as we park outside, and there seems to be a party going on outside one of the ground-floor flats. Looking closer, I recognise Barry and Tony, the neon glow of Amy’s T-shirt, and Holly in the wheelchair wearing a fluffy bright pink dressing gown and a knitted hat. Nan has her back to us in the NCB donkey jacket, and an older woman whom I take to be Sally Downstairs is sitting in an armchair on the pavement. Cans of beer are being drunk; there is laughter; people come and go from the flat. When the leader and I approach, we are waved over and greeted like family.

‘Here’s the lass what sent us to the shops!’ shouts Holly, and shows me her newly manicured fingernails, a treat from her sister.

‘Bugger of a job keeping her bloody hands still!’ laughs Nan.

They have had a wonderful trip out: Holly has loved meeting and greeting friends and neighbours she has not seen for weeks, and all have admired her grit in getting out. She has bought a massive carton of cigarettes, a crate of beer and lots of crisps, and these are now being shared at the impromptu pavement party.

I explain that we need to check her syringe-driver and then give her a small dose of the antidote, to be sure it doesn’t disagree with her before giving a larger dose to last overnight. We need to go up to her flat. Barry and Tony lift the wheelchair as easily as though it is a shopping bag, and carry Holly upstairs to the fifth-floor landing. Nan lets us in, and goes to put the kettle on; Holly’s sister and Amy follow. I introduce the leader, and he examines Holly’s arm movements to satisfy himself about the diagnosis. Tea mugs are produced for the workers, everyone else continues to drink beer. Holly knows she must stick to small volumes of fluids, so she drinks her beer from a dainty china teacup.

I wash my hands in the kitchen to prepare to give the antidote
injection. Someone has tidied the flat since earlier today, and all the surfaces are gleaming. Then I insert a tiny needle under the loose skin of Holly’s forearm, and give the first small dose. Conversation continues around the room; Barry and Tony depart with their mum’s wheelchair; Nan and Amy settle into armchairs while Holly’s sister, Poppy, sits beside me on the sofa, from where we watch Holly threading her restless way around the room, the leader beside her in case she falls. She is still describing the fun of her afternoon.

Eventually she takes a seat on the sofa beside her sister. She fidgets, but remains sitting. She gradually stops talking, and listens to the chatter around her. I can see the leader watching her intently.

‘Are you sleepy, Holly?’ he asks gently. She nods. Poppy and I make space for her to lie on the sofa, but she twists and turns. She is too frail to get upstairs to bed, so Amy, always the practical one, brings down the rolled-up mattress she uses when friends sleep over. Nan and Poppy make up a bed, and Holly lies down. Her eyes are closing.

‘How are you feeling now, Holly?’ asks the leader.

No reply. Holly snores gently, and Amy laughs, but Nan leans forward and says, ‘Holly? Holly?!’ She is afraid.

The leader sits on the floor beside the mattress and takes Holly’s pulse. She is lying completely still now, breathing gently and occasionally snoring. The leader looks up at us all, and says, ‘Can you see how she is changing?’ And she is. She is becoming smaller. Her energy is gone, and the weariness that has been creeping up on her for the last couple of weeks is now overwhelming her.

Nan reaches for Holly’s hand, and says, ‘Amy, get your sister.’

Amy looks perplexed. Her sister is at a friend’s house for the weekend. She won’t want to be disturbed. Amy has not understood what is happening here.

‘Amy,’ I say, ‘I think your mum is so very tired that she may not wake up again.’
Amy’s mouth drops open. Her eyes dance between her mother, the leader taking her pulse, her Nan, and my face. ‘It wasn’t what she did today that tired her out,’ I say. ‘What you helped her to do today was fantastic. But she was already exhausted before her busy night last night, wasn’t she?’

Amy’s wide-eyed stare makes her look very like her mum as she nods in agreement. ‘And that exhaustion is caused by her illness, not by how busy she’s been today,’ I explain. ‘But if your sister wants to be here for her mum, then now is the time to come.’

Amy swallows and gets to her feet. She picks up a notebook and begins to look for a phone number.

‘Give it to me,’ says Nan. ‘I’ll phone.’

Amy silently points out the number, and Nan moves across to the window ledge, where the phone sits beside the cassette player. She dials. We hear the buzzing drone of the ring; we hear a voice answer the phone; then Nan gives her message as Holly opens her eyes and says, ‘Why am I lying down here?’

‘Too drunk to get to bed again,’ says Poppy, trying to smile but with tears running down her nose.

‘Don’t cry, Poppy,’ says Holly. ‘I’m OK. I’m just so tired. But haven’t we had a lovely day?’ She wriggles herself into the eiderdown and says, ‘Where’s my girls?’

‘I’m here, Mam,’ says Amy, ‘and Tanya’s on her way.’

‘Come and snuggle down with me,’ smiles Holly. Amy looks up at us. The leader moves back to leave space and nods at her. Amy lies down alongside her mum, and hugs her.

The front door bangs open, and a girl shoots through it.


Nan walks over and hugs her, then draws her across the room, saying, ‘She’s here, Tanya, she’s here. She’s so tired we’ve made her a camp bed. These are the doctors. Mam’s OK, but she’s very tired, and she wants a cuddle.’

Tanya kneels on the floor by her mother’s head, and Amy
reaches up to take her hand, drawing it down to touch their mother’s cheek.

‘Here’s Tanny, Mam,’ she says. Holly puts her hand over the girls’ hands, and sighs.

Over the next half-hour, the light fades outside and the room becomes dark. No one moves. We sit in the semi-dark, an orange glow lighting the room from the streetlamps outside. Every now and then, the leader gives a quiet commentary.

‘Look how peacefully she’s sleeping.’

‘Can you hear how her breathing has changed? It’s not so deep now, is it?’

‘Have you noticed that she stops breathing from time to time? That tells me that she is unconscious, very deeply relaxed . . . This is what the very end of life is like. Just very quiet and peaceful. I don’t expect she will wake up again now. She is very comfortable and peaceful.’

And then Holly’s breathing becomes too gentle to float a feather. And then it stops.

The family are so mesmerised by the peace in the room that no one seems to notice.

Then Nan whispers, ‘Is she still breathing?’

The girls sit up and look at Holly’s face.

‘I think she stopped breathing a few minutes ago,’ says Poppy, ‘but I was hoping it wasn’t true.’

‘Did you feel her move at all?’ the leader asks the girls, and they shake their heads as their tears begin.

‘Well done, you lovely family. You gave her the most wonderful day and the most peaceful evening. She has died’ – the girls gasp and sob, and he waits for quiet before he continues. ‘She has died so peacefully because she felt at peace with you here. You have done her proud.’

The girls move away from the mattress. The leader encourages them to touch their mum, to talk to her, to maintain the calm in the room. I am fascinated to see them lie down beside her
again, weeping gently and whispering their love to her. It is almost unbearably sad, but this is not my family, and I feel my tears would be misplaced. I struggle to focus on the guidance being provided by the leader.

To Nan he says, ‘We need to telephone an on-call GP to certify her death, and then you can call a funeral director. But there’s no hurry. Give yourselves time. I’ll call the doctor now. She can stay here all night if that helps you and the girls.’

Nan knows what to do. She has buried two husbands and a son.

She offers us more tea, but the leader has informed the on-call GP of the death, and says we must be going. We let ourselves out of the smoky flat and onto the lamp-lit balcony, walk in silence down the gloomy stairs and out onto the pavement.

‘You OK?’ asks the leader.

Of course I’m not. I think I just killed someone. ‘Yes, fine,’ I reply. ‘You know the injection didn’t kill her, don’t you?’ ‘Mmmm . . .’ I sniff.

‘She was so exhausted that she would probably have died last night if she hadn’t got that false energy from the akathisia. If you hadn’t controlled it she would simply have danced herself to death, agitated and upset. Instead, you managed her restlessness. And that gave her the peace to lie down and cuddle her girls, after her magnificent last day.’

We walk back to the car as a new mist rolls up from the river, and evening turns to night. My first day on call for the hospice. Not a day I will ever forget.

I learned a very important lesson watching the leader talk Holly’s family through the sequence of changes as her body relaxed, and dying displaced the restless energy she had been given by her anti-sickness medication. He was naming what they could observe; he was leading them through the process; he was reassuring them that all was expected, and usual, and safe. This is the task of the
experienced midwife, talking the participants through the process, delivering them safely to the expected place. It is a gift that allowed the daughters to remain present and involved, and enabled them to look back and know that their calm presence was their final gift to their beloved Mam. It was a rare opportunity to watch a master at work, and to learn from that gentle, observant example.
Wrecking Ball

Watching people approaching an anticipated death offers families and friends a comfort as they all arrange their priorities and live each day as it arrives. Sometimes, though, death arrives unannounced and unanticipated. In some circumstances this is seen by the survivors as a blessing, although adjustment to sudden death is often harder than a bereavement when there has been a chance to say goodbye.

Perhaps the cruellest circumstance, though, is when a sick person has been getting better and seems to be ‘out of danger’, only to be snatched by death in a completely unforeseen manner. When this happens, a shocking adjustment has to be made by loved ones – and by professionals too.

Alexander and his brothers, Roland and Arthur, were named after heroes. Their mother had hoped that this would inspire them, but Alex shortened his name at school to avoid the taunting his older brothers endured daily. Alex was a quiet soul. He liked art and rock-climbing; he preferred his own company; he loved colour and texture, finding deep pleasure in creating huge canvas artworks that begged to be touched and stroked; he relished the challenge of solo climbs on solitary pinnacles. Eschewing his family’s encouragement to train as an accountant, he took up an apprenticeship as a painter. He neither captured continents nor courted fair damsels: he could feel his mother’s tense anxiety for his future.

But there were heroic aspects to Alex. He was tenacious and determined about his art, and he tolerated physical discomfort without complaint. He endured pain in his back for months, thinking he had pulled a muscle while moving ladders. Only when
he was unable to help his boss paint a ceiling because of his pain
did he consult his GP. He was then passed between health profes-
sionals for six months before someone X-rayed his chest. The X-ray
showed a snowstorm of golf-ball-sized cancer masses throughout
Alex’s lungs. And then the penny dropped.

‘Alex, before all of this back pain and tiredness started, did you
ever have any pain in your scrotum, or feel a lump in one of your
testes?’ asked the doctor who had ordered the X-ray. Alex had not
anticipated such an odd question, but he could clearly remember
that several months previously he had had a ‘hot, sore ball’ for a
few weeks. He had thought it was a football injury, and was too
embarrassed to seek medical advice. He just waited for the swelling
to disappear – which it did, although his testis continued to feel
hard and misshapen, and he remained too shy to mention it. Then
his back pain had distracted attention from it. All that time, a
cancer that had begun in his testis had been slowly spreading up
the chain of lymph nodes that lies deep in the abdomen and close
to the spine, causing the lymph nodes to swell and hurt, and
eventually allowing the cancer cells to escape into his bloodstream
and invade his lungs.

Alex arrived as a new boy to the Lonely Ballroom, the six-bedded
bay where our crew of young men with the same cancer, testicular
teratoma, assembled for their regular five-day infusions of chemo-
therapy. He was anxious, of course. Like all the visitors to the
Lonely Ballroom, Alex had the cancerous testis removed and a
range of scans and blood tests to detect how far his cancer had
spread. It had found its way into not only his lungs, but also his
liver and kidneys, and tumours were scattered around the abdom-
inal cavity like pearls from a broken string. Getting his treatment
started was urgent. And now here’s the good news: testicular
teratoma can be completely cured, and even when it is widely
spread, the cure rates are very high. In our hospital in the 1980s,
that treatment took place in the room dubbed the Lonely Ballroom
by its brotherhood of occupants.
Waiting for his drip to be set up on his first day, Alex paced restlessly around the ward and up and down the high, glass-walled staircase, from which there is a great view of the locality: the huge, rolling green park near the city centre, the roofs and chimney pots on the terraces of local houses, and the Victorian cemetery at the back of the hospital. The cancer centre was built with its windows facing away from the cemetery (*Don’t mention the D-word*), but all our patients could see it as they parked their cars or disembarked from their ambulances and came up the staircase to the wards.

Teratoma is a cancer of young men. When Alex was shown to his bay, he found five companions already comparing notes on how their last three weeks had gone, debating whether the local football team would ever get off the bottom of the league table, and whether bald can ever be sexy – of specific importance to young men whose chemotherapy had rendered their heads as shiny as polished eggs. They all had drips in one arm and, dressed in shorts and T-shirts, were lounging on their beds or walking around with their drip stands, sharing magazines and chewing gum. They were waiting for their first dose of anti-sickness medication, after which the saline bags on their drip lines would be replaced by bags of chemotherapy. They welcomed Alex like a brother.

‘Which side, mate?’
‘Spread far?’
‘Tough luck, mate, but they’ll see you right in here.’
‘You gonna shave your head or just wait for your hair to drop out?’

I was the most junior doctor in the cancer centre, and I was attached to this thirty-two-bedded ward. Drawing the curtains around Alex’s bed for privacy, I explained the way the chemotherapy would be given. The other five young men in the room gathered in the far corner and continued to discuss last night’s TV and the football World Cup in Mexico, in voices loud enough to demonstrate that they were not eavesdropping: each of them had, in his turn, once been here for the first time, scared and embarrassed...
and embarrassed to be scared; each had learned the dark humour of the cancer ward and of the Lonely Ballroom. It wasn’t just the remaining testis that was lonely.

All the Lonely Ballroomers were participating in clinical trials. Data were (and still are) gathered from centres all over Europe, and it is this constant, trans-European collaborative effort to find the highest possible cure rate that has made it possible to expect cure in more than 95 per cent of teratoma patients; even people with cancer as advanced as Alex’s have a cure rate of over 80 per cent. Their chemotherapy is highly toxic, not only to their cancer cells, but also to their bone marrow, kidneys and other organs.

During this arduous treatment, the hardest toxicity to bear is nausea. These boys are really, really sick: they vomit and retch and feel horribly nauseated for the full five days. Far better drugs are now available to manage treatment-induced sickness, but back then we had a cunning plan to reduce their experience of nausea: for the full five days they were given a mind-bending combination of drugs that included high doses of steroids, a sedative, and a drug related to cannabis. This made them sleepy, happy and very high. Random laughter and ribald jokes became the norm once the drugs began to disinhibit them. The Lonely Ballroom may have been a cancer ward, but it was always a cheerful one, and as the drugs wore off on day five, the guys could remember remarkably little about the experience apart from their mellow fellowship.

I explained all this to Alex, who had been told it all in clinic, but as is often the case with shocking news, he had retained only a little: cancer, everywhere, chemotherapy, blood tests, sperm count, bald, sick, off work. Helpful details like curable, optimistic, getting back to work, had simply gone over his head. He was terrified, and ashamed of being terrified; like all mountain climbers, he could face the fear of a fall and sudden death, but the idea of watching as death approached, helpless as the sacrificial virgin tied to the stake to await the dragon, was paralysing. He should be a hero like his namesake, not a helpless victim. He felt his fear and
labelled himself a coward. His shame outweighed even his fear.

Laughter from beside the windows: ‘Butch’ Wilkins, the England midfielder, was being interviewed on TV and had just been asked whether coping with the harsh tackles sprung on him by other teams’ defenders took balls. Cue belly-shaking laughter from the men with surgically adjusted tackle and single balls. Vicious humour was their weapon of choice in public. Behind the curtain, Alex regarded me with sorrowful eyes, slid down the bed while raising the sheet towards his chin, and whispered, ‘I can never be as brave as them . . .’ as a tear rolled slowly down his cheek.

‘You only need to get through this a day at a time,’ I began, but he started to rock backwards and forwards, gulping and trying desperately to remain silent as he was overtaken by sobbing. The window boys diplomatically turned the TV up. They knew, so much better than me, how the fear of the fear is the worst aspect of all.

*I feel so helpless and inept. Is crying in front of me even more undermining for him? If I leave now, will that look like abandonment?*

I could feel my cheeks burning, and my own eyes brimming with an overwhelming sense of helplessness before the immensity of Alex’s struggle.

*I mustn’t cry, mustn’t cry, mustn’t cry . . .*

‘I just can’t imagine how hard this is for all of you in here,’ I said. ‘All I know is that everyone looks like you on their first day. They all did – and look at them now.’

‘I’m such a coward,’ he whispered as he continued to rock, his sobs abating.

Lost for words of comfort or of hope, I reach for my tray of kit to set up Alex’s drip, and he holds out both arms as if to be handcuffed.

‘Are you right- or left-handed?’ I ask, and like so many artists he tells me he is left-handed. While I prep the skin, tighten the tourniquet and look for a suitable vein, I ask about his art, and he tells me how much he loves the creative process: imagining the
work, almost feeling it as a reality; building each canvas, layer by layer and colour by colour; how he dreams in textures and surfaces as well as pictures and colours, endlessly fascinated by the combinations of surface and space, colour and blankness that he sees in nature when he is walking and climbing. He is completely transported as he speaks, and in minutes his drip is attached and his face is calm. I ask permission to pull back the curtains, and we see his five room-mates playing cards beside the TV, a circle of shiny heads and drip stands like a peculiar toadstool ring sitting in a copse of metallic trees.

‘Want to join in, mate?’ one of them asks. Alex nods, and grabs his drip stand. I escape to ponder whether bravery is about being fearless or about tolerating fear. Why do the ideas for helpful responses arise only as I walk away from the bed?

By late afternoon, all the lads are high as clouds and vomiting for England. They lie on their beds and attempt to aim their laid-back heads towards the washing-up bowls that are provided for them: they are too sleepy and slow to catch sudden vomits in the small plastic kidney bowls used for the rest of the ward. They laugh at each other and cheer each other on, and by the time I head for home they are all singing along tunelessly to that year’s World Cup song – which may not, in fact, have had a tune anyway.

Three weeks pass, and it’s another Monday in the Lonely Ballroom. Six lots of blood tests to collect; six drips to set up; six sets of mind-altering drugs to prescribe; six reviews of the last three weeks. Alex is no longer a new boy; he knows the drill, and his shiny head now matches his room-mates’. There is shared outrage at Maradona’s ‘hand of God’ goal against England. Alex’s chest X-ray shows that his many cancer deposits are shrinking very quickly. I take the big, grey transparencies to show him, and he is intrigued by the images, by the contrast of dark and light, the puffball shadows looming large and white against the dark lung tissue, and the huge reduction in size after only the first round of chemotherapy. I explain that all the other secondary
deposits in his liver, kidneys and abdomen will be doing the same thing: shrinking away as the chemotherapy has its effect. This increases his chances of cure even further. He nods, serious and thoughtful. I wonder about asking how he feels in himself, whether his fear is still so raw, but I am afraid I may undo his mask, and that he may not wish to go there. I move on to the same, yet always completely different, conversation with each of the other patients.

That week, I was on call on Wednesday evening. I always inspected the Lonely Ballroom drips before going home, because if any failed during the night I would have to drive back and resite them. The guys were quiet. England were on their way home from Mexico, there was a heatwave and the ward windows, facing south, turned the room into a hothouse that was only just cooling as the evening wore on. Most of the drips looked fine, but Alex’s skin was becoming slightly red around the drip-site, and he noticed that when he moved his arm, the drip stopped, causing an alarm to sound. I gathered a kitbox, pulled the curtains and set about resiting the line.

‘I still don’t know how to bear this,’ he said softly once the curtains were drawn. The ‘happy drugs’ have taken his guard down. ‘I mean, I know it looks as though I’m getting better, but even if it all goes away, we don’t know that it will never come back, do we?’

I was trying to thread a plastic tube into a vein in his forearm, too focused to respond. Into the silence, he sighed, ‘I can’t bear waiting. How do people bear it if they’re waiting to die? I wouldn’t want to know.’

I taped the tube in place and pressed the button to restart the drip. The ‘on’ light winked encouragingly. I sat back and looked at Alex. He lay against his pillows, bright-eyed with the absence of eyelashes and brows. He looked very relaxed, yet he was scowling to try to hold the threads of his thoughts.

‘Do people realise when they’re dying?’ he asked languidly. The
effect of the drugs would mean that, however useful our conver-
sation might prove to be, he was unlikely to remember it. Yet in
the here and now, helped by the deep relaxation induced by his
drugs, Alex was genuinely asking about the things he feared the
most. *This is a chance that might not arise again.*

I sit still and wait. A change comes over Alex’s face. He pauses,
looks up at the curtain rail, and squints as though trying to focus.
Then he says, very slowly and deliberately, ‘I’m not sure whether
to tell you this . . .’

Pause. *Don’t interrupt. Let him keep his train of thought.*

‘Have you looked out of the windows here?’ he asks eventually.

*Oh no, is this about the view of the cemetery?*

‘Yes . . .’ Cautious response. *Where are we going?*

‘So you know how high it is, right?’ he drawls.

I do. *I climb those stairs many times a day.*

‘And you know I’m a climber, yeah?’

Yes . . .

‘I’ve been thinking. I don’t need to wait. It’s an easy traverse
from the window ledges to the corner of the building. If you
dropped from there, you’d hit the concrete full-on. Like, over in
a second. Bam!’ His extended arm bangs the bed, and I jump.

*Oh, dear goodness: he’s worked out a suicide plan to avoid waiting
to die.*

‘You’ve been thinking about that a lot?’ I ask, holding my voice
as steady as I can.

‘First thing I noticed when I arrived. Then I checked the stair-
well too. But too many things to hit on the way down – too
narrow. Outside’s better.’

‘And when you think about that, how does it make you feel?’ I
ask, dreading the reply.

‘Strong again. I have a choice. I can check out – bam!’ – he
whacks the bed again, but I am ready this time – ‘any sweet time
I choose . . .’ He lolls back on the pillows, grinning and locking
his eyes on mine to assess my response.
'And do you think you might need to do that . . . um . . . soon?' I ask, desperately wondering how I would summon help if he bounded out of bed now and tried to squeeze through the window.

‘Nah,’ he smiles. ‘Not now we know the bugger’s on the run. But if it comes back, I won’t hang around for it to mess with me.’

‘So should I be worried about you doing it this week?’ I ask, but he is sliding back into sleep. Within minutes, he is snoring. Tomorrow I will need to ask the liaison psychiatry team for advice, but for tonight I can see that Alex is too sleepy to move from his bed. I can go home.

The bedside phone rings in the early hours. Stupid with sleep, I answer the hairbrush before identifying the phone set. I can barely say ‘Hello . . .’ before the voice of our night-time charge nurse interrupts me.

‘Alexander Lester!’ he barks – he’s ex-army. ‘Bleeding both ends. Have called ICU team. Just letting you know!’ The phone rings off.

What? What has happened? Why is he bleeding? His blood counts were fine. He must have done something. Has he jumped? Oh, hell – what if he’s jumped? Where are my shoes? Car keys? What’s going on?

It is a five-minute drive to the hospital, less at 2 a.m. with no traffic. I park in an ambulance bay and run up the stairs to avoid the Lift of Unreliability. Panting and sweating, I arrive on the ward to find the charge nurse striding along the corridor.

‘Ah, Dr Mannix, ma’am! Patient has been transferred to ICU as I came off the phone. Blood pressure unrecordable. Fresh red blood in vomit and per rectum. Extra IV access established and fluid resuscitation commenced. Family informed. Anything else, ma’am?’

‘What happened?’ I ask, bewildered. ‘Did he jump? Where is he bleeding from?’

‘Jump? JUMP?’ barks the charge nurse, and I myself jump, as if commanded. ‘Whaddayamean, jump?’
I take a deep breath and say, ‘Just tell me exactly what happened,’ as calmly as I can.

The nurse describes how Alex was restless around midnight, then asked for a commode, then passed a very bloody motion and dropped his blood pressure, then began to vomit what looked like fresh blood. *No jumping. If I knew he was considering it and took no action, it would be my fault.* Mixed waves of relief and alarm struggle for supremacy, and are trounced by a tsunami of guilt: *I am worrying about myself when Alex is in ICU.*

‘Looks like he’s having a massive GI bleed,’ continues the nurse. ‘Blown through to a major blood vessel if you ask me.’

That doesn’t sound good. Ascertaining that I am not needed for other patients in the cancer centre, I am propelled by a mixture of concern and shame up the over-illuminated hospital corridor to ICU. They have called Alex’s consultant oncologist, who is on his way in.

Alex lies on his side, unconscious; the room smells of bloody poo, a sweet, clinging aroma that I recognise and dread. He has two drips, one into a neck vein; his monitor shows a rapid pulse with a very low pressure. *This is bad.* A nurse keeps pressing the ‘low pressure’ alarm to silence its insistent shrieking. Pale beside the bed sits his mother; alongside her, a young man (‘Roly,’ he says briefly) looking very like a second Alex is shredding a polystyrene coffee cup. The ICU consultant is in the room. She is explaining that Alex has lost a huge amount of blood, that they are waiting for a cross-match from the blood bank because he must have virus-screened blood during his chemotherapy, that they are giving clotting factors and plasma, but that he is very, very sick, and not fit enough for surgery to try to stop the bleeding. *This is really bad. We are curing his cancer – how can this be happening?*

And then Alex’s head is thrown back, almost as though it is a voluntary movement. A huge, dark-red python slithers rapidly out of his mouth, pushing his head backwards as it coils itself onto the pillow beside him; the python is wet and gleaming and begins
to stain the pillowcase and sheets with its red essence as Alex takes one snoring breath, and then stops breathing. His mother screams as she realises that the python is Alex’s blood. Probably all of his blood. Roly stands up, grabs her and removes her from the room, accompanied by the nurse. Her sobbing screams become more distant as she is led away to a quiet room somewhere.

I am stunned, paralysed by horror. Is this real? Am I still asleep, dreaming? But no. The coiled python is collapsing into itself like a large, maroon blancmange. Alex would appreciate the dense colour, the changing texture, the dark-meets-white on the bedding. Shouldn’t we do something? What?

The ICU consultant seems to be far away, as though on a cinema screen, as she checks Alex’s pulses and says, ‘Not a good way to go . . .’ Attempts at resuscitation would be futile. She shakes her head, then offers me coffee, which seems strangely calming, and I accept. We meet Alex’s oncologist as he arrives, and sweep him up with us to the staff room for coffee and debrief. The oncologist has seen this before: beads of tumour that have glued gut to large blood vessels, shrinking to leave a hole as the cancer responds to the chemotherapy, channelling the whole blood volume out of the body. It is rare but recognised, and untreatable if the bleeding is massive.

And I keep thinking, He didn’t want to see it coming. He got his wish.

Yet I know that, after the serpentine blood clot has been removed, the bedding changed and Alex’s body washed, and his family are allowed to see him to say goodbye, they will find no comfort in the notion that he will never need to jump from a high building to escape the fear of knowing that he is dying. Alex has left the building, without ceremony or leave-taking. But the absence of farewell will be a lifetime burden for the little family of heroes.

And in the morning, we will need to tell the Lonely Ballroom occupants that Alex has finished his treatment.
This was a hard story to tell, and probably shocking to read. While most dying is manageable and gentle when it approaches in an anticipated way, the truth is that sudden and unexpected deaths do happen, and not all of them are ‘tidy’. Although loss of consciousness during a sudden death usually protects the dying person from full awareness of the situation, those around them retain memories that may be difficult to bear.

Bereaved people, even those who have witnessed the apparently peaceful death of a loved one, often need to tell their story repeatedly, and that is an important part of transferring the experience they endured into a memory, instead of reliving it like a parallel reality every time they think about it.

And those of us who look after very sick people sometimes need to debrief too. It keeps us well, and able to go back to the workplace to be rewounded in the line of duty.
The vigil around a deathbed is a common sight in palliative care. In some families it is peaceful; in some there are rotas and care-for-the-carers as well as care for the dying; in some there is vying for position – most bereaved, most loved, most needed, most forgiven; in many there is laughter, chatter and reminiscence; others are quieter, sadder, more tearful; in some there is only a solitary sitter; occasionally it is we staff who keep the vigil, because our patient has no one else. So I had seen it many times before I had the perspective-changing experience of sitting at the bedside of someone I loved dearly, and would miss greatly, for the first time.

Well, this is unexpected.

The room is dark. A nightlight above the door casts a dim glow over the four beds and their sleeping occupants. Occasional muttered mumbles or stertorous snores from the other three beds emphasise the silence of the white-haired woman in the bed before me. I am perched on the edge of my chair, gazing at the pale face on the pillow, her eyes closed, her lips moving gently with each breath in and nostrils flaring briefly with each breath out.

I am searching her face for clues. A slight flicker of an eyebrow movement – is she wakening? Is she in pain? Is she trying to speak? But the metronome of the breath in, breath out continues unflurried. Unconscious; unaware; untroubled.

This is my grandmother. She is nearly one hundred years old. She has seen wonders in a lifetime lived in step with the twentieth century: as a girl, she watched as the lamplighter lit the gas lamps outside her home, and admired the dresses and evening capes as...
With the End in Mind

her neighbours boarded horse-drawn hansom cabs for a night on the town; as a teenager, she saw her brother falsify his papers to be allowed to fight in France, and welcomed home the hollow remnant of him that returned, twitchy and restless, after six months as a prisoner of war carrying German shells to their front line; as a young wife she saw the Great Depression, the death of one son from a disease now prevented by routine infant immunisation provided by the National Health Service, and later the death of her husband from an infection now treated simply by antibiotics that had yet to be invented then; she accompanied her remaining children into evacuation in the countryside during the Second World War, working in a munitions factory where the women on the production line twisted the detonator wires of occasional bombs in the hope that civilian lives in Germany would be spared; and then returned to her inner-city home through which an unexploded German incendiary bomb had dropped, its own detonator inactive thanks to unknown sisters in Germany. She saw the birth of the NHS; her children had access to higher education; she watched men walk on the moon. She is the matriarch of a family that now counts four living generations. And she is dying.

She draws a sharp breath in, and mutters on the out-breath.

‘Nana? It’s all right, Nana. We’re taking you home tomorrow. You can sleep now. The rest of us are here.’

I listen. I mean I really, really listen. Are there words in the muttering? Is she dreaming? Is she awake? Is she afraid?

The monotonous rhythm of unconscious breathing returns. I sit and gaze, searching for clues in this dear, familiar face.

I have seen families keeping this watch, maintaining this searching vigil, many times. I have been working in palliative care now for eleven years, watching deathbeds on a daily basis. How can I have been so unaware of the deep, analytic attention of the families who sit and wait? This is not a passive activity; I am actively, keenly alert, probing her face for clues, interrogating every
breath for evidence of – what? Discomfort? Contentment? Pain? Satisfaction? Serenity? This is the vigil, and suddenly I am encountering its familiar pattern of gathered family, and sitting rotas, and detailed reporting of almost no information, from an utterly new and unexpected perspective.

I happen to be in my home city to deliver a lecture. I was delighted to accept the invitation, because it would give me a chance to stay with my parents and to visit other family members. Then, while I was on my way here a few days ago, the family called from the hospital to ask me to divert my journey. Instead of sharing a meal at my parents’ home, we assembled in a cubicle in the city hospital’s emergency department around Nana’s uncomplaining smile. Here, her back pain was assessed, her large but unsuspected colon cancer was finally identified, a bed was found in this bay, and once I had managed to convince the shiny, newly qualified ward doctor that painkillers would be appropriate, the hospital’s palliative care team arrived to give their expert and welcome advice, so that I could be simply one of her grandchildren.

The next day, we palliative care professionals met again at the conference they had invited me to address. I stepped out of ‘family anxiety’ and into ‘conference speaker’ mode for two welcome hours of respite from my sadness, leaving a small posse of the family with Nana. The speaker after me was a social worker whose moving talk about bereaved families pierced my armour; I paused in the ladies’ cloakroom to remove the mascara stains from my cheeks, and rushed back to the hospital. The posse reports that Nana has had ‘tests’. She has widespread cancer. She wants to return to her nursing home, because it has a chapel and being close to God is her top priority. She is not alarmed – she has been preparing to die for decades, and has astonished herself with her own longevity, the solitary survivor of her generation and lonely for beloved people she has not seen for many years.

The news of the cancer had an interesting effect on Nana:
almost as though she had been waiting to know what would bring about her eventual death, she seemed so relaxed that several family members wondered whether she had really understood the news. But this is the wisdom of a long life: none of us is immortal, and every day brings us closer to our last. In her eighties, Nana had a stroke that affected her use of language. She lost words, and substituted others in ways that sometimes made her speech impenetrable, and on other occasions was unintentionally wildly comical. Her mobility became limited too. She accepted these burdens with determined stoicism. In retrospect, I suppose she expected that another, fatal stroke would rescue her from living a limited life, but here she is more than a decade later, still talking to us about sausages and ‘You know, that . . . whatever . . .’ with a roll of the eyes that says, ‘Mm-hm! You know exactly what I mean!’ while we cast around for ways in which ‘sausages and something else’ might be relevant to the conversation about, for example, her new duvet cover or what she would like to send her great-niece for her new baby.

So now she knows. Not another stroke, but cancer. Painful pressure on her pelvic nerves has been giving her a pain ‘down there’ (rolls eyes) that she didn’t like to mention. She has been losing weight, and off her dinners a bit, but not enough to cause any alarm. When the palliative care team’s recommendations for the nerve-compression pain are effective, she is quietly pleased. ‘That was like a . . .’ – rolls eyes – ‘a . . .’ – eyes indicate ‘down there’ – ‘Polaroid,’ she explains, and while my aunt looks perplexed, my sister remains heroically straight-faced as she says, ‘Yes, Nan, like a haemorrhoid.’ The rest of us rummage in bags and pockets to avoid catching each other’s eyes and creasing with inappropriate laughter.

So, because I am here and I may not get another chance, I am in the watching rota. Last night I slept in my childhood bedroom in my parents’ house, and no one was on watch because Nana seemed comfortable and rested. But today, suddenly, she has begun
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to change. Sleepy and awake by turns; too weary to eat; accepting occasional sips of fluid; asking for the Pope. The priest came to visit; she was delighted. Fancy the Pope coming so quickly! Goodness knows how that conversation went, but she seemed very peaceful afterwards.

By evening it was clear that, her burdens laid down, Nana was preparing to die. A visitor from her nursing home, a diminutive and very experienced nursing nun, spotted the signs and asked her where she wanted to spend her last days – no beating about the bush. Nana wanted to ‘get home’, and the knee-high nun said they would expect her home tomorrow. The ward staff agreed to make the transfer arrangements. Nana smiled and slept and slipped into a coma. All things I have seen many, many times, yet never really seen at all.

And that is how I come to be perched on the edge of this chair in the darkness, searching the face and the sounds of my frail and failing grandmother. Suddenly she opens her eyes and says, ‘You should be . . . not here . . . asleep . . .’ Almost a sensible sentence. I touch her cheek, and notice that her nose is cool at the tip.

‘Nana, you have walked the floor at night for all of us. Now it’s our turn. Just sleep. I’m comfy here, and it’s lovely to be with you . . .’ And she smiles, a gummy benediction of a smile that brings tears to my eyes. ‘Mum and Auntie have gone for a cup of tea. They’ll be back soon. Can I get you anything?’

She shakes her head and closes her eyes. From out of nowhere, the sound of Brahms’ lullaby floats into my mind, its halting waltz-time reinterpreted as a bedtime lullaby sung to each of her thirteen grandchildren in our turn (and probably to our parents before us, too) in Nana’s deep, cracked yet soothing voice. Here, at the edge of her dying, I contemplate the meagre understanding I have of her long and often troubled life, and the intimate knowledge that she has of mine. She is a remarkable woman, yet I hardly know her. She modelled self-reliance and resilience to my mother and her siblings, and to her eight granddaughters and five grandsons.
Before she became unable to converse with fluency, she was a confidante of our woes and transgressions, an adviser in anxieties and a source of solace in times of trouble. She knows us inside-out, but she said so little about herself, and we self-absorbed youngsters never thought to ask.

How many people attending a deathbed must realise these truths, as they see a future they had taken for granted slipping away from them, a much-loved person slowly descending through the layers of consciousness towards coma and death? No wonder there are fantasies about swansongs, in which people linger for a last word, a deep revelation, a declaration that all will be well.

Nana’s breathing is soft now, panting and shallow. How many times have I described periodic breathing to families, to medical students, to patients themselves? And yet, it never sounded like this before. This sounds like someone who has run a long way, who is breathless, who is anxious. But her face is serene, her brow unfurrowed, and her pulse (I feel her wrist) is steady, regular and sedate – and I notice that, like her nose, her hand is cold. I tuck it beneath the crocheted shawl Auntie brought from home earlier today, as though in some way I can warm it into life. My professional self is satisfied that she is not in distress, yet I am poised and alert, like a security officer guarding an at-risk target. All my senses are primed to spot the least disquiet.

The shallow breathing pauses. I hold my own breath – Oh no, please don’t die when they’ve gone for a tea break. And then she takes a huge, snorey breath, and that other pattern of periodic breathing begins, slow and deep and noisy. I think of the number of times families have asked me if the sound indicates distress, and I have wondered why they mistake snoring for intentional vocalisation; yet here I am, listening intently for any suggestion of an edge of perturbation to that well-known, sonorous boom of a snore that kept me awake at night whenever she came to stay when I was a child. Slowly, as I know it will, this automatic breathing gets faster and shallower, and then so shallow that I
can’t hear it, while I scan every breath, and watch her face, and search for any suggestion of a wagging toe or a tiny hand movement that may suggest that she is trying to make contact one last time.

The next twenty minutes pass in this way before Mum and Auntie reappear with a paper cup of orange hospital tea for me. I feel as though I have been alone here for an eternity, watching and evaluating my comatose grandmother, searching for meanings and discarding them again. We are past the point of communicating; the loss weighs like a heavy stone in my chest. I offer to stay the night, but Auntie will not hear of it – the night shift is hers, and tomorrow I have a long train journey back to my small children and my busy job and my kind husband. I know that I will not see Nana again.

In fact, getting home perked Nana up immensely, and we did see her the next weekend, propped up on pillows, pale and diminished yet delighted to see us all. Between long snoozes she enjoyed short conversations.

I was not there when she gave the last out-breath the following week. But I had learned the lessons of the vigil, and through the kindness of the natural order – watching a grandparent’s death. Since then there have been other vigils, with the same intensity of active watching and exhausting focus, and with sadness at the untimeliness of deaths before their right time (as though there is a right time), but also with recognition and appreciation of the last lesson I learned at my grandmother’s knee.

Now that I understand how minutely attentive to detail the watchers are, how active and probing their attention is, how exhausting the responsibility feels, I am a better servant to their needs and questions, and so much more patient with their frequent requests to check for any sign of discomfort or distress. This last vigil is a place of accountability, a dawning realisation of the true value of the life that is about to end; a place of watching and listening; a time to
contemplate what connects us, and how the approaching separation will change our own lives forever.

How intently we serve, who only sit and wait.
Pause for Thought: Patterns

The stories in this section have been chosen to illustrate the gradual, predictable sequence of events as we die that used to be familiar before medicine progressed and dying at home became more unusual. Knowing what to expect is immensely comforting to the dying person and their supporters. Once we all know what we need to know, we can relax with each other. It’s surprising how relaxed a well-prepared family can be around a deathbed.

Have you ever been with somebody while they died? How does what you saw match the patterns described in these stories? Is the description of dying what you were expecting? In what ways does this information affect your view about the experience of dying? How well do you think TV dramas, soaps and films deal with dying and death? Do they help us to be better prepared, or does drama displace reality?

When you are dying, where would you like to be? What are the pros and cons of being at home in your own bed (perhaps moved to a more accessible room), or staying with a relative or friend, or in hospital, or in a care home, or in a hospice?

If you have seen a death that appeared uncomfortable or shocking, how have you dealt with that memory? What information in what you have read in this section could allow you to re-evaluate what you experienced?

If you regularly have upsetting memories of a difficult situation, whether it is a death or something else, and especially if the experience still feels as though it is happening again there and then, this suggests that your experience may be causing post-traumatic
stress disorder (PTSD). Your doctor can help. Please don’t suffer more than you need to – ask for advice. There are some useful suggestions in the Resources section at the end of this book.