A Good Life

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The Power of Palliative Care

Jerry Pinto

juggernaut

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What Is Palliative Care

It is an inclusive approach to medical care for any serious illness, at any age, right from the moment of diagnosis. Care that helps you be as pain free as possible, allowing you to find joy and peace amidst your journey. Care that keeps you and your family at the heart. A true partnership between medical professionals and yourself, which accompanies you in your most difficult of times.

Foreword

Reading Jerry Pinto's seminal novel *Em and the Big Hoom* compelled me to seek him out.

Few voices capture the onerous, often unspoken burdens of life in prose as delicately and insightfully as Jerry's. His deeply personal narrative draws us into the everyday struggles of his family, bound by love and tested by the complexities of his mother's mental illness, revealing layers of vulnerability and endurance. His family navigated incredibly overwhelming challenges without holistic, supportive care, yet they miraculously managed to remain unshakably committed to each other. Their suffering was not inevitable, they should have been embraced with care. How were they not? Why were they not? For the last two decades, these questions have guided my

personal search to bring this care within reach, so we don't fail others like Jerry.

When Jerry and I finally met, he told me what I had already divined from his book – that he had not known about palliative care. And that no one had needed it more than his mother; than him. His family was not offered an additional layer of support, mitigating suffering, easing symptoms, anchoring them in capable, compassionate care. We spoke about how this care might not have been as readily accessible back then, but it exists today, and with Jerry's voice, more people in need could find their way to it through greater awareness.

Now, two years later, I'm thrilled that with this book Jerry brings this to light through his insightful journey into palliative care. He has travelled across the length and breadth of India, meeting, engaging, learning and listening to people who are at the heart of this care – medical professionals, patients and families seeking to answer the most fundamental questions of what we deserve, what we need and what we get when we are seriously ill. While serving as a guide, this book lays out the unique landscape of palliative care in India, inviting all those facing serious illnesses to find the

right care and comfort they need. It emphatically alerts us that palliative care should start at diagnosis, allowing both adults and children with serious illnesses to live fully and meaningfully.

My own understanding of palliative care began in 1993. I was just about twenty-one when my father took me to see a barren plot of land on the outskirts of Pune. It was there that I first heard the term 'palliative care'. He told me this land would hold a place where people with serious illnesses, along with their families, could find relief from pain and helplessness. 'It will be free, of course,' he said, 'because you can't be tranquil if you're worrying about doctors' bills.'

The Cipla Palliative Care and Training Centre opened in Warje, Pune, in 1997, built around a community courtyard, the *aangan,* with wards named after flowers to bring beauty into a medical setting. Here, patients are known by their names, not bed numbers – each one a story, a life. Loved ones are not left on the sidelines but are invited to stay, learning the art of caregiving while finding strength and solace themselves.

Five years later, I witnessed the gift of palliative care first-hand when my dearest friend Hazel D'Souza's cancer returned, in its final stages. We sat up with her, bracing ourselves as she cried out in pain. She had seen our centre in Pune and asked to be moved there. On her first night at the centre, with her pain finally managed, Hazel slept peacefully for eight hours straight – and so did we, after weeks of sleepless vigils. Hazel had only a few weeks left, and she spent them at the centre, free of pain. That, in the end, was what mattered most to all of us who loved her.

I will always remember a story my father shared about what palliative care means to him. 'For me, it's summed up by an incident about ten years after the centre opened,' he said. 'An elderly patient asked who I was. When he learned that I had helped to set up the place, he insisted on speaking with me. He said, "*Bhau* (brother), this is the place where I first understood the meaning of the word love." My father hugged him because in that simple statement lay the essence of palliative care.'

If we think of healthcare in terms of numbers alone, we miss the big picture of our country's health story. But if we think of stories like those of Hazel,

the love-touched elderly gentleman, and thousands of others that Cipla's palliative care centre has served since it began, we can hope that access to palliative care for all can be possible – and perhaps even dream that light can be shone into the darkest corners.

In this book, you'll meet many incredible palliative care professionals, team members, volunteers and more, each guiding patients and families through illness. For palliative care is a collective effort where everyone plays a part – from the nurse to the ward boy, from the attendant to the counsellor. In each chapter, Jerry takes us into the lives of people facing illness, bringing us close to their courage, their humour, their sorrows and the resilience of those who care for them.

I hope these stories bring you alive to palliative care and deepen your understanding of the challenges of living with serious illnesses. Both you and I need it more than we know. Our parents already do. We are caregivers already and some of us will need caregivers sooner than we imagine. Who will stand with us then? Only a palliative care approach to medicine will be able

to come through for us. And that care is possible, and every day people are seeking it out.

These are stories of hope and joy, pain and loss. Jerry's, mine, yours. Universal, binding, uncomplicated – we love, and we are loved. And we deserve to be able to give those we love a good life.

Rumana Hamied
Director
Veha Foundation

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Ignorance Is Not Bliss

I wish I had known about palliative care earlier.

I wish my parents had known about it, too. After I was born in 1966, my mother began to experience depression. The doctors dismissed this as a post-partum phenomenon. It happens, they said, it will pass. Take up knitting, they said. Within six months, she had thrown herself in front of a bus. She survived. Passers-by put her into a taxi where she sat cross-legged and apologized again and again to the taxi driver for dirtying his car with the blood flowing from the wound on her foot.

In the hospital bed, she must have wondered what had gone wrong. She had not had it easy – a refugee from Burma, a child making a wartime crossing, an adolescent who wanted to be a teacher but who was forced to become a stenographer because companies

paid better salaries than schools and money was needed at home. But she was no different in her troubles from thousands of other women, and they were not trying to kill themselves.

Up until then, my parents were a bright young couple on the ascent. They had a library that was the envy of their friends in Bombay. My mother wrote beautifully – her letters to my father, an engineer with blue eyes – an abiding delight. She sang for a while in the Paranjoti Choir of the city. She was known as a warm, witty woman with a job in the American consulate, which my father had found for her. They hung out in bookshops and loitered over Coke floats at Bombelli's. They married late and settled into a one BHK in Mahim. A year later, their first child, Andrea, was born. Then I came along, and something threw a switch in our mother's brain.

After her first suicide attempt, the doctors stopped telling her to count her blessings, to pull herself together and to think of those less fortunate than her. They said she was bipolar, and that there was no cure. She would have to learn to live with it. And with a prescription, they turned my parents out into the world to make the best of it. The doctors did not mean badly.

They did the best they could. They were not trained to think about suffering, nor even pain.

Dr M.R. Rajagopal, the founder of Pallium India, dedicated to increasing access to palliative care throughout the country, would have been a young medical student the year that my mother became ill. He was among the first people I met when I started writing this book. 'I had an excellent medical education,' he told me as we sipped coffee at his office in Thiruvananthapuram. 'We had the finest doctors teaching us. But never once did they mention pain or suffering. It was there. We knew it because we could hear the moans and the screams. But my generation of doctors were not taught to deal with it or even acknowledge it.' As I would discover through the course of writing this book, only now is this beginning to change in our country – or, indeed, in much of the world.

I have lost count of how many times my mother tried to end her life. She's gone now, and the nightmare has ended. Time has begun the sealing over of life's wounds, leaving only memories of her raucous laugh, her witty retorts, her self-mocking humour and her sharp sense of the ridiculous.

But when I heard of palliative care, something inside me started a low keening. It was the age-old song of 'What if'. What if my mother had had access to palliative care? What if there had been someone she could call when she was depressed and found it hard to breathe, when she did not want to breathe? What if she had someone to call and say, 'I want to die. I want them to kill me, but they won't'? What if I had had someone to call and say, 'She wants us to kill her and if she asks again, I'm worried I just might'?

My sister, the quiet one, capable of huge acts of empathy in her silence and by just being there, bore the brunt of it. What if she had had someone to offer her a hand? What if my sister and I had had a place where we could go to talk about our anger and our hurt – and the attendant guilt we felt when we prayed or wished or longed for a 'normal' mother? What if I had had someone to look me in the eye and say, 'This is not your fault'?

In *Em and the Big Hoom*, the novel that I wrote about life with our mother, Em, the manic-depressive superstar of her own drama, dies in her sleep, leaving

her family shell-shocked and adrift. I wrote it like that because I knew that I had to open the door of the tiny Mahim flat in which the novel was set and let the readers out. I had to release the pressure. But that was not how it worked out in real life. There, my father died at fifty-nine, exhausted by carrying so many responsibilities, felled by his first and last heart attack. And that left the three of us to figure things out the best we could. We pulled through somehow, but it would have been so much easier on all of us if we had had someone to walk with us, someone with whom we could have talked about our pain.

Pain is an inevitable part of human life; it is an evolutionary gift, our best teacher. To be born without the ability to feel pain may sound like a blessing, but it is actually a terrible disability that hastens death because pain alerts us to a problem in the body that needs attention. Steps can then be taken, whether these are reflex actions or conscious steps, to alleviate the pain and to address the underlying problem. We need to accept then that pain is inevitable. But

suffering need not be. Palliative care seeks to lessen both the pain and the suffering caused by illness.

I have since forgiven myself for the gaps in my knowledge of palliative care. When a medical stalwart like Dr Armida Fernandez, ex-dean of Lokmanya Tilak Municipal Medical College and General Hospital, Mumbai (otherwise known as Sion Hospital), neonatologist, and founder of Asia's first human milk bank, tells me that she had not heard of palliative care, how could I have possibly known? Early in the writing of this book, I met this redoubtable octogenarian who still visits daily the Romila Palliative Care Centre in Mumbai, which she founded. She told me about her family's brush with cancer.

Her daughter Romila was a precious child, born after many years of waiting. The infant had health issues: acute jaundice that meant her blood had to be completely changed, which could have caused other developmental delays. But she came through it all.

And then, at the age of sixteen or seventeen, 'Romila was diagnosed with Hodgkin lymphoma when it was already stage 3,' says Dr Armida.

Romila's education was to suffer a setback because her college would not accept her illness as a reason for poor attendance. Undeterred, she shifted to a women's university and finished her degree. Dr Armida tells me of Romila's love for life and her compassion for others. But then the cancer returned. 'Fourteen years later, she developed cancer of the breast. This may have been caused by the radiation she'd had for Hodgkin. Radiation itself can cause cancer,' says Dr Armida.

The young woman died, leaving behind a bereaved husband and a grieving family. 'When I lost Romila to cancer, there was pain and anguish. No one had heard of palliative care,' Dr Armida says. So when she did hear of palliative care, she decided that it was something she could do for others. She had already founded a community-driven NGO in Mumbai called SNEHA (Society for Nutrition, Education, and Health Action) to improve the health and well-being of vulnerable women and children. To its ambit, she added palliative care.

Beyond this, Dr Armida has now become an advocate of palliative care. 'I enjoyed teaching neonatology at Sion Hospital. Retiring as the head of the department means many generations of doctors have worked with

me. Some of my students teach at neonatology colleges and all of them have been sensitized to the need for palliative care. I spread the message of palliative care wherever I go,' she adds.

As she tells me this, Dr Armida has no idea that Romila and she have managed another healing. Listening to her, I put down my guilt. We just did not know, Dr Armida and I. But we're trying to do something about it now. Dr Armida with her tireless advocacy, and I, by writing this book.

This book seeks to start a conversation about what palliative care is, challenges the misperceptions around it, and addresses who needs it and where it can be found. It is meant for all doctors who would like to shape a better life for their patients. It is meant for carers in the family who find their resources stretched but do not know that help could be a phone call away in some cities. It hopes to reassure everyone who is dealing with chronic illness or life-limiting conditions that there is no shame in asking for help. In fact, the

shame should be ours as a society if there is no help to hand.

You cannot undo the past. But you can remake the present. By what we know, by what you will know at the end of reading this book, we will effect change. We will talk about palliative care to each other. We will be the change we want to see.

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Living Fully