Book Review: A Good Life - The Power of Palliative Care

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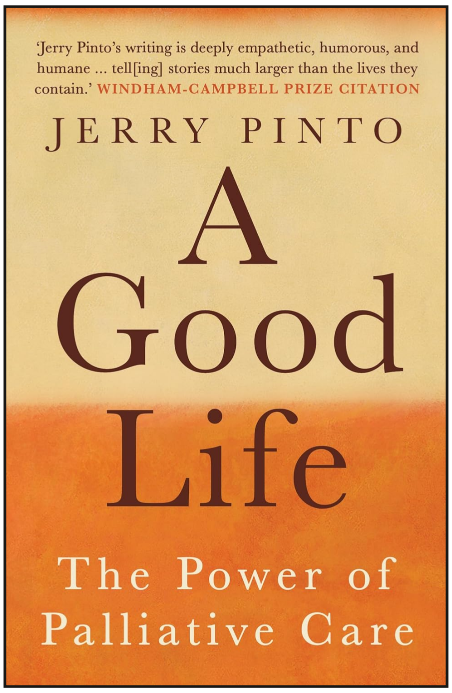

A Good Life: The Power of Palliative Care

Publisher: Juggernaut Books, New Delhi

Author: Jerry Pinto

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Hardly anyone I know is aware that palliation is not a small part of end-of-life care, that it includes more than pain and nausea relief. Palliative care stretches to buying appropriate furniture or equipment in case of mobility issues, providing occupational therapy, spiritual and psychological guidance through turbulent or depressing times, getting financial and nursing assistance for patients with chronic, lifelong, distressful neurological/genetic conditions where there is no cure, but hope for a better quality of life is possible.

I lost two family members to cancer last year; I was not able to give them or their caregivers relief from physical or emotional pain. The treating doctors did not guide us towards palliative care, although it was available nearby. Whilst the suffering was inevitable, it could have been much reduced. And the quality of our lives and of those who passed away, could have been so much better.

Prize winning author Jerry Pinto's 'A Good Life' has covered all aspects of palliative care in India, which, I might remind, is not necessarily restricted to end-of-life care. In his brilliant novel, 'Em and the Big Hoom',

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based on his mother's suffering from depression and his family's coping with her problems, medical, social and financial, he had brought to the fore a deep, latent empathy for people with chronic mental conditions.

'A Good Life' has interviews with doctors, nurses, social workers, patients, their families, the bereaved, the volunteers, and the pioneers, from Maharashtra and Gujarat to Assam, Chennai, Delhi, Kerala, Telangana, and more, and Pinto has documented his experiences in fine prose. Throughout the text, there is generous use of quotes.

"Doctors see it as their moral responsibility to fight for the patient until the last breath. It's not easy, but that mindset has to change. The death of a patient is not a failure. Death is inevitable; it is what happens to all those who have been given the gift of life. We must train the younger generation to accept this, and to help our patients die a good death, in peace, made as comfortable as possible and with their loved ones around them.' Sadly, many deaths are in cold ICUs, surrounded by masked strangers in weird clothes.

Indian families don't often like transparency. Decisions are often taken by fathers, husbands, sons and patients are often not told what is happening to them."

"He has come with this seventy-seven-year-old father who has been diagnosed with acute myeloid leukaemia. The doctor asks whether the family would like to tell him or whether she should tell the patient herself.
The answer is no.

'Would they like to tell him then?'
Another flat no.
'Why not?'
'Tension mein aayega (He will get tense),' says the young man.
'Do you think he is not tense now?'
A shrug.
The doctor tries again: 'Imagine you have an exam tomorrow, but you don't know what subject it is. How can you prepare for it?'
'Just walk away, forget it,' the young man says with a victorious smile. The doctor acknowledges defeat.

The question is: To whom should the doctor break the bad news?

Palliative care is not the responsibility of a doctor alone. There are many people involved beyond the hospital who can lighten the load of a family which has a child or adult with a life-limiting condition. Neighbours, colleagues, auto-rickshaw drivers, local charitable folk eager to help, all can pitch in. Trained help is valuable, of course."

"We are a country that believes deeply in magic and lives in the hope of miracles. The families of patients will say to a doctor, "Yes, the textbooks say that this is incurable, but anything is possible, no, doctor?" They will tell you how someone's friend's cousin recovered and lived for ten years when the doctors gave him two months. Finally, the doctor will say, "Yes, I suppose anything can happen," and the family hears this as "Yes, a miracle is on its way."

Financial constraints, the problems of very young children with very short lifespans, and several heartbreakingly demanding and complicated situations, all need many hands, often over decades, to tide them over. Shame, secrecy, and avoidance only add to the woes.

The book is rich with examples of shared journeys, of changing the mindsets of doctors, of fulfilling seemingly impossible wishes of those facing The End, but also offers insight into the burnout of nurses and caregivers, those who have risen from the pits to lend a hand to others. Every topic has examples, situations, and interviews that help a reader recognize a simple fact: that palliative care is a definite need, and it must be quickly included in all aspects of healthcare in India.

This book belongs in health humanities libraries, but is also important for lay people to read. The lack of access to morphine or its derivatives, the despair of poverty, the longing to live, the need for inclusion of palliative care in the MBBS syllabus, all are topics lay people should be aware of.

Through education of healthcare professionals and of the general public, hopefully, no other member of any family will have to suffer the way the two recent segments of my family did.