

To quote the famous American feminist-writer Susan Sontag, "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship in the kingdom of the well and in the kingdom of the sick."

For those living in the kingdom of the sick, needless to say, suffering is a constant companion. Illness and suffering always go hand in hand. From a minor flu to a dreaded disease like

It was the search for such a treatment that led Taif, a UAE resident of Indian origin, to Palliative Care for her mother who had been diagnosed with gall bladder cancer, already at stage four. "Palliative, isn't it a morphine treatment? How could it help my mother who is fighting cancer at an advanced stage?" That was the question that had sprung up in her mind when she came to know about palliative care from an Internet friend. She has changed her stand long since.

She lost her mother eventually but was thankful that she gave palliative care a shot. "Without that my mother wouldn't have a comfortable life or a natural death," she says. "For I have witnessed cancer patients moaning in pain. But thanks to palliative care my mother's pain was considerably less and it was such a relief for us all."

# THE PEACEFUL WAY OUT

PALLIATIVE CARE IS A RELATIVELY UNKNOWN APPROACH IN HEALTHCARE. IGNORANCE, PREJUDICE AND LACK OF TRUST—ALL ADD TO ITS UNPOPULARITY

by Nazeem Beegum



cancer, pain is the accompanying factor. And there is no better place than a hospital to realise this numbing truth. In that world of suffering and affliction, hopes and tears, human knowledge faces one of its biggest challenges — how to bring relief to terminally ill patients and make their remaining days comfortable.

Dr Rajagopal, the pioneer of palliative care initiative in India, has this to say: "When we look after people with prolonged life-threatening illness, we go into not only physical problems, but also into their emotional, social and spiritual issues."

Dr Rajagopal, an anesthetist by profession and at present head of

Palliative Care Unit in Sree Uthradam Thirunal Hospital in Thiruvananthapuram, Kerala, got involved with palliative care out of sheer curiosity and decided to "do something" for those battling severe pain.

As an anesthetist, he knew very well how morphine was capable of relieving pain. In 1999, he got the rules for the availability of the medicine amended as a pain killer, making it easily accessible to patients undergoing palliative treatment. Until then its sale was restricted for fear of it being fallen into the hands of drug addicts.

To substantiate his argument, Rajagopal cites a World Health Organisation statement on palliative care: "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

While this approach is very popular in developed countries like the US, UK and Canada, it has few takers in developing countries. Lack of awareness in alternative approaches to healthcare and over-dependence on curative treatment as well as willingness to spend on aggressive and expensive medicines have kept people away from this holistic approach.

The biggest criticism of palliative care is its use of morphine on terminally ill patients. Some say overuse of morphine brings intense pain to patients and its efficacy decreases with time. Dr Rajagopal rejects this argument saying science



Dr Rajagopal

has clearly established that there is no significant decrease in efficacy even if morphine is taken for a long time.

It is important to note that morphine does not work in everybody and in all kinds of pain. A small number of patients may not respond adequately to it. Palliative sedation comes to rescue at this stage. "It is undertaken with the consent of the patient as well as the carers and members of the family," Dr Rajagopal says. "Morphine is not just for terminally ill people. We had a lawyer under palliative care who practised for two years while on morphine and even attended court hearings. We had a builder who continued his construction business for more than a year while on morphine. We now have a man who has been doing a part time job as a vegetable seller for the last three years while on morphine," Dr Rajagopal said.

Palliative sedation is used only on patients who have failed to respond to all other curative and palliative options. Some may view it as euthanasia, but in reality there is a vast difference. In euthanasia, there is a deliberate intent to end life whereas in palliative sedation the objective is to only reduce the pain.

Not all terminally ill people are given palliative sedation though.

"My mother was not given any palliative sedation," Taif says. "I am surprised to see how a cancer patient like her would die from a massive heart attack like any normal person. And she proved herself that she was right in choosing palliative care over chemotherapy and radiation knowing that nothing was going to help her get rid of her illness."

Taif's 69-year-old mother was adamant that she wouldn't be given the usual cancer treatment. Instead she made her children look for something that would make her comfortable in the endgame of life.

Is the patient then the sole master of his/her body? Dr Rajagopal has no second thought about this, "Yes, it is the patient who has to decide about the kind of treatment she/he has to undergo. But that person must be given empowered with adequate information to take an intelligent decision."

Usually when somebody is diagnosed with a life-threatening disease, what follows is shock and helplessness. The next thing the carers can think of is to rush the person to the best hospital to ensure the "best" of treatment. All this, of course, after a nerve-racking diagnosis process. The final stage is the inevitable hospitalisation and treatment. From that moment onwards, the patient loses his or her right over his or her own body.

But when viewed against palliative care, which offers maximum relief from pain to a patient by taking into consideration their needs, physical as well as emotional, this conventional approach seems to be so unfair. Death, even when it seems inevitable, doesn't have to be painful.