Today’s hospitals are no place for the dying. Both culturally and clinically they are mostly unsuited to provide end-of-life care, according to Dr M. R. Rajagopal, the “father” of palliative care in India.

The former consultant anaesthetist has spent over 20 years developing care for the dying in the tiny green and fertile state of Kerala in the south-west of the country. Today, with 3% of India’s population, Kerala has two thirds of the country’s palliative care services.

His interest developed when he was working as an anaesthetist at Calicut Medical College in northern Kerala in the early 1990s. He recognized early on that tackling pain and supporting the dying could not be achieved by medical staff alone. The need was too great. It would depend on harnessing the commitment of volunteers.

“Pain is just the visible part of the iceberg of suffering. What is ignored is the part below the surface – feelings of hopelessness and despair, worries about children, about money. That is what palliative care is about.”

The movement grew and today he estimates there are 300 voluntary groups across the state (there are no official figures), providing care to patients in their own homes, identifying those in need and helping direct limited medical resources to where they can do most good. The “Kerala model” now attracts attention from around the world.

After moving to Trivandrum in the south, in 2006 he founded Pallium India, which supports 11 voluntary groups and five mobile medical teams providing palliative care in the area, as well as campaigning to improve palliative care throughout India. Now aged 69, he still visits patients at home and teaches younger colleagues how to approach them.

“If I wear a tie, hold myself with muscular rigidity, and talk only about pain, I will not discover much. With a different, gentler approach, placing a hand on the patient’s arm, they will talk about deeper problems.”

He warns about the importance of language. “You can do harm with the wrong dose of a medicine – and equally with a wrong word.”
As diagnosis and treatment have become increasingly dependent on technology, something has been lost, he says. The growth of the commercial health care industry, driven by profit, has compounded the sense of alienation. The result is that the disease has become more important than the person who has it. Most doctors believe they have a duty to prolong life, rather than ease death. Cure has come to matter more than care.

“The patient has become a bit of a stranger amidst the machines. The health care system seems to have forgotten that health is not just the absence of disease but the presence of physical, mental and social well-being.”

He argues that every hospital must integrate palliative care with its disease-focused work. Most people, given the choice and the appropriate care, would choose to die at home, surrounded by their loved ones. But some feel more secure in a hospital environment, with their familiar doctor close at hand. It should be a personal choice, he says.

Having access to pain relief is vital to that choice but morphine is not easy to obtain. Figures show India uses 320 kilograms of morphine a year, just 1% of the amount required to meet the need.

It is not the cost that restricts access, but the law. Morphine has been highly restricted in India since 1985 because of fears about drug abuse. As a result, two generations of doctors have grown up unfamiliar with it, condemning millions of terminally ill patients to an unnecessarily painful death.

Here, too, Kerala has led the way. Since 1995, palliative care centres in Kerala have been permitted to administer morphine orally. Dr Raj’s institution is now a WHO Collaborating Centre for Training and Policy on Access to Pain Relief and plays host to a stream of international visitors.

“Health care should be a partnership between the doctor, the patient and the family. Doctors should not work alone but with nurses and counsellors, volunteers from the community and social workers. My duty is to build a relationship with my patients and their families and care for them as human beings. Life is not just existence – there is more to it than that.”