

The people who help you die better

February 28 2017, by Jeremy Laurance

Thirty years ago a young anaesthetist, newly appointed as head of department at Calicut Medical College Hospital in the Indian state of Kerala, encountered a case that would change his life.

A college professor aged 42 with cancer of the tongue had been referred to him by an oncologist. The man was in severe [pain](#) and the anaesthetist, Dr M R Rajagopal, was asked if he could help. He injected the mandibular nerve in the jaw in a procedure known as a nerve block, and told the patient to return in 24 hours. Next day, the pain had almost completely gone and Dr Raj, as he is known, was pleased with his work.

"He asked me when he should come back. I told him there was no need to come back, unless the pain returned. I thought he would be happy I had cured the pain. Instead, he went home and killed himself that night."

It turned out that the oncologist had avoided explaining to the college professor that his cancer was terminal. Instead he had said he was referring him for further treatment.

"It was only when I told him there was no need to come back that he realised his cancer was incurable. He went home and told his family it was all over."

Dr Raj reaches for a glass of water. We are sitting in his simple home in Trivandrum, the leafy state capital, where he now lives with his wife, Chandrika, a pathologist. In front of us, a plate of yellow jackfruit gleams in the low afternoon light. A fan whirrs above.

That experience caused Dr Raj to examine his own practice. In addition to putting people to sleep for surgery, an anaesthetist's job is to tackle pain. So what was he missing, he wondered.

"In those days pain was all over the hospital. It was everywhere. We pretended not to see it, but it was there. Injections of morphine were used sparingly, after surgery and for patients injured in accidents. It was never used in cancer pain."

Medical staff coped with the suffering the same way they cope everywhere. "No one teaches you, but you learn to see only the disease, not the human being who has it. Maybe if there is nothing you can do it is easier to turn your back."

Dr Raj had had two earlier traumatic experiences involving the dying. Aged 18, in his first year in medical school, he had lived close to a man who had terminal cancer of the sweat glands. "I would hear him screaming in the night. He had nodules all over his scalp. The family knew I was a medical student and asked if I could do anything. I didn't know how – I was helpless. I am ashamed that I never visited him after that. I did not want to go there and feel helpless again."

Later, he was looking after a patient with a gangrenous toe who was in excruciating pain. "I asked my head of department if I could try a nerve block. He refused – it was not part of routine care and there was a shortage of anaesthetists. I had to tell the man there was nothing I could do. I still remember the look of hopelessness on his face."

When he became head of department at Calicut, there was no one to tell him what he could and couldn't do. That is how he came to treat the college professor. But his patient's suicide showed him that treating the pain was not enough.

"I realised that thinking about nerve blocks was too narrow. 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 money, about children. That is what palliative care is about. That man gave up his life to help me understand it."

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We all wish for a pain-free, dignified death. Too few of us achieve it. Worldwide, the last year of life is marked by widespread unnecessary suffering. At least 40 million people need palliative care each year, but only around half that number receive it, according to the Worldwide Hospice Palliative Care Alliance.

India comes near the bottom of the global league in access to end-of-life care – ranked 67 out of 80 countries in 2015 – but Kerala is an exception. This small green and fertile state in the south-west has just 3 per cent of India's population but provides two-thirds of the country's [palliative care services](#). These have developed over the last 20 years, driven by the local community and supported by a unique system of volunteers. Some claim it is Kerala's strong ethos of community involvement that is the secret behind its palliative care provision, which would be difficult to replicate elsewhere.

Dr Raj, one of the drivers of the movement, disagrees. "Yes, of course the strength of the community is important. But is Kerala the only part of the world where there are compassionate people? Is Kerala the only place where people who may have gained material success then want to do something meaningful with their lives?"

Now a youthful 69, he recognised 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.

In 1993, after he had attended a course run by an English nurse, Gilly Burn, he and his colleague Suresh Kumar established the Pain and Palliative Care Society in Calicut, a town in the north of Kerala, together with an activist friend, Ashok Kumar, who ran a printing business and provided a vital layman's perspective.

"Six of us put in 250 rupees each, worth about £10 then," says Dr Raj. "We found two volunteers, young women with children at school, to register patients and sit and talk to them. Then I would come after work to see them."

The project took off after Burn, who ran a trust, Cancer Relief India, donated 100,000 rupees (£4,000 in the mid-1990s), enabling them to appoint their first doctor. Calicut hospital provided two nurses.

"It very quickly got attention. In the hospital, we were working in a sea of suffering. But in the clinic, you could see people smiling, talking, finding comfort."

Within a year, it was being copied – by a medic whom Dr Raj met on a train and by a former student who wanted to open a clinic in his own town. The ball was rolling.

There was a limitation, however. It was exposed early on when a young man came begging for help for his mother, who was in severe pain. She lived in a remote spot where there was no road and could not be moved. When Kumar told the man that the doctors could not prescribe without seeing the patient, he broke down in tears. Kumar weakened and told the man someone would come. It was their first home visit. Gradually demand increased. Then someone donated a vehicle.

The doctors, working in their spare time, could not meet the demand alone. The organisation of the clinics and the home visits depended on volunteers. But the volunteers also provided the link between their communities and the service – they knew who was sick and where to get help. Over time, they became more and more involved. Some assisted with nursing tasks, following brief training, but most provided social care – advice, support, a shoulder to cry on.

By 2000, there were 30 palliative care groups in northern Kerala, run by volunteers and supported by mobile medical teams. Today, though there are no official figures, Dr Raj estimates there are 300 voluntary groups across the state, providing care to patients in their own homes, identifying those in need, and helping to direct limited medical resources to where they can do most good. Kerala is now a World Health Organization demonstration site for palliative care and plays host to a stream of international visitors wishing to learn how it was done.

The strength of the groups is that they have grown organically, rooted in their communities, by popular demand, and thus have strong local support. They are largely funded by local donations, some as little as 10 rupees (12 pence) a month.

They supplement the work of the 167 institutions licensed to dispense morphine and the 900 government–funded panchayats, or village councils, each of which employs a nurse who provides palliative care – though they may visit patients only once a month.

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Thirty kilometres outside Trivandrum, in the district of Uzhamalakkal, the white van carrying the community team turns off the road and bounces along a rutted track to a group of houses half-hidden in the rubber trees. The team of doctor, nurse and volunteers enter a house

where Surendran, a former rubber tapper aged 50, is lying on a bed naked to the waist, his lower body covered by a striped cloth. His chest rattles, his stick-like arms are drawn up to his face and his breath comes in painful rasps. He is in the terminal stages of lung cancer, and for the last week has been unable to swallow – food, liquid or morphine tablets. A Josco Jewellers calendar hangs on the bare cement walls, under a strip light, and a blanket covers the window. Mini, his wife, stands at the foot of the bed.

Dr Raj lays a hand on Surendran's arm and gently explains that, as he can not swallow, to treat his pain the morphine will have to be administered rectally. The nurse will teach Mini how to do it. Dr Raj asks if he has any questions. "Can I get out of this?" Surendran says. Before Dr Raj can answer, Mini intervenes: "Yes of course you can. You will get better."

Dr Raj suspects she knows the truth, but decides against trying to broach it with her at that point, worried about the reaction it might provoke. Just as a wrong dose of a drug can harm, so can an ill-chosen word, he says later. A reflective man, with kind eyes and neat moustache, he comes ever ready to lay a soothing hand on a fevered brow. Wearing a blue open-necked shirt and sandals, his gentle demeanour and soft voice put patients at their ease while he probes for their stories before quietly instructing his team, who hang on his words.

"We help people live at home and die at home. Most want that," he says. But Surendran's condition is extreme, and his suffering severe, so Dr Raj urges Mini to bring him to the city, where there are a few hospice-style beds. She says she can not leave her 17-year-old daughter alone, so Dr Raj suggests bringing her too. While neighbours are often supportive, in this case they stopped visiting when they heard Surendran had cancer. Mini says she will consider it. The volunteers will help arrange transport.

The group that requested the home visit, called Sangamam (meaning "confluence"), was started four years ago by Dileep, 43, the manager of a paint shop, whose wife died of cancer. It is one of 11 that have sprung up in the Trivandrum area in the last decade. They are supported by Pallium India – the organisation Dr Raj founded in 2006 after he retired from the government medical service and moved to the city – which provided the mobile medical team.

Sangamam is one of the most successful groups, with 12 active volunteers and another 50 whose help can be drawn upon. It is funded by donations from the local community. In this case, friends have been generous enough to allow Dileep to hire a nurse and buy some land, where he hopes to construct a clinic. The local panchayat gives 50,000 rupees a year for drugs. "Because they are convinced we are doing good work," Dileep says.

Guided by the Sangamam volunteers, the Pallium India team sees two more cases this Tuesday morning in January. One, a woman of 55, who had her tongue removed a month previously because of cancer, has developed severe pains in her neck, which prevent her sleeping. Wearing a pink sari, she breaks down in tears as it emerges from Dr Raj's careful questioning that she has argued with her son in a dispute over land, and he has left. Sobha, a volunteer, has learned from neighbours that the son is planning to get married but has not told his mother. She undertakes to contact him to try to negotiate a reconciliation. Palliative care, in this conception, is about tackling emotional pain, as well as the physical kind.

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What Kerala has recognised, though the rest of the world has been slow to do so, is that the scale of the need for palliative care cannot be met by professionals alone. In the UK, the hospice movement provides the gold standard for end-of-life care. Yet just 4 per cent of deaths occur in

hospices. Most people – over three-quarters in some surveys – say they would prefer to die at home, but less than a quarter do so.

Julia Riley, consultant at the Royal Marsden Hospital, London, and visiting professor at the Institute of Global Health Innovation, Imperial College, says: "Hospices do terrific things – but there are not enough of them. We have got to get the service out into the community – it can be done at home. Only 10 per cent of people who are terminally ill need specialist palliative care. The rest need only generic care.

"Palliative care is so cheap. We can do so much, relative to other areas of medicine, for so little. Giving people a dignified death is so important – both for them and for their families."

In the UK, the number of deaths is rising as the postwar baby boomers age, says Max Watson, consultant in palliative care at the Northern Ireland Hospice and visiting professor at the University of Ulster. "To continue in the way we are – relying on hospices and specialist care – isn't an option," he says. "It is really important to democratise specialist knowledge. We need to engage carers, voluntary groups, nursing homes and patients themselves so they can be empowered to provide good-quality end-of-life care. Most of those helping are over 60 themselves. They are a fantastic resource we are not using properly."

In the US, hospice care is more widespread – 45 per cent of Americans at the end of their lives in 2010 received hospice care, more than half of them at home. These are among the highest rates in the world, according to Atul Gawande in his book *Being Mortal*. However, spending on the US health system is widely acknowledged to be out of control, substantially outstripping the costs of comparable systems in Europe.

The Kerala model is thus drawing attention from around the world. The estimated 300 voluntary groups are often described as a network. This

suggests, wrongly, that there is some overarching organisation that links them all. In truth they are a series of networks that have grown organically, from the ground up, wherever the community has decided there is a need. One of the biggest is the Neighbourhood Network in Palliative Care in northern Kerala, led by Suresh Kumar, Dr Raj's former colleague.

In Trivandrum, Pallium India, staffed by six doctors, five social workers and 20 nurses, provides five mobile medical teams to support the 11 local groups. It also runs an outpatient clinic and an inpatient unit with 17 beds at Arumana hospital in the city, and provides outpatient services at four government hospitals.

In 2016, the mobile teams made 6,397 home visits. Some patients are starving and Pallium India currently provides 225 families with a monthly food kit, containing basic supplies, and supports the education of 300 children, in addition to supplying free drugs.

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The work of creating the voluntary groups starts with talking to local people, explaining that hospitals are no place for the dying and that caring for the terminally ill is the community's responsibility. The concept of palliative care has been extended to include the chronically ill and the paraplegic, such as stroke survivors and people with complications of diabetes, including blindness and amputation, who now constitute up to half the patients.

Once a group is formed, Pallium India encourages the organisers to register it – for the sake of transparency and to gain tax advantages on donations – and offers support with regular visits from a doctor or nurse. But the aim is that the groups should ultimately go it alone.

Their origin in the communities they represent is their strength. But the absence of any top-down organisation is also a weakness. It means there is no mechanism for spreading the concept to other parts of Kerala, or other parts of India. Organic growth is slow growth.

Out of frustration with the lack of progress, Dr Raj established Pallium India to act as an agency to spread palliative care more widely, beyond the state's borders. "What has happened in Kerala is beautiful. But it should not be stuck in Kerala. It could be 1,000 years before we get universal pain relief [across India]," he says.

With the help of grants from foundations, donations from well-wishers and support from the Tata group, Pallium India has established 23 palliative care centres across India by providing initial funding to interested groups, training doctors and nurses, and giving support.

Kerala has been a pioneer in other ways. Its government launched the first state Palliative Care Policy in 2008. Two other states, Maharashtra and Karnataka, have followed suit and a National Palliative Care Strategy for India was published in 2012. A working group appointed by Pallium India drew up a list of essential standards, including a minimum 10 days' training in palliative care for doctors and nurses, an uninterrupted supply of morphine, and documentation of patients' pain scores.

But Dr Raj, who lobbied for the strategies, is not satisfied. "I am upset when the palliative care community boast about what we have achieved. We are not doing nearly enough. 99 per cent of people in India do not get access to palliative care."

He pauses to reconsider this bleak assessment. "Okay, if I want to be optimistic, I can put it another way. 1 per cent of people do have access to palliative care. That is 12 million people."

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Central to the provision of care for the dying is the alleviation of pain. But even this is not being satisfactorily achieved. India is the world's largest legal producer of opium for medical purposes. But most is exported to the West. Over 90 per cent of the world's morphine consumption is in the countries of North America and Europe. All middle- and low-income countries combined consume just 6 per cent.

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

Kerala has again proved more enlightened than other Indian states. Since 1998, palliative care centres in Kerala have been permitted to administer the drug orally. Much more recently, in 2014, the law was finally relaxed to allow access to morphine across India.

But Dr Raj is again unimpressed. "Changing the law is not translated into practice unless someone is pushing it. The new law has not had a big effect. Figures show India uses 320 kg of morphine a year. To meet the need we would need to use 30,000 kg."

He added: "This is why it is vital to seize this moment, when the iron is hot. If we do not act now, it may be too late."

Volunteers are the linchpin of the Kerala model. Krishnaraj Manikoth, a retired chartered accountant who now helps at Arumana hospital, says the work offers a sense of purpose. "I worked for 30 years in Dubai. I had a comfortable life, two wonderful children – I was blessed. What bothered me was that I had not done anything for society. I wanted to

give something back."

Sintu Suresh, a former journalist and speechwriter whose father died a painful death in an intensive care unit, says she wanted to protect others from over-treatment. "Doctors don't see the whole patient, the human being. They see only the disease," she says.

"I begged those treating my father to give him something for the pain. I told them they could keep sending the same bills but to stop torturing him. Only on the last day did they mention palliative care."

In the UK, it has been estimated that there are more than 100,000 volunteers working with hospices (and nearly 500,000 in the US). Few, however, visit patients in their homes. An exception is the Hospice Neighbours scheme run by St Nicholas Hospice in Bury St Edmunds, Suffolk.

Established in 2011, the service helps between 120 and 150 people with terminal illnesses in their homes at any one time, supported by more than 150 volunteers who provide comfort, companionship and assistance with household tasks. The scheme, started by chief executive Barbara Gale, won the Queen's Award for Voluntary Service in 2014.

Gale interviewed 16 volunteers for a paper published in BMJ Supportive and Palliative Care in 2015. She found what chiefly motivated them was the opportunity to "make a difference". Many said they found the patients "inspiring", death became "less scary" and the experience made them think differently about life.

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Death and dying are taboo topics in many countries. Essential medicines are in short supply and there is little spending on [palliative care](#) research.

Dying is seen as a failure of the health system to successfully cure.

The pain of dying is compounded when families desperate to find a cure but ignorant of the poor prognosis are aided by doctors ready to impose high charges for ever more interventionist, but useless, treatments. The result is increased suffering for the patient and often penury for the surviving relatives.

The Kerala model helps protect its citizens from the excesses of the medical system by enlisting the support of the community to comfort the dying, enabling the terminally ill to be cared for at home, where most prefer to be, and providing support to bereaved families in their hour of loss. It is one from which the world can learn.

Since this article was written, Surendran has died.

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