

## **A Doctor and his 'Wisdom of dying'**

**Dr. Suresh Kumar**

**Institute of Palliative Medicine**

**"Hello doctor, come and have some tea."**

Dr. Suresh Kumar turned to see who was inviting him. It was a person whose sister had received palliative care from Dr Suresh.

"He called me when I was passing by his house. Our connection was through death. His sister had passed away recently due to a debilitating bone cancer. The good thing was, the family had been positive. They didn't grieve about the suffering. Then you realise you play an important role since you are easing the pain during the most difficult phase of one's life. It may not be a heroic role. You know the person will die soon. But as a doctor, you need to do all that you can to help the person and make the transition easier," said Dr Suresh in a candid manner, about his work.

We hardly think about death. Where would one like to be when he or she dies? How much comfort is crucial for anyone, emotionally and physically? Whose hand would one want to hold when one is about to die? Though death is a common fact of life, not much is known about this phenomenon from a subjective point of view. But thoughts of death may cross the minds of those who are sick, especially the terminally ill. Medical care given to such patients with terminal illnesses that have no curative treatment is known as palliative care. Dr Suresh Kumar is an intensivist - as a palliative care doctor is called - and has to interact with the terminally ill and soothe their pain in the final phase of their life.

He understands such patients' need to talk about the countless facets of their lives, their regrets, desires, their sins and so on. Also, there is a desire to die at home or a familiar place, away from beeps of various monitors wired to your body and to have a conscious goodbye to the world, holding the hand of a loved one.

### **Palliative care – an explainer**

Before the emergence and wide application of palliative medicine, it was a common practice in the '90s to discharge terminally ill patients from the hospital wards. Their families, lacking in finances and awareness, were left with the challenge of caring for their loved ones in their last days.

Family members also suffered along with the ill person at home, more in fact, when the patient was suffering and in pain. It was an extremely difficult responsibility for the family to take care of the patient and to take the patient frequently to the hospital for multiple and recurring complaints. Patients often died on the way to the hospital or on their way back home; families found such an end hard to take and were riddled with guilt and anguish for a long time.

With improvements in the determinants of health, combined with the success of modern medicine, life expectancy has increased. In the early '90s, life expectancy of Indians was 57; this gradually increased to 68, by 2014<sup>1</sup>.

The elderly, who are older than 60, has increased from 6% of the total population in 1991 to 8.3% of the total population in 2014<sup>2</sup>. Kerala is a state which saw this demographic transition first in India, and also saw the increase in morbidity rates (more than 50% in the age group of 60 years and above).

WHO defines palliative care as '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'. Initially, the focus of palliative medicine was on cancer patients, where after the cancer reached a certain stage, the treatment would not be able to cure or control the spread of cancer.

Eventually, this branch was applied to other chronic diseases such as AIDS, cerebrovascular illnesses like stroke, respiratory disorders and kidney failure. In all these diseases, definitive treatment is not available, the patients need regular medical support and the painful symptoms persist till the end.

In 2011, around 29 million people died from diseases that required palliative care. Most of these people - 94% to be precise - were adults above 15 years of age and roughly 69% of them were over 60<sup>3</sup>.

In Kozhikode, the Institute of Palliative Medicine (IPM) has been providing palliative care to patients at the institution level as well as at the community level. There is a new state program for community-based palliative care. An extensive network of trained volunteers across the state including in rural areas, provide relief to needy patients to ease their pain in terminal phase. Journey of the person who played a major role in this movement and

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<sup>1</sup>World Bank data: accessed at <http://data.worldbank.org/indicator/SP.DYN.LE00.IN> on 18th Jan.'17

<sup>2</sup>SRS Statistical Report 2014, accessed at [http://www.censusindia.gov.in/vital\\_statistics/SRS\\_Report\\_2014/6.%20Chap%202-Population%20Composition-2014.pdf](http://www.censusindia.gov.in/vital_statistics/SRS_Report_2014/6.%20Chap%202-Population%20Composition-2014.pdf) on 18<sup>th</sup> Jan.'17

<sup>3</sup> Global Atlas of Palliative Care at the End of Life: World Health Organization (WHO) and World Palliative Care Alliance, January 2014

brought change on the ground, Dr Suresh, is interesting as well as inspiring; not because of the achievements but because of the path by which he brought masses to walk along with him and ultimately created a parallel, community-based system for care.

### **The formative years**

The first-born of a teacher couple, Suresh was born on 15 January, 1961 in Keechery village in Ernakulam district of Kerala. He had a happy childhood, sometimes 'bossing over his four young brothers', as he recalled. Gandhian philosophy had been a great influence on his parents. "Just across the road from our house there was a small school. I used to go to the school whenever I wished. When I was five, I was already in standard III and my parents and teachers felt that I had to be formally enrolled. Thus, my formal education began by skipping two classes altogether. There was no pressure from my parents about our studies. There were no tuitions. By 4 O' clock in the evening we used to be free," he reminisced.

Suresh was exposed to books at a very young age, thanks to his parents. He read fast and hence borrowed one or two books every day from the small panchayat library in the village. History, literature, fiction – he read whatever he could lay his hands on, without confining himself to any genre. With no television and computers back then, books were the windows to the outside world.

"I saw a computer for the first time when I was in the fourth year of my MBBS. Also, there was no electricity at home till I graduated. Our education system was such that even English was taught using our mother tongue Malayalam. It took me many years after graduation, to learn English. But I don't see these as difficulties, but accept them as a part of life," he said. All the factors seem to have played a role in moulding him.

### **Learning medicine and more**

Back then, with limited career options, a student good at his studies chose to become a doctor or an engineer. Suresh graduated in chemistry from Kannur. His family being politically active, he engaged in student politics from a fairly early age. This experience helped him in understanding the masses and in mobilising them, though he left politics when he joined medical college. As a medical student, he became interested in development issues. He said that he tilted to the leftist ideology during his medical college days, although he never joined any political party.

"We were a small group of students, trying to do something at a time when a lot of campuses showed a lot of creativity post-emergency in the 80s. It had nothing to do with medical education. Many considered us 'The Associated Anarchists of the People of the Streets'. I used to engage with protesting groups of fishermen, students in other campuses

and political activists. No medical student would have done so. It was a period when the gates of college campuses were more open and it was used as an opportunity.”

His understanding eventually started becoming deeper and wider. He used to organise meetings, interact with various young student and political leaders, and participated in student agitations. Dr Ranjini, one of his classmates in medical college, recalled many incidents where he was at the forefront of major protests in college. Suresh used to question everything including the teachers and the management, which was in contrast to the expected upbringing of a typical Indian child of that period. Although, looking back Ranjini agreed that he led agitations for a good cause. Though many of his classmates opposed his views and actions then, there is no lingering resentment; and their friendship has strengthened and matured over time. He became a member of the ‘Medico Friend Circle’ a pro-poor group of health practitioners that includes colleagues such as public health specialist-cum-activist Dr Binayak Sen and medical ethics expert Dr Amar Jesani. All these engagements changed his perspectives. He started asking questions to himself which were difficult to answer, propelling himself to do something.

Suresh reminisced that his was the last batch of students in Kerala that joined professional courses without an entrance examination. Admission was based solely on the score at the degree level. “In our batch, we had a lot of students from the lower middle class, but later on this percentage dropped dramatically. But even when a person from middle class or lower middle class joined medical college, he or she developed an aristocratic attitude by the time of graduation. Medical school transforms you,” he said.

But some like him did not go through such a transformation. When someone asked him how he stayed rooted, he jokingly replied, “I skipped a lot of classes. I spent a lot of time on the streets of Kozhikode.” On a serious note he added that he managed to resist this attitudinal change. “Even when I graduated, money was not important for me; not that I had a lot of money. I think I was never influenced by money. That perspective helped me take the important decision of switching from anaesthesia to palliative care,” he said.

After graduating from medical college, he wished to pursue psychiatry, but changed his mind after seeing the unethical treatment methods and indifferent and rude behaviour of the doctors towards patients and their families.

He worked in a mission hospital for a while. Frustrated, he took to teaching biochemistry, his favourite subject. He taught for almost a year, while preparing for his post-graduation.

## **Foray into palliative medicine**

He joined a post-graduation course at Calicut Medical College in 1988, to specialise in anaesthesia. After post-graduation he worked in a couple of private hospitals and soon established himself as a good anaesthetist.

While working as an anaesthetist, he felt disconnected with his patients as there was hardly any interaction. But he was also working on pain relief with Dr Rajagopal, one of his professors.

In the late '80s and early '90s with no radiological assistance, finding the right vein and blocking it was quite challenging. But Suresh soon gained mastery over it and was very happy with his work. Initially he thought that they were helping the patients, especially terminally ill ones, by relieving them of their pain. But while interacting with patients on subsequent review meetings, he found out that pain was only a part of their larger set of problems. He said, "I used to be very happy after blocking the right nerve for patients. But when you speak with them and get to know about the other aspects of their life, you realise that you are not doing much. Of course, there is a limit to what a doctor can do. But you realise the futility of doing something that does not improve the patients' life."

Aspects such as loss of livelihood, food security and travel related issues particularly for bed-ridden patients, set the doctor duo ponder about caregivers' responsibility towards these patients. His earlier ideological stances and involvement in student politics, had given him different perspectives of life. He felt that he was better-placed in society due to certain circumstances. It was also likely that the circumstances might have been reversed where he was the patient. He felt that helping these patients, especially the marginalised and vulnerable ones, was very much a part of his responsibility.

Around this time, incidentally, a nurse from the United Kingdom came down to the Calicut Medical College to deliver a lecture on palliative medicine. Suresh realised that it was his calling and it was something he could do his entire life. Although Rajagopal and Suresh were practising something of a similar nature, they felt the need to learn more about palliative medicine. Suresh went to the United Kingdom in 2000 to do post-graduation in palliative medicine at the University of Wales in Cardiff.

Prior to the formal training, he had already set up the Pain and Palliative Care Society along with Rajagopal in September 1993 with the intention of providing institutional and home-care to terminally ill patients. Through the society, they also wanted to have a specialized in-patient care unit, besides providing support to doctors treating the terminally ill. There were no funds available for their work and at that time hardly any funding agency was able to understand the significance of their intended work.

## **Full-time dedication to palliative medicine**

Initially Suresh practised anaesthesia in the morning and palliative medicine in the afternoon. They started the practice from a small room in the Calicut Medical College. For the first six months, Suresh tried to balance his practice of anaesthesia and palliative medicine.

When the free service was started, there were nearly 200 patient registrations the first year. Soon their work became known and the number of patients increased to 2000 the very next year.

In the early days of the Society and his marriage, Suresh told his wife that he wished to quit his practice as an anaesthetist. His family supported his decision, after overcoming their initial apprehension. They were quite relieved that he was not getting into active politics, which had seemed inevitable earlier. Suresh said, "I actually liked anaesthesia but I had to leave it. It was a time of uncertainty and insecurity. My wife was not happy but supportive. Fortunately, our lifestyle was very modest and we had minimal needs. My well-wishers questioned my decision since I had established a good practice."

The family's major concern was that his income would drop to 20% of what he was earning as an anaesthetist. His wife Mohana said candidly, "It was a big decision. It was so early in our married life. We were ready to face challenges, but we were also confused. In spite of mixed feelings and concerns about our financial status, we went ahead. My fellowship money was enough as we led a very simple life." Fortunately Mohana got a central government job as a zoologist and their anxieties about the finances vanished.

Initially, the services were only institutional, based from the small room in Calicut Medical College. However, their work was recognised and they were successful in signing a Memorandum of Understanding with the Government of Kerala, whereby the government gave them land, with the support of an IAS officer and health secretary, Mr Vijaya Chandran. It was the first big step for the organisation. "With the MoU, we became more secure and it kind of gave legitimacy to our work."

The doctors had no set blueprint to develop the organisation. It was quite serendipitous that they moved in the direction of community-based care. As their work grew, they started getting requests for home visits. Initially, community care involved visiting patients' homes as most of them were cancer patients, whose conditions start deteriorating over time. Home-care was a concept new even to the doctors, but they responded to patients' calls. They knew it was not possible to bring every patient to the medical college hospital, as various reasons were involved. "I have even travelled to villages in Kasargod, which is around 200 km from the hospital. There was a patient who had ascites or accumulation of fluid in the abdomen. The local doctor was not willing to drain, so I went and drained it. Some of the patients were bed-ridden and to bring them to the hospital in an ambulance

would have been very expensive. So, we visited patients at home and we kept the cost of palliative care it free right from the start.”

### **Initiation of the volunteer-driven services**

As their work fell into a routine, one of Suresh’s friends approached him to find out if his wife could contribute to their work in any way. Trained as a laboratory technician, she was one of their first volunteers. She brought another friend and it soon snowballed into many more volunteers. Suresh said, “We had not even thought of it. When we started we were not sure of what help the volunteers would be. Dr Rajagopal and I were used to a system where volunteers were not involved in active services, but only in back-office operations. But we were open and flexible and hence when this opportunity arose, we started thinking of how to use it.”

From two, their team has grown to more than 15000 volunteers in Kerala alone, who contribute extensively to the community-based care of patients.

The Society started their first satellite clinic in 1996 at Manjeri in Mallapuram district. Their model was still largely institution based, where the patients were brought to the institution by the volunteers. The volunteers were from the same village as the patients. More than six years after this practice started, they realised that the volunteers could support the patients at the village itself, instead of bringing them to the hospital. So gradually they started community-based trainings, initiated community services and their entire model became community focused by the late 90s.

### **Challenges of setting up their palliative care model**

The path they trod to establish a community-based model has not been easy. There were several criticisms to the volunteer-driven model. Detractors pointed out ethical concerns in maintaining confidentiality of the patients’ medical history. But the doctors were clear about delegation of tasks to the volunteers. The volunteers provide psychosocial care, but are never allowed to prescribe. The volunteers checked for compliance of the patients’ intake of medicines based on the prescriptions given by the doctors.

The initial problems that the doctors faced with the volunteers was that they got false negatives, i.e. the condition of a patient reported by a volunteer as serious would turn out to be not very serious. Such teething troubles disappear once the volunteers gain some experience. Suresh is pretty satisfied with the way the volunteer-driven model has evolved.

There was opposition from some local oncologists, when the number of patients in private practice started declining as a result of the new palliative care program. The Society was

giving home-based services for people with advanced cancer, besides helping them deal with other issues. Many private practitioners seemed suspicious of this kind of practice.

Suresh explained that their views were completely different. He said, "This is death; and dying is not a medical issue. There have been questions about volunteers participating in palliative care. I used to counter argue, about the efficacy of a physician in social and spiritual care. Basically, this problem is seen from a biomedical paradigm since that's how doctors are trained to see it. We tried to change the context and defined it as a problem of the social paradigm."

Initially volunteers used to come to the OPD or Out Patient Department. The doctors used to treat the patients. Volunteers would interact with the patients, take care of their needs and offer emotional support.

It was a major transition in the sector and many were sceptical about the sustainability of the model, as it was predominantly dependent upon volunteers and not health workers. The medical fraternity disliked the idea of delegating responsibility to volunteers. However the volunteers did not give any treatment but just helped in alleviating patients' pain, coordinate with doctors and refer to the hospital. So there was no risk involved.

The volunteers were trained and told what to do in specific situations. There was always a component of supervision some way or the other. Drugs such as morphine were handed over to the patients or the care-givers, who were mostly family members. Morphine is a good and low-cost medicine, effective in relieving severe chronic pain of many patients.

Distribution of morphine was under strict control making it almost impossible for a common patient to get it. Its availability at the palliative care centres was a big step for controlling pain of many patients. Suresh said that before the control over morphine was eased, there was much advocacy, with some overplaying the impact.

"Morphine is like any other drug and now we have a balanced approach towards it. One should not equate palliative medicine with morphine. Unfortunately, in some parts of India it's still not available, since medico-legal aspects and community perception are involved. In Kerala, patients on palliative care can get it if necessary, with the help of volunteers," said Suresh.

While many programs across India find it difficult to get and retain volunteers, Suresh has managed to get a large battalion of volunteers. Earlier he used to tell people that they should be compassionate, should consider the well-being of the society and how one could play his or her part in reducing the suffering of the sick. But over the years, the Society has changed its stance. "We now focus more on the individual's self-interest. We tell people that suffering towards the end of life is universal. Only 15% of the people die a sudden death; the rest experience some sort of illness. Anyone of us, including me, may develop a similar illness. We tell the volunteers that this process will establish a system that will



eventually help them in future,” he explained, adding that it is a sort of a selfish appeal to the people.

Some of the other critics say that they are not doing enough for cancer treatment. Many still equate palliative care to cancer. Most of the palliative centres outside Kerala are attached to cancer hospitals. Suresh explained that they realised this when they moved into community-based services, much before the concept of palliative care changed globally. WHO statistics released in 2014 state that only 20-25% of patients requiring palliative care are cancer patients; the rest have other disorders.

Suresh explained that community-based work is more important, as highlighted by an earlier study. The study found that on an average the survival rate of a patient in the care of the community, is around 12-18 months, whereas it is less than six months in the case of institution-based care.

“When you go into the community, you meet a larger population with varying disorders. In institutions, 70% of the patients seeking palliative care are cancer patients, whereas it’s the opposite in community care. An old patient, bed-ridden with multiple disorders or someone who has suffered a stroke are unlikely to come to a palliative care institution. They know nothing about palliative care and how it could help them. A community-based model makes people aware of these services,” explained Suresh.

### **The Institute for Palliative Medicine**

The number of people seeking palliative treatment kept increasing, necessitating a separate in-patient unit. The training program that had been initiated for the volunteers and lasting for 15 days also needed a larger space .

Ms Val Hunkin, a nurse from the UK, came to Kerala with the support of Mr Bruce Davis, an industrialist, to teach one of the courses. When she went back to the UK, she informed him about the organisation’s work and he was very impressed. He visited IPM and promised his support to build the infrastructure to establish an institution. He sold one of his houses to fulfill his promise.

Assured of financial support, the Pain and Palliative Care Society applied to the government for land. The then health secretary, Vijay Chandran forwarded the request to the cabinet. It was approved by the cabinet immediately. The government gave permission to construct buildings and directed the district collector to allot land. Suresh said that they sought permission to construct the building, but not land. “The district collector pointed out that this was a once-in-a-lifetime order from the government. He said he would allot 10 acres so that there would not be any problem in future,” recalled Suresh. He feels that they were lucky in getting the land and the funds to construct the building, as they could never have

raised the funds on their own. This is the story behind the current building that houses the 'Institute of Palliative Medicine' that was inaugurated in 2001 near the Calicut Medical College.

### **Advocating with the Kerala government**

When Suresh initiated work in any part of Kerala, he asked the volunteers to meet the local politicians and panchayat members to brief them about the work. This helped them reap dividends later.

Suresh believes that his earlier foray into politics helped him in these aspects. Unlike his contemporaries working in NGOs, he believes that the political system is a part of the civil society and they should not be excluded from community-based activities. Suresh and his team always kept their doors open for politicians and even trained them in palliative care. People criticised him and said that the politicians were doing it to get votes.

But such criticisms did not bother Suresh as he said, "I would rather have an elected representative who is sensitised to palliative care rather than a person who does not know anything about it. If they are doing it for votes, then what are the others doing it for? Someone religious may say that by virtue of his deeds he seeks salvation. Ultimately you do it for some reward. Their reward is votes. Unless they don't do any harm, there's no problem." An interesting observation he shares is that local politicians who associated themselves in their work garnered more votes in panchayat elections.

Once panchayat and local governance entities started affiliating themselves with this cause, the movement gained political importance. Politicians understood the importance of palliative care and the emotional connect of the masses to the care movement and they also started supporting it. The movement made its space in political circles and there was no opposition and all the parties irrespective of their different ideologies were supportive. Unlike Kerala some states lack community participation and even though there is policy on provision of palliative care, nothing much is delivered on ground. "Without community participation, policy is just a piece of paper. We need to take people along with us to make a difference," said Suresh.

In 2008-09, the Kerala Assembly passed Pain and Palliative Care Policy (including ease on morphine availability) for the state, a legislation introducing palliative care as an agenda for panchayats. Suresh and his colleagues spoke with the then health minister who already knew about palliative care. When the bill was introduced in the cabinet, more than half of the cabinet ministers knew about palliative care and supported the bill. Even in the Assembly, there was no opposition. Such unopposed passage of the Palliative Care Policy may be unthinkable in other states. But it had its roots in the earlier hard work put in by Suresh and his team.

The Assembly not only passed the Palliative Care Policy, but also made it mandatory for the panchayats to implement palliative care projects at the panchayat level. Some panchayats had introduced palliative care on their own, but the Act gave a new meaning to palliative care across Kerala. Suresh was made the nodal officer to implement the project under the National Rural Health Mission's (NRHM) Palliative Care Project under the Ministry of Health and Family Welfare. He explained that his role was only of facilitation; they provided a template and each of the panchayats implemented it. The idea was to sensitise people about home-based care to facilitate palliative care through primary health centres (PHCs) across Kerala .

### **Role of media in advocacy**

Suresh highlights the role of media in achieving the current status of palliative care and even in developing the volunteer base. The doctors' drive was supported by Malayala Manorama, a Malayalam daily widely read in Kerala. In 2008, they ran a three-month-long campaign called 'We are with you'. It was a very unique and successful campaign, creating awareness among people, bringing them together for this cause and increasing the community's involvement, thus leading to increased enrolment of volunteers. People started to understand the needs, pain and suffering of patients for whom there was no cure. The campaign touched the hearts of the masses and made them more compassionate. All sections of society participated in various possible ways – including monetary contribution and volunteering. Even though the campaign was for just three months it had a huge impact. Youth came forward to be a part of the palliative care program and a volunteer unit was created in almost every panchayat. It also increased the awareness about the need for palliative care for patients with other disorders too, as awareness spread amongst the medical fraternity as well.

The campaign and its impact were unprecedented as it was solely based on community leadership and ownership. Reporter and writer Joshua P Joseph said, "It was a great revolution in health care. I saw the mindset of the society transforming. People really didn't know what one could do to their loved ones in such a condition." The hugely popular newspaper raised awareness about paralysis, cancer, stroke and cerebral palsy. People contributed to this cause by making micro-donations consistently and supporting IPM in its work. Suresh acknowledges the role of the Press Club of Kozhikode, which has never charged them for press conferences.

It was a sincere and grounded movement' according to Joshua. "Community ownership and avoiding corporate funding are the unique aspects of this effort. This has helped the initiative thrive without any dilution in motives. Dr Suresh is spreading spirituality and the concept of death has changed in our minds," said MrJoshua.

## **Funding support for IPM**

The Society never relied on institutional donors. They received their first big grant from Department for International Development (DFID), United Kingdom. Later they received funds from other institutions such as Tata Trusts, but the main funding source has always been individual donations. Over a period of time, they have realised that this is more practical. Suresh explained that micro-donations have been more helpful and more stable than institutional funding. Big capital investments are garnered through institutional investors, but recurring costs are met through micro-donations.

They have launched a program called 'Tracks we leave' and encourage people to donate for compassion. They plan to build a base of at least 15000 donors who would be able to contribute a minimum of Rs 1,000 per year. There are administrative problems in such initiatives, as people don't contribute on a regular basis. Suresh said, "You get funding for one or two years from big institutions, but unless you don't develop a local platform, the program won't be sustainable and it then leads to questions about your credibility. Most people are willing to pay. But the issue is how one mobilises so many people and ensures that they pay."

## **Retirement from IPM**

By 2012, Suresh was already planning to dissociate himself from the institute he had created. But he was emotionally attached to IPM and the work. He knew at heart that he had to leave, but found it extremely difficult to do so. After having seen death so closely through the eyes of different people, he knew that for the organisation to sustain, he will have to leave at some point of time.

In 2012, he was selected as an Ashoka Fellow, a prestigious award and recognition with financial support for taking a new endeavour towards betterment of society in an innovative manner. He was very delighted on receiving the Ashoka Fellowship, and utilised it as an opportunity to handover the mantle of IPM to his colleagues. He started reducing his work hours at IPM and started travelling to other parts of the country more frequently. He started working on different platforms and initiated activities on a broader plane. The fellowship helped in all this, as they offer financial support in the first three years, although one remains a fellow for ones lifetime.

He knew that the real challenge was always within himself. "Developing an institution is easy, but leaving it is the most difficult part. The issue is within you and not with the people working with you. While talking to my colleagues, I used to feel that they were also dependent on me. But from the interactions with my patients, I know that nothing is

forever. If tomorrow I die suddenly, the institution and its people will have to survive. But once I decided to quit, I had to do it. I had to overcome the barrier within me. It's very emotional. It's like giving up your own child," he said. So now even after leaving, he knows that there might be some work that needs his support. People still discuss the institution's activities with him. He still remains a part of the IPM family. He continues to be associated with IPM as a technical advisor, but not as a decision maker.

According to Suresh the institution is more independent now, but not without hiccups. The institution has always had a fairly good second line, but the problem is the availability of physicians. There are pressures from the family and the society for the doctors working at IPM. The pay is less in comparison with what may be available in government or private hospitals.

"Families appreciate the work at IPM only if their neighbours are doing it and not their own kids," he said. So most of the junior doctors leave IPM after one or two years of work, most of them citing societal pressure. But he is satisfied that there is an option for medical graduates. He remembered his own college days when he was not interested in working under the ambit of a hospital. It was one of the most difficult periods in his life and everyday was a struggle. He said that there are many more like him and palliative medicine has given them a different option. "It's a different system altogether, where you practise medicine in a more open and holistic manner and you work really closely with local people. For someone, who gets disillusioned with the current system, for someone especially like me, there is at least the option of palliative medicine now," he said.

### **Expansion of work outside Kerala**

While initiating his work, Suresh struggled to bring people together to work along with him. Convincing people to do something new is always difficult. "People told me that I was crazy. Though they asked me why I was doing it, they knew it was necessary. There are no systems to take this challenge and one needs to start at some point." But as people observed the impact of his work, they got convinced and things started falling in place. Community not only accepted the ideology but started participating in it.

"Initially people said this wouldn't work. Later they said that it worked in Kerala but wouldn't work outside. So now we are proving that it can work outside Kerala too. As my involvement at IPM has come down, I am able to concentrate on expanding this work to other places. For example, I am setting up a similar palliative centre in Bangladesh. There is no blueprint for doing this kind of work. You plan as you work with communities. There cannot be one model that will suit every situation. We train them, take them through our experiences, and link them up with the system. Depending upon the situation you try differently. It's a trial and error sort of a thing, learning and re-learning, and you become confident as you go with these experiences. I have projects which are going very good in

their starting phase in the poor and rural district of Nadia, West Bengal –, Pondicherry, Manipur, Thailand, Sri Lanka and Indonesia. You have to appeal to the good side of the people. It need not to be a religious or spiritual reasoning. Only 15% people die suddenly and it's more likely you are going to be in the other 85%. Today someone else is there, tomorrow you will be there. It's for their own good. You need a system to take care of the people.”

Very modestly Suresh said that in all these places, he plays the role of facilitator to support and link people and to train them. He is willing to share the knowledge and experience he has gained. His work in Manipur was initiated through Dr Sorokhaibam Jugindra who did MBBS with him in the Calicut Medical College. They had lost touch after leaving college, but connected after quite some time, thanks to social media. During their online conversations, Suresh explained his work and Sorokhaibam found it quite fascinating. He expressed a wish to initiate a similar service in Manipur. Suresh visited Manipur in June 2014 and within two months he trained a few doctors in Imphal. Sorokhaibam who is a general surgeon registered an NGO called Palliative Care Society, Imphal in August 2015. Currently they provide home-based voluntary services for approximately 30 patients free of charge.

Globally around 8% of the people need palliative care. Our healthcare systems are not capable to deliver such a high volume of specialised care. People in most of the low and middle income countries struggle for access to primary health care. The model has to be community-based and volunteer-driven under the supervision of specialist. Unfortunately, there are very few specialists and in current medical training there is not much emphasis on palliative medicine.

Recently Tata Memorial Hospital, Mumbai received approval to start a course in palliative medicine with two seats per year. It is currently the only centre in India which offers palliative medicine as a specialisation. Other experts are either trained abroad or have acquired the skills by their own interests. Suresh was trained abroad where care is institutional and of high quality. It differs with the Indian scenario since hospitals abroad are better-funded, have an efficient public health system and there is less population to cater to. But the Indian community needed a radically different model. The government has limited resources and there is hardly any awareness of the need for palliative medicine. Hence the movement needed base in the masses and this has been the major contribution of Suresh.

### **Work-life balance**

Through the years Suresh had constantly been on his toes to serve needy patients. On the one hand, he was trying to mobilise palliative care movement and build IPM, and on the other he was trying to bring academic rigour to the care models. He was so engrossed in this work that he could not give time to his family.

“He gives all of his time for palliative care and he has no time for the family. I was frustrated, especially after my parents passed away, since they used to help me a lot. Then I had to look after our son Gautam single-handedly and take care of all the domestic responsibilities. But I knew that he was out there for a cause and not partying,” Mohana explained the impact on their family life.

“But he was very supportive to my career and research. He gave me complete freedom. Many men restrict their wives but Suresh let me pursue all that I wanted to. I had to do multi-task but that exposure helped me to develop,” she revealed. She added that he is a focused person with wide interests. “You can talk to him on almost any topic. Many people seek his advice for their personal problems also and they find his suggestions acceptable. He is a very stable person and never loses his temper. I myself seek motivation from him,” she revealed. Mohana is a scientist who has been awarded twice for her exceptional performance at the Zoological Survey of India. She gave credit to her husband for her success.

Gautam their son said that he did not expect his father to be there for him always. “He has his own commitments; but it helped me gain confidence and resolve things on my own,” he said. Gautam admitted that he did not have much of an idea about his father’s work till recently. “One day we were at a restaurant, arguing about his lack of time for us, when a person came and thanked him for his work and contribution. Then I started looking at it differently. When people come to know that I am his son, they talk about his work and treat me differently. So eventually I realised the importance of his work,” said the young engineer. But after volunteering with IPM Gautam has decided to move from engineering to social work and development.

Suresh worked in UK to as a consultant in palliative medicine in 2000. “Within one-and-a-half years I earned enough money to build a house and I returned. People felt that I was making a mistake. But I like India more. Life in India is spicier. There is spontaneity and this place is colourful,” he said with a smile.

### **Moving on from palliative medicine**

Now that he is away from the ambit of IPM’s work, he feels that he has moved on to the next level and on to a broader plane. Apart from spreading the message of palliative medicine, he dedicates most of his time to different projects like ‘Compassionate Kozhikode’ (<http://compassionatekozhikode.in/>). This is an expansion of his work at the PPCS where a volunteer-driven network is creating a culture of sharing towards betterment of the society. He has started conducting workshops called ‘Living well and dying well’, wherein he advocates changing behaviour and thought process to become more compassionate, mindful and empathetic towards other people. “Practically when you look at it, it is not

related to palliative medicine, but I could see a continuum. Most of this has happened because of the 'wisdom of dying'. You start seeing things in a different light," he said.

He is also involved in a Government of Kerala project to improve hospital facilities for people with mental health disorders. On asking why the shift to mental health, he said, "It's a demand from the community. People used to ask us about care of psychiatric and chronically disabled patients. As medical professionals, we see mental health or other chronic disorders or cancer as different diagnoses, but from the community it is only suffering. You go to the community with an agenda of cancer, but they show you it is not just cancer, the person has depression also. That was a big lesson from the community and a learning for us".

Globally also the scenario is changing. Most of the countries with programs on palliative medicine started with cancer only. But now they are slowly moving. WHO has recently come up with a manual on palliative services care planning at the primary care level and home/community level. Cardio-vascular diseases, AIDS, chronic liver disease, kidney failure and chronic respiratory diseases that require palliative care have been included in the manual. But IPM was already providing services to such people from within the community, "We have already cared for people with hemiplegia or quadriplegia, which was earlier not looked at from the purview of palliative medicine. It was an ethical and moral issue for us, when people showed patients who have been bed-ridden even for ten years. They would say, "If you do not take it up, who will? So we have already moved from a medical paradigm to a social paradigm," Suresh explained.

Aim of the medical practice is to prevent or delay the death but very less focus is on the process of death and needs of the dying. "Unfortunately in our medical training death is seen as a failure and not as a natural phenomenon It took me some time to come out of this mentality. People stay away from it, try to avoid it or postpone it. But as doctors we hardly recognise our role to facilitate the process and to do something about it. I probably hold the record for maximum number of patients dying under my care (which is typically considered very bad and looked down upon in medical practice). Many of my colleagues ask how I survive when 70% of my patients die. Well, it took some time for me to overcome. But, yes initially it was a problem," he said.

There have been many happy times for Suresh. Completing his MBBS or finishing his anaesthetist course made him feel very happy. He was happy when he was blessed with a son. Recently he felt very happy when he received the Ashoka Fellowship. But he reminisced, that although these are happy moments, the excitement dies after a few days. But the most happy moments that have stayed with him are when some relatives of a patient come back and thank him. The positive exuberance of these people makes him very excited. "It is not a happy moment, but a moment which adds meaning to your life; it's a fulfilling job. You feel that you have done something worthwhile."



There have been difficult times also, but he learnt to adapt himself. He reminisces that it was a struggle when he was building up this institution. Now he does not get frustrated with difficult situations; instead he has changed the way he responds to such situations.

There are huge needs of the family members as well as the care givers when they are providing end of the life care. So, all the training materials and modules at IPM focus on these aspects along with the technical knowledge. There are different modules for training volunteers, health care workers, nursing staff and doctors. Depending upon their responsibility and role modules are designed by the experts all across the world, making these training very opt and empowering to the participants leading to good impact on their services. There is also focus on self-care of the care givers and doctors. "Sometimes you get disturbed... especially when it's a young patient... you get attached to them...they ask questions... you feel really bad."

On seeing so much of death Suresh said, "Regular encounter with death makes you understand the value of life. You listen to their dreams. So, you realise that something that is in your hand is very valuable. And I get the privilege of listening to hundreds of dying persons, during last stage of their life, reflecting on their life. They are brutally honest about life. You also encourage them to find meaning in their life. We call it the 'wisdom of dying'. And I realised that dying well is possible only if you live well."

### **About Institute for Palliative Medicine**

The Pain and Palliative Care Society was formed in 1993 and started as an outpatient clinic at the Calicut Medical College. They recruited their first community volunteer in 1993 and have now grown to around 15,000 volunteers in Kerala. They started palliative home care with a mobile unit donated by the British High Commission in 1995 and setup a satellite centre in Malappuram district of Kerala in 1996. It was designated as WHO demonstration project in 1996 and they also initiated a Foundation Course in Palliative care in the developing world in the same year.

In 1999, with the help of four organisations, they formed a Neighbourhood Network in Palliative Care (NNPC) as a joint initiative. It is an attempt to develop sustainable community-led service capable of offering comprehensive long-term care. The Institute of Palliative Medicine was launched in 2001 and in 2007, was designated by the National Rural Health Mission, as a state level coordinating and resource centre to implement the first palliative care program in the country. This program has managed to cover 60,000 patients in four years and Kerala became the most well-covered regions in palliative care in the world. In 2008, they signed a Memorandum of Understanding with Bangabandhu Sheikh Mujib Medical University, Dhaka to start first palliative care service in Bangladesh. They launched 'Footprints' in 2009, a social rehabilitation program for bed-ridden patients, and helped more than 50 patients to become financially independent. In 2010, with the launch

of a 24X7 home care program, Kozhikode became the first city in India to have round-the-clock services for bedridden patients. In 2010, IPM became designated as WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care, becoming the first institution in the developing world to attain WHO Collaborative Centre status in palliative care. In 2011, they launched the first professional training program in Palliative Care in Thailand.

Today, because Suresh and likeminded group there is significant change in perception of society, social action, policy and health system towards palliative and end of life care, not only in Kerala but in whole of India. He has also has done academic contribution in community based palliative care and currently busy in capacity building in other developing countries. This comprehensive work towards this cause makes him inspiration for young public health and social work professionals.

## **About Dr. Suresh Kumar**

- Dr Suresh is the first to conceptualise and implement a community-based and volunteer-driven palliative care as against institution-based care
- Over 15,000 trained volunteers help the Institute of Palliative Medicine that Dr Suresh founded, care for the terminally ill
- Offers palliative care not only to cancer patients, but to others suffering from debilitating illnesses as well
- Has replicated the same model in many other states of India, besides in Thailand, Indonesia and Sri Lanka
- Has reached out to more than 60,000 patients so far

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