



10 March 2008

Dear Friend:

February was an eventful month. We had an international meet of palliative professionals in Kochi. There were deliberations on palliative care organized in Manjeri, a northern Kerala town, under another organization's auspices. In thiruvananthapuram, capital of Kerala, we had a refresher course which also featured world luminaries as faculty. Dr Robert Twycross, whose name has become a synonym for palliative care, was among them. Appropriately, he was honoured at the world meet in Kochi.

It was all a great deal of brainstorming. Lots of ideas on palliative care were developed and shared. From them emerged the awareness of a need to lay down standards for palliative care on a national basis. As we were engaged in all this, others were excited. So much so that BBC aired two radio programmes on palliative care. More about it later.

If you are tempted to skip the last paragraphs of this letter, resist the temptation. We have reserved some painful thoughts for you towards the end. Since the thoughts are tinged with pain, propelled by the experiences of a friend working abroad, you should not go away without savouring them. As in many cases, you may find the end here more relevant.

Care with Quality

Is the "quality of care" something to be discussed only in the context of developing countries? Is it a luxury in a developing country? This was discussed at length during the XV annual conference of the Indian Association of Palliative Care at Kochi, Kerala, 8-10 February 2008. In a plenary discussion with more than 300 participants, there was unanimous opinion that it was by no means a luxury, but an essential requirement during the early days of palliative care development in any country.

Pallium India had initiated attempts to address this issue in 2006. NHPCO offered financial aid to the project and Dr Stephen Connor gave his expertise and time. A working group formed for this purpose met first in February 2007 in Mumbai to study the issue and decided on a plan of action. Following preliminary preparations and discussion over email, the group met again at Kochi on 7 February 2008 and prepared a draft document for "National Standards in Palliative Care". After incorporating the suggestions from the plenary body, the final document was prepared. It has now been submitted to the Indian Association of Palliative Care (IAPC) for consideration.

The document can be viewed in Pallium India web-site: www.palliumindia.org (Please follow the link on the home page to "National Standards for Palliative Care in India"). Please send your comments to pallium.india@gmail.com.

EPEC-India Training Programme

A pre-conference introductory course was held at Rajagiri College of Social Sciences, Kochi on 7 February 2008. Rajagiri College of Social Sciences, Kochi and the Consortium of Palliative Care Units of Kochi were co-hosts at this program. The EPEC-India program (collaboration between EPEC program of Northwestern University of Chicago and Pallium India) met the financial requirements as well as the scientific input. Faculty members from USA and India handled the educational program. All the sessions used the EPEC-India curriculum which was developed by EPEC and Pallium India with the support of Lance Armstrong Foundation.

There were 163 delegates. They attended the first plenary session and then had the choice to decide between one of two parallel sessions. They were requested to fill up an evaluation form at the end of every session. Generally the response of the audience was very good, and the feedback is gratifying.

The service of volunteers – students and staff of Rajagiri College--was commendable. Their enthusiasm and service were exemplary.

Honour to Dr Twycross

The Palliative Care Community of India honoured Dr Robert G Twycross with a citation for his exceptional contributions to the palliative care scene in India. It was presented to him by Dr Sukdev Nayak, president of the Indian Association of Palliative Care (IAPC) during the inaugural function of the XV Annual Conference of IAPC at Kochi, Kerala on 8 February 2008.

Dr Robert Twycross' contributions to the Indian palliative care scene span over the last decade and a half. During most of this period, he visited the country twice a year, traveling through the length and breadth of the country, lecturing and mentoring. Often he would lecture in other countries to raise the money for his work in India. The majority of palliative care physicians in India are either his students or his students' students. He gave copyright of his book "Introducing Palliative Care" free so that a low cost edition of his book could be produced in India at a negligible cost of about \$ 2.5. At the ceremony, in the true Indian way of honoring a *guru*, Dr Sukdev Nayak touched his feet. Many of us in India do the same, in spirit.

Refresher course

A refresher course in palliative care was organized by "Pallium India" in Thiruvananthapuram, Kerala, India from 15 -17 February 2008. It was an educational program with a difference. Eighteen faculty members, including some who have taught and worked in India over several years, participated as faculty members. With Dr Mhoira Leng acting as course chairman and with Ms Raelee Jensen and Dr Baburaj Chakrapani acting as coordinators, the faculty included Ms Gilly Burn, Dr David Brumley, Dr Bill Gretch, Ms Liese Groot-Albert, Dr Jeremy Johnson, Ms Penny Johnson, Mr Gary Kirlew, Dr MM Sunil Kumar, Dr Sue Marsden, Ms Shakila Murali, DrLalitha Kanny, Dr Biju Raghavan, Dr MR Rajagopal, Dr Robert Twycross and Dr Odette Spruyt.

The participants included 29 doctors and nurses, all of them trained, and practising palliative care. The whole teaching program was interactive, including video demonstrations and role plays, and as it progressed, the difference between faculty and participants gradually evaporated, and it was one three-day long learning experience together.

In a developing country with limited opportunities for palliative care training and for updating knowledge, a participant opined, the need for such refresher courses cannot be overemphasized.

BBC on palliative care

We had two visitors from BBC Radio, both doing separate programmes on palliative care. Their broadcasts highlighted the growing importance of palliative care in a stressed world. The first one was done by Ms Kathleen McCaul and it appeared in BBC World Service “Outlook” on 29 January. The second one – a half hour program – particularly deals with the opioid availability issue. It was done by Ms Mukti Jain Campian and was broadcast on 03 March on channel 4 of BBC. It can still be heard at <http://www.bbc.co.uk/radio4/science/pip/4gv0m/>

Doctor’s Distress

Let us call him PM. That is, obviously, not his real name. He does substantial, indeed seminal work in America as a doctor, but he does not like it to be attributed to him publicly, at least not now. PM had happened to talk to a relative who worked with us in Trivandrum Institute of Palliative Sciences (TIPS) and so got interested and visited us. A casual visit, true, but our discussion brought out serious issues, which we share with you here.

PM is a cancer specialist in USA. His work, or that of any oncologist, is more palliative than curative, he says. His team would monitor all his patients for pain and distress – he talked about the distress monitoring tool that he used – and took appropriate measures, no matter if the patient had no chance of cure. He did talk about his work, but he talked more about his experiences with treatment of his parents here in India.

His mother had developed a stroke some time back. She was treated in a “good” hospital, with all the required facilities. She was unconscious, and when she was close to death, she was shifted to the “Intensive Care Unit”. On admission, they were told that the neurosurgeon would see them only the next morning, and when he saw her, decided that no active treatment was possible. The rules did not allow his father to stay with her and she died alone.

If the neurosurgeon had nothing to offer, why indeed intensive care unit for the dying, PM asks. Intensive care units are for those who need intensive monitoring and intensive therapy, so that vital organs can be supported in the road to recovery. But if someone is clearly in an incurable state, and is dying, why shut them up inside intensive care units? “Why was she separated from my father at that time? Why was my father denied the privilege of holding her hand, and saying his quiet good bye? This was a woman who gave a lot of love to others in her life--she did not deserve to die alone.”

We are ashamed to say, but let us say it honestly, PM, we do not know why. This never happened two decades back. It is a new disease. Intensive care rooms now imprison the dying in air-conditioned rooms. Conventionally, prisons at least had bars. Some ICUs do not even have windows. Perhaps your mother was lucky enough to be unconscious. Many people await death when still conscious, shivering with cold, a tube in every orifice and yearning for a loved one, for a human touch, for an end to the unearthly beeps and screams of monitors and their alarms. Some have painful tubes down their airways, and are kept “alive” for days together, till the heart fails to respond to all the medications and eventually stop. Even then they are often subjected to the indignity of cardiac massage.

Pardon us; did we get carried away? PM had more to say. His experience about his mother was capped by one last episode. He shared his pain of the whole ICU experience with a senior medical professor. The professor giggled, of course unfeelingly, made some facetious remark and changed the subject. PM was offended, hurt, but he had learnt good manners not to take it out straight on the garrulous speaker.

One could, well, be tempted to defend the poor professor, if one were in the mood. Medical education in our country almost never discusses death. Doctors have no notion of how this unfortunate event is to be handled; they have had no lessons on communication skills when dealing with relatives. They are not even taught about management of symptoms close to death like the “death-rattles” or delirium. The apparent insensitivity could well be a manifestation of the sheer helplessness of not knowing what would be the right course to pursue. The learned professor might not endorse this view but that alone could be any defense of his patent unconcern. .

That was about PM’s mother. He had something more to say about a more recent experience of his hospitalized father. Here was his father, an intelligent person, and here was his son, a senior doctor working in the US. They needed to know what was wrong, what the future course of treatment would be. There was no communication. The doctor in charge would talk to neither of them; his instructions mumbled to the staff in monosyllables, the self-important apothecary would and move on like an inert shadow without dimensions. “Does my father not have the right to know what is wrong with him?” PM asks, his question addressed to a still, stinking wind, as it were.

They put up with it. PM had problems awaiting him at night, when spending the night in his father's hospital room. All day long and all night long, there was this wailing from the next room, of a man in pain. PM was disturbed, as any normal human being would be. Why was no one doing anything about it? When the wailing rose in pitch at night, PM approached the drowsy nurse and asked her why no one was doing anything about the poor man's pain or delirium. The nurse was incoherent.

PM then recognized the ugly reality of it all, life's very ugly reality: here he was, facing agony, willing and wishing to relieve it, and yet able to do just nothing about it, the pain of life or death in those hideous environs. Ultimate helplessness, as a memory, keeps haunting him, continually.

Any help, ever? We think, yes, definitely. It may not be easy for hardened doctors to change all of a sudden. We need to reach medical and nursing students. They must learn symptom control too; not just curative medicine. And they must be trained to face the inevitability of death, not with trepidation; but with compassion and tenderness.

It is happening, PM, slowly, but surely. At least half a dozen medical colleges in the country now have palliative care as part of the undergraduate curriculum. The numbers will rise, no doubt. And we promise to do our best.

Editor