



Reaching Out to them
... Together
E-Newsletter

PALLIUM INDIA
CARE BEYOND CURE

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December 22, 2009

The call came from the capital city of a North Indian state. The caller was in some distress; he was a doctor who had just finished our six weeks' training in palliative care at Trivandrum and returned to his regional cancer center. He would be starting a palliative care service soon as part of a Pallium India-PPSG-USCPRC project – in a state which till now had no effective palliative care facility.

But in the meantime, he was confronted with this situation – a five year old boy with a rhabdomyosarcoma in an upper limb, in excruciating pain. The child also had severe lymphoedema and extensive blisters and some abscesses. The child was receiving an NSAID, but it had not helped much. What could the doctor do?

No, they do not have oral morphine yet. No, they do not have injectable morphine either. Nor even injectable pethidine. They do have injectable fentanyl, though.

God, why is it that hospitals in our poor country have only the most expensive medications? Even if it were affordable, how would this child get pain relief round the clock with such a short-acting drug? Would someone study this international phenomenon which affects the 80% of the globe that forms the developing world? Fentanyl and morphine are controlled by the same narcotic regulations; but you cannot get hold of morphine!

Dear doctor, we sense your patient's pain and your distress. We will work with you and fight with you till you have access to morphine.

“Evidence-based medicine” – Too much of a good thing?

The concept of evidence-based medicine came like a breath of fresh air to the medical community. It helped, up to a point, to exclude bias and to base decisions on solid science. But perhaps our expectations of it were unrealistic? Plenty of questions have been asked, but they are not taken seriously. Questions like, who generates evidence? Ninety per cent of scientific medical studies are funded by the pharmaceutical industry. Does that not automatically exclude studies (and thus evidence) in favour of inexpensive medication? And not forgetting the recent recommendations that negative results must be published, can we realistically expect implementation of this recommendation? And finally, in the matter of something as subjective as pain or distress, is it reasonable to rely only on grade 1 evidence?

These are factors that we must consider when evaluating the recent NICE guidelines about management of low back pain. Read about the controversy at http://www.britishpainsociety.org/bps_nl_autumn_2009.pdf - in the 2009 autumn issue of British Pain News.

It is dangerous to let any concept – evidence-based medicine included – assume the status of a religion where challenging it invokes wrath and holy wars!

Palliative sedation and EAPC framework

Several years back, the European Association for Palliative Care (EAPC) had appointed an international panel of palliative care experts to formulate guidelines for palliative sedation. The task force's recommendations were published (de Graeff A, Dean M. *J.Palliat.Med.*2007 Feb;10(1):67-85) but were not accepted by the EAPC. Now the board of the EAPC has published not guidelines, but a framework. You can find the framework (Nathan Cherny and Lukas Radbruch) and an accompanying editorial (Katherine Hauser and Declan Walsh) in *Palliative Medicine* 2009 23(7).

“Refractory symptoms” are a cause of immense suffering to the patient and family and of considerable stress to professionals and other carers. Despite the controversy surrounding the issue, palliative sedation does offer an ethical choice to a large number of people.

Public interest litigation in Supreme Court of India

Two years back the Indian Association of Palliative Care (IAPC) had filed a case before the Supreme Court of India asking for a national palliative care policy, simplification of narcotic regulations and for inclusion of palliative care in the medical curriculum. The case came up for hearing on 7 December 2009, but the court decided to give one more chance to some government agencies to respond and postponed the final hearing to an unspecified date.

India court admits plea to end life of rape victim

The public, as well as the medical and legal professions, continue to be confused about the distinction between euthanasia and withdrawal of life support in the face of futility of treatment.

Aruna Shanbaug, a nurse in Mumbai, has been paralysed and considered "brain-dead" since she was attacked by a rapist in November 1973. Pinki Virani, a journalist who has authored a book on Aruna, has filed a case before the Supreme Court of India asking for permission to end Aruna's life. The BBC report goes on to say that "The court will examine if the plea is 'akin to euthanasia'." The medical communities, and particularly palliative care experts, have a responsibility to clear the confusion.

Please read about it at http://news.bbc.co.uk/2/hi/south_asia/8417549.stm. Thank you Dr Charu Singh, for bringing this to our attention.

University of Iowa-Pallium India course on Palliative Care.

Pallium India joins hands with the Department of Geography at the College of Liberal Arts & Sciences at University of Iowa, USA to conduct a course on Palliative Care from 30 December 2009 to 15 January 2010. The course hopes to accommodate approximately 10 students each from the University of Iowa and from within India. We thank Dr Rajagopal Rangaswamy from Iowa and his team for making the course possible and also for providing some scholarships to facilitate participation of some from within India. For details please visit

<http://www.uiowa.edu/~geog/india/>

One month certificate course certificate course at MNJ Institute of Oncology

The next one-month Certificate Courses in Pain and Palliative Medicine (CCPPM) and in Palliative Nursing (CCPN) will start at MNI Institute of Oncology on 1 February 2009. For details, please contact R Vineela at mnj.palliative@gmail.com.

Six weeks' certificate courses at Trivandrum

The next six-week Certificate Course in Pain and Palliative Medicine (CCPPM) and in Palliative Nursing (CCPN) will start at Trivandrum Institute of Palliative Sciences (TIPS) on 17 January 2009. Please see <http://www.palliumindia.org/courses.htm>

IAHPC scholarships

The International Association for Hospice and Palliative Care (IAHPC) has funded some scholarships which are available for people wishing to avail the certificate courses at MNJ Institute of Oncology and at Trivandrum Institute of Palliative Sciences during the next one year. Details can be seen at <http://www.palliumindia.org/courses.htm>

Tom Middlemiss in British Pain News

Dr Tom Middlemiss, a palliative care physician from the UK, had done eight months of voluntary work with us in Trivandrum and ended it in triumph by doing a 1,600 kilometer bicycle ride to Mumbai promoting palliative care. Tom has written about his experiences in British Pain News. Please read pages 18-21 of http://www.britishpainsociety.org/bps_nl_winter_2009.pdf. You will not regret it!

During his bike ride to Mumbai, Tom used to send detailed emails describing his journey. The travelogue was translated to Malayalam and serialized in 'Sahayatra', a monthly magazine for palliative care workers, patients and families. The last episode comes out in the January issue.

Thank you Tom for giving us such a huge chunk of your life, and thank you IAHPC for your support.

Sahayatra

Talking about 'Sahayatra' (Pallium India's monthly Malayalam magazine), if any of our Malayalam-speaking readers in any part of India would like to receive it free by post, you only have to email at us pallium.india@gmail.com and give us your full postal address including PIN code. And contributions would be welcome. Contributions in English are acceptable. We can get them translated.

Hospice tour of India by Dr A K Dam. Delete full stop

Dr Abhijit Dam of Koshish, the hospice in the state of Jharkhand, undertook a 3,000 kilometer tour of seven Indian states – he and a colleague driving all the way. Their mission was to spread awareness about palliative care. Congratulations Dr Dam and best wishes. Read about it at <http://www.pcn-e.com/community/pg/file/ratuldam/read/3802/hospice-tour-india>

Thank you for the precious gift

We thank Alpheusmedia, Lance Armstrong Foundation and Anne Nagelkirk and colleagues for a precious Christmas present – a three-minute video on Pallium India. To watch it please visit <http://www.palliumindia.org/video1.htm>

Palliative care institute at Trissur

Founded by Dr E Divakaran and colleagues, the Pain and Palliative Care Society at Trissur (http://www.painandpalliativecarethrissur.org/nonframe_pages/instit-of-palliative.htm) has established a successful palliative care institute at Trissur, the city often called the cultural capital of Kerala. Two of us at Pallium India had an opportunity to attend a refresher course in palliative care for doctors held at the institute and to see first-hand the tremendous progress made by the center.

The course demonstrated the great value of educational opportunities for professionals who go through short training programs and feel the need to update their knowledge. We congratulate the Trissur team.

This IS sharing:

Please read the following from a doctor who wishes to remain anonymous. "Dear friends at Pallium India, I am happy to say that my daughter is getting married in the week after Christmas. I have decided to skimp a bit on the festivities, and to send you the amount thus saved. Please find enclosed, a cheque for Rs. 10,000. I pray that this amount will help in palliating some people's suffering and hope that their blessings will enrich my daughter's life."

Truly a precious Christmas gift! Thank you very much doctor!

Merry Christmas! Happy New Year!**Editorial Board:**

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