



Reaching Out to them
... Together
E-Newsletter

PALLIUM INDIA
CARE BEYOND CURE

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19 December 2008

Dear friend,

It is now a few weeks since the terrifying attacks in Mumbai. Media coverage is already fading. In no time at all most of us will forget it all – till the blasts occur at another time, another site, another country. But the bereaved, the grieving and the survivors – they will not forget. What will their suffering involve? How long will it be before they are able to get a good night's sleep? Many affected families have been offered financial compensation by the government. As if financial loss is the only loss that they have! How many will be asking the empty nothingness around them, “Why me?” “Why my child?” Broken stories, shattered lives, how will these be evaluated? How many orphans will get a hug and a caress? How many lives will be scarred for life with something that medical science will dismiss as “post-traumatic stress disorder”, as if the diagnosis is enough and it is no one's job to do something about it?

This will not be the last calamity in this world. There are going to be many more, natural and man-made. When will healthcare systems anywhere recognize that suffering is not only physical and financial, but also social, emotional and spiritual? Let us hope for the day when people involved in healthcare would care enough and would not be afraid to wipe a tear or to offer a tender touch, a hug, a smile! Not just for a day or a week, but for as long as the suffering lasts.

The principles of palliative care are needed not only in cancer, and not only for the dying, but wherever there is suffering!

The Euthanasia debate;

Traditionally, most of the global palliative care fraternity has taken a stand against Euthanasia and has endeavored to make the general public aware that not only are the two very different, but that palliative care is indeed a viable and humane alternative to euthanasia.

But sadly, things seem to be changing. Please see the latest newsletter from the International Association for Hospice and Palliative Care (IAHPC) and Dr Derek Doyle's comments (<http://www.hospicecare.com/news/08/12/aom.html>) on the "article of the month" by Perieira J. entitled *Assisted Suicide and Euthanasia Should Not Be Practiced in Palliative Care Units*.

In Switzerland, euthanasia is legal now. Some major hospitals which have palliative units, now offer physician assisted suicide service (PAS) as well. The understandable fear is, would it not tempt the health care system to offer the *easier* and more *cost-effective* option of euthanasia in favor of the more expensive, but humane alternative of palliative care? Dr Derek Doyle concludes his comments by saying, "*Today Switzerland, tomorrow.....? Let no-one imagine that the rest of us will be immune. There are many other countries where, as we have been warned for years, PAS may soon be introduced, palliative care provisions weakened and threatened, and the way opened for euthanasia. Call me a cynic but I see us living in the "age of disposables", an age when expediency is sometimes dressed as compassion, an age when "respect for human rights" can be used to justify almost anything*".

Morphine in SGPIMS in Lucknow:

Let us have some good news for a change. Two months back we had reported to you about the sad situation in the poppy-growing state of UP in which doctors were forced to ask patients to go to the market and seek illegal opium for pain relief. Mr Piyush Gupta from Cancer Aid Society reports that his joint efforts with the prestigious Sanjay Gandhi Post-graduate Institute of Medical Sciences (SGPGIMS) have proved fruitful. The institution has oral morphine now and people can now access quality pain relief legally! Congratulations SGPGIMS and Mr Piyush Gupta. Pallium India is proud to have been associated with your efforts!

Promoting access to palliative care in cancer centers: new Pallium India / PPSG project:

Thanks to generous funding from United States Cancer Pain Relief Committee (USCPRC) applications have been invited from cancer centers in India for a project to improve access to

palliative care. The project will be jointly undertaken by Pallium India and Pain and Policy Studies Group (PPSG), a WHO Collaborating Center at Madison-Wisconsin. The last date for receipt of applications is 31 December 2008.

Three cancer centers will be chosen from areas in India which have no effective palliative care service now. The selected centers will get support for training of staff and will get a take-off grant for two years for running the service. For details go to www.palliumindia.org or email pallium.india@gmail.com

TRANSITIONS: an educational program with a difference:

Some of you who saw the February edition of this newsletter might remember the poignant story of the experiences of a doctor based in USA when his parents were treated in a hospital in India. (<http://www.palliumindia.org/newsletter/newsletter-feb2008.pdf>). We had ended the note with a hope that the situation is changing for the better. Well, it is, albeit slowly.

At an educational program at AIMS, Kochi, on 29 November 2008, Dr Anand Kumar, Dr Shyam Sunder, Dr Suresh Kumar, Dr Gayatri Palat, Dr Sanjeev Vasudevan, Dr Somnath Chatterjee, Justice Padmanabhan Nair, Dr Nagesh Simha, Dr Rajashri Suresh and Dr Vallath Nandini discussed end of life issues and a “care pathway” that can be followed (Adapted from “Liverpool Care Pathway”). What are the criteria for admission to the pathway? What should the care team remember about that particular patient- family unit? For example, what is their insight into the condition? Does the management include anything that is meaningless or even discomforting for the patient at that stage and should be discontinued - for example, some nursing routines, naso-gastric feeding etc?. Are pain and other symptoms adequately taken care of? What emotional and ethical dilemmas are the family struggling with?

It is hoped that the deliberations on these questions will facilitate a transition from defensive aggressive care schedules to empathetic, empowered care, and from paternalistic unilateral decision making by the medical community to informed shared decisions along with the patient-family unit.

New Palliative Care Unit in Mangalore, South Karnataka.

Ms Lavina Noronha writes to say that a 15-bedded, free-standing, palliative care facility has been started in Mangalore for the care of those diagnosed with cancer, dementia or other life-limiting conditions. AMPC doors are open to people of all faiths free of cost. The facility is equipped with spacious private rooms, family rooms, kitchen, laundry and a prayer hall. There is

provision for one family caregiver to stay with the patient at all times. The facility offers physical comfort care, psychosocial and spiritual support to patients and their families. For more information write to:

Ave Maria Palliative Care (A unit of CDSE ®)

Mangala Nagara, Kudupu Post

Via Vamanjoor, Mangalore- 575028, India.

Phone: (0824) 2016629; E-Mail: ampalliativecare@yahoo.com

Palliative care support group at Bangalore:

Dr Barathi reports about a new Palliative Care Support Group that was initiated on the occasion of world palliative care day celebration at St. John's Hospital, Bangalore. There were 16 attendees at the first meeting the theme of which was Quality of Life. Here are a few extracts from comments from patients and family members:

"It is important to look after yourself, so that you would be able to take care of your loved one efficiently."

"I am ready to talk to people like me who are hesitant to undergo CT fearing vomiting and hair loss. Counseling from Palliative care team helped to decide to take chemo and I am doing well now. I want to tell people like me, 'You will suffer a while but it is worth it; approaching palliative care early would help in deciding such difficult matters'."

"Now I can enjoy the sunshine, the rain, the rainbow and flowers. I am enjoying life in full now. Don't hesitate to take morphine for your pain when prescribed by the doctor. It brings you back to life".

Congratulations, St Johns' palliative care team!

Indian palliative care physicians are mentioned in British Parliament!

Please see the following extract of a recent speech in the House of Lords by Professor Ilora Finlay (who is Baroness Finlay of Llandaff): *"... I want simply to tell the human story of Commonwealth scholarships, ... I want to talk about the five students in my department at Cardiff University, who have been Commonwealth scholars since 2006. That cohort entered and competitively gained scholarships—three from India and two from Pakistan. They were all highly motivated and ...have done astoundingly well..... They are Dr Jeba (Jenifer) and Dr Barathi from India and Dr Rozilla Khan from Pakistan. They all passed phase one of their courses in the top third. Two—Dr Jeba and Dr Barathi—were in the top 10 per cent. Dr Jeba went on, in phase two,*

to be the top student out of the whole of the world cohort ... and won the Cicely Saunders medal.” ([http:// www. publications.parliament.uk/pa/ld200708](http://www.publications.parliament.uk/pa/ld200708))

Congratulations Dr Jenifer Jeba of CMC Vellore and Dr Barathi of St Johns' Medical College, Bangalore! We are all proud of your achievement.

Movie: The Wit

Can we recommend a movie to you? “The Wit” directed by Mike Nichols and starring Emma Thompson - what a moving end-of-life story! If you want to read about it, please go to [http://en.wikipedia.org/wiki/Wit_\(film\)](http://en.wikipedia.org/wiki/Wit_(film)).

Gilly Burn in Hospice Information Bulletin:

Ms Gilly Burn, without any doubt, is one of the greatest pioneers of palliative care in India. Gilly writes of her work in India in “hospice Information Bulletin, Vol.6, issue 3, October 2008. She concludes her article, “Twenty years living a dream” saying, “*The diverse and imaginative delivery of palliative care in India has much to teach the West in terms of creativity and maximizing scarce resources...*”

By the way, do you have access to Hospice Information Bulletin? You can get it free! Please see the following information that Ms Avril Jackson has kindly sent in:

“The Hospice Information Bulletin is a quarterly magazine that includes stories, news and research activities from the world of hospice and palliative care. Many articles demonstrate new practices and ideas that you can adapt and apply to your own setting. A free subscription to the magazine is available to people involved in palliative care. To subscribe, please contact info@helpthehospices.org.uk

More good news on morphine availability:

In the few years till 1998, we used to face the painful ordeal of supply of morphine running out with replacement taking months! Action by the department of Revenue of Government of India had solved the problem by ensuring uninterrupted availability of morphine powder from the Government Factories. But that problem reared its ugly head again in 2006 and 2007, with painful interruptions of morphine supply in some parts of the country. Imagine the plight of the

person with agonizing cancer pain being told , “Sorry; no, there is no morphine. Sorry; no; we do not know when it will come. Yes, it could be weeks. Yes, we fear so; it could be months too. Sorry; no; no drug that can replace morphine is available in our country!”

Fortunately, the department of Revenue has stepped in again and saved the situation. On 12 September 2008, the department has given instruction to the Government factories that they should always keep a buffer stock of at least 60 Kg to prevent such shortfalls in supply in future.

Thank you, all the officials who made it possible. We would have loved to name some of you; but fear that it may be frowned upon!

*We wish you all a Merry Christmas!
And thank you all for your support!*

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