



Reaching Out to them
... Together
E-Newsletter

PALLIUM INDIA
CARE BEYOND CURE

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Too many issues of our newsletter had ended with heart-rending stories of pain and suffering. This time we promise a change. We shall end this newsletter with a heart-warming 'happy' story. But some "breaking news" first.

Human Rights Watch releases India report:

At a press conference at India International Center at New Delhi on 29 October 2009, Diederik Lohman of Human Rights Watch released the report, "Unbearable Pain: India's Obligation to Ensure Palliative Care". Audiovisual and print media in India and abroad carried the story. This should add considerable strength to our efforts towards integration of palliative care into routine medical practice. Thank you Diederik, Rebecca and others for making this happen.

There was something special about the press conference: the expression on the faces of the journalists as the report of human suffering in India unfolded before them. There was no apathy, no rush to get it over and rush to the next one; nothing but eager interest in what was discussed. Some anger was expressed, about the poor communication on the part of doctors and about unrelieved pain, about abandonment by the medical system towards end of life, and about inappropriate intensive care during dying phase. Most journalists lingered after the meeting to talk to the experts and to express their sentiments.

The whole report (including a three minute video) can be accessed at <http://www.hrw.org/en/reports/2009/10/28/unbearable-pain-0>

Several newspapers and other media have come out with reports on this; here are a few links from India and abroad.

- http://news.bbc.co.uk/2/hi/south_asia/8330517.stm
- <http://www.indianexpress.com/news/a-fight-for-life-and-death-with-dignity/534982/0>
- <http://worldfocus.org/blog/2009/10/30/rights-group-says-terminally-ill-suffer-needlessly-in-india/8073/>
- <http://www.hrw.org/en/news/2009/10/28/india-provide-access-pain-treatment>
- <http://www.theglobeandmail.com/news/world/indians-suffer-in-a-land-awash-with-painkillers/article1343095/>
- <http://worldfocus.org/blog/2009/10/30/rights-group-says-terminally-ill-suffer-needlessly-in-india/8073/>
- <http://dying.about.com/b/2009/10/29/report-find-unbearable-pain-underused-pain-meds-in-india.htm>
- <http://www.ihrablog.net/2009/10/unbearable-pain.html>
- http://www.upiasia.com/Top_News/International/2009/10/28/India-faulted-for-poor-pain-relief/UPI-46281256770616/
- <http://www.dailyindia.com/show/341534.php>
- http://news.indiaid.com/blog/_archives/2009/10/28/4363938.html

Good news! Scholarships!

The International Association for Hospice and Palliative Care has funded 10 scholarships for doctors and nurses in India to attend 4-6 weeks' "hands-on" certificate courses. In this first year of its operation, it will be given a trial run at the two centers that Pallium India is associated with, namely the INCTR training center at MNJ Institute of Oncology and Trivandrum Institute of Palliative Sciences (TIPS). The scholarships will cover traveling expenses as well as boarding and lodging of participants. Those interested, please contact pallium.india@gmail.com

Thank you Roberto Wenko (president), Liliana De Lima (Executive Director) and the board of IAHPC.

Children with cancer and Cankids' workshop:

A child with terminal cancer is sent out from the acute care hospital; they have no space for him. The mother who hails from a distant city has no place to take the dying child to; a volunteer puts them both in an autoriksha and goes from hospital to hospice looking for an accommodation for the child for the night. No one can help. The child eventually dies in the autoriksha.

This is the sort of painful situation that volunteers at Cankids have to live with. As part of their efforts to improve the situation, they are organizing a workshop at Delhi from the 6th to 8th November 2009 at Vasant Vihar Club. INCTR provides faculty for the workshop. Best wishes, Poonam, Gitanjali, Sonia, Huma and others at Cankids, we admire you.

Certificate courses in January 2010:

Those interested in our six weeks' certificate course in Trivandrum please note: the January course will not be starting on the first Monday of the month, but instead on the 18th of January 2010.

Media support and visible results!

We have always enjoyed a lot of attention from the media around World Palliative Care Day. This year was no exception; both visual and printed media were generous to palliative care. One of the reports is transforming life for someone. On 11 October 09, the New Indian Express carried a story by Reema Narendran, "Gomathy cant afford to complain of pain", describing the life and courage of a woman battling a back pain while fending for and looking after five chronically ill people in her family, three of them needing help even to sit up and to eat or wash. It was a story of unbelievable courage in the face of suffering; Gomathy is indeed somebody special.

Pallium India's intervention brought help from several quarters, including from the Shruthi Social Circle of the staff of State Bank of Travancore that paid for repairing the leaky roof of the house, for rewiring the house and for padding up the walls of one room so that the three with involuntary movements would no longer hurt themselves. One kind visitor donated a television set so that the immobile young men had a source of entertainment.

But following the New Indian Express story, help has started pouring in. Gomathy should now be able to improve on her modest business of vending fish and vegetables under a convenient tree on the roadside!

More about World Palliative Care Day at Trivandrum:

In Trivandrum, the 10th of October started with a motorbike rally to promote palliative care. It was organized by Sreekumar and team of Sukrutham Palliative Care Society. The rally ended in Cotton Hill School where Pallium India, its link centers in Trivandrum district and S.U.T Hospital jointly organized a get together of patients and relatives. Boys and girls from seven schools in the city treated the audience to a musical and dance program. Dr Sanghamitra Bora of Cansupport who was spending six weeks with us led a memorial program for people who had left us. There was a session in which some patients and families talked – about how the disease treated them, how they coped with it, and how palliative care helped. It was a humbling and

fulfilling experience. And in the evening, we were all treated to a Voice for Hospice program organized by Rajeswari Foundation.

Surya Dance and Music festival is renowned to be Asia's largest cultural show, lasting 111 days every year. Their 'bharatanatyam' program on the evening of the 10th of October was dedicated to palliative care. We thank Mr Surya Krishnamoorthy for making this happen.

Santhwanasamgamam (A "Palliative show")

Imagine about 100 celebrities getting together for a stage show! It actually happened on the third death anniversary of Srividya, a much-loved actress of the South Indian screen who died in pain from cancer on the 19th of October 2006. Two organizations – ATMA, the Association of Television Media Artistes, and MLV Srividya Charitable Society – got together to conduct a fund-raising program, the bulk of the proceeds earmarked for Pallium India's activities. In the program at which the Union Cabinet Minister Sri Vayalar Ravi was the chief guest, veteran actor Madhu gave a remembrance lecture on Srividya and then the audience was treated to a four hour stage show. We thank Sri Ganeshkumar who was the main person who made it all happen, Mr Dinesh Panickker who directed the show, Mr Poojappura Radhakrishnan, Ms. Leela Panicker, Ms Maya Gopinath, Mr Shamsudeen and many others from ATMA who worked hard for this. And we cannot forget Ms Seema who got us in touch with ATMA.

AMMA, we love you!

AMMA, the Association of Malayalam Movie Actors, proved their social commitment yet again! This year, they donated 500,000 Rupees for palliative care in Kerala state, which was shared by four organizations. Pallium India was the proud recipient of one-fourth of the amount. Mr Idavela Babu, the secretary of AMMA had brought along a cheque, which we received from the great actor Madhu during Santhwana Sangamam. We thank AMMA for this donation and also for all the support that prominent members of the organization have always given palliative care. Bharat Mammooty has been the patron of Pain and Palliative Care Society of Calicut for more than 10 years. Sri Innocent, the president of AMMA is the patron of Alpha Charitable Society at Edamuttam. Famous actors, Mohanlal, Suresh Gopi, Dileep, Ganesh Kumar and many others have participated in palliative care activities in many parts of the state. Thank you AMMA!

From Nicola Connelly, a medical student from UK:

Nicola underwent a month's palliative care course with us and at the time of leaving, shared her thoughts with us.

- I have learnt a lot of palliative care theory and especially enjoyed the communication skills sessions.

- I liked the home visits a lot, and it was especially exciting when there was a snake on the path! However, on a couple of occasions I found the experience challenging - seeing the poor living conditions and seeing that patients had become so ill because they had not been able to afford cancer treatment. I had to step out of the house on one occasion and then I realised that I was walking away from the situation because it was too painful to see. I realised that the patient was not able to do that and what is so amazing about the work of Pallium India is that the patient is not left by himself, no matter how emotionally difficult it can be and I think I have learnt not to be afraid of properly empathising with patients.

- I felt really part of the Pallium India team and all the staff were extremely welcoming. I realised how important it is to immerse yourself in a different culture - i.e. to feel like one of the gang. I felt this most whilst I was automatically made part of the group in the back of a truck shouting mantras with the Durga Puja celebrators, before the statues were thrown into the river.

- Also, many of my values and beliefs have been challenged and even changed after visiting Trivandrum. Before arriving I thought I was pretty clued up on ethics, that the individual was sovereign and the family should come second. But now I realise that need not always be the case. I realize how relative ethics is because for some patients, family is everything and decision making is shared amongst the family unit because there is more of a collectivist identity?!

Things I found hard:

- Learning not to walk away from upsetting situations.

- I did miss a good cappuccino. (But then I found "Cafe Coffee Day"!

- Eating Indian food three times a day was a little too much, but I do appreciate proper Indian cuisine more now!

- The language was a bit of a barrier but really, if you smile and say *Namaste* - it works wonders. It is also amazing what you can pick up from body language!

Mysterious ways of Providence:

We have a monthly publication in Malayalam, *Sahayatra*, for our patients, families, donors and well-wishers in Kerala. A young engineer working in Technopark found it on a friend's desk, glanced through it and got sufficiently interested to arrange with his bank to send us a monthly donation. And then one day in a Malayalam newspaper he read about the story of a woman in dire straits in a hospital in Alleppey which is four hours away from us by road. He asked us whether we could help.

The woman (let us call her Suma) has a potentially incurable disease called chronic calcific pancreatitis – a very painful and incurable disease to have. Her husband and she had little money, but they went from hospital to hospital seeking treatment. They got plenty of medicines, expensive scans and other investigations and even a major operation, but no explanations about the disease. When they took a huge loan to pay for the operation, they expected that it would be curative, while it was nothing more than palliative at best. Eventually, when they were in debt of more than one hundred thousand Rupees with no end to her pain, in one weak moment Suma's husband forced some poison on her and killed himself. Suma survived - to fend for herself and her young son.

A phone call to Dr Veena, Anaesthesiologist and palliative care physician at Alleppey Medical College Hospital, got us more information and brought a helping hand to Suma. When she got discharged from the hospital, Shafeeq, a volunteer from her neighbourhood whom we had contacted, brought her across to us. She is now being treated by us. She is reasonably pain-free on medication now, understands the nature of her disease and is assured of free treatment from us for the future and of support for her son's education.

The engineer who made it happen (and wishes to remain anonymous), has promised to continue to support the cost of her treatment. We thank the mighty providence for people like him and for the turn of events that brought Suma's plight to his attention.

We are left with a nagging question. Were all those scans and the operation advisable or necessary? Oh, we do not mean medically. We mean, was the cost of the high-tech interventions justifiable in view of her condition and Suma's financial background? At least, did they not deserve explanations about incurability and counseling on how to cope with the future?

Alain Enthoven, a Professor at Stanford University once said, "*Increasing medical inputs at some point will become counterproductive and cause more harm than good*". Was it not so in Suma's case? Unfortunately, it is not a rare happening!

Progress at Manipal

Dr Naveen Salins from Manipal (South Karnataka) informs about expansion of palliative care work at Kasturba Medical College, Manipal Academy of Higher Education (MAHE). Dr Naveen Salins is a General Medicine physician who underwent 3 years of training in Palliative Medicine in Adelaide, Australia and had worked as Palliative Medicine consultant at The Royal Adelaide Hospital. The address is: Palliative Medicine Unit, Department of Radiotherapy and Oncology, Shiridi Saibaba Cancer Hospital and Research Centre, Kasturba Medical College Hospital, Manipal, India 576104 and telephone numbers, +91-820-2923118 and +91-9964182348.

This is particularly good news, because we were saddened recently to hear that the several year old palliative care program at Mangalore under the same University had folded up. Best wishes to the Manipal team and let us hope that the Mangalore unit will be revived soon.

Mobile telemedicine unit at Kannur

Malabar Cancer Care Society in Kannur (a city in Northern Kerala) has been a pioneering organization offering comprehensive cancer care – awareness, early detection, support for treatment and palliative care. Its founder, Mr Krishnanadha Pai reports that in yet another pioneering step, it is starting a Mobile telemedicine unit to get care more into rural areas. This has been made possible with the help of Government of India, ISRO (Indian Space Research Organization) and C-DAC (Center for Advanced Computing Technology and Development). To know more about the program, please email mccskannur@gmail.com

Palliative sedation:

Several years back the European Association of Palliative Care had appointed a task force for producing guidelines for palliative sedation, but did not eventually adopt the task force recommendations. Now the president of EAPC, Dr Lukas Radbruch reports:

As president of the EAPC I am very happy to be able to present not guidelines, but a framework for the development of institutional guidelines. Each organisation can now use this framework to draft their own set of guidelines, taking specific local or regional cultural and social factors into consideration. The framework provides guidance on how to prepare, organize, initiate, titrate, monitor and evaluate the sedation procedure.....I hope that the framework will lead to the development of institutional guidelines in many settings, and I look forward to forthcoming data from these guidelines. The EAPC will be happy about feedback and comments on the guidelines, and hopes that a vivid discussion on the principles of palliative sedation will follow. (You can view the online publication if you go to: <http://www.eapcnet.org/projects/Sedation.html>)

About hope and exploitation:

Dr Nathan cherny [chernyn@netvision.net.il] writing on behalf of his Mindful Medicine Journal Club, invites us to give some thought to the thorny issue of sustaining the hope of patients without exploiting hope.

Nathan points out several situations in which the clinician may be interested in encouraging false hope:

- When we have a research agenda.
- When we have a new treatment that we would like to build experience with.
- When we would rather want to avoid all the distress involved with discussions about the limited benefit of further treatments or ending disease modifying treatments.
- When we would rather avoid discussions about end of life care.
- When we stand to gain when patients undergo procedures or treatments that we propose.

He also mentions the “mutually advantageous exploitation”. This is interesting. Would encouragement of false hope not sometimes promote quality of life at least transiently?

The promised story with a happy ending:

Martina Pestinger was a German visitor to Pallium India earlier this month, on a mission of initiating some joint work between Pallium India and her University in Germany. One Friday, Martina lost her satchel with her passport, credit card, SIM card and money. We looked everywhere, but with no success. Martina must have passed through hell that evening.

Eventually she reported the loss to the police. The police officer said, "Martina? Martina, eh? Let us see. Ah, here it is. Your bag has been found. Go and collect it from Police station".

Martina found her bag, with all contents intact, down to the last currency note. Subhadra, a peon working in a bank had found it in a busy thoroughfare and handed it over to the bank manager, Mr Ashok. He was pleased with her, delved into his pocket and gave her a gift on the spot.

Martina went to the bank on Monday to thank Subhadra and to give her a gift. Subhadra hugged Martina and started consoling her, "Oh, you poor darling, you must have been very very worried. Oh, it must have been terrible for you. I wish I could get it back to you sooner. But we had no address for you and so our "sir" had to take it to the police. I am so very sorry that we had you worried for hours!"

Dear Subhadra, we are proud of you and people like you. You may be poor, but the thought of removing a currency note from that wallet would never occur to you. We know you have a lowly job and that you are by no means rich. Yet amidst all your own problems, you found it possible to empathise with Martina's worries and to make light of your own good deed. You represent the integrity, love and courage of the "poor" people all around us and whom we have the privilege of helping sometimes. You enrich our lives. Thank you very much.

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