



Reaching Out to them
... Together

PALLIUM INDIA
CARE BEYOND CURE

E-Newsletter

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Dear friends

The French scholar Romain Rolland said, "If there is one place on the face of earth where all dreams of living men have found a home from the very earliest days when man began the dream of existence, it is India". That is great, isn't it? See, we have a great country to dream in!

And we did dare to dream. For the last quarter of a century, some Indians have shared a humble dream - the dream of getting some relief across to people in needless pain and suffering. Where has that dream taken us? Not very far, we sadly understand. We have just received a report from the Government Opium and Alkaloid Works (GOAW), the sole agency distributing morphine for domestic consumption. Here are the quantities of morphine that went out of GOAW since 1998.

1) 1998	45.739 Kg
2) 1999	116.098 Kg
3) 2000	261.000 Kg
4) 2001	178.108 Kg
5) 2002	76.100 Kg
6) 2003	109.400 Kg
7) 2004	87.000 Kg
8) 2005	121.113 kg
9) 2006	73.100 kg
10) 2007	264.667 kg
11) 2008	237.500 Kg

There has been some improvement, no doubt. But it is so slow! We estimate that if all Indians with cancer pain were to get pain relief, we would need 36,500 Kg of morphine! (India: Opioid

availability – an update. Journal of Pain and Symptom Management 2007; 33:615-622.) In 2008 the coverage was a mere 0.65% of the projected requirement for cancer alone!

Progress in Mangalore and referral patterns:

In December 08 we had reported to you the opening of the new Ave Maria Palliative Care center at Mangalore in Karnataka. Its founder Lavina Noronha writes to say, "Five people have had very peaceful deaths since our inception in September, 2008. We have five patients with us at present. Interestingly, of the ten patients, only two have been referred by oncologists and the others have been family referrals which shows we have a long way to go in terms of convincing the medical profession that palliation is a significant and an inevitable branch of medicine." It is the same old story. The major failure of Indian palliative care today is that palliative care stands clearly outside mainstream medical practice! Oh, there are exceptions, of course.

New palliative care centers opened!

While on the subject of integration of palliative care into mainstream medicine, in the last issue of this newsletter, we had reported to you the Pallium India project (<http://www.palliumindia.org/newsletter/newsletter-may2009.pdf>) for starting new palliative care services in cancer centers, in collaboration with Pain and Policy Studies Group (PPSG) and funded by USCPRC. We are glad to report that the training has been completed and that new palliative care centers have opened in Meherbai Tata Cancer Institute at Jamshedpur and at Sanjay Gandhi Post-Graduate Institute of Medical Sciences at Lucknow. Congratulations, the palliative care teams at Jamshedpur and Lucknow!

New Department of Palliative Care at Kidwai Institute of Oncology, Bangalore.

Kidwai Memorial Institute of Oncology is one of the premier cancer centers in the country. It has been one of the pioneers of palliative care. In the 1980s, Dr Vijayram, the then head of Anaesthesiology of Kidwai Institute founded one of the earliest pain clinics in the country. He also established a system of procuring morphine powder from the Government Opium and Alkaloid Factory at Ghazipur and preparing Kidwai's own liquid morphine preparation.

Since his time, the palliative care division worked under Dr Saraswathi Devi, Head of Anaesthesiology and former president of Indian Association of Palliative Care. Dr Saraswathi Devi was the chief force behind simplification of narcotic regulations of Karnataka State in

collaboration with Mr David Joranson of Pain and Policy Studies Group (PPSG) of Madison-Wisconsin.

On the 4th of May 2009, a new department of Palliative Care has been created. Dr Lingegowda (drlingegowda@yahoo.com) who has been with that team since 1992 has been appointed the new Professor and Head of Department. Congratulations and best wishes, Dr Lingegowda!

Tom's bike ride for palliative care advocacy:

Dr Tom Middlemiss, a British palliative care physician, has been doing voluntary work with us in Trivandrum for the last 8 months. Tom did his MRCP in UK in 2007 and since then worked as a palliative care registrar in the UK and in New Zealand, till he joined us in Trivandrum. The International Association for Hospice and Palliative Care (IAHPC) gave him a grant for this. He became rather famous in Trivandrum, particularly because of his practice of riding a "Hero" bicycle (no gears!) from his rented house in Muttakkad (20 kilometers away) every day to work and back. Manorama Metro picked up on the news and some television channels followed up to do stories on him. The Indian Express titled their report "The Healing Hero"! As a palliative care physician and as a member of the team, his services have been invaluable.

As we write this, Tom is just leaving Kerala's border to cross over to Karnataka on a bicycle ride from Trivandrum to Mumbai (about 1700 kilometers), to spread the message of palliative care. All over Kerala, palliative care teams in individual towns received him and made use of the ride for palliative care advocacy. Tom's ride will end with a reception at Gateway of India in Mumbai on 16 July 2009. We join you in wishing Tom well on his arduous trip! And thank you Tom!

Grant from Help the Hospice:

Help the Hospices in the UK writes about the 2009 round of Wolfson international bursaries. These are available to nurses, doctors and clinical officers from resource-poor commonwealth countries to attend palliative care education courses anywhere in the world. Bursaries are up to £1,500 and the deadline for applications is **Wednesday 5 August 2009**. Successful applicants will be informed by the middle of November 2009. More information is available on the grants section of www.helpthehospices.org.uk/our-services/grants/internationalgrants/wolfson-international-bursaries/. You can apply online.

If you have any questions or would like more information then please contact Tricia Jones, Grants Officer, Help the Hospices, Hospice House
34 - 44 Britannia Street, London WC1X 9JG (Phone 020 7520 8219)
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Sarat gets good grades and someone goes pain-free!

Sarat is the 17 year old who acted the role of the paediatric patient in our EPEC-India trigger video. He got excellent grades at the recent 12th standard examination. His father brought us sweets - some *laddus*. And also some money and a suggestion. When there is a festive occasion, why not exercise a little restraint and earmark a part of the money to support some needy patient?

We now have a collection box ready in our clinic in Trivandrum – ready to share any happiness in the families of the team members. Hearty congratulations, Sarat. And we thank you and your family for a powerful lesson. And for showing us the way!

Video on palliative care:

Mr Ashley Elanjikkal from the organization “Care and Share” in USA writes to ask, “Do you have an awareness video?” We expect that others could be interested in a video too. We do have something prepared in the local language of Kerala (Malayalam). If you would like to see a nine-minute video, please watch <http://www.youtube.com/watch?v=LzCsHcjKKgo>

Silverline award:

Pallium India was proud to be chosen to receive the annual award for social service from the Architects’ magazine *Silverline*. A cash award and a plaque were received by Dr M.R.Rajagopal on behalf of Pallium India at a glittering function at Bishop Pereira Memorial Hall at Trivandrum on 19 April. Thank you Silverline!

Legal issues:

In our last issue of this newsletter, we had raised a question. Should palliative care teams involve themselves in legal issues of patients?

(<http://www.palliumindia.org/newsletter/newsletter-may2009.pdf>) The question brought a few responses. The general trend of the responses was, yes, when we have to; that we cannot deny the patient the support if that is what is needed most to improve quality of life. Dr Anne

Merriman from Uganda writes to say yes, they do get involved in legal issues, for how can we desert someone when they need us most? They use volunteer lawyers when help is necessary.

A word of caution, though. Generally, we are likely to know our patients better than we know the family. It is easy to be biased in favor of the patient and to get into legal issues which might end up in an injustice to a family member!

Refresher course: 30-31 May 2009.

We conducted another successful refresher course at Trivandrum. We had 24 participants. In addition to the faculty members from Trivandrum, we also had with us Dr Peter Kirk from Canada, Dr Reena M George from Vellore and Dr Mallika Tiruvadanan from Chennai. The program on 30th of May focused on symptom control and we discussed psycho-social issues on the next day. The emphasis was on issues that palliative care practitioners face in their day to day practice.

To conclude: More about dreaming.

We started this letter with a rather pessimistic mention of a dream; let us end with another one, on a more optimistic note.

“The only dream worth having”, says Arundhati Roy, “is to dream that you will live while you’re alive and die only when you are dead”.

Isn’t that a great summary of what we palliative care workers try to help people to achieve! We will get there!

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