



InTouch

The newsletter of the
Palliative Care Department
Emmanuel Hospital Association

Striving to Serve – Stretching to Love



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Training

It was wonderful to have several training programmes over the past few months. 2 doctors and 1 nurse are enrolled in the 8-week course offered by the Indian Association of Palliative Care. Dr Tony Biswas (Lalitpur) appeared for his exam and Dr Jerine and Sr Bliss (Tezpur) will appear shortly. HBM Hospital, Lalitpur applied to the Indian Association of Palliative Care to become a training centre for contact classes for the course. If approved, this will be the first training centre in Uttar Pradesh.



Two PC workshops organized by EHA, Cairdeas (Scotland) and SGPGI, Lucknow were held from Jan 28th – Feb 6th, 2013. 14 EHA staff from 6 units attended the first workshop on Leadership and Training in Palliative Care. 15 EHA staff from the same units attended the second workshop that focussed on 12 symptom management protocols developed by the PC Department, Makerere Hospital, Uganda. In addition there were 8 participants from Lucknow, Rajasthan and Kerala.



The national and international resource persons were Drs Mhoira Leng (PC Physician, Uganda & Scotland), Chitra Venketesh & Charu Singh (PC Physicians, Kerala), Carl Furst (Sweden), Sanjay Dhirraaj (SGPGI, Lucknow), Ann Thyle (EHA) and Sr Angela Kabawezha (Tanzania).

The EHA participants had a great time of sharing during a meeting to flesh out the new service planned at Baptist Christian Hospital, Tezpur, Assam.

The symptom management protocols are available with Ann Thyle if required by other hospitals: ann@eha-health.org



The PC team from HBMH, Lalitpur made a presentation at Lalitpur Bible Seminary to 26 students and 2 pastors. There will be ongoing teaching every week based on the Toolkit modules in the hope that some students become interested to volunteer.

Sarah Victor taught 4 Toolkit modules at BCH, Tezpur – communication, team building, bereavement care & spiritual care.

New Palliative Care Service at BCH, Tezpur, Assam

Baptist Christian Hospital, Tezpur, Assam started their new palliative care service at the end of February under the leadership of Dr Jerine (Family Physician). With much support from the hospital administration, the team was established with Jerine, Nurses Bliss and Ruhini and Susan, who is a social worker. Leela Pradhan and Ann Thyle made presentations to the staff and nursing students, taught a few modules of the PC Toolkit, discussed documentation and also did a home visit with the team.

A Rest House for Patients' Relatives

A 4-member team (Drew and Robin Nagele & Philip and Maggie Kuhl) from Grace Presbyterian Church, Pennsylvania visited HBM Hospital, Lalitpur to help renovate the existing 'dharamsala' to become a rest house for the relatives of patients admitted in the wards. The new building will have 4 rooms, each with a small kitchenette and a common toilet/bath complex. The team worked very hard alongside local workers and also blessed the staff with their morning devotions, songs and evening craft times. We're very grateful to the church for their support and the team for their willingness to become involved.



Ganpat Jagtap



Ganpat Jagtap lives in Malumbra, a village close to GM Priya Hospital, Dapegaon. He had a stroke 5 years ago, losing movement on the right side of his body. Admitted at the Government Hospital, doctors did not discuss his illness with either him or his family. Experiencing no signs of improvement he went home. Since then he has been confined to bed with little care. The palliative care team of GMP Hospital visited him at home. He was alone, had high fever and was crying. The team did cold water sponging and gave him medicines. Soon he was feeling better and asked for food & water. During their next visit the PC team taught his wife to give oil massages and exercise his paralyzed arm and leg. Ganpat now feels better supported and wants the team to visit him every day.

Palliative Care at Shalom, Delhi

Shalom, Delhi moved from their present location to a new area in Swaroop Nagar. The work was originally done for 10 years from the 3rd floor of a factory building in Janakpuri with the components of home based care, medical care, capacity building of NGOs, church mobilization, and urban, adolescent and palliative care services. During the past few months the palliative care team provided food & hygiene items and emotional support to 1 cancer and 2 HIV positive patients and their families. The patients are able to access medicines from Government hospitals. The team also acquired 2 wheelchairs for people paralysed in both lower legs from Joni and Friends.

International Journal of Palliative Nursing Award



For the ninth consecutive year, IJPN worked in partnership with Macmillan Cancer Support, UK and hosted the prestigious International Journal of Palliative Nursing Awards, which took place in London on 14 March 2013. The palliative care team of HBM Hospital, Lalitpur won first prize in the 'Development' category. The fundraising director of EMMS, Cat Rawlinson-Watkins accepted the award on our behalf and will hand it over during a visit to Lalitpur at the end of March.

The award committee states on the IJPN award website, "The Harriet Benson Memorial Hospital Palliative Care Team provides care and hope to the terminally ill beyond all expectations, reaching out to a very neglected segment of the rural poor who have no other avenue for receiving help at the end of life."

For more details, please see:

<https://www.ehospice.com/india/ArticlesList/IJPNawardsforPalliativeCareteamatHMBHLalitpurandDNIPCareDelhi031913042127/tabid/5631/ArticleId/3694/language/en-GB/View.aspx>

Our Best Efforts Don't Always Work

Ram Vishal (60) lived in a village called Sukheti Gajipur near Broadwell Christian Hospital, Fatehpur, U.P. As a farmer he lived on daily wages with his wife and 2 sons. He had 2 married daughters living in other villages with their in-laws. In July 2012, noticing a lump under his left ear, he went to Allahabad where a biopsy revealed cancer. The doctor did not give any explanations and only prescribed painkillers. Unsure of what to do he took herbal medicines.

When the palliative care team of BCH, Fatehpur visited him, he was in great pain and had difficulty swallowing. The team assessed his problems, identified the goals of care and prescribed better pain medication. Unfortunately, after 2 visits to the hospital, his elder son refused to take medicines from the hospital. He felt that it was unnecessary to spend money on someone who was dying. Despite all efforts the PC team was unable to convince the family. Ram Vishal passed away a month later without any symptom control.

Praise and prayer:

1. Palliative care services starting in 3 more hospitals this year. Pray for narcotic licences for all hospitals with this service
2. Peaceful and comfortable passing away of several patients with special mention of Raghuvver (20) with bone cancer and lung metastasis, who 'saw Jesus and was ready to go home' just before dying.
3. Mending of family relationships & opportunities for patients to say. 'Thank you', 'I love you', 'I forgive you' & 'Goodbye'. Families do not allow disclosure of the diagnosis so chances are missed.
4. Safety and protection of the home care teams especially in the coming hot summer months.
5. Supporters, friends and visitors who have blessed us with training, sharing, building & fellowship.

Fatigue among cancer patients

“It feels like my body is just worn out”

Fatigue is the most common chronic symptom associated with cancer and other chronic progressive diseases. The assessment and treatment of fatigue at or near the end of life can be complex. Some of the challenges include its subjective nature, with great variability in how it is expressed, and perceived, requiring treatment to be based on patient report of frequency and severity; its multidimensional character; and the limited understanding of its pathophysiology¹.

Many scales are available to measure fatigue, the simplest being the Visual Analogue Scale.

The Visual Analog Fatigue Scale (VAFS)	
Date: _____	
	I do not feel tired at all I feel totally exhausted
07.00:	_____
12.00:	_____
17.00:	_____
21.00:	_____

If fatigue is due to irreversible global deterioration the management approach will be:

Non-pharmacological:

- Patient and caregiver education to help in understanding that fatigue is to be accepted and clinicians are trying to help².
- It may also help to define realistic expectations and goals of care as desired by the patient.

Pharmacological

- Corticosteroids: prednisone 40 mg per day has beneficial effects for 2-4 weeks³
- Megestrol acetate – 160 mg three times a day; rapid improvement in 7-10 days⁴
- Methylphenidate – 5-30 mg/day improved depression in 87% and appetite in 33%⁵
- Emerging drugs – thalidomide, fish oils and melatonin. Olanzapine, an atypical neuroleptic produces significant weight gain and positive metabolic effects.⁶

This newsletter is for other EHA units, our partners & supporters to stay informed about Palliative Care in EHA. We hope to send it out every 8-10 weeks. We welcome your comments and suggestions.

Write to: ann@eha-health.org and check out annthyle.blogspot.com (Feed One Another)

¹ JAMA. 2007;297:295-304

² Berger Ann. Treating Fatigue in Cancer Patients. The Oncologist 2003;8(suppl 1):10-14

³ Sweeney C. et al. Fatigue and Asthenia In: Doyle D, Hanks G, Cherny N, Calman K, eds Oxford Textbook of Palliative Medicine. Oxford: Oxford University Press, 2004:560-8

⁴ Buera E, et al Effectiveness of megestrol acetate in patients with advanced cancer: a randomized, double-blind, crossover study. Cancer Prevention Control 1998; 2: 74-8

⁵ Homsy J, Nelson KA, Sarhill N, et al. A phase II study of methylphenidate for depression in advanced cancer; Am J Hosp Palliat Care. 2001;18:403-407

⁶ Mantovani G., Madeddu C., Cancer cachexia: medical management, Support Care Cancer (2010) 18:1–9