InTouch

The newsletter of the

Palliative Care Department

Emmanuel Hospital Association

Striving to Serve – Stretching to Love

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New Beginnings

Two new palliative care services were started in September, one at GM Priya Hospital, Dapegaon, Maharashtra under the leadership of Dr. Jaishree and the other at BCH, Fatehpur under the leadership of Dr. Sunitha. At both places the teams underwent the Toolkit Training (Worldwide Palliative Care Association), which has 17 modules. Several EHA staff have done the Training of Trainers Course for the Toolkit under the guidance of Drs. Mhoira Leng and Chitra Venkatesh.

At GM Priya Hospital, Dapegaon there were 10 participants – 2 doctors, 3 nurses, 1 pharmacist, 1 community health worker and 3 outreach workers. The hospital has a 2-bed in-patient ward and other rooms that can be used for patients needing admission.

Since the service started on September 1st, the hospital has enrolled 27 patients. 15 patients have cancer; 7 patients are paralysed from road traffic accidents or after strokes; 2 patients have chronic renal failure; 2 have complications of diabetes; and 1 patient has a tuberculoma in his brain. 3 patients died in October.

10 awareness programmes have been held so far where none of the participants knew anything about palliative care. 8 meetings were at community level and 2 at local schools. School children in particular, 151 and 800 students at both schools, were very curious and asked many questions about the prevention of cancer and the scope of palliative care.

6 nurses attended the **Toolkit training at BCH, Fatehpur** in very interactive sessions. The picture shows an exercise they did to demonstrate team building – making a giraffe from newspaper.

6 patients have been enrolled so far – 2 with cancer, 3 are paralysed and 1 patient has been referred for further investigations of a mouth ulcer. 12 awareness programmes have been held.

We rejoice that BCH now has an opioid licence, our second hospital in U.P to obtain this vital permit.

BCH, Fatehpur PC Team Give Hope

Bablu Patel (33) lives in Palhana village with his elderly parents near Fatehpur. His father is a farmer. His married sister lives in a faraway village. During a home visit by the PC team they heard his sad story. Bablu completed school at the age of 17 years. He injured his back when he fell from a tree. Realizing that he couldn't move his legs his parents took him to several medical centres. Investigations revealed that the damage was extensive and he would remain paralyzed below the waist life-long. His family then applied herbal medicines and resorted to witchcraft.

Bablu is so tired of being bedridden and dependent on his parents. His frustration with an accident that changed his life was so apparent to the team. He is also very anxious about his future especially when his parents pass away. He used to give home tuition to village children but he now he feels too unwell to continue.

The PC team supported the family by listening, simple nursing care, and counseling. They suggested that he provide tuition again. They explained that this would occupy his time, give him a sense of purpose and the satisfaction of helping with family finances. The team will continue to visit, support and encourage him.

You can always give without loving, but you can never love without giving

Amy Carmichael

Training

Dr. Jerine (BCH, Tezpur) and Dr. Tony Biswas (HBMH, Lalitpur) are presently doing the 8-week palliative care course offered by the Indian Association of Palliative Care. Jerine will do her contact classes in Guwahati and Tony in Indore.

Dr. Mhoira Leng (Palliative Care Physician UK & Uganda), and other faculty members, will conduct 2 workshops in Jan/Feb 2013 at SGPGI, Lucknow organized by Dr. Sanjay Dhiraaj, Addl Professsor, Anaesthesiology. The first is from January 28-Feb 1 and focusses on leadership and training in palliative care. The second workshop from Feb 4-6 is on symptom management using 11 protocols developed in Uganda that covers the main problems patients with life-limiting diseases encounter.

Visit of the EMMS team

The Executive Director of the Edinburgh Medical Missionary Society, Mr. James Wells, visited HBM Hospital, Lalitpur to observe the palliative care service. He met the senior management and palliative care teams and then did a home visit to see Laxmi and her family. Laxmi (30) had chronic renal failure and passed away a few weeks ago.

We're very grateful for the support that EMMS has given to the palliative care initiative that has allowed us carry out this service at Shalom, Lalitpur, Dapegaon and Fatehpur. Other members of the EMMS team visited Chinchipada, Prem Jyoti and Shalom.

Savitri – a 'Good Death'

Savitri had osteosarcoma of her leg which was amputated and followed up with chemotherapy and radiation. When the palliative care at Lalitpur first met her in mid-2011 she looked healthy and was symptom free. Her family was affluent and very supportive, such a difference from the patients and conditions that we normally encounter. The picture shows her in happier times with her two daughters

In July this year the cancer spread to her lungs. She was admitted in the palliative care ward in Oct with superior vena cava obstruction. Her face was badly swollen; she was breathless, coughing and hoarse, and had chest pain. She was unable to lie flat. Her family had taken her to Bhopal's regional cancer centre but was denied admission since no further treatment was possible. At HBMH she was given morphine, a diuretic and steroids along with other soothing measures such as directing the breeze of a fan on her face. Her sons and mother-in-law were explained about her worsening condition and spent all their time by her side. She was soon able to lie flat and had 2 nights of good rest. As the breathlessness increased she was given a benzodiazepine and felt more comfortable. She passed away peacefully the next day, what would be called 'a good death.'

Is there such a thing as a good death?

There is no single definition of what constitutes a *good* death. The definition of a good death will vary for each patient. In 1997 The Institute of Medicine (IOM) defined a good death as:

A decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.

Factors important for a good death include:

- Control of symptoms
- Preparation for death
- Opportunity for closure or "sense of completion" of the life
- Good relationship with healthcare professionals

A central concept to a 'good' death is one that allows a person to die on his or her own terms relatively pain free with dignity

Sources

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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).