



InTouch

The newsletter of the
Palliative Care Department
Emmanuel Hospital Association

Striving to Serve – Stretching to Love



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Palliative Toolkit Training

EHA's Palliative Care Department, in partnership with the Cairdeas International Palliative Care Trust, hosted a 5-day introductory course in palliative care at St. Stephens Hospital, New Delhi from Oct 31st - Nov 4th, 2011. The instruction was provided from the Toolkit Training manual (Worldwide Palliative Care Alliance & Help the Hospices). The Toolkit was designed to teach how to improve care from the roots up in resource-limited settings. 15 modules covered a basic understanding of palliative care, symptom management, communication skills, bereavement care and caring for children with end of life diseases.



The resource persons were: Dr. Mhoira Leng: Palliative Care Physician, Cairdeas, Scotland (presently working in Kampala, Uganda); Dr. Jane Bates: Palliative Care Physician, Malawi; Dr. Ed Dubland: Palliative Care Physician, Canada; Dr. Chitra Venkatesh, Psychiatrist; Josephine: Senior nurse in palliative care, Kampala, Uganda.

24 participants from 6 EHA hospitals, from Helpage India, and from St. Stephens Hospital greatly enjoyed the very participatory sessions. Evaluations revealed that the majority of participants appreciated all the sessions with a particular inclination towards learning about holistic care, pain and symptom assessment and management, communication skills, and spiritual care. They valued the different teaching methods such as case studies, group discussions, film clips and slideshows.



Evaluation of the PC Service at HBMH, Lalitpur

An evaluation of the 19-month old palliative care service at HBM Hospital, Lalitpur was undertaken from Nov 7-9, 2011. Drs. Mhoira Leng, Jane Bates and Ed Dubland were the main evaluators.

Report on Achievements in Palliative Care at HBM Hospital, Lalitpur

- It is a holistic service with a clear Christian witness and a cohesive team
- It is a unique and the only rural home care palliative care delivery service in whole of the state of U.P.
- Planning for clinical support is flexible and responsive to the needs of the patients. The care is given with compassion and empathy.
- There has been extensive and successful networking, community engagement and awareness, and mobilization of local resources.
- There are good clinical guidelines and standard record keeping with excellent documentation of the whole process. A narcotics license has been obtained.
- There is a spacious ward that was renovated along with a meeting room and office space
- The service is appreciated and valued by patients and families



Feedback

- a. The model of care (home based, out-patient, in-patient) can be widened so that it is not so disease specific (restricted to cancer and HIV patients at present).
- b. Consider the pros and cons of having a specialist (present model) versus an integrated generalist PC service where all the hospital doctors are available for providing care. There should be continued integration into HBMH service with clinical rotations (HBM staff with Palliative Care Team).
- c. Continue to develop Palliative Care staff capacity – training, distribution of tasks, volunteers, exposure visits/clinical modeling
- d. Keep a high standard for quality of care rather than concentrating on coverage area. At present the target population is within a radius of 25 kms from the hospital. This can be widened if there are more volunteers.
- e. Continue to focus on empowering families and skills sharing.
- f. Keep a focus on caring for the staff and their emotional needs. Reflect on boundaries.
- g. Consider sustainability and reproducibility to other EHA sites.

Palliative Care at BCH, Fatehpur

Dr. Sunitha Verghese and Mr. Daud Masih visited the PC service at Lalitpur in early December last year to observe, participate in and plan the new service to be started at that hospital. Sunitha will attend the training course at the Trivandrum Institute of Palliative Services under the guidance of Dr. M. Rajagopal. Two nurses from BCH will spend a week at HBMH for an orientation programme. The hospital hopes to start the home-based care service as soon as possible.

Jaishree, a patient at Shalom, Delhi

Jaishree, a 26-year old HIV positive woman, was abandoned by her husband 7 months ago and lives on her own. She receives some help from a local NGO (Intermission). She presented to the Shalom Centre in 2009, was diagnosed with tuberculosis and started on medication. A year later she was diagnosed with cancer of the cervix. She was admitted to the Shalom in-patient services for terminal care as she was very weak, unable to sleep, and had extensive metastasis. Jaishree was born and brought up in a traditional Hindu family. But now she believes in Christ through the sharing of caring staff at Shalom. She entrusted her problems to Him and died last week with much of her physical and emotional suffering laid to rest.

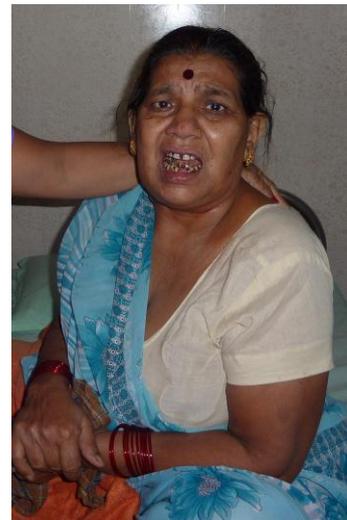
Training in Palliative care for Makunda Christian Hospital, Assam

Nurse Martina is undergoing training in palliative care at Cachar Cancer Hospital. A group from Australia will visit in February to complete the training, conduct an examination and issue certificates. Dr. Athikho at Ambassa will also attend the training in February for medical officers. After this is completed Makunda will likely have an MoU with Cachar Cancer Hospital for palliative care. At present it will be hospital based but it

will become home-based after it has settled in well. At Cachar Cancer Hospital only 7% of patients are completely cured after treatment as most of them present very late in the course of the disease.

Why Won't the Doctor stop it From Hurting? Tehelka Article: 15 December, 2011

The Indian law to regulate production and sale of narcotics is one of the harshest in the world. Passed in 1985, the core of the Narcotic Drugs and Psychotropic Substances Act is to crack down on drug trafficking. It introduced a long, complex, bureaucratic procedure to obtain permission even for medical use of narcotics. In the process the availability of opiates for medical purposes has plummeted. Immediately after the law was passed, legal morphine use fell 97%. Only government-approved hospitals can obtain morphine after registering and submitting an application. In most States, each hospital is allowed only a fixed quota, and each shipment requires five licenses. The morphine pills must be locked in a two-key cabinet, and usually, a separate pharmacist must be hired to maintain records for every pill prescribed by the doctor.



No more than 90 pills can be given to a patient at a time. Due to this bureaucratic nightmare, clinics dispensing morphine are scarce. ***The entire state of Uttar Pradesh, however, currently has 4 lakh people with cancer*** but only one pain clinic*.

Haryana has close to 60,000 people with cancer, but not a single pain center.

Lad Kuwar (50) had cancer of the tongue. She was taking pain medication from several doctors but the pain was unrelieved until the palliative care team at Lalitpur started her on morphine. She died pain free on Jan 28th this year.

Kerala is the odd exception. This is because the first WHO workshop in the country in the eighties was in Kerala. There, WHO treat pain, and at the top of trained doctors on how to conduct annual workshops. long battle waged by hospitals Revenue Department of India, narcotics rules were relaxed in the state. Now, for a population of 75,000 people with cancer, there are 140 palliative centers.

It's not just about relieving the pain. Morphine also prevents its very occurrence

introduced a clear step ladder to the ladder comes oral morphine. It treat pain, and some of them still Thanks to this, and the 20-year-

with the Kerala government and Revenue Department of India, narcotics rules were relaxed in the state. Now, for a population of 75,000 people with cancer, there are 140 palliative centers.

The good news is that in 14 states, rules are being similarly relaxed. The real issue is with awareness – getting doctors to prescribe oral morphine. There is a stunning ignorance about not just morphine, but pain treatment itself. Out of close to 300 medical colleges in the country, only five in the entire country include palliative care or even pain treatment in their curricula. Dr. Rajagopal, who runs the Pallium India in Trivandrum says there is no real shortage of morphine as is often believed. “It is just that the system fails to get it across to the person who needs it.”

***At present HBM Hospital, Lalitpur runs the only home-based palliative care service in the state of U.P.**

InTouch

This newsletter is intended to keep other units in EHA, our partners and supporters informed about what is happening in Palliative Care in EHA. We hope to send it out about every 8-10 weeks, with news on how the program is developing, special events related to palliative care, and human interest stories about our patients. We welcome your comments and suggestions. Write to: ann@eha-health.org.