



InTouch

The newsletter of the
Palliative Care Department
Emmanuel Hospital Association

Striving to Serve – Stretching to Love



Volume 6

Number 1

March 2015

Evaluation of BCH, Tezpur Palliative Service

An evaluation was carried out in November 2014 of the 1-year old palliative care service, using a combination of rapid evaluation methodology and most significant change. Direct observation, document review and interviews of 5 cadres of service users, providers, referrers, and other key informants including community and church leaders was done. The evaluators were Drs Mhoira Leng, Dan Munday, Gurs Purewal, Dinesh Goswami and Ms Grace Kivumbi. The findings revealed that the teams and clinical care have been developed with active support of the leadership and Dr Jerine Liankimi. So far 114 patients have benefited from home care, out-patient and in-patient care. Future plans include: procuring an opioid license; a 5-year scale up plan; over time all nursing staff will be able to provide basic palliative care; a separate ward and vehicle for home care; and continuing medical education for Dr Jerine (Cardiff Course), the 'Link Nurses', nursing staff & students. Palliative care courses are planned in the community college.

International Conference of the Indian Association of Palliative Care



George (Utraula), Saira, Ann, Leela (Lalitpur), Jerine & Puspa (Tezpur) and Tony (Lalitpur)



Ann and other alumni of Flinders University Palliative Care Diploma course with Dr David Currow

7 EHA participants attended the International IAPC Conference in Hyderabad from February 13-15, 2015. Very well organized, with a wide range of interesting topics and speakers, the conference provided a great deal of learning, introduction to innovative interventions for patient care, networking and promises to help one another in providing a much needed service. Drs Saira Paulose (Director, Shalom Delhi) and Ann Thyle (EHA Palliative Care Consultant) were faculty members who gave presentations; Saira on 'HIV and Pain' and Ann on 'Establishing Palliative Care in Rural North India'.

EHA's Palliative Care Service was mentioned in several papers. Dr Mhoira Leng, Palliative Care Physician and Director Cairdeas International Palliative Care Trust spoke on influencing health systems giving the example of EHA as a 'value-based' organization. Dr Gurs Purewal, UK Palliative Medicine Specialist Trainee, presented papers on EHA's research workshop and the evaluation of the palliative service at BCH, Tezpur. Dr Tony Biswas attended the contact class for the **Diploma in**

Palliative Care, Cardiff University and Ann Thyle met with alumni of the **Flinders PC course** along with faculty member, Dr David Currow.

Grateful Thanks to Cairdeas International Palliative Care Trust

An amazingly fruitful partnership has existed between EHA and Cairdeas International Palliative Care Trust, a Scottish charity. Dr Mhoira Leng, Medical Director of Cairdeas, visited Lalitpur with Ann in 2009, providing much needed advice and mentorship. She also conducted our first ever palliative care workshop at Shalom Delhi in Feb 2009 along with Dr Ed Dubland. This was followed by the Toolkit Training at St Stephens Hospital in 2011; workshops on 'Taking Palliative Care Forward: Leadership and Training in 2012 & 2013; Mentoring and Research workshops in 2014. In addition, Cairdeas also funded Communication Skills Workshops, starting new PC services in Tezpur, Chhatarpur, Utraula and Madhipura.

During Nov 2014, Mhoira and Ann planned and prepared for an EHA 'mentorship programme'. The mentors attended the Hyderabad conference and then set out straight away to visit Dapegaon and Fatehpur with the aim of providing mentoring and review that would assist in the ongoing development of palliative care services at EHA hospitals.



Richard & Karilyn; Felicity & Dan

Drs Richard and Karilyn Collins, with their considerable experience in the Tanga region of Tanzania, spent 2 weeks at GMPH, Dapegaon, contributing widely in different areas: re-enforcing the principals of PC, encouraging good practice and forging community links. Drs Dan and Felicity Knights spent a week at the same hospital, also supporting the team in very practical ways. Their input

Drs Grahame Tosh & Andrew Eastaugh spent 10 days at BCH, Fatehpur. Their insight and suggestions were very important and much appreciated by the team.

Last year Andrew Cox (intensive care nurse) and Dr Marian Davis spent time at Utraula and Tezpur respectively, providing much-needed encouragement.

Care Quality Commission: independent regulator for health and social care, UK

Has a themed review of End-of Life Care - read about it at

<http://www.cqc.org.uk/content/themed-review-end-life-care>

10 Key Quality Indicators for Palliative Care are listed below:

1. Palliative care patients receive a comprehensive assessment (physical, psychological, social, spiritual and functional) soon after admission.
2. Seriously ill palliative care patients are screened for pain, shortness of breath, nausea and constipation during the admission visit.
3. Seriously ill palliative care patients who screen positive for at least moderate pain receive treatment (medication or other) within 24 hours.
4. Patients with advanced or life-threatening illness are screened for shortness of breath and, if positive to at least a moderate degree, have a plan to manage it.
5. Seriously ill palliative care patients have a documented discussion regarding emotional needs.
6. Palliative care patients have a documented discussion of spiritual concerns or preference not to discuss them.

7. Seriously ill palliative care patients have documentation of the decision-maker's name and contact information, or absence of a surrogate.
8. Seriously ill palliative care patients have documentation of their preferences for life-sustaining treatments.
9. Vulnerable elders with documented preferences to withhold or withdraw life-sustaining treatments have their preferences followed.
10. Palliative care patients or their families are asked about their experience of care using a relevant survey.

Pravin Dhumal: Maintaining Hope, Dying Peacefully

12-year old Pravin Dhumal, was diagnosed with cancer of his left nostril. He had surgery and 6 cycles of chemotherapy at the Cancer Centre in Barshi, a town some distance from GMP Hospital, Dapegaon, Maharashtra. The mass reappeared, increased in size and caused severe pain.

Pravin's father approached GMPH's palliative care service for pain medication. On their first home visit, the PC team found Pravin in bed, his lower face swathed in a cloth. The team gently asked if he would remove the cloth. It was pitiable to see his distorted face, bulging lip and nostrils, all badly infected. Self-consciously, young Pravin quickly replaced the cloth. He yearned to go to school and play with his friends but his illness and appearance prevented social contact. He was sure that with treatment he would look normal again. Pravin's parents, aware that their son had incurable cancer, did not tell him.

The PC team gave him books and advised his parents to consider home schooling. At their next visit, Pravin excitedly showed his new textbooks. He was studying regularly at home, his teachers agreed to let him appear for final exams. He was filled with hope. Pravin had many talents. He was a wonderful artist. He also crocheted well, not allowing the absence of a crochet hook to deter him. He fashioned one with a stick and wire and crocheted a beautiful doormat. His mother often cried, wondering why such a brave and gifted child was given life when he was to die so soon.

Pravin was amazingly mature for his age. He overheard his mother wish his disease on herself. Pravin gently reminded her that his father and the rest of the family depended on her. Pravin often expressed his sadness at the pain it caused his dear ones. Gradually, he deteriorated, became bedridden, unable to eat and in severe pain. The palliative team controlled the pain well and grieved for this special child. One evening, after developing fever and drinking water, he slipped away, peaceful in death.

On a subsequent visit his sorrowing parents expressed their gratitude for the GMPH palliative service. It was a great consolation to them that their child did not suffer. His peaceful death remains a good memory despite the emptiness of losing a well-loved son.

Praise and Prayer

Praise God for:

- a. EHA's palliative care teams who have prepared and participated well in the EMMS evaluation at Lalitpur, Fatehpur, Utraula, Chhatarpur and Dapegaon.
- b. The enthusiasm and commitment of the palliative care team at Madhipura.
- c. For excellent support from trainers and mentors.

Pray for:

- a. Protection of the teams during the oppressively hot summer months and the end-of-life patients who suffer even more in the heat.
- b. The basic course of the Indian Association of PC scheduled from June 8-12 and other workshops.
- c. The challenges of providing hope in the midst of neglect, poverty and healthcare apathy.

This newsletter is for EHA units, our partners & supporters to stay informed about PC in EHA. We welcome comments/ suggestions.
Write to: ann@eha-health.org and check out annthyle.blogspot.com (Feed One Another)
Emmanuel Hospital Association. 808/92 Nehru Place New Delhi 110019 Phone: 011-30882008