

Need to Strengthen Palliative Care in India

The burden of cancer looms large and Palliative Care in India is pathetic. **Dr Sankha Mitra**, Consultant Clinical Oncologist, Brighton & Sussex University Hospitals and Chairman, Board of Trustees “ Eastern India Palliative Care”, shares his vision of care and concern with Shahid Akhter, ENN

Please define Palliative Care?

Palliative Care is the holistic care of the dying cancer patient and any patient with a chronic life limiting illness. It includes pain and symptom control, psychosocial and spiritual support. The word comes from the latin “ Palliare” which means to cloak or hide the symptoms of disease. The aim of Palliative Care is to reduce suffering and facilitate a dignified and humane death.

How is Palliative care delivered?

Palliative Care is delivered by a multidisciplinary team of trained doctors, nurses ,social workers, psychologists, physiotherapists etc working through Cancer Hospitals, Out patientclinics, hospices and home care services.

The main aspects are proper documentation of and relief of pain and other symptoms, psychosocial support by proper assessment of psychosocial needs of the patient and their families, spiritual support including grief and bereavement counselling. The staff need advanced communication skills training, training in breaking bad news, training to prescribe morphine and other painkillers according to the WHO pain ladder, support of the whole family by social workers, financial counsellors etc.

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What is the status of Palliative Care in UK?

Palliative Care is a well recognized specialty in UK with higher medical training of registrars, referral of cancer patients by Oncologists to Palliative Care Consultants and nurses in hospitals when patients have life limiting cancer and other chronic diseases and referral to community palliative

care nurses and the local hospices for further management. Patients are looked after in the community and in their homes and have a dignified and humane death.

How did Palliative Care develop as a specialty in UK?

This was not very easy and took about 30 years. This was mainly be-

cause of Dame Cicely Saunders who was working as a social worker after being invalidated out of nursing and realised that there was no one to listen to dying cancer patients and hold their hand and provide them with pain control and help alleviate their total pain which included physical pain as well as psychological pain, economic pain and spiritual pain. However, she realised that no one would listen to her so she then studied Medicine and developed St. Christopher's Hospice in London which really started the whole Palliative care movement. This then spread across western Europe and USA.

What is the status of Palliative Care in India?

Palliative Care is a developing Specialty in India which needs to be highlighted to the general public who don't know about the benefits of it. At the moment there are 925 Palliative Care Centres in India of which 840 are in Kerala. There is a huge need to expand Palliative Care in the whole of India. At the moment no one gets good quality of palliative care in most parts of India.

The poor die in neglect because there is no one to look after them at the time of death, the middle class die in ignorance because they are unaware of it's benefits and they could pay for palliative care services if they were available but at the moment in a market health care system, there is no one selling palliative care as there is no one buying palliative care. The rich die in agony on a ventilator because there is no understanding of terminal care and prognosis and patients with very poor prognosis who are not appropriate for resuscitation end up on a ventilator with no benefit to them and considerable distress. We have to change this terrible situation.

What is the main problem?

The main problem is the draconian National Drugs and Psychotropic Substances Act NDPS 1985 which has pre-

vented access to Morphine , which is the cheapest drug produced in bulk in India yet not available to more than 5 percent of the cancer patients in India needing it for severe pain. The amended NDPS Act is at the moment tabled in Parliament waiting to be discussed and has been delayed everyday and has not been passed in the current session of Parliament. We have to get the amended NDPS Act through winter session of Parliament. Otherwise if it is delayed, 18 years of hard work will be lost forever and we will be back to zero. We need to highlight this important bill to the public so that they can petition their MPs so that they understand the importance of passing the amended NDPS Act during winter session of Parliament.

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What is the problem with the NDPS Act 1985 ?

The NDPS Act 1985 is very complicated and confusing with those needing a morphine license being sent from health ministry to drugs controller to excise commissioner and back to health ministry. There are several separate licenses including a separate possession license , export and import licenses so that by the time one license is acquired , the others expire. The amended NDPS Act aims to simplify the whole process so that genuine medical institutions seeking a morphine license to treat cancer patients in severe pain can easily get it. This will be immensely beneficial to poor patients as 10 mg of morphine costs only 1 rupee.

Please share your road map to develop Palliative Care across India?

Apart from the amended NDPS bill, we need to develop education & training centres of Palliative Care across India working with Pallium India and IAPC; we also need Out Patient Community Palliative Care Clinics across the whole of India with facility to develop Home Visits and Hospices. This will improve Palliative Care & Cancer Care across India.

Please share your precise role and initiatives taken.

I am a Consultant Clinical Oncologist based in UK. I am developing Palliative Care in Eastern India at the mo-

ment and with the aid of UKDFID I have started a " Train the Trainers" THET-Pallium India course in SGC-CRI. Thakurpukur, West Bengal. This is a 6 weeks course run every 3 months which is free for doctors, nurses and social workers. I am also running four free Community Palliative Care Clinics in West Bengal in Barrackpore, DumDum, Behala and Maheshtala. The experience of running these clinics show that Palliative Care is actually improving Cancer care across these areas.

Hence I want to roll out this model of Community Palliative Care Clinics linked to Cancer Hospitals across India as I believe this will help improve cancer care and palliative care across the whole of India. ☺