



# Care Beyond Cure



No. 9, JAN-MAR 2006

A quarterly newsletter on Palliative Care issues by the Policy Advocacy Group of CMAI

## Now Home. Now What?

Dear Friends,

Now that we've determined that 'Home Care is the best care', how do we go about developing it?

As suggested in the last *Care Beyond Cure* Newsletter, there are many models that can be followed. At the base of each of those is teaching, empowering, and supporting. Family members need to be taught how to provide the basic nursing care that the patient needs and the care that the team anticipates that the patient will need in the future. The Palliative Care team nurse plays the main role in patient and caregiver education. Family members are taught about diet and nutrition, bowel and bladder function, hygiene and skin care, pain and symptom management, communication, and emotional and spiritual support.

Care needs must be translated into the particular home setting, keeping in



mind the presence or lack of adequate water, toilet facilities, consistent electricity and the like. We must also be sensitive to the financial constraints of our patients, teaching them to make a normal saline solution from boiled water and salt, creating dressing and pads out of old clothing and so forth.

Caregivers need to know about diet and nutrition because food is such a

central part of every day life. Often, the needs of the dying cancer patient are different from their family members.

Teaching caregivers about offering small, frequent meals and permitting the foods enjoyed by the patient are essential. The difference between "encouragement" and "forcing" is an important lesson. Caregivers must also know that there may come a time where the patient can no longer eat — or will no longer want to eat — and that this is a very normal part of the dying process.

Communication and support are also needs in home care. We work with the family dynamics and we work toward helping families communicate. This helps them determine what the patient's priorities are in their final days and better helps all of us, especially the family, to begin to meet them.

Rev John S Lunn  
Editor

### *Palliative Pearls*

The sun at home warms better than the sun elsewhere - *Albanian Proverb*

We must make our homes centers of compassion and forgive endlessly - *Mother Teresa*

Make two homes for thyself... One actual home... and another spiritual home, which thou art to carry with thee always - *St. Catherine of Siena*



# Home Care

There was a time when many palliative care groups, including ours, considered home care programmes to be one of the extra facilities of a palliative care programme. Now, after more than a decade of experience in palliative care in the developing world, many of us consider it to be the most important component. Now we know that, in a third world situation, not having a regular home care service amounts to excluding a large majority of the most needy patients from receiving care.

Home care programmes are very much required for effective delivery of palliative care. The aim of palliative care is improving the quality of life of patients and their families. At times, even though care is available, the patient and his/her family are not able to access it because of physical disability, financial problems, difficulty with transportation, living in a remote place, or a caregiver's inability to support the patient all through the day. Home care programmes make care available to these patients where they live.

These people may need regular medical and other support. But for most of these patients and their families, staying in a hospital is very stressful. Not only are they far from familiar surroundings, but normal routines are also affected. Through home care, the palliative care



team can support these people in their homes.

In an out-patient department, the patient would be just one of many waiting to see a healthcare professional who may not understand the patient's real living conditions. Home care gives the palliative care team an opportunity to understand the patient and the family better and help them to prioritise and individualise care. Patients and families may be more open and may discuss various issues regarding the illness with more ease when they are at home.



Home care demonstrates to the community what palliative care is, and can also be used to motivate the community. Our community projects have been using home care as a way to involve local volunteers in palliative care. The actual caregivers, most often women, do not come to the out patient department. Addressing their needs, training them and supporting them are very important in maintaining the quality of life of the patients. The team would never meet many

of these principle caregivers if they did not make home visits. Regular round-the-clock medications are often part of caring for the chronically ill. This requires great motivation, both from the patient and the caregiver. Lack of motivation as well as other factors such as inability to understand the instructions, misconceptions about the medications, non availability of a watch/clock, etc., can affect compliance and lead to poor symptom control. Regular home care helps assure an understanding of the real picture and provides a check on compliance.

Home care need not be reserved for someone who is dying. Home visits starting early in the course of an illness help to build rapport between the caring team, the patient, and the family. This will increase their confidence in the home care team and will help them manage other issues including terminal care at home with the support from the team.

Even though the cost of home care may be higher than out-patient care, it will still be much less than what the community would have to spend to take these patients to a hospital. It would be even less if one takes into account the loss of income to those who accompany the patient to the hospital. The community can pool this money to support home care services, and the community can also contribute manpower to run the programme.

In short, home care programmes are an indication of the effectiveness of an area's palliative care services as it tries to provide care to everyone who needs care.

**Dr Anil Paleri**  
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Calicut  
Kerala

# Home Care — How it effects the doctor

**H**ome care programmes are an integral part of palliative care. In India where palliative care is just a seedling - outside of Calicut - home care programmes will provide more space for the growth of palliative care.

A home care programme strengthens the humanitarian bond between the patient, the relatives, and the home care team. The challenges faced in caring for dying patients are complex, and no one person can provide all the needed services, so many people are involved, and this forms a palliative care team. The needs of the patients leads to obtaining help from a variety of providers and these providers become a team. It is essential that all these individuals are aware of and agree with the management goals and that the treatment plan addresses these goals.

Our home care team consists of a doctor, a nurse, a social worker, and a chaplain. All the members of the team are well trained to handle the questions and the doubts of the patients and their relatives. We usually cover a 40km radius around CMCH, Vellore, but in some instances, we have gone farther to help desperate families.

We see three to four patients per visit. We bring along their medical records, and if there are specific socio-economic problems to be addressed, we discuss these within the team and make a tentative plan. When we reach the patient's house, some relatives are surprised, some are overjoyed and some are confused. Taking account of these mixed emotions, we extend a friendly hand to them. The doctor assesses the patient's physical status and inquires



about symptoms and control measures. Our nurse checks the stocks of medicines and crosschecks with the primary care giver. A home visit reveals the full picture of the patient and their care givers, as well as their socio-economic and psycho-spiritual conditions. The team needs to make decisions about care givers. We give helpful tips about maintaining hygiene or nursing care and make sure the caregiver can do what is suggested so that any difficulties can be tackled while we are there. Counselling staff may help the patient and the caregivers resolve spiritual or family issues. If a patient appears to be close to dying, we teach the relative about the dying process. If time permits, we try to bring awareness about cancer to others in the neighbourhood and encourage them to help each other in times of need. At the end of the visit, we check to be sure that all the required tasks are being carried out. After all the bumpy rides to villages, the gratitude we see in the gestures and smiles of patients and caregivers is the highest reward of the day.

**Dr T Shanthi Prasoon**  
Palliative Care Unit  
Christian Medical College  
Vellore



*Below is a poem written by a hospice patient*

I huddle warm inside my corner  
bed, watching the other patients  
sipping tea  
I wonder why I'm so long  
getting well,  
And why it is no one will talk  
to me

The nurses are so kind, they  
brush my hair  
On days I feel too ill to read  
or sew,  
I smile and chat, try not to show  
my fear  
They cannot tell me what I want  
to know

The visitors come in, I see their  
eyes  
Become embarrassed as they  
pass my bed  
'What lovely flowers' they say,  
then hurry on  
In case their faces show what  
can't be said

The chaplain passes on his  
weekly round  
With friendly smile and calm,  
untroubled brow  
He speaks with deep sincerity of  
life  
I'd like to speak of death but  
don't know how

The surgeon comes with student  
retinue  
Mutters to Sister, deaf to my  
silent plea  
I want to tell this dread I feel  
inside  
But they are all too kind to talk  
to me

Source: <http://re-xs.ucsmac.uk>

## Forum News

### Students of Fellowship in Palliative Medicine (FPM) from the network

The present batch of students of Fellowship in Palliative Medicine 2006–2007 (January) has 5 out of 12 students from the network. They are Dr Sarah Walter from St. Stephen's Hospital, New Delhi, Dr Nirmala Varghese from Shalom project of Emmanuel Hospital Association, New Delhi, Dr Sheila Grace from Lady Willingdon Hospital, Manali, Dr R Sanghluna from Presbyterian Hospital Durtlang, Mizoram and Dr J Jacob. They will appear for the exam which is scheduled to be held in December 2006. Some of these hospitals have existing hospice and others are in active process of starting.

The admission for the next batch of students will be held in August 2006. Forms will be available from May 2006 from CMAI.

### Palliative Care Unit at CSI Hospital, Erode

The CSI hospital, Erode has started Palliative Care Unit in the hospital since September 2006. They have four beds assigned to Palliative care. There is a dedicated team who sees an average of two patients a week. Patients are referred to them for chemotherapy and consultation. The hospital is in the process of starting home-based care.

### Malankara Orthodox Syrian Church Medical Mission (MOSCOMM) Hospital, Kerala

The MOSCOMM hospital have obtained permission to stock and dispense oral morphine. The patients are admitted at different departments. The hospital is in the process of forming a separate ward for palliative care.

### Padhar Hospital, MP

The palliative care work in Padhar hospital is going on well. Patients are seen at the out-patient department. The patients are from all around MP even from far off villages. Padhar hospital is planning on having a separate building for palliative care and are in the process of consultation for the same.

### Two-day Conference on Palliative Care, TRADA, Kerala

A two-day State Conference on Palliative Care & Mental Health Counselling will be held on February 24 - 25, 2006 at TRADA, Kerala. Starting of a short-term training programme for Health Workers in Palliative Care Counselling is in the process.

### On-line Journal

Indian association of Palliative Care has launched its on-line edition of 'Indian Journal of palliative care' - [www.jpalliativecare.com](http://www.jpalliativecare.com). This has full text articles and has a lot of information and useful links.

### Handbook on Palliative Care

CMAI has re-published The International Association for Hospice & Palliative Care's (IAHPC) "Hospice & Palliative Care Manual" edited by Rev John Lunn, Palliative Care Unit, CMC, Vellore, adapted for use in India. The manual is a practical and clinical guide book for palliative caregivers and is available at CMAI at a cost of Rs.80/- (postage & packing extra)



If you are interested or involved in palliative care and wish to receive a copy of this newsletter, contact Dr Ronald Lalthanmawia, CMAI, Delhi at [ronald.l@cmai.org](mailto:ronald.l@cmai.org)

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