



Care Beyond Cure



No. 16 & 17, OCT 2007 TO MARCH 2008

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

Caring for Caregivers

Dear Friends,

Caregivers – family, neighbours, community, volunteers and healthcare professionals are the primary determinants of Palliative Care. Support to the caregivers is an important area which is an integral part of providing best possible palliative care.

Support to caregivers will include capacity building, training and also constant support. Families require more emotional support and technical knowledge in home based and supportive care while healthcare professionals will require more technical training, improvement in knowledge and building skills. Caregivers, especially family members go through different emotions and feelings when palliative care is suggested. They need care and support as family members as well as caregivers.

Caregivers should be assessed for their level of perceived burden and for the presence of affective disorders such as depression and anxiety. In addition, it is important to assist caregivers, especially family members with coping strategies, counselling them about ways to handle behavioural management issues that arise during the course of the illness.

This edition of *Care Beyond Cure* has an article on how to help a family to cope with these situations. There is also an article on understanding and dealing with the anxiety and fear of patients and their families and also an article on caregiver exhaustion.

Another area of caring for caregivers is to enhance their technical knowledge and skill. They have to be technically sound to be able to deal with situations which otherwise may not be comfortable for them.

With the support of HelpAge India, CMAI took initiative in conducting workshops on 'Palliative Care for Cancer, Geriatrics and Terminal Illnesses' at its nine member institutions in different parts of the country. This edition has a brief report of each of the workshop. The methodology and process can be replicated as each of them is specific to the need of the area and to different audiences.

CMAI would like to take this opportunity to thank HelpAge India for its support and the member institutions for conducting the workshops, and a special 'thank you' to Mr Hamilton, CMC Vellore for his valuable contribution as Editor of CBC for this year.

Ronald Lalthanmawia
Guest Editor

Palliative Pearl

Learn to get in touch with the silence within yourself and know that everything in this life has a purpose.

The ultimate lesson all of us have to learn is unconditional love, which includes not only others but ourselves as well.

Dr Elizabeth Kubler-Ross



Caregiver exhaustion

Several studies have indicated that the primary determinant of palliative care at home is the presence of a willing and able caregiver. The families in these studies indicated that the ability to carry out this role is determined in part by the nature of the home care services available. Recognising these factors highlights the importance of caring for the caregiver.

Each patient's situation is unique in the combination of available informal caregivers. There is often a primary caregiver who will require an increasing amount of support depending on several factors: the duration of care, the care needs of the patient, and the emotional and physical resources of the caregiver. Home care referral is best made early. This allows for care planning and for a relationship to be established well before crises develop. An informal network of support can be mobilised through neighbours, friends, and community affiliations to supplement the resources available through home care. Volunteer agencies can also provide some relief.

Caregivers can be given information about community resources, such as respite care or hospice care where these are available. Knowledge of the patient's resources, such as insurance coverage, helps in planning for caregiver support particularly if there is coverage for private-duty nursing under an extended medical care plan.

Occasionally, caregivers will appear to block the use of available forms of support, even when the need appears obvious. Exploring the nature of these barriers often reveals an inability to accept impending or actual losses, feelings of guilt, family dysfunction, fear of separation, lack of trust, or other factors. The manner in which patients and families have faced previous transitions is also a major factor and is thought to be related to personal style and past experiences with loss and death. If these factors can be identified, it could be possible to explore sensitively, the ways to make support services acceptable to a caregiver.

Anxiety and fear

In taking a holistic approach to care, time is required to attend to the emotional concerns of patients and their families. This time is often well spent, as alleviation of anxiety affects symptoms and their control, and the overall perception of management in the home.

Patients experience anxiety, most commonly from fear of the unknown and fear of suffering. They could have difficulty expressing these fears to others. Regularly scheduled visits, having a private time with the patient etc., can help to set the tone for an open and trusting relationship. Examining the patient and explaining what appears to be happening physically can help to reassure and inform the patient. This could lead to a discussion of what might happen. A physician can then suggest strategies for coping with anticipated or feared situations. Allowing the expression of fears could also present an opportunity to involve other professionals, such as clergy or social workers.

An important part of allaying anxiety and fear can be providing an opportunity for patients to express their wishes

about their care. Patients often express a personal preference about their activities of daily living, their wish to die at home, or their decision regarding resuscitation. They sometimes also express more specific directives about implementing or withholding treatments, procedures, or investigations. The patient's wishes are best reviewed with the family and documented in a manner that is accessible to all care providers. An open letter can be appended to the nursing chart in the home. Home care programmes generally have guidelines for "do not resuscitate" orders, designed to ensure that all health professionals are aware of the order. Patients and families should be aware that any directive is open to modification or withdrawal at any time and need to be reviewed from time to time.

Patients and family members do not always agree. Family members could be denying what is happening or need to hold on emotionally to the patient, or the patient's wishes could place an intolerable burden on family members acting as caregivers. A family meeting can allow expression of these difficulties.

How do families cope?

When the question of palliative care is raised, family members may feel confused, overwhelmed and frightened. They may experience many reactions like shock, disbelief, a sense of unreality, numbness, sadness, fear, anxiety, anger, guilt, emptiness, hopelessness, and other intense feelings. It is important to know that these feelings and thoughts are all experienced by many and are not unexpected at such a difficult time. They are natural expressions of the feelings when they cannot protect their loved ones from a life-threatening illness.

Many families experience great turmoil as a result of major changes. Sometimes families find that their experience of the good days can be affected by the knowledge of the illness.

In order to assist the families to understand the situation better, it is important to understand the emotions they go through. The following hints enumerate some of the different emotions that can be used:

Helpful hints to help family cope

- Give them opportunity to take decision to do what is right and/or comfortable for them, the patient and the family, not what is expected of them.
- Let them ask questions for further understanding and clarification. Remember that no question is too small or too silly to be asked.
- It is alright if they want to know everything or only some things at a time.
- Wait for them to be ready to talk about the disease progression, symptoms, timing of death etc.
- Help them to seek second opinion if they want to.
- Tell them the importance of taking care of themselves like having their own time.
- Give them an opportunity to openly discuss what changes that are going to happen in the family.
- Keeping diaries would help if they do not want to discuss in open.
- Give them information on supports available.

Workshop on Palliative Care for Cancer, Geriatrics & Terminal Illnesses

Nine workshops on Palliative Care for Cancer, Geriatrics and Terminal Illnesses were held across the country from March 25 to April 2, 2008. The workshops were organised in various CMAI member institutions, supported by HelpAge India and coordinated by Palliative Care Forum of CMAI with active support by re-gional representatives of CMAI.

The workshops provided a platform for professionals like doctors, nurses, social workers, counsellors, chaplains, NGOs, advocates and volunteers to come together, and work together to understand the challenges involved in the area of Palliative Care. The workshop topics were customised according to the need and relevance of the area. The main areas discussed were:

- Introduction to Palliative Care
- Communication Skills
- Interactive Session on Ethics
- Pain Management

- Geriatrics Palliative Care
- Home Care for the terminally ill
- Palliative Nursing
- Emergencies in Palliative Care
- Ethical & Legal Issues for End of Life
- Role of families and communities

Students from medical colleges and nursing colleges were sensitised to Palliative Care and Geriatrics issues. The workshop also builds the skills of nurses and doctors, and in some places, that of caregivers including relatives, NGOs and volunteers. Communication skills and interpersonal/professional relationships were focussed. Legal and ethical issues in end-of-life care and in geriatrics was discussed with great interest and various opinions were shared. The success of the workshops was evident from the enthusiastic response and participation of institutions and individuals, not only from CMAI network but also from outside.

1. MOSC Medical College & Hospital, Kolenchery, Kerala

Dates: March 29-30, 2008

Venue: MOSC Medical College & Hospital, Kolenchery, Kerala



Resource Persons

1. Dr Rajagopal, Chairman, Pallium India
2. Ms Deepika, Pallium India
3. Ms Aneesa, Pallium India
4. Dr Lal, Palliative Care Physician, Vazhakkulam

5. Dr Marina Rajan, MOSC Medical College

Participants

Day 1: 207 Nurses and Nursing Students

Day 2: 129 Medical Students & Doctors

Hospitals

1. MOSC Medical College, Kolenchery
2. Carmel College of Nursing, Aluva
3. MGM Muthoot Medical Centre, Pathanamthitta
4. A P Varkey Mission School of Nursing, Arakunnam
5. Peace Foundation School of Nursing
6. Sanjo Hospital, Perumbavoor
7. Samaritan College of Nursing, Pazhanganadu
8. St Gregorious College of Nursing, Parumala

9. St John's Hospital, Kattapanna
10. Rajiv Gandhi School of Nursing, Koothattukulam
11. Najath School of Nursing, Aluva
12. Devamatha Hospital, Koothattukulam
13. Morningstar Hospital, Adimali
14. St George Hospital, Nazhakkulam
15. MAJ School of Nursing, Elappally
16. St Joseph's, Kothamangalam
17. Lakeshore Hospital, Kochi
18. Vathiath Hospital, Perumbavoor
19. Lissie Hospital, Ernakulam
20. Medical Trust, Ernakulam
21. Holy Cross Hospital, Pattimattum

The workshop was formally inaugurated by Mr Joy Jacob, CEO of MOSC Medical College. Dr Rajagopal, Chairman, Pallium India gave the presidential address and Dr Radhakrishnan, Dean; Dr Sojan Ipe, Medical Superintendent; Dr Sam Philip, Organising Secretary and Fr Johny George, Regional Secretary, CMAI were some of the delegates present among 700 participants.

The afternoon sessions on both the days were dedicated to 'communication skills'. The participants were divided in smaller groups to interact freely. There were plenty of role plays. The last sessions on both the days were on Ethics. Certificates were distributed to all delegates.

2. St Stephen's Hospital, New Delhi

Dates: March 28-29, 2008

Venue: Conference Hall, St Stephen's Hospital, New Delhi

Resource Persons

1. Dr Vinod Kumar, Prof. Emeritus & Consultant in Geriatric Medicine
2. Dr Reena George, Head, Palliative Care Unit, Christian Medical College & Hospital, Vellore
3. Dr Sushma Bhatnagar, Head of Dept., Palliative Medicine, AIIMS
4. Dr Jamila Koshy, Consultant Psychiatry
5. Dr Rani Bhatia, Head of Department, Department of Psychiatrist, St. Stephen's Hospital, New Delhi
6. Sr Sophiamma, Palliative Care Nurse, CanSupport New Delhi

Participants

70 including Doctors, Nurses, Counsellors, Social Workers

Hospitals/NGOs

1. St Stephen's Hospital, Delhi
2. Holy Family Hospital
3. Shanti Avedna
4. CMC Vellore
5. CanSupport
6. CBM

Dr Sudhir Joseph, Director of St Stephen's Hospital, welcomed the guests. Ms Anuradha Goel, Head of Patient's Welfare Society at St Stephen's Hospital lighted the lamp and formally inaugurated the workshop. Mr Suresh Kumar, from HelpAge India explained the 'ethos' and working of HelpAge India. Ms Indira Kurapati spoke about CMAI network and their involvement in Palliative Care. The sessions were very informative and interactive. The hospital is planning to have similar workshop at community level through the outreach programme of the hospital at Sundernagri, Shahdara. A nurse, a psychiatric social worker and a doctor have been selected for a short training in 'Care for Terminally Ill'.



3. Deenabandhu Hospital, ESAF Health Care Campus, Thachampara, Palakkad

Dates: March 30, 2008

Venue: Deenabandhu Hospital, ESAF Health Care Campus, Thachampara, Palakkad, Kerala

Resource Persons

1. Dr JC Vijayan
2. Dr Carlton
3. Ms Cicy George
4. Dr Shaji
5. Dr Baburaj
6. Dr Anandkrishnan
7. Mr Anand Jim
8. Ms Little Flower

Participants

Total: 77 (14 doctors, 60 nurses, 3 others)

Hospitals

1. Deenabandhu Hospital, Palakkad
2. Bethany Hospital, Anaikatty
3. Assumption Hospital, Kanjirapuzha
4. Palana Hospital, Palakkad
5. CSI Hospital, Codacal
6. CSI Diocese of North Kerala

The workshop started with an inaugural session chaired by Dr Shaji of Palliative Care Society and Mr Jacob Samuel, Director of ESAF Health Care as the Chief Guest.

The participants were actively involved in discussions and shared their experiences and comments. They appreciated the arrangements and the contents of the workshop. Everyone wanted to know more about the subject. Everyone volunteered to work with the Palliative Care Programme in their respective area of work. The participants and the faculty were issued certificates.



4. Nava Spoorthi Kendra, Bangalore

Dates: March 28-29, 2008

Venue: Nava Spoorthi Kendra, Cookson Road, St. Thomas Town Post, Bangalore

Resource Persons

1. Rev David Rajan, CSI, CMAI Chaplains Section Secretary for Karnataka region
2. Dr Stanley C Macaden, National Coordinator, CMAI Palliative Care Initiative & Head of Department, Palliative Care Department, Bangalore Baptist Hospital
3. Dr B Bharathi, Fellow Palliative Medicine, St John's Medical College & Hospital, Bangalore

Participants

26 participants of doctors and nurses



Hospitals

1. Catherine Booth Hospital, Nagercoil
2. Bethesda Hospital, Ambur
3. Scudder Memorial Hospital, Ranipet
4. CSI Medical and Leprosy Centre, Vandavasi
5. SIHR & LC, Karigiri
6. Holdsworth Memorial Hospital, Mysore
7. Lombard Memorial Hospital, Udupi
8. St. Gregorious Mission Hospital, Parumala
9. Christian Fellowship Hospital, Oddanchatram
10. CSI Hospital, Bangalore.
11. Ellen Thoburn Cowen Memorial Hospital, Kolar

The workshop programme was effective and had a good feedback from the participants. The workshop was evaluated keeping in mind the aspects of interaction, questioning skills, involvement, observation and participation.

The participants came for this workshop without having much knowledge about the palliative care and they are now sensitised to a level that they can go and share with others about palliative care and the acquired skills in the area. The workshop came to a close with preparation of action plans by the participants and evaluation of the workshop.

5. Emmanuel Hospital Association, Imphal

Dates: March 28-29, 2008

Venue: Hotel Imphal, Imphal, Manipur



Resource Persons

1. Prof Th Tomcha Singh, Head of Radiotherapy & Regional Cancer Centre RIMS, Imphal
2. Dr Y Indibor MD, Assoc. Prof. Radiotherapy Dept. RIMS
3. Ms Radharani, HIV/AIDS Nurses In-charge, JN Hospital
4. Dr Diamond Sharma Hidangmayum MBBS, VS (UCLA-USA), HIV/AIDS Clinical Researcher
5. Dr RK Lenin Singh, Associate Prof. Psychiatry Dept. RIMS
6. Dr L Jaichand Singh, Prof. Radiotherapy Dept. RIMS
7. Dr Memchoubi MD, Demonstrator, Forensic Dept. RIMS

Participants

Total: 51 – 10 doctors, 21 nurses, 9 counsellors/social workers, 1 advocate, 10 others, medical doctors, nurses, social workers and church leaders from different districts of Manipur.

Hospital/NGO

1. Resource Centre for Social Welfare and Community Development (RC-SWACD)
2. Care Foundation
3. Dedicated People's Union (DPU)
4. Regional Institute of Medical Sciences (RIMS)
5. Project Orchid
6. Sahara
7. Lamka Rehabilitation & Research Centre (LRRC)
8. Mashunrin Society
9. Emmanuel Hospital Association (EHA)
10. Social Awareness Service Organization (SASO)
11. Kripa Foundation
12. Tangkhul Mayar Ngala Long (TMNL)
13. Educated and Self Employed Women's Social Service Association (ESEWOSSA)
14. Participatory Action for Sustainable Development Organisation (PASDO)
15. JN Hospital, Porompat, Imphal

Dyadic method of training and powerpoint presentations were used by all the resource persons to facilitate the workshop followed by question and answer session. On behalf of EHA and CMAI, Ms Ching Songput welcomed and thanked the participants. In her introductory remarks, she emphasised on the importance of Palliative care and expressed gratitude to the Help Age India for generously funding the workshop.

6. Dr Somervell Memorial CSI Medical College, Karakonam, Kerala

Dates: March 25-26, 2008

Venue: Women's Fellowship center, South Kerala Medical Mission, LMS Compund, Palayam, Trivandrum

Resource Persons

- | | |
|-------------------------|-----------------------|
| 1. Dr MR Rajagopal | 2. Ms Aleyamma Thampi |
| 3. Dr Baburaj C | 4. Dr K Leelamoni |
| 5. Dr S Gopinathan Nair | 6. Sr Sheeba |
| 7. Sr Valsa | 8. Dr Biju Raghavan |
| 9. Dr Sunil Kumar | 10. Dr CV Prasanth |

Participants

103 - A total of 71 medical students and 32 nursing students

Hospitals

1. Govt. Medical College, Kanyakumari
2. Govt. Medical College, Trivandrum
3. Sree Gokulam Medical College, Trivandrum
4. Pallium India
5. KGMC, Nagarcoil
6. AIIMS, Bangalore
7. Christian College of Nursing Neyyoor
8. Dr SM CSI Medical College, Karakonam
9. St Xaviers Catholic College of Nursing, Nagercoil

Followed by the registration, the inaugural session started at 9:00 am. Dr Bennet Abraham (Director, Dr SMCSI Medical College, Karakonam) delivered the welcome address. Dr Elsy Philip (Rtd. Principal, Govt. Medical College, Trivandrum)

presided over the function. Most Rev Dr JW Gladstone (Moderator CSI & Bishop, South Kerala Diocese) inaugurated the meeting. Dr Glorine Gnanathankom (Former Principal Dr SMCSI Medical College) Ms Aleyamma Thampi (Regional Deputy Director, HelpAge India) Mr Jeremy Bliss (Chairman, College Union Dr SMCSI Medical College Karakonam) felicitated the function. Dr S Gopinathan Nair (Chairman, organising committee) delivered the vote of thanks.

To conclude the workshop and to give away the certificates, a small valedictory function was organised towards the end of the workshop. Dr Samson Nessim Principal of Dr SMCSI medical college presided over the function. The question-answer session was informative and exciting. Dr Samson distributed the certificates.



7. Miraj Medical Centre, Miraj, Maharashtra

Dates: March 29-30, 2008

Venue: Wanless Hospital, Miraj Medical Centre, Miraj, Maharashtra

Resource Persons

1. Dr Anuradha Sowani, Consultant Medical Oncologist, Palliative Care, Pune
2. Mr Suresh Saler, Consultant, College of Nursing, M M C
3. Dr (Ms) Jacob, MMC, Miraj
4. Dr NS Sase, Consultant Neurologist, Wanless Hospital
5. Pastor Ghosh, Chaplain, Wanless Hospital
6. Dr Anand Sakate, Consultant Physician, Wanless Hospital
7. Dr (Ms) Pawar, Ashwood Memorial Hospital, Daund
8. Ms Madhale, Professor & Vice Principle, College of Nursing, KLE Belgaum
9. Dr PD Pawar, Medical Superintendent, Ashwood Memorial Hospital, Daund
10. Dr V C George, Director, VADKET, Miraj
11. Mr Satralkar, Advocate, Pune

Participants: 125

Hospitals

1. Wanless Hospital, Miraj Medical Centre, Miraj
2. Ashwood Memorial Hospital, Daund
3. WF Pierce Memorial Hospital, Wai

4. Mary Bhole Nursing School
5. VADKET, Miraj
6. College of Nursing, KLE Belgaum
7. Leprosy Hospital, Miraj
8. College of Nursing, MMC, Miraj
9. Cancer Hospital, Miraj

Nurses, doctors and people associated with palliative care participated in the discussions. The participants appreciated the workshop and the sessions. The Keynote address was well appreciated and the skill-building sessions benefited the participants. The session on ethical and legal issues was of interest and topics like Euthanasia, Mercy Killing, and Prevailing laws of the land were discussed. The participants were given certificates of participation.



8. Presbyterian Hospital, Durtlang, Aizawl, Mizoram

Dates: 31st March, 1st & 2nd April 2008

Venue: Presbyterian Hospital, Durtlang, Aizawl, Mizoram

Resource Persons

1. Dr Dinesh Goswami, Guwahati Pain & Palliative Care Society, Guwahati
2. Dr Zothankima, Radiotherapist, Civil Hospital, Aizawl
3. Dr Jeremy Lalrinsanga, Pain & Palliative Care Centre, Civil Hospital, Aizawl
4. Dr Eric Zomawia, Pathologist, Civil Hospital, Aizawl
5. Ms Lalchhamhimi, Civil Hospital, Aizawl

Participants

Day 1: 33 Patient's relatives and NGOs, Cancer Society

Day 2: 14 Doctors

Day 3: 59 Nurses

Hospitals and Institutions

1. Civil Hospital, Aizawl
2. Cancer Society
3. DCCP

4. Aizawl Adventist Hospital
5. CSM Comm. Member
6. Grace Inn
7. Agape Home
8. Khualbuk Lawngtlai
9. Khualbuk Khawzawl
10. Khualbuk Saiha
11. KTP Durtlang Branch (Youth Group)
12. Presbyterian Hospital, Durtlang, Aizawl
13. Regional Institute of Para Medical & Nursing
14. Aizawl East CMO Office
15. Living Hope Ministry
16. Durtlang VCP (Village Council)
17. MHIP Durtlang (Women's Group)
18. Positive Network of Mizoram
19. Church leaders and representatives

The workshop was inaugurated in the presence of the Medical Director and Medical Superintendent of the hospital. The workshop was first of its kind in this area. The workshop included the community members especially those affected by cancer. They found the workshop very useful as it addressed the issue that the relatives of the patients are faced with.

The NGOs also gave good suggestions for the future actions. The workshop introduced the concept of Palliative Care and helped healthcare professionals to know more about the issue.



9. Christian Institute of Health Sciences & Research, Dimapur, Nagaland

Dates: 31st March & 1st April, 2008

Venue: Conference Hall, CIHSR, Dimapur

Resource Persons

1. Dr Baghabati, Dr B Baruah Cancer Centre, Guwahati Pain & Palliative Care Society, Guwahati
2. Dr Victoria Seb, ART Centre, Civil Hospital Dimapur, Fellow of Palliative Medicine
3. Ms Alemla Walling, Psychologist, Trinity Theological College

Participants

47 including doctors, nurses, social workers, hospital administrators

Hospitals/NGO

1. Christian Institute of Health Sciences and Research, Dimapur
2. Civil Hospital, Dimapur
3. Charava Home

CIHSR is a newly established tri-partite effort of Government of Nagaland, CMC Vellore and Emmanuel Hospital Association. With support from CMAI and HelpAge India, CIHSR was able to conduct a two-day workshop on Palliative care.

The participants were drawn from various institutions in and around Dimapur, involved in healthcare delivery at various levels. A good number of participants were from the CIHSR. The participants felt the contents of the workshop were relevant to their area of work.



Forum News

Sessions on Palliative Care at the 39th Biennial Conference of CMAI Shillong, Meghalaya

During the 39th Biennial Conference of CMAI held at Central Library, Shillong, Meghalaya, a session on Palliative Care for HIV and AIDS was taken by Dr Stanley Macaden. Nineteen doctors from different states from the NorthEast and other states attended the workshop.

Dr Stanley Macaden talked about Palliative Care and particularly, the newer initiatives of Bangalore Baptist Hospital at the Doctor's Section meeting.

Workshop on Palliative Care at Trivandrum

On November 13, 2007, a workshop on Palliative Care was conducted for seminary students at Kannamoola Seminary, Trivandrum.

For more information on the Fellowship Programme in Palliative Medicine, or if you are involved in palliative care and wish to receive a copy of this newsletter, contact Dr Ronald Lalthanmawia, CMAJ, Delhi at ronald.l@cmai.org

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Printed at: Impulsive Creations