



Jeevodaya Hospice

1/272, Kamaraj Road, Mathur, Manali P.O., Chennai - 600 068.
Tel. : 2555 5565 / 2555 9671 Email : jeevodayahospice@gmail.com
Website : www.jeevodaya.com



For Private Circulation - Re. 1.00

Sr. Mello F.C.C., Chairman

Dr. R. Nanjunda Rao, President

From the editors desk

Who can resist the smile of a baby? What joy can equal the pleasure of the moment when a child pauses in her play to come running and whisper 'I love you daddy, I love you mummy'. An infant's smile, a little child's bug, can warm and gladden the hearts of the most hardened criminal. Perhaps that is why God chose to be born as a little babe; perhaps that is why the infant babe, lying in a manger wrapped in swaddling clothes, enchants all people, young and old, believer and cynic. At a time when the world is torn apart with strife, when man is pitted against man, when random acts of violence kill and maim thousands of innocent people, when communal ill will corrupt the hearts of men, - the tender smile of the Holy Infant reminds us once more to love God and to love our fellow men.

If we open the papers or switch on television set, our mind reels under images of starving children with bloated stomachs, or children scavenging among the garbage bins, or slaving from morn to night. This Christmas let us honour God who chose to become a little child, by praying for children who are abused and exploited, who are sick and in pain. Let us also, along with our prayers do what we can with money or time to help these children who are all around us, if only we had the eyes to see. Let us reach out to all in need, especially the little children who are crying out silently to us.

May the Holy Infant's loving gaze heal the wounds on our hearts and may the Christmas tidings of joy and peace spread through the world.

With warm regards,

Sr. Lalitha Teresa, FCC

World Hospice and Palliative Care Day Celebrations

*Date - 10th October, 2009. Time - 2.30 pm.
Venue - MRF Hall, Loyola College, Chennai.*

[The following is a report of the deliberations of the "OPEN HOUSE" held on the above occasion].

The theme was 'Improving the Quality of Life of Cancer Patients'. The panelists were **Dr. Bose** [Surgical Oncologist], **Dr. Bala** [Radiation Oncologist], **Dr. Vanitha Krishnamurthy** [Prof. NuclearMedicine], **Ms. Selma** [Nurse-private sector], **Ms. Prasanna** [Nurse- Govt. Hospital], **Dr. Pacifica Simon**, **Dr. Ponni** and **Sr. Lalitha Teresa**, **Fr. Joy** – Counsellor and **Dr. Udaya Mahadevan** –Social Work Consultant, representing Jeevodaya The whole session was coordinated by **Dr. Manjula Krishnaswamy**, Hon. Medical Director of Jeevodaya.

Dr. Manjula started the proceedings by saying that this exercise was in tune with the theme of the World Hospice Day - 2009 – "DISCOVERING YOUR VOICE". There were innumerable patients out there crying in silence, stifling their sobs or even wailing aloud but seemingly falling on deaf or near deaf ears. Today's effort would be not only to help them find their voices, but make sure that they are heard by the society, to awaken them to shoulder their social responsibility.

Four patients and two relatives of patients who had expired were asked to share their experience with cancer and what they thought was the most difficult part of their journey.

Following are the highlights.....

Patient : The day she was informed by the doctor that she had Cancer – she was alone, had not even remotely considered the possibility of it being Cancer, it came as a bolt from the blue for even before the news could sink in, she was being told that being a widow, if she was to stay alive for the sake of her two children , she should immediately undergo mastectomy.....

Anchor : The best way of breaking bad news?

Panelist: Doctors, who were generally entrusted with the job of telling people they had cancer should be very sensitive to



Drawn by Mrs. Anbu Arumugam, wife of a patient of Jeevodaya.



Merry Christmas

the feelings of patients. While it was not possible to alter the bad news, everything should be done to soften the blow. Certain minimal protocols should be followed, eg. making sure the patient is not alone, ensuring enough privacy, allotting reasonable time, issuing a warning shot and only after ensuring that the patient is prepared to receive the news, should it be divulged, allowing and accepting the patients reactions, following it up with the treatment protocol available ,all the time assuring them of the best possible care [the whole exercise could take one or more sittings].

Anchor : How feasible is this in a busy out-patient dept. of a Govt. Hospital?

Panelist: While the process may sound protracted – it was not impossible-what mattered was the quality time that the doctor spent with the patient not the duration. More importantly, it was time that the mindset of the public as to how they perceive the disease – Cancer -is drastically changed. For example, nobody panics if somebody is told they have a heart attack – here too, some may survive with treatment and others will succumb. It is the same with Cancer – one-third of cancers can be prevented, one-third can be cured and one-third might succumb –which can happen with any major illness. We must first of all dispel this stigma attached to Cancer and pass on the message that cancer is curable if detected early, which can be done by creating mass awareness.

Patient: The next nightmarish aspect was going through Radiotherapy and Chemotherapy.

Anchor: We have heard patients tell us that they started vomiting even as they approached the hospital. How can they be helped?

Panelist: It is true that that RT and CT have a lot of side effects but if the patients are adequately counseled and informed what to expect and with proper medication to counter it, the side effects can be minimized– but unfortunately most patients get their information from other patients - once fear creeps in, all symptoms tend to get exaggerated as at least part of it is psychological, so much so some patients even refuse treatment.

Patient: I was very scared, other patients who had taken treatment told me I'll be vomiting continuously, will not be able to eat, will become very weak, that is why I refused to even swallow tablets, but after coming to Jeevodaya, doctors and sisters have convinced me to take treatment, now I am feeling much better.

Anchor: The nurses have an important role to play in supporting the patients during treatment unfortunately many patients taking treatment in Govt. Hospitals, have said that quite a few nurses have not only been not sympathetic but positively rude.....some have even discontinued treatment because of this.....

Panelist: [Govt. Nurse] While it may not be correct to generalize, we cannot also deny that this happens – it is usually due to pressure and volume of work due to which the nurses are unable to give individual attention to patients – but this cannot be given as an excuse – it is important to re-orientate them and change their attitudes by giving them training in Palliative Care and communication skills.....

Anchor: How is it in the private sector?.....

Panelist:[Nurse - Private] It totally depends on the individual personality of the nurse but by and large, as the volume of patients is much less than in Govt. Hospitals, the nurses get to spend a lot more time with the patients.....

Anchor: [to a doctor patient] - You have had your treatment abroad [USA] – is there anything positive that you can take away from there which you think may be helpful in our setup.....

Patient: The one thing that struck me was the amount of time the team spent with me, even though I was a doctor everything, every little procedure starting from anatomy was explained to me and my consent obtained.....this is something that even I as a practicing doctor here for many years have not done.....

Anchor: [to panelists] Do you think it is necessary to explain in detail to patients? Do we respect the patient's autonomy at all?.....

Panelist: In our setup, if we start explaining in such detail, most patients will get scared and run away. It will be enough to give sufficient details and tell them what is best for them. The explanations and choice of treatment, if there is one, should be left for the more educated or more importantly for those who ask for it.....

Anchor: The scenario here is most times no explanation is given at allwhich leads to quite a few treatment dropouts.....we definitely need to communicate more with our patients, drop our paternalising attitude and involve the patients actively in their own care.....How does the counselor help in this regard?

Panelist: [Counselor] Counselors can have a major supportive role, to pep them up psychologically as they go through their difficult treatment protocols, simply being there for them.....to allay their fears, to answer their questions.....

Anchor: So far we have been discussing how to support patients during treatment, what happens when we see patients coming to us in an advanced stage of disease or the treatment itself proves futile how do we handle them.....this is the second phase of breaking bad news....

Panelist: [Doctor] Most often there is no need to tell the patient who is going through treatment as he knows that treatment is not benefitting him and he voluntarily opts out

of further treatment, there are others who however want to try till the end, we have to be very honest with them regarding their chances of cure especially if they are draining all their resource which they can ill afford..... regarding those whom we see in an advanced stage the same protocol for breaking bad news applies

Anchor: Would it help to have a palliative care team working along with you.....

Panelist: [Doctor] Definitely... then the transition to palliative care will be smoother.....

Anchor: The problem is the assumption that palliative care should come into play only in the advanced and incurable stage of the disease whereas it should be an integral part of care right from the beginning, in fact the WHO has modified its definition to say that it is applicable in the early course of the disease to be continued to the end, to ensure a good quality of life for the patients.....

Panelist: [Doctor] Whatever may be the definition, the word palliative care still has a negative connotation for both the patient and the doctor – it would help to use the word “Supportive Care” instead .

Anchor: Whatever the terminology we use, the greatest challenge here is the management of pain....

Patient: I am suffering from Cancer of the cheek, for three months I had such severe pain, I had to take 2 or even 3 injections of voveron every day – which would relieve my pain for half to one hour, I never slept during this period – the pain would never allow me to sleep, I would sit up the whole night holding my head..... but after coming to Jeevodaya clinic, I am totally pain free, I sleep well at nightsee I have even been able to come here by myself without anybody accompanying me.....

Anchor: You can imagine the seriousness of this problemone patient told me that when he had this pain, he would bang his head against the wall..... another well to do educated patient, top manager in a company-one minute he was calmly describing his pain, next he was rolling on the ground crying out in pain, much to the distress of the family,.....in a third instance, a patient’s son described how he had to restrain his mother who tried to jump off the train because she could not bear the pain.....

Panelist: [Jeevodaya doctor] Almost all patients come to Jeevodaya with severe to very severe pain, pain being one of the main reasons for admission. If you consider that less than 1% of patients have access to palliative care services-you can imagine the number of patients out there who are suffering from unrelieved, excruciating pain

Anchor: What do you think is the reason for this state of affairs, especially when we as doctors know that there are

simple ways of relieving pain using inexpensive drugs such as oral morphine

Panelist: [Doctor] Pain is inevitable and part and parcel of cancer – this assumption has to be immediately changed both in the minds of patients and doctors alike. Doctors are more concerned with treating the disease rather than looking at the patient as a whole and addressing their specific problems. Most doctors have not been trained in pain management and palliative care and are not confident of treating such patients. There is also the problem of non availability of oral morphine in many centres

Anchor: How can this be changed?

Panelist: All doctors must compulsorily have training in pain relief and palliative care. Palliative care must be included in the undergraduate and post graduate curriculum of doctors and nurses. Oral morphine must be made available in all hospitals

Anchor: Is there any procedural difficulty In getting oral morphine?

Panelist: [from Jeevodaya] Oral morphine being a scheduled drug ,the institution must have a license to procure, store and dispense the drug. The procedure used to be difficult, but with the simplification and amendment of the laws by many state governments, including Tamilnadu – it is not at all difficult, one has to apply to the drug controller who will grant the license after inspection. It should not be a problem for Govt. Hospitals.

Anchor: In Palliative Care we talk about ‘Total Pain’ – can you explain what that means?

Panelist: [from Jeevodaya] Patients not only suffer from physical pain, they also have a lot of emotional and psychological distress, social and financial problems and also start questioning their very existence – what we call spiritual pain. All this namely, physical, psychosocial and spiritual problems put together constitutes ‘Total Pain’ and unless all these issues are addressed simultaneously one cannot achieve total pain relief.

Anchor: What is the role of the family?

Husband of a patient who had lost his wife: These last 2 years have been nothing short of hell for me – I am an old man with diabetes and heart problem and I get paid only when I go for work – my daughter moved away taking her children with her because she thought her children were in danger.

Anchor: This is the plight of a lot of patients who are either driven away from their homes or abandoned by their kith and kin in Govt. Hospitals

Panelist: We must create more awareness about Cancer especially the fact that it is not a contagious disease.....



Panelist: [from Jeevodaya] This is where Jeevodaya steps in to take care of the abandoned and destitute.

Anchor: We must realize that the patient can never be considered in isolation – he is part of his family. We know for sure that in many instances that it is the family that suffers more than the patient and very often they are over protective which is not in the best interest of the patient

Panelist: [from Jeevodaya] The family needs as much support as the patient – one needs to talk to them regularly to ease their fears and break collusion if any so that the patient and the family are in same plane of understanding which makes communication more easy

Anchor: [to patient] What makes you to keep smiling in spite of all problems?

Patient: [still smiling] Everybody has to go someday, so what is the point in worrying – I try to think of each day as a gift and spend it as best as I can without thinking of tomorrow

Panelist: [Counselor] Each individual has his or her own coping mechanism including spirituality which we must try to reinforce -whatever keeps them going never destroying their hope which may be the only thing that they clinging on to.....

Panelist: [Doctor] A doctor's role is only fifty percent, how a patient responds to treatment and even survival centres a lot on patient's attitude to life – the more positive the patient, better the outcome

When the discussion was thrown open to the audience , one doctor thanked Jeevodaya for their services, commended the training given to home-care staff and wanted home-care facility to be expanded, so that more and more patients could be looked after in their own homes

The discussion ended with the anchor thanking all the participants and observing that it was not the responsibility

of any one individual or group of individuals but the collective responsibility of the society as a whole to ensure that our patients live a whole and pain free life.

The Chief Guest, Dr. Balu David, Director, Govt. Regional Cancer Centre, Tamilnadu, while delivering his address said he whole heartedly endorsed the views of the panelists. The State Government had allotted sufficient funds to cancer centres to provide free treatment for the poor. In the next five year plan, the NCCP has included Palliative Care along with prevention and treatment of Cancer and is planning to deliver palliative care in all Govt. Hospitals and make available oral morphine even in Primary Health Centres. He felicitated Jeevodaya for their excellent services and wished that God would confer His blessings on them to continue their work.

From Jeevodaya, we would like to place on record our heartfelt thanks to Dr. Balu David and Mrs. Sally Abraham for consenting to be our Chief Guests, to the panelists and also to Ms. Brinda and Saranya, Master Sbarad and Mrs. Jaya Rajagopalan, Mr. Meganathan. The Terminators, Mrs. Anbu and students of Loyola College for putting up a wonderful variety programme of music, mimicry, mime and poetry to lighten the hearts of patients and all others assembled there.

**Protect and Nourish
Your Skin**

Medimix Ayurvedic Soap
18 herbs in pure coconut oil

Published by Sr. Lalitha Teresa, on behalf of Jeevodaya Public Charitable Trust from Jeevodaya Hospice,

Editor Sr. Lalitha Teresa, 1/86, Kamaraj Road, Mathur, Manali P.O., Chennai - 600 068.

Printed by : J.A.E. Diaz, at Pio Printers Pvt. Ltd., 83, East Mada Church Road, Royapuram, Chennai - 600 013. Ph. : 2590 4242