

# Jeevodaya Hospice

1/86, Kamaraj Road, Mathur, Manali P.O., Chennai - 600 068.  
Tel. : 2555 5565 / 2555 9671 Email : jeevodaya@vsnl.com  
Website : www.jeevodaya.org

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Sr. Hermas F.C.C., Chairman

Dr. R. Nanjunda Rao, President

## Editorial

*Christmas is round the corner. It is time to rejoice and celebrate. Most of us spend our lives worrying; we are professional worriers. Rick Warren, author of 'The Purpose Driven Life' writes, "When you think about a problem over and over in your mind, that's called worry. When you think about God's word over and over in your mind, that's meditation!" So, let's stop worrying and start meditating on Christ's message. His message is encompassed in a single word - Love. Love for God, love for others, love for oneself. If you are worrying about what gift to get for Baby Jesus, the answer is simple: reach out to God, reach out to everyone around you, and finally reach out to yourself!*

*Here's wishing all our readers and well wishers 'A Merry Christmas and A Happy New Year.' May you all experience the peace and joy of the Lord.*

*– Sr. Lalitha Teresa F.C.C  
Editor*

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## ***Social Problems of Cancer***

The word Cancer flashes a horrible picture in front of any one who has lived with or come across a suffering Cancer patient. It crushes one in various ways such as physically, economically, mentally as well as socially.

To live a life with full of expectations and dreams is normal and almost a happy life: but to live a life counting the days or hours left for one on the earth is heart breaking. This in turn affects every aspect of not only the patient's life but also the lives of the dear and the near ones of the sufferer. Cancer is not a single person's disease alone, but it eats up the surrounding society. The amount of stress the relatives and the friends have to put up with is very severe; and if the patient is the bread winner of the family, the situation is still worse.

### **How the Patients are affected :**

The physical, psychological and social effects of this killer disease are manifold.

#### **Physical :**

The fungating wounds, the unbearable pain, decreased or total loss of appetite, insomnia, fatigue, and psychomotor slowness; all these are certain characteristics of the cancer patients, which in turn affects the psyche of the patients.

#### **Psychological :**

Once the result of the test for cancer is out and is not favorable to the patient, there is a crisis



period. This period varies from person to person; some (patients as well as relatives) experience a brief period of denial or despair. The extent of the crisis period depends on the coping skills each one has learned; the extent of disease; physical symptoms and the degree of debilitation.

Some patients suffer from depression and some others develop anxiety disorder. When the mind is affected, then the body is also affected and vice versa since they are inter-related.

Uncontrolled pain is mostly the cause of the depression. Fear of bad prognosis and the dependence in the activities of daily life cause a lot of anxiety. The medication can also cause anxiety. Being put in a hospice i.e. away from family and friends add to the problem. The loss of job and self respect closely tied to it, further compounds the problem.

### **Social Aspects :**

The first and the foremost impact terminal stage, Cancer has on the Social Aspect of patients/care givers is, as the intervention of a professional Social Worker reveals, the physical and the psychological paralyzing of the patients. It is heart breaking to see some one so dear and close to us lying with miserable pain.

The disease not only paralyses the lives (social life, occupational life & family life) of the patients, but the family members lives also are affected. The reason for this is that these patients need constant care in the form of cleaning & dressing their wounds, feeding and ablutions consume a lot of energy and time. The agony the care givers go through is not narratable especially if the patient is the bread winner of the family. For the patients it is just as severe as it is for the care givers. The suffering increases if they are laden with guilty conscious because they have not done anything for their family; if they see that their dependents are not self-sufficient or if they have been cruel to their family members.

Majority of the patients, in the experience of a Professional Counselor, have suicidal ideation. And usually their statements are off hand

comments due to frustration or despair, due to pain and being dependent on others. The suicidal ideation due to pain or being dependent is particularly traumatic. At times we have to face situations like even the relatives begging us for mercy killing. They beg, and even threaten saying that they would get the patient discharged and get it done. They are driven to such extreme behaviour by their inability to stand the pain of some one dear to them. This is a typical situation where we, the rest of the members in society feel helpless; we are forced to be mute bystanders.

In the case of many of the patients, primarily they lose their contact with their: families, friends/ neighbors, work place and their own selves. The ignorance of the disease also adds to the problem. Maggot formation at the wounds and stench from the wound bring an abhorrence towards the patients. This would naturally alienate them from each other as well as inducing in the patients self pity. At this juncture the patients can show either withdrawal or agitation.

Various studies conducted among the terminally ill Cancer patients reveals that the patients are very much affected because the education of their children is affected due to their illness. This in turn affects their relationship with their family members, friends and even their spouses. This has, as the study reveals, a high significance in social relationships.

A lot of patients feel that even the Doctors who treat them do not really care for them and do not treat them appropriately. The same complaint is made about relatives and even spouses. These comments are from the patients not because their illness is neglected or they are not respected, but

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from the desperation and disgusting inconvenience they are put into due to the illness. In the experience of the professional social worker with the terminally ill Cancer patients and their relatives, the exasperating comments from the patients put the bystanders off. This further isolates the patient socially.

The intervention of the Social Worker among the terminally ill cancer patients again reveals that these patients are kept away from the main stream of the society due to the stench that comes from the wounds. Along with this the patients themselves run away from social life because of the disfigurement it creates. The emotional trauma one undergoes in such a situation is terrible. A well respected man or woman in society who develops a deformation such as a cavity with terrible stench on the cheeks or in the throat or a stinking wound on any part of the body, finds it is impossible to go back to society where she/he belongs to.

Cancer is not like the other diseases. Here the disease eats up the patient literally. Any one who has come across a terminally ill Cancer patient would realize the dreadfulness of the disease. The flesh is eaten up, and a part of a living human being starts decaying. A living Human becomes the habitat for maggots. Such a scene can make the patient insane. Even the relatives and the other close ones parry close contact with the patients. This definitely brings a skew in the social relationship of the patients with the others and vice versa.

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The patient realizes that she/he is dying inch by inch, and the same is realized by the relatives. As each one of us has social responsibilities of various sorts which is not transferable, the havoc the disease creates in a

family is unimaginable. Consequently it affects the other aspects of a family such as the education of the children, work of the spouse/parents.

And if the patient and the family lives in rented house, as in the case of many of our patients at Jeevodaya, what is their plight? The type of harassment they have to face from society and the house owner are at times humiliating and very painful. There have been a few instances in our hospice, where such type of incidents have been reported. In these situations the friends and the relatives can be a source of comfort, but for how long? They can not be the eternal source. In the process of coping with the reality, some fall and can never get up; and others struggle and struggle and adapt to the newly formed situation.

The economical burden that falls on the shoulders of the family members during and after the treatment of the patient is heavy. During the treatment by whatever means possible, the family members try to save at least the life of the patient. The amount of debts it brings on the family is very often beyond their capacity to repay. At the end the family realizes that all their efforts have come to an end without bearing much fruit. The trauma they undergo is heart breaking.

The situations where the bread winner of the family loses his/her job is not rare; also the patient's spouse or children may lose their jobs in the course of looking after the patient.

The heart breaking moment is when a person, even in semiconscious state, murmurs that she/he has not done anything for the family. Such guilt feelings are deep rooted in some patients.

As a slogan goes 'Cancer cures smoking', I feel the slogan can be extended to other areas of life also such as modifying our life style and diet, which may cause cancer.

As studies show that the number of people affected by cancer is on the rise, the number of people whose social life affected are also on the rise, since Cancer is not a single person's disease alone. Just like Cancer spreads in a person's body,

its ill effects spread to every part of society which in turn destroys the quality of life of people.

Thus, the psycho-social aspects of the disease have a severely damaging effect on the lives of the patients as well as on the family members. So, in order to cope with the disease, we should identify, assess and integrate the psycho-social factors by periodical observation and assessment of the psycho-social reaction of the patients.

### **The role of a Social Worker And the Palliative care Centres**

In a given situation the role of a Social Worker and the Palliative Care Centres is very essential. But the sad part of it is that in our country it is not as well recognized as in the west. The concept of a Palliative Care centre in the west has been long back recognized as well as appreciated; the same story goes for the role of a Social Worker. Their roles are yet to be recognized.

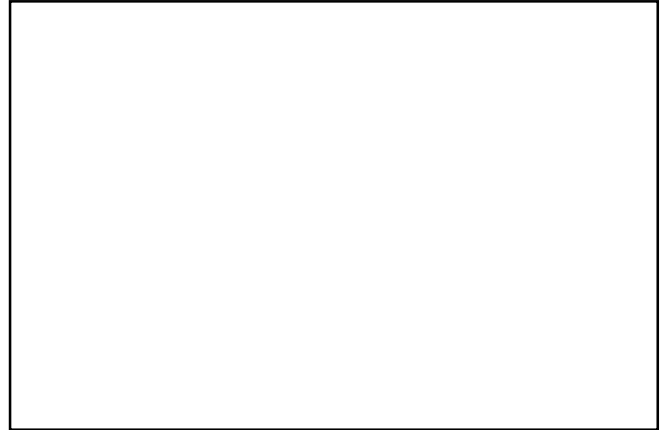
In short we can describe a Social Worker's role as :

1) Accepting the patient and their relatives with an empathetic attitude; 2) Crisis intervention as and when required; 3) Giving supportive therapy to the patients as well as to the relatives; 4) explaining the reality to the relatives as well as helping them to cope with the reality; 5) in the case of the patients, we will have to make them ready to face reality as well; 6) liasoning with the other N.G.O's and the generous persons to gain support for the dependents.

The role of the palliative care centres can never be forgotten in the case of a suffering patient. The palliative care centres give a holistic treatment to the patients as well as to the relatives of the patients; considering the physical, spiritual, psychological and the economical aspects of the sufferer; and helping the parson to have a peaceful and holy departure from this world.

*– Joby Thomas  
Medical Social Worker*

## **Jeevodaya Celebrates World AIDS Day**



*To commemorate the World AIDS Day, 1st December, as well as to make sure that our nation grows healthy, Jeevodaya conducted half a day training programme for the women of Kosappur Village. 30 selected women were given training on various health issues, with a main focus on AIDS. These women are equipped to give training to others in the village. It is a beginning for a long term activities on health aspects in the village, with the participation of the people in the village.*

*Mr. Balamurugam from CIOSA was the resource person. He was powerful in giving training and in explaining things.*

*The feed back from the participants is encouraging.*

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