



Jeevodaya Hospice

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Sr. Lilly Maria F.C.C., Chairman and President

From the Editors Desk

Can one person make a difference?

One day a man was walking along the beach, when he noticed a boy hurriedly picking up and gently throwing things into the ocean. Approaching the boy, he asked, "Young man, what are you doing?" The boy replied, "Throwing starfish back into the ocean. The surf is up and the tide is going out. If I don't throw them back, they'll die." The man laughed to himself and said, "Don't you realize there are miles and miles of beach and hundreds of starfish? You can't make any difference!"

After listening politely, the boy bent down, picked up another starfish, and threw it into the surf. Then, smiling at the man, he said,

"I made a difference to that one."

The world is full of change makers. Many are famous, their names instantly recognized. But there are many more, unsung heroes whose actions have impacted thousands of lives. This newsletter carries an article that celebrates the change makers who came together to start a palliative hospice. Jeevodaya has been a boon not just to the dying but also to their families reeling under emotional and financial strain.

Udaya Mahadevan, the young girl who was determined to do something about the terminally ill exemplifies Gandhi's exhortation, "Be the change you want to be." And she was joined by others like FCC sisters from Alvernia Province lead by Rev. Sr. Liberata, Kerala, Dr. Manjula and Usha Mathur who helped her dream become a reality. It is a remarkable story with many unsung heroes, written by Usha Mathur, sister of Udaya Mahadevan who was with Udaya as the guide and support in forming Jeevodaya Hospice.

May we all become change makers, even if it is in one person's life?

Sr. Lalitha Teresa
Editor

Jeevodaya

Mrs. USHA MATHUR

Down memory lane and ...on to the future

As many of us may be aware, leaders of all religious faiths, led by the Archbishop of Madras-Mylapore, came together on one platform, on 15th August, 1991 to bless the foundation stone of Jeevodaya - Hospice for cancer patients, dedicate the same to the nation and inaugurate the fund raising campaign.

Jeevodaya, the hospice was built virtually on four solid pillars and the men and women behind each of these pillars were present that momentous day to watch, with glistening eyes, their dreams turn into reality. These were dreams they had been pursuing over the years - with a mixture of frustration and hope. The amazing serendipity through which these four pillars united to build the edifice of Jeevodaya needs to be recorded for posterity. It is generally believed that if we fervently will something, then that thing happens twice - first in our mind and then in the real world.

The journeys of the men and women who constituted each of these four equal pillars of Jeevodaya is told below in the chronological order of the conception and articulation of their vision for a hospice for cancer patients. Firstly therefore, we begin with the mid 70s and with Dr Shanta, the iconic oncologist of the Adyar Cancer Hospital and Honorary Adviser, Jeevodaya, the guiding force behind Udaya Mahadevan, Honorary Social Worker - together they formed the mainstay of the first pillar. Dr Shanta was acutely conscious of the fact that the chronic shortage of beds for treating cancer patients meant that terminally ill cancer patients would necessarily need to be discharged to make way for patients who can be beneficially treated. These terminally ill patients required palliative care in a hospice - no such facility existed in India in the 70s.

It was a hard choice to abandon a dying patient and Dr Shanta, envisioned a future where such patients could be given palliative care which was gradually gaining recognition abroad as the golden standard of care for the terminally ill. It was at this stage that Udaya Mahadevan, a student of MA Social Work, (1974-76) Stella Maris College Madras came to Adyar Cancer Hospital for field work . Udaya a fiery twenty something, would repeatedly challenge the hospital policy of discharging terminally ill patients and would tell Dr Shanta that this is tantamount to playing God “How can the doctors be so sure that such patients will not respond to treatment?” Dr. Shanta would indulge her in her outbursts and explain the imperative of providing palliative care in a dedicated hospice.

Realizing Udaya’s zeal for the cause of such patients, Dr. Shanta advised her to found a hospice once she finished her studies and settled down to a steady income. She assured Udaya that she would mentor and guide her in fulfilling this mission. Udaya knew she had a lot to do before she could achieve this mammoth task. She joined the faculty in the Department of Social Work, Loyola College in 1977 and went on to do her PhD in Psychiatric Social Work in NIMHANS, (National Institute of Mental, Health and Neurosciences), Bangalore, in the early eighties. However, all through these years, she continued to meet with Dr Shanta and discuss the various aspects of palliative care in a dedicated hospice - free service, no special wards, no restrictions on visiting hours. It was all very daunting - finding funding for the land and buildings, locating doctors devoted to palliative care and a team of dedicated nursing sisters to attend to patients 24x7. Land for establishing the hospice was eluding her despite a couple of serious leads. But the search for doctors who would be willing to exclusively devote their time and lay down the protocol for palliative care in a hospice setting as opposed to the hospital seemed the biggest challenge. But the Almighty had His plans in NIMHANS, Udaya met her colleague Mr. Murali, who told her about his sister in law, Dr Manjula, a surgeon who was passionate about palliative care and setting up a hospice.

The second pillar is a flashback to the mid 80s. Dr. Manjula, Hon Medical Director, Jeevodaya along with Dr Snehalata Hon Medical Director and Dr Nanjunda Rao, President, Jeevodaya

constituted this pillar. Dr. Manjula and Dr. Sneha, were both young dynamic surgeons, posted to the surgical oncology ward of Royapettah Hospital, Chennai. The ward had 20 beds each, for males and females, but had at any time, nearly double that number - patients were all over the floor and the young doctors would kneel on the floor to examine the patient while gingerly jumping over from patient to patient. They were trained surgeons (those days surgical oncology did not exist as a separate practice) and were dismayed to note that most of the patients were not in an operable state - they were in terrible pain and needed pain management and not surgery. In the mid 80s this was through paracetamol (APC as it was called) and even that was in short supply and not cheap.

To add to their frustration, the RMO would discourage keeping such terminal patients in the ward. The term “palliative care” was not part of the medical curriculum those days, nor was it even known, nor available in India. So, when instinctively it dawned on these two young doctors that what these dying patients required was pain management and not active surgical treatment of cancer they were actually reinventing the wheel in their quest to provide such care in a safe place outside the hospital to these countless, homeless and hopeless patients. They had even contemplated renting a place to shelter such patients because the old age homes refused to take them in, sensing objections from other inmates. To those, learning of Udaya, a likeminded social worker seemed purely serendipitous. Dr. Sneha’s father, Dr. R. Nanjunda Rao, a very senior and highly respected medical professional was fully supportive of their cause and offered all help. He was rightly named President Jeevodaya. Two of the four pillars were ready to be cast. But the edifice could not arise without two more pillars.

The third pillar, the Franciscan Clarist Congregation sisters from Irinjalakuda, Kerala, arrived on the scene as if on cue, by some angel waving a magic wand. In November 1989, the sisters led by Sister Provincial Sr. Liberata and team, with Sr. Lalitha Teresa in the forefront would come to Chennai to buy land in Mathur village near Chennai. They had a hybrid project in mind - a centre for the differently abled, an old age home and another home for the terminally ill. Shri Babu Thelappilly, a student of Udaya, coming to

know of these proposals took the sisters to meet Udaya. Udaya was of the firm view that it may be prudent to take up one project at a time, instead of spreading scarce resources and precious time thinly on three projects simultaneously. She advised them to prioritize their proposals and if the terminally ill patients were considered a top priority, she would give them all her support. Sr. Lalitha would get back with the clear mandate from the FCC, Chalakudy the setting up of the hospice at Mathur, Chennai would be their overriding priority.

The land for the hospice was ready for construction and so were the doctors. The enormous challenge of locating a team of nursing staff for day to day running of the hospice remained. Udaya had spent an entire college vacation with the first hospice in India - Shanthi Avedana Ashram in Bombay - to get firsthand knowledge of the running of the centre from the sisters there and was desperately looking for similar support. Her prayers were answered in a most unexpected manner - she had gone to Alwaye to attend an academic Board of Studies meeting and a colleague (also a former student) offered to take her to meet the Provincial Superior of the Franciscan Clarist Congregation Alvernia Province at Chalakudy. Udaya went and was overwhelmed by the assurance of full nursing support, trained nursing sisters as required would move to Jeevodaya and take charge of the nursing care. Udaya lost no time in introducing Sister Liberata and Team to Dr Manjula and Dr Sneha - the decision to come together to set up the hospice at Mathur village was taken in less than a minute. The three sets of dots representing the FCC sisters, the doctors and the social workers would thus be irrevocably joined and the bond sealed.

The unanimous view was that the vacant land should be put to beneficial use immediately through a clutch of outreach programs for the local community, considering that raising huge resources for the hospice and thereafter constructing the whole complex on the land would take four to five years. It was decided that a small structure that could house a team of 6 to 7 FCC sisters should be erected to start with. This would provide a base to organize

preventive/screening camps in the nearby villages, integrate the families through running a nursery school and health education sessions. These were acted upon and the various programs were held regularly during 1990 duly enlisting the services of the Doctors, FCC sisters and social workers. At the same time, fund raising efforts for the main complex were initiated. This would not be possible without the fourth pillar. the general public, philanthropists and corporate houses.

The fourth pillar - small and big donors were contacted to raise funds for the construction of the building. Udaya took on board a young, dynamic Social Worker, Bhagyalakshmi to assist in all Public Relations work related to fund raising. A souvenir was planned for release and various corporate houses and philanthropists were contacted for advertisements. But as a first step they needed an architect who would make the plans and process required approvals and also supervise the construction.

Udaya contacted a couple of architects but found the fees prohibitive. One day, after attending a meeting as a faculty member of Loyola College she was walking back through the corridors of Madras University building when a name board stared at her - it read Prof Mohammad Haris, Dean of the School of Architecture. She stood transfixed and in a split second her mind was made up - she would ask him for help with the architectural plans and supervision. She knocked and walked in with mixed feelings but seeing an amiable gentleman she gushed out her proposal. Prof. Haris heard her out bemused, and the rest is history. Over several meetings with Udaya, Sister Lalitha Teresa, Doctors Manjula and Sneha, the various facilities were discussed and plans drawn meticulously.

Prof. Haris and his team of faculty members and students immersed themselves in the conception, construction and supervision of the building from start to finish without charging any fees whatsoever. Next was to raise funds for the construction. A public function was organized on 15th August 1991 in German Hall, Chennai, for blessing the

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foundation stone and initiating the fund raising campaign. Dr. Shanta addressed the audience and explained the need for a hospice. A video of India's first hospice - Shanthi Avedhna Ashram, Mumbai was also shown to the public. A brochure showing the pain and suffering of patients needing palliative care and unveiling the logo and motto of Jeevodaya was released. The august presence of the religious leaders added great solemnity and serenity to the occasion. The entire atmosphere that evening was so emotionally charged and more than Rs. 30 lakhs was raised from the audience in those few hours.

The ambulance and mortuary vans were donated by the chassis manufacturer fully fitted for use. Shri Vasudev a celebrated artist from the Cholamamandalam Arts Village near Madras was present at the function. His late wife Arnawaz, also a well known artist and friend of Udaya, had fought cancer bravely. Shri Vasudev lovingly donated her paintings for reproduction on greeting cards and sale by Jeevodaya. These cards were all sold out that evening and repeatedly reprinted in the next few years. Support in cash and kind came pouring in to enable this massive project to be completed in time.. no one was considered too small to be

excluded. The generosity and involvement of the general public was truly overwhelming.

These four pillars strengthened the foundation of Jeevodaya and the building was completed and inaugurated on the 18th March 1995. Udaya had captured their undying spirit by selecting an appropriate logo - a flickering flame representing life as it ebbs away, caressed protectively by the hands of palliative care givers - and an all embracing motto of service expressed so touchingly in the simple but profound four lines :-

*If I can stop one heart from breaking
I shall not live in vain
If I can ease one life the aching
I shall not live in vain.*

Jeevodaya exemplifies this beautiful and sublime bond between the palliative care receiver and the giver. In her awesome Journey, Jeevodaya now seeks to add one more milestone, by providing holistic 'end of life care', in a new shelter for the geriatric bedridden, who are in need of palliative care whether arising out of disease, illness, accident or just advanced old age. This new venture will truly reflect her inclusive spirit and respect for dignity in death.



Our doctors and team at the site of Geriatric Palliative care Home, Nemallur



Scan this QR code on your Smart Phone to view the Jeevodaya Anthem on YouTube

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