

Friends of Survivors

WHILE SUPPORT GROUPS ADDRESS THE MAJOR CONCERNS OF CANCER SURVIVORS THE PALLIATIVE CARE CENTRES ATTEND TO PAIN MANAGEMENT ISSUES OF THE TERMINALLY ILL, SAY SUREKHA KADAPA-BOSE & HIREN KUMAR BOSE



Support groups counsel and advise others grappling with the trauma of having been diagnosed or under treatment for cancer. These are like a haven for cancer patients and their relatives. They help people to communicate their feelings and experiences—that may seem too strange or too difficult to share with family and friends—with those living with cancer. Presently, all major cities and two and three-tier towns have support groups. These address major concerns of cancer survivors like rising medical costs and a lack of awareness about common symptoms.

A support group active in Delhi/NCR region, the Cancer Sahyog has been working with Indian Cancer Society since 1991 and its volunteers attend clinics in 10 major hospitals. Mumbai has majority nine cancer support groups, like Cancer Patients & Association, Dream Foundation and others. The city also hosts the non-profit global health organization, Max Foundation. Its Friends of Max is one of the largest patient associations in the world and serves people living with chronic myeloid leukaemia and gastrointestinal stromal tumours. "As the environment is sullied by misinformation, heresy and superstition an exchange of experiences and knowledge between patients, caregivers, and physicians can mean so much," says Viji Venkatesh, the Regional Head of

Max Foundation in India and South Asia and known among patients as "Amma". Her initiative, "Chai for Cancer-Drink To A Cause", a unique awareness and fund-raising campaign raised nearly Rs 25 lakhs last year.

Palliative care is an important part of cancer care. For someone with cancer, the goals of palliative care include treating symptoms, managing emotional and social needs, and addressing spiritual and practical concerns. Only a tiny minority of the needy in India has access to palliative care.

"Unfortunately, for most, palliative care reaches too late because in the minds of the public as well as many professionals, cancer is commonly associated with death and dying," says Dr M. R. Rajagopal, Padma Shri awardee, palliative care physician and the founder chairman of Pallium India, a palliative care NGO based in Kerala. Responding positively to a request from Pallium India, Kerala government created a palliative care policy in 2008.

A landmark research, published in New England Journal of Medicine, carried on patients with a particular kind of lung cancer (one group receiving only anticancer treatment

alone and the other receiving palliative care along with anticancer treatment) showed that those who got palliative care along with disease-specific treatment lived for an average of three months longer. In addition, they also had a better quality of life making it clear, that both in terms of longevity as well as well-being, palliative care needs to be integrated into health care.

"In the majority of our medical institutions, modern pain management or palliative care is not available. But the most important reason is simply the lack of access to palliative care. Unless a palliative care centre is available, where can a doctor refer a patient to?" says Dr Rajagopal.

CanSupport, Delhi and the National Capital Region (NCR) NGO, operates the largest home-based palliative care programme looking after 2000 cancer patients in the region. There are few other centers like the two palliative care centers managed by WHO demonstration centers in Calicut and Thiruvananthapuram run by Centre for Community Based Palliative Care and Pallium India respectively (for more visit <https://palliumindia.org/resources/clinics/>).

Survivor Speak

'I'M NOT CURED, BUT A SURVIVOR'

An unimaginable fatigue and feeling of tiredness made me approach a physician. Initially, I thought it was due to my hectic work schedule. But a regular blood and urine test showed that my WBC count had gone up to 1,26,000. Normally, WBC count is in the range of 4,000 to 10,000. I also had a urinary infection. Then, 15 years back, I wasn't aware of the implication of increased blood count. A week's treatment brought down the urinary infection but didn't affect the WBC blood count. Meantime my wife delivered our second son. We were happy but tensed due to my reports. On my physician's suggestion, I met haematologist Dr M B Agarwal, who suggested that I repeat the blood tests at Tata Memorial Centre. He told me that I had CML (Chronic Myeloid Leukaemia) and there is a treatment for it and I could lead a normal life but with lifelong medications. The medicines prescribed were valued at Rs 1,25,000 plus the cost of supplements to be taken every month was beyond our means. I was suggested that I could take the Indian equivalent of the same, which would cost me Rs 10,000. This too was much of burden for our family of five even though both my mother and my wife were employed. This was when I came across Max Foundation where I started getting free medicines besides counselling and chance to interact with other cancer victims. It was here that along with a few like-minded people we formed a 'Friends of Max', an NGO which today has more than 18,000 CML patient-members spread all over India. Being one of its trustee members I make it a point to interact with new patients regularly. The moment they realise that they are in the midst of a 15-year-old survivor, their approach to the disease changes and develop hope. I'm not cured, but a survivor. I have experienced side effects, like my skin becoming pale and irregularly go through severe leg cramps. I've developed kidney stones and also have a heart problem. At my office, I have become a reference point for cancer which actually makes me happy!"

Pramod George (47), a marketing professional with the Indian Express Group, Mumbai

DON'T DEMONISE CANCER

When my physician confirmed that I've CML the thoughts about cancer being synonymous to death came to my mind. Now, 13 years later, I realize how wrong the depiction of cancer is. The society at large has stigmatized the disease and many times patients try to hide it with the result they deprive themselves of the support system that this disease needs. I've endured a lot of hardships as well as lost our father, a mill worker, very early to alcoholism. Along with my sister I was brought up in an orphanage. With the help of State scholarship, I completed my Diploma in Engineering and got a job at BSES, later taken over by the Reliance Group. I got married and with a loan bought a 1 BHK flat and have two children. When I was diagnosed with CML, my salary was a mere Rs 7,000 and I had four dependents. As my wife is unlettered the first thought that came to my mind was will both my kids end up in an orphanage. This is when, the then, director of TMC oncologist Dr. S. H. Advani helped and boosted my morale. I sought help from the Max Foundation and with free medicines offered by them, I'm able to live my life albeit with all the problems associated with the medicines. But I do make it a point to reach out to other cancer victims.

Suresh Pawar (45), deputy manager (Low-Tension Maintenance), Reliance Energy, Mumbai



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