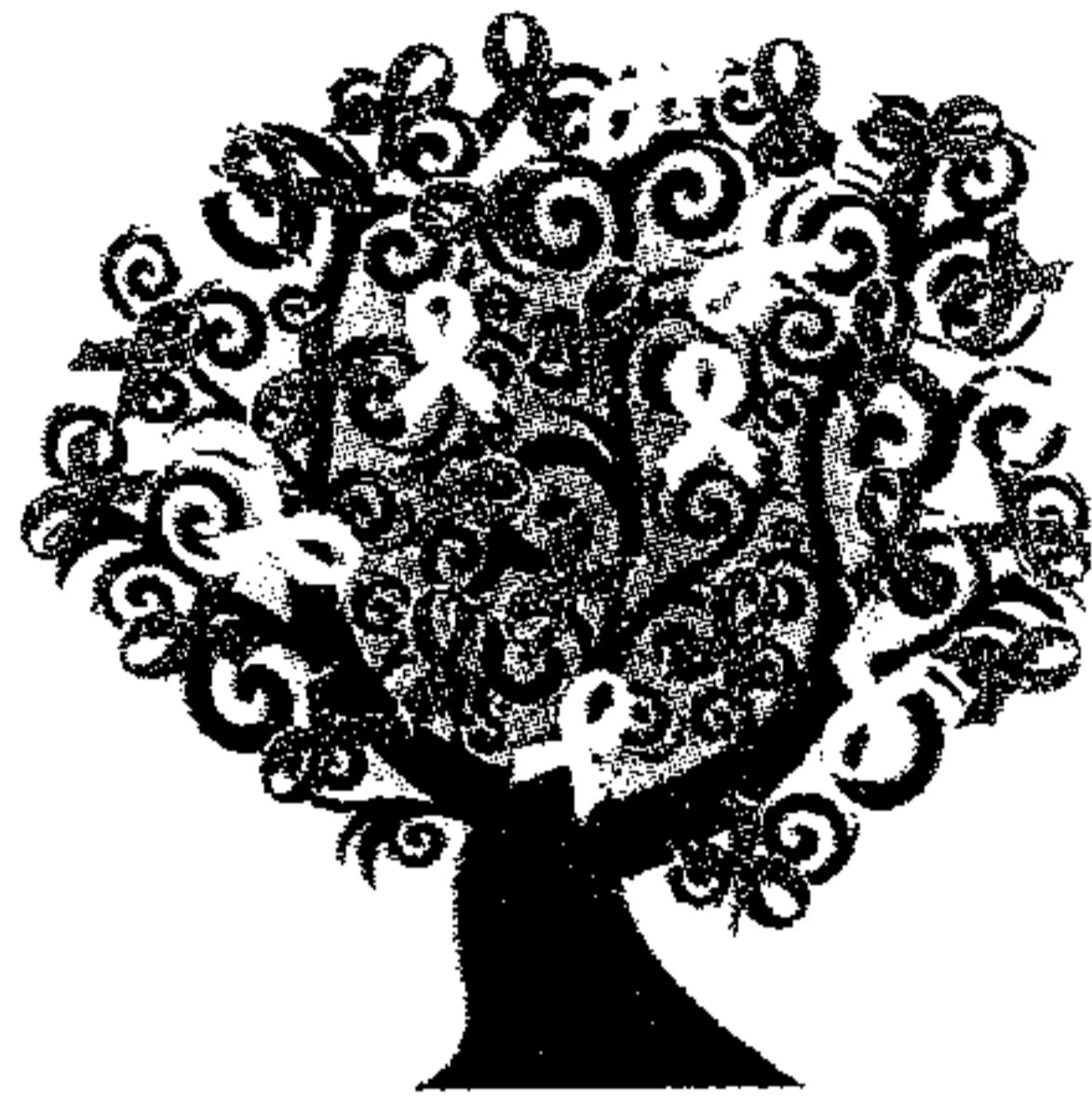
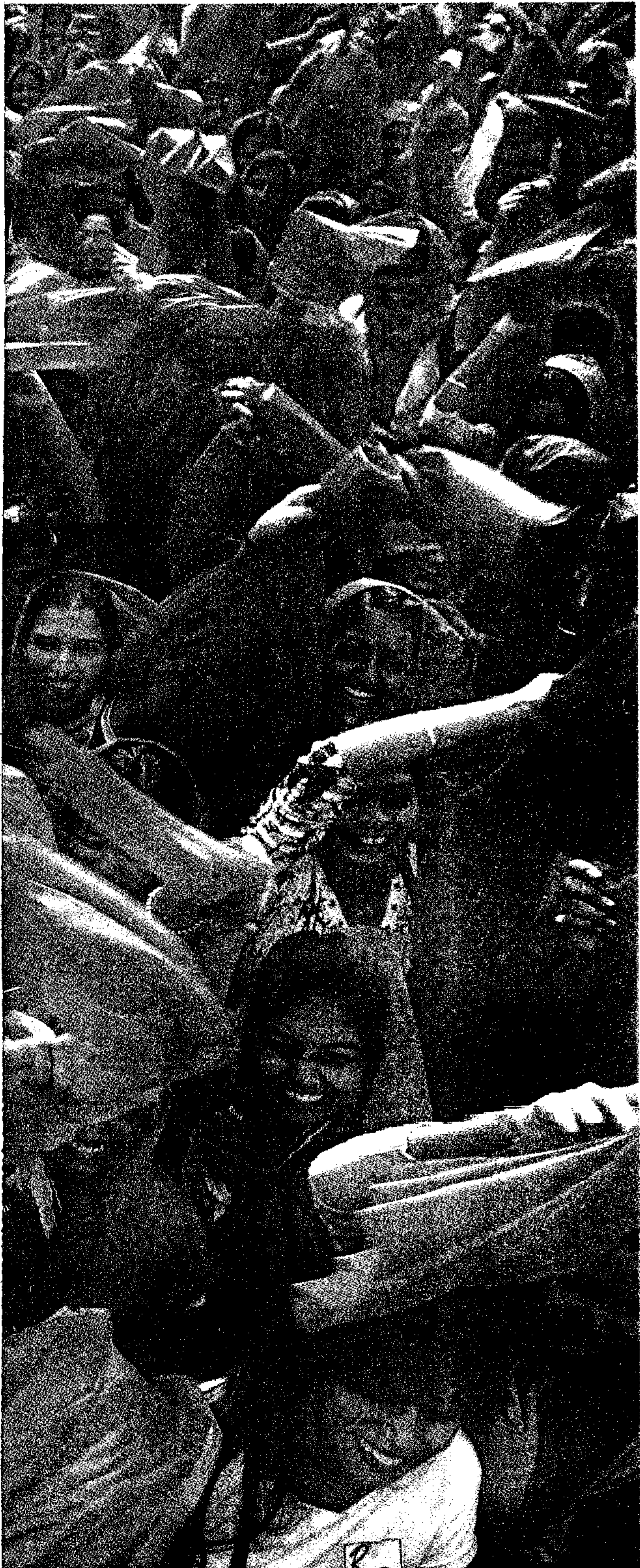


Making Friends with Cancer



by SHEFALEE VASUDEV

THE HOMEPAGE of Terry Fox Run Chennai website shows the resilient face of 19-year-old Akash Dube. As the photo strip fades in and out, Dube is seen everywhere: holding placards, filling forms, and addressing large crowds of people, mic in hand. The man who set up the Chennai arm of the cancer support organisation, he led the Run to Outrun Cancer campaign this August. Around 10,000 people from different social backgrounds and age groups ran to be a part of what Dube calls “a dream that one day a world without cancer will be possible.” The campaign aimed to increase awareness about early detection, acceptance of cancer patients and raise funds. This young man was diagnosed with acute lymphoblastic leukaemia when he was 16. He spent two traumatic years as doctors tried to revitalise his cancer-blasted bone marrow through blood and platelet transfusions. The experience changed him, instilling a stronger sense of self through which he found the will to work for cancer research. “Cancer,” says Dube, now a freshman at Stanford University in the US, “is one of the realities that define me and I draw strength from being a survivor.”

THE DREADED C-WORD IS NOW A COMMON REALITY, ONE THAT CAN BE COMBATED AND DEFEATED. AWARENESS DRIVES AND SUPPORT GROUPS, NEW THERAPIES AND INITIATIVES, ARE TURNING ‘VICTIMS’ INTO ‘SURVIVORS’ >>>

In Delhi, a radiant Kiran Taneja, now 58 and a multiple myeloma survivor, shares Dube's cheer. She became a grandmother within a few months of her diagnosis, and it is easy for those who listen to her story to forget that six years ago, her cancer left her jolted and bald. “But look at my bountiful hair now,” says Taneja, smiling widely. Treated with stem cell therapy, for which her own, healthy stem cells were harvested and re-injected into her body, Taneja continued attending office through her illness. A regulatory affairs executive with a pharmaceutical company, she only took time off during aggressive phases of the treatment. “I played cards with my mother and re-read *The Alchemist*,” she says.

The cultural acceptance of cancer in In-

dia is slowly growing. The number of cancer patients has increased, but so has awareness about the disease. The dreaded C-word that once meant the end of life is now a common reality, that can be combated and defeated. Consider the graph of change: awareness leads to early detection which in turn leads to better treatment and cure; targeted medical therapies; cancer counselling to deal with psychological fears and depression; psycho-social rehabilitation; prostheses and reconstructive surgeries to replace lost limbs or body parts and efforts by civil society groups to bring solutions to underprivileged patients. If there are quit-smoking drives at colleges and IT offices, there are anti-gutka programmes in towns and villages. Efforts are on to rip cancer off its stigma. Dharamshila Cancer Hospital in east Delhi dropped the word "cancer" from its name a couple of years ago to make it inclusive rather than exclusive, says oncologist Dr Nirupam Naik.

All this has changed the way we now look at cancer. Many one of us know someone who lives with the disease or those who have passed on after a valiant fight. Loss has inspired some to initiate cancer support programmes, others hold out hope to families who feel the world is crumbling around them. Like Vandana Gupta, founder of V Care, a cancer support group in Mumbai. Gupta was diagnosed with Stage-III cancer of the lymph in 1993. She started V Care to roll out what she didn't have: information. "My aim is to reassure patients that they

may face many financial hardships, employment problems and psychological struggles; but they can live an active and productive life," says Gupta. V Care provides information about hospitals, assistance in contacting blood donors, treatment modalities, nutrition, hygiene and infection-control kits, prosthesis, wigs and utility articles. It holds awareness programmes for patients and families. There are numerous such organisations in India.

The "victim" word has faded away to be replaced by the vigorous "survivor" — a big change for those who go to hell and back during chemotherapy. In the words of Dr Sameer Kaul, head of the department of oncology at Apollo Hospital, New Delhi, "Cancer was earlier the announcement of death. But today any type, if detected early, is curable."

Kaul says that oncologists now listen, empathise and treat patients holistically, involving them in all decisions. "Cancer is an economic and social illness too and an onslaught needs to be launched on all its aspects," he says.

Acceptance instead of denial has made a crucial difference in coping with cancer. Spreading these simple but powerful facts is an army of volunteers across towns and cities, some work in hospitals, others through community health programmes. Dr MA Muckaden, professor and head of the department of palliative care, Tata Memorial Hospital in Mumbai, says the hospital, considered to be the last stop for cancer patients, too has integrated holistic care into

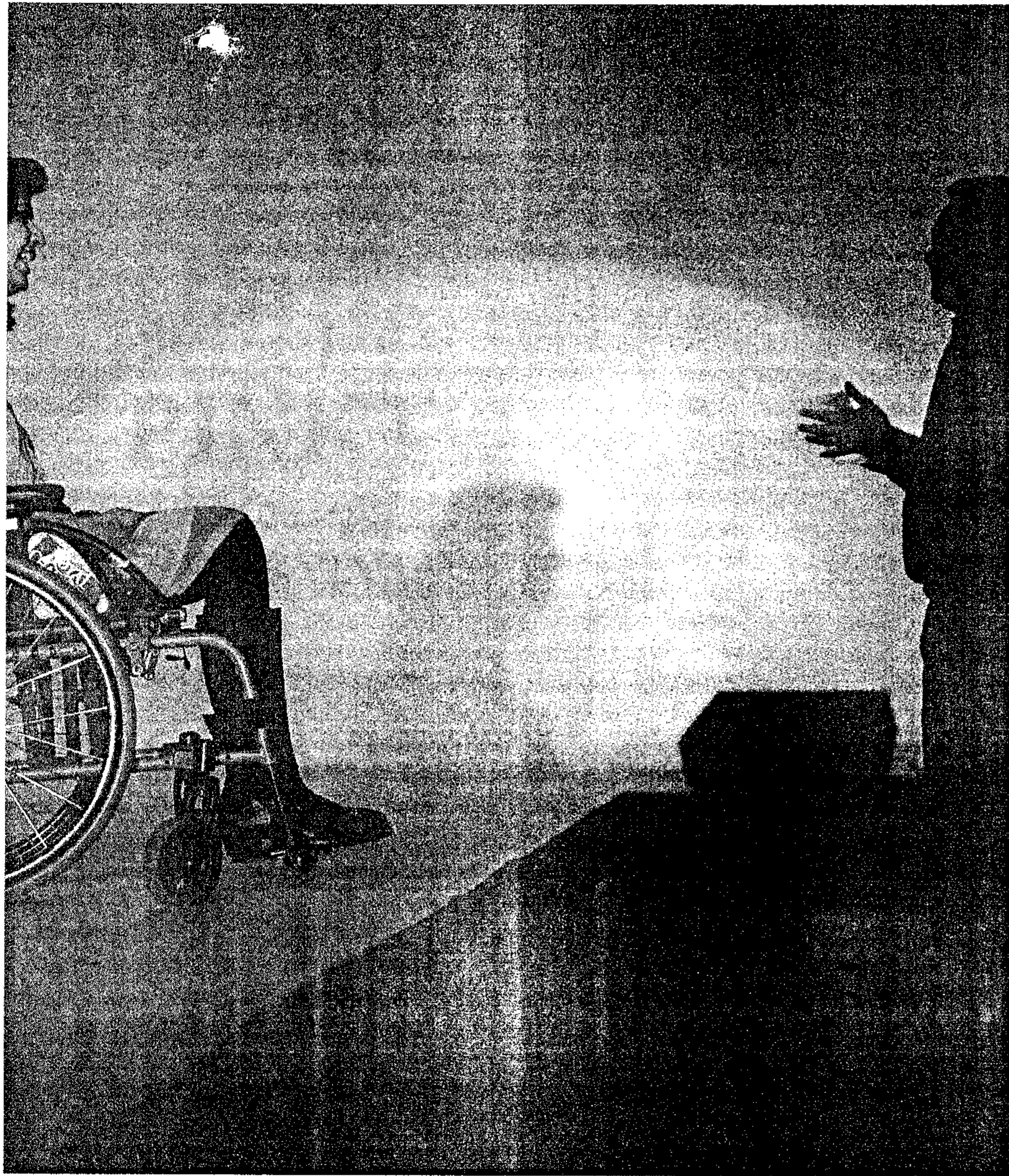


RENUKA PURI



VASANT PRABHU





“Cancer was earlier the announcement of death. But today any type, if detected early, is curable,” says senior oncologist Samir Kaul

pen to be one of them,” he says. Fascinated by cell mutation, Dube worked as an intern for a few months at the cancer biology lab at IIT Madras.

Cancer’s own headstrong nature, described with ingenuity by Dr Siddhartha Mukherjee in his Pulitzer Prize winning *The Emperor of All Maladies: A Biography of Cancer*, necessitates an equal and opposite fight against it. “Cancer’s life is a recapitulation of the body’s life, its existence a pathological mirror of our own... Down to their innate molecular core, cancer cells are hyperactive, survival-endowed, scrappy, fecund, inventive copies of ourselves,” wrote Mukherjee. Which is why, argues Dr Kaul, “Nothing exposes human relationships like cancer, nothing else rips away control like it does; it needs a crusade to defeat it.”

A part of the crusade are psychologists who specialise in onco-psychology. Bangalore-based onco-psychologist’s Dr Brinda Sitaram’s book *Not Out: Winning the Game of Cancer* focuses on developing a battle plan to live with cancer. What was once labelled as the C-Type or the Cancer Personality, suggesting that people who suppressed emotions were more prone to cancer, is a view now rubbished by onco-psychiatrists. These doctors address the “here and now” dilemmas of patients and help them adjust to the diagnosis. “Psycho-social oncology can change the outcome of the disease in a positive way,” says psychiatrist Dr SK Chaturvedi of National Institute of Mental Health and Neuro Sciences (Nimhans) in Bangalore, who works with cancer patients. “A lot of studies have shown that patients with a positive attitude respond better to treatment whereas those who are aggrieved, stressed or depressed increase chances of developing a new cancer or getting a relapse,” he says.

Cancer also opens up reservoirs of strength in some people. “Anup was always very positive and insisted on calling his book *The Joy of Cancer*,” says Amrita Kumar, wife of the late Anup Kumar, whose 2007 book went into many reprints. Kumar was given only four months to live by his doctors when diagnosed with cancer but lived for seven years; his wife believes his attitude made the difference.

FIGHTING BACK (Clockwise from top) A fashion show in Delhi held to raise awareness about breast cancer; survivors Gopalkeshu Joglekar and Kiran Taneja

its approach. “We have a large body of volunteers, trained to speak to families and patients. Once they understand their state of mind, they convey it to doctors who treat them in a particular manner,” she says. These volunteers also make patients aware of the small goals they can achieve and how they could live optimistically.

A positive attitude is what helps survive cancer. As Dube battled the side-effects of three intensive chemo sessions, umpteen lumbar punctures, losing almost 15 kg of weight, he worked out a rationale about his disease. “I began to rationalise that my becoming sick was not because of some karmic targeting but just a random selection where healthy cells had mutated into cancerous ones. I told my grandmother that 2,00,000 children have the possibility of getting leukaemia and I hap-



For 74-year-old Mumbai resident Gopalkeshu Joglekar, music became therapy. Diagnosed with rectal cancer two decades ago, Joglekar, a music teacher, underwent surgery, chemo and radiation and lost 20 kg. It was upon the insistence of doctors, friends and family that he resumed singing and teaching music. He would join musical groups to sing for other cancer patients who lived in the dharamshala of Tata Memorial hospital, as well as on stage. He also taught music to blind and deaf children, an activity that instilled him with happiness and the will power to fight his cancer.

Cancer survivors are indeed made of steel. Terry Fox, Lance Armstrong, actor Sean Connery, pop singer Kylie Minogue, Indian actor and model Lisa Ray are among those who not only fought the disease but also stood up to tell their story and spread a positive message. Steve Jobs, who will be remembered as one of the most influential personalities of this century, continued to work till the last months of his life without making a fuss about his seven-year ordeal with the illness. Cancer activist Terry Fox ran across Canada with one leg, and Armstrong fought cancer with a valour now recounted as an example in oncology wards across the world. He defeated cancer and returned to win the Tour de France for the seventh time, raising the bar of positive survival to a new height.

"Resources, prognosis, and quality of life change for different people but the hum for survival seldom changes its lyrics," says author Shinie Antony who has written about women who lose a breast to cancer in her short story collections. She reveals how for cancer patients, the starkest part is when their hair falls or when they lose a body part. In a story titled *Vani*, Antony writes of a married woman having an affair and how the imminent loss of her breast signals a rethink of her sexual role. "An altered silhouette is ahead and she wants to be aware of bodily proportions one last time. The breast, its impact on gender identity, aesthetics and symmetry are on her mind the night before her surgery. More than the long-term call of the cancer, she is consumed by its short-term toll," writes Antony.

On the cosmetic level though, people do grapple with depression due to hair fall and loss of body parts. "I felt really dejected when I lost my hair; my skin too had darkened and shrunk," says Taneja. Many patients now opt for wigs to hide baldness and go for facial treatments. Taneja did too till her natural hair grew



Lisa Ray's inspiring story is an example for cancer survivors; (left) Siddhartha Mukherjee wrote a biography of cancer

Reconstructive surgery has become a sought-after branch of treatment. "If a cancer surgeon is the bad cop, the plastic surgeon is the good cop"

back. This is also why reconstructive surgery has become a sought-after branch of cancer treatment. "If a cancer surgeon is the bad cop, the plastic surgeon is the good cop," says plastic surgeon Dr Shahin Nooreydzan of Apollo Hospital, Delhi, who extensively works on reconstructive surgeries for cancer patients. "Cancer surgeons now aggressively counsel patients about reconstructive surgeries. The patient can wake up to an almost normal body — the tumour is excised and a new limb or breast has been constructed in its place," he says.

A lot more is happening on India's cancer battlefield. Some patient adoption programmes now go beyond financial support; there is better

palliative care in the country and awareness drives through marathons, fashion and art shows have helped. Media's focus through print, radio and TV campaigns has incrementally helped the process. Last month, the Ogaan Cancer Foundation and Elle Breast Cancer Campaign invited corporates to urge their employees to wear pink.

More than 40 corporate houses did so. Earlier this week, the Imperial Hotel in Delhi hosted a fashion show called Pinktober with Cancer Patients Aid Association and Satya Paul — October is breast cancer awareness month. Hardrock Café had Pinktober events too. As you read this, hundreds would be participating in Walk for Cancer, the Indian Cancer Society's Annual Walk 2011 planned for today. It's a Cancer Didn't Kill Us club, and it is growing. "It is a time of transition and for the change to take root, the gulf between those who can afford care and those who can't needs to be reduced. The government must ensure health and insurance coverage for cancer patients," says Harmala Gupta, who started CanSupport in Delhi in the Nineties, becoming a pioneer in community work for cancer.

Dube is convinced that things will change. He will be on maintenance chemotherapy till the end of 2012 but believes that cancer is about overcoming it. Or, as Carla Reed, a leukaemia survivor in Mukherjee's book told him "Cancer is my New Normal". □

(With inputs by Priyanka Pereira)