



ANGEL FOR CANCER'S 'Untouchables'

BY ASHOK MAHADEVAN

With compassion Harmala Gupta fights the disease on many fronts, especially the widespread indifference to the agony of patients

Raising himself on his bed, Ramesh Chand looks at the tall, fine-featured woman sitting opposite him. "Because of you," he says, "I can walk to the park and talk to my friends—something I thought I'd never be able to do before I died."

"That's wonderful," Harmala Gupta says with a warm and gentle smile.

Chand is dying—slowly but inexorably—of bone-marrow cancer, also known as multiple myeloma. After

doctors at his hospital decided that the Delhi autorickshaw driver was beyond treatment, he was discharged and prescribed no further medication even though he was continually racked by pain. "I used to bang my head on the floor," he recalls, "I wanted to jump off the roof and kill myself."

Then Chand came in contact with CanSupport, a Delhi NGO founded by Harmala Gupta that ministers to terminally ill cancer patients. A

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CanSupport doctor gave him morphine tablets whenever he was in pain. The team also included a counsellor and a nurse who visited Chand and his wife in their tiny apartment every week for a check-up and a chat. As a result, Chand is living his last days in dignified tranquillity.

Chand is lucky. The last days of most Indian advanced cancer patients are hellish because of excruciating pain. And this, despite there being effective and inexpensive medication, such as morphine, to end their suffering. Alas, restrictive drug laws, poorly trained medical staff, and the attitude “Why spend money on people who are dying anyway?” doom innumerable cancer patients to needless misery.

CanSupport is one of the few bright spots in this heartbreaking scenario. Since Harmala Gupta started it in Delhi 14 years ago—the first such organization in northern India—it has been a godsend to several thousand terminally ill patients and their families. It has also taught hundreds of doctors, nurses, counsellors, social workers and volunteers about the principles and practices of good palliative care, which includes pain medication, symptom management, nursing and counselling.

CanSupport has lobbied the government to pay attention to this much-neglected side of cancer care. Says Firuza Patel, a Chandigarh radiation oncologist who has studied the organization, “CanSupport does excellent work.”

Harmala came to her life’s mission a little late. She’d wanted to be an academic. And everything about her promised a brilliant intellectual career. The daughter of Harbakhsh Singh, one of the Indian Army’s most distinguished generals, she was the head girl of her school and president of her college’s debating society. She topped her class at New Delhi’s Jawaharlal Nehru University. Enrolling for a PhD in Chinese politics at Canada’s McGill University, she passed her prelims within a year—a record for the university.

Then in 1986, just before she was to go to China on a field trip, she was diagnosed with advanced (stage four) Hodgkin’s Disease, a cancer of the lymphatic system. She was 33, married, with a three-year-old son.

It had taken several months to diagnose the disease, and by the time she was admitted to a Toronto hospital, her husband Dipankar recalls, “she looked wan and very emaciated.” Somehow she held up till she was wheelchair to the hospital.

But Harmala is a woman who, as Dipankar puts it, “bites the bullet with steely determination.” She fought the disease with all she had. Luckily, she also received excellent treatment and her spirits were buoyed by support groups of fellow cancer survivors. In 1987 she returned to Delhi, free of the disease.

India, of course, was light years behind Canada as far as attitudes to cancer were concerned. “There was

a stigma attached to it,” Harmala recalls. “Practically nobody was willing to admit they’d had it; people were even scared to say the word.”

Cancer patients who’d been cured were often considered unemployable—even a health NGO refused to give Harmala a part-time job. Moreover, few doctors accepted that cancer was a major public health problem, pronouncing it a disease of the rich.

In the battle against her own cancer, Harmala had come to realize how helpful cancer support groups could be. Keen to start similar net-

patients laboured under,” Harmala says, “especially those who were poor. In fact, most such families not only couldn’t provide emotional support—they needed it themselves.”

Finally, in 1991, a friend introduced Harmala to Dr B.M.L. Kapur, a breast cancer specialist at the Delhi’s All India Institute of Medical Sciences (AIIMS). Kapur asked Harmala if she could help him get prostheses for his patients, and Harmala in turn asked him if she could counsel his patients. As soon as he agreed, she and her volunteers got to work.

The conditions at the AIIMS breast

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works in India, she’d taken courses in Canada on how to start and conduct them. She now began to search for volunteers who’d help her. They had to be either cancer survivors or those whose loved ones had had the disease.

It took a while before she managed to round up half a dozen. But when she mooted the idea to Delhi doctors, they were dismissive. Westerners live mostly alone, was their refrain, so they need help from outsiders. Not so Indians, since we have our families.

“Most doctors paid little heed to the crushing financial and psychological burdens the families of cancer

cancer clinic were appalling. Most patients waited mutely, heads bowed, as if waiting for the sword to drop. They were examined in poorly screened areas while even male family members of other patients watched. The indifferent staff didn’t bother to remove the vomit of those who threw up.

Harmala and her team were undeterred. They persuaded Air India to donate airsickness bags for patients to vomit into. They bought curtains to ensure privacy for those being examined. They put up cheerful paintings to brighten the dull walls.

To their amazement, they were



Harmala Gupta (seated, left) with two patients and CanSupport volunteers.

rebuked for their attempts to dispel gloom. “Don’t you know all the people here are dying?” the relative of a cancer patient told Harmala. “You should be installing idols of gods they can pray to.”

Some relatives even tried to discredit the volunteers. When Harmala revealed her history to a patient, her relative cut in, saying, “She’s lying. Nobody survives cancer.”

The patients themselves, though, reacted very differently. “They’d cling to us and cry with relief,” Harmala says. “Finally, here was someone who knew what they were going through.”

Cancer Sahyog, as Harmala and her volunteers christened themselves,

was the first cancer support group in the country. Gradually, more volunteers joined and began visiting patients in other Delhi hospitals. And as word of its work spread, Cancer Sahyog received praise in the media and people asked Harmala to help start similar groups in other cities.

But as she grew more familiar with the cancer situation in Delhi, Harmala realized that for all its good work, Cancer Sahyog was not addressing the problems of nearly two-thirds of the capital’s cancer patients.

These were the terminally ill patients beyond medical help, usually because they had sought treatment too late. Conventional medicine paid

little attention to their plight, since most doctors were concerned only with those whom they had a chance of curing. Nor did they favour the use of effective painkillers like oral morphine, on the grounds that this could lead to addiction and other undesirable side effects. In effect, terminally ill cancer patients were the disease's untouchables, condemned to spend their last days in pain and despair. "Indeed," Harmala says, "Many unscrupulous doctors also fleece terminally ill patients by charging for useless tests and medications."

Meanwhile, by the beginning

of the 1990s, change was in the air. In the West, a new branch of medicine called palliative care had taken firm root. Its goal: to improve the quality of life of patients with progressive and incurable diseases by providing medication, nursing support as well as psychological and spiritual counselling to them and their families.

In 1993, a small group of doctors and social workers in Kozhikode, Kerala, started an outpatient palliative care clinic for the care of terminally ill cancer patients—the first of its kind in the country. Shortly afterwards, AIIMS started a similar facility.

But since most terminally ill patients were too sick or too poor to travel regularly to the hospital, such facilities were of limited use. Then, in 1995, Harmala was introduced to an Englishwoman who'd just arrived in India with her husband, a BBC journalist. The two women immediately

hit it off and Harmala learnt that her new friend Ruth Wooldridge was a palliative care nurse who had helped start a home-based service in Nairobi a few years earlier.

Here was the opportunity to start a similar service in Delhi under an experienced professional and Harmala approached AIIMS's top doctors. Luckily, its director Dr P.K. Dave had been trained in Edinburgh and knew about palliative care. He was sympathetic, as was Dr Vinod Kochupillai, who ran AIIMS's cancer hospital. It took a while, but finally a three-month pilot project to provide palliative care to ten of AIIMS's terminally ill patients began. It was a two-woman affair, with Ruth as the nurse and Harmala as counsellor.

A lot has happened since that modest beginning. Today, CanSupport has six centres in different areas of Delhi. Last year, its ten teams of medical professionals ministered to the needs of more than a thousand terminally ill cancer patients and their families. CanSupport has a telephone helpline as well as staff to spread the word about its services, and its referrals come from a variety of sources. So well regarded is it that, in 2007, the ladies wing of FICCI, the Federation of Indian Chambers of Commerce and Industry, chose Harmala as the "Outstanding Woman Social Worker of the Year."

The battle for a fair deal for terminally ill patients is far from over, though. Delhi alone has more than 150,000 such patients not getting

the palliative care they need. Yet, at a recent conference, a senior health bureaucrat told Harmala: "You should be more positive. You should think in terms of curing everyone."

"It is," Harmala says with a sigh, "a classic case of denying cancer's reality."

Manoj Kumar looks at his wife and then addresses the 20-odd people sitting on the floor with him. "Her name is Veena. But she has taken such good care of me that I've renamed her Savitri."

"How do you feel about that, Savitri?" asks Usha Kala, a CanSupport volunteer.

ADVERSITY DOESN'T ALWAYS CEMENT COUPLES. CANCER CAN PUT TERRIBLE FINANCIAL AND PSYCHOLOGICAL STRAIN ON FAMILIES.

Tears fill Savitri's eyes, and she wipes them away, shaking her head. She's clearly too overcome to speak.

We are at CanSupport's day care centre. Although home care for the terminally ill is the main focus of CanSupport's activities, every Friday out-of-town cancer patients like Manoj Kumar and their caregivers who've come to Delhi for treatment spend a day on its premises. Volunteers teach them yoga and other stress relaxing techniques, encourage them to bond with each other, and provide a home-cooked lunch.

Manoj has handed over the floor to Rafiq, a fellow-Bihari, whose wife Parveen has cancer. "She keeps asking me if I will take a second wife," he says, looking at Parveen, a pretty young woman in a blue sari. "But the thought has never ever occurred to me. I love her. We have two children. Together we will overcome."

Parveen begins to cry, and Usha tells the group, "Talk about your love for each other. Everyone likes to be told they're loved, that they are not alone."

Adversity, of course, doesn't always cement couples. Cancer can put terrible financial and psychological strain on families, Harmala points

out, relating a story of a wife who fought with her husband over what to do with their meagre savings: spend it on his treatment with no guarantee of success, or keep it so that she and the children wouldn't be destitute after his death.

Roop Bhalla, a 45-year-old garment industry executive, looks at Harmala and starts crying. Without saying a word, Harmala, her eyes filling with tears, gets up and puts her arms around Roop.

Roop has recently had surgery for breast cancer. Although her cancer

was caught early and doctors have pronounced that her prognosis is excellent, she has sunk into a deep depression. She is convinced that she is, as she puts it, "on my way out." Roop has never met Harmala until now; an uncle has forced her to come to the CanSupport office.

At that first meeting, Harmala reassured Roop, answered all her questions, and gave her a book on the right kind of diet for cancer patients. And over the next many months, Harmala talked to Roop over the phone, dropped in at her home, and advised her to recite the *Mool Mantra*, the key Sikh incantation.

"No matter when I called, she never said 'I'll call you back,'" Roop says. "She was so encouraging that talking to her for just a few minutes was enough to buck me up for several days. In my list of angels, she's right on top."

Harmala's personal attention to every cancer patient is remarkable, given the myriad organizational matters she has to deal with. She also suffers from severe osteoporosis and

remains at high risk for breast cancer and heart complications—all side effects of the radiation she underwent a quarter century ago. She'd like to step down from the day-to-day running of CanSupport and concentrate on campaigning to change the in different attitudes of the government, the medical establishment and the public towards the terminally ill. She's been on the lookout for a successor for the last couple of years. But finding one with her skills and compassion isn't easy.

It is Harmala's 58th birthday and at the head office of CanSupport, cake and ice cream are being served to celebrate. A staff member hands her a large package. It's a painting of a Rajasthani woman sitting on the ground, head covered, in green clothes and gold jewellery.

"Beautiful," Harmala says.

"You should put it up where you can always see it," someone suggests.

"In that case," Harmala says, "I'll keep it in the office. After all, I spend most of my time here."

GAME FOR ANYTHING

Some fans will go to extremes to watch their teams in the finals. According to a US newspaper, when football team Broncos reached a championship final in 2006, three fans offered goods or services in exchange for tickets. Dr Steven Broman was willing to give a free vasectomy; Glenn Laurent, a professor at the University of Colorado, offered a semester of tutoring; and Scott (he wouldn't reveal his last name and you'll see why) put up a half-carat diamond ring costing \$2195, which he'd planned to give to his wife on Valentine's Day.