



They talk about it, they fight it, they research it, heck they even run for it.

Follow the lead of these women and men—survivors, doctors, innovators and communicators—to learn how to hit back. *by* **SUNALINI MATHEW**



SHRUTI SHARMA AND
NEETI LEEKHA

The Helping Hands

(started Uday, to provide emotional support to young cancer patients)



The duo, in their early 30s, didn't know each other before they got breast cancer. But under the guidance of Renuka Prasad, a senior member of the Indian Cancer Society and a breast cancer survivor herself, they have now started a support group that meets in Delhi. A number of the people prefer to call, though. The service fills a gap that the two felt when they were going through the treatment process. "The emotional trauma of a young woman is different from someone older: there are doubts about sex, marriage and children that women may feel diffident to discuss with a doctor that they can discuss with us," says Sharma.

The focus, they say, is always on keeping life as normal as possible. Even during their own treatment, both would go out regularly—to the movies, to parties or just for a walk in the park. They derived strength from their families, with both partners supporting them even as they had a mastectomy. "As you lose your hair and get hot flushes (because your periods stop and so you show signs of pre-menopausal women) your self-esteem plummets," says Sharma. "My husband never made me feel that I looked any different from before."

The two also do awareness talks and volunteer work for the Indian Cancer Society.

TIPS FOR FIGHTING:

// **Understand the taboos:** People feel radiation may harm them, or that they can 'catch' cancer.

// **Take care of your diet:** "This has made me so much more conscious of what to eat and what not to, and it has affected the way the extended family eats too—because breast cancer has a way of affecting everyone around you too," says Leekha.

// **Avoid the sympathetic eye:** "Just treat a friend who has breast cancer normally; don't look at her like she's going to die!" says Sharma. And definitely skip stories of possible cures.

// **Be involved as a caregiver:** But not to the extent that you fall sick yourself. Help the person you're looking after build willpower.

// **Remember that you are young:** Breast cancer in young women (below 40) may be aggressive, and so is the treatment. "But your body can take it and remember, you have your whole life ahead of you," says Leekha.

// **Open your organisation up:** Whether it's a school, college or workplace, invite organisations to do workshops to build awareness about early detection. It can save your life.

// **Stay positive:** Whether you use pranamaya and meditation or any other way, surround yourself with positive thoughts.

// **Appreciate the little things in life:** "I love the feel of my hair flying or raising my eyebrows, because my hair has grown back now!" says Leekha.

// **Live in the present:** Time is precious, whether or not you have breast cancer.

DR RAGHU RAM

The Breast Investigator

(came back to India to set up one of the sub-continent's first breast centres)



When Dr Raghu Ram was in England, his mother, who was over for a visit, was diagnosed with breast cancer. "As the only child, I was shattered," he recalls. Ironically, Ram was a breast surgeon himself. "India had no concept of breast centres at the time." So Ram moved back to India to establish a breast health centre, the KIMS—Ushalakshmi Centre for Breast Diseases in Hyderabad, in 2007, naming it after his mother. Wanting to make a difference in the city he was born and raised in, Ram spread his work out over both urban and rural areas. Today, in tandem with the Andhra Pradesh government, he runs a programme where up to 28,000 underprivileged women have been clinically examined and educated on the disease. Ram has also started the Ushalakshmi Breast Cancer Foundation along with his gynaecologist mother. The organisation has

events and raises funds and awareness for the cause, one of which is the Pink Ribbon Walk (in its fifth year now), where celebrities and almost 3,000 people come out on to the streets of Hyderabad to walk. City monuments are lit up in pink. "The aim is to salute survivors and spread the message of hope and courage," he says.

Tips for fighting:

Look out for the following:

Any painless lump in the breast, blood-stained discharge from the nipple, in-drawing of nipple, puckering of skin overlying the breast, eczema around the areola. It doesn't mean you have the disease.

Visit your doc if you find anything abnormal:

Since breast cancer is occurring a decade earlier in Indian women than it is abroad, you need to be alert.

Be aware: In case of a lump, your doctor may carry out a triple assessment:

- a) a clinical breast exam
 - b) breast imaging: an ultrasound in women under 40 and a mammo in women over 40
 - c) ultrasound-guided core needle biopsy of lump (in the case of a solid mass) or a fine needle aspiration cytology (FNAC—in the case of a cyst filled with liquid, usually benign).
- An MRI is done in very specialised cases when the patient is considered to be at a very high risk of developing breast cancer.

Milind Soman

The Campaign Runner

(started the Pinkathon)



Milind Soman combined his passion for sports, especially running, with the breast cancer cause. Pinkathon was born last year, as a race for women, in a 3, 7 and 10 km format. It began in Mumbai, with a participation of 2,000 women. Soman hopes to extend it to four

cities this year, and finally to 10 cities in India. "I want to create a community of women, who, by taking a step towards their own health, promote running as a way to get healthy." He currently raises money for the Women's Cancer Initiative through this running event.

TIPS FOR FIGHTING:

Focus on health:

69 per cent of breast cancer deaths occur in developing countries, according to the WHO.

Run: It's free! You don't need fancy equipment.

Talk about it: Be a part of an initiative that supports the cause, so you can talk about it.



Exercise may cut down your chances of getting breast cancer

DEVIEKA BHOJWANI

The Action Hero

(helps build awareness and raises funds for treatment through the Women's Cancer Initiative)



"Sometimes," says Devieka Bhojwani, "the universe sends you a message. You've just got to be smart enough to read it." Ten years ago, when Bhojwani was diagnosed with breast cancer, almost incidentally (she got a mammography on a whim), she was admittedly "blown": there was fear and there were "many, many down days". But her will to fight it, her family's support ("they never treated me as unwell") and her doctor's guidance helped her through. In fact, in 2003, it was her radiologist and then director of Tata Memorial Hospital, the late Dr Ketayun 'Katie' Dinshaw, who encouraged Bhojwani on to start what is now the Women's Cancer Initiative, under the aegis of the Tata Memorial Hospital, Mumbai. Bhojwani honed in on her skills of raising funds and organising events. The initiative has a five-point mandate: to create awareness, to raise funds for underprivileged people (they currently support 500 women annually), to network with NGOs working in the field, to support research and technology transfer and to communicate with the media (the first survivor's conference was widely publicised).

TIPS FOR FIGHTING

// Be breast aware: You possibly notice the tiniest zit on your face, but have no clue about how your breasts are changing. Ask your doc to show you how to do a

Jaskeerat Bedi The Evangelist Biker

(cycled for the cause at the MTB Himalaya race)



This 26-year-old's dad, a supporter of the breast cancer charity—Forum for Breast Cancer Protection, introduced her to oncologists at the NGO. "They told me how people often came to them in the final stages of the disease. I wanted to change this." So she cycled for the cause at the MTB Himalaya race, distributing pamphlets, showing videos, speaking to folks about it.

TIPS FOR FIGHTING:

Skip the excuses to exercise: Choose a low-impact sport like cycling—it can also become a hobby. **Listen to survivor stories:** Because they offer a clue about lifestyle changes you can make.

FARIDA RIZWAN The Thought Leader

(blogs about breast cancer)



In her touching blog (*Chaptersfrommylife.com*) about how she lost her older sister (at 32) and then her mother, to breast cancer, and how she dealt with getting it herself, Rizwan takes us through an emotional roller-coaster of a ride. She talks of the experience from both a survivor's and a care-giver's perspective. She was diagnosed with the disease (in the third stage) at 29, just as

her sister was fighting it. "I was careful about my health," she says. So you can't find the answer to 'Why me?' The only thing you can do is go for regular check-ups and screening tests," she says.

TIPS FOR FIGHTING: Be aware that the care-giver's position is more difficult:

"My sister refused treatment and though I knew medicine could save her, I had to let her take her own decision," she says.

Reach out to your sisters: If you know someone who has had the disease, help them get in touch with survivors. "I feel close to women who have gone through it. No one else will ever know what it feels like, whether it is treatment or losing a breast to a mastectomy."

self-exam. "The idea is not to look for a lump, but to understand the anatomy of your normal breasts, so that even if there's a small change, you can have it checked out," says Bhojwani.

// Speak about it openly: When Bhojwani wrote of her experience in a magazine, "hundreds of women wrote back to thank me for being their voice."

// Understand, no one is to blame: If you, or someone close to you gets the disease, know that it's not divine retribution. "We're still looking for reasons why breast cancer happens," says Bhojwani.

// Choose a doctor you can talk to: Bhojwani founded the initiative with support from her radiologist.

// Never lose your sense of humour: When she was undergoing radiation, "People would tell me, 'Oh Devieka, you're looking radiant.' I'd have loved to have told them why!" she quips.

**You
Never
Know
What Lies
Beneath,
So Start
A Breast
Self-Exam
Today**

LEENA BEKAL The Writer Striker (wrote a book called A Bit Of Pink)



Six years ago, when Leena Bekal's mother was diagnosed with breast cancer, she realised that it is an easily treatable disease if detected early.

But, she says, "women tend not to prioritise their health". As she took care of her mother, she realised that there were many books out there that were heart-warming and touching, but they seemed too 'heavy' to digest, often leaving them sitting on the shelves. So she wrote a fictionalised book in a lighter vein, so women would pick it up.

The book is about two sisters, the older of whom is diagnosed with the disease. It is written from the perspective of the care-giver, Leena being one herself. "I thought it would be easier to read,

and the disease would be less frightening," she says. It was encouraging when women told her they went for a mammo after reading her book.

Tips for fighting:

Deal with it: It's a reality: Whether it happens to you or to someone close to you, you could be affected. "It's like an accident—you don't want to talk about it until it happens to you, but you should," says Bekal.

Read about it: There's a great deal of material out there. Don't avoid it because you're scared or you feel it can't happen to you.

Dr Sumeet Shah THE MEDIUM WITH A MESSAGE

(started a website for
basic breast cancer
awareness)



When he worked at Tata Memorial Hospital, Dr Sumeet Shah, a surgical oncologist, came across many cases that had gone wrong, because patients were wrongly diagnosed. He started the website Breastcancerindia.net to "arm people with the knowledge to detect and fight the disease," he says. He derives inspiration from his patients. "Their positive attitude and courage is truly amazing."

TIPS FOR FIGHTING:

Pick your doctor with care: Choose someone who is sensitive to your specific needs.

Get the right specialist:

If your gynae detects a lump, she should put you onto a surgical oncologist, not continue treatment herself or send you to a general surgeon.

DR RAMESH SARIN AND DR (COL) CS PANT The Kind Physicians (started the Forum for Breast Cancer Protection)



Way back in 2001, before breast cancer became a topic of discussion, a group of doctors, alarmed at the growing number of women who came to them in the final stages of the disease, got together to make a change. A change to create awareness about breast cancer, to make people aware of the disease so early detection is possible. They also hoped to help people understand the treatment modalities, so they could participate in their own recovery. "Even today, about 65 per cent of cases come in at stage 3," says Dr Ramesh Sarin, senior consultant surgical oncology, Indraprastha Apollo Hospitals, who, along with Dr (Col) CS Pant, consultant radiologist, Col. Pant's Imaging Centre, New Delhi, founded the forum, in tandem with other doctors who work in the area. "Mothers who have breast cancer come with concern that their daughters may not get husbands—the stigma runs so deep," she says.

In the past, the forum has both supported and organised events—car rallies, screening camps and workshops in schools and colleges. They have also raised money for education and to help the less privileged. They will soon be releasing their third film



on the breast cancer gene. "It will tackle what women who may have the BRCA1 and 2 gene need to do: whether they need to get tested, whether their daughters do, and of course, if they do, what next," says Sarin.

Previous films have focussed on basic questions about breast cancer and on how to do a self-exam. And while the doctors ask women to call in case of any doubt, "Women should take responsibility for themselves. We can empower everyone with awareness and education, but finally, it is up to you to come forward and get themselves checked," says Sarin.

TIPS FOR FIGHTING:

// **Do a breast self-exam:** This should happen once a month, ideally after the age of 20.

// **Do a clinical exam:** Make sure you visit your gynae or a breast surgeon once a year after the age of 30.

// **Get a mammogram:** When you hit 40 do this once in two years. A mammo picks up upto 80 per cent of diseases. After 50, have one every year.

// **Know the tools:** While a mammo can be both a screening tool (a part of routine examination) and a diagnostic technique (a test done when something is suspected), an ultrasound is an adjunct to diagnosis (it is a supporting test to what the doctor suspects).

Ritu Biyani
The Breast Cancer Crusader
(links adventure sports with a cancer awareness mission across the country)



She's been in the army, a dental surgeon, an avid traveller and she's been in the *Limca Book of Records* for driving 177 days over 30,220 km covering the length and breadth of the country with her then 14-year-old daughter... And she's a breast cancer survivor. In fact, the reason she did the drive in 2006 was to do workshops on breast cancer. She conducted 700 of them. Today, her NGO, High

Ways Infinite focusses on taking awareness and funds to regions where others don't reach.

TIPS FOR FIGHTING:

Filter your info: A lot of it online is only for the West. Pick what you and your doc feel works for you.

Don't make your counsellor your doctor: Separate the two.

Fuse your passion and mission: "I can't separate the two, and neither should you," says Biyani. ■