



SPECIAL REPORT: BREAST CANCER

THE SHOCKING TRUTH: *unnecessary* mastectomies

Few women diagnosed with cancer in one breast benefit from having both breasts removed. So why are more of them choosing this surgery?

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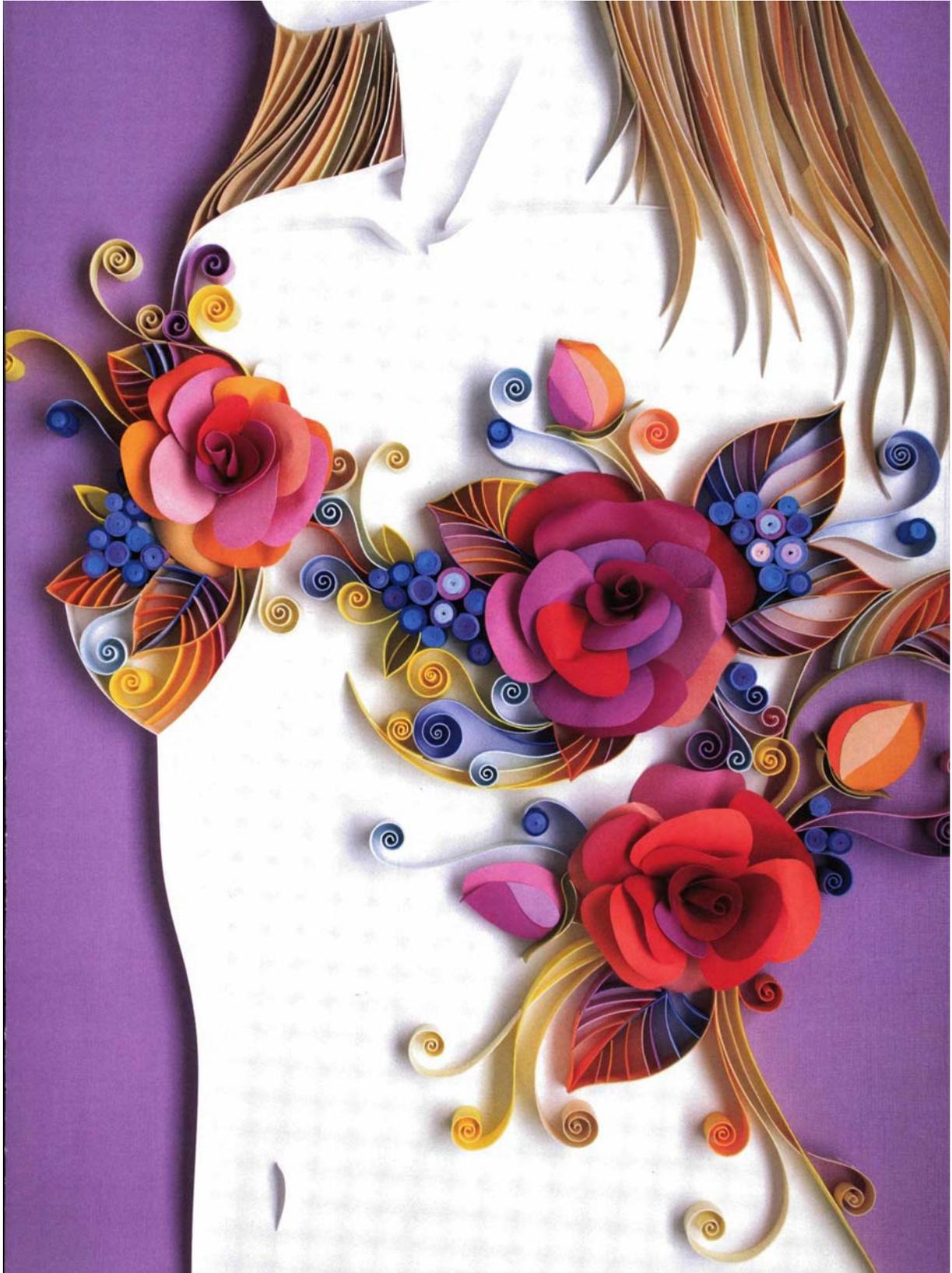
Debbie Horwitz was 32 when she felt a lump while soaping up her armpit in the shower. Her mother had died of breast cancer when Horwitz was nine years old, so she quickly made an appointment with her doctor. After an ultrasound and a biopsy, she was diagnosed with stage 1 triple-negative breast cancer, which can be very aggressive.

The good news was that because Horwitz's cancer was caught early, doctors didn't need to remove her breast. "My surgeon told me there was the same statistical evidence for survival with a mastectomy as there was for radiation and a lumpectomy," says Horwitz, now 45. The breast-sparing lumpectomy would have removed only the cancer and a small amount of tissue surrounding it. The risk of complications would have been lower and the recovery time shorter if she'd chosen the lumpectomy. But Horwitz admits that when it came time to make the decision, the facts were overshadowed by her family history – and the word aggressive. Horwitz not only rejected the

lumpectomy in favour of having the cancerous breast removed but also decided to have a double mastectomy, with her healthy breast removed as well. "I knew that otherwise I would spend the rest of my life worrying that cancer would develop in my other breast," she says.

Her decision, while seemingly drastic, isn't unusual. In Australia, doctors and researchers have reported a noticeable increase in contralateral prophylactic mastectomies, or CPMs, where the healthy breast is removed in addition to the affected breast. That's not because more women are getting breast cancer, nor is there evidence to suggest that more women need such extensive surgery. On the contrary, the Breast Surgeons of Australia and New Zealand Society, advises against the routine use of CPMs. What's happening is that an increasing number of women are *choosing* to have their healthy breast removed.

In an article published in the *Medical Journal of Australia* last year, Professor Andrew Spillane, a surgical oncologist at the University of Sydney ►





Genetic testing

Currently we know of several 'cancer protection genes' that, when working properly, lower the risk of breast and ovarian cancer, and other types of cancer. The best understood protection genes are called BRCA1 (BREast CAncer 1) and BRCA2 (BREast CAncer 2) genes. Mutations in these genes result in impaired repair of DNA, and an increased risk of breast and ovarian cancer.

Most people who develop breast cancer have no family history of the disease. However, when a strong family history is present, or if these cancers develop at an early age, there may be reason to believe that a person has inherited a mutation in one of these genes. In this instance, you may choose to undergo genetic testing, which involves giving a blood or saliva sample that can be analysed to pick up any abnormalities.

As of November 2017, a Medicare rebate of \$1,200 was made available for a test panel of up to eight genes, including the BRCA1 and BRCA2 genes, for women diagnosed with breast or ovarian cancer who are assessed as likely to have a genetic mutation that increases their risk. This is usually determined by genetic counsellors at a familial cancer clinic. Women diagnosed with breast cancer will be able to access genetic testing under this rebate if their family history or the clinical characteristics of their cancer put them at high risk of having a genetic mutation. A cancer specialist will be able to assess the risk using one of the established tests that predict the likelihood that someone has a mutation that increases their risk of breast or ovarian cancer.

For more information about eligibility for genetic testing under the new rebate, visit bena.org.au.



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and past president of BreastSurgANZ, wrote: "CPM is increasingly performed at the time of initial breast cancer management, largely driven by patient preference." The reasons for this choice vary, depending on the individual, but preventing a recurrence of the cancer and improving chances of survival are important factors.

The problem is that numerous research studies have shown that for most women diagnosed with breast cancer, undergoing a CPM doesn't accomplish either. This has led experts to worry that many women are being over-treated – a concern that only grew after a 2014 *JAMA Surgery* study revealed that 70 percent of women who underwent a CPM did so despite being at very low risk of cancer developing in the healthy breast.

Now researchers want to know whether breast cancer patients are getting the guidance they need to make informed treatment decisions and whether other factors prompt women to choose a CPM over less invasive options.

MYTHS THAT FEED FEARS

Although tremendous strides have been made over the past few decades in raising awareness of breast cancer, some doctors say that knowledge of how the disease could return – and how frequently that actually happens – is still lacking.

"There's a huge misconception that cancer could spread to the other breast," says Elisa Port, chief of breast surgery and codirector of the Dubin Breast Center at Mount Sinai Hospital in the US. "If the cancer did return, that's one of the last places you'd see it."

When breast cancer recurs, it usually appears in either the affected breast or nearby lymph nodes or is discovered in another part of the body – typically the lungs, liver, bones or brain.

Less than 1 percent of breast cancer survivors experience a recurrence in their healthy breast later in life. And a CPM doesn't increase the chance of survival when compared with a lumpectomy. "If you get all the cancer out of the breast, removing additional healthy tissue does not improve a woman's survival rate," Port explains.

If anything, we should be seeing a decline in mastectomies due to improved screening, she adds: "Once it became easier to detect breast cancer at an earlier, more confined stage, doctors started to wonder if it was necessary to remove the

whole breast. The concept of a lumpectomy was really only made possible by better screening."

Lumpectomies have largely replaced mastectomies as the initial surgical choice, with experts saying that just 10 per cent of women should consider a CPM – specifically, those who carry a BRCA1 or BRCA2 genetic mutation, and even then, only on a case-by-case basis.

MISSING INFORMATION

Not surprisingly, the large number of unnecessary CPMs has prompted researchers to question whether doctors are doing enough to help patients make an informed decision.

It is important that women understand the difference between the risk of recurrence, which can happen anywhere in the body, and the risk of developing a new cancer, explains Associate Professor Elgene Lim, a leading breast cancer researcher at the Garvan Institute of Medical Research in Sydney and medical oncologist at St Vincent's Hospital Sydney. "The one that is more serious is the former, and so it's more important



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that patients have therapies that reduce that risk [of recurrence], rather than worry excessively about reducing the risk of a new breast cancer developing in the other breast," Lim explains.

Unfortunately, there's still a lack of clarity for women and when you add that to all the stress experienced at this time, making a decision can be very difficult. A recent review of studies that considered what factors influenced a patient's decision to have a CPM found that fear of breast cancer was the most commonly cited reason.

"Our review showed that fear or worry about the cancer and insufficient knowledge (in particular overestimating the risk of recurrence and benefits of CPM) are strongly associated with women considering CPM," says Dr Jesse Jansen, senior research and NHMRC early career fellow at the Sydney School of Public Health, Sydney Medical School, The University of Sydney.

It has been shown that another aspect women consider is that regular breast screening tests are very stressful and consider having surgery on the other breast to avoid them. ►



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DNA-BASED DECISIONS

Another potential cause of increasing CPM rates is the rise in genetic testing. Such testing to guide decisions after a diagnosis is becoming the standard of care, with every state having familial cancer centres that are publically funded. This is where people can be screened for appropriate testing and which, more importantly, have a relatively fast turnaround for results. Genetic counsellors are also involved in the multidisciplinary management of patient care in major hospitals.

It's a crucial advance for those who could benefit from undergoing a CPM. Women who are diagnosed with the disease and test positive for a BRCA1 or BRCA2 mutation, for example, have a risk of developing breast cancer in the other breast that is three to four times higher than that of a woman without a genetic predisposition. Years ago, genetic testing wasn't so readily available – no

realistic implants and nipple-sparing techniques, may influence a woman's decision to have both breasts removed.

According to Jansen, who was a co-author of the review conducted by the University of Sydney and the Peter MacCallum Cancer Centre, "A desire for symmetry after a unilateral mastectomy was a key motivating factor" for patients.

Breast reconstruction is not simple, however, with the removal and reconstruction of both breasts being a larger procedure with more chance of unwanted effects such as pain, fluid build-up and infection. It is also important to note that reconstructed breasts will have a different appearance to natural breasts. There are emotional issues with reconstruction, too. Women may think that they'll look and feel the same as they did before, when that's not always the case as reconstructed breasts will have a different appearance to natural breasts.

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one suggested that Horwitz, who was diagnosed in 2004, get tested. But the benefits of genetic testing became less clear once more women without a cancer diagnosis began having it to assess their risk, a trend spurred at least in part by Angelina Jolie's highly publicised decision to have her breasts and ovaries removed after she learned she had the BRCA1 mutation.

"About half of my patients with risk associated with genetic mutations have a bilateral mastectomy at some point," Lim says.

"The timing depends on multiple factors, including whether they have completed childbearing, and their desire to breast feed. It's a surgery that doesn't need to be done immediately, and best timed after thoughtful consideration."

Interpreting the results is complicated, and it can be costly but as of November last year, genetic testing was made available through Medicare for people at a high risk of developing breast and ovarian cancer (see 'Genetic testing' on page 116).

APPEARANCE MATTERS

Genetic testing isn't the only advancement that may be fueling the CPM trend. Researchers say that improved reconstruction options, like more

CHANGES AHEAD

There are some hints that mastectomy rates may begin to decline. Preliminary findings presented at the American Society of Clinical

Oncology's 2017 annual meeting suggested that more than half of BRCA breast cancers occur in the upper outer quadrant of the breast, raising the possibility that removing that area alone might lower breast cancer risk enough for some women to avoid a preventive mastectomy.

The next step is to find a non-surgical approach to cancer prevention for BRCA 1 or 2 carriers. One trial being conducted in Melbourne, the BRCA-D project, is testing a drug called denosumab that has the potential to prevent breast cancer from developing. It is hoped that an international prevention study will be initiated in 2018, which will be a placebo controlled trial of the drug for women who have not had breast cancer.

But until scientists discover more ways to identify those at highest risk of breast cancer – and more women receive the counseling they need to make an informed decision – experts say that some women will continue to have healthy breasts removed. And that may be true even when women know a CPM isn't truly necessary.

"There are always two parts to the decision making," Port says, "and only one is medical. I'm the expert in cancer, but women are the experts in themselves. As long as a woman is informed, it's her choice." ■



Deciding what is best for you

A diagnosis of breast cancer is very stressful – not a good time in which to take in all the information that will help you make the decisions necessary about the type of surgery to have to treat your breast cancer, prevent cancer occurring in the future and/or improve your chest appearance. It can be a very challenging time but one way to cope is have as much information as possible. Organisations such as the Breast Surgeons of Australia and New Zealand (breastsurganz.org) are working to make things easier with tools that take you through the decision-making process. It's difficult to remember, but with early diagnosis and advances in treatment, breast cancer can be treated and, in many cases, cured. And the resources are there for you, so you can access information, practical help and emotional support.

For more information visit the Federal Government's Cancer Australia website at canceraustralia.gov.au