

# A man with a woman's cancer

How can we do better for male breast cancer patients?

→ Jim Boumelha

Being diagnosed with a “woman’s” cancer can pose all sorts of problems for a man. Should breast cancer advocacy groups be more welcoming? Do men need their own groups, or don’t they do that sort of thing? And can greater public and professional awareness combat the awkwardness and marginalisation felt by many men being treated for a disease so heavily branded by the pink ribbon?

“**A**ll you have to do is kiss it and it pops right out.” This was the jokey response Darrell Foreman made to his wife Anita, when she pointed out that his right nipple had become inverted. Unamused, she sent him to his doctor, who found a grade IV malignant breast cancer. Foreman was later to feature in an article in the *Philadelphia Daily News*, which took a slightly lighthearted look at the strange experience of being a “real guy” diagnosed with breast cancer. Forced to endure the full works – mastectomy followed by heavy chemotherapy and radiotherapy – the *Daily News* listed as his main complaints the metallic edge it gave to the taste of his bourbon, the giggles in the mammography waiting room (“I’m Mrs Foreman”), and the feeling of being marginalised by the main breast cancer advocacy groups. But then “real guys don’t whine about stuff like that,” is the tongue-in-cheek conclusion.

Whether they whine about it or not, being

outnumbered 99 to 1 by women is bound to raise unique problems for any male breast cancer patient, but so far, these problems seem to have attracted little interest among either the research or the public health community.

Rachel Iredale was shocked to find how invisible male breast cancer patients were when she began to research the disease with her team at the Institute of Medical Genetics at Cardiff University. “As we were doing this work we came to the realisation that there was absolutely nothing there for men. In Britain almost three hundred men a year are diagnosed with breast cancer, there was no information for them, there were no leaflets and no support. When they went to get their drugs from the pharmacy, tamoxifen for example, and there would be a male name on the prescription, the pharmacist would query it as an error.

“There seems to be low levels of awareness of male breast cancer not just among the public, but also among healthcare professionals.”

ALAMY / ANDREW PARKER



Though male breast cancer accounts for no more than 1% of all breast cancers, it is not classified as a rare cancer, and therefore does not qualify for the research and development incentives that apply to ‘orphan’ diseases. “As far as I am aware there are no randomised controlled trials,” says Iredale. “There are a couple of groups in the States who are looking at gender issues and they may be doing randomised controlled trials that include both men and women, but I don’t think that there are any that have separated out men and women specifically, the numbers of men are simply not there.” Much of the current knowledge regarding the biology and treatment of male breast cancer is therefore drawn from the vast plethora of studies done on women.

**A gender thing. Scars on the face, stomach or legs can be seen as signs of masculinity, but scars from breast cancer surgery can be embarrassing for a man**

Ian Banks of the UK Men’s Health Forum believes the pharmaceutical industry must take some of the blame for this paucity of research. “They are not interested, not least because there are not so many people affected – I think that could be part of the problem. There is no co-ordinated push or will to actually do anything about it, particularly from the commercial sector.”

There seems, however, to be a broad consensus on the dominant pathological themes. Most of the clinical signs are similar to those found in women: a painless lump, nipple

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### RISK FACTORS

Risk factors that have been associated with male breast cancer include:

- Age. The disease is most common in men in their sixties<sup>1,2</sup>.
- Mutations in the BRCA2 gene (which account for between 4% and 16% of male breast cancer). A 70-year-old man with the BRCA2 gene mutation has an almost 7% risk of breast cancer<sup>3</sup>
- First-degree relative with breast cancer<sup>4</sup>
- Klinefelter's syndrome, a rare disorder in which men have an extra X chromosome<sup>1,2</sup>
- Jewish ancestry<sup>1,2</sup>

The following concomitant disease or disorders and environmental or occupational factors have also been linked with male breast cancer. More research is needed to build up the evidence base.

- Benign breast conditions<sup>1,2</sup>, testicular disease<sup>1,2</sup>, prostate cancer<sup>5</sup>
- Bone fracture after the age of 45 years<sup>6</sup>
- Diseases associated with hyperoestrogenism, such as cirrhosis of the liver<sup>3</sup>
- Obesity<sup>5,8</sup>, diabetes<sup>5</sup>, hypertension<sup>5</sup> hypercholesterolaemia<sup>5</sup>
- Radiation exposure<sup>7</sup>
- Alcohol consumption<sup>5</sup>
- Exposure to ionising radiation, petroleum and combustion products, high temperatures or electromagnetic fields<sup>5</sup>
- Oestrogen administration<sup>7</sup>
- Working as a wood machinist or aviator<sup>5</sup>

Sources: <sup>1</sup>Avanzo et al (*Br J Cancer* 1995), <sup>2</sup>Goss et al (*Cancer* 1999), <sup>3</sup>Yu Chuan Tai et al (*JNCI* 2007), <sup>4</sup>Daly et al. (San Antonio Breast Cancer Symposium 2007), <sup>5</sup>Donovan and Flynn (*Cancer Nurs* 2007), <sup>6</sup>Brinton et al (*JNCI* 2008), <sup>7</sup>Giordano et al (*Ann Intern Med* 2002), <sup>8</sup>Hsing et al (*Cancer Causes Control* 1989)

discharge or a change in appearance of the nipple.

Identified risk factors also show some commonalities, ranging from hormones and genes to an environmental role in the development of the disease (see side panel).

As for the biology of male breast cancer, interestingly, it appears to be very strongly linked to female sex hormones – over 90% of cases are oestrogen-receptor positive, and men are far less likely to have amplification of the HER2 gene than are women.

Despite emerging knowledge of the distinctive biological profile of male breast cancer, its diagnosis and treatment have remained, on the whole, similar to breast cancer in women.

Mammography and cytological investigations are typically used to confirm the diagnosis. Surgery is always considered the first treatment. Though breast-conserving surgery can be offered in some cases, it is not always possible where there is too little breast tissue. Techniques that preserve the nipple, which have recently been introduced in general breast cancer surgery, can however be used in men.

But when it comes to the experience of breast cancer – above all its psychological and psychosexual impact – men's breast cancer has little in common with the disease in women, as Henk van Daele, who was diagnosed with the disease in November 1999, can testify.

### ISOLATION

Now an indefatigable campaigner on the rights of men with breast cancer, he describes the terrible sense of isolation he first felt. "In the beginning, each cancer patient falls into a very deep valley, into the Grand Canyon, each cancer patient is afraid, anxious and thinks his illness is the only one . . . Most men who receive the diagnosis of breast cancer do not know any other male breast cancer patient – that's the problem. In the first month and the first year, I was in that valley."

“Many men had stopped swimming, or if they were working in their garden they would not go shirtless”

## “With male breast cancer, men have to engage with what they perceive as a feminised illness”

Male breast cancer is often described as a unique lived experience for men. Some even go so far as articulating the unwelcome and unexpected new condition as stigmatising. After her numerous in-depth discussions with male patients, Iredale concluded, “it became apparent that men did experience some anxiety, stigma and depression, and that was reflected in how they behaved. They would not take their T-shirt off on a sunny day for example when they used to previously. Many men ... had stopped going swimming or if they were working in their garden they would not go shirtless. So, even when they said they were not feeling embarrassed, if they had a scar, their behaviour demonstrated that they were actually embarrassed and experienced some of that stigma.”

Indeed surgeons are now reporting an increasing demand for the relatively new technique of nipple-sparing surgery among male breast cancer patients. “We are noticing that, as a result of changes in societal values, the pursuit of body symmetry has become a reality also for the male sex,” comments Alberto Luini, a breast cancer surgeon at the European Institute of Oncology.

Delving into the psychological difficulties that arise for men with breast cancer, Tom Donovan, of the nursing division of the University of Liverpool, UK, identified masculinity and its wide spectrum of cultural meaning as a core component of the cancer experience. He argues that, unlike other conditions, the issue of gender is a defining feature of male breast cancer. In other gender-related malignancies such as prostate or testicular cancer, men can feel a sense of ownership. With male breast cancer, men have to “corporally and conceptually” engage with what they perceive as a feminised

Men get it too. This badge is part of an awareness raising project ([www.outoftheshadowofpink.com](http://www.outoftheshadowofpink.com)) started by an American couple after the husband was diagnosed with stage IV breast cancer



illness, which can even compromise their sexual orientation. “I want to take my shirt off – but I can’t now... Some people think that a man with breast cancer cannot be a ‘real’ man. They think ‘he must be gay’ or ‘he is half-woman’.”

This sense of stigma, he adds, can be unintentionally compounded by health professionals. While women tend to receive good information and counselling about the impact breast cancer can have on their body image and sexual function, no such support is given to men. Some men talk about being asked to wait in different areas to women patients or use alternative entry and exit routes. The idea, apparently, is to assuage the discomfort of female patients, but it takes scant account of how it might make the men feel.

One point that everyone seems to accept is the urgent need for psychosocial information and support. Iredale, however, cautions against simply transposing to men ready-made interventions to support women. But male-specific information may not be the answer either. “The information that existed when we did our study was all focused towards female breast cancer – all the images, the diagrams, all the statistics that were presented were about women. The men we talked to said they did not want gender-specific information, they did not want information specifically designed for them – as they realised the cost implication that carried – but they did want some acknowledgement in existing literature that men can also get breast cancer,” she said.



## “Getting together for provision of information... is somehow more acceptable than a support group”

It's not just a question of psychological support, argues Banks – well-targeted information can save lives. You can be diagnosed with advanced testicular cancer and still survive, he points out, but when breast cancer is diagnosed late, your chances are vastly reduced. “We need different levels of influence. We need to be able to influence the men themselves to be much aware of it, and also influence the media to talk about it more. This kind of thing really should get mainstream media attention, but they tend not to talk about it. We need healthcare providers to be more aware of it as well.”

Educating the professionals is something Van Daele also feels very strongly about. In the years since his diagnosis, he has become an expert on male breast cancer, doggedly grappling with complex scientific papers, and now speaks regularly on the subject to audiences of retired men and even at training courses for health professionals. “It is simply a question of cancer education – of doctors, nurses and most importantly of the general public. This is why I give my lectures.”

### PATIENT GROUPS

One key to achieving a higher profile for male breast cancer is to build active patient groups – but bringing men with breast cancer together has proved a major challenge. Van Daele ended up joining a female advocacy group, Leven Zoals Voorhen (Live as Before) – the chairwoman, as it happened, had just lost a brother to breast cancer. Soon after, the group recruited its second male volunteer, and together they provide a support service for newly diagnosed patients. “We accompany new male breast cancer patients. I counsel them, I help them by going to hospital, by telephone, by e-mail and so on. Just so they realise that they are not alone.”

Banks, who presides over the Men's Health Forum in the UK and in Europe, laments the lack of specific organisations for men. “As far as I am aware,

there are no breast cancer organisations for men. The topic is actually covered by women's breast cancer organisations that look after that area.

But, as Van Daele points out, the main breast cancer advocacy group in Europe actually calls itself Europa Donna. “They should have taken the name of Europa Seno. By choosing Europa Donna they exclude males,” he says.

According to Iredale, however, the problem is not so much that men are precluded from forming their own support group – it's simply that they don't find them attractive, because they see them as a weakness – it's a female sort of thing.

“But if you get together groups of men for the provision of information or into a discussion group, somehow this is much more acceptable than a support group. Also we found that men in our study would be quite keen on what we call a matching scheme, where they are given the contact details of a patient who is in a similar situation, who they could phone, or e-mail, or meet and have this one-on-one support as they progress through their disease and their treatment.”

Men don't require the same things as women, she adds. “Men tend not to talk about breast cancer even within their family or with their male friends, while many women will talk to a lot of people.”

She believes that rather than trying to operate within existing breast cancer advocacy groups, or wasting energy trying to convince men to form their own support groups, the way forward may lie in building on the awareness men are already beginning to develop about testicular and prostate cancer. “We need to add breast cancer to that list,” says Iredale. “And we need to be a bit creative about these health promotion strategies. So focus on places where men go, pubs and clubs, men's magazines and link up with activities that men like to do. An understanding of how men try to deal with and adapt to their condition will go a long way to enhance care for male breast cancer.”