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Angelina Jolie and the dilemmas of genetic screening

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The actress Angelina Jolie's announcement in The New York Times this week that she had both her breasts removed, even though they are currently healthy, left some people confused and others grateful. Ms Jolie has a hereditary flaw in her BRCA1 gene, which suppresses tumour growth. Women with such mutations have, on average, a 65 per cent risk of contracting breast cancer. Ms Jolie's doctor estimated her risk at 87 per cent. Such women are also at high risk of ovarian cancer, which killed Ms Jolie's mother at the age of 56. This is a teachable moment. But, since there ought to be nothing surprising about a person's aggressively treating a serious medical condition, it is hard to put one's finger on what exactly is being taught.

Ms Jolie has been praised for "going public" about her problem. It is not clear she had any choice. Various magazines and television shows describe her as the world's sexiest woman. Of course not everyone imputes her sexiness to merely physical attributes. But her having a mastectomy will be thought as inherently newsworthy as, say, David Beckham's rupturing an Achilles tendon on the eve of the football World Cup. Ms Jolie has never shown an inclination to hide her ups and downs from the public. As her husband Brad Pitt told USA Today: "It was really important to her to share the story, and that others would understand it doesn't have to be a scary thing."

But it is scary. Ms Jolie's condition is rare. Only one in every several hundred women has dangerous BRCA1 mutations. A third of those diagnosed choose to have a pre-emptive double mastectomy, as Ms Jolie did. Even more opt for removal of the ovaries and the Fallopian tube, which reduces the chances of breast cancer by 50 per cent. While Ms Jolie's position is unusual, it raises questions of almost universal applicability. In the new era of genetic medicine, advanced cures and ethical quandaries go hand in hand.

Those who test positive for BRCA mutations have some excellent treatment options, including magnetic resonance imaging scans. But such screenings cost thousands of dollars. And most breast cancer has to do with things other than this specific mutation. It disproportionately hits the overweight, smokers, heavy drinkers and childless women, but there is also an element of chance. And campaigners have raised "awareness" of the disease to the point at which the average woman overestimates her chance of contracting it. Who gets screenings for genetic susceptibility will be much fought over. In the US, the Affordable Care Act of 2010 has expanded access to genetic testing somewhat. The Genetic Information Non-discrimination Act, passed during the Bush administration, stipulated that insurance companies could not require gene-testing or use it as an excuse to refuse coverage.

The US Supreme Court will soon rule on a case that asks whether Utah-based Myriad Genetics, which holds a patent on BRCA1 and BRCA2, is entitled to patent genes that occur naturally. Some commentators saw Ms Jolie's urging that more women have access to gene testing, "whatever their means and background", as a swipe against Myriad's position. Others noted that Myriad's stock leapt to a 52-week high in the wake of Ms Jolie's statement.

Some awkward questions arise with new medical technology. Bioethicists have long claimed a distinction between using genetic medicine to cure illnesses, which is all right, and building "better" humans through eugenics, which proved calamitous in the 20th century. The distinction is beginning to break down in the public mind. Consider the solution that a New York Times report suggested this week to the problem of BRCA mutations: "It is also possible for women who are mutation carriers to avoid passing the gene to their children, by undergoing in vitro fertilisation and having embryos screened for BRCA genes. Then, only embryos free of mutations can be implanted."

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Pre-emptive mastectomy does not raise those troubling ambiguities. But it is a procedure in which certain familiar distinctions can blur, including the one between therapeutic surgery and cosmetic surgery. Women have every right to be worried about what their bodies will look like and how they will function after surgery, but it has sometimes been hard to say this, at least in the forthright tones that Ms Jolie has adopted. "There have been many advances in this procedure in the last few years," she wrote, "and the results can be beautiful".

In alerting the world to the ways today's medicine is different from yesterday's, Ms Jolie has become what one columnist calls "the instant figurehead for taking control of your own medical destiny". That is indeed something to be proud of, so long as we remember that people are never in control of their medical destinies to more than a limited extent.

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The name's Bond, James Bond. I'm a programmer

The last king of Wall Street, defending his two crowns

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