PRACTICE

WHAT YOUR PATIENT IS THINKING

I chose reconstruction, but not to “look good”

Stella Duffy flags up problems of concentrating on aesthetics in breast reconstruction surgery. For series information contact Rosamund Snow, patient editor, rsnow@bmj.com

Stella Duffy

I have had breast cancer twice. The first time, when I was 36, I had a wide local excision, followed by chemotherapy and radiotherapy. In 2014, my annual mammogram showed ductal carcinoma in situ in breast tissue left from the original breast conserving surgery in 2000. Since the first cancer I had, naturally, been thinking about the possibility of recurrence. Therefore, it didn't take long for me to agree to a mastectomy and breast reconstruction. My consultant told me that implants tend not to be recommended for patients whose skin has already been irradiated.

Making a choice

I chose a reconstruction for many reasons:

- I have had breasts for almost 40 years, and a two breasted person is how I perceive myself
- I do a lot of work in public. Women's clothes are designed for two breasts and I didn't want to feel self conscious when presenting
- Friends with prostheses say they are uncomfortable and heavy
- I live in a sexualised culture where a woman's breasts are considered a prime signifier of her sex. As a feminist, there is an enormous amount to consider when understanding our relationship to our bodies, but I was eager to have the cancer out of me. I did not take a very long time to choose.

I did not choose a reconstruction because I wanted my breasts to look “good” or “better” but because I wanted to feel like myself and—after having cancer twice—that was important. To feel physically and emotionally like myself, not the disease.

Remember the inside as well as the outside

Yet everything to do with the reconstruction was discussed in terms of how my reconstructed breast looked. Even when the pulse flap was checked every hour for the first 24 hours, I was

told my breast looked good—I did not ask for such comments, but this view was constantly volunteered. I appreciate that it was generously meant, but at the time, in pain, the last thing I wanted was virtual strangers' opinions on how my body looked.

In the run-up to the surgery, despite the competence, compassion, and generosity of the plastics team, at no point did anyone tell me that my breast would feel physically different.

Despite a few complications my scars have healed well, but the breast still feels different—not only the lack of feeling in the flap and the immediate surrounding area, but inside too. I can feel, sometimes with pain, where the piece of rib was removed to remove the mammary aorta. I feel the places where the flap taken from my stomach is attached. The breast pulls from the mid-point of my chest. It feels like something else, it does not feel like a breast.

Language is important

To have been advised that breast reconstruction can result in patients feeling physically different would have been helpful to inform my thinking about my choices. A mastectomy is, in effect, an amputation. A reconstruction is a rebuilding. Language can help us understand how it might be for us. Different language, possibly more brusque, but certainly clearer, would have helped prepare me better.

We live in a society where an inordinate emphasis is placed on appearance, but reconstruction is not merely about appearance. We also, each of us, live in and through our bodies, and to ignore the physical feelings relevant to a reconstruction is to ignore a great part of the process.

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What you need to know

- Remember the inside as well as the outside: tell women about potential changes to physical feeling and appearance after reconstruction
- Rather than saying "It looks great" ask "How does it feel?" Or, if the discussion is about appearance, "how do you think it looks?"
- The road to reconstruction is long. The more often you remind us that several operations will be needed, the more likely we are to take this in before making our choice