

Intimate memoir of a journey to an embodied self

I have always felt I had all the attributes to be described as an attractive, good-looking woman. Nice curly hair, regular features, great passion for life. I was slim and fit; I used to do horse-riding, lots of swimming, jogging... I loved my body and felt at one with it.

When I was diagnosed with cancer, I felt betrayed. I felt my body had let me down and will never look normal again. I got additional kilograms and felt I couldn't control my weight. I had grown to take pride in my hair, I didn't know what to do when the first strands of my hair began to fall out. And then, along with the loss of my breasts, I felt I had completely lost my femininity. I was not sexually attractive anymore, the marker of womanhood, of female sexualisation had been lost. I thought that my body which gave birth to a new life just some years ago, was no longer productive. I have failed- as a wife, and as a mother. I will not be able to experience the quintessential mothering feeling of breastfeeding again; the intimate relationship between my husband and me will never be the same.

I have had many sleepless nights and nightmares about me getting rid of my body, throwing it out of a window, as if it were a thing which is not of use anymore. I felt helpless-I couldn't get a new body, I couldn't go back to my old one and I was unable to accept this disfigured one. I felt I lost my companion, I felt bereft and empty. In a helpless attempt to change the situation, I started a war- my mind over my body. I pretended it wasn't there and cut off communication from it. I was going through periods of anorexia, depression and anxiety. Weird as it may sound, I considered my physical symptoms as a war trophy, as something offering a kind of embodied re-enactment of the drama played out in my mind.

I knew this 'war' wasn't a good strategy but the bodily changes were so radical and came along so suddenly that I just felt overwhelmed, unable to cope with them. Instead of protecting myself through supportive relationships, I started rejecting my husband and people around me. I felt I couldn't give them the full strength of any positive emotions anymore, I felt the disease had killed the quality of my love for them.

My family was desperately trying to help me. They sent me to various specialists, who, understandably, couldn't be aware of all the complexities of cancer and bodily concerns. From one specialist I was referred to another one, desperately searching for a suitable treatment. I couldn't stand any of the group therapies offered within the NHS; I found it disturbing when other people talked about intimate feelings. I also tried the Cognitive Behaviour Therapy (CBT), highly recommended by my GP, but the improvement lasted only a couple of days.

The turning point came when, one evening, my husband tried to touch me and my immediate reaction was to freak out. I went crazy, I shouted at him not to approach me. I couldn't answer my husband's questions-Why was I refusing any physical contact? Was it for fear of shame, embarrassment, guilt ? He still loved me as a whole person, so why was I separating his love and my identity from my physical body ?

There are parts of our experience of which we find it difficult, if not impossible to speak. My emotions were operating out of the realm of words, I felt drained and sad, I was holding back and rejecting people around me. In my hunt for words, I immersed myself in the literature of embodiment and identity-making theories. I became interested in Burkitt's notion of mind and body reunification. Burkitt (1999) in his

endeavour to understand the mechanisms which lead to a formation of body as an object, talks about the mind and body divide in the context of power relations operating in society. He argues that the society's ideological and normative control over the body results in a separation from the embodied self, in a view of body as a 'machine' (or as an object which can be thrown out of a window). There seems to be a powerful Western cultural view which both expects female independence and demands female compliance. The pressure and force to adhere to this prevailing societal trend are especially marked in women whose bodies are visibly different from what is considered a 'norm'. I had never fully recognised how much the relationship between my inner and my outer self depended on the social context. Reading some books by disabled poets, I came across Nancy Mairs who once said: 'It's a double whammy if you're crippled and female'. Like many women, I have always had an uneasy relationship with my body. Culture puts unrealistic expectations on your female body.' (p.2, 2007). Doubts and questions ran through my head: Is it the media, my husband, my friends who are transforming my self- and-body image? Is it the societal pressure to be attractive which is accountable for my behaviour?

Another brainwave came through Kundera's words: 'When we ignore the body, we are more easily victimized by it' (1985, p.39). At home, I was constantly putting a face on, I was worried to let my feelings out. With my parents, my husband and my daughter we were all playing some sort of a silent game, a bit like 'Let's pretend nothing really happened and you still look the same'. I don't blame them for not knowing how to deal with such a sensitive situation-I myself didn't know how to cope with it. But I knew that the ostrich approach we took was not helpful.

I searched for help on the Internet and came across a charity called Changing Faces. Since its inception in 1992, the charity has been developing and providing effective

social support for people with facial or bodily disfigurement. Building on research and their own clinical experience, Changing Faces seemed to be able to provide a comprehensive framework that would address the psychosocial impact of disfigurement as well as an effective care delivery. One morning, I made a telephone call and briefly summarised my situation. The lady on the other end must have guessed how uneasy I felt talking about my feelings and without too much inquiry offered a one-to-one session. I found this single session more effective than any support I had received from other professionals or my relatives. This one session made it clear to me that social support may have many different components-some of which would work better for some people and others for other people.

The specialist I saw at Changing Faces shifted the focus from generic medical support to a very personal and private approach. I don't know whether it was his carefully worded questions, or his sensitive concern that made me feel so comfortable, understood and able to talk about my intimate feelings. I did not worry about speaking of the value that I previously placed on my appearance, I talked about the huge loss I now feel and my daily secret battle. Together, we thought about ways of re-accepting my body and reconnecting with the people I love. His advice was to give myself more time and space to experience the contradictory feelings inside me. When talking about my inability to disclose my emotions, he asked whether I tried to communicate with others through another medium than language. I mentioned how I used to enjoy piano playing but expressing my feelings through music was something I was not sure could work.

On the very night after my first session at Changing Faces, I came home, I sat at the piano and played one of my old favourite songs. I played and cried and then talked and cried in the arms of my husband. As miraculously as it appears, the bottle started to open up and I felt an enormous relief.

The music's transcendence made me self-reflect in some new major ways. Strawson's idea (1963) that our uniqueness comes from the wholeness, the completeness of embodied selves, started to make sense. In art, there is something in-between a precise meaning and metaphor, there is something you can only feel through your body, something revealing the most delicate peculiarities of yourself.

I realised how nicely I fit the 'LeShan's (1966) 'cancer personality' definition with my tendency to undervalue my skills and repress my genuine feelings. Apparently, people who are less likely to acknowledge and express strong feelings and people who suffer from low self-esteem are more prone to developing cancer. I started looking back at my relationships, and realised how I always struggled to express my 'true self'. I started to comprehend more fully how much my emotions depended on the social environment.

I believe that Changing Faces helped me in a very significant way to battle my way through the complex feelings I had during my 'mind and body crisis'. People working for the charity are well aware of the fact that the success of a therapeutic intervention is largely dependent on the individual's unique needs and particular circumstances. The segmented perspective held in mainstream treatment/counselling centres may not afford sufficient help for people with a visible difference. Given the variety of causes, types and degrees of physical disfigurement, it is invaluable to find an effective support technique. I believe the vital feature of Changing Faces is the potential to recognise that each of us has unique circumstances in which we construct our selves. In my case, the initial emotional support I was offered needed to be complemented with some practical problem-solving techniques. I overcame my reluctance to go to group sessions and went again to a CBT one. This time, I found the advice offered by others extremely relevant. As unhelpful as I found them before,

the promises of how group sessions normalise one's experiences and offer role models came through. I experienced first-hand how crucial the right match-up and timing of a particular treatment affects its effectiveness.

Borrowing from Burkitt, I would say that emotions, be them negative or positive, are complex lived experiences. For people with disfigurement, the role of the body in construction of emotions is particularly important. As human beings, we are constituted in various overlapping networks of relations to others as well as within personal relations to the biological world. Such premise intrinsically calls for thinking across epistemologies. The medical model of disfigurement can no longer be viewed in isolation from its social components; health care must be a holistic endeavour. Integrated programmes which will touch upon our everyday experiences could lead to the creation of interdependent embodied selves. In my case, a shift to personal emotional support helped to identify and address my psychological needs. I learned how to use my coping resources to fight against the disease instead of wasting them on shutting down my emotions and isolating myself.

I now wish to aid in wider dissemination of the experience I have had. Our bodies are a place where our biological and social selves meet; we all play an important role in helping ourselves- the people with disfigurements- as well as helping you- our friends, family and people around - to change the way we think about our physical and emotional selves. I wish I could tell everyone with or without a visible difference that no matter how different our physical bodies appear, do not lose the belief in the whole embodied identity which we have evolved through relationships with others and, very importantly, through the relationship with our inner selves. With its mission to provide personal support as well as to share emotions, experiences and knowledge of people with a visible difference, Changing Faces helps those of us who

have been lost in the attempt to reconnect with their embodied selves and is thus
'changing the face' of many lives.

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