

## ***No sex, please - We're disabled!***

by

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I was very excited when I was approached to write an article about women with disabilities and issues of sexuality. I am the founder and proprietor of *BLISS for women*, Australia's only Adult Shop for women (and their partners). The fact that BLISS exists at all can be traced back to the fact that I have a physical disability, and have personally struggled with many of the issues I want to talk about.

Before I begin I would like to offer a very broad definition of what comprises a disability. There are physical and intellectual disabilities of varying degrees of severity, as well as disabling life events such as surgery, accidents and diseases that affect a wide range of people. In addition, many of life's events and experiences can have a disabling effect on sexual response. In this article I will be using some of my own experiences to illustrate this point.

In 1977 I went to see an eye specialist because I had an annoying 'floater' in my field of vision. Imagine my horror when he told me that I also had an incurable, degenerative, genetic eye disease – Retinitis Pigmentosa! I was only 23 years old and only a year into my relationship with the person I eventually married. The effect on my self-image and self-esteem, especially my sexual self-esteem, was devastating. The eye specialist tried to cheer me up by saying that at least I didn't have Huntington's Chorea – at least RP didn't hurt and wouldn't kill me – so straight away I realised that any fears I had about my sexuality would be seen as selfishly trivial. Many women who have been sexually disabled by ill health tell me that their sexual concerns can sometimes be trivialised by their health professionals. They are told that they should be glad to be alive and shouldn't worry about 'all that' or that they should forget sex 'at their age'. This reflects the health worker's hang-ups, but makes the client feel like a deviant or 'weirdo'.

My initial reaction to my diagnosis was to feel ugly and physically imperfect even though my problem was not visible to others. I imagined everyone expecting me to be 'marvellous', to be sitting in a corner weaving baskets (I loathe handicrafts!) – a noble but completely un-sexy blind woman. I had been an active participant in the permissive '70s but feared no one would ever find me desirable again. This might seem paranoid, but only last year I had a blind customer who had just been to Myer where she had asked for a spray of a new perfume. The saleswoman had refused because this was a new, sexy fragrance that wouldn't be suitable for her! Society has difficulty linking disability with sexiness.

When my partner proposed to me I was glad that he had done so *after* the diagnosis because otherwise I would have feared that, given the choice, he would have preferred an able-bodied wife. As it was I still wondered if pity was a motive. Crazy, I also kept thinking that no one would ever want to have an affair with me (not that I wanted one, but I wanted to be desirable).

At the age of 30, and expecting baby number three, I was experiencing the loss of libido often associated with being a new mum. I visited another eye specialist for a check-up. He looked scornfully at my belly and asked, 'How many more babies do you plan to have? I can't guarantee you'll see to raise this one!' I was devastated. His tone was so disapproving that I felt like a freak for being sexually active. I felt that I was irresponsible

doing what other, healthy women could do, that is, having sex and having the family I wanted. Although my vision is limited I have raised all of my children successfully. Those comments were wrong as well as extremely damaging. How carefully health professionals need to consider what they say to people.

When that baby was two years old, I returned to part-time study at University. At first I felt as though I had a neon sign on my head saying 'bored house-wife – deeply uncool and un-sexy'. After a few months, however, my confidence increased but I still carried my baby weight and was resplendent in loud, 80s-style tops and ski-pants! I felt more like 55 years old rather than 35 – socially disabled as well as physically!

There are many natural life events which crop up in the lives of most, otherwise healthy women that can be temporarily disabling for many. The hormonal changes caused by childbirth, breast-feeding and menopause can all negatively affect a woman's libido and sexual self-esteem. Many women feel that behaviour that was acceptable when they were single is inappropriate when they are mothers. Mothers are meant to be like the Holy Mother, not sexy. Also, in a society that bombards us with sexual imagery in advertising, songs, films, TV, magazines and so on there is an astonishing level of ignorance about normal, real sexuality and the things that can disrupt desire. Women feel sexually disabled by new motherhood, or menopause, and their partners also feel that there is something wrong with the woman or the relationship. Often, simply discovering that what you are feeling is normal can help people to survive these times.

Divorce, widowhood and relationship difficulties, all affect people sexually as well as in other ways. Often widows confide in me that they really miss the sexual relationship that they have lost but can't talk about this aspect of their bereavement to their friends. Again, the trivialisation and marginalisation of sex causes people to feel that they must be weird to feel so strongly about what is, in fact, a fundamental part of life.

Finally, people can become sexually disabled as a result of their upbringing and childhood experiences. I was brought up in a fundamentalist Christian family that held very conservative views about sex. I often have customers whose religious upbringing has left them feeling guilty about enjoying sex. Many of them have never had an orgasm. Others tell me about an event that might have occurred 40 years earlier such as being slapped for showing their knickers as a child. Their eyes fill with tears and they say that their whole adult sex life has been inhibited as a result of such an experience. Even more troubled are the women who have been victims of sexual abuse. The disabling effect of abuse can be extremely acute and difficult to overcome, and yet these women are not conventionally 'disabled'.

In 1990, I spent two weeks at the Guide Dogs Centre doing my white-cane training. Although the staff members were marvellous, my self-esteem took another major pounding. Because of limited funding, most disability support organisations have to tailor their programmes to cater to the widest group of clients. This can be seen, for example, in the dearth of specialist texts available in Braille or on tape (particularly erotica); in the kinds of activities offered and so on. Apart from white cane training, we were being taught skills which seemed to suggest that we were all going to be housewives. One day, as I was tapping my way up and down the corridor I suddenly saw myself through the eyes of others – a sinister, creepy figure that people shrink from in horror and embarrassment. Another day I was being taught how to locate a dropped item. As I was on the floor, feeling around with my hands, suddenly I felt degraded and ugly. In a society that places so much store on physical perfection, how much more acute must this feeling that one is not sexually viable be when the disability is more severe?

Traumatic as this time was, it marked a turning point in my life. When I got home I started exercising, eating less and taking better care of my appearance. I was determined to avoid becoming a stereotypical blind person. As I lost weight I bought a new wardrobe that featured a lot of short skirts, black lace, leopard print, high heels and low necklines. I figured that you didn't see many 'tarts' with white canes. Looking back, probably I was a bit over-the-top at that time but it had the desired effect on my sexual self-esteem. Wolf-whistles in the street, compliments from male students and my poor hubby's increasing paranoia fuelled a confidence I hadn't felt in years! I was overcompensating but it was what I needed to do at the time.

In 1994 we moved to Melbourne. I returned to University but I wasn't really enjoying academia any more. I had been on a Blind Pension for years and didn't need to work, but I started to feel very strongly that I wanted to achieve something significant in the world, to use my education, talents and abilities. Being disabled wasn't going to stop me making my mark on the world. One night I was watching a panel discussion on SBS TV on the subject of 'Women and Pornography'. One panellist was a Sydney woman who'd opened a sex shop for women (since closed). It struck me like a bolt of lightning that this was an area in which I felt that I could contribute. My varied experiences equipped me to assist others on their sexual journey.

In addition to my own problems, I had observed the lives of others. Many people I knew had experienced relationship problems that had their roots in sexual dissatisfaction. Society was suffering an unprecedented level of relationship breakdown and stories of abuse were cropping up everywhere. I believed that I could make a positive contribution to society by offering a new approach to marketing books and products relating to sexuality. I decided to open Melbourne's only Adult Shop for women, and their partners.

It took me a year to research the project, to find out what range of stock I wanted and where to get it from, and to find suitable premises. This was complex because I wanted to work out what women would want from a shop like mine. For example, I didn't want racks of pornographic magazines but I did want a specialist bookshop. I wanted to sell products that pamper *all* of the senses and set a sensual mood such as candles, incense, aromatherapy oils etc., and I wanted to cater to *all* women, including those with disabilities.

This last point influenced my choice of premises. I went to the Melbourne City Council to find out what was required when opening a shop like this. No one wanted to commit themselves on what I could and couldn't do, but in the end I was told that I had to find a premises in a basement or upstairs so that I would be less likely to be closed down if anyone complained. I started to look for a shop with a lift, as I was determined to be able to cater to those with limited mobility. I found the ideal place in Flinders Lane with a lift opening right into the shop. However, when word got out about what I was planning to do, all the other tenants signed a petition to the landlord asking to have me refused a lease. Eventually I was forced to take the only other affordable upstairs space available in the City, and I wanted to be in the City because it is accessible from all areas and is convenient for visitors to Melbourne. Unfortunately, it had no disabled access which was a great disappointment to me. Some people who are unaware of these circumstances criticise me for not being serious about assisting the disabled.

To overcome this limitation I have tried to put the word around that I am prepared to come out to hold evening sessions for groups of people with disabilities where I can show them a range of products. I haven't been taken up on that offer yet, but it still stands. I also worked with Achievable Concepts to ensure that vibrators can be modified to suit individuals with limited mobility, as well as irons and can openers. If I ever get to the point

where I can expand, I'll certainly open my next shop on the ground floor. Certainly, many people with disabilities have told me how much they would like to just shop like other people and I'm sorry that this is not possible. I am hoping that my website will assist more people in accessing our services and I would be grateful for any suggestions as to how else I can be of help.

In an attempt to discover how I can be more helpful I have liaised with a number of support organisations, with varying levels of success. Not only do their funding restrictions mean that they can only offer services to the widest range of clients, but there is an added problem when it comes to addressing issues of sexuality. There can be reluctance on the part of these groups to deal with their clients' sexual needs. This stems from a number of sources. Many organisations are church-based and have conservative mores in this area. Many carers tend to unconsciously infantilise their clients and feel very uncomfortable seeing them as sexual adults. Many carers, like most members of society, have their own sexual issues and don't feel equipped to deal with this part of life.

In addition, all carers are restricted by legislation and cannot legally proceed beyond a certain point in this area. I had a call from a health organisation that had an intellectually disabled client who had been penetrating herself with a vacuum cleaner hose. She had given herself an infection but the health professionals were 'legally' restricted from helping her to buy a vibrator. There is a fine line between assisting someone with a disability to access sexual things and sexually abusing them. Judging this line, especially where the client is intellectually disabled, can be virtually impossible. Some individuals are trying to be more proactive in this area, such as the organisers of ACCSEX based at Yooralla, but it is complex and difficult. The challenge is to find the balance between protecting the disabled and allowing them to be fully human.

Every human being is on a sexual life journey. Some people are celibate or are without partners, but they all still have a sexual life. On this journey we can encounter physical, psychological and spiritual experiences that can disable us and our ability to access or enjoy sex. When someone is severely disabled these issues can become much more problematic but that person is still on a sexual journey and deserves to be able to enjoy this aspect of their life. It is important that those who care for them respect them as sexual adults and recognise that this aspect of life is not trivial but is as important as any other when it comes to being fully human.

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