Introduction

In September 2009, BCNA surveyed members of our Review & Survey Group about their experiences of sexuality and sex after breast cancer.

We asked all 850 members of the Review & Survey Group to complete an online survey. We received 240 complete responses, which corresponds to a response rate of 28%.

The purpose of this survey was to gain an understanding of how the experience of breast cancer impacted upon women’s sexuality and sex life from the perspective of single women, women in relationships with men and women in same sex relationships. Unfortunately we only received two responses from lesbian women, so those results have not been included in this report.

We used both quantitative and qualitative questions, so women who responded were able to tell us in their own words about their personal experience. The results have been used to inform a new section in the second edition of BCNA’s My Journey Kit.

Demographics

![Figure 1](image)

Figure 1 shows the age range of women responding to the survey

The majority of women who responded to the survey were younger than the average population of women diagnosed with breast cancer. This may be because younger women are more comfortable talking about issues around sexuality than women in older age groups. When comparing the number of responses from older age groups with the membership of the Review and Survey Group, we can see only a small percentage of these women participated in the survey.

Ninety three percent of women experienced early breast cancer, while seven percent of women told us they had been diagnosed with secondary breast cancer. The majority of women told us they live in metropolitan areas (59%), followed by regional areas (29%) and rural areas (12%). This corresponds with the geographical spread of our broader membership.
Survey Results

We asked women to tell us the extent to which breast cancer affected their sexuality or sex life. **Figure 2** shows responses from single women and women in relationships.

![Figure 2](chart.png)

**Figure 2** compares the experience of single women and women in a relationship.

Women in relationships were more likely to report a more significant impact on their sexuality than single women. Interestingly while the majority of women told us that breast cancer affected their sexuality and sex life “somewhat”, women’s qualitative responses indicated that the real impact on women may be greater than this.

*After my mastectomy I was at first very conscious of appearing naked before my husband. Once I realised it made no difference to him, I felt more confident, but it has taken a while – Ann*

*The treatment made me feel disfigured (mastectomy) even in clothes I felt so uncomfortable and unfeminine as I couldn’t comfortably wear many of my tops or dresses any more. I also became so ill and tired with chemo and hormone therapy, a sexual relationship was physically impossible - Sarah*

**The challenges women faced**

We asked women to tell us what, if any, physical changes to their bodies affected their sexuality or sex life.

As shown in **Figure 3** many women, particularly women in a relationship, reported they did not experience any physical challenges (24%). The most common physical challenges women experienced were pain in the upper body or arm (20%), weight gain (15%) and vaginal dryness (12%). Women were able to select more than one option which many of our respondents did, showing that many women experience multiple physical challenges.
The physical issues experienced by women

![Bar chart showing physical issues experienced by women]

Figure 3 highlights the key physical challenges that women experienced (Multiple responses allowed. Total number of response = 679)

*I had a tram flap reconstruction, so have sustained a scar across my whole stomach and unwanted love handles from the surgery. Unfortunately I am stuck with them - Marilyn*

We also asked women to tell us about the emotional challenges that affected their sexuality or sex life. Figure 4 shows us the types of emotional challenges women experienced.

The most common were lack of interest in sex (17%), not feeling attractive (13%) and feeling uncomfortable exposing body (12%). Once again women were able to select multiple options and many did, showing a similar trend of women experiencing multiple emotional challenges.

*Feeling very unattractive and also very tired didn’t help in those early days after my diagnosis. Just getting through a day was a battle enough - Louise*
The emotional issues that affected women’s sexuality and sex life. (Multiple responses allowed. Total number of responses = 829)

Seeking support

More than 50% of women told us they hadn’t spoken to anyone about the issues with sexuality or their sex life they were experiencing.

The small number of single women who had discussed the issues they were experiencing told us they were most likely to speak to a nurse; however it is important to note that the number is relatively small. Women in relationships told us they had spoken to their partner/husband (77%) and their GP or doctor (29%). Very few women sought help for issues relating to their sexuality from a counsellor or therapist (13%).
We asked single women and women in relationships some specific questions about sexuality and breast cancer. Below is a summary of these questions.

**Single women**

Despite reporting many concerns, around 50% of single women started a new sexual relationship after their breast cancer diagnosis. Once again, the number of women responding to this question was relatively small. Many single women were concerned about revealing their cancer experience. For these women, the emotional impact on sexuality was significant.

> It felt weird. I couldn’t believe some one would be interested in me knowing I was going to commence chemo and lose all my hair. It gave me a confidence boost. Wilma

> I stopped dating or even thinking of trying to find a companion. So I stopped going out to any social functions. Carmel

Single women also provided advice to other single women thinking about starting a new sexual relationship after a breast cancer diagnosis.

> Don’t be afraid! With a caring person, you will be appreciated for who you are. Body changes will not matter. Tess

Common suggestions from women included:

- Be yourself
- Be honest
- Sexuality is more than a woman’s breasts
- Ask for advice from people who have been there or health professionals
- Talk about your sexual needs
- Take time out for yourself
- Do things that make you feel good about yourself

> Keep making the effort to dress well. Put on makeup and wear great shoes. Look at yourself in the mirror and say to yourself, “I look great”. Get lots of exercise and go to the beautician if you can afford that. If not, give yourself a pedicure (or whatever you like)… Carmel

**Women in a relationship**

We asked women in a relationship to tell us about their partner’s response to the changes in their body. For many women, their relationship changed dramatically. Women reported changes from partners feeling uncomfortable touching their breasts, breakdown of their relationship, while other women told us their partners were supportive and some women told us their breast cancer diagnosis strengthened the relationship.

> Totally negative! He only had to take one look at my mastectomy scar and refuses to try and get used to it. He constantly dropped hints that I should always wear makeup and a wig at home (I did wear them when I went out). He always nagged me about my weight and still does. Chris
He seemed ok at first but after 25 years of marriage he left for another woman. I can’t say breast cancer directly caused this but it was a huge impact on our relationship. Lyn

However, many women also told us that the relationship was strengthened and that they felt totally supported by their partner or husband. Several women told us their partner made them feel secure and loved.

He was totally supportive throughout. It really made me realise that he loves me and is turned on by me regardless of having one or two breasts. He touched my scars gently and lovingly and that helped me to embrace them as part of the new me. Jennifer.

My husband was totally supportive and kind and caring and never once made me feel unattractive. He was always encouraging and telling me how beautiful I am to him… Denise

We also asked women in relationships to tell us about their partner’s response to their libido and feelings about sex. Many women reported that their partner or husband did not understand the emotional aspects of sexuality, and they felt frustrated and rejected.

He would get angry that I wasn’t interested in sex and the fact that he couldn’t look at my scar made my libido even less. I eventually couldn’t stand him touching me. I felt like sex was just to gratify him but there was no feeling in it. Donna.

My husband wishes my libido was normal! He tries to understand, however sometimes gets frustrated with me. Rebecca

Women in relationships also told us about adjustments they made that improved their sex lives:

- Lubricants
- Massage
- Different positions
- Oral sex
- Vibrator or masturbation
- Creating an environment to help “getting in the mood”
- Believe in yourself

Sometimes I like to keep my bra on to feel a little prettier. Loosing my breasts has helped our sex life in some ways; we have learned to explore all different parts of our bodies instead of focusing on one particular area. Using lubricants as a matter of routine also helps because it just becomes something that you do, instead of a sign of ‘failure’ of your body. Deborah

We keep communication open and discussed what did work and what didn’t. We tried new positions that were easier for me with my sore arm and chest. We started using lubricating gel (which helped with the dry vagina but stings) and we bought a vibrator. My husband was a lot more patient and slow in our foreplay and lovemaking. Denise

Common suggestions for women newly diagnosed from women in relationships on how to deal with issues relating to their sexuality and sex life included:
• Seek help from professionals
• Talk to your partner and be open
• Spend quality time with your partner
• Encourage your partner to seek help
• Be creative and aware of your partner’s needs
• Recognise the importance of the sexuality part of your journey
• Have faith that your body will respond

*Discuss your breast cancer and the changes affecting you, as openly as possible with your partner. If this is too difficult, seek help from professionals. Remember that even cuddling is part of your sexuality and can make both partners feel wanted. Anne*

**Products and resources recommended by women**

![Resources or products women used](chart)

Figure 7 shows the products or resources that women have used to assist reconnecting with their sexuality and sex life.

Women told us about the types of products and resources that they have used, with the majority of women using lubricants (58%) and vibrators or sex aids (12%). Women told us about a range of specific items that other women might find useful.

*Sylk is a personal lubricant made from the kiwi fruit vine and other plant extracts that I've been using for sometime... I like it because it's made from plants and does not smell of anything weird. Sally*

Other women went along to workshops or joined online forums which enabled them to speak to other women about issues they were experiencing.

*I am a member of an online forum which has enabled me to read of other women’s experiences with their sexuality and their limitations in that area since having breast cancer. This has also helped me to see that it’s not my fault that I feel the way that I do, and my reservations about sex and intimacy are experienced by many women diagnosed with breast cancer. Kerri-Ann*
Conclusion

Changes in attitudes towards sexuality and sex can be significant issues for women who have experienced breast cancer. Women reported a variety of experiences with sexuality and sex, whether they are single or in a relationship. Providing support to women and their partners about issues related to sexuality and sex may assist them to maintain strong and understanding relationships. The responses to our survey have contributed to the development of a section on sexuality in the updated version of BCNA’s *My Journey Kit*.

In addition the March edition of our *Beacon* magazine is focused on sexuality. We received a strong response from women sharing their stories and experiences of sexuality after breast cancer, highlighting how significant an issue this is for women. The stories combined with our survey results have also demonstrated the lack of information and support available to women around sexuality. For this reason BCNA will continue to work on this issue throughout 2010, with a view to improving outcomes for women. We will provide updates on our work via our website, and through our *Beacon* magazine.

*Last updated 1 March, 2010*