

Starting the conversation: supporting sexual wellbeing for women with breast cancer

Introduction

This resource is designed to support health professionals to initiate discussions on sexual wellbeing with women and their partners following a diagnosis and treatment of breast cancer. It includes information for women and health professionals, and a summary of interventions for common symptoms relating to sexual wellbeing.

Health professionals have a responsibility to raise the topic of sexual wellbeing as part of routine health assessment, with the aims of initiating discussion, responding to general questions, directing women to further information in response to their needs, and referring women to specialist services as required.

KEY POINT

Health professionals should initiate discussions on changes to sexual wellbeing with all women diagnosed with breast cancer, providing appropriate advice and intervention as required.

What is sexual wellbeing?

Sexual wellbeing is an important element of quality of life, relating to more than sexuality and sexual function. Breast cancer and its treatments can have significant impact on a woman's sexual wellbeing, her sexuality and intimacy. Sexual wellbeing may have a number of different meanings for an individual, and is influenced by many factors apart from a diagnosis of cancer and treatment. These may include body image, cultural and religious beliefs, age or life stage, menopausal status, health and comorbidities, sexual orientation, and nature of sexual or intimate relationships. Sexual wellbeing may also be influenced by a woman's partner and any issues he or she may experience. Sexual wellbeing may be a concern for women of all ages, and for women in a relationship with a male or female partner, or women without a partner. A woman's sexual concerns should not be limited to treatment of physical symptoms, and should be considered in a broader context.

KEY POINT

Sexual wellbeing may have a number of different meanings to different women. A sense of an individual's meanings of sexual wellbeing should be sought to support fully addressing their concerns.

Sexual wellbeing and breast cancer

A woman's sexual wellbeing after breast cancer will be influenced by her sexual wellbeing prior to diagnosis, in addition to changes that occur as a result of the treatment of breast cancer. These changes may include psychological and physical side effects of surgical and medical treatment and associated changes in hormonal levels. Many women experience an acute menopause, or if post-menopausal a further reduction in hormonal activity, which may further impact on sexual wellbeing.



New concerns about sexual wellbeing, or concerns about pre-existing issues may arise at any stage throughout a woman's experience of breast cancer. Research shows that when compared to healthy women of similar age, women with breast cancer experience lower levels of sexual satisfaction, and have more difficulty maintaining their sexual life¹. Women with breast cancer often report disturbances to sexual wellbeing² including pain, fatigue, decreased vaginal lubrication, decreased sexual interest or desire, decreased sexual arousal and difficulty achieving orgasm¹. These changes can result in distress or relationship difficulties¹, and can therefore influence women's psychological wellbeing. Women may also experience issues other than physical symptoms, such as body image concerns, changed priorities within or external to their relationship, or psychosocial distress including fear, grief and loss, anxiety and depression.

Treatments for common symptoms are suggested in **Table 1** on page 7.

KEY POINT

Following a diagnosis of breast cancer, women of any age and who are single or in a relationship may experience a range of issues, both physical and psychological, relating to their sexual wellbeing.



Partner concerns

Partners play an important role in offering support to a woman with breast cancer, however they may experience concerns regarding how the treatments may affect them or the ways they interact with their partner. Women may be anxious about their partner's response to their diagnosis or treatment. Health professionals can encourage communication between partners, and note that partners may benefit from seeking individual support.

It is important that women in a same-sex relationship feel their sexuality is respected when discussing how their sexual wellbeing is affected by their diagnosis and treatment for breast cancer.

MENOPAUSE

This resource provides some information on management for common symptoms associated with sexual wellbeing, including symptoms associated with menopause.

Women may also like to access *Breast cancer and early menopause: a guide for younger women*, available from **Cancer Australia**: www.canceraustralia.gov.au.

FERTILITY

Although important, issues regarding fertility such as contraception or fertility preservation are not covered in this resource. For further information, women may find it helpful to access *Fertility-related choices: a decision aid for younger women with early breast cancer*, available from **Cancer Council Australia**. For referrals to fertility specialists, the **Fertility Society of Australia** lists accredited fertility units at www.fertilitysociety.com.au/patients-information/

SUPPORT

The **Cancer Council Helpline** offers support to partners of people with cancer: **13 11 20**.

A male partner may find it helpful to contact **MensLine Australia**, a telephone support, information and referral service: phone **1300 78 99 78** or visit www.mensline.org.au.

Cancer Australia has developed audio CD resources to support men when their partner has breast cancer. When the woman you love has breast cancer is available from Cancer Australia: www.canceraustralia.gov.au.



Starting the conversation

Discussions about sexual wellbeing after breast cancer should be held in the context of awareness of a woman's overall sexual health and history. Health professionals should be aware of any assumptions they may make about a woman's age, culture, relationships and overall health.

Conversations about sexual wellbeing may be confronting for women, particularly when they already feel vulnerable. Some health professionals may find it challenging to initiate a conversation on issues of sexuality. The following tips and examples may help to start a conversation.

Introduce the topic and assess readiness for a discussion:

- ▶ Acknowledge that breast cancer and its treatments affect sexual wellbeing, and that the extent varies among women.
- ▶ Consider that some women view their sexual wellbeing as private and may not want to discuss their concerns; providing access to information may be sufficient for these women.

'Many women diagnosed with breast cancer find that it affects their confidence in a relationship or their interest in sex, but they may feel it is difficult to talk about. Is this something you would like to talk about? Would you like some information about this?'

Support a woman to discuss her feelings:

- ▶ Provide permission for a woman to discuss her sexual feelings and validate her experiences and concerns, noting that some women may feel guilt or embarrassment that they view their sexual wellbeing as a concern.

'Many women find that treatment for breast cancer changes their interest in sex and intimate relationships – this is more common than you may think, and it can have a big impact on your life.'



Support a woman to identify her sexual wellbeing concerns:

- ▶ Support a woman to explore and prioritise her own sexual wellbeing concerns, noting that these may not be limited to physical symptoms.

'Many women experience side effects of treatments that impact relationships or sexual activities, such as loss of desire or pain. Do you feel like these or other symptoms are affecting your sex life or relationship? What do you (and your partner) find most concerning?'

KEY POINTS

- ▶ Provide permission for the woman to consider and discuss her sexual feelings and concerns
- ▶ Provide tailored information and support the woman to identify methods for her and her partner to deal with particular feelings or side effects of treatment
- ▶ A conversation about issues relating to sexuality may need to be initiated on different occasions dependent on the woman's needs



Support a woman to consider her expectations regarding her sexual wellbeing:

- ▶ The changes to sexual wellbeing experienced may or may not be acceptable for a woman and her partner. Health professionals can encourage a woman and her partner to consider the ways in which they express sexuality and intimacy, and if they can explore alternative practices.

'Considering your symptoms, what would you (and your partner) consider an ideal outcome to be? How would you (and your partner) feel if you couldn't achieve this?'

Provide information about what to expect:

- ▶ Women should be aware that their sexual wellbeing concerns and priorities may change along the continuum of care associated with their treatment, their relationship with a partner, or their perception of themselves.
- ▶ Let the woman know that you are available to discuss sexual wellbeing at any stage and reinforce that their concerns are valid:

'You may not feel like thinking about or discussing your sexual wellbeing now, but you can always ask any questions you or your partner may have at any time in the future.'

SUPPORT

If the impact of symptoms remains a significant concern, consider referral to a local sexual health centre. See the **Sexual Health & Family Planning Australia** website for links to state-based organisations: www.shfpa.org.au. Access to psychosexual counselling is available for women and their partners through the **Cancer Council Helpline 13 11 20**.

FURTHER INFORMATION FOR WOMEN

- ▶ Breast Cancer Network Australia Breast Cancer and Sexual Wellbeing. An information booklet to support women to manage their sexual wellbeing issues. <http://www.bcna.org.au/living-breast-cancer/sexual-wellbeing>
- ▶ National Breast Cancer Foundation, Cancer Council NSW and University of Western Sydney Sexuality, Intimacy & Cancer: a self-help guide for people with cancer and their partner. www.uws.edu.au/cancerandsexuality
- ▶ Sexual Health Australia Cancer & Sexuality. Discusses the impact of cancer on sexuality and provides tips for women and their partners. <http://www.sexualhealthaustralia.com.au/page/cancersexuality>
- ▶ Cancer Council Helpline - **13 11 20**. Free, confidential telephone information and support service run by Cancer Councils in each state and territory. See also Cancer Councils in your state or territory for printed information on sexuality and cancer
- ▶ Breast cancer and early menopause: a guide for younger women, available from Cancer Australia: www.canceraustralia.gov.au
- ▶ Jean Hailes for Women's Health provides information on early menopause and fertility <http://www.earlymenopause.org.au/>
- ▶ Look Good...Feel Better is a free national service supporting cancer patients to manage changes to their appearance during treatment for cancer: www.lgfb.org.au



Beyond a discussion: Support and interventions

Women with concerns relating to sexual wellbeing can be encouraged to adopt healthy lifestyle modifications such as diet and exercise to enhance and improve quality of life. Other behaviour modifications that may provide benefit include scheduling time for sexual activities around the time when a woman feels most relaxed and free of disruptions.

Communication between partners is important to improving sexual wellbeing – encourage open communication with their partner, and promote sharing feelings and concerns about their situation.

Interventions for particular symptoms are suggested in **Table 1**, and further information and referrals are provided below.



FURTHER INFORMATION FOR HEALTH PROFESSIONALS

- ▶ Family Planning clinics provide contraception and fertility advice, sexual health checks and information, counselling services. Sexual Health and Family Planning Australia provides links to state organisations: www.shfpa.org.au
- ▶ Relationships Australia provide relationship support for individuals, families and communities: www.relationships.org.au
- ▶ Sexual Health Australia provides sex therapy and relationships counselling to individuals and couples experiencing sexual problems, intimacy issues or relationship difficulties: www.sexualhealthaustralia.com.au
- ▶ Many large hospitals hold menopause clinics regularly, providing access to services including gynaecology, endocrinology and psychological support. The Australasian Menopause Society lists health professionals with a special interest in menopause: www.menopause.org.au/find-an-ams-doctor
- ▶ National Lymphoedema Practitioners Register (NLPR) includes a national register of lymphoedema practitioners in Australia and New Zealand <http://nlpr.asn.au/>
- ▶ Local Women's Health Centres provide a range of medical and clinical services including counselling, health promotion and education and consumer advocacy
- ▶ Referrals to clinical psychology services should be considered through existing referral processes
- ▶ Local sexual assault support services may need to be engaged for women who have experienced sexual trauma
- ▶ ASSERT National is an organisation supporting and educating health professionals working in the area of sexual health: www.assertnational.org.au
- ▶ Cancer Council Helpline – **13 11 20**. Staffed by oncology nurses who can assist with searching for, local services specialising in sexual wellbeing, and support health professionals in discussing sexual wellbeing with patients and their partners.
- ▶ *Practical clinical guidelines for assessing and managing menopausal symptoms after breast cancer*
M. Hickey, C. Saunders, A. Partridge, N. Santoro, H. Joffe, & V. Stearns, *Annals of Oncology* 19: 1669–1680, 2008



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Table 1: Interventions for common symptoms

Symptom	Management options
Vaginal dryness and dyspareunia	<ul style="list-style-type: none"> ▶ Encourage increased communication and support with their partner – consider personal, relationship or sexual health counselling ▶ Encourage exploring non-penetrative sexual practices ▶ Improving self-esteem and body image^{3,4} ▶ Pelvic floor muscle relaxation for pain due to hypertonicity³ ▶ Discuss with medical oncologist if a change in adjuvant hormonal therapy may help ▶ Vaginal lubricants or a vaginal moisturising gel³ ▶ Vaginal oestrogen treatment when no contraindications are present – prescribe only in consultation with the medical oncologist/ specialist team <p>Assessment by a gynaecologist may be required if dryness or dyspareunia is not resolved</p>
Low sexual desire and libido	<ul style="list-style-type: none"> ▶ Encourage assessment of what has changed or missing, how satisfied woman (and her partner) is with the current sexual situation and any distress associated with these changes ▶ Suggest woman considers how she wishes to re-establish how she expresses her sexuality ▶ Suggest woman and her partner allocate time for sexuality and intimacy
Sexual arousal/ orgasmic problems	<ul style="list-style-type: none"> ▶ Encourage a focus on intimacy, such as hugging, massage or non-genital touch ▶ Personal/relationship counselling may support increased understanding of woman’s needs ▶ Increased intensity and duration of genital stimulation may be required for arousal and orgasm. Sexual aids, such as vibrators, can be beneficial³
Low self-esteem and body image	<ul style="list-style-type: none"> ▶ Encourage the woman to participate in regular physical activity ▶ Encourage the woman to explore her changed body alone before engaging with a partner, and to focus on aspects of self or body that are positive ▶ Encourage open communication with their partner ▶ Sexual/relationship counselling may improve the quality of intimacy and preserve communication ▶ Personal counselling may improve self-confidence
Hot flushes	<ul style="list-style-type: none"> ▶ Hormonal treatments: Due to the potential risk of hormonal treatments after breast cancer, these should only be prescribed in consultations with the specialist team. Oestrogen and progestational agents reduce hot flushes however increase the risk of breast cancer recurrence. ▶ Selective serotonin reuptake inhibitors (SSRIs) and Serotonin and norepinephrine reuptake inhibitors (SNRIs) reduce the severity and frequency of hot flushes however may interact with tamoxifen⁹ ▶ Gabapentin reduces the frequency and severity of hot flushes⁹ ▶ Clonidine reduces hot flushes, however has significant side effects which may outweigh any benefit⁹ ▶ Behaviour modification to avoid triggers including hot beverages, spicy foods, caffeine, layering clothing, keeping core body temperature low may decrease the frequency of hot flushes.^{5,6} ▶ Stress management, relaxation training, cognitive behaviour therapy⁷ ▶ Reduce alcohol intake and increase physical activity, maintain healthy weight, and avoid smoking⁸ <p>Note that some complementary treatments for the treatment of menopausal symptoms may contain compounds contraindicated after breast cancer – confirm that the woman is only taking treatments checked by a health professional who is aware of her history of breast cancer</p> <p>Women seeking further information on managing menopausal symptoms after breast cancer may like to review Breast cancer and early menopause, available to order or download from Cancer Australia: www.canceraustralia.gov.au</p>



Symptom	Management options
Fatigue ¹⁰	<ul style="list-style-type: none"> ▶ Encourage the woman to use the best part of their day, when they have more energy, less pain, etc. ▶ Physical exercise has been shown to have a positive influence on fatigue and quality of life ▶ Encourage the woman (and her partner) to set realistic goals/expectations
Mobility challenges/pain due to surgical scars/lymphoedema ³	<ul style="list-style-type: none"> ▶ Consider use of cushioning or supports ▶ Consider different sexual positions to alleviate pain; encourage talking with partner prior to sexual activity and agreeing to say if pain is felt. ▶ If the look of scars are a concern, consider clothing, lighting etc, talking about concerns with partner ▶ Consider use of analgesics prior to sexual activity
Loss of feeling/ Hyperesthesia	<ul style="list-style-type: none"> ▶ Encourage exploration of new feelings/sensations in different parts of the body
Anxiety/ Depression ¹¹	<ul style="list-style-type: none"> ▶ Management is similar to that of non-breast cancer survivors, although additional cancer related issues such as body image or fear of cancer recurrence may need to be addressed. Some anti-depressants may interact with breast cancer treatments such as tamoxifen
Changed priorities	<ul style="list-style-type: none"> ▶ Validate that it is healthy to explore changed priorities ▶ Encourage open communication with their partner regarding priorities and expectations – negotiation may be required between the woman and her partner ▶ Encourage woman (and her partner) to set aside time for sexuality and intimacy

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