

Sexuality, Intimacy and Cancer



A Self-Help Guide for People with Cancer and their Partner

Acknowledgements

This self-help guide draws substantially on the booklet *Sexuality, Intimacy and Cancer: a guide for people with cancer, their families and friends*, published by Cancer Council New South Wales (2009) – ISBN 978-1-921619-01-4.

It also draws on research into experiences of sexuality and intimacy following cancer conducted at the University of Western Sydney, Gender, Culture and Health Research: PsyHealth, funded by an Australian Research Council Linkage grant, in conjunction with Cancer Council New South Wales, the National Breast Cancer Foundation, and Westmead Hospital. The contributors at University of Western Sydney were: Professor Jane Ussher, Associate Professor Janette Perz, Dr Emilee Gilbert, Dr WK Tim Wong, and Ms Janet Marie. In addition, reviewers included: Ms Kim Hobbs, Westmead Hospital; Dr Katharine Hodgkinson, HeadWay Health Clinical Psychology Services; Dr Gerard Wain, Dept Gynaecological Oncology, Westmead Hospital; Dr Kendra Sundquist, Cancer Council NSW.

We also thank the reviewers of the Cancer Council booklet: Dr Lisbeth Lane, Psycho-oncology, Wollongong Hospital; Margot Beach, consumer; Phillip Gray, Cancer Voices NSW; Narelle Hanly, Prostate Cancer Clinical Nurse Consultant, Urology Department, Concord Hospital; Elisabeth Kochman, Cancer Voices NSW and Cancer Connect volunteer; Dr Michael Lowy, Sexual Health Physician, Sydney Men's Health and St Vincent's Prostate Cancer Centre; Siri May, Lesbian and Same Sex Attracted Women's Health Project Coordinator, ACON; Brett McCann, CEO, Impotence Australia; Catherine McGrath, Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney; David Sandoe OAM, National Deputy Chairman, Prostate Cancer Foundation of Australia and Co-Leader of the Sydney Adventist Hospital Prostate Cancer Support Group; Pam Sandoe OAM, Co-Leader of the Sydney Adventist Hospital Prostate Cancer Support Group; Dr Kendra Sundquist, Manager, Supportive Care Development Unit, Cancer Council NSW; Ben Tart, Campaign Coordinator, ACON; Susanna Wells, consumer; and Dr Lesley Yee, Sexual Health Physician. Editor: Vivienne O'Callaghan. Cartoonist: Greg Smith.

Note to reader

Always consult your doctor before beginning any health treatment. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your doctor's or health professional's advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication.

Introduction

This booklet is for people diagnosed with cancer or recovering from it, as well as their partners*. It will help you understand more about changes to sexuality and intimacy that may occur because of cancer and its treatment. We will also offer suggestions of strategies you might like to try to deal with the changes.

Treatment for cancer such as surgery, chemotherapy, radiotherapy and hormone therapy can affect your sexuality. This includes your interest in sex, your ability to give or receive sexual or intimate pleasure, how you see yourself and how you think others see you. Some of these effects are temporary while others are permanent. There are many ways to manage these effects.

This booklet aims to help you understand and address the emotional and physical impact of cancer on your sexuality. The information is relevant to all people affected by cancer, regardless of sexual preference or relationship status – your partner may be a man or a woman, or you may currently not be in a relationship.

This booklet does not need to be read from cover to cover – just read the sections that are relevant to you.

Some medical terms that may be unfamiliar are explained in the glossary.

If you're reading this booklet for someone who doesn't understand English, you can contact the Cancer Council Helpline on 13 11 20 for services available in different languages.

** In this booklet, the term 'partner' means husband, wife, boyfriend, girlfriend, or same-sex partner.*

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What is sexuality and intimacy?

For many people, sexuality and intimacy are major parts of their lives. Sexual intimacy isn't just about sexual intercourse. It is about who you are, how you feel about yourself, how you express yourself sexually and your sexual feelings for others.

The role of sexual intimacy in your life may depend upon your age, social situation, health, relationships, culture, beliefs, opportunities and interest.

Sexuality is expressed in many ways: the clothes you wear, the way you groom yourself, the way you move, the way you have sex and with whom you have sex. We are all sexual beings; having cancer, or whether or not we have a partner, doesn't change that.

Intimacy means being physically and emotionally close to someone else. It is about loving and being loved; it is about being cared for and showing concern for someone else. Intimacy is also expressed in different ways: by talking and listening on a personal level, by sharing a special place or a meaningful experience, or through physical affection.

Many of us have concerns and worries about our bodies and sexual functioning at different times in our lives, and cancer may raise some new concerns. A number of physical and emotional changes associated with the cancer can affect our expression of sexuality and intimacy. The impact of these changes depends on many factors, such as treatment and side effects, the way you and your partner communicate, and your self-confidence. Addressing these changes early on may help you and your partner adjust more easily.

Is intimacy different to sexuality?

For most couples, intimacy is a major part of their shared lives. However, intimacy doesn't have to lead to sex. Enjoying time alone together, kissing, cuddling, caressing and talking are other ways of being intimate and showing love. Sharing intimacy allows people to feel valued. Intimacy is important because it allows people to feel emotionally close and share their feelings and experiences.

Intimacy is also important for people who aren't engaging in sexual activity. Non-sexual touch through holding hands, hugging or massage can be valuable for people's well-being, offering them comfort, reassurance and a connection to others. Intimacy can help make the experience of cancer more manageable, and can assist your recovery.

"When he got sick I remember cuddling him all night. He could lie there and touch my hand or my leg and talk to me. It's very important."

"I'll put my legs up on his lap and he'll put his arms around me. It's wonderful."

"We've become more intimate on other non-sexual levels. Cancer has opened up a whole lot of things quite surprisingly."



How cancer can affect your sexuality

When you are first diagnosed with cancer, it's natural to focus on getting well. You may not think about or be interested in sex or intimacy for a while. However, some time during or after treatment, you may start to think about the impact of cancer on your sexuality. Changes to your emotions, changes to your relationship, and changes to your body can all have an impact on this area of your recovery.

Changes to your emotions

Dealing with a cancer diagnosis, its treatment and other challenges can make you feel like you're on an emotional roller-coaster. You may feel a whole range of different emotions in response to your diagnosis and these may fluctuate over your recovery. You may also feel less confident about who you are and what you can do, particularly if your body has changed physically.

These negative emotions can affect your sexuality and your attitude towards intimacy. It can be helpful to acknowledge the different emotions you feel so you can try to address them as soon as possible if they are affecting your day-to-day life.

It will help to talk about how you feel with your partner, other people who have had cancer, or a professional you feel comfortable with, such as your doctor, a cancer nurse coordinator or a counsellor. See page 56 for information on support services.



Common emotions you may feel include:

- **Anger:** It's normal to feel angry about having cancer and how it may have affected your sexuality or fertility (ability to have children).
- **Anxiety:** The thought of being sexually intimate again after treatment can cause anxiety. You may be unsure of how you'll perform sexually, fear being touched, or be self-conscious about being seen naked. If you're single, you may feel anxious about when to tell someone about the cancer and getting involved in a new relationship. Worrying that you're not satisfying your partner sexually may also be a concern.
- **Fear:** You may worry that others will avoid or reject you when they see how your body has changed. You may not be able to imagine yourself in a sexual situation again. You may worry that sex will now hurt.
- **Depression:** It is common to feel down at various times during or after cancer treatment. You may have trouble sleeping, lose interest in activities you previously enjoyed, have no appetite, or lose your sexual desire. If you find you are feeling down day after day and that it is hard to pick yourself up, it is important to tell your GP or treating team as there are many treatments that can help.
- **Guilt:** Some people wonder if past sexual activity has contributed to their cancer. Cancer itself is not sexually transmitted, but a few cancers may be linked to a sexually transmitted infection. For example, human papillomavirus (HPV) is linked to cervical, throat and anal cancers.
- **Self-consciousness:** If your body has changed physically after treatment, you may feel very uncomfortable about these changes and self-conscious. People in relationships often discover that their partner isn't as concerned about these changes as they are, and communicating with partners about this is important.
- **Shame:** You may feel ashamed by changes that affect your sexuality, your appearance or the way your body functions. You might feel less of a man or a woman.

Call the Cancer Council Helpline on 13 11 20 to talk to someone neutral about your feelings or to order a free copy of the booklet Emotions and Cancer.

For more information on depression and tips for dealing with it, contact the Black Dog Institute on (02) 9382 4523 or Beyond Blue on 1300 224 636.

"I sailed through the diagnosis and treatment phase until I went into remission. Then the emotions hit me - and they really hit me."

"We had a very strong physical relationship up until the cancer was discovered and after it, it just faded away."

"Each day felt like a struggle. Sex was the last thing on my mind at the time. Losing that intimacy made me feel worse, so it was a vicious cycle."



Changes to your relationship

Cancer can place huge stresses on couples, even those that may have been happy together for many years. The demands of treatment and recovery may affect your relationship with your partner and change the expression of intimacy within your relationship. Your partner may be helping you with medications or providing other forms of care such as bathing. They may be taking on more responsibilities in the home. This can alter your pattern of relating, and make it difficult to be intimate in the ways you are used to.

You may be too tired to do the things you usually do together as a couple - it may seem as if there is no time left for intimacy any more. Many couples say that they really want to talk with each other about their feelings, but are afraid of upsetting each other. This can leave you both feeling isolated and unsupported at a time when you really need support. Many people miss the life they had before cancer, or wish that cancer hadn't interfered with their intimate relationship.

"I would love to go back to how our married life used to be."

"The changes seemed devastating because we had always been very sexual, touching each other a lot and kissing a lot...as the cancer progressed even cuddles seemed to reduce in frequency. I felt 'lost' and then guilty at times because I still had all the desires and feelings"

Some people can feel rejected if there is a big change in their sexual relationship. A lack of fulfilment in relation to sex is another common feeling:

"I felt excluded and unwanted. Sex became a chore and mechanical";

"On the infrequent occasions we now have sex she wants it over and done with as quickly as possible"

Cancer can also bring some couples closer to each other, as they feel like they have undergone a major life event together. Some couples find that they can share a new level of intimacy after cancer.

"He knows how to make me feel special and he hasn't lost that. We can talk about absolutely anything now."

"The cancer brought us so much closer. It's just purely understanding and respect for each other."

All couples need to put extra effort into their relationship at various times. You may be able to think back to another time in your lives when you both needed to try a bit harder. It may have been after children were born, or when one of you were working away or had a particularly tiring job. See if any of the following ideas can help:

- ✓ Show your appreciation to each other for the everyday things you do – verbal recognition can be really meaningful.
- ✓ Try to find time to do activities you enjoy together – think about what you used to enjoy doing together and whether you can work out a way of enjoying that again.
- ✓ Talk to your partner about how you feel about any changes to your relationship. Choose your time carefully: ask them how they are going and really listen to what they say – don't dismiss their feelings or rush in trying to "fix" it. Even if you are concerned about what is going on, your partner may understand. It is always important to let your partner know what they are doing that is helpful so they can do more of it!
- ✓ Relive your favourite memories of special times by looking at photos together.

Showing Your Love

"Having breast cancer has given me the chance to redefine what and who is important... I never leave the house without telling her 'I love you'."

There are lots of ways you can show your partner that they are loved and important to you. Some ideas can be found below.

- Write your partner a love letter
- Send your partner an SMS or email with a brief message telling them how you feel about them
- Write a little love message on a post-it note and then leave it in an unexpected place
- Give your partner a gift, it doesn't have to be expensive - perhaps a flower or their favourite food, a CD or a book.
- Make a 'date' with your partner - you can either stay in or go out together. Switch off your phones so you won't be interrupted; dress in clothes that make you feel good about yourself and ask your partner to do the same

Changes to your body

Cancer treatment can change your appearance and how your body works. You may think you are less attractive or you may worry that others will avoid you after treatment. These feelings may make you feel less sexual or you may think that your partner is no longer interested in being intimate with you.

Common changes include weight gain or loss, hair loss, scars from surgery, loss of a part of your body or changes to how your body responds sexually. These changes can affect how you see yourself (your self-esteem) and your body image. Your body image is influenced by what you think about your current appearance, how you would like to look, and how you would like others to see you. For many people, their perception of their body may not match how they appear to others. You may find that you are focusing on changes that other people do not notice or tend to overlook. Are you disregarding attractive aspects of who you are – your eyes, how you dress, or your pleasure from enjoying the company of others? Although sexual attractiveness is often judged on how you look, sex appeal is a combination of physical appearance and other qualities, such as friendliness, thoughtfulness and sense of humour.

“No-one being able to tell that I had a mastectomy was important to rebuilding my self-esteem. I wanted to feel normal.”

“Through my partner’s understanding I have come to know and accept myself and body as it currently is.”

“I still can still dress up and have a good time when I go out - cancer hasn’t stopped that”

Find ways to increase your sense of self-worth, as this boosts self-confidence and can help you feel more attractive. Look at all aspects of who you are:

What are your positive qualities as a friend? As a partner? In the work setting? Within your church or local community? What have been some of the achievements in your life?

Think about what others would say about you or compliments you have received – try to focus these and what you can still do, rather than what you can’t.

A program called *Look Good...Feel Better* helps men and women manage changes to their appearance. Call 1800 650 960 or visit www.lgfb.org.au for more information.

Resuming sexual activity

While some people find sexual intimacy is the last thing on their mind when they're going through treatment, others feel an increased need for closeness.

Whether you are single, with a partner, heterosexual or homosexual, you will probably find cancer treatment impacts on your sex life. This doesn't mean your sex life is over but you may need to work at overcoming the different challenges. See the section *Overcoming sexual concerns* from pages 36 to 55 for tips to help you address different concerns.

An intimate connection with a partner can make you feel loved and supported during cancer treatment and your recovery. However, cancer can strain a relationship, particularly if there were relationship problems before the diagnosis.

If you have a partner, it is important to work together to improve your sexual intimacy. Even if the changes have affected one partner's body, they affect both of you and so you need to work out ways to manage these changes together. Problems can arise due to misunderstandings, differing expectations and different ways of adapting to changes, so talking is important. Communication doesn't come "naturally" – even for couples that get along well or have been together for a long time

The following sections from pages 11 to 18 explain how your mind and body functions sexually, and how this may vary across different stages of cancer. Pages 19 to 21 offer suggestions for talking about sexuality and intimacy with your partner, as well as preparing for sexual activity.

The mind and sex

Sexual intimacy starts in the mind. Your brain is responsible for making you feel interested in sex through feelings, memories, imagination and fantasies and these thoughts are created by what you see, smell, touch, taste and hear.

Levels of sexual desire vary greatly between different people and can vary over time due to stress, illness and other demands. People differ in their levels of interest and desire and need to negotiate how they manage this within their relationship. Cancer may affect each person's level of desire differently, and if you are anxious, worried or depressed, you may feel less aroused by thoughts of sex. Your partner may share many of your concerns and might also not feel like having sex. Alternatively, for some, maintaining sexual intimacy can help them to manage their stress levels and provide a sense of relaxation and 'escape' from all the current worries.

“Sex was the last thing on my mind when I found out I had cancer. I couldn’t imagine ever having desire again. But after the treatment was over it came back”.

“My wife went off sex completely during her cancer treatment, which was difficult for me. When we talked about it, and she told me she still loved me, it made me feel better.”



The body and sex

Female sex organs

A woman's sex organs (genitals) are mostly inside her body:

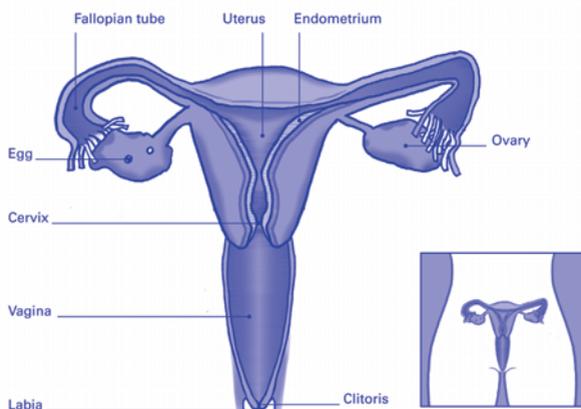
- Vagina – a muscular canal extending from the entrance of the uterus to the outer sex organs.
- Uterus – a hollow muscular organ shaped like an upside-down pear. The uterus, also called the womb, holds and nourishes a fertilised egg (ovum). The entrance to the uterus is called the cervix.
- Fallopian tubes – two long, finger-like tubes that extend from the uterus and open near each ovary. These tubes carry eggs from the ovaries to the uterus.
- Ovaries – two small, almond-shaped glands that contain eggs. The ovaries are found on either side of the womb, close to the end of the Fallopian tubes. The female sex hormones, oestrogen and progesterone, are made by the ovaries.

The outer sex organs are called the vulva. They include:

- Mons pubis – the area of fatty tissue covered with pubic hair.
- Labia majora – the outer lips, which protect the vagina.
- Labia minora – the inner lips, which join at the top to cover the clitoris.
- Clitoris – the main sexual pleasure organ for women. It is located where the labia minora join. The clitoris has a similar role to the penis. When stimulated, the clitoris becomes erect and sends messages of pleasure to the brain.

The breasts and nipples respond to stimulation. Some women may find that other areas of their body, such as the inner thighs, the area between the vagina and anus, and the neck and arms are also sensitive. These are called erogenous zones and responses are often very individual.

Female sex organs



Male sex organs

A man's sex organs (genitals) are mostly outside his body:

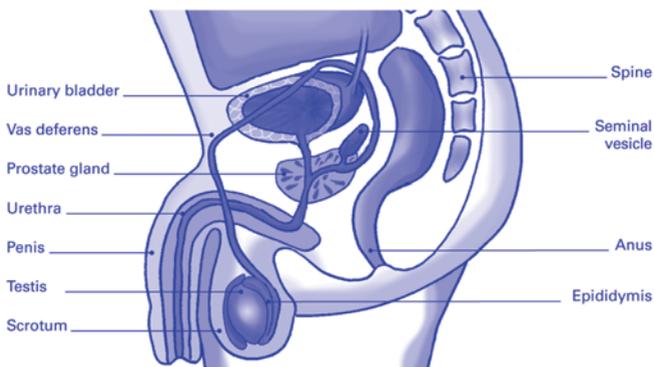
- Penis – the end of the penis is covered by the foreskin, if it hasn't been removed by circumcision. The ridge on the underside of the penis head, called the frenulum, is usually a man's most sensitive part. At the end of the penis is a narrow opening to the urethra, through which semen and urine pass.
- Scrotum – a pouch of skin found at the base of the penis. It contains the testes.
- Testes – two small, egg-shaped glands that sit behind the penis in the scrotum. The testes make and store sperm. They also produce testosterone. It is normal for one testicle to sit higher than the other and to vary slightly in size.
- Epididymis – coiled tubes found behind each testis, where the sperm mature.

The other parts of a man's reproductive system are inside his body. They include:

- Prostate gland – a small gland about the size of a walnut. The prostate sits below the bladder and surrounds the urethra, the tube that carries urine (from the bladder) and semen (from the sex glands) out through the penis. The prostate produces most of the fluid that makes up semen and nourishes the sperm.
- Seminal vesicles – glands that lie close to the prostate and produce secretions that form part of the semen.
- Vas deferens – tubes that transport sperm from the epididymis to the penis.
- Cowper's glands – tiny, pea-sized glands at the base of the penis. During sexual excitement, the glands release a tiny amount of fluid that neutralises any traces of acidic urine that may remain in the urethra.

The penis, testes and anus are highly sensitive and respond to stimulation. A man's other sensitive areas (erogenous zones) include the chest, nipples, neck, ears and fingers.

Male sex organs



Aspects of sexual response

There are a number of aspects of sexual response for both men and women, which include sexual desire, excitement or arousal, orgasm and resolution. You don't have to experience all of these to engage in sexual intimacy.

- Sexual desire – also called libido, this is the interest you have in sex. This can change after cancer, or during treatment.
- Excitement or arousal – this is when your body shows signs of getting ready for sexual activity or intercourse. You can become aroused by seeing someone you like; having a sexual thought or fantasy; reading or watching erotic material; having your body or genitals touched; or masturbating. The body responds to this excitement in various ways: blood pressure and heart rate increase, the breasts or chest become more sensitive and the nipples harden. In women, the clitoris becomes erect and sensitive, and the vagina expands and moistens. In men, the penis hardens, becomes erect and is more sensitive. The scrotum becomes firmer and the testes move closer to the body.

Sexual arousal can occur even if you don't have a great deal of sexual desire, as your body will respond to intimate touch and stimulation.

- Orgasm – this is the peak of sexual response, and can occur if arousal continues, but it doesn't always happen. The nervous system creates intense pleasure in and around your sex organs, causing muscles in the genital area to contract in rhythm and send waves of feeling through your body. Breathing becomes faster and shallower, heart rate and blood pressure increase and you may perspire.
- In women, orgasms can vary in length and intensity, and can be reached in different ways, depending on how the body is stimulated.
- In men, an orgasm usually happens simultaneously with ejaculation, which occurs when the muscles around the base of the penis squeeze in rhythm, pushing the semen through the urethra and out of the penis. It is possible to have an orgasm without ejaculating. This is called a dry orgasm.
- Resolution – this is when one's breathing, heart rate and blood pressure return to normal, and the body usually feels very relaxed. Some women are able to become excited again straight away or within a few minutes; men usually can't become aroused again immediately but may still enjoy the intimacy of kissing and physical touch afterwards.
- Sexual intimacy can be very pleasurable without orgasm, and can often last longer.

Ageing and illness can affect people's physical sexual response, although not necessarily their experience of pleasure. After cancer treatment, you may notice that your sexual responses have changed.

It can be helpful to re-think your triggers for being sexual – you may decide to resume intimacy even if your level of desire is not as high as it was in the past. Many people find that with pleasurable physical touching they become aroused and their desire increases. Try to focus your mind on pleasurable sensations, rather than on whether you have certain feelings or an orgasm. You may not experience orgasm, but you may still have enjoyed the physical closeness and feel satisfied.

The role of hormones

Cancer treatments can involve changes to various hormones. Hormones are like chemical messengers that affect how your body works. They carry information and instructions from one group of cells to another. They control reproduction and growth, and are important for sexual interest and response.

Women

The major female sex hormones are oestrogen and progesterone, which are mainly produced in the ovaries. The adrenal glands and fatty tissue also make small amounts.

Oestrogen keeps the vagina moist so it can expand during sex. When a woman ovulates (releases an egg), her oestrogen levels rise. This can make her feel sexual. Oestrogen levels fall after menopause, often causing the vagina to become tight, dry and less elastic. Oestrogen also affects libido (sexual desire). Cancer treatments can result in a drop in oestrogen and an early menopause for some women.

Progesterone is important for reproduction, helping to prepare a woman's body for pregnancy.

Women's ovaries and adrenal glands also make small amounts of male sex hormones known as androgens. The most common androgen is testosterone, which increases sexual desire.

Men

In men, the major sex hormone is testosterone, which is mainly produced by the testes (testicles) and, in lesser amounts, by the adrenal glands. It promotes development of the reproductive organs and secondary sexual characteristics such as a deep voice, facial hair, muscles and sexual desire.

Men's hormone levels vary widely but most men have more testosterone than they need. A man with a low testosterone level could have trouble with erections and may lose his libido.

Self-pleasuring

Self-pleasuring or masturbation can be a positive and satisfying way to enjoy sexual activity when you don't have a partner or you aren't ready for intimacy with a partner. It can help you find out how your body feels sexually and how it might respond to intimacy. Many couples enjoy mutual masturbation as an alternative to penetrative sex. Many partners are also happy to masturbate themselves with the other present if their partner is feeling too tired or unwell to be actively involved in love making

If you have had treatment in your breast or genital region, it may be useful to spend time alone touching these areas to find out whether there are changes in how you feel, whether there is any, soreness or numbness, and to explore what provides pleasurable feelings. When you are ready to be intimate with your partner, this preparation and exploration can help you to guide your partner as to what feels good.

“I learnt that I could still experience sexual pleasure after cancer by touching myself. Sometimes I used a vibrator.”

“After the surgery we found that touching each other was the most enjoyable form of intimacy. We still do it now.”

Sexuality across different stages of care

Cancer can affect sexuality differently, depending on the stage you are at since diagnosis.

At Diagnosis

Close to diagnosis sexual intimacy may seem a low priority as you are coping with the shock of being told you have cancer, are busy with medical appointments, feeling tired, or just have too many other things to think about. If you're finding that the frequency of sex has decreased, remember that this is not uncommon during this stage.

"We still loved each other very much. Sexuality goes on the back burner when one is so tired and the other is so sick."

During Treatment

The side effects of treatments can cause discomfort, pain, fatigue, or nausea which can all affect your sex drive. It is not unusual for your partner to worry about hurting you during sex or making you feel uncomfortable by touching sensitive areas. Your partner's desire for sex may also change during this time, or they may feel it is inappropriate to be sexually intimate with someone who is not well. This is a time when couples can spend time being close through touching in order to maintain a close connection.

"I lost interest in sex as I was more focused on my recovery."

After Treatment

After treatment is over, you may be adjusting to changed body image, or to resuming activities that were put on hold for some time. Cancer can result in changes to your sexual needs. Some people find that intimacy becomes more important than sexual activity. For other people sexual activity can remain a high priority, but the changes brought about by cancer mean that they have to make some adjustments to their usual sexual activities. Talk with your partner about how you are feeling and what you desire. Be open to hearing their feelings and desires too.

"We make sure we are well rested for at least one session of high quality love making per week. I make sure I have an early night on Saturday nights so we can have a Sunday morning session."

When living with ongoing/advanced disease

If you or your partner have ongoing/advanced disease and are receiving palliative care, the need for touch can be especially important. Holding hands, sitting or lying together, or stroking are ways to be close that show you care and that you are there to support each other.

"We deliberately kept the double bed. And then, when he got sick and needed a more supportive bed, I brought my single bed in, and we got it set at the same height, so that he was always next to me."

Talking about sex and intimacy

Communication is a vital part of maintaining intimacy in a relationship. If you have a partner, discussing your fears, concerns, preferences, desires and expectations can help improve your sexual experience. Talking about your sexual needs can be difficult if you are not used to talking about this area of your lives, but you often can't accurately guess what your partner is thinking or would like, so it is helpful to find out. Embarrassment, a lack of time, little privacy, a fear of offending our partner, or our fear of rejection can lead us to avoid the topic (see below). However, avoiding the topic can lead to frustration and misunderstanding, and can make it harder to renegotiate our needs and manage changes to our sexual functioning.

What are the barriers to talking about sexual intimacy?

You can use some of the examples below to help you to work out solutions:

- lack of time
- fear of burdening your partner
- embarrassment
- not knowing enough about sex to talk about it
- feeling that sex is too private
- fear of offending your partner
- not wanting to seem intrusive
- waiting for your partner to mention it
- having the idea that sex is only for healthy people
- feeling that sex is not a priority
- assuming that if "I'm not interested in sex, my partner wouldn't be either"
- feeling guilty that you have sexual feelings
- it's never the "right time" to talk about sex
- not wanting to deal with it
- feeling that nothing will help even if you do talk about sex
- not wanting to "make the effort"
- feeling that your partner "has enough on their plate"
- feeling that you've never talked about sex before, so why start now?
- fear of rejection
- feeling that because you have incompatible libidos, talking isn't going to change that

Talk about when you think you'll be ready for sex and ask how your partner feels. Your partner might be worried about hurting you or appearing too eager. Discuss whether they should do anything differently, how they can help you to get in the mood, and your sexual preferences.

“The experience of having good communication with my partner was a blessing. It was the total difference in being able to cope.”

“I think both of us realise that problems are going to surface if we bottle it up.”

If you're not interested in sex, let your partner know that you are not rejecting them, it's just that you don't feel ready for penetrative intercourse. You might like to offer alternatives ways of maintaining intimacy, for example, cuddling, kissing, offering a massage, or a form of non-penetrative sex, such as masturbation or oral sex.

It can be very hard to deal with visible physical changes to your body, but it is best to share these changes with your partner before starting sexual activity. Work out how you both will manage these changes upfront, for example, whether you prefer to wear a cover over a stoma or feel comfortable having certain areas of your body touched. These changes can be very upsetting for both of you and it may take a while for both of you to get used to your different appearance and how these changes make you feel.

We often think sex should be spontaneous, but the first few times you resume intimate contact it can be a good idea to plan ahead. Use strategies to help you cope with pain and fatigue, and to help you both get in the mood for sex (see below). Be patient too. You will probably find that any problems you have with sex will become less of a concern with time and practice.

Remember that there are other important aspects of your relationship – sexual intimacy is just one area of giving and receiving pleasure.

“By asking my husband for a bit more TLC and explaining how I was feeling, we have managed to fumble through these times.”

“I am not able to bounce around the bedroom as I could before, but we have managed to get around most of this. Good communication has been the key.”



Tips:

- ✓ Think about your sexual needs and how you might be able to communicate them by remembering how you have dealt with difficulties together in the past.
- ✓ Remember that communication can be non-verbal, involving actions as well as words.
- ✓ Don't be afraid to use humour to communicate your sexual needs.
- ✓ Talking about sex, even with your partner, can be confronting and difficult so be prepared for unexpected reactions. It may be a good idea to ask your partner if there is a time that suits them to talk about the impact on your intimate relationship – giving them some warning and time to think about how things are for them. Think about things you can do to help get you talking about intimacy - write your partner a note, talk in bed when the lights are out, or when taking a walk together.
- ✓ Ask questions about what your partner likes or doesn't like. Be open to hearing what your partner has to say, and encourage them by listening.
- ✓ If something is brought up that one of you is uncomfortable with, respect that and move on; now may not be the right time to discuss something. Don't try to force your partner to try something they are uncomfortable with, and don't make them feel guilty for their feelings. We all have different time lines for adjusting to changes and there may be much sadness and loss to work through.

Information for partners

Adapting to changes

It is important to let your partner know that even though they have had treatment for cancer and they may have experienced physical and emotional changes, you still love them and find them attractive. It may take time to get used to your partner's changed appearance – it may feel like a real loss for you too. The fluctuating emotions both you and your partner may be feeling may make it hard to get along together at times. This is a very challenging time for each of you as individuals as well as your relationship. Remind yourself and your partner of all their qualities, for example, their sense of humour, intelligence, smile or generosity - this will help you both see past the recent changes.

“I initially felt angry, frustrated and hurt when my partner refused to discuss our sex life or lack of sex life. Over the last 6 years I have accepted her point of view and now enjoy different hobbies and projects together.”

You might feel awkward because you think your partner is not ready for sex, or that physical contact may hurt. These feelings may affect your own sexual desire but these effects should be temporary. You can talk about what level and types of intimacy you both would like to have.

Be prepared to go at your partner's pace. Give them the time and space to recover. If they are not ready for sexual contact, try other ways of showing your love or managing your own sexual needs. Ask your partner to tell you or show you what feels good or what areas are sensitive to touch. Stroking the scar – or not avoiding touching it – may help show your partner that you have accepted their physical changes. If your partner is unwilling to have the area of treatment touched or seen, accept the need to use clothing or dim lighting to conceal it.

If your partner is not interested in sexual activities you used to enjoy, be creative in finding alternative ways to satisfy each other. Many couples find a whole range of sexually intimate behaviours to be an important part of their intimate relationship, and sexual activity without penetration or orgasm can still be fulfilling.

“We found that the hugs, cuddles, and closeness were more important than the actual act of making love.”

“There are new things that we can do, new positions, new and different ways to touch.”

“A vibrator, lubricant, good old fashioned rumpy-pumpy and a bit of soft porn - that's what works for us.”

Tips:

- ✓ Put aside time together to explore creative ways to satisfy each other.
- ✓ Think about some of the ways you and your partner could satisfy each other without penetration. This may be oral sex, kissing, mutual masturbation, or watching erotic movies.
- ✓ Think about giving each other a massage using a scented oil or body lotion.
- ✓ Remember to talk to your partner about what feels good for you and to ask them about what feels good for them.

Buying aids to your sexual pleasure

Many people find it embarrassing to go into a sex shop for vibrators, penis pumps and other sexual aids. There are many places on the internet where you can buy different sorts of personal aids and your local adult shop may also have a website. Look at different retail outlets on the internet – some may seem more accessible or tasteful to you than others. Like other internet services, quality and reliability varies widely. The advantage of going into a shop, telephoning, or sending an email is that the staff will be able to talk to you about the best quality personal aids and how they work. Their job is to ensure you are satisfied with the products they sell – so make the most of their expertise! Pharmacies may also stock or be able to order some personal aids and massagers.

Other concerns

You may be worried that cancer treatments may be harmful to you. If your partner is having radiotherapy, they will not be radioactive once they return home. If your partner is having chemotherapy, check with the treating team about whether a condom is required or whether you need to take other precautions if you have intercourse within 48 hours of treatment.

It is not possible for your partner to transmit their cancer to you through intimate activities such as kissing or intercourse.

If you are providing a lot of your partner's care, it can sometimes be difficult to switch between the roles of carer and lover. You may be physically exhausted yourself and thoughts about the cancer and the way it has impacted on your own life can interfere with your desire for sex. Your partner may want intimate contact, and your difficulty giving it may cause conflict and feelings of guilt. These are common feelings to have as a carer. Caring for another person is very demanding and draining, and no one can perform such a difficult task without good support themselves. Address concerns as soon as possible, by talking to a counsellor or a psychologist about how you're feeling and how physical needs in your relationship can be met.

“Even if he was still interested in the sexual side of our marriage I think I would have been too exhausted to have taken part.”

“I worry myself sick thinking every time he moves, is he in pain?”

“When you are a carer it's hard to be a lover, for either party.”

For more ways to cope, call the Cancer Council Helpline for a free copy of the booklet *Caring for Someone with Cancer* or download it from www.cancercouncil.com.au.

You and your partner should avoid pregnancy if one of you is having chemotherapy or radiotherapy, as the baby could be harmed. You must use some form of birth control or avoid intercourse.

People without partners

Many people face cancer and its treatment without the support of a partner. In time, you may wish to meet a new partner and start a relationship. Alternatively, you may decide that you don't want to be in a relationship, either temporarily or for the long term because of what you've been through or for other reasons.

"I've been on my own since the cancer diagnosis, and that feels right for me. I enjoy having my own space, and don't feel I can cope with the emotional issues involved in a relationship right now".

"Life after cancer has more meaning and I've realised I don't need a partner for my happiness."

If you decide you want a new partner, this can seem daunting after treatment. You may feel that you are no longer attractive. You may worry about starting a relationship and then getting ill again. You may also fear how a new partner will react when they know about the cancer, even if your body appears unchanged.

"I'm worried that it will make me seem less attractive if I say I've had cancer, or make a new partner feel they have to look after me".

It can be difficult to decide when to tell a new partner about the cancer. The cancer experience is one aspect of who you are now, and sharing it is a part of getting to know each other. It's probably best to wait until you've been out a few times and feel things could develop, but if the subject comes up earlier, it may be a good opportunity to talk. It might help to practise what you want to say and to remember that, at first, you don't have to go into a lot of detail; just reveal what you're comfortable with.

It may be helpful to rehearse a few phrases you could use when talking about cancer. Be guided by the questions your partner asks about how much information they want at that time, and let them know you are happy to tell them more if they have questions down the track. Before starting any sexual activity, talk to your partner about any changes to your body or sexual function. You might also want to show your partner changes to your body. Through honest communication and 'trial and error' you will both be able to work out how to deal with these changes and ensure that your experiences are pleasurable.

"I was worried about telling someone new that I had cancer. But, I recently started a new relationship and the woman was very understanding."

It is important to remember that potential partners may also have aspects of themselves that they are wondering how to share. However, in sharing we can enhance closeness within the relationship. If a new relationship doesn't work out, don't automatically blame the cancer. Remember that not every relationship worked before you had cancer.

Sharing your concerns with someone who has been in a similar situation can help. See page 57.

If you are in a same-sex relationship

It is important that you feel your sexuality is respected and included when discussing how you are affected by treatment. Although many of the major issues will be the same for you as for heterosexual people, recognition and validation of your sexuality is a crucial part of receiving support. Your clinical team should be able to openly discuss your needs and support you through treatment.

Try to find a doctor with whom you feel comfortable talking about your sexuality and relationships. If you have a partner, take them along to doctor's visits. This will show your doctor who's important to you and will enable your partner to be included in discussions and treatment plans.

You can also seek help from services for same-sex attracted people in NSW:

- ACON is an organisation promoting the health and well-being of the gay, lesbian, bisexual and transgender (GLBT) community.
For support, call 1800 063 060.
- For other suggestions, contact the Cancer Council Helpline on 13 11 20.

“When my partner developed cancer we realised we needed to be open about our relationship to the medical staff, so I could be part of her care. Everyone has been very positive - we're so glad we discussed it”.

How cancer treatment can affect sexuality

The main cancer treatments are surgery, radiotherapy, chemotherapy and hormone therapy. These can affect your sexuality in many ways. Tips for dealing with these changes are in *Overcoming sexual concerns* from page 36.

Surgery for women

Surgery can change a woman's sex organs, both in appearance and function. This can impact negatively on body image.

Breast surgery

Most breast cancers are treated with surgery. Some women have part of the breast removed (lumpectomy or breast conserving surgery), others have the whole breast removed (mastectomy).

Breast surgery may make a woman feel like she has lost part of her female identity. She may feel less attractive or worry that her partner will no longer be interested in her because of her changed appearance.

A mastectomy can damage the nerves that influence nipple feeling. This means that even if you have a breast reconstruction, you may no longer feel sexual pleasure when your breast is fondled. Breast and nipple sensation usually remains the same after breast conserving surgery.

Hysterectomy

A hysterectomy is the removal of the uterus. It may be used to treat gynaecological cancers such as cancer of the uterus, cervix, ovary, endometrium or vagina. After a hysterectomy you are not able to get pregnant.

When the uterus is removed, the top part of the vagina is stitched up. This may shorten the vagina, but its length doesn't affect your ability to feel sexual pleasure. You also don't need the uterus to have an orgasm. However, you may notice some difference in feeling because some of the muscles that normally contract during an orgasm have been removed. The clitoris, vulval area and the lining of the vagina remain sensitive.

Oophorectomy

The removal of an ovary is called an oophorectomy. If one ovary is removed before the menopause, the other should continue to produce hormones and eggs. If both ovaries are removed, you will no longer have monthly periods and you will go through menopause. This means you will not be able to become pregnant and you may have menopausal symptoms such as vaginal dryness, tiredness, hot flushes, mood changes, and difficulty sleeping. These symptoms may occur more quickly than with a natural menopause because your body hasn't had time to get used to the reduced amount of hormones.

Vaginal surgery

Some women need a small operation to remove cancer from the vagina. Usually the remaining vaginal tissue can be stretched so you are still able to have intercourse. Some women need a larger operation that removes the whole vagina (a vaginectomy). A vaginal reconstruction may be an option, but the scar tissue from surgery can make intercourse painful. If this is the case for you, talk to your doctor about the use of vaginal dilators and creams to manage it.

Vulvar surgery

There are different types of surgery used for vulvar cancer, including removing some of the tissue of the vulva (local excisions), vulvectomy (removal of some or all of the outer sex organs), and pelvic exenteration (removal of the vulva and other affected organs). Surgery will change the appearance of the vulva and can affect sensations, especially if the clitoris has been removed. However, sexual pleasure and orgasm is still often possible.

Radiotherapy to the pelvic area

Radiotherapy for cancer of the rectum, bladder, uterus or cervix can stop the ovaries producing female hormones, because they are very sensitive to radiation and can be easily damaged by the radiation treatment. Your gynaecologist and radiation oncologist will work together to try to keep radiation away from the ovaries if possible, but they are often difficult to protect because of their position close to the site of the cancer that needs treatment.

Radiotherapy can cause menopausal-like symptoms, such as irregular menstruation and a dry vagina. Scar tissue may form, which will shorten and narrow the vagina. Penetration may be painful but your ability to reach orgasm should not be affected. After treatment, periods may sometimes return, but women usually lose their fertility permanently after pelvic radiation therapy. Fatigue from treatment can affect people's level of desire for intimacy.

Radiotherapy to the breast

Radiotherapy to the breast can make the skin red and sore. Your breast may also change in size or shape. The change is permanent, but it is usually only slight and not noticeable under clothing. Some women may notice that their breast feels firmer, but it usually softens over time.

Chemotherapy for women

Chemotherapy can reduce the amount of hormones produced by the ovaries or can affect the eggs produced by the ovaries. This may cause some women's periods to become irregular but they usually return to normal after treatment.

For other women, chemotherapy may result in the cessation of menstrual periods, which can be temporary or permanent. Thrush can also occur, causing vaginal itching, vaginal dryness, burning and discharge.

Chemotherapy can also cause severe tiredness, nausea, vomiting, hair loss, and weight changes which can all indirectly reduce a person's sexual desire.

Immunosuppression

Some women who are receiving chemotherapy or who have had a transplant can be immunosuppressed or immunocompromised. This means they are more prone to infections such as chickenpox, the flu and sexually transmitted infections. They may also experience severe fatigue and vaginal dryness, which can reduce their enjoyment of sex.

Immunosuppressed women should avoid having sex if their partner has an infection that could be passed to them. Barrier contraception, such as condoms, should be used to minimise the risk of infections spreading.

All women need to be screened with a Pap test every 2 years for cervical cancer. Women who are immunosuppressed may not easily clear infections of genital human papillomavirus (HPV), which is a risk factor for cervical cancer. Women who are immunosuppressed and who have any abnormality on their Pap test should see a gynaecologist for specific advice about managing this and other sexuality issues.

Hormone therapy for women

Hormones that are naturally produced in the body, such as oestrogen, can make some cancers grow. Hormone therapy reduces the amount of oestrogen in the body or stops cancer cells from getting oestrogen.

There are different types of hormonal therapies:

- **Anti-oestrogens:** These work by stopping cancer cells from getting oestrogen. Tamoxifen is the most common anti-oestrogen therapy. It can slow the growth of, or stop, new breast cancers, lower the chance of the cancer returning and reduce the risk of heart disease or osteoporosis. Women may experience menopausal-like symptoms, which can impact on their libido.

- **Aromatase inhibitors:** These work by stopping oestrogen from being produced. They are usually used in women who have already been through menopause before cancer treatment. The three commonly used aromatase inhibitors are Arimidex, Aromasin and Femara. Side effects include osteoporosis, vaginal dryness, hot flushes and weight gain.

Hormone treatment may cause you to become temporarily or permanently infertile. However, many women on hormone suppression treatment go on to have a baby when their menstrual cycles have been re-established after treatment.

For information on how fertility can be affected for men and women, see pages 34 to 35.

Surgery for men

Surgery can affect the functioning and/or appearance of men's genitals, resulting in sexual or self-esteem difficulties.

Prostate surgery

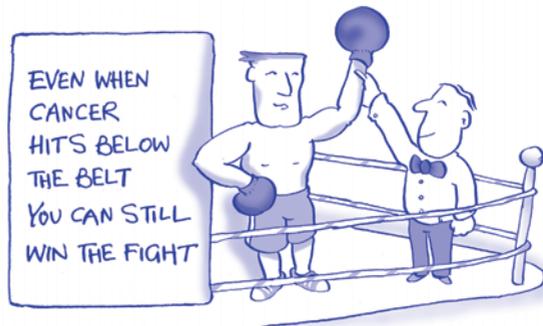
Many men with early prostate cancer have the prostate removed (radical prostatectomy). Afterwards, most men will experience problems getting and keeping an erection (erectile dysfunction or impotence). The ability to have an erection usually improves, often over several years, but the problem can be ongoing for some men.

The prostate and seminal vesicles are removed during a radical prostatectomy, which means men will not ejaculate semen when they climax. This is called a dry orgasm. Although orgasm still happens, the sensation may change.

Another side effect is loss of bladder control, which can be temporary or permanent. This can inhibit sexual pleasure. It can also mean that it

is less desirable to have some forms of sexual activities (e.g., oral sex).

Infertility is likely to occur after prostate cancer treatment. Although sperm may be produced after surgery, it cannot be ejaculated as the vas deferens are blocked during surgery. After radiation therapy, the radiated prostate cells and seminal vesicles produce less semen. This semen is of poorer quality than before treatment and is generally unable to transport and nourish sperm sufficiently for pregnancy to occur. The sperm may also be damaged.



Nerve-sparing surgery for prostate cancer

In nerve-sparing surgery, the prostate is removed but the erection nerves are spared if possible. These nerves can only be saved if the cancer has not spread along them. This surgery works best with men who had good quality erections before the operation.

Orchidectomy

An orchidectomy is the removal of one or both testicles. If you have one testicle removed, there are no lasting effects on your fertility or your ability to have an erection or intercourse. This is because the other testicle continues to function, making enough testosterone and sperm.

Having both testes removed will cause permanent side effects. The lower testosterone levels may affect your sex drive and you will be infertile.

If you're concerned about the appearance of the scrotum, it can be maintained with an artificial testis, called a prosthesis. Ask your doctor about this.

“The surgery felt like an amputation. Without a testicle, I felt like I wouldn't be a man anymore.”

Bowel or rectal surgery

Surgery to the bowel or rectum may sometimes cause nerve damage that makes it difficult to get an erection. Erections may improve over time but they are sometimes affected permanently. Some men with bowel cancer need a stoma, which is an artificial opening on the body for waste products to be removed.

Cystectomy

In a radical cystectomy, which is the full removal of the bladder, the prostate gland is taken out too. This can affect sexual function if the nerves in the pelvic area are damaged, making it difficult for a man to get and maintain an erection. It also causes dry orgasm, as semen is no longer produced.

Removal of the penis

This operation is only done for cancer of the penis, which is very rare. Depending on the location of the tumour, the entire penis or part of it may be removed. The remaining part of the penis may still get erect with arousal and be long enough for penetration. A man can still reach orgasm with sexual stimulation, and will ejaculate through the opening at the end of the penis.

Reconstructive surgery is still experimental, but it is sometimes possible to have a penis reconstructed. This requires another operation and uses skin and muscle from the arm. Some surgeons have successfully manipulated blood flow and reconnected nerves to allow the reconstructed penis to become erect. A penile implant is another option.

Radiotherapy to the pelvic area

Radiotherapy anywhere in the pelvic area may cause painful ejaculation, as the urethra becomes inflamed. The pain usually disappears a few weeks after treatment.

Problems with erections are common. The nerves and blood vessels needed for an erection become scarred and are unable to let enough blood through to fill the penis. This problem may not develop until 12 months after treatment finishes.

Reduced sperm production is also common after radiotherapy. Normal production usually returns after treatment, but this may take some years. For some men, infertility is permanent (see section below on sperm banking). However, if the testes are outside the treatment area, they can usually be protected from the radiation.

Radiotherapy and chemotherapy treat a range of cancers and can affect your desire for sex. For more information on ways to cope with side effects, call the Cancer Council Helpline for free copies of the booklets *Understanding Radiotherapy* and *Understanding Chemotherapy*.

Chemotherapy for men

Chemotherapy can cause erection difficulties in men, but this is usually temporary. The drugs can also lower the number of sperm produced and reduce their ability to move. This can cause infertility, which may be temporary or permanent. Extreme fatigue, hair loss, and nausea and vomiting can also impact on sexuality.

“My husband was constantly tired when he was undergoing chemo, so sex was the last thing on his mind”.

Hormone therapy for men

Testosterone can make prostate cancer grow. By blocking its production using hormone therapy, the cancer may stop growing or even shrink. Hormone therapy is often given for several months before radiotherapy to help reduce the size of the cancer.

Hormone treatments to lower testosterone levels may cause side effects such as tiredness, erection problems, reduced libido, weight gain, hot flushes, breast tenderness, depression and loss of bone strength (osteoporosis). These can be treated by medication or hormonal supplements.

Stoma for men and women

A stoma (or ostomy) is formed when any portion of the small or large intestine is surgically altered to open out onto the abdomen so that waste products can be removed from the body. Stomas may be temporary or permanent.

A number of strategies can be helpful for maintaining intimacy when you are managing a stoma (see below, page 46).

In women, if the rectum is removed, the nerves that control genital sensations are not usually damaged but there may be a different feeling in the vagina during penetration. It may be uncomfortable, as the rectum no longer cushions the vagina.

Effects on people who enjoy anal penetration

If you enjoy anal stimulation or penetration, surgically closing the anus may be a problem. Intercourse via the stoma can cause damage, and sexually transmitted infections can still be passed via the stoma.

Fertility and contraception

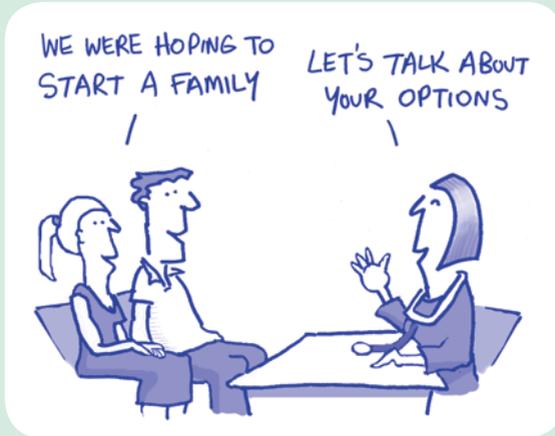
Some, but not all, cancer treatments can cause infertility (inability to conceive a baby), which can be temporary or permanent.

If fertility is important to you, you should talk to your doctor before treatment about your risk of infertility and ways your fertility might be preserved. You may be able to store embryos or sperm for use in the future.

When people learn that they may be permanently infertile they often feel a great sense of loss. You may be devastated that you won't have your own children or additional children, and you may worry about the impact of this on your relationship. Even if your family is complete, you may experience distress.

“When the doctor told me I wouldn't be able to have children after the treatment, I cried all night”

Fertility and contraception



Discussing your situation with a counsellor, radiation oncologist, urologist or gynaecological oncology doctor or nurse can be beneficial.

Although chemotherapy and radiotherapy can reduce fertility, it is still possible for women having treatment, or the partners of men having treatment, to become pregnant.

Your doctor may suggest you wait two years before trying to conceive.

This gives the body time to recover and allows the eggs and sperm to become healthy again. During treatment and for the waiting period afterwards, some form of contraception must be used.

Ask your doctor about your contraceptive options and talk to your doctor immediately if you become pregnant.

If you have a stoma, the effect of the contraceptive pill may change depending on the type of surgery and stoma you have. Talk to your surgeon, stomal therapy nurse or gastroenterologist about the most suitable contraception for you.

"Before going ahead with radiotherapy, the doctor informed me about sperm banking. I decided I did want a family, so this would be the smartest thing to do."

Overcoming sexual concerns

Most sexual concerns caused by cancer are temporary. Some problems are experienced by both men and women; others are unique to either men or women. With patience, practice and time, and by dealing with concerns as early as possible, people can maintain intimacy in their lives. There are many practical tips in this section that can help.

If you are in a relationship it is important to remember that although the changes may have primarily affected one partner's body, they affect both of you, and you both are part of the solution.

If you need further assistance to work through problems or to help you communicate with your partner, talk to your GP, oncologist or nurse who can refer you to a specialist sexual health physician, sex therapist, counsellor or psychologist/clinical psychologist.

Fatigue

During and after cancer treatment, many people feel tired and have no energy (fatigue), it is common for this to lead to a reduced interest in sex.

Tips:

- ✓ Plan your day so you have time to take a nap or break.
- ✓ Pace yourself throughout the day and don't do more than is comfortable; if needed, delegate tasks and accept offers of help.
- ✓ Eat well and drink plenty of fluids.
- ✓ Take short walks or do light exercise.
- ✓ Try relaxation exercises or have a massage to restore energy.
- ✓ Be intimate at the best time of day for you (e.g. in the morning when you feel refreshed) and have shorter lovemaking sessions.

Losing interest in sex

Lack of interest in sex – low libido – is common because of fatigue, the effect of medications, or anxiety relating to treatment. Libido usually returns when treatment is finished. For some people, their interest in sex doesn't return to what it used to be. Sometimes one person loses interest in sex while their partner still has an interest. It is important to know that there are many ways to help you and your partner deal with this.

“I am totally not interested which is silently causing problems in our relationship.”

Tips:

- ✓ Most people find their libido doesn't completely vanish, so try to work out when you are more receptive to intimacy and make the most of these times. Try different ways of getting in the mood; what has worked in the past? Try taking a shower together, having a romantic meal, or wearing something sexy - whatever makes you feel relaxed and good about yourself.
- ✓ A weekend away or even some time for just the two of you can help you to emotionally connect with each other and enhance intimacy.
- ✓ Show affection by touching, holding, hugging and massaging.
- ✓ Watch a romantic movie, look at erotic magazines or DVDs, talk sexily with your partner, or create a sexy atmosphere with dim lighting and music.
- ✓ Physical activity can stimulate sexual desire by increasing energy and lifting your mood.
- ✓ Take a bath together with candles and bubbles and soft music.
- ✓ If you have a low libido, but your partner does not, talk to them about how their needs can be satisfied in a way that works for you both. For example you may be willing to stimulate and help your partner to reach orgasm, even if you don't want this for yourself.
- ✓ Partners may need to rethink how they can manage their own needs, for example having their own private and intimate time. Partners may need help adjusting to changes to ensure they don't become resentful and that intimacy is maintained.
- ✓ Avoid making judgements about each others needs and desires; your needs may not match at the moment, it's not because one partners needs are too high or too low.



Changed body image

Physical changes such as experiencing lymphoedema (swelling in the limbs) or losing a body part due to cancer treatment can affect your self-esteem. It will take time to get used to the changes.

"The changes to my body such as bloating etc were depressing but I didn't always feel I could express this as everyone was focused on curing the cancer."

Tips:

- ✓ Wear pyjamas or lingerie, or use soft lighting or no lighting.
- ✓ Lie on your side to prevent pressure on painful areas, or face away from your partner if you are embarrassed.
- ✓ If you have lost a limb, try wearing your prosthesis during sex, or remove it and support yourself with pillows.
- ✓ Remind yourself that what makes you unique is much more than your body.

Being mindful

This exercise is about taking a moment to feel your body in its environment and notice positive aspects of it.

When we are ill we give most attention to what is wrong and what hurts. That's usually OK because we can get on with dealing with the problems caused by the illness. But it is not OK when that is all that we notice. Sometimes it is easy to only think of the body as ill, painful and no good anymore. Taking a little time to notice what is pain free, works well or feels good helps stop the illness taking over every part of you all of the time and can help you feel better about yourself, your body and your sexual and intimate relationship.

Here are some ways to be mindful. It is good to be doing a relaxation breathing at the same time but certainly isn't essential.

In the shower, notice how the water feels; if it feels OK on your body, take a moment to simply enjoy it. Does it feel better on some places than on others?

Find a part on your body that doesn't hurt, just notice that and if you can, touch it and stroke it lightly.

Find a part of your partner's body that you like and focus some gentle loving touch on that.

When you are using hand cream or lotions, take time to notice what feels good; is the cream warming or cooling, is it soothing or does the touch irritate you.

With a partner you might like to lightly touch hands and just appreciate the sensation where your skin is touching.

Or be next to each other and notice the rhythm of each other's breath.

Perhaps being mindful might bring some less than good things to your attention. If showering hurts your skin perhaps there is another way to bathe, if someone putting cream on you irritates or hurts, you might like to ask for a different lotion or a different way of applying it.

Specific concerns for women

- **Mastectomy:** After a mastectomy, you may choose to use a breast form (prosthesis). This can either be a piece of specially made foam or a liquid-filled sac worn in your bra. If you find the prosthesis uncomfortable, you may want to consider a breast reconstruction.

A breast reconstruction may help improve your body image and make you feel more attractive. It can also give you confidence to wear different types of clothes.

See Cancer Council's booklet *Your Guide to Breast Forms (Prostheses)* for more information.

- **Vaginal surgery:** Women who have their vagina removed during surgery may have a reconstruction. Many women may feel self-conscious about this. Intercourse can be possible with the aid of lubricant as natural lubricant is no longer produced.
- **Vulvar surgery:** Surgery for vulvar cancer makes the genital area look and feel different. Understandably, many women are nervous about being seen naked. For some women, removal of the clitoris and lower vagina can significantly affect their ability to orgasm. For other women, depending on the extent of their surgery, stimulation of the vagina, breasts and inner thighs, can bring them to orgasm, even if they no longer have a clitoris.

Encore is an exercise and relaxation program for women who have had breast cancer surgery. Call 1800 305 150 or visit www.ywcaencore.org.au.

Tips:

- ✓ Remember that the removal of an area of your body, such as a breast or part of the vulva or vagina doesn't make you less of a woman.
- ✓ Allow your partner to work together with you to help to problem solve how you will both deal with the changes.
- ✓ Touch your genitals to find out if your sexual response has changed. Explore other areas of your body that are sensitive to touch and ask your partner to caress these areas.
- ✓ Use a lubricant if it is safe to do so.

"In my youth I was an underwear model - Berlei's perfect 12B. Even though I'd breastfed three children and my breasts were heading south, they were mine and I liked the way they looked. Losing one breast changed the way I felt about myself."

Specific concerns for men

- **Testicular surgery:** This probably won't affect your sexual ability, but you may not feel as desirable. You may wish to have a prosthesis inserted into the scrotum to improve the way it looks.
- **Surgery to penis:** After surgery, men are still usually able to have penetrative sex or they can reach orgasm from stimulation of the surrounding genital area.

“Currently I can't get an erection, but I would rate our sex life as nearly as good as before the operation.”

Tips:

- ✓ Remember that the removal of a testis or the penis, or the inability to get an erection, doesn't make you less of a man.
- ✓ Allow your partner to be part of the decision-making process for how you want to deal with the changes.
- ✓ See page 51 for ideas to help erectile dysfunction.

Painful penetration or intercourse

Sexual positions that you enjoyed in the past may now be painful after cancer treatment.

In women, pain in the vulvar area is called vulvodynia. Even if the pain is not in the genitals, it can distract you from feeling pleasure during sex.

Sometimes the pain causes the muscles around the vagina to tighten. This is called vaginismus. It is often caused by fear that you'll be hurt during intercourse. It can make penetration difficult and, sometimes, impossible.

Some men who've had radiotherapy to the penis may feel pain due to scar tissue, which causes their erection to curve. This is called Peyronie's disease. The pain usually settles down in time and sometimes the curve disappears.

Irritation of the prostate gland or urethra from surgery or radiotherapy can cause painful ejaculation.

Talk to your doctor if the tips below don't work or if you continue to experience pain in the genital area. The Cancer Council Helpline (13 11 20) can also let you know where you can get help and support for this problem.

Tips:

- ✓ Avoid sexual activity when you are tired or stressed.
- ✓ Plan sexual activity for the time of day when your pain is lowest. If you are using pain medication, take it shortly before sex so it will be in full effect during lovemaking.
- ✓ Use positions that put minimal pressure on the painful areas of your body and allow you to control the depth of penetration. Use pillows for support.
- ✓ Try to focus on your feelings of pleasure and excitement rather than the pain.
- ✓ Learn relaxation techniques to help stop the muscles tensing up.
- ✓ If it is safe to do so, use a water-based lubricant.
- ✓ Women may benefit from using a dilator (see page 48) to widen the vagina.



Trouble reaching orgasm

Treatment for most cancers does not affect a person's ability to reach orgasm.

Women who have had their clitoris or other sensitive areas of the vulva removed may still be able to orgasm, but they will probably experience difficulties at first and will need to explore different ways to climax.

Most men who have had surgery to their penis still feel pleasure on the remaining skin and can learn how to reach orgasm in different ways.

Some medications interfere with the ability to orgasm, particularly antidepressants, hormones, tranquillisers and narcotic pain medication. If this side effect is a concern, talk to your doctor.

It is not necessary to have intercourse to achieve orgasm. Many other parts of your body, such as the inner thighs, feet, buttocks and breasts, are sensitive and can be stimulated to bring you to orgasm. People who may have found it difficult to orgasm before their treatment may benefit from talking with a counsellor, sex therapist or psychologist.



YOU CAN STILL MAKE MUSIC ...
TO THE BEAT OF A DIFFERENT DRUM

Tips:

- ✓ Think about pleasurable sexual experiences, watch romantic or erotic DVDs, or read sexy literature to stimulate you. Try not to let your mind wander to worries or whether the washing needs hanging out!
- ✓ Show your partner what you find pleasurable; guide your partner's hands or fingers to areas that arouse you.
- ✓ Consider using a vibrator to give you extra stimulation to help you reach orgasm.
- ✓ Focus on your breathing to help you relax and heighten the pleasure of the whole experience.
- ✓ For women, tighten and relax your vaginal muscles in time with your breathing during penetration or while sensitive areas are being stroked.

Incontinence

Incontinence is weak bladder or bowel control, causing leaking or increased frequency or urgency to urinate or open your bowels. It can occur after treatment for cancers of the bladder, bowel, prostate, penis or female reproductive organs. It may be temporary or permanent and many people find this to be very distressing. They may worry about any odour or leakage problems and the thought of resuming any sexual intimacy may seem impossible. There are ways to help manage this:

Tips:

- ✓ Plan ahead for sex and ensure the bowel or bladder is emptied beforehand.
- ✓ Use a condom to contain mild incontinence.
- ✓ Try having sex in the shower or bath, and have towels on hand if needed.
- ✓ Use plugs for the bowel.
- ✓ For indwelling catheters, tape the catheter to your skin, remove the bag and insert a flow valve or stopper.
- ✓ Exercise the pelvic floor muscles (see page 45)
- ✓ An oestrogen cream or tablet inserted into the vagina may help improve the strength of the pelvic floor muscles.
- ✓ Talk with your doctor about a urinary sphincter implant to help with incontinence.

Contact the Continence Foundation of Australia on 1800 330 066 or visit www.continence.org.au for further information or advice.

Pelvic floor exercises

These exercises help tone the muscles in the pelvis to give you better bladder and bowel control, and, for women, more strength and sensation in the vagina.

Identify the pelvic floor muscles:

- Pretend you are trying to stop the flow of urine or avoid passing wind. You should feel a tightening and lifting of muscles around your rectum (and vagina for women). These are your pelvic floor muscles.

Do the exercises:

- While sitting, standing or lying, slowly tighten and lift the pelvic floor muscles, holding for five to 10 seconds. Release and relax for 10 seconds.
- Repeat the contractions up to 10 times, relaxing between each squeeze.
- Then do five to 10 short, fast, strong contractions in quick succession.
- Repeat the routine three times a day.
- Your buttocks and legs should not move and you should be able to breathe easily.

Source: Adapted from Cancer Council Victoria's Sexuality and Cancer: a guide for people with cancer.

Adapting to life with a stoma

Sexual activity with a stoma for the bladder or bowel can still be satisfying but can benefit from some planning.

Tips:

- ✓ Let your partner see or feel the stoma, if they want to, and give them time to adjust to it.
- ✓ Change the appliance before having sex and make sure it feels comfortable.
- ✓ Cover your appliance with soft material if you don't like the feel of plastic on your skin.
- ✓ Wear a mini-slip, bathrobe or crotchless underwear if you feel uncomfortable showing the stoma. You can also purchase a tailor-made ostomy cover from places that advertise on the internet.
- ✓ Choose a position that keeps your partner's weight off the stoma, or place a small pillow over it so your partner is not lying directly on the appliance. You can lie on top or underneath – you will not damage the stoma.
- ✓ If you are worried about the stoma leaking, be intimate in the shower.

For more information, speak to a stomal therapy nurse, available at most large hospitals, or contact the Ileostomy Association of NSW on (02) 9568 2799 or the Colostomy Association of NSW Inc. on (02) 9565 4315.

For a free copy of *Sexuality for People Who Have a Stoma*, call the Cancer Council Helpline on 13 11 20 or download it from www.cancercouncil.com.au/cancerinformation.

Depending on the type of surgery you've had, having a stoma may not affect your fertility. Women will probably be advised to wait one or two years after surgery before conceiving to give their body time to recover.

Other concerns for women

Reduced vaginal size

Vaginal narrowing from radiotherapy or surgery may make penetration uncomfortable.

“I have used a series of implements to stretch the vagina - this is not so pleasant - but I suppose I can laugh about it.”

“I’m doing internal stretches and using lubrication cream. I’m also seeing a vaginal physiotherapist. Doing the stretches has helped loosen the vaginal muscles.”

Tips:

- ✓ Gradually widen the vaginal entrance by using a dilator (see page 48) or if possible, have regular, gentle, penetrative sex.
- ✓ Use a water-based lubricant.
- ✓ Try sexual positions that don’t involve deep penetration or that ensure you can control of the depth of penetration, for example, the female on top position.
- ✓ Make sure you ensure you are fully aroused before you attempt penetration. It may be helpful to use your own or your partners fingers to help relax the vagina before moving on to penetrative intercourse.
- ✓ Be aware of what you are saying to yourself in your head during intimacy: if we are anxious and are expecting discomfort it will not help the vagina muscles to relax.
- ✓ Communicate with your partner about how you feel during sexual intimacy. If you feel pain, stop and switch to another pleasuring activity. It may take a while for your body to feel comfortable again so make sure that you and your partner are realistic about this.

What is a dilator?

A dilator is shaped like a tube and is made from plastic, glass or rubber. It comes in different sizes and helps women to gently increase their vagina's size over time.

A dilator is different from a vibrator. A dilator is used to maintain the shape of your vagina, while a vibrator is used for sexual pleasure.

Talk to your doctor or nurse about how to use a dilator.

Vaginal dryness

Vaginal dryness is common after cancer treatment. It can make you more prone to vaginal infections, such as thrush, because the natural lubricating and cleaning process is not working. Dryness can cause pain with penetration.

Tips:

- ✓ Avoid soap, bubble bath and creams that irritate the genitals.
- ✓ Talk to your GP about alternative contraception if your usual contraceptive device is irritating.
- ✓ Seek advice from your medical specialist about the possible role of hormone medications or topical creams.
- ✓ Try non-perfumed, water-based lubricants, available from chemists and supermarkets.
- ✓ Use lubricant as part of your sexual play.
- ✓ Take more time before and during penetration to help the vagina relax and become well lubricated.

Thrush

Thrush, also known as candida, can occur when genital dryness causes an overgrowth of a fungus that is commonly found in the vagina. It causes itching, burning and unpleasant discharge, and can make intercourse painful. It is common in women having chemotherapy, hormone therapy or antibiotics.

"My vagina gets very dry and I get thrush a lot. You feel like you're 60 and not 40 anymore."

Tips:

- ✓ Treat thrush with prescription creams or, to soothe the genitals, use home remedies such as unsweetened, acidophilus yoghurt inserted into the vagina.
- ✓ Wear loose, cotton clothes. Avoid nylon pantyhose, tight jeans or trousers.
- ✓ Avoid baby oil, Vaseline or petroleum-based lubricants.
- ✓ Use a condom to stop the spread of thrush to your partner.

Loss of sensation

Some women experience a loss of sensation in their vagina temporarily or permanently, depending on the type of treatment they have had. This can make sex uncomfortable or unsatisfying, or may cause low libido.

Tips:

- ✓ Focus on other areas of your body and genitals that feel pleasurable when touched.
- ✓ Experiment with different sexual positions to see whether this affects sensation.
- ✓ Use a vibrator to enhance sensation in the vagina and surrounding area.

Early menopause

The average age for menopause is 52 years. Menopause before the age of 40 is considered early. After menopause, you are no longer able to have children and you may worry that your partner finds you less attractive, less sexually appealing or less feminine.

Oestrogen loss in menopause can cause hot flushes, mood swings, weight gain, insomnia, tiredness, vaginal dryness and lowered libido. Early menopause may cause osteoporosis (the loss of bone density).

Tips for menopausal symptoms:

- ✓ Use relaxation techniques and light exercise to reduce irritability, anxiety, insomnia and fatigue.
- ✓ See page 48 for tips to reduce vaginal dryness.
- ✓ Eat a healthy diet with lots of fresh produce and wholegrains.
- ✓ Seek specialist support from your local menopause clinic or Women's Health Centre.

Tips to help prevent osteoporosis:

- ✓ Eat low-fat dairy products and other high-calcium food.
- ✓ Exercise regularly. Walking, dancing and weight training help to reduce the rate of bone loss.
- ✓ Get vitamin D from fortified foods or regular, safe sun exposure.
- ✓ Talk to your doctor about medication or vitamin and mineral supplements for osteoporosis.

Vitamin D is necessary for healthy bones. Just 10 minutes in the sun on most days of the week in summer, 15-20 minutes in spring and autumn, and 30 minutes in winter will give most people enough vitamin D. Exposure should be before 10am and after 3pm to avoid sunburn.

Other concerns for men

Erectile dysfunction

When a man is unable to get or keep an erection firm enough for intercourse, it is called erectile dysfunction or impotence. This condition affects many men at different stages of their lives for many different reasons. Many men experience erectile dysfunction after cancer treatment, but this isn't always because of surgery or radiotherapy. Ageing, illness (e.g. diabetes or heart disease), medication side effects, smoking, high alcohol intake, and emotional concerns can all take their toll. It is helpful to first speak with your medical practitioner to determine whether there are any physical causes of your problem that can be treated.

Anxiety, depression and self-esteem issues can cause erectile problems,. Counselling can assist you to deal with emotional concerns and help if you have lost your sexual confidence after treatment.

“He won’t go for help because he is embarrassed by his failure to achieve an erection and his incontinence.”

“My husband uses a penis pump to engorge the penis. This has helped immensely in his ability to have a ‘hard on’.. he feels much better about it.”

Tips:

- ✓ Take time to get aroused and focus on enjoying the pleasure of sexual play, rather than worrying about your erection and “performance”.
- ✓ You can have sex and an orgasm with a half-erect penis. This works best with your partner on top guiding the penis inside.
- ✓ Help your partner reach orgasm without penetration. Experiment with other sexual activities, such as oral sex, masturbation or all-over touching.
- ✓ Try the tips for reaching orgasm on page 42.

Other options to help you get an erection include:

- **Tablets:** A variety of prescription medications help increase blood flow to the penis, resulting in an erection. You may need to try them a few times before you notice a difference. These medications can cause headaches, nausea, a blocked nose and facial flushing, and may not be suitable if you are on other medication. Ask your doctor what is best for you.
- **Penile injections:** Injecting a medication into the penis causes the blood vessels to expand and the penis to become erect. You can learn to do this yourself, although you need to take care that the injection dose is right. This treatment works well in most men, but some people experience a bit of pain after injecting or if the penis tissue becomes scarred.

- **Vacuum pump device:** Vacuum pump devices (or vacuum erection devices) draw blood into the penis where it is trapped with a rubber ring that is placed around the penis base. After sex, the ring is removed and the blood flows normally again. A pump may be an option if injections or tablets have not worked, or if you don't want to take any more medications.
- **Penile ring:** If a man is able to get an erection without assistance but has difficulty maintaining it, a rubber ring can be placed around the base of the penis, which will help keep in the blood so intercourse can take place.
- **Surgical implants:** Implants can be surgically placed in the penis, along with a pump in the scrotum, which is squeezed to inflate the implant and produce an erection. This is also called a penile prosthesis.

More information about these options is available from the Cancer Council Helpline (13 11 20). Your doctor can also help you, or call the Impotence Australia Helpline on (02) 9280 0084 or 1800 800 614 (free call).

Other therapies for erectile dysfunction

Erectile dysfunction is a common problem. It is not unusual to see advertisements for products and services offering a range of treatments for this condition, including herbal preparations, nasal sprays and lozenges. Some of these products contain testosterone or natural products that act like testosterone in the body.

Men who have had treatment for cancer need to be cautious about using these products, as there is a risk the remedy may cause side effects. If you have a testosterone-dependent cancer, such as prostate cancer, it could also be harmful to use these remedies.

Talk to your doctor or sexual health physician before taking additional over-the-counter or prescription medications to improve erections.

Ejaculation difficulties

A 'dry orgasm' is common after surgery for prostate cancer – this is when orgasm happens but no semen is actually ejaculated. Another form of dry orgasm is 'retrograde ejaculation', which can occur following surgery for an enlarged prostate or due to some medications. It is caused when a valve between the bladder and prostate does not close properly, making semen travel into the bladder instead of through the urethra. This is harmless.

Most men say that a dry orgasm does not feel as strong, long-lasting or satisfying as an orgasm with semen, but they still feel pleasure. Some men find that a dry orgasm feels the same as, or more intense than, an orgasm with semen.

Premature ejaculation may be a problem for some men. If you are worried about maintaining an erection, you may ejaculate too quickly. This is more often caused by anxiety than by cancer treatment; your doctor, a sexual health specialist, counsellor or psychologist should be able to assist.

Tips:

- ✓ Try to enjoy sex without worrying about ejaculating. Focus on your pleasure and being in “the here and now”.
- ✓ Talk to your partner about the problem. Even if you feel you ejaculate too quickly, your partner may be satisfied.
- ✓ Take the focus off of penetration – enjoy a wide range of sexual activities and avoid rushing through foreplay, as your partner may not be sufficiently stimulated for penetration.
- ✓ Increase the frequency of orgasms, perhaps by masturbation, to help delay ejaculation.

What else might help?

Hormone therapy

Most men, even after age 50 or 60, continue to produce enough testosterone. However, hormone therapy is a temporary way to restore sexual desire and erections in men who have damaged testes or low testosterone levels caused by large doses of radiation or chemotherapy. As prostate cancer is influenced by testosterone, this is not a safe option for men with this diagnosis.

Women can also have testosterone therapy if their ovaries have been removed or efforts to improve libido have not worked.

Talk to your doctor about hormone treatment if you have tried the suggestions in this booklet without success.

Complementary therapies

Complementary therapies may help enhance your general well-being and enable you to cope better with side effects such as pain, fatigue, stress, anxiety and mood swings.

There are many types of complementary therapies, including acupuncture, massage, hypnotherapy, relaxation, yoga, herbal medicine and nutrition.

Let your doctor know about any complementary therapies you want to use. This is important as some therapies may not be appropriate, depending on your conventional treatment. For example, some herbs and nutritional supplements may interact with your medication. Massage and exercise therapies may also need to be modified to accommodate the changes in your body.

For further information, call the Helpline for a copy of Understanding Complementary Therapies.

Relaxation and exercise

Some people find that relaxation, meditation and exercise help them feel better by reducing tension, anxiety and pain, and increasing energy levels. These can all improve your sense of emotional wellbeing and interest in all areas of life including intimacy.

Creative activities, such as playing music, sewing or writing, help people to relax and increase self-confidence. The hospital social worker or nurse will know whether the hospital or community health centre runs relaxation, exercise or creative therapy programs. You may also enjoy exploring different activities at home using CDs or DVDs. Contact the Cancer Council Helpline to access relaxation and meditation resources, or your local library for resources on other activities.

Regular exercise can have many benefits for your emotional and physical wellbeing. The amount and type of exercise you do will depend on what you

are used to and how you feel. Start by making small changes, such as walking to the shops, using the stairs or doing stretches. If you want to do more vigorous exercise or weight-bearing exercise, ask your doctor what is best for you.

“I got back into my swimming as soon as I could. I didn’t wear the prosthesis but I would wrap the towel around me and drop it when I reached the edge. The exercise made me feel good about myself and, with time, I forgot the towel.”

Learning to Relax

Here is a simple exercise that might help you relax. It can be done anytime and any place without anyone else noticing. There is no need for special equipment or for you to be sitting or lying in a particular way. You don’t have to set time aside in a life that is probably already busy enough; they are a pause, not an extra “task” to do as part of your health care “work”.

Relaxation Breathing

Place one or both hands on the lower part of your stomach. Breathe in slowly through your nose until you feel your stomach move. Hold it like that for a moment. Then slowly let the breath out through your mouth. Getting your stomach to rise and fall is the trick. Most of us take shallow breaths that make our chest move; that is not relaxing and can work to increase anxiety instead of being calming.

There are many variations on this sort of relaxation breathing.

Some people:

- Take one or two breaths like this to relax or calm down.
- Count silently; “breathe in 2, 3, 4 and, pause, breathe out 2, 3, 4”.
- Imagine breathing in peace or serenity and breathing out their stress.
- Imagine breathing in a colour that has meaning for them.
- Imagine the air moving in a circular motion in through the nose, through the body and out through the mouth.
- Add “remember to breathe” in their list of “things to do today”.
- Experiment a little and see what works for you.

When might this sort of breathing be useful:

- When you are waiting for an appointment.
- Lying in bed with your partner; you might like to do this together.
- When you are feeling stressed and tensed up.
- When you want to say angry words but know it isn’t OK to do that and need to pause or distract yourself.
- When you have a spare moment.
- During uncomfortable treatments and procedures.

Seeking support

Our sexual and intimate lives are personal and not something we usually discuss openly with others. This can make it hard to talk about our sexual concerns, but you don't have to cope alone. If you are in a relationship, try to talk with your partner. Sexual concerns are common and many people benefit from discussion with a professional with expertise in this area – there are many strategies and resources that can really help. Services to help you adjust emotionally to the cancer and to build your self-esteem are also available. You can have counselling by yourself or with your partner. Support groups can also be a source of information and provide an opportunity to discuss this area of your life.

“We attended a counsellor before his operation which was helpful.”

“I consulted a women’s health physiotherapist who was excellent.”

Try the strategies discussed in this booklet and if you need further guidance, discuss this with your doctor. You can ask for a referral to a relationships counsellor or a sex therapist who can assist with ongoing or complex issues. Sometimes health professionals are embarrassed to discuss sexuality, or may not realise that it is important for people with cancer and their partners. You may need to raise the issue with your doctor yourself. Use the questions on page 63 to help you ask about the things that are important to you.

“I haven’t had a lot of medical advice about how we should continue to conduct our intimate relationship”;

“They did not educate us on anything at all. But when I asked the questions, I did get answers.”

If you don't get the answers you need from one health professional, ask others in your team or contact the Cancer Council Helpline for advice.

Talk to someone who's been there

It can help to talk to other people who have been through a similar experience. There are many ways you can make contact with others for mutual support, to ask questions and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Support services available for patients, carers and family members include:

- face-to-face support groups, which are often held in community centres or hospitals
- telephone support groups for certain situations or types of cancer, which trained counsellors facilitate
- online discussion forums where people can connect with each other any time – see www.cancerconnections.com.au
- Cancer Council Connect, a program that matches you with a volunteer who has been through a similar cancer experience and who understands how you're feeling.

“Before I joined the men’s group, I hadn’t talked much about sexuality. Now it’s just a normal part of conversation, and I think it ought to be. If a group trusts in each other, people will share a whole lot of stuff”.

“Only a person with a similar experience can really talk with understanding.”

Ask your nurse or social worker to tell you about support groups in your area, or call the Cancer Council Helpline to access the Cancer Services Directory and to find out how you can connect with other people.

The C Word is a cancer support group for lesbians and their partners. ACON also offers support and referrals for gay men with cancer. For more information see www.acon.org.au or call 1800 063 060.

Understanding Cancer and Living Well After Cancer programs

The Cancer Council runs two programs for people who have been diagnosed with cancer, their partners, carers, friends and families. Courses are held at hospitals and community organisations throughout NSW.

- **Understanding Cancer:** This is for people who have recently been diagnosed or who are having treatment. It offers practical information on symptoms, side effects, treatment, palliative care, diet, exercise and complementary therapies.
- **Living Well After Cancer:** This is for people who finished treatment two or more years ago. It helps survivors learn how to adjust to the emotional and social effects of cancer.

For more information on either of these programs, call the Cancer Council Helpline or visit www.cancercouncil.com.au.

Cancer Council Helpline 13 11 20

Monday to Friday 9am to 5pm

The Cancer Council Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call, you can talk about your concerns and needs confidentially with oncology health professionals. Helpline consultants can send you written information and put you in touch with appropriate services in your area. You can also request services in languages other than English.

You can call the Cancer Council Helpline, Monday to Friday, 9am to 5pm. If calling outside business hours, you can leave a message and your call will be returned the next business day.

If you have difficulty communicating over the phone, contact the National Relay Service, a Government initiative to assist people who are hearing and/or speech impaired (www.relayservice.com.au). This service will help you to communicate with a Cancer Council Helpline consultant.



Contact information for support services:

Cancer Council ACT

5 Richmond Avenue
Fairbairn ACT 2609
Tel: (02) 6257 9999
Fax: (02) 6257 5055
Email: reception@actcancer.org
Website: www.actcancer.org

Cancer Council NSW

153 Dowling Street
Woolloomooloo NSW 2011
Tel: (02) 9334 1900
Fax: (02) 9358 1452
Email: feedback@nswcc.org.au
Website: www.cancercouncil.com.au

Cancer Council Northern Territory

Units 1-3, Casi House, Vanderlin Drive
Casuarina NT 0810
Tel: (08) 8927 4888
Fax: (08) 8927 4990
Email: admin@cancernt.org.au
Website: www.cancercouncilnt.com.au

Cancer Council Queensland

553 Gregory Terrace
Fortitude Valley QLD 4006
Tel: (07) 3258 2200
Fax: (07) 3257 1306
Email: info@cancerqld.org.au
Website: www.cancerqld.org.au

Cancer Council South Australia

202 Greenhill Road
Eastwood SA 5063
Tel: (08) 8291 4111
Fax: (08) 8291 4122
Email: tcc@cancersa.org.au
Website: <http://www.cancersa.org.au/>

Cancer Council Tasmania

180-184 Collins Street
Hobart TAS 7000
Tel: (03) 6233 2030
Fax: (03) 6233 2123
Email: infotas@cancertas.org.au
Website: www.cancertas.org.au

Cancer Council Victoria

1 Rathdowne Street
Carlton VIC 3053
Tel: (03) 9635 5000
Fax: (03) 9635 5270
Email: enquiries@cancervic.org.au
Website: www.cancervic.org.au

Cancer Council Western Australia

46 Ventnor Avenue
West Perth WA 6005
Tel: (08) 9212 4333
Fax: (08) 9212 4334
Email: inquiries@cancerwa.asn.au
Website: www.cancerwa.asn.au

- **National Breast Cancer Foundation**

Level 9, 50 Pitt Street, Sydney NSW 2000

General enquiries: 1300 708 763

NBCF Reception: 02 8098 4800

Fax number: 02 8098 4801

Website: www.nbcf.org.au

- **Prostate Cancer Foundation of Australia**

Level 2, 51-53 Chandos Street, St Leonards NSW 2065

Mail Address: P.O.Box 1332, Lane Cove NSW 1595

Freecall: 1800 220 099

Telephone: 61 2 9438 7000

Facsimile: 61 2 9438 7099

Email: enquiries@prostate.org.au

Website: www.prostate.org.au

- **ACON – ‘Same-Sex Attracted People + Cancer’**

9 Commonwealth Street, Surry Hills NSW 2010

Mail Address: PO Box 350, Darlinghurst NSW 1300

Telephone: 02 9206 2000

Free Call: 1800 063 060

Hearing Impaired: 02 9283 2088

Email: women@acon.org.au

Website: www.acon.org.au/womens-health/cancer/What-Forms-of-Cancer-Affect-Lesbians-and-Same-Sex-Attracted-Women

- **Breast Cancer Network Australia**

293 Camberwell Road, Camberwell VIC 3124

Freecall: 1800 500 258

Telephone: 03 9805 2500

Facsimile: 03 9805 2599

Email: beacon@bcna.org.au

Website: www.bcna.org.au

Information on the Internet:

The Internet can be a useful source of information, although not all websites are reliable. The websites listed below are good sources of trustworthy information.

- **Continenence Foundation of Australia**

AMA House, 293 Royal Parade, Parkville VIC 3052

Telephone: 03 9347 2522

Facsimile: 03 9347 2533

Email: info@continenence.org.au

Website: www.continenence.org.au

- **Impotence Australia**

Telephone: 02 9280 0084

Freecall: 1800 800 614

Email: admin@impotenceaustralia.com.au

Website: www.impotenceaustralia.com.au

- **Talk It Over – Men’s Line Australia**

Telephone: 1300 789 978

Website: www.menslineaus.org.au

- **Cancer Connections**

Website: www.cancerconnections.com.au

- **Gynaecological Cancer Support**

Website: www.gynaecancersupport.org.au

- **National Breast and Ovarian Cancer Centre**

Website: www.nboocc.org.au

- **Andrology Australia**

Website: www.andrologyaustralia.org

- **Beyond Blue – The National Depression Initiative**

Website: www.beyondblue.org.au

- **Black Dog Institute**

Hospital Road, Prince of Wales Hospital, Randwick NSW 2031

Telephone: 02 9382 4523

Facsimile: 02 9382 8208

Email: blackdog@blackdog.org.au

Website: www.blackdoginstitute.org.au

Use search engines

The internet changes constantly with new information and sites being added and deleted all the time. Use a search engine such as Google to see what is 'out there'. A useful tip is to put phrases in speech marks, for example "breast cancer" or "stoma cover" and to look at a few pages in each lot of search results.

Cancer information library

Following a cancer diagnosis, many people look for information about new types of treatment, the latest research findings and stories about how other people have coped.

The Cancer Council Library has a wealth of information on these topics. There are more than 3,000 resources in the collection, including books, CDs, DVDs, videos and a large range of medical journals.

You can visit the library at 153 Dowling Street, Woolloomooloo (9am-5pm Monday-Friday), borrow by post or ask your local librarian to organise an inter-library loan. Contact the librarian on 13 11 20 or email library@nswcc.org.au.

Related publications

Cancer Council has a range of booklets on different cancer types, treatments and lifestyle issues. You might find the following publications relevant:

Emotions and Cancer

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Complementary Therapies

Massage and Cancer: an introduction to the benefits of touch

Caring for Someone with Cancer.

Call the Helpline for free copies, or download them from the website www.cancerCouncil.com.au/cancerinformation.

You may also find these books helpful:

- Sally Kydd & Dana Rowett: *Intimacy After Cancer*, Big Think Media, 2006.
- Jimmie C. Holland & Sheldon Lewis: *The Human Side of Cancer*, Quill, 2001.
- Sandra Pertot: *Perfectly Normal: Living and Loving with Low Libido*, Rodale, 2005.

Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your illness, treatment and how your sexuality and intimacy are affected. If your doctor gives you answers that you don't understand, it is okay to ask for clarification.

1. How will this treatment affect my sexuality?
2. How will treatment affect my fertility?
3. Are the changes likely to be temporary or permanent? If temporary, how long will I experience them for?
4. When will I be able to have sex again? Am I likely to have any problems when I start having sex?
5. Are there times when sex should be avoided or should I take any precautions?
6. I'm not interested in having sex. Will this be permanent?
7. It hurts when I have sex. What can I do about it?
8. Sex doesn't feel the same anymore. What can I do?
9. I am having trouble reaching orgasm. Will it always be like this?
10. I am afraid I can't satisfy my partner anymore or my partner is no longer interested in sex. What can I do?
11. Could having sex make my cancer worse or affect my partner in any way?
12. Should I still use contraception? What kind is best for me?
13. If I want to have children later but cancer treatment might reduce my fertility, what options are available?
14. Who can my partner and I talk to if we have problems we can't resolve ourselves?

For women

1. What do you recommend for vaginal dryness?
2. Would hormone replacement therapy be necessary or beneficial for me?

For men

1. If I have erection problems after my treatment, will this be temporary or permanent? Can I do anything to help?
2. It hurts when I ejaculate. Is this normal? What can I do about it?

Glossary

adrenal glands

Triangular glands resting on top of each kidney that produce adrenaline and other hormones, including sex hormones.

androgens

Male sex hormones producing male sexual characteristics and promoting sexual desire. The main androgen is testosterone.

body image

What you feel about your body, how you think it looks, how you present it to others, and how you think others see you.

breast conservation surgery

Surgery to remove part of the breast. Also called a lumpectomy.

breast form

An artificial breast worn in a bra cup or attached to the body to recreate the look of a natural breast. Also called breast prosthesis.

breast reconstruction

The surgical rebuilding of a breast after mastectomy.

cervix

The end of the uterus that forms a canal and extends into the vagina.

chemotherapy

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth.

climax

The peak of sexual response. Also known as orgasm.

clitoris

The main sexual pleasure organ for women. It is made up of tissue with rich sensory nerve endings, which becomes erect on arousal.

dry orgasm

Sexual climax without the release of semen from the penis.

ejaculation

When semen passes through the urethra and out of the penis during an orgasm.

erectile dysfunction

Inability to obtain and maintain an erection firm enough for penetration. Also called impotence.

external genitalia

In women, known collectively as the vulva and including the clitoris, labia minora, labia majora and mons pubis. In men, it includes the penis, scrotum and testes.

Fallopian tubes

The two long, finger-like tubes that extend from the uterus to the ovaries. The Fallopian tubes carry fertilised eggs from the ovary to the uterus.

fertility

The ability to conceive a child.

genitals

The sexual organs.

hormone

Chemical messengers in the body that transfer information between cells. They are responsible for growth and reproduction.

hormone therapy

A treatment that blocks the body's natural hormones, which sometimes make cancer grow. Hormone therapy can also be given after cancer treatment to stimulate the hormones again.

hysterectomy

The surgical removal of the uterus and cervix.

impotence

See erectile dysfunction.

labia majora

The outer lips of the vulva.

labia minora

The inner lips of the vulva, which join at the top to cover the clitoris.

libido

Sex drive.

lymphoedema

Swelling caused by a build-up of lymph fluid when lymphatic vessels and nodes don't drain properly.

mastectomy

The surgical removal of the whole breast.

masturbation

Stimulation of the genitals without sexual intercourse to reach orgasm.

menopause

When a woman stops having periods (menstruating). This can happen naturally (usually around the age of 52 years), or because of chemotherapy, hormone treatment or removing the ovaries.

mons pubis

In women, the area of fatty tissue covered with pubic hair.

nerve-sparing surgery

A type of surgery to save the nerves that affect ejaculation and urination.

oestrogen

A female sex hormone produced mainly by the ovaries.

oophorectomy

The surgical removal of one or both ovaries.

orchidectomy

An operation to remove one or both testicles. Also called orchiectomy.

orgasm

Sexual climax.

ova

The female eggs produced by the ovary.

ovary

A hormone-producing female reproductive organ that is located near the uterus. It also produces eggs (ova).

ovulation

The release of an egg during the menstrual cycle.

Peyronie's disease

Pain in the penis as it becomes erect, or a curve in the erect penis. This may develop due to radiotherapy to the penis.

premature ejaculation

The inability to delay ejaculation.

premature menopause

Menopause that occurs before the age of 40.

progesterone

A hormone produced by the ovaries that prepares the lining of the uterus (endometrium) for pregnancy.

prostate

A gland about the size of a walnut found only in men. It produces most of the fluid that makes up semen.

prosthesis

An artificial replacement for a lost body part.

radiotherapy

Energy in the form of waves or particles, including gamma rays, x-rays and ultraviolet (UV) rays. This energy is harmful to cells and is used in radiotherapy to destroy cancer cells.

retrograde ejaculation

A condition where the sperm travels backwards into the bladder, instead of forwards out of the penis.

scrotum

The external pouch of skin behind the penis containing the testes.

semen

The fluid ejaculated from the penis during sexual climax. It contains sperm from the testes and secretions from the prostate and seminal vesicles.

seminal vesicles

Glands that lie very close to the prostate and produce secretions that form part of the semen.

side effect

Unintended effect of a drug or treatment.

sperm

The male sex cell, which is made in the testes.

stoma

A surgically created opening of the body. Also called an ostomy.

testes

Two egg-shaped glands that produce sperm and the male sex hormone testosterone. They are found in the scrotum. Also called testicles.

testosterone

The major male sex hormone produced by the testes. It promotes the development of male sex characteristics. A small amount is also made in the ovaries and helps increase sexual desire in women.

urethra

The tube that carries urine from the bladder to the outside of the body. In men, the urethra also carries semen.

uterus

The hollow muscular organ in which a fertilised egg (ovum) grows and a foetus is nourished until birth. Also known as the womb.

vagina

A muscular canal about eight to 10 centimetres long that extends from the entrance of the uterus to the outer female sex organs.

vaginectomy

An operation that removes all of the vagina.

vas deferens

Tubes in the male reproductive system that carry sperm from the testes to the prostate.

vulva

The region incorporating the external sexual organs of a woman. These include the mons pubis, labia and clitoris.

vulvectomy

Removal of some or all of the outer sex organs (the vulva).

vulvodynia

Pain in the vulvar area.