



**Recovering after
Pelvic Radiation Therapy**
A guide for women

ACKNOWLEDGEMENTS

This booklet was conceived and developed by a team from the Centre for Medical Psychology and Evidence-based Decision –making (CeMPED) at the University of Sydney, led by **Dr Ilona Juraskova and Ms Fran Lubotzky**.

We gratefully acknowledge the following people for their valuable input into the development of this resource:

Ms Kathryn Nattress who was largely involved with the development and revision of the booklet and provided invaluable input, expertise and time – Sydney Gynaecologic Oncology Group (SCOG), Sydney Cancer Centre, Camperdown, Sydney.

The cervical, endometrial, anal and rectal cancer patients who participated in the pilot study of the booklet and in the reviewing and revision of the booklet.

- **Associate Professor Chris Milross, Professor Jonathan Carter, Dr Susan Carroll and Ms Shannon Philp** – Sydney Gynaecologic Oncology Group (SCOG), Sydney Cancer Centre, Camperdown, Sydney.
- **Ms Ellen Barlow** – Gynaecological Cancer Centre, Royal Hospital for Women (RHW), Randwick, Sydney.
- **Ms Jayne Maidens** – Gynaecological Oncology, Royal North Shore Hospital, St Leonards, Sydney.
- **Ms Sherin Jarvis** – RHW, Physiotherapy Department, Randwick, Sydney.
- **Ms Rosalind Robinson** – Clinical Psychologist, Gynaecological Cancer Centre, RHW, Randwick, Sydney.
- **Professor Phyllis Butow, Carissa Bonner and Esther Davis** (review of the booklet content) – CeMPED; The University of Sydney, Camperdown, Sydney.
- **Ms Susan Thorpe** – Research assistant.

The graphic design and printing of the booklet has been funded by Sydney Gynaecologic Oncology Group (SCOG) at the Sydney Cancer Centre, Camperdown, Sydney (Professor Jonathan Carter).

The illustration on page 6 by Con Stamatis, The Cancer Council Victoria ©

The illustration on page 7 by Margaret Carew

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Centre for Medical Psychology and Evidence-based Decision-making (CeMPED)
Transient bld. F12
School of Psychology
The University of Sydney
NSW 2006 Australia

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*"Knowing what was going on helped me greatly.
I believe knowledge is power."*



1 | This booklet and you

Why we developed this booklet

If you are reading this booklet, you have undergone (or will undergo) pelvic radiation therapy for gynaecological, anal, rectal or bladder cancer.

Your diagnosis and treatment can have an impact on how you feel, how your body functions and on your pelvic health and sexual wellbeing. This booklet suggests ways that may reduce the impact of the cancer and its treatment on your pelvic health. The booklet also provides information on radiation treatment side effects and recommended rehabilitation options which may help follow-up pelvic examinations to be performed more comfortably.

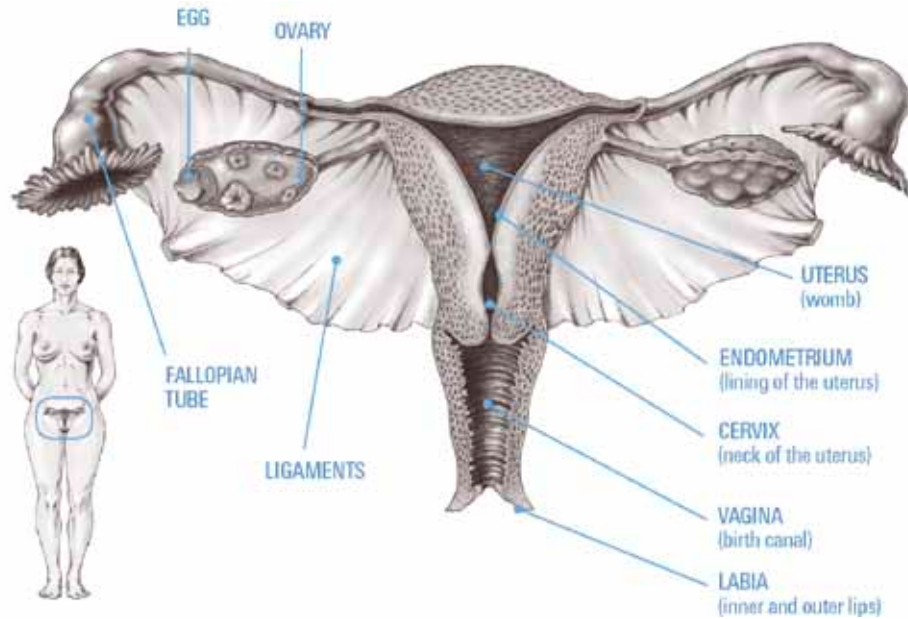
From previous research we know that many patients would appreciate receiving information from their health professionals about sexual issues that could possibly arise post-treatment. However, some women may feel uncomfortable and therefore reluctant, to ask questions about this topic. This booklet provides a summary of relevant information as well as a list of questions that you might like to ask your doctor or a member of your healthcare team (see page 48). Ways to address these issues are also recommended.

This booklet has been designed, and has important information, for all women, **with or without a partner**. If you have a partner, we encourage you to share this booklet with them (or others close to you). They may find the information helpful in understanding what you are experiencing and this may help you to discuss these experiences together. If you are unfamiliar with any of the terms used in this booklet, please consult the glossary (page 42).

2 | Understanding your body

Below are some diagrams and information about the female anatomy to help you understand the parts of your body likely to be affected by pelvic radiation therapy and the possible side effects of that treatment.

The female reproductive system



Reproduced with permission by Cancer Council Victoria.
From the booklet 'Sexuality and Cancer', 2007, p. 9.
Illustrations by Con Stamatis.

A woman's sex organs consist of the outer lips or *labia majora*, found under the *mons pubis*, which is the fatty tissue under the pubic hair. When parted these lips show somewhat thinner, inner lips, called the *labia minora*. Both *labia* join at the top to cover a tiny knob of tissue sensitive to touch, called the clitoris. Together these external organs are called the vulva.

Below the clitoris is the urethra, through which urine is passed. Below the urethra is the vaginal opening. Inside a woman's body is the vagina, the cervix, uterus (womb), two Fallopian tubes, and two ovaries. The vagina is lined with a mucous membrane (skin) and muscle that stretches to accommodate a penis, and stretches even more during childbirth.

The Vulva

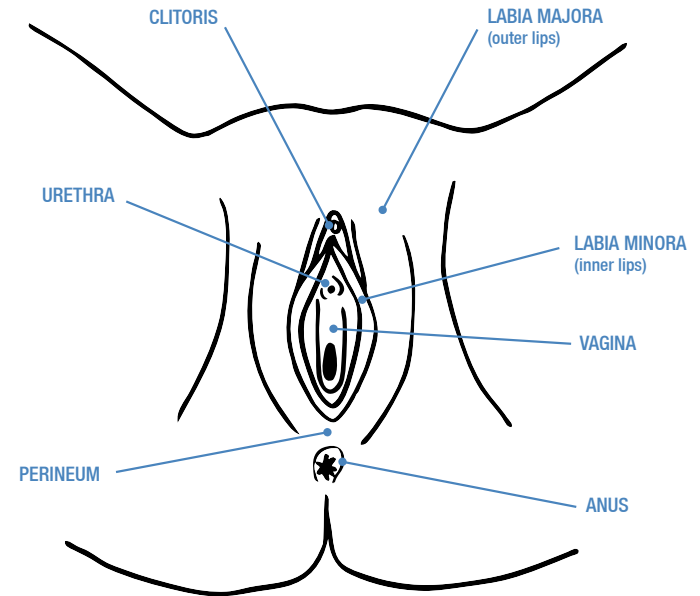


Illustration by Margaret Carew.

Radiotherapy may lead to acute and/or late effects, due to damaged tissue and the formation of scar tissue. One of the areas more commonly affected following pelvic radiation treatment is the vagina. (The general, acute and late effects of pelvic radiation treatment are discussed after this section.)

Vagina

During radiation therapy to the pelvic area, the muscles and lining of the vagina may become tender and sore due to inflammation, and this soreness can last for a few weeks after treatment has finished. The mucous membrane lining the vaginal walls may also be damaged and as it heals it may stick together, causing adhesions that partially close the opening in the vagina. A damaged mucous membrane can prevent adequate lubrication, which can make the vagina feel dry and itchy and make sexual penetration without the use of a synthetic lubricant uncomfortable. As the deeper vaginal tissue heals, inflexible scar tissue can form. This tissue is more fibrous and bulky than the normal tissue in the vagina and more rigid, not allowing the vagina to stretch as it needs to do during sexual intercourse. This rigidity and inability to stretch is called **stenosis**. Because of these changes, the vagina may feel as if it is narrower and shorter.

Your treatment team will try to limit the damage caused by radiation as much as possible, but nonetheless some damage may occur. Some tissues take much longer to heal than others, so some of the side effects may be there for a long time. *Most side effects can be improved with appropriate care and techniques.*

Your healthcare team may be able to suggest ways to reduce these side effects. For example, you may be advised to use vaginal lubricants, moisturisers or dilators or continue to have regular intercourse. If recommended for you, the regular use of a dilator (once the acute inflammatory phase has settled - no earlier than 6 weeks after treatment has ended) may help prevent the lining of the vagina from sticking together. Scar tissue can be gently stretched so it does not tighten and shorten the vagina. **This makes vaginal examination at follow-ups easier to perform.** This booklet provides information on the use of dilators (see page 20).

3 | Pelvic radiation therapy

Pelvic cancers include: rectal cancer; anal cancer; colon cancer; cervical cancer; uterine (endometrial) cancer; vaginal cancer; vulva cancer; and bladder cancer.

Radiotherapy uses x-rays and other forms of radiation to kill or injure cancer cells so they cannot multiply. For some types of cancer, radiotherapy is the only treatment given. However, it is more often used in combination with other forms of treatment, such as surgery and/or chemotherapy (anti-cancer drug treatment). Your treatment is carefully planned so that as little damage as possible is done to your normal tissue.

Radiotherapy can be given in two ways: externally or internally.

External pelvic radiation therapy is given externally via a machine placed a particular distance from the body and cancer site. The machine directs radiation into the cancer mass and surrounding tissue.

Internal pelvic radiation therapy (brachytherapy) is commonly used for cervical and endometrial cancer. Radioactive material is placed in thin tubes and inserted into the body on or near the cancer site. Internal therapy can be given in two ways:

- 1) the tubes are inserted into the body and left to emit a continuous low dose treatment for up to 30 hours, or
- 2) more commonly, the tubes are inserted several times for several high-dose rate treatments over a much shorter length of time.

Your healthcare team will discuss with you what to expect from your particular radiotherapy treatment process.

This booklet will discuss some side effects of pelvic radiotherapy that may affect your post-treatment pelvic/vaginal health and your sexual life. The degree and extent of such side effects will depend upon the type and stage of your cancer, the area of the body included within the radiation field and the total dose of radiation used.

4

Pelvic radiation therapy side effects

General side effects

Radiotherapy for cancer can cause a range of both acute and late effects, depending on the type of radiotherapy received (e.g. brachytherapy, external beam radiotherapy). The most common effects occur during or soon after the treatment. Side effects happen because radiotherapy can cause damage to healthy cells as well as cancer cells. Some effects of radiotherapy may affect how you feel about yourself as a woman. These will be discussed below and throughout the rest of the booklet. Please speak to a member of your healthcare team, a counsellor, or see the contacts section of this booklet if you would like to talk to someone about any difficulties you may be having.

Acute effects

Diarrhoea Radiotherapy may irritate the bowel and cause diarrhoea and abdominal cramps. Diarrhoea may persist for several months following treatment. If there is a problem, let a member of your healthcare team know because effective treatment can be prescribed.

Hair loss Radiotherapy can cause hair loss in the area being treated. This may be permanent.

Other effects You may have slight bleeding or discharge from the vagina once the radiotherapy treatment has ended. If this continues or becomes heavy, it is important to let your doctor or nurse know. A heavier and offensive smelling discharge may mean you have an infection which requires treatment.

Pain may be experienced due to inflammation of the tissue and skin in the irradiated area. Most women will notice their skin becomes red, itchy and dry initially. Your treatment team can provide you with advice as to how to care for your skin during treatment.

Radiotherapy to the pelvic area can also cause tiredness and a burning sensation when passing urine (cystitis). These side effects can be mild or

troublesome depending on the type, dose and length of the radiotherapy treatment.

Late effects and long-term implications of treatment

Radiotherapy to the pelvic area can sometimes lead to long-term side effects, with some occurring later on (for example, up to 1 year or more post-treatment). However, improvements in treatment planning and the way in which the radiotherapy is given have made these late effects much less likely.

Bowel and bladder problems In some people the bowel or the bladder may be permanently affected by the radiotherapy. If this happens, then more frequent and looser bowel motions and bleeding may occur. Speak to a member of your treatment team who can suggest treatment if you are experiencing these side effects.

Fertility problems Radiotherapy to the pelvic area for cancer of the rectum, bladder or cervix can stop the production of female hormones in the ovaries. Radiotherapy to the pelvic area for anal, rectal, gynaecological or bladder cancer can affect sexual organs and functioning. This is likely to have a permanent effect on your ability to have children (fertility). It is best for you (and your partner if you have one at present) to talk about these issues with your doctor. If you still wish to have children, speak with your doctor before you start radiotherapy.

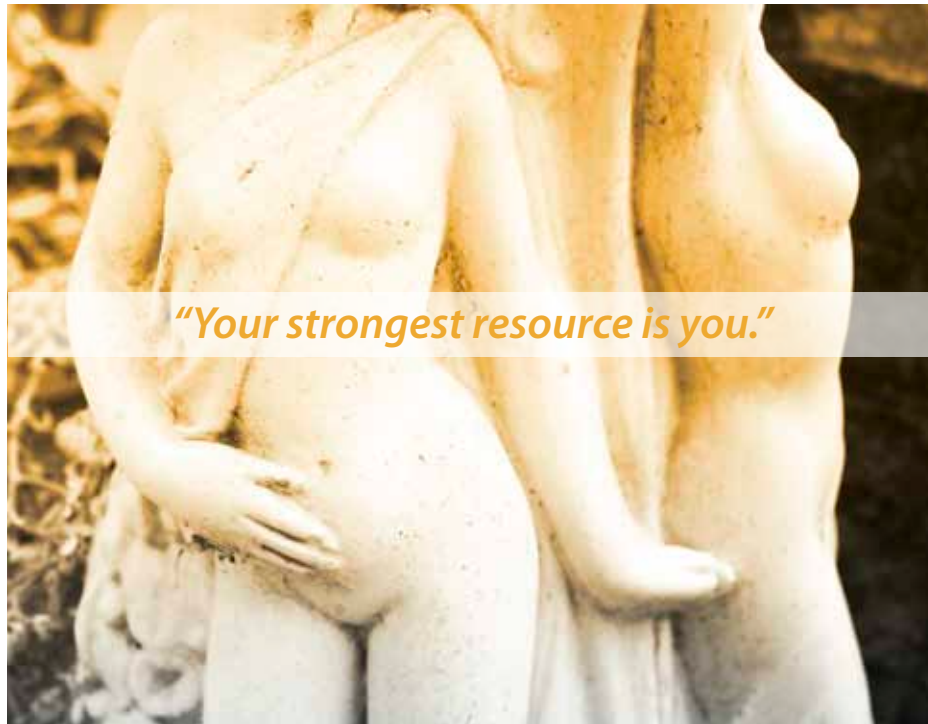
Women who hope to have children or to have added to their family may feel deeply upset about a possible loss of fertility. These feelings are understandable and it can help to talk to a specialist nurse or counsellor who can provide support and offer resources to help you (and your partner if you have one at present) cope.

Menopause When the ovaries remain within, or close to, the radiation field, pre-menopausal women may experience early menopause as damaged ovaries cannot produce oestrogen and the lessening of oestrogen contributes to the cessation of monthly periods. Some menopausal symptoms, such as vaginal dryness, hot flushes and mood swings, may occur. Post-menopausal women will have already dealt with these symptoms.

Talk to your doctor about what you can expect from your specific radiation treatments. In some cases, certain side effects may be preventable.

Ask your doctor about your options.

If you would like more information, the Cancer Council's booklet "Understanding Radiotherapy" describes ways to manage the side effects of radiotherapy. Also see the contacts sections of this booklet (pages 38–39) and/or speak to a member of your treatment team if you have any concerns about your treatment and effects which may or may not occur.



5

Sexuality during and after pelvic radiation therapy

The diagnosis of cancer and its treatments can have a dramatic effect on a person's sexual identity. It may challenge many beliefs, sexual behaviours and issues of intimacy, and cause you to confront issues of survival and mortality.

At the moment, sexual activity may be the last thing on your mind as you consider various treatment options and cope with any anxiety surrounding a cancer diagnosis. However, as you start to feel better following the treatment, your life may return to a more familiar pattern. This may include recommencing your sexual life. You may find it helpful to discuss your sexual life with your healthcare team so that any known sexual doubts can be addressed, and any problems, real or anticipated, can be dealt with. *Desire, patience and practice, together with a willingness to investigate, and a sense of humour, will really help.*

Common sexual problems after pelvic radiation therapy

Women treated for cancers anywhere in the pelvic region may experience treatment side effects that make resuming sexual activity physically painful and/or difficult. **It is normal to be anxious about becoming sexually active again after treatment for any pelvic cancer.**

In addition to the physical changes, having cancer can also affect you emotionally and psychologically. For instance, you may feel anxious and worn out by your illness, your treatment, and your prognosis. Your mood may go up and down, and you may feel you have lost your femininity (identity as a woman), your body image and/or control over your body.

All these emotions may affect your sense of being sexually desirable and sexually competent, and your willingness to resume an intimacy with your partner.

Being aware of ways pelvic radiation therapy may affect your post-treatment sexual ability may help you make some adjustments to your usual practices.

Expert professional help is always available. If you feel comfortable, speak to a member of your healthcare team and/or see the 'contacts' section on pages 38–39 of this booklet.

A selection of sexual problems that might occur following radiation treatment is listed below. Later in the booklet there are tips and advice on overcoming some of difficulties you may be experiencing (see pages 20–29).

Vaginal Dryness

Cancer treatments may cause a variety of changes that lead to vaginal dryness which, if left untreated, can lead to small tears in the lining of the vagina, bleeding, ulceration and an increased risk of infection. These conditions can lead to pain during sexual intercourse. ***Extra lubrication may make intercourse more comfortable (see page 27).***

Reduced vaginal flexibility and size

Vaginal rigidity and scar tissue may lead to a feeling that the vagina is shorter or less flexible since the vagina will have lost the ability to soften and stretch to the degree that it previously had. ***The vaginal dilators provided for you to use as part of your post-treatment rehabilitation are intended to help maintain as much softness and flexibility in the vaginal tissue as possible.***

Pain

Following radiotherapy, the vagina may feel tender and sensitive. Apprehension and fear that it may hurt when touching, rubbing or when penetration takes place, may cause an involuntary tightening of the pelvic floor muscles and increase any pain already felt (see pages 28-29).

Lymphoedema (swelling of legs)

When the lymph nodes have been damaged as a result of surgery and radiation, the lymphatic system may not carry all the fluid away as efficiently as before. Swelling is caused by a build-up of lymphatic fluid, which is a colourless liquid that normally surrounds our cells and has its own circulatory system. Those who have had both surgery to remove the lymph nodes and external beam radiotherapy are most at risk. Many women with lymphoedema find that this impacts on how they feel about their bodies and sexuality. Compression stockings and massage may help with the swelling, however, these require a referral from your doctor. Feeling swollen may impact on your feelings of comfort with your body sexually; ***speaking to a member of your healthcare team or a counsellor may help with your concerns.***

Damage to the skin in the radiation field

Damage to the internal tissues during brachytherapy (internal radiation) can cause soreness, redness and swelling.

Since internal tissue is often more fragile than our surface skin, it may split and ulcerate more easily, leaving the way open for infection to enter the body. External radiation may cause some slight discolouration and pigment changes on the skin at the site of the radiation. The skin may first look and feel sunburnt, but this will gradually fade to a tanned look, returning to its normal colour within 6 to 12 months. ***It is advisable to avoid soaps, perfumes, creams, sun, scratching and synthetic fibres in order to minimise pain, irritation and further discomfort.***

Loss of desire for sex

Loss of libido, as it is often called, may occur for any number of physical or psychological reasons. Many women find the need for intimacy intensifies when they are under stress. There may well be physical reasons that sexual activity is uncomfortable and these can be addressed. Embarrassment, particularly for those women following treatment for anal, rectal and bladder cancers, at having a bag to gather their urine and/or faeces may take a while to overcome. Becoming menopausal at an early age, and the loss of fertility, can have a significant psychological impact on your sexual relationships and how you feel about yourself as a woman. Talking to a member of your healthcare team or counsellor can be helpful if you are experiencing any difficulties with your body image and/or sexual relationship (see pages 38-40 for support contacts in this booklet).

Although it may be difficult or different at first, it is still possible to have a satisfying sex life after radiation treatment. If you are experiencing worrisome concerns, discussing these difficulties with a member of your healthcare team or a counsellor may be helpful.

Difficulty reaching orgasm

This may occur if there has been damage to the extensive nerve network that serves the clitoris, since clitoral stimulation is seen as an important precursor to orgasm for many women. Many women find difficulty reaching orgasm. This can be for a number of reasons, including fear and anxiety, nerve damage as a result of surgery and radiation, and fatigue due to treatment (see pages 8-10).

Pain during intercourse

This is known as dyspareunia, and may result from abdominal or other bodily pain, vaginal soreness, hypersensitivity and/or rigidity of vaginal walls, preventing the vagina's stretching and lubrication. Often an involuntary tightening and spasm fear response to the mere thought

of penetration can occur. Insufficient preparation for sexual penetration, both physical and psychological, can make this worse. Some women find that sperm stings after radiation therapy and have found that using condoms helps reduce the sting and reduces friction during penetration. *Finding more comfortable sexual positions, using extra lubrication, being gentle and patient may all help if pain is experienced during sexual intercourse. To help reduce pain and vaginal tightness some women have found it helpful to use vaginal dilators just **before** sexual intercourse.*

Some of these effects will be temporary whilst others may seem more permanent. You can receive expert professional advice from your specialist nurse or doctor to help you manage, relieve and control some of these conditions. This, in turn, can make a big difference to your health, your quality of life and your intimate relationships.

Not all women experience these side effects. Some women experience very few side effects, whilst others seem to be affected by several of them. It is important to consult with your doctor and your healthcare team about initiating and/or continuing sexual intercourse during radiotherapy. Each person is unique in their treatment and responses to that treatment. It may, or may not, be appropriate to continue any sexual activity you normally engage in while you undergo your treatment. You and your partner can discuss this with your doctor.

“Sometimes it can seem difficult to discuss, but intimate relationships are often affected by cancer ...”

Myths about cancer, treatment and sexuality

Many women and their partners have fears and concerns about how the cancer and/or treatment will affect their sexual life. On the following page we dispel some of the common myths.

Myth: Sexual intercourse will cause or spread your cancer, or make it return following successful treatment.

Current understanding: **Sexual intercourse will NOT cause or spread your cancer, nor will it make your cancer return following successful treatment.***

Myth: You can transmit your cancer to your partner through sexual intercourse.

Current understanding: **You CANNOT transmit your cancer to your partner through sexual intercourse.***

Myth: You are ‘radioactive’ following your treatment, hence you can harm your partner.

Current understanding: **You are not ‘radioactive’ following your treatment. It is safe to engage in sexual activity as soon as there is a mutual desire and ability to do so, and there are no contra-indications.**

Myth: Sex and/or masturbation will make cancer worse.

Current understanding: **Sex and/or masturbation will not make cancer worse.**

Myth: I’ll never enjoy sex again.

Current understanding: **Most women are able to resume a healthy sexual life after their treatment. Although the vagina may be smaller or narrower after your pelvic radiation treatment there are things you can do that can help, including using vaginal dilators so that you can still enjoy sexual intercourse.**

Myth: You need to have intercourse to keep your vagina open.

Current understanding: **For some women, the use of a dilator may be recommended to keep the vagina open. If you feel comfortable to, you may choose to engage in sexual intercourse. Some women may prefer to use a vibrator or finger. However, do not feel obliged to engage in sexual activities in order to keep the vagina open.**

* Many women have concerns about the HPV and its link to cervical and anal cancer. Your healthcare team will be happy to discuss any concerns you may have in more detail.

6 Coping with sexual difficulties following pelvic radiation therapy

An intimate relationship with a partner may help you to feel loved and supported as you go through your cancer treatment. The loving support of family and friends is just as important. Restoring sexual activity may take time, particularly if there are continuing side effects from your cancer treatments. *Where possible, it is recommended to prevent or minimise these side effects even if you have no intention of being sexually active now or in the immediate future.*

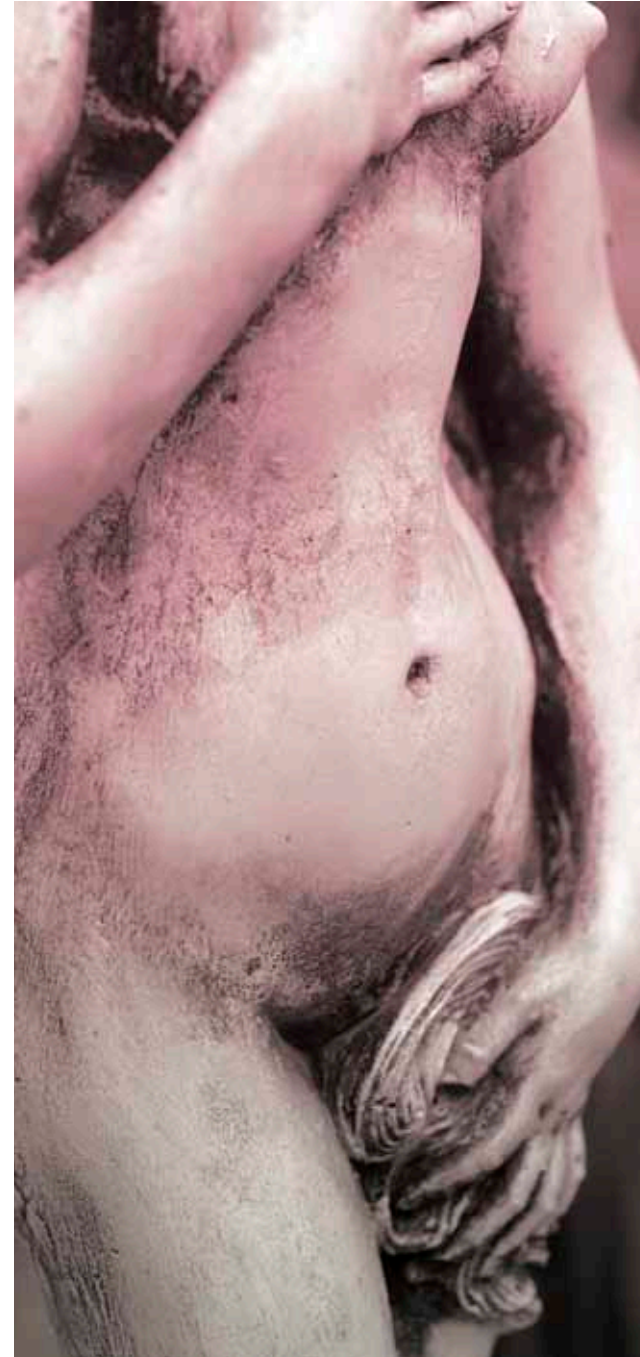
Listed below are some tips on how to anticipate, cope with and get help for common sexual difficulties that you and your partner may be experiencing.

What can you do to regain your sexual life?

Knowing what sexual side effects could occur before you begin your cancer treatment can help you be more prepared to deal with them as you go through treatment. If you experience side effects, find out from a qualified health professional as much as you can about what may be causing them and methods to manage them. This will help you feel more in control of the situation and be aware of all the treatment options available to you.

It may also just simply take time for you to regain your sexual function after cancer treatment. While that can be frustrating it is good to remember that if you had a positive and satisfying sex life before cancer you'll likely resume that after your treatment. *A rewarding intimacy with your partner is not dependant on sexual intercourse.*

"My healing journey is my responsibility."



"Cancer affects so many parts of people's lives, yet we often don't talk about things that are very important to us."

When asked, many people admit that the cancer has affected their relationships and sex life – yet they usually don't talk about it unless asked...

It is important to know about any concerns that you have about issues like this, as there are quite a few ways of helping."

7 Practical strategies to enhance vaginal health following pelvic radiation therapy

Vaginal dilators

Your healthcare team may recommend using vaginal dilators which are thought to prevent or reduce vaginal narrowing (stenosis) after pelvic radiation treatment.



Example of four different size dilators, a brush to clean the dilators and a lubricant.
Picture by Juraskova

What are vaginal dilators?

Most cancer centres provide vaginal dilators, or will give you information about where to access dilators, as part of your post-treatment care.

Vaginal dilators are rehabilitation devices specifically thought to prevent or reduce narrowing of the vagina (vaginal stenosis), which is a condition which affects a significant number of women following radiation treatment for cancer in the pelvic area. Dilators are used to gently stretch both the muscles around the entrance to the vagina and the tissues inside the vagina.

Some centres provide packs which can include up to four vaginal dilators, which are smooth, white tubes rounded at the end (see picture on previous page). They conveniently graduate in size and length depending on the appropriateness of their size and the stage you are in your treatment with dilators. The smallest dilator is about the diameter of a tampon. The largest dilator represents the size of the average erect penis, which is helpful for re-commencement of sexual activity. If you receive only one dilator, it will be the size of the largest one.

Why is it important to use vaginal dilators?

Your healthcare team may recommend that you use vaginal dilators no earlier than six weeks after your treatment has ended, once the acute inflammatory phase has subsided. If left untreated, vaginal changes can develop over time (up to five years post-treatment) and impact on your pelvic health and sexual function. The walls of the vagina can thicken and harden with scar tissue, thus making the passage seem narrower. This may cause considerable distress to you and your partner, or the partner you may have in the future.

If recommended for you, using dilators may allow for more comfortable pelvic exams and the detection of cancer recurrence. Dilator use may lessen the effect of vaginal scarring, maximise the vagina's flexibility and prevent the walls from thickening and sticking together.

For most women, vaginal examinations will be a necessary part of your follow-up care so your doctor can check for cancer recurrence. Using dilators may make it easier for you to be examined more comfortably and assist your doctor in monitoring your recovery. Using a range of dilators, going gradually up in size, can help to keep the vagina open and able to stretch to a level that is comfortable for you so any changes such as cancer recurrence can be seen and assessed easily. Dilators can also make it easier for you to start or continue sexual relations after your pelvic radiation treatment.

Although you may not have the desire for sexual relations during your treatment and for quite some time after the treatment ends, you may feel differently in the future and wish to have a sexual relationship again. By using vaginal dilators you will give yourself the option to engage in sexual relations at a later stage should you wish to. *Regardless of whether or not you wish to resume sexual activity in the future, vaginal dilators should be used to make pelvic examinations more comfortable.* Many women find that using dilators daily helps establish a routine.

Discussing the use of vaginal dilators also gives you the opportunity to discuss sexual problems and fears linked with pelvic radiation therapy and/or cancer with your healthcare team.

“Well I’d been told right at the beginning by the nurse who took me through the actual treatment that I would need to use a dilator and why. So um, I was not particularly concerned...”

How often should I be using the dilator?

The majority of centres will recommend that you start using your vaginal dilators no earlier than six weeks after you’ve completed your treatment, once the acute inflammatory phase has settled. Most women will be seen for follow-up at this point.

The recommended frequency of using dilators is at least **three-five times per week**. Daily use of vaginal dilators may be recommended for women who have a tendency to form scar tissue and if stenosis/narrowing is evident/noticed. This may change after recommendation by your doctor.

How long should a woman continue dilation for after the initial period?

It may be recommended by your health care team that dilators are used for an ongoing time period at least 3-5 times per week in order to avoid narrowing of the vagina. This is to aid future pelvic examinations to assess changes such as cancer recurrence and to maintain your vaginal health and sexual life. For the longer term, it is not necessary to use them as frequently, particularly if you have resumed sexual intercourse. You should talk to your specialist nurse for further advice.

How to use vaginal dilators

- Find a private and comfortable time and place where you can relax and use the dilator.
- At first you may benefit from using a mirror in order to see the vulva and vaginal opening (see diagrams on pages 6 & 7).
- Locate the labia and clitoris as well as the opening to your vagina.
- Having a bath before using a dilator may make you feel more relaxed.
- There are **various positions** in which to use the dilator. **You can:**
 - Lie down on your back on a lounge or a bed with your knees slightly apart and bent, or

- Stand with a leg raised on the side of the bed, on a chair or bath, or in the shower to insert the dilator.

- **Make sure you have the appropriate size dilator and lubricant handy.**

Wash your hands. Locate the labia and clitoris and feel down to the opening of your vagina. Gently explore the opening with a lubricated finger (make sure nails are short). Warm the dilator by running it under hot water then drying it. Lubricate all around the dilator and vaginal opening.

- Anticipating that an activity may be painful can cause muscles to tense involuntarily, as self-protection. **So it is helpful to take a few slow deep breaths and allow yourself to relax before beginning the insertion.** (See Pelvic Floor Muscle exercises on pages 28-29, which help with relaxing the muscles and ease dilator use).
- **Insert the dilator slowly and gently,** feeling the way the vagina tilts as you go. Insert the dilator **as deeply as is comfortable, without strongly forcing it.** Hold the dilator handle using the thumb and forefinger to limit the force. The first few times you use a dilator, it may be too uncomfortable to insert it completely. Do not worry or become discouraged, as it may take some time before you are able to insert even the smallest dilator completely. Consistent use will usually overcome this.
- **Once the dilator is inside the vagina, move it in a forward and backward motion,** then in a left to right motion. If possible, gently rotate the dilator using the handle.
- If you are offered a range of dilator sizes, it is usual to start with the smallest size. You should progress to the largest as it becomes comfortable to do so.
- If you have problems moving your hands or other physical restrictions, information will be tailored to your individual needs as you may find it difficult to rotate the dilator.
- **Each time the dilator is used it should be in the vagina for at least 5 minutes.** Although this doesn't seem like much each time, it will require planning and consistency. You may find it helpful to make it part of a regular routine, for instance, after brushing your teeth or showering.

- **The dilator should be removed slowly, withdrawing it by rotating it in clockwise and anticlockwise movements** as you are able until it is out.

- Slight vaginal skin loss and blood spotting is not uncommon when using dilators. If you experience any discomfort, bleeding or signs of infection, ask for advice from your healthcare team.

Please be aware that it is not unusual for there to be symptoms, such as bleeding or discomfort, following a period of not having sexual intercourse and/or not using a dilator.

- Douching (rinsing of the vagina) is not advised at any time.
- **If comfortable, your partner may also be encouraged to be involved with dilator use.** Whilst this is recommended, it may be more useful for you to do it yourself for the first few times so you are familiar with how it feels and you have total control of the procedure.
- Some women have found it helpful, for reducing pain and vaginal tightness, to use vaginal dilators just **before** sexual intercourse.

How to look after dilators

- Dilators do not need any special treatment but they do need to be particularly clean, especially if there are areas of broken skin in the vagina into which you can introduce infection. As soon as you withdraw the dilator, it is advisable to wash it and clean it and keep it in a clean bag or case.
- The dilators can be cleaned with soap and water, making sure they are rinsed thoroughly. They may also be sterilized by boiling or soaking in a sterilizing agent such as is used to sterilize babies' bottles. They should be rinsed and warmed before using again.

If you need any further advice or to raise any concerns, please ask a member of your treatment team with whom you feel most comfortable (also see contacts at the end of this booklet – pages 38-39).

Potential difficulties with dilator use and how to overcome them

Common reasons for insufficient use of vaginal dilators are:

- **Having insufficient information regarding dilator use.** This is why this booklet has been developed, so that you have the information at your finger-tips.
- **Some women have been brought up to see any sexual self-exploration or touching as wrong, dirty or sinful.** However, dilators are not a sexual device. They are part of rehabilitation. It may help to talk to a member of your healthcare team to help you overcome any difficulties. Remember, using a dilator is recommended for maintaining pelvic health following radiotherapy.
- **Modesty.** Although it may feel immodest or like masturbation, using dilators may allow adequate future pelvic examinations and Pap smears and make sexual intercourse more comfortable.
- **Having been told about using dilators after vaginal narrowing (stenosis) is established. Dilators are recommended to reduce narrowing. It is much easier to help stretch the vagina before the vagina becomes narrow than to fix it afterwards.**
- **Experiencing anxiety about using vaginal dilators.** This can be normal. Hopefully with time, you will become more familiar with using the dilator. It will feel more comfortable and simply become another part of your post-treatment rehabilitation programme.
- **Experiencing a fear of damaging the vagina.** The phase for potentially causing harm is during and just after pelvic radiation treatment, during the acute inflammatory phase. This is why it is not recommended to use dilators earlier than six weeks following the end of treatment, until this inflammation has settled.

- **Forgetting to use dilators.** To help you remember to use your dilators, you could complete a diary to document your use.

Lubricants

- **Vaginal lubricants** (water-based, with no perfumes or colourings - e.g. Sylk, Wetstuff). These seem to be the best lubricants available on the market since they don't evaporate as fast as some other lubricants (e.g. KY jelly). **Extra lubrication will make dilator use and intercourse much more comfortable.**



Sylk



Wetstuff



Replens

- **Vaginal moisturisers** Many women prefer to use moisturisers, which are inserted into the vagina and are less sticky in consistency. An example of such moisturisers is REPLENS, which can be bought at pharmacies and some supermarkets. Vaginal moisturisers can be inserted with a special applicator, up to three times per week, and not only at times of having sexual intercourse. It is beneficial to use vaginal moisturisers and lubricants at the same time. **This puts water into the vaginal tissues and keeps them moist, which is helpful for vaginal dilator use and sexual intercourse.** Many women find it more comfortable to buy vaginal moisturisers and lubricants online.
- **If you are still experiencing lubrication problems speak to your doctor who may have other lubrication options for you.**
- If you feel comfortable to do so, vibrators may be used in conjunction with, or instead of, dilators. They should be cleaned and maintained the same way as a dilator.

Pelvic Floor Muscle (PFM) Relaxation Exercises

Muscles in your body can tense or spasm when you experience pain or anticipate that something will be painful such as inserting a vaginal dilator or having intercourse. This can cause your Pelvic Floor Muscles (PFM) to “switch on” and contract tightly as a protective response. *There are a number of strategies that help to keep the Pelvic Floor Muscles relaxed and these are described below.*

- If you clench your jaw closed, your PFM may clench also, *so try keeping your mouth open during insertion of the dilators*, so that your PFM are more inclined to open.
- If your hands are gripping the examination table, bed, or each other, your PFM may be gripping closed also - *try keeping your hands soft and relaxed so that your PFM are soft and relaxed.*
- **Breathing** – if you hold your breath, your diaphragm will be rigid and this can cause the same with your PFM. *To help the PFM relax, try exhaling with a wide opened mouth, sighing ‘haaaa’.*
- *Anything going into the vagina should go in slowly, in stages,* approximately 1 cm at a time, coinciding with each breath out (i.e. with you letting go of your PFM).
- If this is still difficult, the PFM contract-hold-relax exercises (described below) may also be used for penetration/dilation in stages, with each “relax” of the contract-hold-relax exercise.
- **The PFM Relaxation Exercises** – these exercises are described on the following page. These are NOT to strengthen your muscles but to teach you to relax them.

C = Contract as if stopping the flow when urinating

Do a medium squeeze.

H = Hold

Even hold for **10** seconds.

R = Relax

Let the PFM release, fully feeling the relief of letting go.

“Contract-Hold-Relax”

Can you let go/relax a little further each repetition?

- Another benefit of PFM Relaxation Exercises is that they increase blood flow to the pelvic area, which enhances lubrication.

Other Exercises

Some women have found it effective to “work” the pelvic floor muscles while they are taking a shower. They put a foot up on the side of the tub, use a little bit of lubrication (which is slipperier than water) on their fingers, and again locate the vaginal opening and massage it gently. Squeezing an inserted finger or two can help gain control of the pelvic floor muscles.

Joining a Yoga class is an excellent way to practice strengthening pelvic floor muscles and to learn relaxation techniques.

8 Psychological/emotional effects of pelvic radiation therapy

In addition to sexual difficulties, women at various stages of cancer diagnosis and treatment may also experience anxiety, depression, remorse, guilt, uncertainty, alienation, loss of self-esteem, and changes in body image. Further psychological difficulties, such as post-traumatic stress, loss or mourning, and sexual relationship difficulties have been experienced after diagnosis or treatment.

There are many ways to cope with the emotional difficulties of pelvic radiation therapy experienced or post-treatment. *Some women strive to maintain an optimistic attitude, some find acceptance of the situation helps and others find strength in their faith.* Many women speak of trying to appreciate every day and continuing to live as normally as possible.

However, it is not unusual to find these feelings overwhelming. Having someone to talk to can make a significant difference to your well-being rather than suffering alone or feeling that you cannot talk about the feelings that may be troubling you. Please see pages 35-39.

“Apart from the physical effects of cancer, we’re aware of the emotional toll cancer and its treatment can take on you and your family...”

“Pleasure, laughing and love help me to stay well and look forward”

Anne (29) has been through pelvic radiation therapy for Cervical Cancer

I am a 29 year old cervical cancer patient. I have had chemo-radiation treatment for early stage cervical cancer. My treatment ended six months ago. I found having sex very painful at first and I was frightened to have sex. Often my partner cannot get his penis in very far so we often haven't been able to complete our lovemaking. I get tense and anxious about having sex and was very tired after the treatment. I have been having hot flushes which have woken me up in the night.

I feel so different since I had the treatment, even though I have the support of my family, I am finding it so hard to come to terms with not being able to have children. I use dilators three times a week, at first I found them painful to use. Now I am using Replens vaginal moisturiser and Sylk at the time of using the dilators. It has become less painful to use dilators now and I am able to use the larger ones. Occasionally I use the dilators with my partner. We use the dilator together, in the bath, before we have sex and it helps me to know what I will be able to take when we do have sex.

Mary (78) has been through pelvic radiation therapy for Endometrial Cancer

Well I have to say I was a little surprised when they told me the nurse wanted to speak to me about using vaginal dilators after I'd finished my brachytherapy treatment. Edward died three years ago but he'd been ill for a long time before that so we hadn't made love for a good number of years. Not that it affected our relationship, we were still very close and happy. So I couldn't quite understand why I needed to use the dilators as I couldn't ever imagine that I'd have that sort of relationship again.

The nurse explained that it was still important I use the dilators to try and prevent the vagina from getting narrower and shorter. I now understand an important part of my follow-up is the doctor doing a vaginal examination to check for signs of the cancer coming back. It also makes the examination a lot more comfortable too! I perhaps don't use them as often as I should but try to use them at least twice a week. I find it's most comfortable if I use them after I've been in the bath when I'm a little more relaxed. I was given a pack of different sizes and I still don't use the biggest size as it was just too uncomfortable.

Georgina (44) has been through pelvic radiation therapy for Anal Cancer

The doctor told me before I started radiotherapy that the treatment would put me into the menopause and that because of the effect the radiotherapy has on the vagina that I might find sex uncomfortable or even painful. Sex has always been a very positive and good part of my relationship with my partner and I was concerned that things might change and was very keen to do anything that might help. I started using the dilators about six weeks after finishing my radiotherapy and tried to use them every day. I found it easier that way as I just made them part of my daily routine.

It's now almost a year since I finished treatment. Although I was quite anxious about having sex again and it definitely was uncomfortable when we tried for the first few times things have improved. At my six month follow up my doctor explained that as I was having regular intercourse I didn't need to use the dilators any more as sex serves the same purpose.



9

Where can you get information and support

Our sexual and emotional lives are usually private and not openly discussed. Due to this it may be difficult to talk about these problems and you may feel uncomfortable talking about them with your partner, family members or friends. You may be more comfortable talking to a member of your healthcare team, such as your specialist nurse, psychologist or social worker. Services are available - you don't have to cope alone.

You may want to:

Talk with your healthcare team

You may be embarrassed to talk about the sexual side effects you're experiencing. It may be helpful to write down questions (see question prompt list at the end of this booklet – pages 48-50). In addition, your doctor may be embarrassed or hesitant to instigate conversations about sex. If this is the case, ask to be referred to a specialist or seek support from other members of your healthcare team, such as nurses and counsellors. It may be easier for you to introduce sexual topics you would like to discuss with your doctor and/or healthcare team as you talk about the use of the dilators you are given and report your progress using them.

Talk with your partner

Let your partner know what you're experiencing and how he or she can help you cope. For instance, you might find that using a lubricant eases your vaginal dryness or changing positions helps you avoid pain during sex. Together you can find solutions to ease the way back into a fulfilling sex life.

If you are not currently sexually active in your relationship or with a partner you may wish to talk to close family and friends about your hopes and fears (in addition, please see contacts on pages 38-39 in this booklet for those you can talk to about any concerns that you may have).

Explore other ways of being intimate

Intercourse isn't the only option for closeness with your partner. Consider spending more time together talking, cuddling or caressing. Connecting in other ways might help make you feel more comfortable and less anxious about the sexual side effects you're experiencing. *Massage and going on dates together, for example, are some other ways of enhancing intimacy. Having baths and/or showers together can enhance intimacy.*

Talk with other cancer survivors

Your healthcare team might be able to steer you to a support group in your city/town. Another option is to connect with other cancer survivors online, which provides a degree of anonymity if you are uncomfortable talking about these issues face to face.

If you would prefer to talk to someone else

Please see the contact list below. For example, the Cancer Council Helpline is a confidential service where you can talk about your concerns and needs with specialist cancer nurses. The Cancer Council Helpline can send you written information and put you in touch with appropriate services in your area such as a counsellor or someone who has been through a similar experience to you.

There are many helpful books, articles, videos and websites, which will provide you with information, understanding and support (see pages 38-40). *However, it is better to access only those sites recommended by your doctor or healthcare team since there can be misleading information on some sites.*

If possible, try to get as much support as you can from your partner, family and friends. Information for carers of people who are experiencing, or who have experienced, cancer are also available on these websites and helplines.



"Rebuilding your body image is an important part of your emotional and sexual healing. How you feel about your body and yourself as a woman affects your confidence, your own sense of attractiveness and your sexual desire. Massage, touch, relaxation techniques, gentle exercise and programs such as Look Good... Feel Better (call 1800 650 960 or visit www.lgfb.org.au) can help put you back in touch with your body, raise your self-esteem and improve your overall sense of wellbeing."

"The support of my husband, daughters, extended family and my community, as well as my puppies, has helped me through the journey."

10 | Contacts & resources

The Cancer Council Helpline – Monday to Friday, 9am to 5pm, for the cost of a local call: **13 11 20**

As well as English, the Helpline is offered in the following languages:

Cantonese and Mandarin	1300 300 935
Greek	1300 301 449
Italian	1300 301 431
Arabic	1300 301 625

For languages not on this list call **13 14 50** for the Translating and Interpreting Service.

Although the first two websites below are for health professionals, they both provide a significant amount of information on cancer, its treatment and managing a wide range of side effects.

The Psychosexual Care of Women affected by Gynaecological Cancers: A learning resource for health care professionals
www.cancerlearning.gov.au

Sydney Gynaecological Oncology Group – Sydney Cancer Centre
www.gynaecancer.org.au

The Cancer Council Australia
www.cancer.org.au

Australian Society of Gynaecological Oncologists (ASGO)
www.asgo.net.au

Cancer Council NSW (CCNSW)
www.nswcc.org.au

Gynaecological Cancer Support
www.gynaecancersupport.org.au

Australian Association of Stomal Therapy Nurses
www.stomaltherapy.com

Continence Foundation of Australia
www.continence.org.au

Lymphoedema website
www.nbocc.org.au/lymphoedema

National Public Toilet Map
www.toiletmap.gov.au

The Wellness Community – this is an international non-profit organization that provides free online support, education and hope to people with cancer.
www.thewellnesscommunity.org

Online support – chat rooms can be helpful and also a good resource for those who can't get to groups/counselling etc.
e.g. **Carers Australia**
www.carersaustralia.com.au

Look Good... Feel Better
www.lgfb.org.au **1800 650 960**

If you need help at anytime during the day or night call the Lifeline
24-hour telephone counselling service on 13 11 14

International websites:

Macmillan Cancer Support (UK)
www.macmillan.org.uk

National Cancer Institute (US)
www.cancer.gov
Their cancer and sexuality link:
www.cancer.gov/search/results.aspx

A few good books and booklets:

Below are a few recommended books and booklets. There are many to choose from, so these are just a few suggested titles.

Understanding Bowel Cancer: A Guide for people with Cancer, their Families and Friends

Cancer Council, NSW, 2011

Sexuality and Cancer – For People with Cancer, their Family and Friends

Victoria Cancer Council, 2007

This booklet is available online – www.cancervic.org.au

Understanding Sexuality and Cancer

NSW Cancer Council, 2006

(Ph. 13 11 20)

Overcoming Loss of Libido

E. Kelly, Health Books.

Living and Loving Together

Dr B. Montgomery, Penguin

Understanding Radiotherapy

The Cancer Council NSW, 2007

(Ph. 13 11 20)

Becoming Orgasmic

J. Heiman & J. Lopiccolo, Simon Schuster

Chicken Soup for the Unsinkable Soul: 101 Inspirational Stories of Overcoming Life's Challenges

Jack Canfield, Mark Victor Hansen & Heather McNamara 1999

Health Communication Inc

The Cancer Council NSW provides a range of booklets which you can also access online. These can be posted to you free of charge.

11

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Lancaster, L. (2004). Preventing vaginal stenosis after brachytherapy for gynaecological cancer: An overview of Australian practices. *European Journal of Oncology Nursing*. 8 (1), pp. 30-39

Ball, Andrea (2008), 'Resilience - A guide for women living with Ovarian Cancer', Ovarian Cancer Australia.

Sexuality for Women with Cancer – A guide for women with cancer, their families and their friends. *The Cancer Council*, 2006.

Sexuality and Cancer – a guide for people with cancer. *The Cancer Council Victoria*, 2004

Understanding Radiotherapy- a guide for people with cancer, their families and friends. *The Cancer Council New South Wales*, 2007

12 | Glossary of terms

Body image: How you feel about your body, how you think it looks and how you present it to others.

Brachytherapy: A type of radiotherapy treatment that implants radioactive material sealed in needles or seeds into or near the tumour.

Cancer: A group of diseases in which malignant cells grow out of control and may spread to other parts of the body.

Cervix: The end of the uterus that forms a canal and extends to the vagina.

Chemotherapy: The use of cytotoxic drugs, which kill or slow cell growth, to treat cancer.

Climax: The peak of sexual response.

Clitoris: The main sexual pleasure organ for women. It is made up of erectile tissue with rich sensory nerve endings.

Diagnosis: Process of identifying a disease from symptoms and tests.

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

Follow-up: Monitoring a person's health over time after treatment.

Gynaecological oncologist: A doctor who specialises in the comprehensive and surgical management of women with gynaecological cancer.

Hormone: A substance that affects how other organs work. Hormones control development, growth and reproduction. They are distributed around the body through the bloodstream.

Hysterectomy: The surgical removal of the uterus and cervix.

Labia Majora: The outer lips of the vagina.

Labia Minora: The inner lips of the vagina. These join at the top to cover the clitoris with a fatty hood.

Libido: Sex drive.

Lymphoedema: Swelling caused by a build-up of lymph fluid. This happens when lymphatic vessels and lymph nodes do not drain properly after treatment.

Medical oncologist: A doctor who specialises in diagnosing and treating cancer using chemotherapy, hormonal therapy, and biological therapy.

Menopause: The time when women stop having their periods. The average age for menopause is 52 years.

Mons Pubis: The area of fatty tissue covered with pubic hair.

Oestrogen: The main female sex hormone produced mostly by the ovaries in pre-menopausal women and by the aromatase enzyme in post-menopausal women.

Oncologist: A doctor who specialises in the treatment of cancer.

Orgasm: Sexual climax.

Ovary: The main female reproductive organ. There are two small, almond shaped ovaries found on either side of the uterus, close to the end of the Fallopian tubes. They also produce the sex hormones – oestrogen, progesterone and testosterone.

Pelvic cancers: Bladder cancer, rectal cancer, colon cancer, vaginal cancer, cervical cancer, uterine (endometrial) cancer, and ovarian cancer among others.

Post-menopausal: The period in a woman's life after the menopause.

Quality of life: An individual's overall sense of well-being. This can often be related to a person's health perceptions and their ability to function.

Radiation oncologist: A doctor who specialises in treating cancer with radiotherapy.

Radiotherapy: The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Radiotherapy treatment can also harm normal cells, but they are able to repair themselves.

Self-esteem: How you feel about yourself.

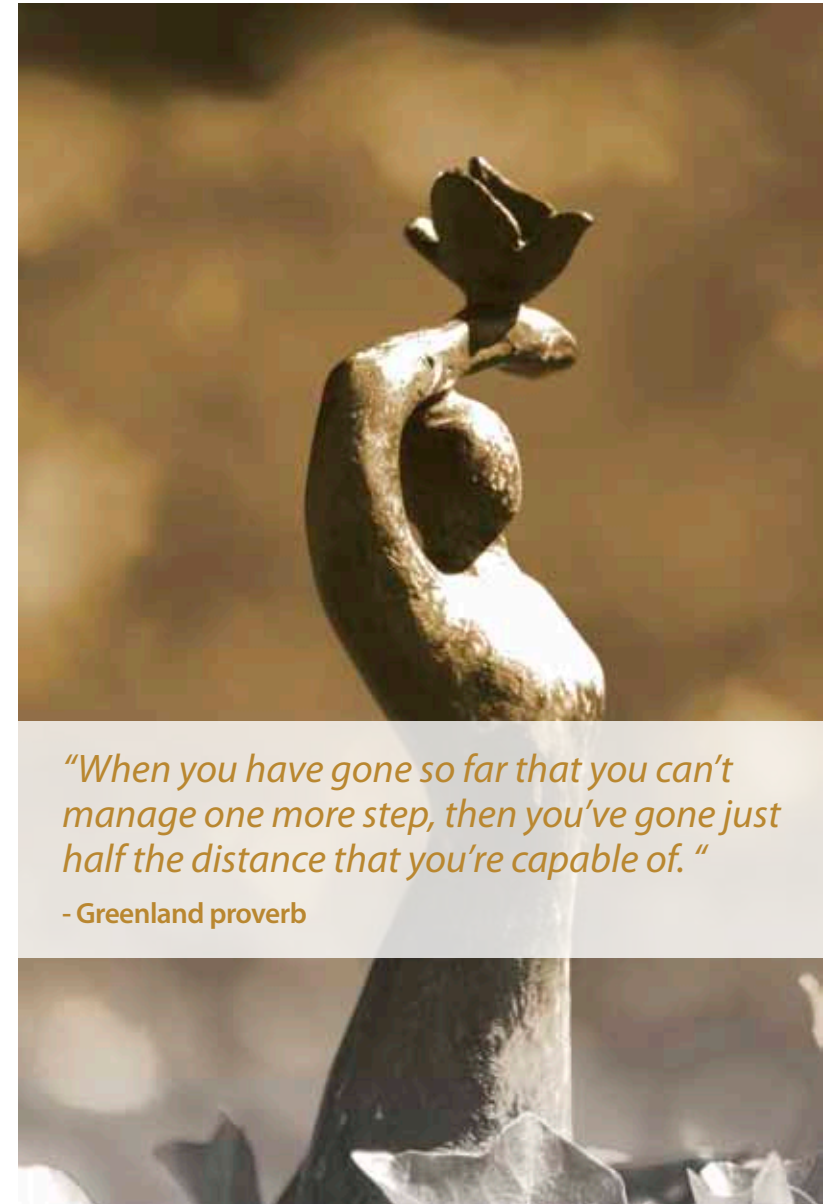
Side effect: Unintended effects of a drug or treatment.

Treatment-induced menopause: Menopause that is treatment-induced occurs before natural menopause.

Uterus: Also called the womb. It is a hollow, muscular organ shaped like an upside-down pear and located between the bladder and the bowel.

Vagina: A muscular canal about eight to 10 centimetres long, that extends from the entrance of the uterus to the vulva.

Vulva: The outer sex organs. They include the mons pubis, labia majora, labia minora and the clitoris.



“When you have gone so far that you can’t manage one more step, then you’ve gone just half the distance that you’re capable of.”

- Greenland proverb

13

Useful healthcare team contacts

Specialist Nurse or Cancer Nurse Coordinator

Name _____

Phone _____

Email _____

Gynaecological Oncologist or Colorectal Surgeon

Name _____

Phone _____

Email _____

Radiation Oncology Nurse

Name _____

Phone _____

Email _____

Medical Oncologist

Name _____

Phone _____

Email _____

Radiation Oncologist

Name _____

Phone _____

Email _____

Support Contact

(e.g. psychologist, social worker etc.)

Name _____

Phone _____

Email _____

14 Asking questions can help

List of questions you may want to ask your treating team:

Below is a list of some questions that you may want to ask your healthcare team. Space has been provided after the questions for you to write which questions you may want to ask or to write any of your own that are not listed here.

General cancer and/or treatment questions

- What are the common side effects of treatment that I could experience?
- Is there anything that can be done to treat these side effects?
- How could my lifestyle be affected (e.g. daily activities, sexual life)?
- Can you give me any advice on how to cope better?
- Is there someone I can talk to who has been through this treatment?
- Are there any services/support groups to help me and my partner/family deal with this illness?
- Who do I contact if I experience any problems?
- Will the treatment affect my fertility?

Sexual health questions

- Will my sex life be affected?
- How soon can I be involved in sexual activity?
- How will this treatment affect my hormones?
- When will I feel like having sex again?
- Is it safe to have sex if I am having radiotherapy treatment?
- What sort of problems may we experience during intercourse?
- It hurt when we had intercourse, why?
- I understand treatment can cause shortening/narrowing of the vagina. Who can I talk to about it?
- I am finding it uncomfortable to have sex. Who can I talk to about this?
- What changes are likely to be temporary and what changes are likely to be permanent?
- It hurts when I have sex. Is this normal?
- Can I get information about finding a sexual counsellor or therapist?

Vaginal dilator questions

- I am experiencing difficulties using my vaginal dilators. Who can I talk to about this?
- I am experiencing pain when I use the dilators. Who can I talk to about this?
- My vagina seems dry. What do you recommend?
- Which lubricant should I use? Is there someone I can talk to about this?

Other questions and notes for medical appointments

You can use this section to jot down additional questions you want to ask at your next appointment and leave space to record the answers.
