

Intimacy & Sexuality

for Cancer Patients and their Partners

a Booklet of Tips & Ideas for your Journey of Recovery



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Introduction: What is this booklet about?

For most of us, during many stages of our lives, sexuality is something we take for granted. It is something which may fall into the background as we deal with other priorities in our lives. Often couples settle into a certain routine. This may be having sex on a Saturday morning or whatever other pattern has crept in. Perhaps they might even feel a little disgruntled at how things are going. But things can take a very different turn, when something like cancer gets in the way and interferes with this routine. Then, each time a Saturday morning comes and the couple can no longer do what they used to do and this is not out of choice, that Saturday might feel very different indeed.

For others, sexuality has always been very important. Maybe they feel it was a big part of who they were: that being sexual was something they were really good at and that gave them and their partner particular enjoyment. Maybe it was also a way they had of de-stressing and relaxing or even of working through difficult emotions and coping with difficult times. When this ability is suddenly affected, this can be experienced as a major loss.

Sex is not just Sex

Human sexuality is about much more than the ability to have sexual intercourse. It helps people to fulfil many of their most fundamental needs as human beings and can help them cope better with life's many challenges. Being intimate with a partner can boost self-esteem, the sense of being a man or a woman, and give people strength by making them feel wanted,

accepted, loved and “whole”. To be consoled and comforted and to be able to console and comfort a partner by hugging or holding each other in private are important parts of being in a close relationship and can also help people to “feel normal again”. Sexuality and intimacy are also the glue that strengthens our emotional bond with our partner and are closely linked with happiness and overall satisfaction with the relationship.

On a physical level, sex and orgasm release tension and help people to relax physically and emotionally. It can also be a welcome distraction from pain and may even reduce pain in a similar way that taking pain medication might.

On an emotional level, sexuality can help people express and work through difficult feelings.

Sexuality is also something which is a basic part of people’s identity, of who they are. It is therefore not necessary to be in a relationship or worried about having sex with a partner to experience a feeling of loss. Single people frequently express a sense that they don’t feel like the same person, or that an important aspect of who they were has been taken away. They may not physically feel the same and may not respond to other people and situations in the same way. Some single people are also concerned about their future ability to attract a partner and lead a normal life if the sexual aspects of their lives have been lost.

Sexuality and Cancer

Unfortunately, all kinds of cancer treatments can potentially affect sexual functioning. It is therefore not surprising that sexual difficulties are amongst the most common and long-lasting side effects of treatment.

For many couples, sexuality may initially lose its importance as they assess the degree of danger and upheaval a diagnosis announces. Even during longer periods of active treatment, people often focus on “just getting through”. Fatigue and other side effects of treatments mean that patients and their partners are often happy to put their love lives on hold under the circumstances. But the majority of patients and their partners will report a point sometime after their active treatment has finished and “survivorship” begins, when they take stock and attempt to recover aspects of their lives that had been lost along the way. It is during this stage of early survivorship, as patients seek to “go back to normality” that patients and couples are most likely to begin to wonder when and how they will be able to reconnect with their sexuality.

For some cancer patients and their partners, sexuality remains an important aspect right through diagnosis and treatment. It is also important to recognize that there are also couples who have had a non-sexual but very fulfilling relationship even before cancer and couples who have adjusted well to a non-sexual relationship after cancer and who do not wish to make any changes.

This booklet has been written to give readers a framework for understanding sexual difficulties after cancer and to begin to think about ways of overcoming them or of “finding new ways of doing things when old ways no longer work”. Unlike other

publications on this topic, it contains a lot of practical information, tips, advice and links to other resources. By the nature of the topic, some of the content and the language used is sexually explicit. Sexuality is a very private and sensitive topic and is influenced by our upbringing, the attitude of our friends, sexual orientation, culture and religious views. Because of this and the differences in specific sexual difficulties experienced, some of the ideas mentioned may not be equally helpful or acceptable to all readers. You may find some of the suggestions very useful but you might also feel surprised or even uncomfortable about others. This will depend on your own “sexual norms” and information needs at this time. You are therefore encouraged to use your own judgement when choosing which sections to read. Please note that it is not necessary to read the entire content of this booklet to overcome your difficulties. It may, however, be helpful to read some of the early introductory chapters before moving on to the specific sections under Tips & Advice that are relevant to you.

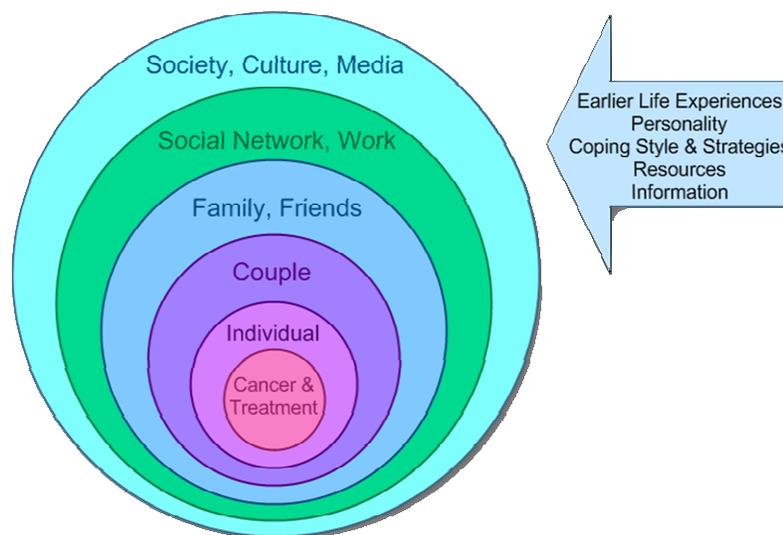
This booklet can be read as an adjunct to treatment offered by a health care professional, who may recommend reading specific parts of the book and who may be able to monitor your progress and offer further suggestions. You can also use this booklet on your own or with your partner to get a better understanding of your sexuality and any sexual difficulty in the context of your life. You may also find some of the practical ideas and suggestions listed helpful. It is suggested that readers contact their GP or cancer service who may be able to provide individualised support and further intervention.

Sex in Context: How the Rest of our Lives Influences Sexual Functioning

by Dr. Darja Brandenburg, Consultant Clinical Psychologist & Sex Therapist, Pan Birmingham Cancer Service

Modern sexology (the scientific study of sex) says that our sexual behaviour is determined by complex interactions between different factors. These include physical and psychological factors as well as our relationships. A person's ability to respond sexually after cancer therefore relies on the complex interactions between medical (i.e. effects of cancer treatments), individual (i.e. psychological, behavioural), couple and social factors (see figure below). In order to discover the best way to overcome a sexual problem, it can therefore be helpful to examine the role of each of these factors in our life.

Biopsychosocial Determinants of Sexual Functioning



Cancer & Cancer Treatments

A diagnosis of cancer and the treatments that follow have many different emotional and practical effects on people. Feelings such as anxiety, worry about cancer returning and depression are very common. Difficulties with confidence and body image are also wide-spread. Many patients will also experience their treatments as traumatic and in some cases such trauma may re-awaken earlier memories. It is important to understand that every single one of these common responses can affect our ability to function sexually.

The psychological aftermath of having had cancer can therefore have a just as negative an impact on our ability to respond sexually as the medical side effects of treatment themselves. In most cases, people are affected by a combination of both.

Ironically, many types of medication offered to ease the emotional effects of cancer will also interfere with sexual functioning. As a result of taking them, a person may feel better overall but may continue to experience sexual problems. It is therefore very important that you discuss any sexual concerns you may have openly with your GP or cancer specialists.

GPs and cancer teams in each locality can give advice on the sexual side effects of treatments and about what help is available. There is also some information in the Sexual Side Effects of Cancer Treatments section of this booklet. The Practical Tips & Advice section gives a list of further sources of information.

Earlier Life Experiences

How easily a person can adapt to changes in their body image and sexual functioning is influenced by the person they were and the relationships they had with people around them before the diagnosis of cancer was made. Important factors include how comfortable a person was with their body, what they had learnt about sexuality and what their way of relating sexually with a partner was before cancer. Some examples of helpful factors include: * being in a long term committed loving relationship where both partners trust each other * having an understanding of sexuality which is not based on performance but on intimacy, love and enjoyment * being able to be flexible and use humour when we are faced with an awkward sexual situations. All of these factors will help us to adjust to changes more easily and feel happier with our sexuality both generally and after cancer.

Individual Coping

In terms of psychological coping strategies, talking about emotional concerns and getting support from family and friends can help many people to cope with the difficulties experienced. It can also be very important to keep an eye on our general activity levels, whether we are in active treatment, in early survivorship or during any later stage. In order to stay emotionally as well as possible, it is important for us to stay engaged in life to the best extent possible. It is particularly helpful to continue to do some things that give meaning to our life or a sense of achievement as well as some things that are pleasurable. Physical exercise, if medically appropriate, also helps people to stay emotionally well.

Regards body image, it is generally best to confront physical changes as early as possible. One perhaps obvious but easily avoided aspect of improving body image is for people to spend time deliberately examining the parts of their body which physically look or work differently. This can include looking at ourselves in the mirror, and starting to touch and familiarise ourselves with our changed body. This is not always easy or pleasant at first but well worth the effort.

It can help to do this gradually, starting with an easier task and only moving on to another task once this has become more comfortable. It is important to keep looking or touching until it starts to feel a little more comfortable before stopping the exercise. It is best to do this daily at first and to repeat the same exercise a few times until it becomes quite comfortable before tackling the next stage. At some point, you may feel ready to invite your partner to have a look at your new body if you haven't already done that.

It can also be helpful to monitor the thoughts going through your mind as you are doing this. Over time, these may go from "Oh, no, how horrible!" or something similar at the beginning towards a greater acceptance of your changed body. People sometimes talk about their "battle scars" which they have begun to wear with pride or something similar but everybody's journey and ultimate outcome is quite unique.

If you are particularly worried about how your partner might react, it might help you to consider the following questions: *
What are all the things that make you the person you are? *
What kinds of things do you value most about your partner?
*How would you feel if the situation was the other way around and your partner had had cancer and their body had changed through cancer treatment? Thinking about these questions

often makes us realise that there are many more important aspects that hold together relationships than what our bodies look like. Speaking openly to our partner and sharing worries and concerns in a supportive manner can be very important.

Finally, it can also be helpful for people to explore their own body sexually to find out about any changes in sensation, about what is still pleasant and what may need to be changed before they become sexual with their partner.

Couple Factors

When planning to be intimate with our partner, things become even more complicated. In addition to considering our own emotional state, any psychological factors influencing our partner also come into the equation. So, if your partner is anxious or depressed, which many partners are when their loved one has had cancer, their mood may affect their own interest and ability to respond sexually in the way they did before. Changes in your relationship, such as changed roles, can also have an impact on how you feel in the bedroom. It is important to think about how both of you feel about the topic of sexuality at this point. It can be important to try to speak openly about this topic, to express fears, wishes, preferences and dislikes. If there has been a period when you haven't been intimate together, it can be difficult to "get started again". If some treatment or medical device has been recommended, it is important to consider how comfortable both of you feel about integrating it in your love play.

Wider Influences

Cultural influences and the opinions of family and friends also affect how we express our sexuality and our beliefs about sexuality and about sexuality after cancer. The media propagate many sexual myths. These include unhelpful messages such as * sex is only for young, attractive or healthy people * a sexual encounter needs to begin spontaneously with high levels of desire in both partners * sexual touching needs to lead to intercourse and orgasm. These messages are all incorrect. It can be difficult but very worthwhile to unravel some of these myths and other unhelpful influences and assumptions and to begin to challenge them.

Using this Model

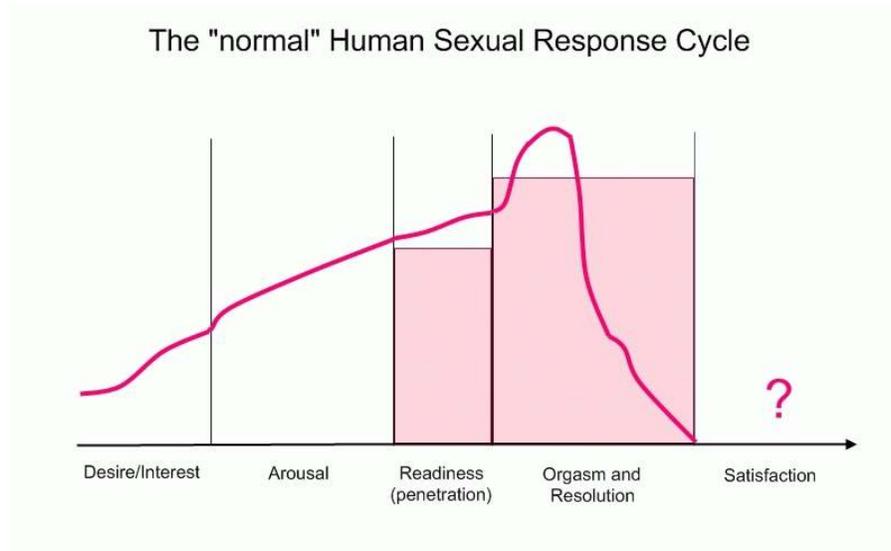
Beginning to understand how the rest of our lives influences our sexuality can help us to find the best way out of our predicament and move towards leading more sexually fulfilled lives. When we begin to better understand the nature of our sexual concerns and both the positives in our background and environment as well as any particular “sticking points” or less helpful influences and when we can start to talk about them to our partners or health care professionals, it is usually possible to overcome obstacles and regain a satisfying sex life.

In addition to the help provided by GPs and cancer teams, it can sometimes be useful to access help from people with expertise in psychological, sex and couple therapy approaches. At the present time, such individuals are not always available within the cancer service. The cancer team or GP are able to advise on what is available locally.

The Sexual Response Cycle and Cancer

by Dr. Darja Brandenburg, Consultant Clinical Psychologist & Sex Therapist, Pan Birmingham Cancer Service

To understand the difficulties we are experiencing sexually, it is useful to have a basic understanding of the normal human sexual response cycle:



Desire/interest:

The “normal” or “ideal” sexual response cycle begins with a person’s innate sense of sexual interest or desire. It is therefore important to realise that lack of desire is the most common sexual problem experienced by cancer patients. If an individual experiences desire or interest in sex, he or she becomes receptive to sexual stimulation and may under the right circumstances begin to feel sexually aroused.

Arousal:

When we become sexually aroused, many changes begin to happen in our body. Many of our blood vessels begin to narrow in a process called vasoconstriction, and our heart rate increases and more blood flows into our sex organs. As arousal increases, these processes become stronger.

Readiness (for penetration):

The man's penis becomes erect as blood flows into the penis and the walls of the vagina produce a fluid which lubricates the vagina, making it wet. These processes of erection and lubrication help our bodies to get ready for penetration. The consequences of cancer treatments frequently interfere with people's natural ability to reach this physical readiness. The use of lubricants and erectile aids can be very helpful in this regard. However, before we use them to produce physical readiness, it is important to ask ourselves how ready we are emotionally and whether the circumstances are right (e.g. "Do I actually feel desire and am I emotionally ready for a sexual encounter" "Is there genuine trust, so that we can feel safe and can we speak openly about our fears and wishes?"). It is important to realise that neither the achievement of intercourse nor the experience of orgasm are actually necessary to achieve sexual satisfaction.

Orgasm & resolution:

During orgasm lots of muscles all over our body muscle contract rhythmically, including those in our sex organs. Our heart rate and breathing also change and we may experience feelings of intense pleasure. In men, orgasm is accompanied

by the ejaculation of semen. Orgasm is followed by a period of relaxation when all systems in the body return to their normal state. After orgasm, men experience the so-called “refractory period”. During this time, they are not physically able to have another erection or orgasm. This period can last from only a few minutes in young men to hours or even days in older men.

Satisfaction:

It is common to think of penetrative intercourse and orgasm as ultimate goal posts and measures of our own or our partner’s satisfaction. When looking a bit deeper and peeling some of our sexual myths away, it is easy to see that the situation is a little more complex than that. In reality, many factors come together to determine whether or not we feel satisfied with any given sexual encounter. It is important to realise that people consider more than a simple check list of whether or not a certain physical act has been achieved. They also consider the wider picture, such as how they felt about the circumstances of the encounter, the person they are with, the larger meaning of their relationship and similar factors to determine how satisfied they have been with any given sexual experience. That is why many people can recall a time in their lives when they did have sexual intercourse and may even have achieved orgasm and to yet they did not end up feeling particularly fulfilled or satisfied. Fortunately, the opposite is also true: it is perfectly possible to experience total satisfaction without the traditional goal posts of penetration or orgasm. After cancer, many people discover new ways of being with their partner, which may not necessarily involve intercourse or orgasm, and yet both partners may feel fully satisfied with their intimate time together. Others may learn new paths of achieving penetration or intercourse.

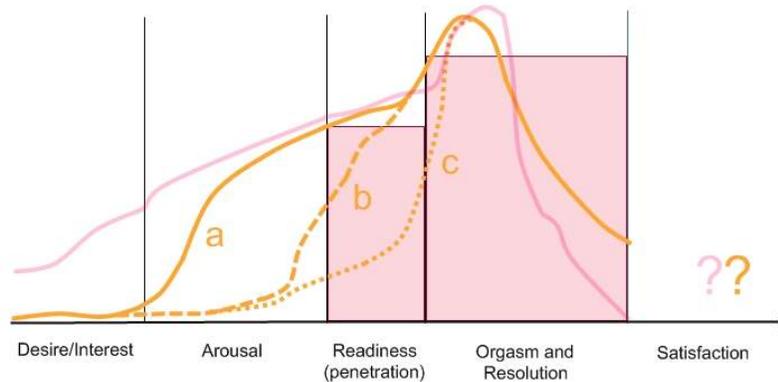
Problems along the Way

Cancer and cancer treatments can produce many challenges, delays or “malfunctions” of aspects of our sexual response. All stages can be affected. The following figures display the multitude of pathways cancer patients may experience through their sexual response cycle after treatment. You may be able to identify the stage where you experience most difficulties.

Problems of Desire

Often, people will experience a general slowing down of their responsiveness (see yellow graph and description below):

Pathways through the Sexual Response Cycle following Cancer

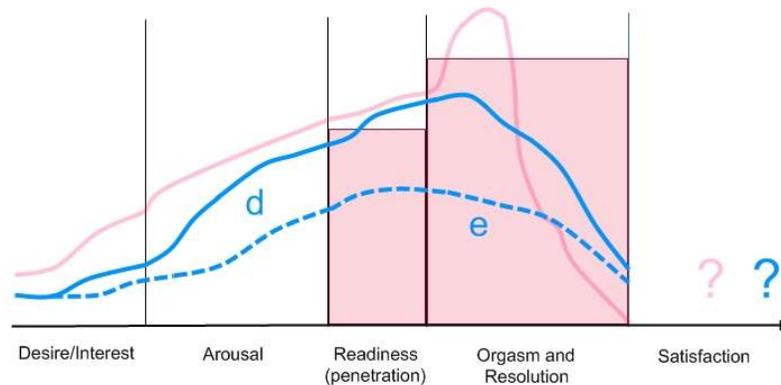


Slowed Cycle: a) person might not have any interest before encounter but interest is quickly awakened and arousal follows in normal way
 b) person has little interest, arousal develops slowly but eventually reaches readiness for penetration or
 c) person may not reach physical readiness, but through use of lubricants or erectile aids achieves penetration and experiences orgasm in desired way

Another commonly experienced pattern is a “dampening” down of the sexual response, during which the full extent of the

“ideal” response at a given stage is no longer achieved (see blue graph and description below):

Pathways through the Sexual Response Cycle following Cancer



Dampened Cycle: d) arousal response is sufficient to achieve readiness for penetration but may not reach orgasmic climax
 e) reduced interest or desire builds slowly into arousal but not sufficient to reach readiness for penetration or orgasm

Following cancer treatment, sexual desire is often minimal or not experienced at all. It is important to ask yourself if you are really ready to focus on this aspect of your life at the moment and to have a clear agreement with your partner about what you will and will not do together at this stage. It can be very helpful to speak openly about your feelings and desires. Engaging in any intimate acts when you actually feel rather anxious or totally disinclined could make your sexual difficulties worse in the long run. Many couples have found their own solutions to this problem. For example, some agree to hug and cuddle only for the time being while others engage in one sided sex play, where one partner is brought to orgasm without the expectation that the other person becomes turned

on in the same way. Yet another solution can be to make it okay for the partner who experiences more desire to masturbate either while being with their partner or on their own as a way of discharging sexual tension.

Other people who complain of a lack of desire actually feel very unhappy about the situation, they describe it is a major loss or as not feeling like the same person they were before. People in these circumstances may feel ready and very motivated to find ways back into a shared sexual encounter with their partner even while spontaneous desire is absent. If this is the situation you find yourself in, a more deliberate effort to increase quality time as a couple along may be a very good start. You will find many other specific suggestions which may help a “slow to warm up” desire to build.

Problems of Arousal

The body’s physical ability to respond with arousal in the shape of lubrication and erection is also often affected following many cancer treatments. As a result, cancer patients may have a slowed, incomplete or possibly totally absent response, i.e. they may fail to have an erection or to lubricate. This may be the case even when earlier stages of desire, interest and emotional readiness have been achieved. If you think you are emotionally ready, help in the form of lubricants or erectile aids can be beneficial in many cases to achieve penetrative sex and possibly to go on to achieve orgasm. It is, however, important to remember that penetrative sex is only one of many ways in which couples can come together in a sexual encounter. Attempts of penetration in the absence of psychological readiness and adequate lubrication are the most common cause of sexual pain in women.

Problems reaching orgasm

The physical mechanisms required for orgasm are often not affected by cancer treatments. Commonly experienced factors such as fatigue, self-consciousness and problems with body image, worry and low mood can, however, all affect the unfolding of the sexual response as a whole and may mean that we cannot give ourselves wholly to the sexual experience and that arousal may not be high enough to be able to reach orgasm. Some forms of surgery lead to retrograde ejaculations. In these cases, a man can still experience orgasm but semen is not ejaculated but passes into the bladder and will be passed in what appears to be cloudy urine the next time the man goes to the bathroom.

We already pointed out that it is a common misconception to see the achievement of penetration and orgasm as goal posts or measures of our own or our partner's satisfaction. It can be helpful to spend some time re-examining the sexual myths we have grown up with. Just as it is possible to have penetrative sex and to either experience orgasm or not while doing so, it is also possible to have a non-penetrative sexual encounter which may or may not lead to orgasm. It is important to note that a man does not have to have an erection in order for orgasm to be possible. Satisfaction is not directly linked to any of these outcomes, even if it is often assumed to be. Many people will be able to identify that it is possible to have intercourse and achieve orgasm and to still feel that "it wasn't that great", perhaps because of specific external circumstances. In the same way, it is possible to develop very satisfying ways of being sexual with a partner which don't include penetration or don't involve orgasm.

Problems with Satisfaction

As previously pointed out our satisfaction with a sexual experience is only partially related to the smooth and complete unfolding of the sexual response cycle but is influenced by a variety of factors. These include our ability to communicate with our partner, the availability of appropriate sexual information and our willingness to challenge assumptions and sexual myths. It can be important to free ourselves from the expectation that desire or arousal must occur spontaneously or that “good sex” has to involve sexual intercourse. Sex is not a performance sport, and sexual satisfaction is not achieved by scoring points for how well one does at each stage of the sexual response cycle. It is perhaps most important to stay flexible and be curious to discover new ways of being with one’s partner when some of the old ways no longer work. Most of all, it is perhaps about having fun in the process.

With a bit of information and support, most couples can solve their own problems. After some, at times difficult, adjustments have been made, many report lives that are sexually more fulfilled than they were before cancer.

Please contact your local GP or Cancer Teams, who will be familiar with services provided in your area, for any further advice required.

Sexual Side Effects of Cancer Treatments and the Person Living with Cancer

by Barry Quinn, Senior Nurse for Oncology & Lead Chemotherapy Nurse,
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Sexuality is not just about the physical act of sexual intercourse or sexual expression, but it is also about how we perceive ourselves and our need to be loved and cared for by others. Whether we are in a steady relationship (homosexual, heterosexual), enjoy casual sex or are single, most of us have sexual needs and desires. There is a danger in simply seeing sexuality as merely a physical act that we may fail to see that sexuality is about the whole person. Therefore a diagnosis of cancer and the treatments required may have a profound impact on you, affecting you physically, emotionally, socially and spiritually. It is worth noting that facing the reality of temporary or permanent infertility (inability to have children) and indeed body changes secondary to treatment can affect someone's sexuality and sexual identity. The health care team is there to sensitively support you through the cancer treatments with accurate information on potential sexual changes, advice on treatment interventions and a listening ear.

While some of these changes may appear obvious, many of the most profound changes that a person may face are often hidden and not so obvious to others. Many people with cancer will have to undergo different types of treatments that may affect their sexuality. Treatments including pain relief, medications to reduce sickness/vomiting, medication to help you feel more relaxed, and anti-depressants may have a positive or a negative impact on your sexuality (see advanced disease). It is also worth considering the impact of other illnesses you may have and the treatments you may be required to take

and how these might be affecting your sexuality. In addressing sexual concerns the health care team will support you with body changes and any psychological concerns that may be interfering with your sexuality and sexual expression.

Surgery

In addressing sexuality there may be a tendency to focus on surgical procedures that are immediately perceived to directly affect body parts associated with sexual functioning. These may include the following - mastectomy (removal of a breast), lumpectomy (removal of a breast lump), oophorectomy (removal of an ovary or ovaries), vulvectomy (removal of the vulva), prostatectomy (removal of the prostate), hysterectomy (removal of the womb), cystectomy (removal of the bladder), penectomy (removal of the penis), orchidectomy (removal of one or both testicles), colostomy, ileostomy or urinary ostomy formation (which may be required following bowel or bladder surgery). Any of these procedures can have a major affect on how a person feels about themselves as a sexual being and how they express themselves sexually. Such procedures may affect a person in many ways including loss of interest in sex or being sexually aroused, difficulties with getting or maintaining an erection, ejaculation or orgasm changes, dyspareunia (pain during intercourse), the onset of early menopause or the practicalities of having a missing sexual organ.

However, because sexuality is so profoundly personal, in reality any surgical procedure may have a profound effect on one's sexuality. It is worth noting that other less obvious forms of surgery can affect a person's sexuality including, an amputation of a body part, lung surgery, spinal surgery, brain surgery, the removal of lymph nodes, the removal of the

tongue or voice box or indeed the removal of any internal organ. Many of these surgical procedures may affect how someone perceives their body and affect how the body feels, how it looks, behaves and moves. It is not unusual to hear people who are required to undergo treatment for cancer to talk of a sense of their body letting them down. The surgical team should give you the opportunity to talk through your planned surgery and to talk about the possible impact the procedure may have on your sexuality and sexual expression and you should be supported while you consider possible surgical choices you may have to make. Following surgery you may wish to have support and guidance in adjusting to an altered sexual expression or simply gaining confidence in being sexually expressive. Such support may take the form of practical advice including adjusting to an altered sex life, adequate pain control, positioning during sex, advice on sexual aids and medical treatments or simply giving you the opportunity to talk about your concerns and fears.

Chemotherapy

Chemotherapy may be given via a number of different routes, including through tablets, as fluid given through a vein, an injection under the skin, as an ointment or directly to a particular part of the body. Any of these forms of chemotherapy may have an affect on a person's fertility and sexuality. While you need to be made aware of the physical changes chemotherapy may cause, you also need to be made aware of the psychological effects that can occur.

Members of the team are aware of the impact that chemotherapy may have on a person's fertility and they should speak to you about this issue prior to commencing treatment.

Most chemotherapy agents have the potential to affect a person's fertility but a group of drugs called alkylating agents are known to cause the most damage, resulting in either temporary or permanent infertility. For some younger people this may be the first time you have had to consider the possibility of planning children and you may need support from the team, family and friends.

You will be advised not to get pregnant during chemotherapy as the treatment may affect the development of the embryo leading to foetal defects and miscarriage. For some couples it may be difficult having to put their plans for a family on hold during the treatment period. Occasionally a woman may discover she has cancer during her pregnancy and may be advised to undergo a medical termination because the pregnancy will not be viable and/or in order to proceed with necessary treatment. This can be a difficult time for the woman and her partner, sometimes the impact of this loss becomes more obvious following the completion of treatment.

The medical team is there to talk to you about the impact of chemotherapy on your fertility, to support you and to discuss the possible options available. For men this may include the cryopreservation of sperm (sperm banking) and the possible cryopreservation of testicular tissue. For women this may include the cryopreservation of embryos (fertilised eggs) or eggs, and ovarian preservation. In some cases the urgency of treatment may mean that some of these options are not achievable. You should discuss this with your medical team, either your doctor or nurse. The impact of treatment on fertility, the loss it may cause and the effect it may have on you as a person and on your sexual identity may only be fully realised months and even years after treatment has ceased. The team may forewarn you of the issues that may arise and what

support is available. Some individuals and couples will need support or advice over their concerns of having passed or passing on genes to their children predisposing them to a higher risk of cancer. Please talk to a member of the team.

Chemotherapy may also affect other aspects of your sexuality and can directly or indirectly affect your sex life. Many chemotherapy agents are known to cause specific problems including a low sex drive, lack of vaginal lubrication leading to dryness which may lead to pain during intercourse and/or allow infections to arise. Other chemotherapy drugs, including a group called vinca alkaloids, may cause nerve damage giving rise to erectile dysfunction and to ejaculation and orgasm difficulties. These difficulties may require interventions including advice on medications and appliances to address erectile dysfunction, hormone replacement therapy (unless not advised), advise on vaginal dilation and lubrication, and/or psychosexual therapy. If you are sexually active you will be advised to use some form of barrier method (condoms, femidoms) during treatment to prevent pregnancy. If you are having oral, vaginal and/or anal sex, you may be advised to use some form of barrier method (condoms, femidoms, dental dams). This is to protect your sexual partner from the potential risk of irritation, caused by small amounts of chemotherapy agents possibly remaining in bodily fluids such as semen, urine, rectal and vaginal secretions. These barrier methods can also reduce the risk of the possibility of infection, especially if you are known to be at risk of infection because of a low white blood cell count (neutropenia). While individuals are advised to take steps to prevent infection, rarely should this prevent you from enjoying sex with your partner. You may find it helpful to talk to the medical team about any fears or concerns you may have. Occasionally, the team, hearing of couples who no longer sleep in the same bed for fear of

contaminating their partner, will reassure you that this is not necessary and you should continue with your usual sleeping arrangements.

Other sexual difficulties and concerns may arise due to body changes including hair loss (this might include hair loss from any part of your body), weight gain or weight loss, skin changes, loss of sensation including peripheral neuropathy (numbness in the fingers and toes). Any or all of these symptoms may lead you to feel less confident in yourself as a sexual person. Some chemotherapy drugs especially those used in blood cancers (leukaemia, lymphoma, multiple myeloma) may bring about the early onset of menopause and the symptoms that go with this. Other sexual concerns may arise from poorly controlled symptoms such as feeling sick, pain, oral damage, including dryness or sores in the mouth, diarrhoea, constipation, extreme tiredness and lack of appetite. Many of these symptoms can be successfully dealt with, enabling you to enjoy the comfort of sexual intimacy with yourself or with your partner. Some patients undergoing treatment may be at risk of bleeding, you will be advised to continue to enjoy a normal sex life but to be aware of reducing trauma during sex, including vaginal and anal intercourse, by using a more gentle thrusting movement during penetration or masturbation.

Biological Therapy

The use of other therapies known as biological therapies, such as monoclonal antibodies, immunotherapy, gene and vaccine therapies, either alone or in combination with chemotherapy, has greatly advanced treatment in some cancers. Because these treatments are relatively new, the short and long-term

effects on a person's fertility and sexuality are not yet fully understood. The support and advice described in the previous section on chemotherapy can also be applied to those receiving biological therapies. You will be advised to take steps not to get pregnant during treatment and to use a barrier form of contraception during sexual intercourse. Because each of these treatments are different and target specific elements of cell development, inevitably the side effects will vary with each treatment. While some therapies may occasionally cause severe and sometimes irreversible peripheral neuropathy (finger and toe numbness), others may cause mild to severe skin reactions, oral sores, tiredness, depression, hair loss, constipation or diarrhoea. It is important that you talk to the team about the possible side effects of these new treatments and how they may affect your sexuality.

Radiotherapy

The impact of radiotherapy on a person's sexuality and fertility will depend on the individual and on the site of radiation. Similar to chemotherapy, when it is known that your fertility may be affected by radiation to the pelvic region or by total body irradiation as in bone marrow or stem cell transplantation, you will be advised on possible options to preserve your fertility (see chemotherapy section). In order to preserve your fertility, you may be offered an option to shield the testicles or ovaries from the radiation field, however this is not an option for everyone. You will be advised of the possibility of temporary or permanent damage to your fertility caused by the treatment. The impact of the loss of fertility may only be realised months and years following treatment and individuals should be advised by the medical team on what to do and where to get support, should this arise.

Radiation can cause localised damage to nerve, vascular and muscle tissue giving rise to erectile difficulties, including the inability to get or maintain an erection suitable for penetration or vaginal changes including stenosis and/or dryness which may cause pain during sexual intercourse. Women may be greatly helped by asking a member of the team to explain the possible use of a vaginal lubricants and dilators to prevent vaginal stenosis. Men may be greatly helped by asking a member of the team for advice about medications and aids that might help with getting and maintaining an erection.

While the focus is often on the damage that may be caused by radiation targeted at the pelvic region and sexual organs, in reality any form of radiation can affect a person and their ability to sexually express themselves. Your confidence in yourself as a sexual person may be affected by unwanted body changes including, hair loss, radiation burns, weight gain or weight loss, urinary or faecal incontinence. Poorly controlled symptoms such as nausea, vomiting, constipation, diarrhoea, loss of appetite, and extreme tiredness caused by the treatment and the underlying disease, may affect someone physically and psychologically.

Hormone therapy

It may be helpful for you talk to the health care team about the impact of hormone treatment on fertility and sexuality.

As a man you may be required to receive anti-androgen therapy aimed at reducing the testosterone supply to the tumour such as in prostate cancer. The depletion of testosterone can lead to a significant loss of interest in sex and

an inability to achieve a spontaneous erection. This may have a profound effect on your confidence as a sexual person. If you are undergoing hormone treatment you may also experience body changes including gynaecomastia (breast swelling and tenderness), less facial hair, occasionally voice changes, less muscle strength and other related symptoms such as tiredness, mood changes and hot flushes.

If you are a woman undergoing treatment for ovarian and breast cancers you may be required to undergo anti-oestrogen therapy leading to changes including the symptoms of medically induced menopause such as vaginal dryness, mood changes, hot flushes and lack of interest in sex. While men may have difficulty in achieving and maintaining an erection, women undergoing such treatment may find it more difficult to achieve satisfactory orgasm. It is important that you get the opportunity to talk to the medical team about these possible changes before treatment commences but also to revisit these issues during treatment. As a man or a woman you may need support and advice in finding other ways to express yourself sexually. It is important to note that although men and women undergoing endocrine therapy may have a reduced interest in sex this does not need to prevent you from being sexually intimate with a partner. You may wish to ask the team for support in how address these changes with your partner.

For those facing advanced disease

There is a danger that others may think that because you are facing the possibility of advancing disease you will not be interested in sex. In reality, whether we are in or have been in a relationship or we are single, we are born as sexual human beings and we die as sexual human beings, what this means

and how we will express ourselves sexually throughout our life, we do in our own individual way. For some people being sexually intimated with a partner may bring comfort, reassurance and hope amidst ongoing uncertainty and change. Feeling loved, accepted and cared for as one faces the uncertainty of advancing disease may bring comfort to both you and your partner.

The team can help to facilitate times of privacy when you can be alone or be with your partner if this is what you wish, whether this is in hospital, nursing home, hospice or in their own home environment. Even in the acute setting of critical care and bone marrow transplant units the team can usually organise treatments in order to provide moments when you and your partner can be together.

Some supportive treatments used in advanced disease to address symptoms can have a very positive effect on a person's sexuality but they also may give rise to sexual difficulties. For example; some pain relief medicines such as opiates may provide relief from pain but may give rise to, constipation, tiredness, nausea, painful vaginal/anal intercourse and erectile dysfunction. Anti sickness medication and some medicines that reduce secretions can provide relief from nausea, vomiting and other symptoms but lead to erectile dysfunction. Some medicines (sedatives) can reduce anxiety but may cause low sex drive, erectile, ejaculatory and orgasm difficulties. Anti-depressants aim to enhance well being, but may cause vaginal dryness and erectile and orgasm dysfunction

There are practical measures that may help you to address sexual concerns arising from the symptoms of advancing disease and the required treatments. The reality of a smelling

wound in advanced disease can be both unpleasant to look at and to smell and the team can help you to camouflage both the sight and odour. The team can provide sensitive and practical advice on how to plan and make adjustments to your living arrangements to allow for moments of intimacy, including suggesting the emptying of a commode or its removal after use from the sleeping area. The careful positioning of syringe pumps may enable you to be hugged and held. Providing advice and the provision of adequate pain relief may mean you can be free of pain. Other practical tips may include emptying your bowels and/or bladder before having sex or how to deal with urinary catheters and stoma bags. Advice on positioning during sex, adequate oxygen and medical interventions may help if you have difficulties with breathing.

While you may lack the energy to participate in sexual intercourse, you may wish to try alternatives including, cuddling, hugging, simply lying on the bed together, increased foreplay, having a bath together or sharing quiet and private moments together.

Medical Treatment Options for Erectile Dysfunction

by Lorraine Grover, Clinical Nurse Specialist & Sex Therapist, St George's Healthcare NHS Trust, London & Wycombe Hospital Buckinghamshire NHS Trust, The London Clinic

Please note that the information in this chapter is given as general guidance only, and should not be used on its own to make decisions about treatment or commence treatment without the advice of a GP or erectile dysfunction specialist.

Erectile Dysfunction (ED) is a medically recognised problem that can be treated through the NHS. Schedule two is the government guideline that allows patients to receive four treatments per month for Erectile Dysfunction if they also suffer from one of the following conditions: diabetes mellitus, multiple sclerosis, spinal cord injury, prostate cancer, chronic renal failure requiring replacement therapy (e.g. dialysis or transplantation), radical pelvic surgery, single gene neurological disease, prostatectomy, poliomyelitis, spina bifida, Parkinson's disease, severe pelvic injury. There is an "extreme distress" category that allows patients to have treatment prescribed in the secondary care setting. Patients are also eligible to receive NHS prescriptions if they have had ED diagnosed and received treatment since 14 September, 1998 (the launch date for *sildenafil citrate*). NHS prescriptions must be endorsed "selected list scheme" (SLS) or "S.2" (Northern Ireland).

Psychosexual counselling (sex therapy) can also be very effective, especially if both the patient and his partner are able to attend. It can be used alone or sometimes in combination

with pharmacotherapy. Unfortunately it is not always available on the NHS.

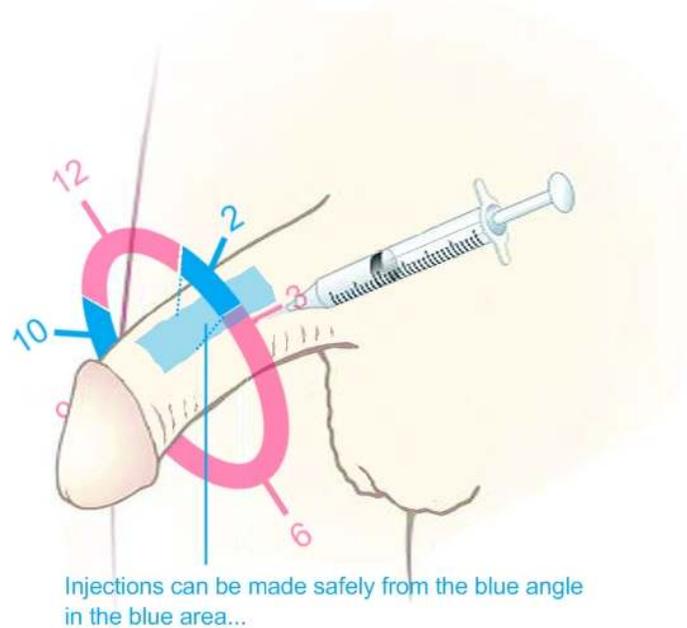
The management of ED has changed dramatically since September 1998 when oral pharmacotherapy, *sildenafil citrate (Viagra)* was launched. There are now also two other tablets, *tadalafil (Cialis)* and *vardenafile (Levitra)*. Oral pharmacotherapy is typically the first line treatment of choice. These medications enable a patient to obtain and maintain an erection, achieve an orgasm, ejaculate and then for the penis to return to its flaccid state i.e. a “natural response”. PDE5 inhibitors are contraindicated for patients that are being treated with nitrates or nitrate derivatives. They should be used cautiously with patients who take alpha blockers. They require sexual stimulation to be effective, this can be either with a partner or self stimulation. A tablet is swallowed, within 30-60 minutes later an erection may be achieved. Generally all three tablets can cause side effects of facial flushing, headache and stuffy nose. Individually they can also have their own different side effect profile.

Intraurethral alprostadil (MUSE) consists of a pellet that is inserted into the urethra after urination. The urine allows the pellet to slip very easily down the ‘head/glans’ of the penis. The pellet is already prefilled inside a plastic applicator that needs to be refrigerated. It can be kept out of the fridge for up to two weeks, but would then need to be used. It is available in three strengths 250mcg, 500mcg and 1000mcg. Side effects can be that the penis and testicles may ache. An erection can occur within 20 minutes of inserting the pellet.

Intracavernosal alprostadil (Caverject Dual Chamber, Caverject and Viridal Duo) requires the patient to be taught how to self-inject the shaft of the penis. It is important to titrate

the dose to achieve optimal efficacy whilst reducing the risk of the patient developing a priapism (defined as an erection that lasts for more than four hours).

Knowing where to inject can be made easier by thinking of the penis as a clock! The upper part of the penis (12 o'clock) should be avoided because of the dorsal vein. 6 o'clock should be avoided because of the urethra. Injections can be at 10 o'clock or 2 o'clock:



At the correct dose the erection can be obtained within 5-10 minutes. Men describe the feeling of the needle being inserted as 'pricking a finger with a rose thorn'. The erection will not fade after orgasm, it will subside when the drug has worn off. That can be a strange feeling compared to the normal sexual response.

Non pharmacological treatment options include *vacuum device therapy*. A cylinder is placed over the penis and air is removed via a pump, creating a vacuum that causes the penile tissue to fill with blood. A constriction ring at the base of the penile shaft maintains the erection (this should not be left in place for more than thirty minutes). Medically designed vacuum devices tend to have a better suction than those bought from newspapers or sex shops! This approach is more acceptable to patients that are in long-term relationships. Vacuum devices can also be combined with pharmacotherapy, to achieve a satisfactory response. In particular with prostate cancer they are very valuable to use to prevent penile atrophy and fibrosis, they therefore can prevent the penis shrinking in size.

A penile implant may be inserted when all other therapeutic options have been tried and failed. Implants consist of flexible rods or an inflatable prosthesis. The tissue in the penile shaft is removed to allow the prosthesis to be inserted. An implant should be inserted by a surgeon who is experienced with this technique.

Practical Tips & Advice for Overcoming Sexual Difficulties after Cancer & Cancer Treatments

by Sonia Malik, Assistant Clinical Psychologist, Pan Birmingham Cancer Service and Dr. Darja Brandenburg, Macmillan Clinical Psychologist & Sex Therapist, Pan Birmingham Cancer Service

Even though they have not been talked about much, sexual difficulties are amongst the most common side effects of cancer treatments. Between 35-50% of all cancer patients report some problems with their sexual functioning. Fortunately, with the right kind of advice and help, it is possible to overcome many of these difficulties. Many patients and their partners learn to adjust to changes in their sexuality and get back to feeling satisfied with their sexual relationship.

When interviewed, cancer patients often say that they found it difficult at the beginning to come up with new ways of thinking about their sexuality. They also initially found it difficult to start doing things differently when some of their old ways of being sexual with a partner no longer worked. In the end, many couples manage to find new ways of being together sexually which feel just as good as their old ways. However, it often takes quite a long time and some experimentation to find out what changes need to be made and what works best. Sometimes couples even find that things work out better than they were before one of them was diagnosed with cancer.

Until now, relatively little practical information has been put together for cancer patients and their partners on this topic. This section attempts to pull together a list of tips and advice that has helped some cancer patients overcome their difficulties. It has been brought together by cancer professionals as examples of what has worked for their patients. By the very nature of this topic, both the content of

this chapter and the language used are very sexually explicit. Sexuality is a very private and individual topic and is influenced by many factors such as the attitudes of our friends, our sexual orientation, our culture and religious views. Because of this, the ideas mentioned in this section will not be equally helpful or acceptable to all readers. You may find some of our suggestions very useful but you might also feel surprised or even uncomfortable about others. This will depend on your own “sexual norms” and information needs at this time. Please note that you do not have to read all the sections in this chapter to find a way forward. You may choose to read only those sections that seem most relevant to your own difficulties. It may, however, be helpful to have read some of the introductory chapters before moving on to this section. Please note that these tips are not presented as formal treatment recommendations. Readers are encouraged to get local support through their GP or cancer service. We recommend that you get an individual assessment and advice from a health care professional.

1. Introductory Tips for Everyone

1.1 Talking to your Doctor, Nurse or Partner

- Build up the courage to talk to your GP or Cancer Team about your sexual difficulties.
- Make an appointment and tell the doctor or nurse in advance that you would like to discuss a sexual problem.
- Prepare for the visit by planning with your partner and writing down questions.

- It can also feel uncomfortable to talk to our partner about sexual issues. Sometimes, it can be helpful to practice talking to each other about your feelings, wishes or concerns about non-sexual topics before you start talking about sex.
- Some people recommend getting started by writing down what you like about each other and to practice talking about (and working on believing!) these positives.
- Here are some ways you could start your conversation about sexual topics: “I know it can be embarrassing to talk about sex but we are both adults.” “I have something to say, but I find it difficult to talk about.” “You may have noticed that I’ve been avoiding situations where we might end up having sex.” “You don’t seem to be in the mood for sex lately. Is there anything you would like to talk about?” “Have you noticed that we’ve fallen into a routine when it comes to sex? Do you ever think about us being more adventurous?” “Let’s try making love when we are fresh and awake in the morning – or let’s plan an afternoon siesta together.” “It’s time we sent the kids to visit relatives and have a weekend to ourselves.” “Let’s try just cuddling and giving each other a massage tonight.” “It’s harder for me to get aroused these days. I’m not sure why but I was hoping we could talk about it.” “I worry that if we have intercourse, I might be dry and sex might hurt.”
- It can also be helpful to ask “What do I do that you like?” or “Let me tell you what you do that I like”.
- Try to share your feelings, fears and wishes with each other.

- Try to discuss and dispel sexual myths if these have been holding you back from adjusting to any changes and enjoying yourselves. (Examples of sexual myths are: Sex is only for the young, healthy and beautiful. Erections, penetration and orgasm are necessary to feel sexually satisfied, etc).
- Examine your ideas of relationships and sex – Can you see sex as an act of mutual intimacy and emotional bonding rather than an obligation that must be fulfilled?
- If you long to be able to hold your partner or touch your partner again but are worried that this might lead to “having to go all the way” and you are not comfortable with this at the moment, it can be very helpful to talk to your partner about your feelings. You could explain what you would like to be able to do again (e.g. hold hands, kiss, give compliments). It can sometimes be helpful to agree on what you will and will not do together for the time being before you start getting intimate. This will help you feel more relaxed and able to give yourselves over to the experience instead of worrying whether you’ll feel up to taking it “to the next level”.

1.2 Confidence and Body Image

- Consider what attracted you to your partner in the first place and what you value them for now.
- If your partner had had cancer and his or her looks had changed because of it, how would this make you feel? Would you still be attracted to them?

- How do you think your partner feels?
- Think about how society or the media portrays men and women. How many people do you know who are/look exactly like that?
- Cancer and its treatment can result in many changes to your body, how it functions and how it feels. Learn to get to know your body again. Take time to regain a sense of your body as your own.
- Research has shown that the sooner you confront the changes in your own body and the sooner you let your partner see your altered body, the easier things might be in the long run, both in terms of confidence and sexuality. However, many people have not had the opportunity or courage to confront changes early on and it is never too late start accepting your changed body. If this is a particularly sensitive topic, you may want to consider getting the advice and support of a professional along the way.
- If you do decide to tackle changes in your body head on, your first few attempts to look at yourself might initially make you feel unhappy or shocked and you may feel a strong desire to avoid looking. Try to be reassured that even if you feel any of this initial intense unpleasantness, this will soon lessen if you keep looking at yourself (this is a process called “habituation”). If you keep looking long enough for the really unpleasant feelings to go away before you stop looking, the next time you look will already be a bit easier. If you keep doing this regularly, you will soon adjust to the changes in your body and you will become much more comfortable with your changed body. One

way of doing this might be to stand in front of a full-length mirror and study your naked body. Describe what you see, what you like and what makes you feel awkward or uncomfortable. Try not to stop until you feel a bit more comfortable with what you see.

- It is useful for self-exploration to include touching as well as looking. If there's been a surgical or other body change, look carefully at the affected area. Also try to be curious about other parts of your body which you might not have considered sexy before. Try to see yourself as a whole person and try to find parts of your body you like.
- Highlight and let yourself feel good about the features that please you. Simply note the features which make you feel uncomfortable.
- The more often you look at your body, the less foreign it will be. What will at first appear as major problems can become aspects of your uniqueness.
- Cultivate kindness towards your changed body – you've both been through this together.
- Some people find it helps to develop a new way of thinking about their changed body. They might for example call their scars "survival devices", "badges of bravery" or "battle scars" they come to wear with a sense of pride. Can you think of a new, more helpful way of thinking about the physical changes in your body?
- Learn to appreciate your body in non-sexual ways, e.g. by having a nice shower or bath, using body lotion,

having a massage or engaging in physical activity. You could think about how you take care of your body, perhaps by eating healthily, drinking enough water, getting enough sleep and exercising, etc.

- All forms of exercise can make us feel better about ourselves. Exercise also increases blood flow to your entire body, and that includes sex organs. Build up your exercise routine slowly. If you are unsure about what kind of exercise is recommended for you, get the advice of a health professional.
- Take time to get to know what or where your 'on-switches' for sexual arousal are with your new body.
- Also find out about areas which are not so nice to be touched ('off-switches'). Surgical sites, areas around stomas and scar tissue often feel uncomfortable, numb or even painful. It's important to determine what's off limits during sexual activity with your partner.
- Think about how to present your body, eg. what to cover up or accentuate.
- Try to accept it when your partner says that you are attractive.
- Getting back to being intimate with your partner may help you feel more confident and help you adjust to your new body.

1.3 Setting the Scene

- Most people find it difficult to experience sexual feelings when they are stressed or anxious. Both the on-going worry about cancer or other life problems and the specific stressful events of a given day, can therefore affect how well we are able to tune into our sexuality. It can be helpful to make a deliberate transition between busy life and quality time with a partner and discover your personal ways of relaxing before a sexual encounter. Becoming more relaxed may help you to feel more comfortable and can help to create the right conditions for experiencing more sexual desire and responsiveness.
- It can be very helpful to explore ways of managing your stress. Find out what relaxes you before you consider becoming intimate. This could include things like going for a walk, having a massage, a warm bath, watching a film, laughing, time away from children or trying formal relaxation exercises. It can be useful to schedule in some times for relaxation every day, even when you are not planning to be sexual.
- Try 'doing a spot of courting' again! This requires making an effort and most couples would agree that they fail to do this as much as they should. The amount of effort involved needs to be in proportion to what you are able to do at the moment. Remember, something as simple as giving a compliment and letting your partner know what it is that you value about them can be a very good starting point.
- If you don't have enough energy to go out, why not arrange some 'special time' at home. An example would

be to have a meal together and get dressed up as though it were a special occasion.

- If you have young children consider asking family, friends or baby sitters to look after them so you can share some time together.
- Turn on the answering machine to avoid being disturbed.
- Re-discover physical experiences that make you feel good, generally or in preparation for being intimate (e.g. having a bath, being pampered, massages, manicures, relaxation techniques, meditation, physical activity, dancing, good food, masturbation).
- It can be helpful to agree clear boundaries of what you will or will not do together at the moment before you become intimate with each other as it removes pressure and can help you to feel relaxed and safe.
- Wear clothes that make you feel confident, attractive and sexy. Consider whether you might initially feel more relaxed by not undressing fully.
- If you feel self-conscious about your body you could set the scene with candles and dim lighting.
- If you feel tired and don't have much energy it might be helpful to make love in less energetic positions where your weight is supported or to try quicker sexual contact rather than lengthy sessions.

1.4 Tips for Men and Women

- You cannot catch cancer or pass it on by having sex.
- Sex does not make cancer worse or increase the risk of it coming back.
- Sex does not interfere with treatments. It is, however, very common not to feel like having sex while you are undergoing treatment. This is usually because of tiredness, side effects or feelings of anxiety or depression.
- While you are having chemotherapy and for a certain time thereafter, it can be important to use some form of contraception to avoid pregnancy. Many health care professionals also recommend use of a barrier method of contraception (condom or femidom) or a dental dam for oral sex to stop small traces of the chemotherapy drugs from causing soreness or discomfort to your partner. It is worth knowing that the extent to which such traces are present in body fluids and how long for has not been fully established. Health care professionals vary in the kinds of recommendations they give to their patients about this matter. Recommendations range from taking no special precautions, over using a barrier method only for the first day after chemotherapy treatment to using it until the whole course of chemotherapy has been completed. It is worth considering that barrier methods can also reduce the risk of infection but that many people find it harder to get sexually excited when using a barrier method, particularly if this is not something they are used to. Please discuss your individual concerns with your health care provider.

- It can help to remember that our most important sexual organ is our brain. Try to find new ways to think about your sexuality. It may be helpful to consider changing expectations and exploring new ways of sharing sexual pleasure and intimacy.
- Some people have found it helpful to consider what is more important to them: the ability to have sexual intercourse or the ability to still have loving and intimate times with a partner. Unfortunately, life doesn't usually give us a choice, but many people discover that being able to hug, kiss, hold hands, cuddle, caress and share intimate experiences can take on a deeper meaning and become more fulfilling than they had previously anticipated.
- Many people report that learning to take time to let desire build up gradually and discovering new ways to reach a sense of sexual satisfaction can become more fulfilling than an earlier "taken for granted" routine which relied on a relatively effortless ability to experience physical arousal (erection or lubrication) and orgasm.
- Remember that each partner in a relationship usually gets turned on by different things. Find out what they are.
- The quality of the sexual experience may be more important than what you are able to do and how often you do it.
- It can be helpful to maximise opportunities for physical contact and closeness in general.

- Relaxation techniques and breathing exercises may help you to become relaxed and increase sexual responsiveness. You could start by having a meal or taking a bath or having a nice shower. Listening to music and creating a nice atmosphere and maybe having a cuddle can also be ways to unwind, to start to relax can help to make the transition from hectic everyday life to some quality time with your partner. Try to take things step by step.
- Being close to your partner by lying next to each other and cuddling can be comforting and reassuring in itself.
- Gradually, as you have the confidence, you might like to start kissing each other. This may be more difficult for those who have had treatment to their face and mouth. Sensations may be different and you may find dribbling awkward. Keep some tissues handy.
- You might like to go on to undressing each other. This may feel particularly difficult if there have been significant changes to your body image (e.g. mastectomy, stoma). It may help to talk to each other about these feelings.
- Do not set goals. Try not to focus on orgasms as the end point. Focus instead on being sensual, exploring and savouring the different feelings and sensations you experience in response to being with your partner. Explore different senses (touch, sight, maybe even smell, taste).
- Try to find each other's less immediately obvious erogenous zones – these might include lips, eyelids, inner thighs, buttocks, back, neck, feet or ears.

- A good position for sex is one that will let you do what you want to do, let you touch the parts of yourself or your partner that you want to touch and let you be comfortable.
- If you are worried about mobility or fatigue problems, you might consider buying a sling or swing which can offer support for one partner to lie or sit in. This can take the weight off joints and limbs and makes more movement possible. These products can be expensive but some people with mobility problems have found them helpful. When looking at photographs and descriptions on websites it is helpful to try to not be put off by the youthful image presented but to think about how a product might be useful to you and your partner. It is also possible to buy pillows to assist with positioning or to use “ordinary” pillows creatively (see bedroom accessories, bedroom furniture, sex furniture, sex slings or sex swings on websites such as www.bettersex.com, www.goodvibes.com, www.comeasyouare.com or www.liberatorshapes.com).
- Modify sexual activity to conserve energy (e.g. consider positions, less thrusting, non-intercourse). The use of sex aids, such as a vibrator, will avoid the need for high levels of energy expenditure. Mutual masturbation and oral sex are also strategies that require lower levels of energy expenditure, while the use of a waterbed may facilitate movement. It can be useful to think about the weight of any sex aid you are considering. The lighter it is, the easier it may be to use for longer periods of time.
- If you are staying in a hospital or hospice, don't be afraid to discuss your needs for privacy. You will be able to hold hands and caress. It may also be possible

to share the bed to be physically close or even to find out if a family or quiet room or even a double bed is available. Ask staff and visitors to respect your privacy when the curtain is drawn or the door is shut and to knock or ask permission to enter. Find out if there are any “Do not disturb” signs available. It is usually possible to organise nursing care and medication in a manner that provides opportunity for privacy & intimacy.

- Don't be afraid to start dating during or after treatment. Someone who can love you when you are ill is someone special and can probably handle other life challenges. Please refer to the resources described in section 13 “Useful Links for Single People” for more tips and ideas.

2. Mostly For Women

2.1 Tips and Advice for Women

- Attractive underwear and nightwear might help you to feel confident again when trying to resume your sexual relationship.
- If you have had breast cancer and feel unhappy with your body image following a mastectomy, you may wish to consider the possibility of a breast reconstruction. Try to get a realistic understanding of what outcome to expect in terms of how it will look and feel and what risks are involved. Also explore different options of prostheses. There are lingerie and swimwear companies that specialise in women who have had a mastectomy (see resource section for some examples).

- If you are at risk of losing your hair during treatment and you choose to wear a wig, it can be helpful to have it fitted before you lose your hair, so that it can be matched for style and colour.
- You can also use wigs as a chance to experiment with different appearances and hair styles.
- Take your wig to your hair-dresser. They may be able to style it for you, layer it or put highlights into it if you like. You could also wear a turban or scarf in bed.
- Taking the wig off is as significant and emotional a moment as putting it on for the first time. Plan the style of your re-grown hair with a good hairdresser.
- Discomfort and pain caused by vaginal dryness can be helped by use of lubricants or creams. These broadly fall into water-based and oil-based varieties. Water-based lubricants are useful when the vagina is still irritated and are also compatible with condom use. Oil-based varieties may irritate the vagina and can also break-down condoms. Oil-based lubricants may also make it more likely for you to develop thrush. However, they do create a more “slippery” effect and better penile sensation during intercourse. It is best to discuss your choice of lubricant with an appropriate health care provider.
- The list of lubricants mentioned by our group of contributors included *Sylk*, *Yes*, *Vielle*, *Replens*, *Aquagel*, *Durexlube* and *Senselle*. This is not an exhaustive list and does not imply superior performance. Please always get the advice of a professional.

- Using a vaginal lubricant before having intercourse will ease vaginal dryness and help prevent pain. This can be particularly important if your ovaries have been removed, you have had pelvic radiotherapy or you have been through the menopause. You may want to put some of the lubricant into the vagina, and some on your partner's fingers, sex aids, penis or anything else which will be inserted into the vagina.
- Depending on cancer type it may also be appropriate and helpful to apply an oestrogen cream to the vulval area and vagina. Many health professionals believe that a small amount of oestrogen applied locally will not affect your whole body system and may therefore be safe even for those with hormone-receptive tumours. The effects of such creams are most beneficial when they are applied regularly. Some practitioners recommend daily use for a few weeks to begin, followed by less frequent application. If appropriate, this can be prescribed by your GP or cancer specialist.
- You could also ask your clinician if HRT (Hormone Replacement Therapy) is a suitable option for you as it may improve your desire for sex and your ability to have sexual intercourse.
- Pelvic floor exercises (also called Kegel exercises) can help you to have an increased awareness of any tension in the muscles surrounding the entrance of the vagina. If these are tense, you may experience pain when your partner tries to penetrate. An extreme tensioning of these muscles sometimes occurs without the woman becoming consciously aware of it. This is a way the body tries to protect itself from any further pain or trauma it may have learnt to associate with anything

coming near the vagina. This response (also called “vaginismus”) can make intercourse impossible. Learning to relax these muscles, often combined with the gentle use of a dilator as recommended by the health care professional, can help the vagina to relax and become able to accept penetration again. Learning to relax your pelvic floor can reduce some types of pain experienced during intercourse. Doing pelvic floor exercises also increases blood flow to the area and heightens sexual feelings (e.g. www.pelvicfloorexercise.com.au).

- If you have had pelvic radiotherapy, it is important to begin to use dilators regularly for a certain period of time to safeguard sexual functioning and to enable future screening and internal examinations if necessary. Their use can also be helpful after surgery or simply to build up confidence in your body’s ability to “handle penetration”. Please speak to your cancer nurse specialist (CNS) or other professional about any concerns or questions you have. If you can’t bring yourself to use a dilator, it may be worthwhile exploring the issue further with the help of a CNS, psychologist or sex therapist. Having sexual intercourse or using vibrators are equally acceptable methods for achieving the required stretching or “keeping open” of the vagina. Whatever methods or mixture of methods you use, try to ensure you stick to the recommended frequency.

2,2 Useful Products for Women:

This list of products and companies has been spontaneously mentioned by our contributors. It is not an exhaustive list and does not imply superior performance. Please always get the advice of a professional.

- Nicola Jane: UK based post mastectomy fashion - www.nicolajane.com - info@nicolajane.com - 0845 0952121 or 01243 537300
- Sujenbi (nightwear) – contact@sujenbi.com – 0845 120 6420
- Womanzone - www.woman-zone.co.uk - sales@woman-zone.co.uk 01925 768 992
- Eloise Lingerie - www.eloise.co.uk - sales@eloise.co.uk - 0845 225 5080
- Betty and Belle - www.bettyandbelle.co.uk - info@bettyandbelle.co.uk - 0161 929 1472
- Oops & Downes: lingerie, swim wear and accessories - www.oopsanddownes.co.uk - 0113 258 0770
- Amoena: post mastectomy lingerie, night wear, swim wear, clothing and accessories - www.amoena.co.uk - 023 8027 0345
- Butterfly Bras: mastectomy lingerie and swim wear - www.butterflybras.co.uk - 024 7641 5983

- Lucinda Ellery: hair loss management - www.lucindaellery-hairloss.com - 020 8741 8224
- Edwina: hair, Wig & Make-up consultant - www.edwinahair.com - 0845 653 2688
- Headline Hats: stylish headwear for women with hair loss - www.headlinehats.co.uk - 0844 357 0418
- Pink: alternative, temporary solutions to hair loss - www.pnkuk.com – 0121 350 3826
- Lingerie Illusions - www.lingerieillusions.co.uk - 01902 482 524
- Trulife: breast forms, bras and accessories - www.trulife.com - 0800 716 770
- Hudsons: wigs, also specialise in semi-permanent make-up and camouflage - bestmove@globalnet.co.uk - 0161 834 6151
- Tints of Nature: hair colourant - www.herbuk.com - 01590 613 490
- Look Good – Feel Better: free make-up workshops - www.lgfb.co.uk - 01372 747 500 (Head Office)
- Women’s Erotic Emporium: sex aids and advice, run by women for women - www.sh-womenstore.co.uk

- Emotional Bliss: useful information & range of female massagers (vibrators) developed with advice from sexologists and research - www.emotionalbliss.co.uk
- A Woman's Touch: Sexuality Resource Centre - www.a-womans-touch.com
- YES: organic intimacy products - www.yesyesyes.org
- EROS: small, handheld vacuum device that improves sexual responses by increasing blood flow to the clitoris and external genitalia (please read contraindications and get professional advice before use) - www.eros-therapy.co.uk
- ZESTRA: botanical female massage oil to enhance female pleasure, www.zestraforwomen.co.uk

Dilators:

- Amielle Care and Amielle Comfort Dilators by Owen Mumford, www.owenmumford.com
- Femmax dilators by MDTI Medical Devices Technology International, www.mdti.co.uk
- Bioteque Silicone Dilators, www.bioteque.com, UK/European distributor info@randjmedical.com, 028 90865523 or jmoult@microsulis.com

- Silicone Dilators available from USA, eg,
 - www.soulsourceenterprises.com set of 8 colourful silicone dilators
 - www.pureromance.com – set of 6 colourful dilators and other products
- Please note that use of fingers or vibrators may be a viable alternative to using dilators. Please refer to other sections of this booklet for further information and remember to discuss your specific circumstances with your local health care team.

2.3 Useful Reading for Women:

- *“Body & Soul”* by Jean Karotkin (photographs of breast cancer survivors)
- *“Winged Victory: Altered Image. Transcending Breast Cancer”* (photographs of breast cancer survivors)
- *“The Boudica Within: the Extraordinary Journey of Women after Breast Cancer and Reconstruction”* by Elaine Sassoon (includes photographs)
- *“Sex Matters For Women: A complete Guide to Taking Care of Your Sexual Self”* by Sallie Foley, Sally Kope and Dennis Sugrue

- *“For Women Only”* by Jennifer & Laura Berman
- *“For Yourself: The Fulfilment of Female Sexuality”* by Lonnie Barbach
- *“Intimacy after Cancer: A Woman’s Guide”* by Sally Kydd & Dana Rowett
- *“I’m too Young to have Breast Cancer”* by Beth Leibson-Hawkins
- *“Sexuality, Intimacy and Breast Cancer”*
www.breastcancercare.org.uk
- *“The Gynaecological Cancer Guide: Sex, Sanity and Survival”* by Margaret Heffernan and Michael Quinn
- The Daisy Network, www.daisynetwork.org.uk -: for women who have had the menopause as a result of medical treatment
- Jo's Trust: www.jotrust.co.uk for women with cervical cancer
- Female Fertility booklet (Cancer Backup/Macmillan)
- Cancer Research UK / Cancer Backup/Macmillan: Pelvic radiotherapy in women Booklet
- *“Autobiography of a Face”* by Grealy, L. (2003)
- *“Bald in the Land of Big Hair”* by Rogers, J. (2001)

3. Mostly for Men

3.1 Tips and Advice for Men

- Speak to your doctor or nurse as erectile dysfunction support clinics are often available.
- Loss of sexual desire, erectile difficulties and continence issues following treatment can pose a real challenge to one's sense of masculinity. It is worthwhile speaking to other men who have gone through the same experiences to find out what has helped them cope.
- Many men find it hard to discuss their feelings and problems with their partner. This can lead to misunderstandings and assumptions being made on both parts which can make intimacy problems much worse. It can be helpful to try to speak openly about any changes in your sexuality and any fears or concerns you may have.
- With support and guidance, many men are able to rediscover sexual intimacy with their partners.
- The belief that men must be able to "provide sexual intercourse" at all stages of their lives is a common one, which can cause men great anxiety. Sometimes it helps to consider the possibility that a healthy sexual relationship can be maintained without necessarily requiring penetrative sex.
- Find out if both you and your partner are ready to get back to making love. There may be mixed feelings of excitement, expectation but also worry or concern at the

idea. Some couples or partners may feel happy to leave the situation as it is. It can feel awkward to get started again if there has been a long break.

- Many men are able to experience an orgasm through manual or oral stimulation even when they do not have an erection.
- If you have problems with erections, it can be helpful to remember that the majority of women never experience orgasms through intercourse and vaginal penetration. Even for women who can experience orgasm through intercourse, orgasms obtained through stimulation of the clitoris are often stronger and more pleasurable.
- Many partners are satisfied and orgasmic without penetrative intercourse.
- Remember that your most important sexual organ is your brain.
- There are many alternatives to intercourse such as mutual masturbation, oral sex, sex toys and dildos.
- Each couple can develop solutions that are acceptable to both partners
- The most important thing for your relationship may be to maintain intimacy, kissing, hugging, holding hands, stroking, etc
- Pelvic floor exercises may help improve erections by reducing the amount of blood flowing out of the penis (“venous leakage”) as well as possibly helping to increase the amount of blood flowing in (“arterial

sufficiency”). As with any fitness training, the results are seen over time. The good news is, the exercises can be done at any time (e.g. pelvicfloorexercise.com.au).

- If you have partial erections, try partial penetration. It is also possible to stimulate a female partner by rubbing or massaging her vulva and clitoris with a flaccid or non-erect penis without penetration.
- Make it easier to get an erection by using positions in love-making that take advantage of gravity, helping blood to flow into the penis. A good position for this might be the man standing up with his partner lying on the bed. The missionary position (affected man on top) will work better than one where the affected man lies down with his partner on top.
- If penetration is occasionally desired, some couples like to explore using a hollow dildo or harness with strap on dildo, which leaves the penis free to be caressed.
- If you are just about to have surgery or have had surgery recently, it may be worthwhile finding out about current ideas around penile rehabilitation. The experience of regular erections soon after surgery, even if you are not currently in a relationship, may be helpful to improve your ability to have erections in the future. Speak to your local urologist or cancer nurse specialist to find out more.

3.2 *If you are considering using erectile aids:*

- A number of different medical treatments for erectile dysfunction are available. These include tablets such as Sildenafil, Tadalafil & Vardenafil, Alprostadil pellets, injections and pumps. Penile implants may also offer a useful alternative to consider for some men.
- Some specialists recommend specific frequencies of taking medication to help overcome performance anxiety. Always consult with a specialist before trying to change the way you take your medication
- Many people believe that medication works first time and without stimulation – this is a myth. It can only work if men are aroused, not under pressure and if their partner is supportive.
- It can be useful to combine medical treatment approaches to erectile dysfunction with psychosexual support.
- If you want to re-establish your sex life, it is important not only to find the “right” medical tool, which might help you (see section on Medical Treatments for Erectile Dysfunction), but also to integrate it into your sexual relationship.
- Find out what using medication or a device means for you or your partner.
- Have realistic expectations. The treatment may not work at all, may work some of the time or may work partially. You may experience side effects.

- Anxiety influences the effectiveness of medication. If you take a relaxed attitude (“Let’s see what happens.”), your anxiety will be minimised.
- Depending on your attitude, medication can function as an “anxiety override” or “starting aid” by giving you more confidence and allowing any remaining natural ability to resurface more easily. Equally, taking medication could lead to an increase in performance pressure and anxiety and therefore make erections more difficult.

3.3 Useful Products for Men:

- The Whitaker Pouch: scrotal garment designed to reduce painful swelling - www.whitakerpouch.com
- Natural Men: Hair colourant for men - www.naturesdream.co.uk - 0845 6018129

Please also look under “More Useful Resources” and some of the problem-specific sections for further ideas.

3.4 Useful Reading for Men:

- *“Intimacy with Impotence: The Couple's Guide to Better Sex after Prostate Disease”* by R. & B. Alterowitz
- *“Saving Your Sex Life: A Guide for Men with Prostate Cancer”* by John P. Mulhall
- *“The New Male Sexuality”* by Bernie Zilbergeld
- *“Pelvic Radiotherapy in Men: Possible Late Effects”* booklet by Cancer Research UK / Cancer Backup/Macmillan
- *“Male Fertility”* booklet by Cancer Backup/Macmillan
- Prostate Cancer Education & Support, includes excellent information on sexuality and relationships
- www.ustoo.org

4. Some Specific Problems

4.1 Problems with Desire

- Making a decision about whether to find out about and try to address problems with desire or not can be difficult. By definition, when a person has lost desire, they do not feel like becoming sexually intimate. They may even describe that on a certain level they would be quite happy if they “never had to have sex again”. It can therefore seem paradoxical to put any effort into getting desire back. It can be important to ask yourself whether and why you would like to make any changes to your desire. This could be for many reasons, maybe to feel like your old self or maybe you miss the feelings of intimacy and closeness that came with it. Whatever the reason, remember that it is important that you truly want this change for yourself. Wanting to revive your sex drive for your partner is not enough and can be counter productive.
- Take responsibility for yourself as a sexual person and for your own desire. It is not your partner’s job to turn you on all by him- or herself. Get to know your body, build sexual self-esteem, learn to talk about sex to your partner and learn to make requests.
- Worry, depression and unhappiness with our body image can all directly affect sexual desire. Getting help with these problems can therefore help to improve your love life.
- Many types of medication, including many antidepressants, can also have sexual side effects. Please refer to the Medical Side Effects of Cancer

Treatments section or talk to a Health Care Professional.

- Sexual desire is stronger when you are in good physical shape. So, it can be worthwhile getting back to doing some sport or other physical activity you used to enjoy, even if in very small steps.
- Try to befriend your body. It has changed but there are many things it can still do terrifically well – you have been through this battle together.
- A person's sexual response after cancer relies on the complex interplay between biomedical (i.e. effects of cancer treatments), individual (i.e. psychological, behavioural), couple and social factors. In order to discover the best way to overcome a sexual problem, it can therefore be helpful to examine the role played by each of these factors in a person's life. Examine the section on Sex in Context to find out how the rest of your life may influence the desire you feel at the moment
- Try to talk to your partner about what each of you might see as an "ideal sexual encounter". Pay close attention to the setting and activities that lead up to lovemaking. You might be able to come up with several ideas each.
- Then think about how similar or different the "ideal encounters" are compared to your actual lovemaking.
- Think about whether there is anything you can do to make your sexual experiences more closely resemble the spirit of the "ideal encounter".

- Find out what circumstances you and your partner need in order to feel most receptive to becoming intimate. These can be psychological, relational, erotic or situational. Make a list of things that used to turn you on (clothes, music, fantasies, movies, books). Pull them out of storage and experiment with them. Also discuss what turns you off.
- Become aware of and find ways of leading into and gradually building up desire. Particular places, dates or times, anticipation, fantasy, initiation patterns, types of stimulation and ways of thinking about what you are experiencing can all become “bridges” to desire.
- Putting new energy or playfulness into an old and tested “bridge” might help to revitalise excitement.
- Tune into all your senses again. Your ability to experience sexual pleasure might be increased if you give yourself permission to enjoy your senses both in and out of the bedroom.
- You may be able to try the “simmering” technique. Nurture anticipation. Tune into sexual signals around you and try to keep a low “flame” of sexual awareness burning throughout the day. This will make it easier to “turn up the flame” when you meet your partner. Depending on what is acceptable to you and your partner, it is possible to use a wide variety of cues to “simmer” – It is, for example, quite “normal” to notice an attractive person passing you by in the street, in the office or on TV. If this seems acceptable to you as a couple, you may be able to become more aware of this fleeting surfacing of a sexual glimmer, to appreciate it as an signal of your underlying sexuality and to then

direct it towards your partner. You could also deliberately spend short periods during your day to try to deliberately call forth a certain sexual memory of having been with your partner, indulge in a fantasy of what you might like to do or perhaps send your partner a naughty text message. Some people like to read short stories or novels or watch films of a romantic or sexual nature to begin to build up desire. Quite a number of such products are nowadays produced with a female audience in mind. Some people prefer very subtle cues, other like more explicit ones. Simply find out what works and is acceptable for you and your partner.

- You can build anticipation and desire through intentional, planned dates. Set aside time and anticipate the sexual experience. Afterwards, acknowledge and savour the experience you have had.
- Keep touching in and out of the bedroom. Not all touching can or should lead to intercourse. Touching is a way to stay connected and serves as a bridge to desire, pleasure and eroticism.
- Consider the time of day and your energy levels
- Spend some time relaxing and leaving the rest of your life behind, make a deliberate transition from the hassle of daily life to the special time you will have with your partner
- Do not expect yourself to feel spontaneous desire. Do not wait for this to happen before you become intimate.
- If one of you is anxious about being expected to “go further than they are ready to” once you start becoming

intimate, it can be helpful to set clear rules. Both partners need to know that they can “go some of the way” without “having to finish what they started”.

- Only when we know we can say no and decide not to take things any further at any point, can it become possible to relax into an intimate situation and enjoy it for what it is. This helps us spend a lot more time interacting in a loving way and actually enjoying ourselves and finding out more about one another. It also makes it more likely that feelings of desire will build up slowly and that we will actually end up wanting “to take things further” than we otherwise might have done.
- It can be helpful to give yourself plenty of time for your intimate encounter with enough foreplay to allow yourself to become as fully aroused as possible before attempting penetration if this is desired.
- It may be helpful to give each other feedback on what kind of stimulation you like best.
- Explore what increases your sexual pleasure, e.g. dreams, deep breathing, remembering positive experiences.
- Explore fantasy. Fantasy can be about things you might like to do with your partner, maybe memories, places you might like to be or you have been to in the past. Fantasy is something you can keep quiet inside your minds or you might like to share with your partner.
- Some people find that looking at explicit photographs (erotic magazines), sexy videos or reading sexy stories together can help awaken a “slow to warm up” desire.

Many books and videos are also available specifically for a female audience.

- Try to maintain a regular rhythm of sexual contact. Resuming sexual activity after a break can make you feel awkward and self-conscious which interferes with pleasure and erotic flow.

4.1.2 *Useful Reading:*

- *“Rekindling Desire”* by Warwick Williams
- *“Rekindling Desire”* by Barry & Emily McCarthy
- *“I’m Not In The Mood”* by Judith Reichman
- *“Reclaiming Desire”* by Andrew Goldstein & Marianne Brandon
- *“Resurrecting Sex”* by David Schnarch

4.2 Pain

- If you are put off having sex because you are in pain, it is worth checking with your doctor if there is anything that can get rid of or lessen the pain.
- Learn about your own pain response. Are there times of day when you have less pain? Where is the pain and what kind of movement or activity triggers it?

- It may be useful to plan taking pain medication before having sex.
- Find out what is still pleasurable.
- Try experimenting with sexual positions that may be more comfortable for you.
- Side-by-side intercourse can reduce body weight on a sore area.
- Placing a thin pillow or cushion over a painful or hypersensitive area can also help. Slings, swings and positioning pillows are other options (see Unisex Tips).
- It is important that your partner understands exactly what kinds of activity may cause pain and what kinds of activities still give you pleasure.
- Decide in advance what activities will or will not be included in sex, so that you can both relax and enjoy what you are doing without undue worry about pain.
- The person worried about experiencing pain should stay in control over the activity. Do things slowly and carefully. Use lubricant.
- Do not override your experience of pain. If you are in pain – stop! Keeping going for the sake of a partner can make the sexual problem worse.
- It may be helpful to be close to orgasm or ejaculation before penetration, which can help by reducing the length of lovemaking.

- Orgasm can promote pain relief through the release of endorphins for up to 6 hours.

4.2.1 Female Pain:

- It can be useful to explore your body on your own first – you may wish to use fingers, dilators or vibrators. This can help you discover what kind of touch is still pleasant and where it is painful.
- Be sure to use lots of lubricant. Put this on the vulva, the vaginal entrance, into the vagina, anus and onto fingers or anything else used to penetrate. Keep lubricants next to you when you make love, so you don't have to get up and get it.
- Pelvic floor exercises (or Kegel exercises) can help you learn to relax the muscles at the entrance to the vagina which can reduce pain (see Tips & Advice for Women, also www.pelvicfloorexercise.com.au).
- Dilators can help to promote vaginal muscle relaxation, give you confidence in your body and help the vagina stay open and flexible after pelvic radiotherapy. The use of dilators should be directed by a cancer professional, physiotherapist or sex therapist who should be able to offer on-going support and guidance. Proceed slowly and at your pace – dilator therapy will not be effective if you are in pain (see Tips & Advice for Women)

- If planning to attempt intercourse, ensure that you are fully aroused, and use fingers or small dilators or vibrators to insert first to gain confidence and increase arousal. When it's time for penetration, guide the penis in and control the amount and intensity of the movement. It can be helpful to just have a brief time of penetration without any thrusting and for your partner then to withdraw the penis and to go on to other sexual play. Build the intercourse time up slowly over many sessions of love-making.
- A woman may be more relaxed and in control if she is the partner on top and can lower herself gently and gradually on top of her partner while he stays still.
- If pain is felt deeper in the vagina, avoid deep thrusting positions. Woman on top or side-by-side with the man entering the woman from behind ("spooning") might be better positions.
- To avoid deep thrusting, another option is for you to use lubricant on your upper thighs and to have intercourse with your thighs squeezed together. To achieve this, let your partner first insert the penis in the missionary position. Then squeeze your thighs closed and let him place his legs outside yours. He can help by then squeezing your legs further closed with his thighs. It can also help if he can shift his pelvis forward so that his pubic bone puts pressure on your inner lips and clitoris. Thrusting should start slowly and evenly.

- As an alternative, you could put lubricant on your hand and encircle the base of your partner's penis with your thumb and fingers. This way he will thrust partially against your hand and partially into your vagina, without reaching the deeper area that is painful.
- Avoid long periods of thrusting – ensure you are fully aroused or close to orgasm before penetration occurs.

4.2.2 Male Pain:

- For scrotal pain, it may be helpful to use a small amount of aspirin or paracetamol containing cream.
- Pelvic floor exercises can also help reduce male pain. As in women, chronic tension in the pelvic floor muscles can contribute to pain during sex. (e.g. www.pelvicfloorexercise.com.au)
- Use of lubricants and choice of position will also affect male pain (see female pain section).

4.3 Incontinence

- Remember that urine is not a toxic substance and is usually sterile. If you have recently had treatments, small traces of the drugs used for treatment may be present in body fluids short term. Please get the advice of a Health Care Professional if you are unsure about whether you are affected.
- Most common points of incontinence are during foreplay/sexual stimulation and during orgasm
- Fatigue and alcohol can make problem worse
- Talk to your partner beforehand about his or her feelings about bladder or bowel incontinence. Make plans together ahead of time for what you will do in the event of an accident, e.g. ignore and continue, dry up with towel nearby, move to shower and continue there...
- Try to keep your sense of humour.
- Empty your bladder, bowel, and stoma or urostomy bag before you become sexual.
- Consider exploring intimacy in the bath or shower.
- Keep a supply of smaller towels for clearing up accidents.
- Use positions which put less pressure on the bladder, e.g. on your side or with incontinent person on top.

- Use absorbent, dark coloured towels or plastic sheets to protect bedding. Rubber sheets are also good as they don't make a crinkling sound but are more expensive.
- If you use lots of slippery lubricant to get wet before having sex, additional wetness won't be noticed as much.
- Try using scented candles, incense, body locations or perfumes to cover odour.
- Consider using condoms if this seems helpful.
- Use of an ACTIS band can be helpful in controlling foreplay and orgasm-related incontinence by compressing the urethra to prevent urine leakage
- It's possible to keep a catheter in during penetration – men can bring it down along the penis and wear a condom, women can tape it out of the way
- Some people prefer not to have intercourse when continence is an issue. They might wear bladder control pads and keep their underwear on while engaging in other forms of stimulation.

4.4 Stomas

- If you have a urostomy, you may be able to use a urostomy cap instead of a standard bag during sex.
- The side-by-side position in which the man is behind the woman ("spooning"), or the L-shaped position, with both

partners lying down, torsos at right angles and legs entwined can be useful by not placing any weight on the ostomy.

- It is often possible to limit food intake before anticipated sexual activity, to watch the type of food consumed and to plan times for intimacy when a bowel motion is less likely.
- You may like to change the ostomy bag before anticipated sexual intimacy.
- An empty or flat ostomy bag will not become dislodged from the stoma and can be rolled up or taped down so that it will not get in the way.
- Many different products are available. These include disposable bags, reusable bags which can be emptied while still attached, bags with filters to control odours and pouches that hang sideways. It is also possible to use deodorant tablets or liquids at the bottom of the bag or as recommended by the manufacturer.
- Pretty covers can be worn.
- Different fabrics can be used to help with sensuality such as satin teddies or silk boxer shorts, ensuring that the waistband is comfortable and is above or below stoma sites.
- Never insert anything into a stoma.

4.4.1 Resources:

- White Rose collection Ltd.: Underwear, Swimwear & Accessories specifically designed for to people with stomas - *PO Box 5121, Wimbourne, Dorset BH21 7WG* - sales@whiterosecollection.com - 01202 854634
- Vanilla Blush: lingerie; also planning swim wear, men's wear, bridal and maternity wear - www.vblush.com - 01415 561035
- CUI Wear: ladies and gents underwear range - www.cuiwear.com - 0800 2792050

4.4.2 Reading:

- *"Body Image after Stoma surgery"* Kelly, M. (2001). Dansac Ltd.
- *"What about sex? For people with a stoma and their partners"* Galt, E. & Hill, H. (2002). Dansac Ltd.

4.5 Breathlessness

- Try to remember that it is normal and usually harmless to become more breathless during a sexual encounter.
- Sexual activity needs energy and makes demands on your heart and lungs. You breathe more and your heart rate and blood flow go up for a short time. They return

to normal levels quickly. The energy you use during orgasm is similar to the energy needed to climb 2 flights of stairs or to take a brisk walk. If this is tolerated, the breathlessness provoked by having sex should not be any more dangerous than that experienced when climbing stairs (Roy Castle Foundation).

- Try using inhaled or nebulised therapy [bronchodilators] before and after sex or any other activity you enjoy to reduce breathlessness, rather than avoiding altogether.
- If using oxygen therapy, try using a nasal cannula instead of a face mask which may interfere with physical contact (kissing etc), eating and talking.
- If you get out of breath during sex, pause to take a few deep breaths from your diaphragm rather than stopping altogether.
- First thing in the morning and late evening may be worse for breathlessness, tight chest, sputum production etc. Plan sexual activity during times when breathlessness is less of a problem.
- Try to have sex when you feel rested and relaxed. It is usually not helpful to try to have sex on a full stomach as this can make breathing more difficult.
- Experiment with different positions for sex as bending or lying underneath your partner may increase feelings of claustrophobia and breathlessness. Standing up, lying side by side or sitting in a chair may be better alternatives.

4.5.1 Useful Resources & Links about Breathlessness

- ‘*A Practical Guide to Breathlessness*’ – The Roy Castle Foundation
<http://www.roycastle.org/patient/patientinfo.htm>
- ‘*Sex and Breathlessness*’ – The British Lung Foundation
- “*Sexual Health and the Respiratory Patient*” Law, C. (2001), *Nursing Times Plus*, 97 (12).

5. And what about me?

5.1 Useful Links for Single People

Being single and having cancer can pose particular challenges. Many people describe they feel lonely and miss the support of an intimate partner particularly at this time. Others may also worry about what the future holds and whether they will still be able to find that special person. Cancer support groups can be great way to overcome feelings of loneliness and isolation and to link in with other people in a similar situation. The following links may also give you some further ideas and support:

- www.cancerhelp.org.uk (“Sexuality and Cancer if You are Single”)

- www.asconews.org (“Being Single with Cancer”)
- www.cancer.org (“The Single Man and Cancer”, “The Single Woman with Cancer”)

5.2 Useful LGBT Links

Little specific advice on sexual recovery after cancer has been written from an LGBT perspective to date. We hope that you will find some of the ideas and tips mentioned in this booklet helpful and applicable.

The following resources may offer some further information and support:

- *Perlman, G. & Drescher, J. (2005). A Gay Man’s Guide to Prostate Cancer. Hawford Medical Press.*
- Brownworth, V. (2000). *Coming Out of Cancer: Writings from the Lesbians Cancer Epidemic.* Seal Press.
- www.healthwithpride.nhs.uk
- www.cancer-network.org
- www.outwithcancer.com
- www.lgbtcancer.com
- www.malecare.org/gay-prostate-cancer

Other Useful Resources

6.1 Links

- Association of Cancer Online Resources. Includes a “cancer-sexuality” mailing list - www.acor.org
- www.macmillan.org.uk , also www.be.macmillan.org.uk for range of patient information booklets, call 0800 500 800
- Cancer Research UK - www.cancerhelp.org.uk
- RELATE - www.relate.org.uk
- BASRT (British Association for Sexual and Relationship Therapy - www.basrt.org.uk
- Sexual Advice Association: for leaflets on non-cancer specific male / female sexual difficulties - www.sda.uk.net - Helpline 020 74867262
- Dana Farber Cancer Institute - www.dana-farber.org
- American Cancer Society - www.cancer.org
- University of Texas MD Anderson Cancer Centre - www.mdanderson.org
- Cancer Council Victoria - www.cancervic.org.au
- Cancer Supportive & Survivorship Care - www.cancersupportivecare.com

- Cancer Council South Australia -
www.cancersa.org.au

6.2 Literature

- Macmillan Leaflets and web content
www.macmillan.org.uk/sex
- *'Coping with Chemotherapy'* by Terry Priestman
- *'Supportive Care in Radiotherapy'* by Sara Faithfull and Mary Wells
- *'After Cure'* by the UKCCSG (contains a range of information about issues after cancer treatment, including fertility issues)
- *'Sexuality and Fertility After Cancer'* by Leslie R. Schover
- *'Overcoming Body Image problems'* - a Self Help guide using Cognitive-behavioural Techniques by David Veale et al.
- *'The Sex-Starved Marriage'* by Michele Weiner Davis
- *'Overcoming Sexual Problems'* by Vicki Ford
- *'Sex for One'* by Betty Dodson
- *"The Complete Idiot's Guide to Sensual Massage"* by Patti Britton & Helen Hodgson Lerma

- “*The Ultimate Guide to Sex & Disability*” by Kaufman et al.

6.3 Accessories

- Hats for Heads: stylish hats for people of all ages - www.hats4heads.co.uk - 0161 9416748
- Bohemia: Fashion Headwear for Ladies, Gents and Children - www.bohemia-fashions.com - 01582 750083
- BlackCare UK Ltd.: wigs for people from black and ethnic minorities - www.blackcareuk.com - info@blackcareuk.com - 020 8279 0335 / 0337
- SexWare: a wide range of sex accessories including help for people with disability/dysfunction - PO Box 883, Oxford OX4 5NT - sales@fpsales.co.uk - 01865 719400
- www.beecourse.com: Sex aids and advice, run by a woman aimed at men and women
- Ann Summers - www.annsummers.com
- www.bettersex.com
- www.goodvibes.com: sex and disability products
- www.comeasyouare.com: sex and disability advice and products

- Clean Sheets: online erotic writing - www.cleansheets.com
- Liberator Shapes: angular pillows designed for helping with sexual positioning - www.liberatorshapes.com
- “*Ageless Desire*” – VHS, available from www.comeasyouare.com
- “*Great Sex for a Life Time*” DVD/VHS available from www.bettersex.com
- “*Still doing it. Women and men over 60 write about their sexuality*” by J Blank, www.comeasyouare.com

Further accessories are listed under the “Mostly for Women” section.

Literature & Acknowledgements

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Intimacy & Sexuality

for Cancer Patients and their Partners

A Booklet of Tips & Advice for Your Journey of Recovery

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