The background features a complex, abstract composition of overlapping, semi-transparent shapes in various colors including orange, green, blue, purple, pink, and yellow. Several speech bubbles in dark blue and black are scattered throughout the design, some overlapping the text and others the shapes. The overall aesthetic is modern and vibrant.

BODY TALK

EXPLORING SEXUAL
WELLBEING FOR PEOPLE
AFFECTED BY CANCER

This booklet was created by the charity **OUTpatients** (charity no. 1190756) in direct collaboration with cancer patients and healthcare professionals. Work to produce this booklet was supported by the Gilead 'Look and You Will C Us' fund.

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WHAT IS SEXUAL wellbeing?

Sexual wellbeing is an important part of our mental and physical health. But what does it really mean?

Let's break it down into three main areas:

Physical: Our bodies and how they work.

Mental: The way we think and feel about things.

Social: Our relationships and how we interact with the world around us.

Everyone has a different “normal” when it comes to sexual wellbeing, and that’s okay. For some people, sex is very important, for others it’s not.

You don’t need anything to be going wrong for you to talk about your sexual wellbeing.

When going through cancer, there might be changes to your sexual wellbeing that you would like to discuss. We know that this can feel a little awkward, but don’t worry!

This booklet is here to help you explore what sexual wellbeing means to you. It will help you to learn some key language that will make talking to your cancer team easier.

We encourage you to grab a pen and interact with the activities, write notes, and draw on the diagrams. This booklet is yours to use in whatever way helps to make sexual wellbeing feel more relevant to you.

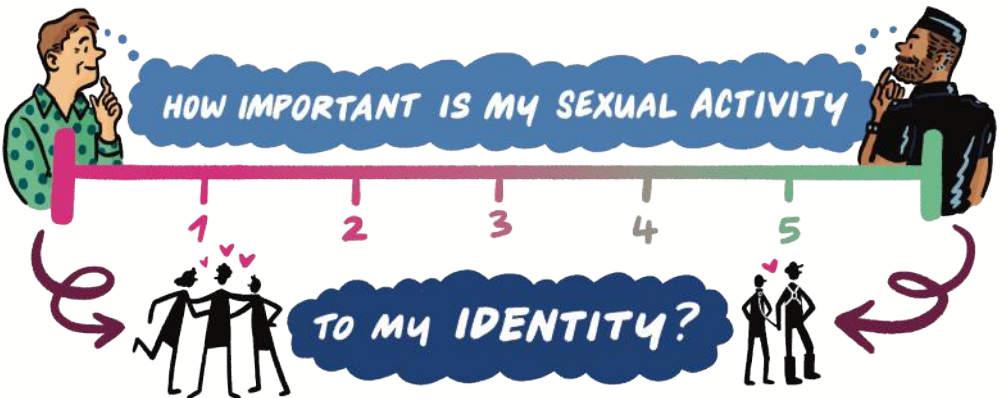
Let's start at the very beginning

My gender is:

I am attracted to:

My current relationship status is:

The type of sex or sexual role I prefer looks like:

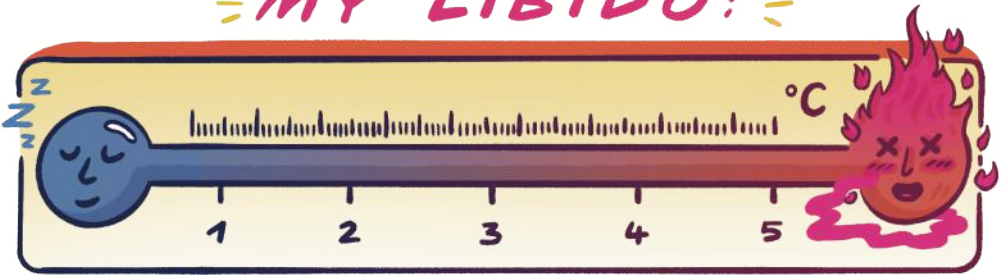


What's your 'normal'?

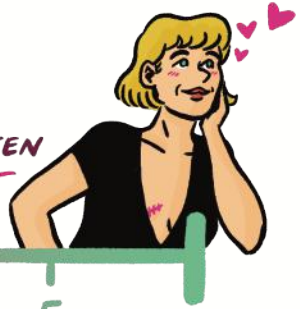
Everyone's approach to sex and intimacy is personal to them. For this reason, it's important to understand what is normal for you so that it's easier to communicate any changes.

When completing this next page, answer it by thinking about yourself before your cancer diagnosis.

MY LIBIDO:



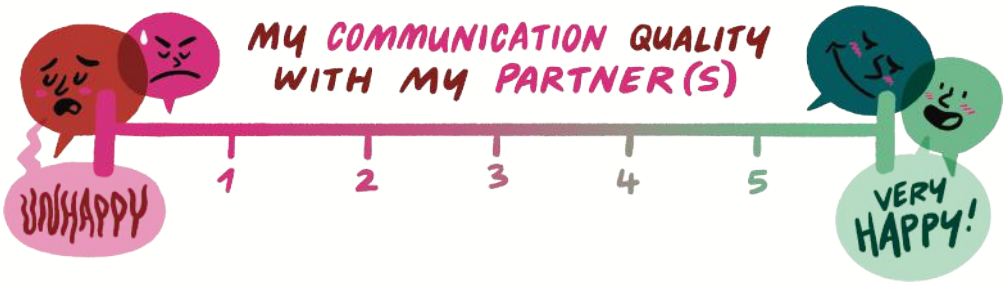
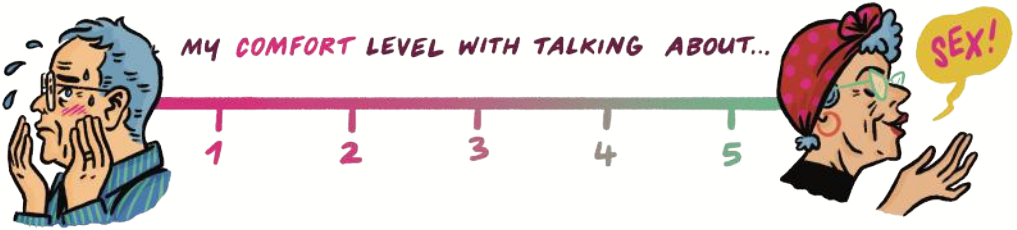
I AM THIS SATISFIED WITH HOW OFTEN I HAVE SEX:



These things make me feel sexually confident:

These things make me feel anxious about sex or intimacy:

Let's talk about sex, baby!



Mark along the line with an 'X' where you fall in your preferred communication style when talking about sex and intimacy:

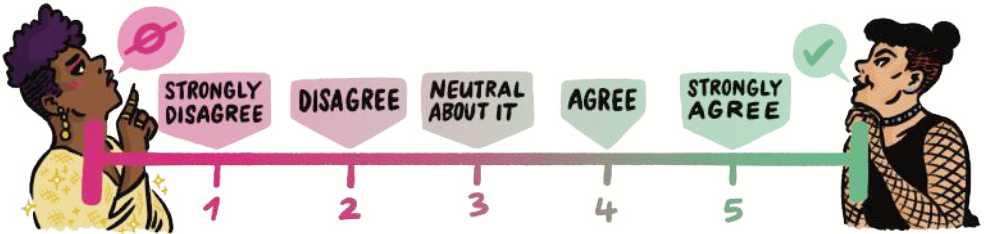
Indirect _____ **Direct**
You prefer to communicate through non-verbal cues and hints *You prefer to openly express your thoughts and feelings*

Passive _____ **Active**
You like to avoid conflict when speaking *You like to ask questions and give feedback*

How I prefer to talk about sex and intimacy:

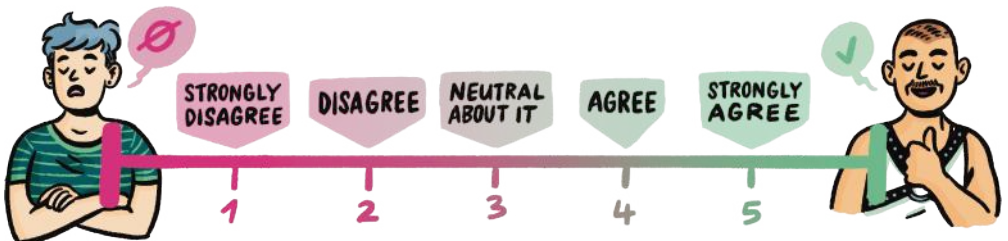
My religion, culture, or community views masturbation as:

I agree with this viewpoint this much:



My religion, culture, or community views sex as:

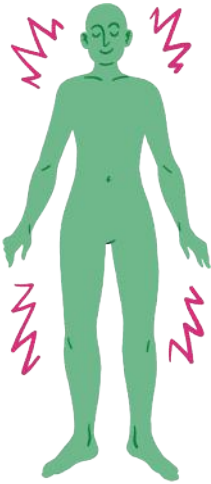
I agree with this viewpoint this much:



My body

On the next few pages, we have some outlines of the body. Take the time to circle areas, draw on them, label them, add notes, or do whatever feels right for you to answer the prompt.

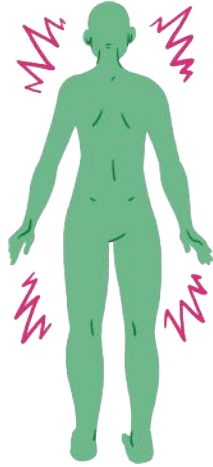
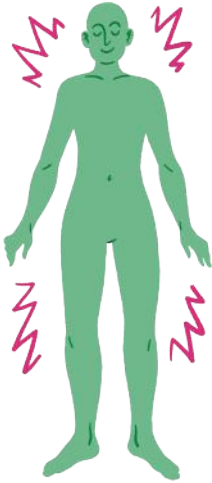
Parts of my body that are important for my identity



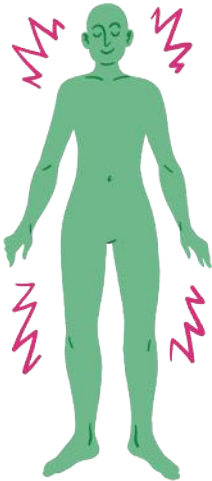
Parts of my body that are important for the sex I like to have



Parts of my body I'm open to exploring sexually alone or with my partner(s)



Parts of my body I am sensitive about or have a complicated relationship with





Even before being diagnosed with cancer there can be things that you are managing in your life that affects your sexual wellbeing. Explore this idea with the prompts below.

I have other health conditions that affect my sexual wellbeing

They are: _____

I have accessibility needs that affect my sex and intimacy

They are: _____

My experience of communicating these needs has been:

My experience of having these needs met has been:

I use medications, drugs, or supplements that affect my sex life (including the ones not given to you by a doctor!)

They are: _____

I am dealing with other issues in my sex life

They are: _____

I have a experienced sexual trauma

It affects me in this way: _____

If you are currently experiencing sexual or partner violence, you can report this to your clinical teams. You can ask to be seen alone for privacy.

If the above does not feel possible, there are other places you can receive help, including:

In an **emergency**, dial **999**.

The **non-emergency** number for the police is **101**.

The NHS phone line for **non-emergency medical help** is **111**.

The 24-hour freephone **National Domestic Abuse Helpline**, run by Refuge is available on **0808 2000 247**.

The rape and sexual abuse support line run by **Rape Crisis** has a helpline on **0808 500 2222** or you can use the online chat (both are free and open 24 hours a day, every day of the year)

The **NHS** has rape and sexual assault service centres. You can find your nearest one online at **<https://www.nhs.uk/service-search/other-health-services/rape-and-sexual-assault-referral-centres>**

Your GP surgery, an A&E department, a GUM or sexual health clinic, a contraceptive clinic, or a young people's NHS service.

A specialist charity, such as Women's Aid, Victim Support, The Survivors Trust, Male Survivors Partnership, Galop (LGBT+), and many others.

If you are someone you know is at risk of female genital mutilation (FGM), you can call the **NSPCC helpline on 0800 028 3550** at any time - it's free and you don't have to tell them your name. You can also email **fgmhelp@nspcc.org.uk**

Don't suffer in silence!

It is important to flag any changes to your sexual wellbeing as early as possible. The sooner that something is addressed, the more likely something can be done to support you.

Your clinical nurse specialist (CNS) is a great place to start if you need some help. If they are not able to help you directly, they should be able to find someone who can.

If you are not sure who your CNS is or if you think you don't have one, don't worry. There are many people in your cancer team who can help. Try asking your oncologist or a nurse who in their team is best suited to support your needs. You may also choose to talk about your concerns with your GP.

When asking for support, use this document to help you describe your sexual wellbeing, your concerns from your cancer or its treatment(s), and your goals for recovery.

Everyone's path to sexual wellbeing with and beyond cancer is different, but each one is equally important.



A BETTER WAY TO TALK ABOUT

SEX



- B - Bring up the topic**
- E - Explain what you are concerned about**
- T - Tell them if you need any support or resources**
- T - the Timing might not feel perfect, but it's better to talk**
- E - ask if there is any Education or information available**
- R - Record the important information by making notes**

Don't be afraid to make notes during an appointment. When making notes, it might help to use a template like the one below. Make sure to think about things you want to raise ahead of time and write them down so you don't forget them in the appointment.

(Before the appointment)

Things I am concerned about: _____

The type of support I need: _____

(During the appointment)

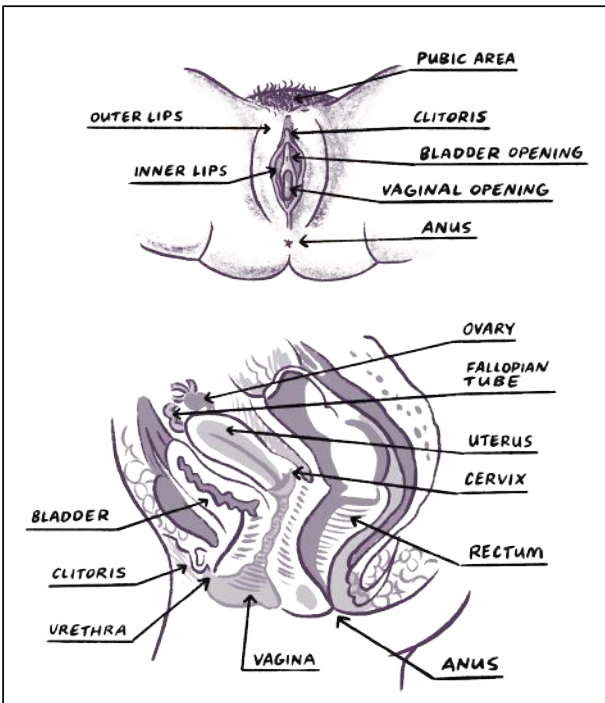
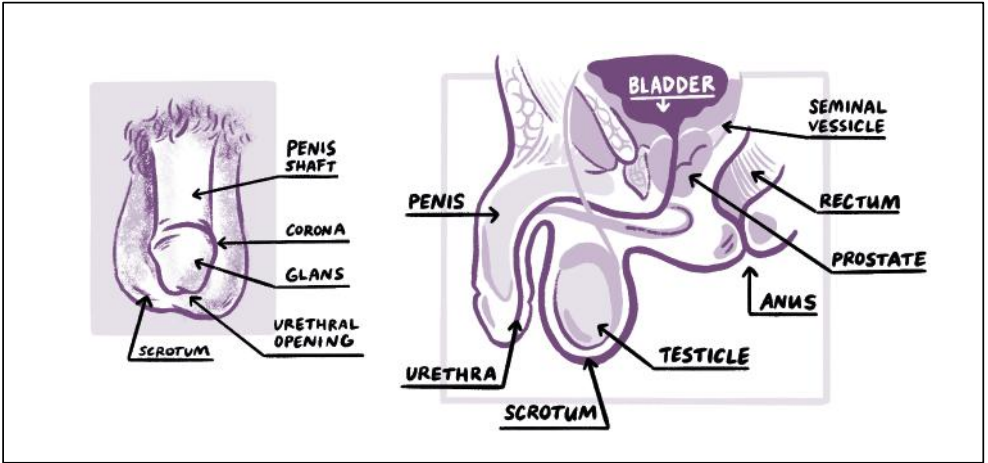
I spoke to: _____ On this date: _____

We spoke about: _____

Next steps: _____

Talking about anatomy

Although there is lots of variation in how our genitals can look, the majority of people will be similar to the following diagrams. The next few pages will cover some useful language to help you describe what's 'going on down there'.



Some people's genitals may look different to these diagrams. This can be from conditions present at birth, puberty, injury, surgery, or many other reasons.

It's important to remember, no one is expecting you to be an expert in anatomy.

You can describe your body to your cancer team in the way that feels most comfortable for you.

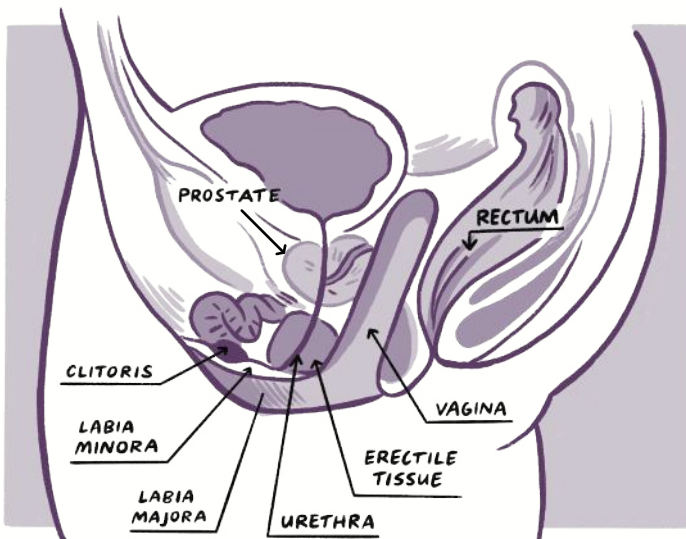
If there is a way that you would like your team to talk to you about your body, let them know.

Did you know:

Sexual wellbeing isn't only about our genitals! It can include our mental wellbeing, our relationships, and other parts of our bodies too, including our head, neck, torso, or our chest to name a few.

It is always worth discussing both the internal and external anatomy we have. For example, some people find that stimulating the prostate is an important part of their sexual activity. If this is true for you, it is worth discussing this when you are making treatment decisions, especially if you are diagnosed with prostate cancer.

If you were registered male at birth and have undergone a vaginoplasty, you will still have your prostate. This is important for trans and non-binary people to know! You can see where the prostate sits inside the body after vaginoplasty in the diagram below.



The pelvic floor

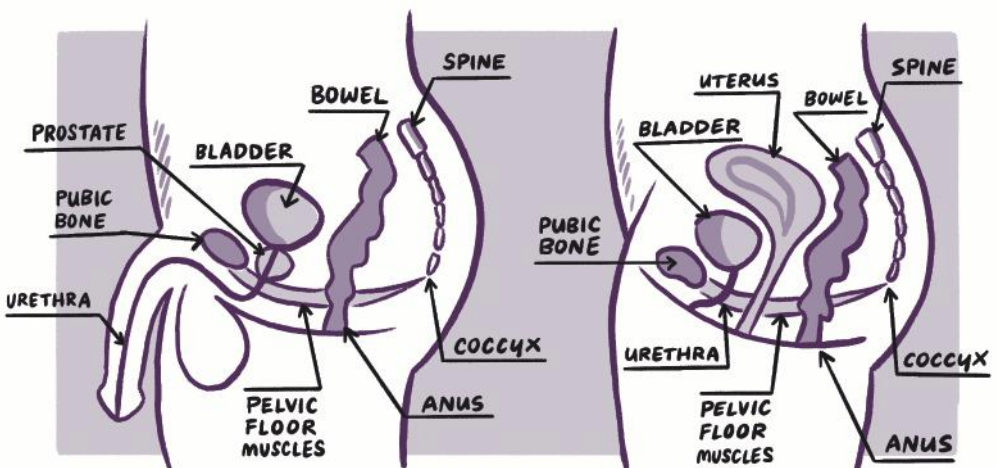
The pelvic floor is a group of muscles that give you the ability to control the release of wee, poo, and wind.

Pelvic floor muscles are important for sex, including erections, ejaculation, and avoiding painful sex. Being able to squeeze the pelvic floor can even improve sensation, arousal, and orgasm.

The pelvic floor stretches like a hammock from the pubic bone at the front of the body to the tailbone (coccyx) at the back. It also connects to the parts of the pelvis you sit on.

The pelvic floor, like other muscles, is talked about by its tone. You might have a low-tone pelvic floor that needs strengthening, or you may have a tight pelvic floor that needs relaxing.

Pelvic physiotherapists have specific experience with supporting cancer patients through a variety of exercises. Don't be afraid to ask about the service. If it is not available where you are, speak to your cancer team. You may also want to try using the Squeezy app on your smartphone.



The sexual response cycle

The sexual response cycle is the pattern of events that happen during a person's sexual arousal and activity. Knowing the stages our bodies go through can help you to communicate where in the cycle you are experiencing difficulties.

Arousal

An early response to feeling, thinking or seeing something sexual

Excitement

The arousal gets stronger and the body gets excited

Plateau

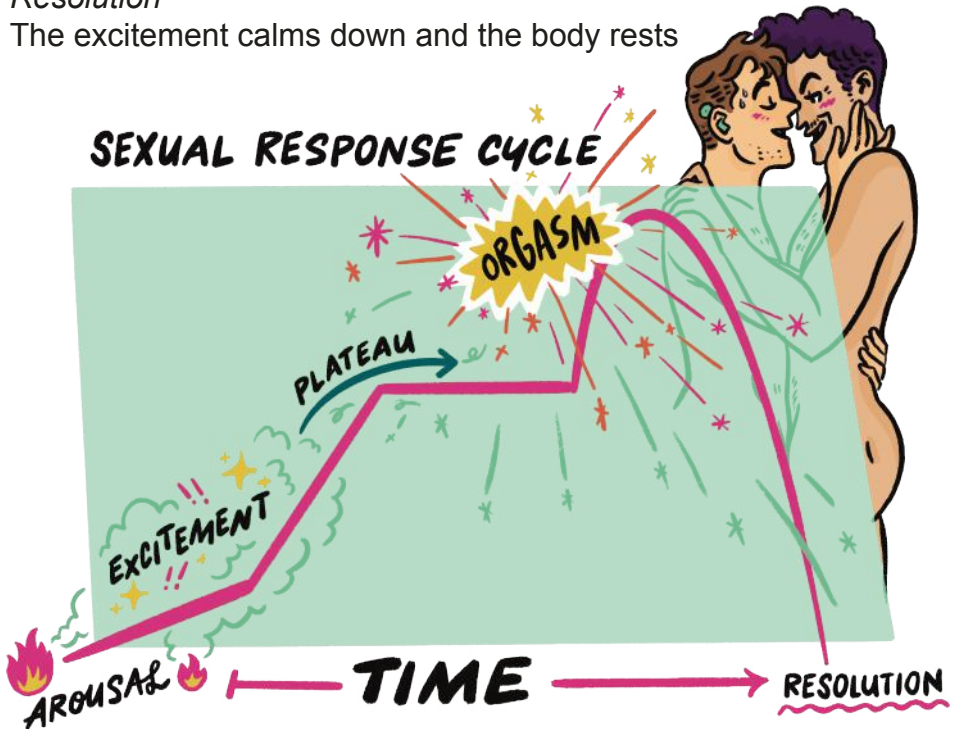
The sexual excitement or activity continues at the same level

Orgasm

A peak of sexual excitement

Resolution

The excitement calms down and the body rests





When people are intimate it leaves them feeling open and potentially vulnerable. This is especially true when facing cancer and its treatments.

You may have less energy than before, you may be adjusting to physical changes, or sex just might not be interesting to you right now. All of these points are valid.

If you do not talk about these changes with your partner(s), they might be misunderstood which can lead to disagreement or avoidance, making the ability to connect even more difficult.

When this becomes a pattern of behaviour, we call it a 'negative feedback loop'. This loop can continue to make things difficult for you until it is interrupted. Talking about the changes you are experiencing can help to break this pattern.

Some, but not all, NHS hospitals will have a sex and relationship therapist available who may be able to help. If you do not have this service where you are, you can find your own therapist through trusted organisations like the College or Sex and Relationship Therapists.



Sensate focus is a mindfulness exercise. It focuses your attention on the feeling of touching and being touched and moves you away from expectations about what intimacy or sexual activity “should be”, allowing you to be more present in the moment.

Sensate focus is helpful for people struggling with their body image, erectile dysfunction, orgasm disorders, adjusting to body changes, and lack of sexual arousal.

The success of sensate focus is built on embracing curiosity, acceptance, and consent. If at any stage one person withdraws their consent, it is important to respect this and retry when they feel ready to do so. It’s also important that you do the exercise for as long as you are interested and stop before anyone gets bored.

Sensate focus is carried out over a series of exercises. To build up momentum, it is best to do the exercises at least once or twice per week.

Although there are no set rules about how long you must spend at each step, it’s recommended that you spend at least a couple of weeks at each exercise before going on to the next one. Progress depends on both partners feeling comfortable and continuing to consent.

In **Step 1**, pick who will be the toucher and the touched. The receiving partner lies down while the toucher gently touches their body for about 15 minutes. After this time, you can swap roles. At this step, breasts and genitals are off-limits. As you are doing the exercise, focus on the physical sensations that happen at various points across the body. You should do Step 1 on several different occasions before moving to Step 2 and only move on to Step 2 when everyone feels ready. This might take a few weeks if you are doing the exercise once or twice a week.



Step 2 is the same as Step 1 except that touching the breasts and genitals is allowed. Don't focus too much on the genitals to the neglect of the rest of the body and don't masturbate your partner. Do Step 2 on several different occasions before moving on to Step 3 when you are ready.



Step 3 introduces mutual touching. After taking turns touching, get comfortable, like laying on your sides facing one another. When you are in a good position, begin to touch each other at the same time. Some people like to introduce body-safe oils or lubes after a few occasions of this exercise.



Step 4 includes outercourse, i.e. non-penetrative sexual activity. After each partner gives and receives touch, the couple gets into a position they could use for sex, such as laying on top of each other. Engage in slow, sensual contact but be sure to have no penetration. The outercourse should be done for brief periods alternating with touching as in the previous steps. Orgasm is not the goal, but it is okay if it happens.



Step 5 is the final step, known as 'sensual intercourse'. Full sexual activity, including penetration, is allowed at this step. The sexual activity should be for short periods between your sensual touching. As before, orgasm is not the goal, but it is okay if it happens. If you find your mind is wandering or you are "watching yourself" from an outside perspective, refocus your attention on the exercise and the sensations you are experiencing.

CHOOSING A *Lube*



Cancer treatment can affect the body's ability to self-lubricate for sex. When choosing a lube, consider the kind of sex you'll be having and whether you'll be using condoms or adding sex toys. There are three main types of lube:

Water-based lubes are typically the easiest to find. They're compatible with sex toys, safe to use with latex condoms, and won't stain fabrics.

Oil-based lubes often last longer than water-based but can break down latex, so are best avoided if you're using latex condoms.

Silicone-based lubes often last longer than water-based but can be irritating for people with sensitive skin and may damage silicone toys or dilators.

Lubes to avoid

Flavoured lubes can increase the risk of vaginal infections, especially yeast infections, due to their additives and high sugar content.

Lubes with high levels of glycerin may also dry out intimate skin and increase discomfort.

Petroleum jelly can damage latex condoms, alter the vagina's natural pH, and contribute to bacterial growth, so it should be avoided.



FREQUENTLY ASKED QUESTIONS

Can I pass my cancer on to my partner?

No, it is not possible to pass cancer to someone else.

Will sex make my cancer worse?

No, sex does not risk the chance of cancer getting worse. Nor will it increase the chance of it coming back or spreading.

Is having a HPV-related cancer my fault?

No, having an HPV-related cancer is not your fault. Around 8 out of 10 people will have HPV at some point in their lives. Most people will never know they have it and clear the virus from the bodies over time without it developing into a cancer.

Is it okay to not want to have sex?

It is up to you to decide if you want to have sex or not. Some people might find that they do not want to have sex during cancer treatment, and that's okay. Some people have never felt an interest in sex and that is also okay. If you do want to have sex during or after your treatment, it's good to be informed about how to do so safely, comfortably, and confidently. Check out the Useful Links in the back of this booklet to find useful information from trusted organisations.

Can I have sex during treatment?

Although physical contact like hugging and kissing are usually okay, your ability to safely have sex may depend on the type of treatment you are undergoing. For more information about specific treatments, check out the Sex and Cancer Info Hub in the Useful Links section at the back of this booklet. There you can browse different treatment types and use these to help you think of questions to ask your cancer team.

How do I talk to my partner(s) about pain?

Some cancer or its treatments can cause pain during sex. When talking to partners, both new and current, it is useful to be honest about any concerns you may have. It is up to you how much information you share about your cancer, but if you think something may make you uncomfortable, mentally or physically, it is important to make this clear. The priority is your safety, wellbeing, and consent at all times. For more targeted support with pain, physiotherapists and sex therapists may be able to help.

I'm so tired all the time, when will I get the energy for sex?

Cancer and its treatments can make you feel very tired. Stress related to your experience may also make you feel more tired than usual. If you are struggling to be intimate with your partner due to your energy levels, consider having sex at a time of day when you know you'll have the most energy. For some couples, this involves not being afraid to schedule sex in the calendar!

Does chemotherapy end up in my bodily fluids?

Traces of chemotherapy can be in bodily fluids for a number of days after having chemotherapy, including your urine, vomit, and also in small amounts in other places like vaginal fluids or semen. Kissing is safe. For any sex involving the transfer of bodily fluids (e.g. oral sex, anal sex, vaginal sex) we advise using a barrier like a condom or dam for 5 days after a round of chemotherapy. For activities where barriers aren't suitable, you may want to avoid the activity whilst receiving chemotherapy (e.g. urine play).

Why have I been given a dilator?

When treatment affects the vagina or anus, people may be given a dilator to use. The purpose of the dilator is to stretch and dilate (keep open) the vagina or anus so that bodily functions and routine internal examinations are easier. The other benefit of using dilators is to make sex more comfortable now and in the future.

What should I use if I'm experiencing vaginal dryness?

If you are experiencing vaginal dryness, you might want to try a moisturiser and a lube. Moisturisers can be used routinely and help to make things generally more comfortable so that you can go about your day. As moisturisers are different from lubes, you may also want to use a lube for when it's time for sex to help make things as enjoyable as possible. Always remember to buy a high quality product from a trusted retailer.

Can I use poppers?

Poppers (amyl nitrite) are used by some people during sex. They help to relax muscles and reduce discomfort so are most commonly used for anal sex. Poppers are known to have health risks, some of which are serious. You should not use poppers at the same time as taking oral medicines for erections (PDE5 inhibitors). This is because both reduce blood pressure and if they are used together this can lead to serious complications and even be fatal.

What is sex and relationship therapy?

Sex and relationship therapy is a specific form of talking therapy that works to preserve or improve your wellbeing, bodily function, and relationships. In some cases, you may be given homework to explore or improve your sexual function. You do not need to be in a relationship to access this type of therapy. If your local NHS service does not provide this type of therapy, you can search for a therapist online via the College of Sex and Relationship Therapists (see the Useful Links at the end of this booklet).

Useful Links

OUTpatients: Cancer sex and information hub

<https://outpatients.org.uk/sex>

Macmillan: Sex and Cancer Information

<https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/sex-and-cancer>

Breast Cancer Now: Sex and the effects of breast cancer treatment

<https://breastcancernow.org/about-breast-cancer/life-after-treatment/sex-and-the-effects-of-breast-cancer-treatment>

Prostate Cancer UK: Sex and relationships

<https://prostatecanceruk.org/prostate-information-and-support/living-with-prostate-cancer/sex-and-relationships>

Sex with Cancer

<https://www.sexwithcancer.com>

Cancer, Sex, and Intimacy

https://www.instagram.com/sex_cancer_intimacy

The College of Sex and Relationship Therapy: Find a psychosexual therapist

<https://www.cosrt.org.uk/search-members>

Institute of Psychosexual Medicine: Find a Specialist

<https://www.ipm.org.uk/patients/specialists>

Pink Therapy: Find an LGBT+ therapist

www.pinktherapy.com

More useful links can be found on our website

