

CANCER & SEX

Everything **oncology professionals**
should discuss with their patients but
maybe were afraid to start...

Sexuality: More than nice to have!

Disturbances in **sexual function** and in **intimacy** are common consequences of **cancer** and its **treatment**. For a variety of populations and of cancer and treatment types, estimates of such disturbances range from **20% to 100%** and involve both **physical** and **psycho-social causes**.

Physical effects on sexual function include loss of libido through anti-hormonal therapy, chemotherapy or radiotherapy; impaired physical arousal (reduced lubrication, erectile dysfunction, sensory limitations) through surgical, chemotherapeutic or radio-oncological therapies; incontinence or stoma; loss of fertility; fatigue.

Psychological effects on sexual experience such as distress and depression, anxiety, insecurity and issues with gender identity, body image change, feelings of shame, self-esteem reduction, withdrawal and development of avoidance strategies in body interaction / sexuality.

Social effects such as withdrawal from body contact with others, mutual protection behavior, seclusion and loneliness, increased relationship conflicts due to dissatisfaction in the relationship and general social withdrawal e.g., due to change in excretory function.

Sexual problems caused by common cancer treatments can lead to **regret, depression, relationship problems**, etc., and, thus, to a considerable reduction in **quality of life**. It is therefore necessary to **address** the negative consequences of treatment on sexuality and to **support** patients in dealing with it.

Talk to your patient about sexuality!

Sexuality often is a taboo topic for both patients and healthcare professionals (HCPs). Intimacy and sexual difficulties are typically glossed over by cancer patients - as the vast majority of them and their partners do not feel at ease to bring up such a sensitive topic. Yet, after a consultation, they might regret missing the opportunity to talk about their sexual difficulties and concerns. Hence, HCPs should always introduce the topic and offer advice and support - as they are regarded as experts in the eyes of the patient and patients may expect them to initiate the discussion.

Displaying brochures and informational material on cancer and sexuality in the consultation room, for instance, would certainly convey the importance and relevance of the topic.

Keep in mind that it may very well be the first time that the patient opens up about cancer-related sexual dysfunction and that talking may be a great sense of relief to them. Do not rush to the "giving advice" phase of the conversation as active listening is key!

How do you start a conversation about sexual issues with your patients?

PREPARE THE CONSULTATION



Bear in mind that conversations about private and intimate issues may take time. Therefore, plan your consultation and schedule ahead in order to allow enough time to have a thorough discussion, or refer the patient to an appropriate colleague. Ensure that the consultation takes place in a comfortable and enclosed space to guarantee privacy and encourage patients to open up about their sexual issues.

Always use neutral and inclusive terms such as 'partner' and pose your questions in a non-judgmental manner. Avoid making assumptions about your patient based on age, appearance, marital status, or any other demographic factor. In particular, unless the person shares more information with you, refrain from making assumptions based on the person's sexual orientation, behaviors, gender identity or cultural background.

In order to build rapport with your patients, start off the conversation with general, medical topics, before addressing personal and intimate issues. At the end of the session/consultation, offer the patient to invite and bring their partner(s) to the appointment or the session when you plan to discuss these issues.

EXPLAIN WHY SEXUALITY ISSUES ARE COMMON PROBLEMS



Addressing sexuality issues can be firstly done by emphasizing that sexual complaints are frequent among cancer patients, and the patient is not in a unique or rare situation:



'We know that many patients with comparable therapies notice effects on their sexuality - do you also feel burdened by changes in your sexuality?'

If so: 'We would be happy to support you in dealing with this - what is your concern in this context?' If not: 'Very well, feel free to contact us if a similar problem arises in the future. Maybe we can find a solution for it'

You can also explain that you, as a specialist, are concerned with quality-of-life issues and you know from other patients that the impact of cancer treatment on relationships and sexuality may be significant. Although you may not be able to answer all questions, you will create a safe space where patients feel comfortable talking about their sexual concerns.

ASK PERMISSION



Given the diverse cultural and religious backgrounds, gender, and age of cancer patients, it might be a good strategy to ask the patient for an explicit permission to talk about sexual issues such as:



'Is it OK for you to discuss these issues in more detail?' or
'Would you like to talk about it now or later on?'

Avoid making any prejudiced assumptions about how the person relates to sexual issues.

- If the patient agrees, this stimulates a sense of ownership and control to explore this intimate domain of life.
- If not, let the patient know you are always available to discuss his/her questions and worries anytime.

ENCOURAGE PATIENTS TO TALK ABOUT THEIR WORRIES AND EXPERIENCES



Start with an open-ended question, such as: 'Have you experienced sexual or intimacy troubles since your cancer diagnosis / since your treatment started?'

Then ask more specific questions (including when? where? what? how?) to elicit precise and clear answers, such as: 'During your last sexual intercourse, did you feel any pain or experience other troubles?' and 'Did you experience troubles before? How do you feel about them? What is your partner's reaction?' Try to avoid yes/no-questions.

Ensure that you and your patient share an understanding of the terms being used to avoid confusion. If you are not familiar with a term your patient used, ask for an explanation. If you are not sure the patient has the same understanding of specific terms, be prepared to explain them. If the patient feels uncomfortable to open up about certain topics, respect them and suggest possible discussion during the next visit or with a specialist

EDUCATE THE PATIENT



Provide concise and clear information to educate the patient about anatomy, physiology, sexual response, the possible side-effects of cancer treatment, and other aspects that may be relevant to their experience.

SUMMARISE AND REPEAT PATIENT'S CONCERNS



Summarise what the patient has said about his complaint(s) and double check whether you have understood them correctly. This helps to validate the patient's experience.

PROVIDE PATIENTS MORE EXPERTS ADVICE AND REFERRAL



Provide practical suggestions and recommendations to help the patient to deal with their complaint(s). Plan a new consultation for further treatment/therapy or advise the patient to seek help from another HCP, such as a psycho-sexual therapist, physical therapist, couple counselor, cognitive-behavioral therapists, etc.). Do not forget to explain why a consultation with that particular HCP would be beneficial. You might also refer your patients to a specialist of the same gender – as this might facilitate discussions regarding sex, sexuality and intimacy.

If you are not comfortable discussing sexual issues with your patients, feel free to refer them to a colleague who feels safer in this area. In addition, tell patients where they can find reliable information on the internet.

Read more about patient sexuality issues

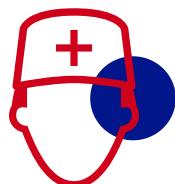
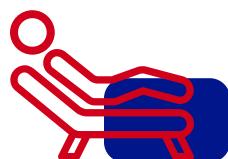
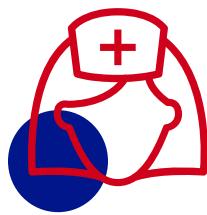
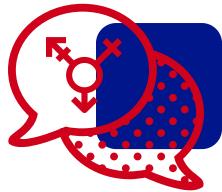
If you are interested in more information about the impact of sexual health issues on your patients, you can check out the below literature and online sources. Be ready to also refer your patients to more information during the consultation.

Expert publications

- Carter, J. et al. (2018) "Interventions to Address Sexual Problems in People with Cancer: American Society of Clinical Oncology Clinical Practice Guideline Adaptation Summary". *Journal of Oncology Practice*, 10, 36(5), 492-511.
- Guntupalli, S. and Karinchik, M. (2017). *Sex and Cancer: Intimacy, Romance, and Love after Diagnosis and Treatment*. Lanham: Rowman & Littlefield.
- Katz, A. (2012) *Prostate Cancer and the Man you Love: Supporting and Caring for your Partner*. New York: Rowman & Littlefield.
- Reismann, Y. and Giannotti, W. (Eds.) (2017) *Cancer, Intimacy and Sexuality: A Practical Approach*. Basel: Springer.
- Schover, L. (1997) *Sexuality and Fertility After Cancer*. New York: Wiley & Sons.

Online resources

- European Society for Medical Oncology, ESMO (2019) E-Learning: Sexuality and Intimacy After Cancer.
- Macmillan UK Cancer Support (2020) Sex and Side Effects of Cancer Treatment.
- National Coalition for Sexual Health, NCSH (2019) *Sexual Health and Your Patients: A Provider's Guide*. Washington, DC: Altarum Institute.
- American Cancer Society (2020) *How Cancer and Cancer Treatment Can Affect Sexuality*.
- Canadian Cancer Society (2018) *Sex, Intimacy & Cancer*.



CANCER & SEX

Everything you wanted to know about
your sexual health but were afraid to
ask.

Cancer, sex & intimacy



Cancer itself and especially the treatment can change much in sexuality and intimacy. In practice, though, the majority of healthcare professionals (HCPs) do not proactively discuss sexual issues with their patients.



Although it is difficult for nearly all patients and partners to talk about sexuality and intimacy, it can be important to ask your medical team for support and information on the possible changes in your sex life. Once the topic has been brought up by you, most HCPs will react adequately making the topic also easier to talk about during future check-ups.



Since it might have to be you who initiates the conversation about sexuality with HCPs, this leaflet can help you navigate through this issue.



According to the European Charter of Patients' Rights, you have the right to all kind of information regarding your state of health, the health services and how to use them. Moreover, you have the right to the best quality of life, which includes your sexual function and health, regardless of your age, marital status and stage of the disease.



HCPs should communicate all information in a manner that is understandable for you/ in plain language. In addition, your doctor should be dedicated to providing competent and timely medical care, with compassion and respect for your privacy, dignity and patient confidentiality.

Is your cancer diagnosis and/or treatment affecting your sexual health? You are not alone!

Sexuality issues belong to the most common side-effects of cancer diagnosis and its treatment. If you are experiencing physical, emotional and social changes impacting on your sexual health, you are not alone.

If you find it difficult to bring up the topic of sexuality, tell your medical professional about it. You are not the only one and this can take away your stress. It is possible that your healthcare team will find this talk difficult as well. Think about which words can better describe what you are feeling or experiencing and be as specific as possible.

What are the most common sexual challenges and changes due to cancer?

Cancer and its treatment can affect both your physical and mental health. Below you can find a list of common physical and emotional side-effects that might impact your sexual health.

Physical health effects Cancer and its treatment can affect your physical ability to have sex. Common physical changes and sexual disorders include:



- **In women:** vaginal dryness, difficult or painful sexual intercourse, vaginal narrowing or atrophy;
- **In men:** erectile dysfunction, ejaculation disorders;
- **All genders:** tiredness, loss of fertility, loss of desire, changes in sexual sensitivity and responsiveness, painful intercourse, loss of sensitivity in sexual organs and capacity for orgasm and/or different quality of satisfaction, incontinence in urine or stool, stoma, body image changes.

Mental health effects As a result of the disease itself or of its related treatment, some of the psycho-social effects you may experience include:



- Anxiety and fear;
- Distress and depression;
- Social withdrawal;
- Self-image changes, low self-esteem or self-confidence;
- Different emotional reactions and feelings (mood changes, sadness, anger, guilt, shame, insecurity and exclusion, uncertainty);
- Altered or disturbed relationship with your partner(s);
- Loss of desire.

How do you start a conversation about sexuality with your doctor/ health care team?

Check out the recommended questions below!

Whether you are single or partnered, it is important to ask for information and support related to your sexual health. It is especially important to ask before the treatment starts, as it may determine which treatment approach is the best for you. **Before going to your consultation, think about your specific issues and write your questions and concerns down.**



- 'Is it normal that I experience sexual changes due to treatment?'
- 'Which sexual side-effects am I likely to experience during and after my treatment?'
- 'Are the sexual side-effects I am experiencing permanent? Will they go away on their own?'
- 'Is it normal that my recommended treatment affects my sexual desire?'
- 'Will my sexual desire come back?'
- 'What can I do if I experience vaginal dryness/erectile dysfunction?'
- 'What can I do if I experience pain during intercourse?'
- 'What can my sexual partner do to make me more comfortable?'
- 'How can/will cancer affect my body image and sexual health?'
- 'Who can I talk to in more detail for this questions/concerns?'
- 'Can my partner and I get professional help for sexual problems? Where?'
- 'Where can I find relevant information on the Internet?'

Do you have any questions about sexuality? Here is where you can find more information and seek advice!

Which healthcare professionals should you talk to?



Most healthcare professionals can offer advice and treatment that can help you or refer you to someone who can help you understand and cope with your feelings or any changes. The most important thing is that you approach someone in your healthcare team you trust and feel comfortable with. If you would like to talk about issues connected to physical side-effects, you can start with your general practitioner, your oncologist or specialist nurse. In case you needed further emotional and social support, ask for a referral to a psycho-sexual therapist, a psychologist or a social worker.

Please note that availability of different specialists and related insurance coverage depends on how the healthcare system is organised in your country. If you are unsure about who to contact, ask your oncologist or oncology nurse.

Be aware that most sexual issues appear only sometime after the treatment. In this case, your general practitioner is the first one who can help you and refer you to an appropriate expert depending on your problem. You may not always find an expert who is sensitive and discussing about your intimacy and sexuality with them can be uncomfortable. In these cases, it is important to tell the professional and find one who you can trust and feel comfortable with.

Which societies provide credible information?



Many cancer societies, patient support organisations, health professionals' associations and hospitals provide plenty of good information and often offer free-of-charge online consultations with experts and phone helplines. You can also check websites of psycho-sexual therapists and psychologists in your country.

If you struggle to find reliable information online, ask your healthcare team to help you. You can start with the websites of your national/local:

- Cancer society
- Patient support organisation
- Hospital
- Cancer information site of medical professionals and societies

KEY TAKEAWAYS!

1. Sexuality means different things to different people, and people express their sexuality in their own unique ways.
2. Sexuality needs do not disappear when a person is diagnosed with cancer, but it can have different meanings throughout the pathway and may require adjustment during the different phases (diagnosis/treatment/ after cancer) of your journey. Even in the last (palliative) phase people continue to be sexual beings and may need intimate or sexual contact.
3. The illness and its treatment can cause disturbances and changes to your sexual health. Some of them can be temporary but others can last long-term.
4. Taking care of your intimacy is very important. Masturbation as well as talking, listening, touching, holding and caressing others can improve your mental health and facilitate your sexual activity.
5. It might be a good idea to invite your partner(s) to the medical consultations and sessions where you plan to talk about your sexual health and problems.
6. Friends, family and other survivors can be helpful to partially alleviate your emotional challenges.
7. Your sexual health matters and taking care of your sexual health is important. It is ok to request information on sexuality issues and to receive practical advice and emotional support from HCPs.