

Sexuality and Intimacy with Lymphoma



OVERVIEW

When you receive a diagnosis of lymphoma or chronic lymphocytic leukaemia (CLL), conversations about sexuality and intimacy are often not made a priority. Sexual health and sexuality are important regardless of your relationship status, sexual orientation or whether you are sexually active. Your sexuality is an essential part of who you are, how you express yourself and how you feel about yourself.

We all deserve to live a healthy sexual life, however a diagnosis of lymphoma or CLL can have negative impacts on our desire for sex and our ability to have sex or be intimate. It can be very difficult to know who the right people are to ask questions relating to sexuality and starting these conversations can be difficult for many of us. The following fact sheet will identify some of the possible causes of sexual dysfunction in people diagnosed with lymphoma, as well as discuss some practical options for support and advice.

HOW DOES A LYMPHOMA DIAGNOSIS IMPACT SEXUALITY?

Reduced sexual frequency and satisfaction is frequently reported by people with lymphoma and CLL at various points during the cancer experience; at diagnosis, during treatment and following treatment completion and into survivorship. There are various physical and psychological factors that can impact on sexual function.

Psychological factors that may impact sexual desire and function:

- Role changes (husband and wife vs patient and carer)
- Fatigue
- High levels of anxiety, stress, worry or fear
- Loss of feeling relaxed and safe
- Altered body image/poor body image (eg. hair loss, weight loss, weight gain)
- Low sexual self- image
- Previous negative sexual experiences

Physical factors that may impact sexual desire and function:

- Dyspareunia (low oestrogen levels)

- Erectile dysfunction
- Vaginal dryness
- Re-emergence of previous STI's due to immune deficiency (eg. genital warts, herpes)
- Nerve damage to extremities (peripheral neuropathy)
- Skin sensitivity
- Nausea and vomiting
- Hot flushes
- Pain
- Orgasmic difficulties (some medications)
- Sleeping problems

WHO DO I TALK TO?

If talking about sex is not something you are used to doing, even broaching these subjects with your loved ones can feel uncomfortable. The best place to start would be with the person or people you feel most comfortable to share with. Someone you know will listen to your concerns without judgement. This might be your close friend or partner or even a sibling. All health care professionals should be able to help you with your questions or concerns regarding sexuality and intimacy, or at least point you in the right direction for further support. If you feel comfortable, bring up your concerns with a member of your treating team. This could be your doctor, nurse, dietitian, psychologist etc. Remember that issues related to sexuality and intimacy are just as important as your other physical concerns.

Some practical tips for starting these conversations with your treating team:

- Come prepared with questions written on a piece of paper
- If you think sexual issues will take up most of the consultation time with your doctor, let the nurse or doctor know in advance that this is what you want to discuss.
- Bring your partner or carer in with you for additional support
- Ask questions in your own language, don't worry if they don't sound clinical
- At the start of your consult, mention that you would like to discuss sexual concerns at some point, this prompts the health professional to ask you the questions
- If the health professional doesn't have the answer to your question, ask for a referral to someone who may be able to help you further

FACT SHEET

Questions to ask your doctor

- What impact does treatment have on my ability to have sex?
- How long will these effects last?
- Is it safe for me to have sex while I'm on treatment?
- Who is the best person to talk to about sexuality? Are there counsellors, sex therapists, support groups or other support services available to me?
- What do I need to know about birth control and sexually transmitted infections during treatment?
- Do any other patients report (insert issue here) during treatment? (eg. pain during intercourse, vaginal dryness, erectile dysfunction, loss of sex drive etc)

WHAT TYPE OF HELP WILL I GET?

Depending on the reason, some common referrals for issues relating to sex and intimacy that you can get through your medical team or GP:

- Psychologists and counsellors
- Sexual health nurses
- Certified sex therapists
- Physiotherapists
- Gynaecologists
- Urologists
- Endocrinologists
- Fertility specialists
- Pelvic floor therapists
- Oncology social workers
- Sex shops (physical or online)

ADAPTING TO A NEW SEXUAL "NORMAL"

Often, the negative impacts on sexuality and intimacy from cancer treatment subside after treatment finishes. However, sometimes the impacts can be longer lasting or even permanently change your desire for sex and your ability to have sex or be intimate. For many people, adjusting to these changes can be difficult and may even cause friction in your relationships over time. If this is you, below are some strategies and interventions you may want to consider implementing:

- Allow yourself to grieve the loss of familiar sexuality and sexual response
- Practice talking openly about sex and your feelings with your partner or people you trust and feel safe with
- Explore new satisfying sexual activity after treatment
- Investigate use of sexual aids - vibrators, dildos, lubricants
- Focus of pleasure not performance
- Consider pain relief and positioning
- Create a relaxing environment for sex and intimacy

(reduced noise, temperature, phones turned off) Remember that relaxation forms the basis for sexual function

- Break the pattern that sex must lead to penetration and orgasm
- Keep in mind that It is possible for both men and women to feel sexually satisfied and bonded with a non-orgasmic experience

RESOURCES AND SUPPORT

Organisation	How can they help?
Lymphoma Australia	<ul style="list-style-type: none"> • Please visit our website www.lymphoma.org.au for further information • 'Sexuality and Lymphoma' video presentation featuring Sexual Health Nurse Consultant Simone Sheridan. View at Lymphoma Australia, YouTube: https://bit.ly/2oP27wF • Lymphoma Nurse Support Line: 1800 953 081 or email: nurse@lymphoma.org.au • Online private Facebook group: Lymphoma Down Under http://bit.ly/2mrPA1k
Cancer Council	<ul style="list-style-type: none"> • Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live. Visit www.cancer.org.au or call 13 11 20 • "Sexuality and intimacy" booklet: https://bit.ly/2o891wU
CanTeen	<ul style="list-style-type: none"> • CanTeen is an organisation working with young people affected by cancer 12-25 years. https://canteen.org.au or email support@canteen.org.au or call 1800 835 932 • "Maybe later baby? A guide to relationships, sex and fertility for young people." https://bit.ly/2mtYJGI
WeCan	<ul style="list-style-type: none"> • WeCan is an Australian supportive care website to help find the information, resources and support services they may need following a diagnosis of cancer. Visit wecan.org.au

This resource was last reviewed and updated October 2019