Sex, sexuality, and intimacy

Lymphoma Australia Nurse hotline: 1800 953 081 nurse@lymphoma.org.au

Learning about your lymphoma can be like learning a new language. It takes time and practice. Please keep this document handy so you can refer back to it as often as you need to. It will become easier to understand the more you read it.

Lymphoma and its treatments can have an impact on your sexuality and emotional, physical and sexual intimacy. This page will give you information on some of the changes that can happen, and practical advice on how to maintain or develop a fulfilling sex life and intimate relationships while living with lymphoma.

What is sex, sexuality and intimacy?

Sex is the physical way we express our sexuality.

Sexuality is the way we express ourselves sexually. This includes the way we feel about ourselves, the way we dress, the way we move, the way we have sex and who we have sex with.

Intimacy is the physical and/or emotional closeness to another person and can be expressed in different ways. It is not just physical but rather, it is a deep trust and comfort in one another. Intimacy can be between friends, family members, or romantic partners.

Whether you're single or in a relationship, sexuality, intimacy, and sexual health is an important part of who you are.



You are not alone

Many people living with lymphoma report changes in sexuality and intimacy.

What sort of changes can happen?

All treatments for lymphoma, and supportive medicines can decrease your:

- libido (sex drive)
- ability to become sexually excited (aroused)
- ability to orgasm
- desire for physical and/or emotional intimacy.



What causes these changes?

Lymphoma can cause a physical and psychological imbalance. These imbalances may impact your sexuality and intimate relationships.

Physical changes may include:

- · Changes in hormone levels
- Erectile dysfunction
- Vaginal dryness or changes to the strength of vaginal wall
- Flare ups of previous sexually transmitted infections (STIs)
- Pain
- Nausea and vomiting
- Nerve damage (usually affects hands and feet but can also affect your genitals)
- Skin sensitivity
- Sleeping problems
- Fertility issues
- Difficulty reaching an orgasm
- Changes in how your body looks and how that affects your confidence. This can impact how you feel about your own sexuality or intimacy with others.
- Some side effects from treatment that may affect your appearance include weight loss/gain, hair loss, or scars from surgery and other procedures.

Psychological changes may include:

- Role changes in a relationship going from partners to patient and carer
- Being a provider of finances or support, to needing help with finances and support
- Fatigue, anxiety, stress, worry and fear
- · Loss of confidence
- Changes in your appearance may

- change the way you feel about yourself, sexually and socially. This can impact your sex life and intimate relationships
- New equipment or devices you need to have with or attached to you may affect your confidence.



Risk of infection and flare ups of previous infections

Treatment for lymphoma will usually lower your immune system. This can put you at increased risk of infections, including sexually transmitted infections.

If you have ever had a sexually transmitted infection such as genital warts, genital herpes or Human Immunodeficiency Virus (HIV), these can all 'flare up' or get worse during treatment. You may need antiviral medicine to prevent them causing you problems during treatment.

Talk to your doctor

If you have ever been diagnosed with a sexually transmitted infection let your doctor know.

There is no need to be embarrassed, because these can be common. Your doctor will be able to give you medicine to prevent or lessen a flare up during treatment.





What can I do? Adapting to my 'new normal' sexuality

How lymphoma and its treatments affect your sexuality and sexual intimacy, and how long these changes last will be different for everyone. For some it's a short-term disruption, but for others it can mean needing to adapt long-term.

Accepting that things have changed, and focusing on how you CAN be sexual and intimate can help. Things don't need to be the way they always were, to still be good – or even great!

Some suggestions that may help you adapt to your new normal sexuality and sexual intimacy include:

- Allow yourself to grieve the loss of familiar sexuality and sexual responses.
- Practice talking openly about sex, sexuality and intimacy with your partner or someone you trust. It may take practice. It may be embarrassing at first, but if you and your partner commit to making a safe space for each other, to share how you're feeling and what feels good, you may reach new levels of intimacy. And remember, everything gets easier with practice.
- Consider using sexual aids or toys such as vibrators, dildos and lubricants.

- Focus on pleasure, and enjoying closeness rather than performance.
- Consider pain relief before sex. If pain is often a problem, aim to take pain relief 30-60 minutes before sex.
- Try different positions, or support your body with pillows to take pressure off areas that may be sore or uncomfortable.
- Create a relaxing environment (soft music, meditation and relaxation techniques may help).
- Try exploring sexuality on your own through self-touch and masturbation.

Not all lubricants are equal!

It is a good idea to use lubricants during sex when you have lymphoma. For one thing, it can feel really good, but importantly, it also helps prevent any small tears that often happen during sex. When you have lymphoma, or are having treatment, these small tears could lead to infection and bleeding.

There is a general rule to consider when choosing the best lubricant for you. If you are:

- using silicon-based toys or condoms, use an oil or water-based lubricant.
- not using condoms or toys, use an oil or silicon-based lubricant.

If you or your partner have had chemotherapy in the past 7 days, you need to use a condom or dental dam with lubricant every time you have sex (including vaginal, anal and oral sex).





External condoms are placed over the penis.



Internal condoms are placed inside the vagina.



Dental dams are placed over the genitals during oral sex.

Only one partner needs to wear a condom – do not use more than one at the same time as this can increase the risk of them slipping off or breaking.

I'm not having sex, do I still need lubricant?

Vaginal dryness is a common and uncomfortable side-effect of many lymphoma treatments. If you have this side-effect, you may be more comfortable if you use a water-based lubricant even if you are not having sex.

Who can I talk to about changes affecting me?

Of course, you can talk to your friends, family and partner if you are comfortable. But some changes may be better managed with the advice of a healthcare professional.

Talk to your doctor or nurse

Most doctors and nurses are comfortable talking about sex and the changes that happen, but they may worry about embarrassing you if they bring it up. Others may talk about it openly.

If your doctor or nurse hasn't asked you about your concerns, ask them. You will not embarrass them by asking, and they will not think less of you for asking.

Be confident knowing that changes you have in your sexuality and intimacy are just as important as any other side-effects you may get; And can be managed and improved!

Talk to other members of the healthcare team

Any member of your healthcare team should be able to help you with any questions you have. If they don't know the answer, they can help you find the answers or refer you to the right person.

Physiotherapists

Physiotherapists can help with some sexual changes. They are able to assess your strength and mobility and provide exercises or activities that can help improve your sexual function.

Sexologists and sexual health nurses

Some hospitals have sexologists or nurses that specialise in the sexual changes that happen during illness or after injuries. Ask your doctor, nurse or other team member about who you could be referred to.



Counsellor or Psychologist

You may also consider counseling – as a couple or on your own. This can be helpful if you and your partner have not previously spoken openly about sex, or are struggling with changes in your relationship. Ask your General practitioner (GP or local doctor) for a referral. Counsellors can help by listening to your concerns and goals and help you to find strategies to reach those goals.

Psychologists can diagnose some mental health conditions and look at how these may impact your feelings, thoughts, behaviours and responses to different situations – including your sexual responses. They can help you to understand why you're feeling and responding the way you are, and provide strategies that may help.

Other helpful resources

Relationships Australia – <u>www.</u> <u>relationships.org.au</u>

Sex and Lymphoma - https://www.youtube.com/watch?v=l_8aJXalof0

Sexuality and Lymphoma - https://www.youtube.com/ watch?v=Zm2DWoOKUIE&t=3s

Find a sexologist near you - https://societyaustraliansexologists.org.au/directory

Find a psychologist near you - https://psychology.org.au/find-a-psychologist.

Summary

- Sex, sexuality and intimate relationships can all be impacted by life with lymphoma.
- Some changes are temporary, while others may need you to adapt longterm.
- Different doesn't have to mean worse
 You can still reach new and better levels of intimacy and pleasure.
- Be open to talking about sex and how you feel – with your health professionals and with your trusted friends/family or partner – This may take practice, but it can be worth it in the end.
- There is help available. Talk to your doctor about a referral to another health professional if you would like more help, advice or strategies to manage the changes to your sexuality and intimate relationships.
- Use the right lubricant for the right activity.
- Set boundaries when needed.
- Call our Lymphoma Care Nurses on 1800 953 081 if you would like more information.



Resources and support

Lymphoma Australia offers a wide range of resources and support for people living with lymphoma or CLL, and their carers. How to access our resources:

- Visit our website <u>www.lymphoma.org.au</u> for more information.
- **Phone** our Lymphoma Care Nurse Hotline on 1800 953 081.
- **Email** our Lymphoma Care Nurses nursealymphoma.org.au
- Booklet: Understanding Non-Hodgkin Lymphoma (NHL)
- Downloadable information: Visit our website, or give us a call if you would like some more information on a variety topics related to lymphoma
- Join our Facebook page
 <u>Lymphoma Down Under</u> (make sure you complete all the membership questions when you join).

Cancer Council offers a range of services, including free counselling, to support people affected by cancer, including patients, families and friends. Services may be different depending on where you live. You can contact them at www.cancer.org.au or by phone on 13 11 20.

Medicare Australia: Check with your GP if you are eligible for a Mental Health Treatment Plan (MHTP). This plan is funded by Medicare and can provide you with up to 10 sessions with a registered psychologist. More information can be found here.

WeCan is an Australian supportive care website to help find the information, resources and support services you may need following a diagnosis of cancer. You can visit their website at www.wecan.org.au.

Canteen provides support for young people aged 12-25 years who have cancer, or, who have a parent with cancer. Find out more at their website here at www.canteen.org.au.

Disclaimer: Lymphoma Australia has taken every precaution to make sure the information in this document is accurate and up-to-date. However, this information is intended for educational purposes only and does not substitute for medical advice. If you have any concerns about your health or wellbeing, please contact your treating team.



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