

HAUORA TŌKAI ME TE TAUPIRI

16+

SEXUAL HEALTH AND INTIMACY AFTER CANCER



‘After treatment I felt I was physically less attractive than previously, which affected my confidence and my sexual health. This has come right over time.’

Young person

This section was developed based on feedback from young people who found there was little or no information available to them on the topic of sex and sexual health after cancer. If you are in a sexual relationship and are experiencing challenges with sex and intimacy, or you have questions about your sexual health or fertility, this section is for you. For young people who are not in a sexual relationship, you are welcome to skip this section or just take the information you feel is relevant to you at this time.

Cancer and cancer treatment can affect your sexuality (which includes how you feel about yourself, your body image and sexual feelings towards others) and your sexual function (your ability to have and enjoy sex). These changes may be temporary or ongoing and can be difficult to manage and talk about. The good news is, with time many sexually active young adults who have undergone cancer treatment can expect to have a normal sex life and engage in healthy intimate relationships again.

Physical challenges with sexual activity

While physical challenges for some can be embarrassing to talk about, it is common after cancer treatment to have difficulties such as painful sex or finding it hard to get an erection. The important thing to remember is that there is support available and we encourage you to speak up.

Firstly, keep track of your symptoms.

If you are sexually active, use the checklist below to help identify any challenges you are experiencing, and talk with someone in your healthcare team.

Symptom Checklist	Yes / No
Loss of libido (desire to have sex)	
Anxiety relating to sexual intimacy or body image	
Reduction in natural lubrication (vaginal dryness that makes sex painful)	
Loss of sensation (reduced feeling during sexual intimacy)	
Pelvic pain (pain in your private parts or lower abdomen)	
Difficulty getting or maintaining an erection	
Difficulty ejaculating (releasing semen or sexual fluid)	
A rash or itching to your genitals (vagina, anus or penis)	
Incontinence (leaking urine)	
Irregular periods or lack of periods	
Difficulty reaching orgasm	
Other:	

Premature Menopause

'I have no sex drive but my hormonal medication helps'

For some young people, the symptoms such as painful/uncomfortable sex, vaginal dryness, irregular or no periods or fatigue may be related to temporary ovarian failure or premature menopause caused by cancer treatment. For more information, please refer to the AYA Cancer Network's Cancer and Fertility brochure which is available at www.ayacancernetwork.org.nz. If you are experiencing any of these symptoms, please discuss with your healthcare team - there are effective ways to manage your symptoms and reduce discomfort.



Who can I talk to about my concerns?

Talk with your AYA Key Worker or someone in your healthcare team first so they can refer you to the right service.

For example, if radiation therapy has narrowed or shortened the vagina and is causing discomfort, a physiotherapist who specializes in pelvic therapy may be the best person to help you learn to manage this. Alternatively, erectile problems can supported by sexual health services.

Many young people comment that the biggest barrier to seeking support is embarrassment. But please don't be embarrassed. Your healthcare team are trained professionals who are here to listen and help you. If you would prefer to seek help outside cancer services, sexual health services such as Family Planning and school or university health centres are easily accessible. See the resources box at the end of this section for more information.

Tip Many people talk to health providers about their sexual health. Remember everything will be kept confidential, so you don't have to worry about other people knowing.

I identify as LGBTQIA+ and don't feel comfortable talking about sexual health or intimacy with a health professional.

'Everyone just assumed I was straight. I didn't feel like I could be myself'

Young person

One of the keys to receiving support is to be accepted for who you are. Challenges with sex and intimacy can be much harder if you cannot be open with your healthcare provider. Share your name, gender identification, correct pronouns, sexual orientation and partner status with your healthcare team. This will hopefully lead to an increased level of comfort, honesty and trust and mean that you get support for your sexual health when you need it.

All young people with cancer have the right to good sexual health information and to feel respected for who they are.

If you feel uncomfortable or experience any type of discrimination discussing your sexual health with your cancer treatment team, please speak with your AYA Key Worker or access services like Rainbow YOUTH, OutLine or Gender Minorities Aotearoa who can support you to address this.

Sexual Health - Common Challenges

I have pain inserting tampons and during sexual intercourse. What can I do about it?

It can be common after treatment to experience dryness in the genital region such as your vagina, which may lead to pain during intercourse or when inserting tampons during your period.

The cause of this can be treatment related, or be a result of anxiety or loss of libido (sex drive) during intercourse. Here are some practical strategies that may help:

Lubricant. If loss of natural lubrication or dryness is a challenge, use a water-based lubricant before inserting anything into your vagina and avoid any products with perfumes or colouring to reduce irritation.

Use Pain Relief. If you experience pain, take painkillers before you insert a tampon or before sexual intercourse or try relaxation exercises to reduce anxiety, which can in turn reduce any pain.

Try at the best time of day. Be intimate at the best time for you, for example when your pain is low or energy levels high.

Pay attention to your body. Changes in the acidity of the vagina can lead to a common condition called thrush. The symptoms of thrush are a creamy white discharge or itchiness in the vagina. Thrush can also occur under the foreskin of the penis. Thrush is easily treated and is not cause for concern. Talk to your GP or nurse who can give advice about creams or tablets you can take to help.

Take it slow. If you are sexually active it might be helpful to spend more time on foreplay exploring different ways to be become aroused and intimate. Intercourse doesn't have to be the main goal unless you're comfortable with it. Take things at a pace that works for you.

I am having trouble getting an erection.

Struggling with an erection after treatment is more common than you might think. It's known as erectile dysfunction (ED) and both physical and emotional factors can be the cause.

In many cases, ED is temporary and can relate to fatigue or stress. However, it can be common with erectile dysfunction to experience performance anxiety, low self-esteem, or a loss of sexual arousal. Try these practical tips:

Arousal. Suss out what turns you on. What kind of things help you feel excited sexually? If you feel comfortable, share these with your partner.

Masturbation. Try masturbating or self-pleasuring on your own using lubricant. Once you know what works for you, show your partner how you would like them to stimulate you. Make sure you have some private time and space available, so you are not interrupted.

Take the heat off. Find other ways to be intimate that don't involve getting an erection. Try touching or kissing, or doing other things together you enjoy.

Talk about it. Speak to your partner or access counselling. CBT (Cognitive Behavioural Therapy) can help you understand what triggers the ED and can help you with strategies to manage it. Talk to your health care provider or contact Family Planning for more advice about how to access this.

NOTE:

In some situations, young people who have undergone surgery or radiation to the pelvic region, can experience permanent erectile dysfunction and it's important that you talk with a healthcare provider.



When whitiwhiti – communication is hard

‘I lost a lot of confidence in having sex with my new partner. Also, I didn’t have the same desire to have sex and felt pretty damn ugly at times.’

Young person

I feel like I have lost the sexual connection with my partner and I’m not sure what to do.

Firstly, be gentle on yourself and take your time. Focusing only on sexual performance can result in added anxiety and challenges with sex. Sexual connection is more than arousal, intercourse and orgasms; it also involves feelings of intimacy and acceptance. Try these tips:

Communicate. Be honest and share your feelings including any fears about sex. Your partner may be feeling confused or uncertain about how to react and may be waiting to take the lead from you.

Pick the best moment to talk. Start a conversation when you are feeling calm, not when you are in the middle of having sex or rushing somewhere.

Write stuff down. Think about what your needs are and what you want to say beforehand and write it down so you are prepared.

Set some ground rules. Let the person know if you find sex hard to talk about, and need them to listen and really hear you.

Offer up some suggestions. Help equip your partner with ideas. Don’t tell them what they’re doing wrong, encourage them to try things that **do** work for you.

If you are struggling to know where to start, try some of the following conversation starters:

IF IT'S A NEW PARTNER:

'Before anything happens – I just want to be up front and let you know that I've recently been through cancer and am still coming to terms with it all. I'm way more nervous about sex/intimacy after what I've been through. I'm keen to take it slow.'

'I really like hanging out, but I've just finished cancer treatment and my body's changed a lot. I feel way more self-conscious than I did before. I might need to take things slow.'

'So, I have super low energy since I finished cancer treatment and sometimes find it hard to get going. I'll be honest with you about where I'm at as we go along, but I'm going to need you to be patient with me.'

IF YOU ARE CURRENTLY IN A RELATIONSHIP:

'You've been amazing looking after me through treatment, but now I'm keen for us to go back to being partners. Can we connect in ways that aren't about you looking after me?'

'What are you most worried about with us being intimate again? Tell me and I'll tell you where I'm at too.'

'I feel way more self-conscious about how I look now, and I find it hard to feel sexy. I just need you to be patient while I work through it.'

'Some things have really changed for me physically in terms of how I feel and what I enjoy. How can I let you know if something feels different or I want to stop without upsetting you?'



If you are in a long term relationship and are finding it tough – you might want to consider seeing a couples' counsellor or a sex therapist for tips and advice to help you re-engage or reconnect sexually and intimately with your partner. While talking about your sexual wellbeing might be challenging, if you and your partner are honest about your wants and needs, you can go on to enjoy an intimate relationship together again.

**Firstly,
be gentle
on yourself
and take
your time.**

Strategies to help with intimacy - taupiringa

I feel like we are both stuck and not sure about how to be intimate again. Where do I start?

Keeping a good connection with your partner can reduce anxiety and pressure around sexual performance and allow you to rebuild an intimate and sexual relationship.

Try these tips:

Take things at a pace that works for you. Show affection through touching, hugging, massaging, talking and holding hands. If you do not want to go any further than that, don't. A date night or doing activities you enjoy can strengthen your connection and make it easier to talk about your feelings.

Practice some self-love. If you feel comfortable, stimulate yourself for sexual pleasure. This will make it easier to navigate what gives you pleasure with your partner.

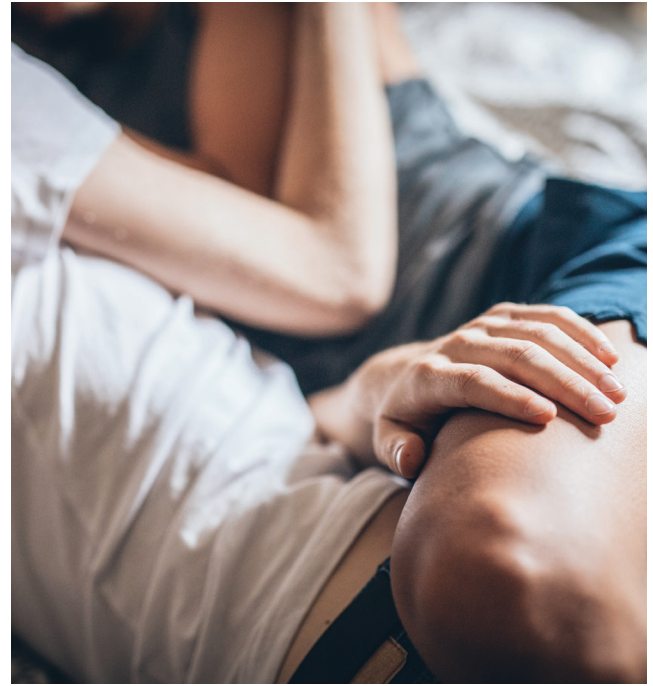
Explore what makes you feel sexy. Some people find getting dressed up or spending time on their appearance makes them feel more attractive. Try reading romance books or watching romantic shows.

Explore your sensuality as well as your sexuality. Light candles, listen to relaxing music, take a bath together or give each other a massage.

Create a positive, safe environment for intimacy to occur. Set a peaceful scene to help you relax. Make sure it's private and free from interruptions.

Explore different sexual activities. Some of the sexual practices you used to enjoy may not be comfortable now. If intercourse is difficult, try oral sex, mutual masturbation, or using sex toys.

Rest. Low libido is common and can be a result of fatigue or low mood. Make sure you are getting enough rest to keep your energy levels up. Refer to the sections on mood and fatigue for more advice.



Your body - your choice - Nōu tō tinana

'I don't always feel like sex, but my partner is just not getting it.'

Young person

If you and your partner are not on the same page, you may want to access support to help you work through this.

However, if you feel pressured or your views and needs are **not being heard, respected or valued - this is not okay.** Remember, sex and intimacy is not just about making your partner happy, it is also about your pleasure and happiness too. Your sexual boundaries and views on intimacy are important, but if your partner is not respecting this, it's okay to decide to end the relationship. There is no reason to feel guilty and there is no reason why you cannot go on to find pleasure and happiness elsewhere if that is what you want.

We're keen to stay together but would like some support. Where can I go for this?

'Counselling really helped. I didn't realise how much I was holding on to, until we started to talk about it.'

Young person

Navigating intimacy after treatment can bring things up in your relationship and many couples turn to relationship counselling or sex therapy for support. Counsellors can offer suggestions for how to reignite your relationship as well as providing a safe and open space to talk things through.

A supportive and understanding partner can help your recovery and working through things together shows a commitment from each of you. Check out the resources on page 9.

Contraception

I am pretty sure I'm infertile. Do I need to worry about contraception?

'One day I went to the doctors not feeling well and found out I was pregnant. Even the doctor was shocked because of the way they put that I was not going to have kids again. Contraception – I didn't think I needed it!'

It is hard to predict who will experience fertility issues, so unless you want to become pregnant and start a family, it is better to assume that you could be fertile and use contraception when having sex. There are many contraceptive methods available such as condoms, the pill, the injection and implant. With your medical history, it's important to discuss the method most suitable for you with either your GP or specialist.

Remember that regardless of the contraceptive method you choose, you will still need protection from sexually transmitted infections. Using a condom or dental dam correctly when you have sex can reduce the risk.



Your AYA Key Worker is a great person to approach if you feel uncomfortable having conversations about contraception with your medical team. All conversations with your health provider related to contraception are confidential.

Fertility - Matahua

I would like to start a family, but I am not sure about my fertility status.

Cancer and cancer treatment (chemotherapy, radiotherapy and surgery) naturally can affect your ability to have biological children. The risk of infertility (not being able to have children) is different for everybody and depends on the type of cancer and treatment you have had. For most young people, conversations around treatment-related fertility risks will have taken place at diagnosis and any potential fertility preservation options explored then. However, many young people say that these discussions become a blur when so much was going on at the time. Now that you have finished cancer treatment, you might find yourself thinking about having a family, and wondering about your fertility status and options.

These are the common questions young people have about their fertility:

- How do I know if my treatment has affected my fertility?
- Who can I speak to about my fertility and when should I do this?
- Should I use contraceptives?
- What happens when I'm ready to be a parent?
- Is there anything that I need to know about the frozen biological tissue i.e. sperm or eggs/embryos I have stored?
- If I am infertile, or have reduced fertility is there anything I can do about it?

All this information is in the **AYA Cancer Network - Cancer and Fertility booklets**. You can access these through the website or your AYA Cancer Key Worker.



If you are keen to try for a baby, the recommendation is to wait 12 months following treatment before you start trying. Make sure to discuss your plans with your specialist first.

For Partners

You might find it helpful to read the information in this chapter to give you an understanding of what your partner is going through. Supporting someone after cancer treatment is not easy and there are many resources in this booklet that can help.

Some charities also offer support groups for partners and caregivers.

Ask your partner to find out more about these through their AYA Key Worker or support worker. Information can give you more understanding, which can help strengthen your relationship.

RESOURCES AND SUPPORT

www.cancersociety.org.nz Enter sex and cancer into search for articles and information specifically relating to cancer. You can also access counselling or support from a nurse.

www.breastcancer.org.nz Enter body image and sexuality into the search. There is a section called 'Talking about Sex'. You can also access counselling or nursing support/advice.

www.youngliveswithcancer.org.uk Enter sex and fertility into 'search for more info'.

www.ayacancernetwork.org.nz Check out for the following booklets on our website or ask your AYA Key Worker for a copy: **Young People Cancer and Sex** and **Cancer and Fertility**.

www.genderminorities.com A NZ website offering online peer-to-peer info share forum for trans and intersex people, their families and supporters.

www.outline.org.nz National Rainbow friendly, free counselling support 0800 688 5463.

www.nzshs.org/clinics Find local sexual health services.

www.familyplanning.org.nz Confidential service covering contraception, STI testing and treatment, cervical screening, pregnancy, menopause and other advice for sexual and reproductive health. Free for under 22. Look online to find a family planning centre in your area.

www.sextherapy.co.nz Check out the network of sex therapists across NZ.

www.villainesse.com/therealsextalk Info on sexual health topics for young people.

Self Check In	Yes / No
I know about sexual health challenges caused by treatment, and where to go for help	
I have strategies for talking to my partner about issues related to sex and intimacy	
I have spoken to my health care provider about my fertility and know my fertility status	
I understand what's involved with starting a family and know where to go for support with this if I need it	
I pay attention to my sexual health and wellbeing and know where I can access contraception or sexual health advice or treatment	

Notes



Notes

[This area is intentionally blurred to protect privacy.]