

HE PIKINGA ORA I MURI I TE IRARUKE Ā-PAPATOIAKE

RECOVERING AFTER PELVIC RADIATION

He aratohu mā Taiohi mā
A guide for young people



TICK
HERE

Checklist

Need more information or
questions I still have are:

Before Radiation

I have received the booklet explaining Radiation

I know what to expect during and after my Radiation

I have talked to my doctor/nurse about my fertility risks

I have been referred to a fertility specialist

I have talked to my doctor/nurse about contraception during treatment

After Radiation

My team have discussed the use of pelvic dilators and exercises

I have the contact details of my doctor/nurse/team if I am having difficulties with my pelvic or sexual health or use of dilators after treatment.

Someone has explained that I should always consider myself potentially fertile and contraceptive use has been discussed with me

If I have questions or worries during treatment the best person to discuss these with is

My Keyworker is: _____

Contact details: _____

Kia ora, nau mai haere mai.

As a young person, being diagnosed with cancer can mean having some challenging conversations.

It also means having to learn new ways to look after your hauora wellbeing before, during and after treatment.

One of these conversations will be around how to best care for your pelvic and sexual health. This book has been designed by young people like you to give you some tips on looking after yourself.

If you have a vagina, radiation can cause effects that make necessary vaginal examinations and sex uncomfortable. Everything in this booklet is written to help you understand the changes you could experience, how to manage these, and the best way to help with your long term recovery.

*Whāia te mātauranga hei oranga mōu
Seek knowledge for the sake of your wellbeing*

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Understanding your body

Before we start, it's important to know the proper names of your body parts so you know exactly what your team is referring to. It can be helpful to know what your pelvic and reproductive parts look like on the inside and out.

You may feel embarrassed to talk about some of this content or have concerns around sex or sexuality.



Your team are there to support you no matter who you are, what body you have or how you identify with it. It is important that they know how you see or view your body so that they can provide you the best support. It could be a good idea to let them know your pronoun.

Be reassured your team are used to talking about these things and nothing fazes them.

'I was so embarrassed and struggled to find the right words to describe my bits and for about a week I held off asking questions...one day I just blurted out that my "V" was sore.' My doctor laughed at the use of the word "V" rather than vagina but she was so good at talking through my concerns and worries and immediately put me at ease talking about the awkward stuff.'

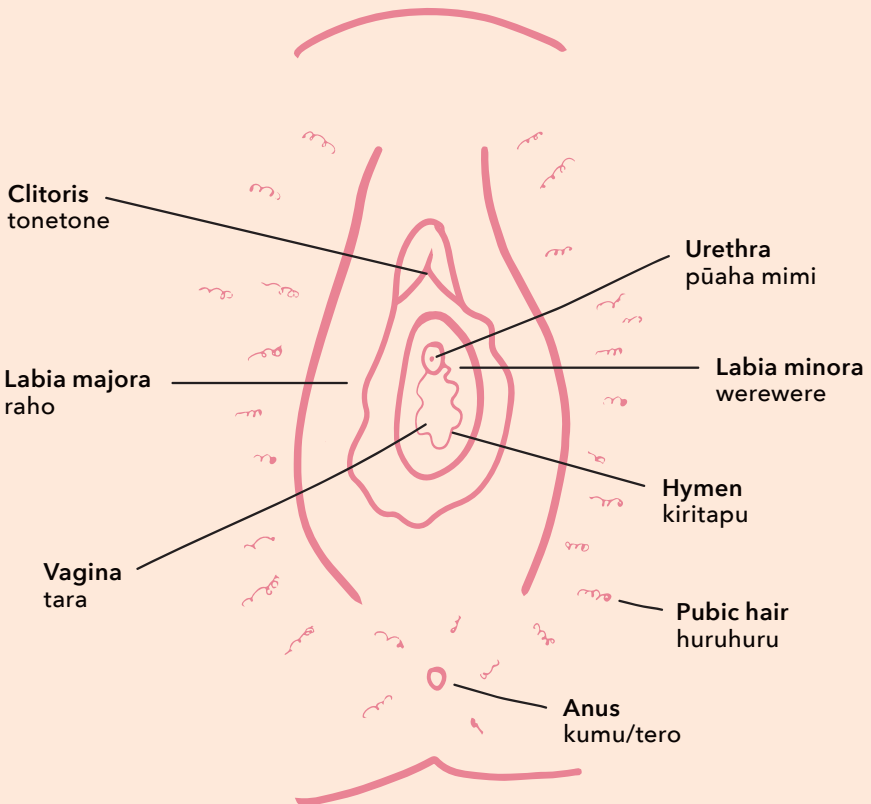
Young person

On the outside: the vulva

The medical terms for the bits that you can see.

There are three holes

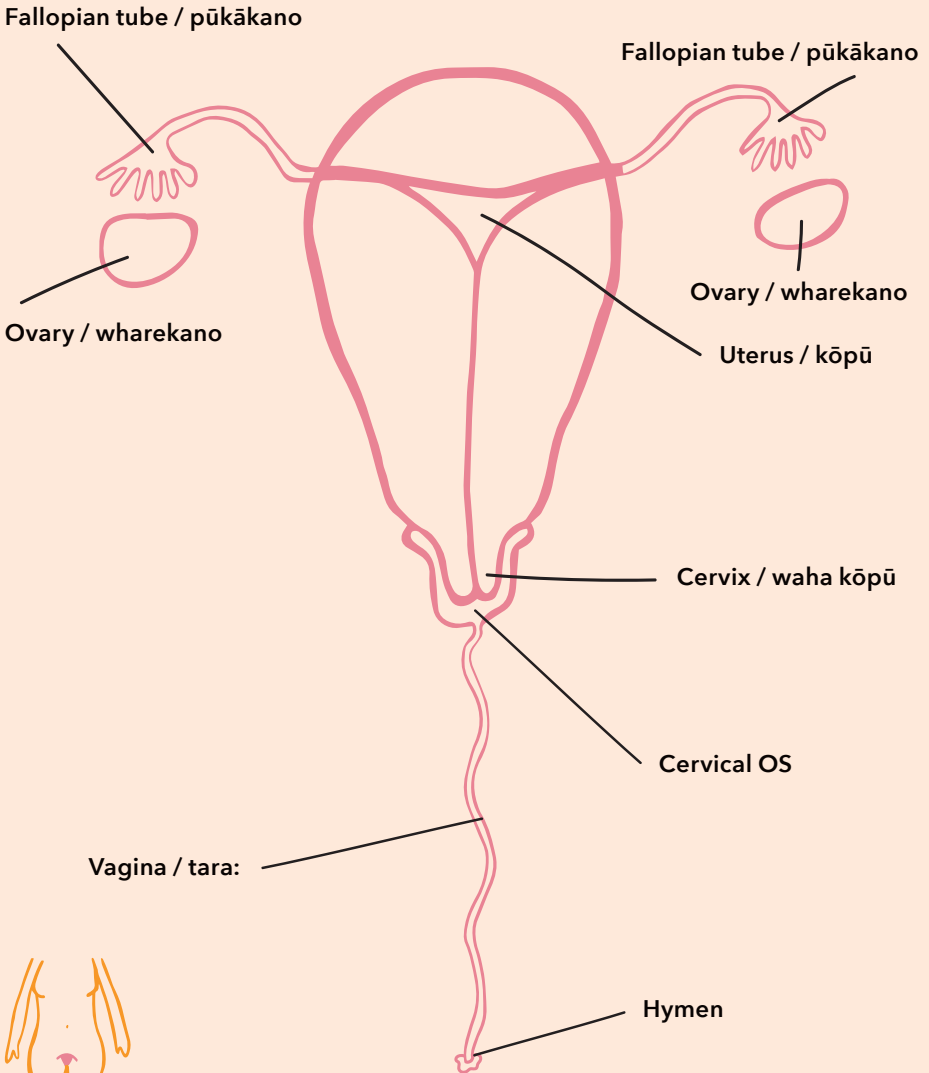
1. Urethra - pee hole
2. Vagina - period hole
3. Anus - poo hole



**On the inside:
the reproductive and sexual
body parts, taihemahema.**

Internal Reproductive System

If you have a uterus, this a picture of what you don't see.



Vagina/ tara:

The vagina has three roles. It's the passageway that expands during childbirth, where you have vaginal sex, and where your period flows out of. It's made up of a stretchy muscle that is lined with lubricating fluid, called mucus. This is the stuff that can dry up after treatment or the part that can get most effected; we will talk more about how to care for your vagina later.

Cervix/ waha kōpū:

This sits at the top of your vagina and forms a narrow passage between the vagina and uterus. It dilates (opens) during childbirth to allow a child to move into the birth canal. The opening in it is tiny so you cannot lose a tampon through it.

Uterus/ kōpū:

Also known as the womb, it holds a pēpi/baby during pregnancy.

Ovaries/ wharekano:

You have two ovaries which are the size of an almond. These hold your eggs and the hormones responsible for puberty, your periods and child bearing.

Fallopian Tubes/ pūkākano:

Two thin tubes that lead from the ovaries to the uterus. This is the passage the eggs travel down each month during ovulation.

The ovaries, fallopian tubes and uterus together are about the size of a small pear and sit behind the pubic bone.

Vulva/ Putanga tara:

This is the external part of your genitals. The lips or flaps of the vulva are called the labia majora and minora.

Hymen/ Himene

The hymen is a cuff of stretchy tissue with an opening in it which sits at the entrance to the vagina. It is like a hair scrunchy, so it can look like it has no opening but it's there when you stretch it out. It is not a membrane so it can't break when you have sex or use a tampon.

Your radiation team will talk about the impacts and side effects of your treatment on the different pelvic organs. It may help to write down any questions you have so you can discuss these with them.

Some helpful websites to find out more about your anatomy are:

- www.justthefacts.co.nz
- www.familyplanning.org.nz/advice
- 216teens.org/about-you/your-body/female-anatomy/

What side effects can I expect from my radiation treatment?

This part will give you a brief overview of what to expect from your pelvic radiation. It doesn't cover all of the side effects but will cover the main vaginal changes to look out for.

Side Effects	Symptoms	Treatment
<p>Vaginal infection (thrush)</p> <p>A common infection caused by an overgrowth of yeast (<i>Candida albicans</i>). It can happen when your immune system is low, especially after radiation and chemo.</p>	<ul style="list-style-type: none"> - Creamy white discharge - Vaginal itching - Smelly discharge - Stinging or burning when peeing - Pain or discomfort - Redness or swelling of the vagina or vulva 	<ul style="list-style-type: none"> - Can be easily treated and managed with medications given by your doctor. These can be either vaginal creams or tablets.
<p>Vaginal bleeding</p> <p>Can be caused by inflammation of the vagina and uterus. The lining can get damaged, making it thin and fragile. This causes natural spotting during or after radiation as your body heals.</p>	<ul style="list-style-type: none"> - Bleeding or spotting (light bleeding) outside of your period - Heavier periods - Bleeding after sexual activity 	<ul style="list-style-type: none"> - Will often resolve in the months after treatment.

Side Effects	Symptoms	Treatment
<p>Pelvic pain</p> <p>Caused by inflammation of the tissues in you pelvis.</p>	<ul style="list-style-type: none"> - Young people describe it much like a period pain i.e. cramping in the stomach 	<ul style="list-style-type: none"> - Simple pain relief, your doctor can prescribe this - Using a hot water bottle or wheat bag can help - Good idea to keep a diary to record symptoms and if the pain is constant - Should resolve over time
<p>Vaginal dryness</p> <p>The vagina produces a natural fluid.</p> <p>This can dry up after treatment meaning that it doesn't naturally lubricate or causes the sides of the vagina to stick together.</p> <p>Note: this maybe treatment related but also happens when people are tired, stressed or less interested in sex which many young people experience before, during and after treatments.</p>	<ul style="list-style-type: none"> - Vaginal sex may feel uncomfortable or painful. See the sex section at the back of this book for more on this. - Placing internal period products i.e. tampons, applicators or moon cups may feel more uncomfortable as there is more friction - Using vaginal dilators or pleasure toys may feel difficult to insert as there is less natural lubrication. 	<p>Tips that can help:</p> <ul style="list-style-type: none"> - Lubricants: using water based lubricants during intercourse, dilators, or using different period products can make insertion easier. - Vaginal moisturisers: a cream prescribed by your doctor that you can apply to draw moisture into the vaginal walls. - Vaginal oestrogen: a special cream or tablet that is inserted into the vagina. This releases the hormone oestrogen to help relieve the dryness - Hormone replacement therapy (HRT) - this can be helpful if treatments have caused early onset menopause, causing vaginal dryness. Your Oncologist or GP may explain if HRT is suitable for you. <p>Always seek medical advice before using any products.</p> <p>Don't be tempted to use anything that's not designed for sex or given by a doctor, as they may damage your vagina.</p>

Side Effects	Symptoms	Treatment
<p>Vaginal narrowing and scarring</p> <p>The vagina is made out of a soft and stretchy material like a rubber band. After treatment your vagina can be less stretchy, shrink, or become tough and form scar tissue.</p>	<ul style="list-style-type: none"> - Uncomfortable medical pelvic examinations i.e. smears or internal exams needed during cancer screening - Discomfort using period products like tampons, tampax applicators, moon cups etc - Discomfort during vaginal sex 	<ul style="list-style-type: none"> - This can be minimised by using a medical device called a vaginal dilator - This is discussed in the next section - If sexually active, resume sexual practices when comfortable

If you experience symptoms or if they persist, it is important to discuss these with your health care team. Conversations around side effects, long term pelvic health, sexual practices and sexuality are all discussions that will happen with your radiation team routinely.

Make sure to discuss any symptoms with your health care team.

‘I had never heard about thrush before but I thought the itchiness was going to drive me insane. I didn’t know that my treatment could cause it until one of the team asked why I was walking funny, turns out I had thrush and it was sorted out that day and it was the biggest relief!’

Young person



Notes

If you have questions that you want to ask but are struggling to bring them up with your team, write them down here and show them at your next appointment.

All vulvas are different, all are beautiful



Just like all fingerprints are unique, so are vulvas. Each one has its own thing going on - and each one is beautiful.



Long term pelvic exercises after radiation: internal physiotherapy - pelvic dilators

Radiation therapy can shrink or narrow the vaginal wall and potentially cause the sides to stick together.

This can affect your ability and comfort during vaginal sex, vaginal medical examinations (such as cervical smears and cancer surveillance tests) and use of internal period products like tampons or mood cups.

To prevent this we strongly recommend the use of vaginal dilators - think of it as internal physiotherapy for your vagina.

The use of vaginal dilators helps to:

- Protect and strengthen the muscles that make up your vaginal wall
- Prevent scar tissue from forming

- Increases blood flow to the area (this is a good thing and helps with natural healing)
- Help to reduce pelvic discomfort and pain.

What do they look like and what's the point of them?

The dilators are smooth plastic tubes that you insert into your vagina. They are a medical device that you do exercises with. They can come in a number of sizes. The smallest one is about the same width as a tampon or your pinky.

The aim of these are to gently separate the side of your vagina, and stretch all of the muscles on the inside.

'I felt really overwhelmed when my radiation therapist explained what the dilators were even about. I had never had sex and it felt weird talking about my "hoo-ha", but the way she talked about it just made it normal and took all the weirdness out of it. The first few times were difficult but as I became more familiar with what to do, it did get a lot easier.'

Young person

Tip

- If your support person is a parent or guardian you may want to do this session with the radiation therapist alone. That way you can relax and ask any questions you want without feeling awkward or embarrassed.
- If you are in a relationship, it can be good to bring your partner to this session. In this session they will discuss changes you could notice and how this could affect your sex life and intimacy with your partner. Some young people find it helpful for their partner to be there to hear the information and to talk about things that you may be struggling to bring up with them by yourself.

How do I use a dilator?

The dilator should be simple and easy to use. It's very normal to feel nervous or uncomfortable talking about the dilators or using them. In time, it will just become part of your weekly routine.

Your radiation therapist will have an education session with you. They will go through all the information that you need in person. Below is a step by step guide to remind you of the main points.

What hole does the dilator go in?

For some, at first this can be confusing –what hole does it go in? Can you get it wrong? These are all valid questions and are a normal part of learning all about your body.

Remember, you've got three holes down there: your urethra, your vagina, and your anus. Your vagina is located in the middle between the other two holes. You're going to insert the dilators into your vagina. An easy way to figure this out is to grab a mirror and take a look at your genitals. Separate your labia (the "flaps" that surround your vagina and urethra) and find your vagina, much like inserting a tampon. If this sounds unpleasant, remind yourself that it's important to know your body! Knowing where your vagina is will make you feel confident when you're ready to use the dilators.

If you are still uncertain head back to the diagrams at the start.

Dilator instructions

- *Find a space that you feel comfortable in.* This could be in your bedroom or bathroom or somewhere that is private where you can lock the door.

Tip Ensure that when you're going to use the dilator, you're in a safe space and you're not feeling stressed that someone might walk in on you.

- *Wash your hands.*
- *Get out the dilators and have plenty of lube handy.* The lube should make things easier. You should have been given a supply of lubricant; if you haven't, ask your team for some or get a **water based** and fragrance-free lubricant from the supermarket or chemist (like KY lube).

- *Assembling the dilator:* lay all 4 dilators down in front of you. Start with the smallest one. At the end of the dilator is a screw head, which fits into the end of the next sized dilator. This allows the two to be screwed together so that one end acts as the dilator, and the other as the handle.

Tip It can be more comfortable to warm the dilator by running it under hot water, then drying it.



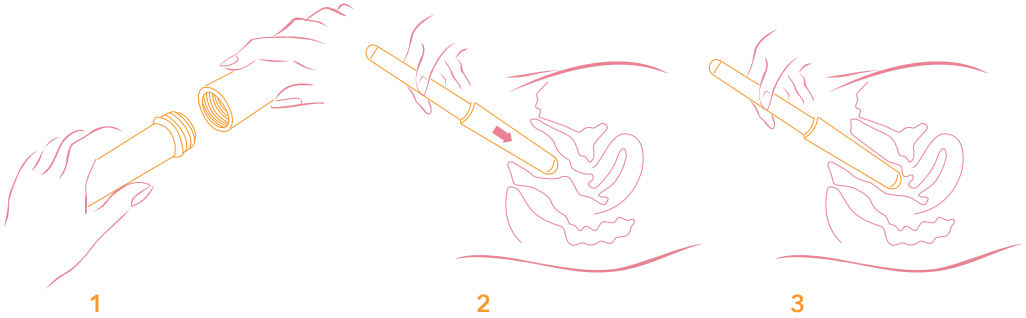
Tip Squeeze all of your muscles in your pelvis as tight as you can like when you really need to pee, hold for 5-10 seconds, then take a nice deep breath and release the tightening of your muscles before inserting the dilator.

- *There are several positions to use a dilator.* Choose what is most comfortable for you. This could be lying on your back with your knees bent and slightly apart; standing with one leg up on a chair, bath tub or bed; in the shower.
- *Take some nice deep breaths:* it is very natural to be nervous and to find this awkward and uncomfortable. The vagina and your pelvic muscle are incredibly strong. When we are nervous, we naturally tighten these muscles. By taking deep breaths and relaxing will help make inserting the dilator easier.

- *Lubricate the dilator*

- **Locate the opening to your vagina.** Place the tip of the dilator at your vaginal opening.
- **Insert the dilator slowly and gently** as is comfortable for you, without forcing it (just like inserting a tampon).

Tip Angling the dilator towards your spine, rather than straight up, makes it heaps easier. That's because your vagina naturally angles towards your spine.



- **Keep taking long slow breaths to relax your pelvic floor muscles.**
- **Move the dilator clockwise, and then anticlockwise** and then change to side to side movements. The aim is to separate the sides of your vagina and to gently stretch all of the muscles.
- **Use the dilator for 5-10 minutes.** It is best to also do pelvic floor exercises during insertion (see the next section). When you are at the point where the dilator you're using slides in without resistance or discomfort, it is time to go up to the next size.

- **Slowly remove the dilator.** Remove it by rotating it in clockwise and anticlockwise movements.
- **Clean the dilator:** Once removed, wash it with mild soap and water. Be sure to wash off all of the soap so it doesn't cause irritation next time you use it.

The first few times you use a dilator, it may be too uncomfortable to insert it completely.

Don't worry, that's very normal.

It may take some time before you fully insert the dilator or get used to them but it is important that you try.

How often should I be using the dilator?

Your radiation team will discuss when to start using these, but usually you should start about four weeks after you have finished radiation treatments. If you are still too sore then wait another week and try again.

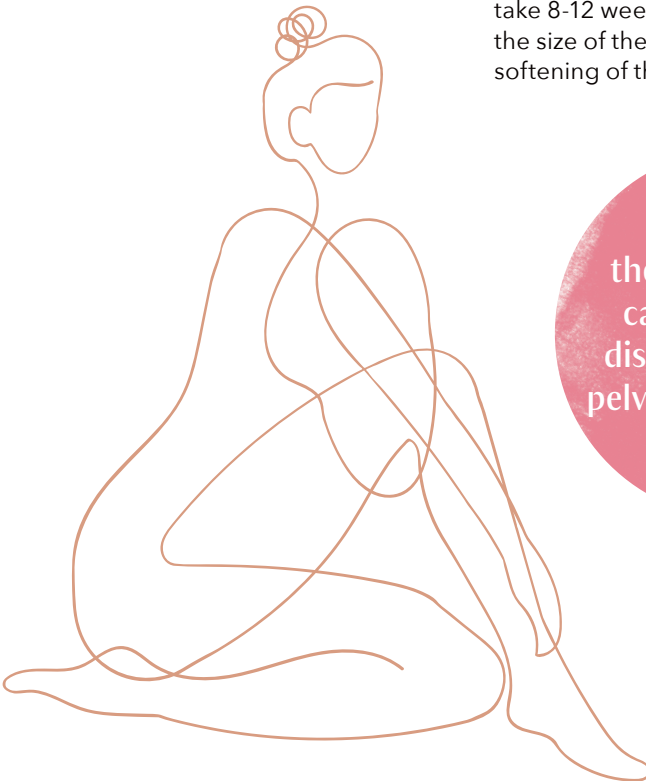
It is recommended to **use dilators at least three times per week for 10 minutes at a time** for the foreseeable future. This is because the effects of the radiation can be present your whole life, and the best way to manage this is with dilators.

It's important to know that many young people will have healthy sex lives across their life. Dilators are just one way to help make this happen.

If you are going on to have **pelvic surgery** you should stop using these. Your surgeon can say when you've healed and its safe to start these again.

How do I know when to go up a size?

The goal is to insert the largest size dilator without any discomfort, if possible. When you can insert one size of a dilator completely into your vagina without any discomfort, you should start using the next size up. It may take 8-12 weeks to feel an increase in the size of the vaginal opening and a softening of the tissues.



Increasing the size over time can help reduce discomfort during pelvic exams, vaginal sex, or both.

What can I expect when I start using the dilator?

You may find that your emotions are somewhat sensitive as you begin this process. It may help to talk to one of your team, AYA Keyworker or even trained psychologist to help process these very normal reactions. For most people, there is a period of adjustment, and then using the dilator becomes part of your routine.

What should I notify my care team about?

Call your health care team if you have signs of an infection such as:

- Vaginal itching
- Fever
- Vaginal discharge with a strong odour
- Abdominal pain.

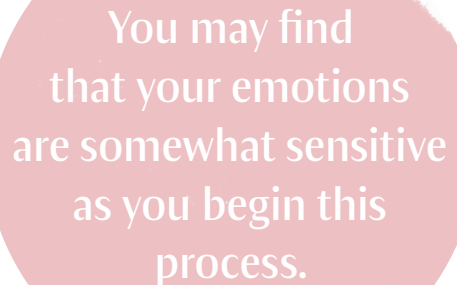
At first, you may have a small amount of bleeding or spotting after using the dilator or having intercourse. This is normal and can occur for several months. This should stop as the vaginal tissue begins to soften and stretch. However, heavy bleeding or excessive pain is not normal and you should contact your healthcare provider if you experience this.

Sexual activity and dilator use:

You might not be sexually active but this could be important to know for the future. If you are sexually active, being able to use the largest dilator comfortably is a good indicator you're ready to resume sex, but it's important to go at your own pace and only restart when you feel comfortable.

Some people also find it helpful to use the dilators or internal vibrators prior to having sex to help relax and stretch the vaginal muscles to help with any discomfort.

If comfortable, your partner may also be encouraged to be involved with dilator use. Sometimes being aroused can help make the whole process easier. Vaginal vibrators and vaginal sex can also be used in conjunction with or as a replacement for dilators, as long as it is regular.



You may find that your emotions are somewhat sensitive as you begin this process.

'I am a 24 year old cervical cancer patient. I had chemo-radiation treatment for early stage cervical cancer. I use dilators three times a week, and at first I found them painful to use. Now I use them with lube and it's so much easier. They're now less painful to use and I am able to use the larger ones. Occasionally I use the dilators with my partner. We use the dilator together, in the bath, before we have sex and it helps me to know what I can manage that day.'

Young person

Potential difficulties with dilator use and how to overcome them

Common reasons for why people find the dilators hard are:

- **Not having enough information about the dilators.** Hopefully this booklet has helped!
- **Some people have been brought up to see any self-exploration or touching as wrong, dirty or sinful.** However, dilators are not a sexual device. They are a medical device and are part of rehabilitation. Remember, using a dilator is recommended for maintaining pelvic health following radiotherapy. Using the dilators does not take your virginity.
- **Experiencing anxiety about using vaginal dilators.** This is normal. With time, you will become more familiar with using it and it will feel more comfortable and simply become another part of your post-treatment rehabilitation program.

- **Forgetting to use dilators.** To help you remember to use your dilators, you could keep a diary to document your use or create a routine. For example, if you go to the gym three days a week do it on these days, or every other day etc.

For people who have had uncomfortable sexual experiences or abuse or people whose gender identity doesn't match their gender assigned at birth, having medical examinations or even using dilators can be more difficult. Your team should ask you if you have any worries or concerns before any procedure, but if not, try to let them know. You can always bring in a support person or a medical team member that you trust like your AYA Key worker. They can also help you get additional support to help you be the best version of yourself.



Pelvic floor exercises

We all should be exercising our pelvic floor muscles regularly, but especially after your treatments would have caused pelvic inflammation.

These are the muscles at the bottom of your pelvis which are responsible for supporting your bladder and bowel opening and closing. If they weaken it can lead to accidents.

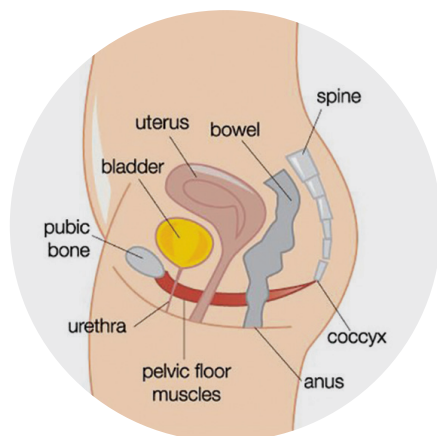
Like other muscles in your body, your pelvic floor muscles will become stronger with regular exercise. Doing these exercises is recommended for all people.

Pelvic floor muscle exercises can help:

- Improve bladder and bowel control
- Increase sexual pleasure
- Increase social confidence and quality of life.

Where are they?

The pelvic floor muscles run from the pubic bone at the front of your pelvis to the tail bone (coccyx) at the back. Your exit pipes from your bladder (urethra), the vagina and back passage (anus) all pass through the pelvic floor, which controls these opening or closing.



How do you exercise your pelvic floor muscles?

You can do pelvic floor exercises while you are sitting or lying down. No one will know you are doing them. Exercising these muscles is like a tightening or squeezing. The pelvic floor muscles should move inwards and upwards when tightened.



Tip

To find them, practice stopping the flow of wee while you are on the toilet or holding in wind. If you can hold it for a second or two you have found them. Don't do this repeatedly as it can cause problems emptying your bladder.

Tip

Joining yoga or pilates class is an excellent way to practice strengthening pelvic floor muscles and to learn relaxation techniques. There are heaps of free videos on YouTube you could check out.

One way to do this:

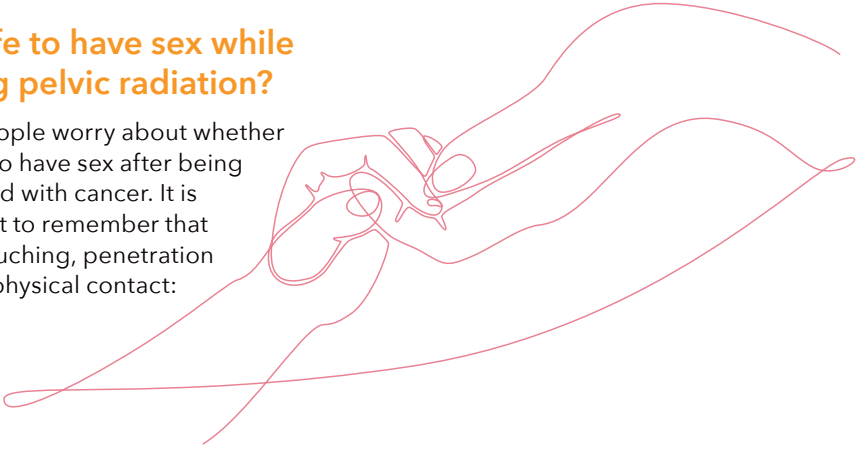
Sit on a chair (could be in the car, at an office desk, at the dinner table):

- Feet flat on the floor, knees apart
- Lean forward slightly. Keeping a bend in your lower back
- Keep your legs, bum, stomach and arms relaxed
- Breathe normally
- Squeeze the muscles as if you are stopping yourself from passing wind, or holding onto pee. Imagine your vagina is lifting off the chair.
- Hold for 3 seconds, let go, rest for one second.
- You may find at the start that these muscles tire quickly, so start off only doing a few sets. With more practice try increasing the hold time for up to 10 seconds maximum.
- Try this exercise in conjunction with using the dilators when they are inserted.

Sexual health information

Is it safe to have sex while getting pelvic radiation?

Some people worry about whether it is safe to have sex after being diagnosed with cancer. It is important to remember that sexual touching, penetration or close physical contact:



- Cannot pass cancer on to a partner
- Will not affect the cancer or your treatments
- Does not make cancer more likely to come back.

Sexual contact and intimacy can come in many forms and looks differently for each person, partner or relationship. There are many ways that pleasure can be received or given. If you feel like having sex then it is usually safe to do so, just use protection (i.e. condoms).

Protection is important as it:

- Prevents unplanned pregnancies
- Reduces sexually transmitted infections
- If you're on chemo, stops the passing of any chemo through your body fluids to your partner.

Your team will talk to you if there are any extra precautions or restrictions to sexual activity while getting radiation therapy or after treatments have finished.



Visit the AYA Cancer Network to see some great resources on young people and sex <https://aya.cancernetwork.org.nz/aya-fertility-and-sexuality/>

'I was so worried about passing something on to my partner. Once my radiation therapist said that it was safe to keep on having sex as long as we used a protection and I felt up for it, it was a massive relief. It took us a bit to find a new normal but experimenting all over again was kind of fun.'

Young person

Preventing pregnancy

Because you are young you will be asked if there is a possibility if you are pregnant (have you had unprotected sex). We need to ask because radiation is harmful to an unborn baby.

Even if you have stopped getting periods there is still a chance you could get pregnant if you are having vaginal sex. That's why it's important to use protection during treatment and while you heal for up to 1 year after your treatment.

Lubricants

Some young people notice discomfort with sexual intercourse due to vaginal inflammation and dryness. The use of lubricants can help with this by reducing friction. It is best to use a water based lubricant as others may irritate your vagina.

If you experience ongoing discomfort during or after sexual intercourse please talk with your oncology team.

If you are sexually active:

Firstly you may notice less interest, energy or comfort around intimacy or having sex. This is very normal and can be from the many cancer medication, changes that a diagnosis can cause in relationships and from being tired. Remember sexuality is much more than just being sexually active; it's about how we see ourselves and how we connect with ourselves, others and the world around us.

Be gentle on yourself and give yourself time. It may be a good idea to take some time just for you and relearn your own body first. This can be a good step forward regardless of your gender, if you are single, in a relationship or married! Being intimate doesn't always have to be with someone else.

If you are in a relationship or starting a new relationship, talking with your partner and letting them know how you are feeling is a really important part of connecting. Intimacy can mean many things and can include things like hugging, kissing, touching

'Generally, after treatment I felt I was physically less attractive than previously, which affected my confidence and therefore my sexual health. This has come right over time.'

Young person

and massage- all good alternatives to sex. Having cancer can make your relationship feel different or complicated and talking about sex with a partner can sometimes be difficult. Often the thing that is most needed is communication.

Often the changes you notice from treatment are temporary and get better with time. It can be difficult, but also helpful, to talk with your medical team. They may offer advice or treatments that can help, or they may suggest that you see a specialist.



Be gentle on
yourself and give
yourself time

There is heaps more information out there about sex, sexuality and intimacy after cancer. See the AYA Cancer Networks website for more information written by young people just like you. For more information on sexual health and contraceptive options check out your local GP, sexual health or family planning clinic. If you are gender diverse there are heaps of amazing organisations that support gender diverse young people like OutLine, and RainbowYOUTH and many more!!

Tips for talking to a health professional:

- Think about who you want to talk to. Is there someone in your healthcare team you feel more comfortable with?
- Write down the questions you want to ask. It could be about loss of libido, vaginal discharge, pain during sexual intercourse or worries about the future.
- Do not worry about using the right medical words about sexual health or your body. Use the words you understand.
- If something is not clear, ask the health professional to explain again.



Notes

Questions I would like to ask my medical team about sexual health.

Please note:

This booklet is designed to introduce you to the topics of pelvic and sexual health after radiation and to outline some of your options, talk to your team if you want to know more. For more information on how this all fits in with your culture, values and beliefs, talk with your team or ask to speak to a cultural support worker. Hei mōhiohio anō mō te hāngai ki tō ahurea, ōu uara me tō whakapono, me kōrero ki tō tima, ki tētahi kaitautoko ahurea rānei.

This information is current at the time of publication. The AYA Cancer Network Aotearoa will endeavour to keep this publication updated, but please note that some of this information may change over time.

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Whāia te mātauranga hei oranga mōu

Seek knowledge for the sake of your wellbeing.

INFORMATION

For further information go to: ayacancernetwork.org.nz

 AYA Cancer Network Aotearoa  @NZayacancer  ayacancernetwork

