Care for Women after Radiation to the Pelvis
This booklet was developed by Vaginal Dilation Working Group of the Canadian Association of Nurses of Oncology (CANO/ACIO) chaired by Lynne Jolicoeur and Joan Hamilton. If you have any questions regarding this booklet, contact joan.hamilton@nshealth.ca. January 2015.

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References


Much of the information in the booklet is based on expert opinions based on an interpretation of the available evidence.
Caring for Your Vagina: Dilating After Pelvic Radiation

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Caring for Your Vagina: Dilating After Pelvic Radiation

Introduction

This booklet was developed as additional information for you, after talking with your cancer care team about dilating your vagina after pelvic radiation.

Some women will be interested in reading all the information in this booklet. Others may only use the ‘Steps to Dilating Your Vagina’ page (found on page 8 and the back inside cover). Still, others may only pick up this booklet and read a certain page if a question or concern comes up.

Radiation to the pelvis can include treatment for many cancers; cervical, ovarian, endometrial, vaginal, vulva, bladder, rectal and anal cancer.

This booklet is for women who are going to have, or who have had, any type of radiation to the pelvis. Pelvic radiation can cause side effects to the vagina, uterus, ovaries, vulva, bowel and bladder. This booklet only describes possible side effects to the vagina. It focuses on preventing and managing one side effect, the narrowing and/or shortening of the vagina, by using a vaginal dilator. A vaginal dilator is a tube that is inserted into the vagina much like a tampon.

Not all of the information in this booklet may be suitable for you. **Always follow your own cancer care team’s directions.** The ‘cancer care team’ are the health care providers who are part of your cancer care (for example your cancer doctor, cancer nurse, radiation therapist).

Dilating begins when treatment is complete. It is part of your rehabilitation, part of your recovery.

For those of you who might want a refresher on the names of the body parts and where they are located, please see the next page.
The Female Genital Area

VULVA
CLITORIS
LABIA MAJORA
LABIA MINORA
URETHRA: OPENING FOR URINE
OPENING OF VAGINA
ANUS

The Internal Organs of the Pelvis

OVARY
FALLOPIAN TUBE
UTERUS
CERVIX
VAGINA
Vaginal Side Effects from Pelvic Radiation

Like most treatments, radiation can cause side effects. Radiation kills or damages cancer cells. Unfortunately, radiation can also damage healthy cells in the treatment area. Over time, many of the healthy cells that were damaged will repair themselves.

How pelvic radiation might affect your vagina will depend on where the radiation is aimed in your pelvis, dose and type of radiation, the number of treatments, and whether you are also receiving chemotherapy.

Physical side effects to the vagina can include:
- Changes to walls (linings) of the vagina: swelling, irritation, soreness/pain, burning, stinging, peeling, blistering, thinning, colour changes, scabs, breaks in the skin, itching, sticking together
- Loss of lubrication, vaginal dryness
- Delicate, fragile, thin vaginal walls (linings) that can tear easily
- Scar tissue forming in the vagina making the vagina less stretchy and causing it to narrow, shorten, and become less flexible (called “vaginal stenosis”)
- Fistulas (openings) between the vagina and other areas of the body near the vagina
- Loss of pubic hair

Immediate and early side effects of swelling, irritation, soreness/pain, burning, and your vagina feeling ‘raw’ can begin during radiation and commonly lasts for 2-6 weeks after treatment is complete.

Side effects, like the vagina becoming less flexible and narrowing may not appear until months to years after radiation is finished. This can happen because of gradual damage to blood vessels and surrounding tissue over time. These side effects can cause:
- Difficult and painful vaginal (pelvic) exams
- Uncomfortable or painful sexual intercourse (or any other penetration into the vagina).

The more permanent side effects of pelvic radiation are commonly vaginal dryness and vaginal stenosis, which commonly cause painful penetration (sexual intercourse). There are things you can do to manage and improve these side effects.

Each woman’s body reacts differently to pelvic radiation.

Some women only have mild side effects, while others will experience severe changes.

No one can predict how a woman will react.
Learning about Dilating

Why do I need to dilate my vagina?

Dilating your vagina is done to try to prevent or manage the side effect of narrowing and/or shortening of your vagina

- It may help make vaginal (pelvic) exams possible.
- It may help make sexual penetration (insertion of penis, fingers, vibrators, or sex toys) possible.
- It prevents the vaginal walls (linings) from sticking together.

What is a vaginal dilator?

A dilator is a firm smooth tube made of plastic, rubber, or silicone. One end of the tube is slightly rounded or pointed. Some are hollow, some are solid, and they come in a variety of different sizes. A dilator goes into the vagina, much the same way as a tampon. A member of your cancer care team will provide you with different sized dilators, or they will tell you where to buy or order them.

Some women use dilators provided by the cancer care team until they reach their desired size and then they buy a dildo (a penis shaped sex toy). They buy a dildo that is the right size, right length, right firmness, and has a good grip. Some women prefer to dilate with these because:

- There are more options in size and are easier to hold
- They find dildos have a bit of “give” (because they are made of rubber or silicone)
- The vibration may make inserting easier and more comfortable

It is not recommended to use your fingers instead of a dilator because a finger will not be able to reach to the end of your vagina or be wide enough to stretch it as much as it could be stretched.

Dilators need to be able to be washed in hot soapy water. They should not have a sharp point. They should be firm enough to stay stiff when being inserted in the vagina.
Steps to Dilating Your Vagina

1. Choose a time and place when you will not be interrupted.
2. Wash your hands and the dilator with hot soapy water. Use unscented soap.
3. If you are leaking urine (pee), wash your genital area with soap and water before dilating.
4. Check that the dilator is smooth with no rough spots or edges.
5. Lie on a towel on your bed, in water in the bathtub, or put one foot up on side of tub. If you lie in bed or in the tub, bend your knees and spread them apart.
6. Put lubricant on your index and middle fingers of your dominant hand. With the other hand, separate your labia (the folds of skin covering your vagina).
7. Insert your lubricated finger(s) into the opening of your vagina. Stretch the opening a few times. Remove your fingers.
8. Lubricate the dilator. Make sure the lubricant covers all areas of the dilator that will go inside of you.
9. Spread your labia with one hand. With the other hand, hold the dilator at the opening of your vagina.
10. Try to relax your pelvis muscles as much as possible. Take a deep breath. Slowly blow out and begin inserting the dilator (It is difficult to contract your pelvic muscles as you blow out).
11. Keep the dilator in place. Wait, take a deep breath, and as you blow out continue to gently push the dilator further in. Do this a few times.
12. Continue gradually pushing the dilator in until you feel it is in as far as it can go.
13. Continue keeping a bit of pressure on the dilator so that it continues to push to the very top of your vagina.
14. Once the dilator is in as far as it can go, turn it one way and then the other. Some suggest moving the dilator from side to side, and up and down to increase the stretching to the vagina.
15. Keep the dilator in the vagina between 3 and 10 minutes.
16. Remove the dilator.
17. Wash the dilator and air dry. Wash off any lubricant. Wash your hands.

See ‘Dilating Guide’ section for when to start dilating, suggestions for how often to dilate and how long the dilator should remain in the vagina when dilating.
Dos, Don’ts and Considerations about Dilating

- Do not dilate during radiation treatment or immediately after (first two weeks). The immediate/early side effects of radiation need to settle before you begin dilating. There is no proof that dilating during or immediately after radiation prevents narrowing and shortening of the vagina or improves quality of life.
- Never force the dilator into your vagina. As you insert the dilator, you may feel resistance, pressure, and stretching. Although a very small risk, if you push too hard, you can push through the vaginal wall. Gently and slowly apply pressure to ease it in.
- If a dilator goes in easily, the dilator is not big enough. Move up to the next size dilator and continue moving up in size until you get to the size you want to be (what is called your desired size).
- It may take a few weeks to get a larger dilator all the way in. Once all the way in, you may want to dilate more often until it becomes easier.
- It is common to have some spotting (small amount of blood) after you dilate. You may notice blood on your dilator or on your underwear.
- If you are having difficulties, if you are not able to get the first dilator all the way in or you haven’t been able to increase the size of dilator for weeks, contact a member of your cancer care team who has talked to you about vaginal dilation.
- If you begin having regular sexual intercourse (or any other penetration in the vagina) at least once a week, and it feels comfortable, you may not need to continue dilating.
- Some women include their partners in dilating.

Staying Motivated!

Dilating is often uncomfortable and inconvenient. For some women, the pressure of needing to dilate seems overwhelming.

It is important not to put off dilating thinking that you’ll have more energy or more time later. Putting it off until later can mean:
- Dilation may be more painful and difficult.
- Your vagina may not respond to the dilation as well as it could have if you had started earlier or kept at it.

Try to include dilating into your week and keep the routine.

If you are nervous about beginning dilation or having a hard time staying motivated, you are not alone.

There are members of your cancer care team who are experienced in helping women just like you. Find out who they are and share your concerns with them.

It may feel hard to talk about your feelings and concerns in the beginning, but many women are surprised at how relieved they feel by talking to others.
# Dilating Guide

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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| **When do I start dilating?**                 | About two weeks after your radiation has stopped, use 1 or 2 fingers to check your vulva and vagina. If it feels swollen, raw, sore to touch, or if you feel moderate to severe pain and burning, wait a few days and check again.  
You want to start dilating as soon as comfortably possible. Many women are not able to start dilating until about a month after they finish radiotherapy.  
If you are **NOT** dilating by 8 weeks talk to your cancer care team. |
| **What size dilator do I use?**               | Start with the smallest dilator you have been given. If it goes in easily, without difficulty, remove it and try the next size up, and so on.  
As you insert the dilator, you should feel stretching, pressure, and possibly a bit of burning or stinging. This discomfort should gradually become less over time. It is normal for it to be uncomfortable and to have a little bleeding. |
| **When do I move to a larger dilator?**       | Once you have confidence in your technique and there is little difficulty inserting the dilator, it is time to move to a larger one.  
When you try the next size up, it may feel a little tight and uncomfortable at first. This is normal. It is also normal to experience some light bleeding.  
Use the new dilator until it can be inserted without pressure or discomfort and then move to a larger dilator. |
<p>| <strong>What size dilator do I need to get to?</strong>    | Ask your doctor or nurse what size dilator you need to reach in order to have a comfortable vaginal (pelvic) exam. Once you get to the size you want to be, your desired size, stay with that dilator. |
| <strong>How long does the dilator stay in?</strong>        | Keep the dilator in for 3-10 minutes. There is no suggestion that you need to try to increase the length of time it remains in your vagina after it has been in for 10 minutes. |
| <strong>What do I do once the dilator is inside?</strong>  | Once you have inserted the dilator as far as it can comfortably go, gently turn it both ways, move it up and down, and side to side. |</p>
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<td>How often should I dilate?</td>
<td>Because there is limited study in this area, experts are only able to suggest how often women should dilate. The following are guidelines. Dilate often enough so that the desired size dilator can be inserted without difficulty. Some experts say that damage from radiation can continue for up to 5 years. <strong>For the first 6 months:</strong> 3 times a week is usually adequate for most women (some women need to dilate every day; others can manage twice a week). <strong>From 6 months to one year:</strong> Dilate at least once a week. If you find it becomes challenging to insert the dilator, dilate more often. <strong>After one year:</strong> Dilate once a month or so to make sure your vagina is not getting smaller. If you do find it becomes challenging to insert the dilator, start dilating more often. Some women find they need to continue regular dilation for up to 5 years. Review the need to continue dilating after a year. You can consider stopping dilation if you are sexually active and sex is comfortable, if pelvic exams are not uncomfortable, or if you no longer require pelvic exams.</td>
</tr>
<tr>
<td>Do I need to dilate if I am having sexual intercourse (or other penetration into the vagina)?</td>
<td>Some women can reduce or stop dilation if they are having regular intercourse (or other vaginal penetration). If penetration becomes uncomfortable, you probably need to start dilating again. We suggest that you learn how to dilate in case you stop having regular sexual activity. If you stop having regular sexual intercourse (or any other penetration into the vagina), it is advised to begin dilating if you require ongoing vaginal (pelvic) exams.</td>
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What If…

✶ I bleed after I dilate?

It is quite common to have some spotting (small amount of bleeding) with vaginal dilation. It will gradually decrease over the weeks.

If you have more than spotting, for example, if you are bleeding enough that you need to use a sanitary napkin (pad), contact your family doctor/nurse practitioner or cancer care team.

If you are bleeding heavily enough that you need to use a new sanitary napkin every hour or so, go to your nearest emergency department.

✶ I notice vaginal changes?

Contact your family doctor/nurse practitioner or cancer care team if you notice any of the following. These may be signs or symptoms of a vaginal infection:

- New fluid coming from your vagina
- A new odor
- New vulva itching
- Menstrual (period)-like cramps.

✶ I have a fever?

There are different reasons for having a fever. If you have been given direction on what to do by your cancer care (for instance, because your blood counts are low), follow their directions.

If you get a fever and also begin experiencing changes in your pelvic area (for instance, new pain, odor, vaginal discharge, bleeding, cramping), contact your family doctor/nurse practitioner, go to a walk-in clinic, or go to your nearest emergency department.

✶ I have new pain?

Contact your family doctor/nurse practitioner or go to the nearest emergency department if:

- You develop new pain while inserting the dilator or continue to feel a new pain after it is removed
- You experience new severe pain putting your fingers or the dilator into your vagina
Common Worries about Dilating

Many women struggle with different thoughts, feelings and fears about vaginal dilation. It is common and normal to have these worries. Some women:

- Have never touched their vulva or vagina and feel very uncomfortable or embarrassed at the thought of it. They grew up being told that touching themselves was dirty, or a sin, or something that “nice” girls did not do. Now, even though they understand dilating is for medical reasons, they are uncomfortable talking about dilation or thinking about what they have to do.

- Think of a dilator as a sex toy and are repulsed or totally embarrassed.

- Are reminded of their cancer and cancer treatment and it brings back distressing thoughts and feelings. It sometimes reminds them of how defenseless and exposed they have felt during procedures/examinations.

- Feel that dilation is yet another violation of their body.

- Have cultural or religious beliefs that can influence their thoughts about using dilators, even for medical reasons.

- Worry about the pain of dilation and it then reminds them that sexual penetration may also be uncomfortable. This can cause women to worry about having sexual intercourse (or any other penetration into the vagina) because they are afraid it may hurt.

- Worry that having to dilate will change their intimate or sexual relationship.

- Feel overwhelmed with the thought of having to learn to dilate. Others worry that they will damage their vagina if they don’t dilate correctly.

- Feel overwhelmed because it’s "one more thing to do" in an already busy life.

- Who have never been sexually active prior to treatment feel very uncomfortable thinking about what they will need to do after treatment.

- Find that having to dilate changes how they feel about and see themselves.

If you are struggling with any of these thoughts, consider talking to a member of your cancer care team. They may talk with you or refer you (and your partner if desired) to a health care professional who can listen, ask questions, and support you. They may be able to help you sort through some of your thoughts and feelings by discussing new ways to manage your concerns.
Common Questions about Dilating

Can I try inserting the dilator before radiation treatment begins?

Some women want to try inserting a dilator into their vagina before the radiation begins to get a sense of what it feels like. Other women want to find out what size dilator they need to work up to in order for their vagina to be the same size as before treatment.

Not every woman can try to dilate before treatment. For instance, for certain gynecological cancers, some women may be at risk of severe bleeding before treatment. There are different reasons why your team may not want you to insert a dilator before treatment.

If you think you want to try inserting the dilator before your treatment begins, it is important that your radiation doctor/nurse practitioner is consulted to ensure it is safe to do so.

Can I lose the dilator in my vagina?

Some women worry that they are going to let go of the dilator and not be able to get it out. This happens very rarely and only if the dilator is small and does not have a handle. If it does happen, stand up, bear down and it will come out.

Can I choose not to dilate?

Talk to your radiation doctor or cancer nurse if you are thinking that you do not want to dilate. Here are some reasons why women choose not to dilate:

- The doctor has told them they do not need to have vaginal exams again in their life
- They do not want to keep their vagina open for sexual activity
- They do not want to have to deal with dilating (even though they know vaginal exams will likely be uncomfortable)

Can I have sex during and immediately after radiation treatment?

If you want to continue sexual activity during radiation and right after it is finished, check with your radiation doctor/nurse practitioner. (For many women, sexual activity is not on their radar screen at this time!)

Is it normal not to have any sexual interest or desire through treatment and into recovery?

Many women have no sexual interest and no thoughts of having sexual activity during treatment or for a period of time afterwards. They feel raw and sore in and around their vaginal opening, worry about pain, have no interest, and/or feel overwhelmed and tired. Listen to your body and go with what feels best for you. If this is concerning you, ask to speak to a health professional who can discuss this with you.

If your partner is insisting on having sexual activity and you do not want to, talk with a member of your cancer care team to discuss how to manage this situation.
What about my partner in all of this?

How informed and involved your partner becomes in this aspect of care will depend on your comfort level, their comfort level, and how your relationship works.

Explaining why you need to dilate and how it is an important part of your recovery from cancer treatment may help open up lines of communication.

It may be helpful to talk about how you are feeling and provide them with some direction about how they can support you. They may have no idea how to give you support.

Think about whether you want them to assist you in any way with the dilating. Do you want them to be part of it? Do they want to be part of it? Can they be supportive in other ways (for example, by making sure you have time away from the children to be able to dilate in private)?

After radiation, many women are tired, sore, worried about pain, and have no sexual interest. Share your thoughts and feelings. Let your partner know that you will tell him or her when you are ready to try having intercourse (penetration) again. If you don’t feel like kissing and cuddling, if you are not ready to show or receive usual affection, explain why. Your partner may worry that you are rejecting them.

Ask your partner how he or she is feeling about sexual activity and affection. Are there things that you can do right now so that both of you will feel better about the changes?

If you find it hard to start the conversation, or the conversation gets difficult, you may be able to get help with talking as a couple by contacting your cancer care team.
Vaginal Lubricants

What is a vaginal lubricant?

A vaginal lubricant is gel-like liquid. It is placed on the dilator to moisten (wet) it so that the dilator is able to enter the vagina more easily. For sexual activity, lubricant can be placed on a finger, penis, or sex toy. It can also be put at the opening of the vagina and on the clitoris.

Things to consider when choosing a vaginal lubricant

- Lubricants can irritate the vulva and the lining of the vagina, especially if a woman is known to have sensitive skin or if they have open areas caused from the radiation.

- Choose lubricants that do not contain perfume, coloring, spermicidal, flavoring, warming, or tingling properties. These usually have more chemicals that can irritate vaginal tissue.

- Paraben can also irritate the lining of your vagina. Choose a lubricant that is paraben-free.

- There are 3 types of vaginal lubricants; water-based, oil-based and silicone-based lubricants.

- Some women find oil-based lubricants more irritating to the lining of the vagina then water-based.

- There is a small bit of proof that oil-based lubricants can increase your risk of vaginal infections. However, many women have used oil-based lubricant for years with no problems.

- One brand of lubricant may irritate (burn, sting) but another brand may feel fine. Different brands contain different preservatives and products. You may need to try a few different brands and types of lubricants before finding one that is right for you. You should be able to find one that is comfortable.

- Sex shops have a bigger and better selection of lubricants than department or drug stores. Staff in sex shops is helpful in explaining the pros and cons of the different lubricants. You can also buy vaginal lubricants on-line.

- Do not use petroleum jelly (Vaseline).

- Vaginal lubricants are different from vaginal moisturizers.

- Vaginal lubricants do not contain hormones.
Resources

Psychosocial support

Talk to a member of your cancer care team if you are:
- Struggling with having to touch your genital area
- Having distressing thoughts and feelings around dilating
- Finding it difficult to dilate
- Feeling tension in your relationship with your partner or having concerns around sexual activity.

They can talk with your or make suggestions of who you might be able to talk to about your concerns.

Pelvic issues

Some women experience ongoing pelvic problems (such as incontinence, pain, tightness, spasms, poor muscle tone and control). Some physiotherapists have expertise dealing with these issues. Talk to your family doctor/nurse practitioner or cancer care team if you are having issues.

Books and booklets


Websites

- Society of Obstetricians and Gynecologists of Canada (SOGC)
  - General information on sexual health: www.sexualityandu.ca
  - Information about menopause: www.menopauseandu.ca
Steps to Dilating Your Vagina

1. Choose a time and place when you will not be interrupted.

2. Wash your hands and the dilator with hot soapy water. Use unscented soap.

3. If you are leaking urine (pee), wash your genital area with soap and water before dilating.

4. Check that the dilator is smooth with no rough spots or edges.

5. Lie on a towel on your bed, in water in the bathtub, or put one foot up on side of tub. If you lie in bed or in the tub, bend your knees and spread them apart.

6. Put lubricant on your index and middle fingers of your dominant hand. With the other hand, separate your labia (the folds of skin covering your vagina).

7. Insert your lubricated finger(s) into the opening of your vagina. Stretch the opening a few times. Remove your fingers.

8. Lubricate the dilator. Make sure the lubricant covers all areas of the dilator that will go inside of you.

9. Spread your labia with one hand. With the other hand, hold the dilator at the opening of your vagina.

10. Try to relax your pelvis muscles as much as possible. Take a deep breath. Slowly blow out and begin inserting the dilator (It is difficult to contract your pelvic muscles as you blow out).

11. Keep the dilator in place. Wait, take a deep breath, and as you blow out continue to gently push the dilator further in. Do this a few times.

12. Continue gradually pushing the dilator in until you feel it is in as far as it can go.

13. Continue keeping a bit of pressure on the dilator so that it continues to push to the very top of your vagina.

14. Once the dilator is in as far as it can go, turn it one way and then the other. Some suggest moving the dilator from side to side, and up and down to increase the stretching to the vagina.

15. Keep the dilator in the vagina between 3 and 10 minutes.

16. Remove the dilator.

17. Wash the dilator and air dry. Wash off any lubricant. Wash your hands.

See ‘Dilating Guide’ section for when to start dilating, suggestions for how often to dilate and how long the dilator should remain in the vagina when dilating.
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