



Everything Nobody Tells You
About Cancer Treatment

and Your Sex Life

from

A

to

Z

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This booklet was written by Catherine Graham with contributions by Marianne Matzo, PhD, APRN-CNP, FPCN, FAAN, Sandi Troup, RN, BSN, and numerous courageous cancer warriors who volunteered their time to help make the cancer journey a little better for other women.

This booklet may be printed as a patient resource, provided no changes are made. We appreciate any feedback on how this booklet is being used and patient perceptions. Questions or comments about this guide can be sent to Dr. Marianne Matzo at info@kanwa.org

Illustrations, design, and poem by Sandi Troup. ©2014

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How to Use a Vaginal Dilator

1. Minimum use is three times weekly for an indefinite time period. Dilators can be used in conjunction with sexual intercourse to achieve a combined frequency of vaginal dilation.
2. Find a private and comfortable place where you can relax and use the dilator. Dilators can be used in the shower or bath if this provides privacy, and/or allows you to relax your pelvic floor muscles. If you wish, your significant other can also be encouraged to be involved.
3. A water-soluble lubricant should be placed on the dilator and around the entrance to the vagina prior to insertion.
4. There are various positions in which to use the dilator: you can either lie down on your back with knees slightly apart and bent, or stand with a leg raised on the side of the bed or bath to insert the dilator.
5. Inserting the dilator into the vagina requires a firm, gentle pressure. Insert it as deeply as is comfortable, without forcing the dilator. Do pelvic floor exercises during insertion.
6. Once the dilator is inside the vagina it should be moved in a forward and backward motion, then a left to right motion. If possible gently rotating the dilator using the handle.
7. Your doctor will fit you for the dilator. It is usual to start with the smallest size and progress to the largest (size 4) in the days/weeks following treatment, as it is comfortable.
8. When the dilator is in as far as possible, leave it in your vagina for about 15 minutes. You can pass the time by reading, watching TV, listening to music, or even talking on the phone. If the dilator slips out, gently push it more deeply into your vagina.
9. The dilator should be removed slowly rotating in clockwise/anticlockwise movements.
10. Vibrators may also be used in conjunction with the use of dilators.
11. Slight vaginal loss and blood staining is not uncommon when using dilators. If you experience heavy vaginal bleeding or pain contact your doctor.
12. When you remove it, wash it with a mild soap and water. Be sure to rinse all the soap off so no film is left to irritate your vagina the next time you use it.

Source: Best Practice guidelines on the use of vaginal dilators in women receiving pelvic radiotherapy *National Forum of Gynaecological Oncology Nurses*. Edgbaston: Birmingham Women's Hospital.



Chrysalis

When cancer's gales blew through my heart
I feared the storm would rip me apart
Yet I found strength to survive from within
And held firm to hope I would see light again

I wrapped myself tightly in a chrysalis
Of love, hope, friendship and well wishes,
Emerged transformed by my endless fight,
Unfurled my wings, and took to flight!

- A Cancer Survivor



Everything Nobody Tells You About Cancer Treatment and Your Sex Life from A to Z

The information in the booklet was not written by a doctor. It is not in complicated medical language, it was gleaned from a series of interviews with women who were struggling with cancer (ovarian cancer, breast cancer, uterine cancer, and cervical cancer). A dedicated group of professionals (whose names are listed somewhere, I'm sure) found that women in cancer treatment had very little help with sexual health issues.



There was nobody to ask, and their health care practitioners were understandably concerned primarily with keeping them alive, not with their sexual health recovery. The few pamphlets they found were medically worded and a little intimidating. These women all expressed a desire for an open, easy to understand booklet that could help as they struggled with an issue that is personal, a little embarrassing and that nobody seemed to want to talk too much about.

Pros	Cons
Oil-Based Products (Continued)	
Durable. Decreased vaginal bacteria/yeast in testing.	Should not be used with condoms (breaks down latex)
Silicone-Based Products (Continued)	
Always slippery and never tacky feeling. A little goes a long way. More durable. Does not dry up as quickly. Not absorbed by the skin. Good for water use ('water play'). Does not change the pH of the vagina (no yeast concerns). Washes away with soap and water. Great for full body massage.	May leave oily residue on sheets but will wash out. Not recommended with silicone-based toys. Usually a little more expensive.

1. Carter J, Goldfrank D, Schover LR. *Simple Strategies for Vaginal Health Promotion in Cancer Survivors*. J Sex Med. Aug 16 2010

Base and Types	Brands
Oil-Based Products	
Vaginal Lubricants	Élégance MenoMoist Zestra Essential Arousal Oils Vitamin E (<i>puncture caplet & use as suppository</i>) Mineral oil Coconut or olive oil Vegetable shortening
Silicone-Based Products	
Vaginal Lubricant	Eros Lubricant Liquid Silver Wet Platinum Lubricant I-E Velvet Lubricating Liquid

Ingredients to consider staying away from

- Glycerin or Sorbitol may contribute to yeast infections in those susceptible.
- Petroleum-based lubricants may increase risk of vaginal infection and also tend to have an unpleasant odor and may damage latex condoms (possible pregnancy or STDs).
- Perfume, spermicide, “warming” or “cooling” lubricants, or other additives that may be irritating.

The courageous and outspoken women who agreed to these interviews (some of whom are no longer with us) were very patient, struggling with difficult medical wordings of questions and awkward interviewers but it was within their voices that we found the true answer to the problem.

The best person to help a woman facing cancer treatment is often another woman, who has faced the same issues. So we decided to get out of the way with all our medical jargon and complicated ideas, and just use these women’s own voices to offer advice, wise counsel and even a few wise cracks.

It is to those brave, kind, nameless women that this booklet is dedicated. It comes to you with their best wishes during your own personal struggle back to sexual health.



A - Afraid to Ask About Sex?

Let's face it; it's never comfortable to ask about sexual health. Who do you talk to? When do you ask? This booklet is an attempt to answer some of the questions you may have, and to anticipate some you may not have yet thought of. Feel free to blush or giggle in the naughty parts.

B - Both of You...

You may want to read this booklet with your partner, because these issues affect both of you. And it can be a way to open a discussion if you haven't already done so. The truth is, both you and your partner are going through a lot of emotional issues right now, related to sexuality as well as general health. Why suffer in silence? Your partner may be afraid of adding to your burden by discussing fears with you, and you may not wish to burden him/her with your sadness or uncertainty, but the truth is you are both facing these things, so why not learn to discuss them openly so that you can shoulder the load together instead of each struggling alone?

If you don't have a partner, then read it with yourself! But be sensitive with yourself, and take yourself out and treat yourself to a nice dinner first. Women in same-sex relationships (and even no-sex ones!) need to be concerned with their vaginal health and recovery of sexual function, so this book is for every woman struggling with cancer.

Vaginal Hydration

Most of these moisturizers are gels administered with a tampon-like applicator or as a vaginal suppository. Regular usage is the key to moisturizing performance.

Vaginal Lubricant: Usually a liquid or gel (water-based), but may also be oil or silicone-based. A vaginal lubricant is meant to be applied around the clitoris and labia minora and inside the vaginal entrance to minimize dryness and pain during sexual activity. Optimally the lubricant should be applied to both partners' genitals prior to vaginal penetration to minimize friction and irritation.

Pros	Cons
Water-Based Products (Continued)	
Vaginal moisturizers are applied 2-5 times per week (ideally every 3-4 days) and need not be applied directly prior to sexual activity.	It is possible that a moisturizer alone is insufficient to reduce frictional pain, so during sexual activity, a vaginal lubricant may also be needed.
<p>All water-based vaginal moisturizers and lubricants share the following Pros:</p> <ul style="list-style-type: none"> Reactivate with a few drops of water. Latex compatible. Clear and is non-staining. Cleans up easily with soap and water. Absorbs into skin & evaporates. Water based lubricants are typically recommended by doctors and health care workers, and they are the kind usually made available for free at sexual health clinics. 	<p>All water-based vaginal moisturizers and lubricants share the following Cons:</p> <ul style="list-style-type: none"> Not compatible with sex acts in water. May contain glycerin and ingredient that turns into sugar in the vagina and may contribute to yeast infection in persons who are susceptible. Tends to dry out. May leave sticky residue (<i>especially if high glycerin</i>). Can be dispersed in water (<i>not good for bathtub sex, etc.</i>).

(Table continued on next page)

Products to Maintain

Understanding Vaginal Moisturizers vs. Vaginal Lubricants: ¹

Vaginal Moisturizer: Non-hormonal, over-the counter, and usually water-based products intended to be used several times a week routinely for overall vaginal health/comfort, regardless of sexual activity. The goal of a vaginal moisturizer is to moisturize the vaginal mucosa for overall comfort. Sometimes a vaginal moisturizer is sufficient for vaginal comfort in regular daily life and for sexual intercourse. Moisturizers restore fluid into the cells of the vagina and vaginal pH. Some female cancer survivors need vaginal moisturizers up to 3-5 times per week.

Base and Types	Brands
Water-Based Products	
Vaginal Moisturizers	Replens Lubrin Luvena
Vaginal Lubricants	
Thin Lubricants	KY Liquid Astroglide
Medium/Thick Lubricants (Thick lubricants are especially helpful when you need a higher level of lubrication as when you are still experiencing pain while using regular lubricants.)	Slippery Stuff Liquid Silk (<i>Glycerin-free</i>) ID Lube Astroglide Maximus Probe (<i>parabens-free</i>)
Other	Maximus (<i>Glycerin-free</i>) Sliquid H2O (<i>Glycerin-free</i>) Hathor (<i>parabens-free</i>) Aphrodisia (<i>parabens-free</i>) BioGlide (<i>Contains carrageen, which has been shown to protect against (HPV and other viruses)</i>) KY – Slide + E, KY-Liquibeeds

C - Cancer Treatments

Whether you are undergoing surgery, chemotherapy, radiation, or a combination of all of these, your sexual health will be impacted and there are some things you will need to know. If you want to talk to your doctor or other health care practitioner about this, you may have to bring it up yourself, as some practitioners aren't comfortable with offering this information unless you ask about it.

Whatever treatment you are facing, you may not realize that there are impacts that are not cancer related. For example, many women will experience menopause and some or all of its charming symptoms, such as hot flashes, mood swings and even vaginal atrophy (which leads to dryness, tightness, and shrinkage -YIKES!). If you are bothered by any of these symptoms, you and your doctor may want to discuss hormone replacement therapy. Women with breast, uterine, or ovarian cancer may not be able to take estrogen, so there are lots of practical suggestions here about how to deal with or alleviate some of those problems. Keep an open mind, and a sense of humor, and remember your return to good sexual function is up to nobody but you! Like you, your sexual recovery is a work in progress. Be willing to accept a new normal and be patient with yourself as you work towards your sexual goals. The trick is staying sexual – whatever that may mean to you.

D - Dilators and Devices

If you have had surgery or are facing menopause, you will need to work at returning your vagina to good health. For some women, cancer treatments may cause your vagina to lose volume, which can make intercourse difficult or painful. (But – Fear not!) You can regain your vaginal health. Dilators are one of the important tools to do this. (They aren't as scary as they sound.) Dilators can seem strange, and even intimidating, but they can make the difference between never recovering your sexual function, and getting back the very best level of sexual function possible for you. Dilators are used to stretch the vagina to maintain the muscles and tissues that have always just kind of maintained themselves. You probably won't have to do it for the rest of your life, but it is the quickest and easiest way back to normal for you. So, don't be intimidated and just lube up and get started! You can get dilators through your health professional, or on line (they even have them on *Amazon.com*). Vaginal dilators are tools of graduated widths used to develop or restore the vaginal opening. Women find dilators, used with sexual lubricants, can also keep their vaginal tissues elastic and comfortable. Typically dilators are provided as a set, along with instructions for exercises to gradually, gently, and comfortably stretch the vaginal opening and the vaginal depth to comfortably accept sexual penetration. (See page 40 for more guidance.)

Dilator exercises are typically done once or twice per day in 20- or 30-minute sessions, and after a hot bath. Lie on your back with your legs bent and use a

lubricants is a really fun way to spend time with that special someone, so have fun, experiment and decide what is best for you. The important thing to remember is that your lack of natural moisture should not be interpreted as a lack of desire for your partner, or as any kind of hindrance to wonderful love-making!

M - Muscle Tone

The last key to maintaining good sexual health is muscle tone. Perhaps you tried Kegel exercises? If not, you are about to gain an important tool in keeping both your vagina and your urinary tract healthy. See pages 13 and 14 for a complete explanation on how to do Kegel exercises.

Getting Help

Finally, cancer doesn't occur in a vacuum. We are all balancing other concerns in our lives, and cancer is just one more challenge added to your particular mix. Sexual health can be impacted by treatments, by other medical conditions, past abuse or trauma, situational or emotional stress, and relationship issues. (Or by the absence of a relationship!) Instead of letting these concerns cripple this important area of your life, use your cancer as a catalyst to make positive changes in your physical and emotional health! In other words, ***"GET YOUR SEXY BACK, GIRL!"***

your vaginal opening. For persistent problems with pain, you may also benefit from a referral to a pelvic physiotherapist.

M – Moisture

Of all the difficulties you face with the decline of estrogen, the loss of natural lubrication is one of the most heart-breaking. The good news is that with diligent treatment, you can easily improve the symptoms. Once again, your recovery and sexual health is completely in your control. The first component in treatment is a moisturizer. This is a product that you apply at least weekly. It's best to choose a product free of fragrances, dyes or paraben, and one that is PH balanced. Replens is available through your doctor, or a product called Luvena has is not only moisturizing, but has a pre-biotic formulation that will help you to keep your new commitment to balanced Flora!

The second component goes hand in hand with moisture, and that is lubrication. You would add lubrication anytime you use dilators, vibrators or share that magic moment with your partner. You can choose KY Jelly, Astroglide or other lubricating products. *(Please see the table starting on page 37 for pros and cons of each form of lubricant.)* Each person's preference is different. Fortunately, trying out different

lubricant on the smallest dilator. With all of your pelvic muscles relaxed, apply even pressure to slowly insert the dilator into your vagina. When it is as deep as you can comfortably push it, hold it in place for 10 to 15 minutes. When you can comfortably insert a dilator all the way into your vagina, you are ready to graduate to the next dilator size. Once you can comfortably insert a larger dilator, you may wish to add Kegel exercises (page 13) with your dilator in place as a maintenance exercise. Use your dilator three to four times per week to maintain your vagina. Vaginal dilation takes patience. It can take three months or longer for your vagina to expand enough for vaginal intercourse. Frequent, short sessions will give you the best results.



You may also want to explore something called an Eros Therapy Device. Blood flow is extremely important in surgical recovery, or to deal with menopause. The Eros device creates a gentle suction which helps to restore blood flow to the clitoris and genitalia. Increased blood flow can increase orgasms, help with vaginal lubrication and overall sexual satisfaction. Eros is only available by prescription. For more information, go to <http://www.eros-therapy.com>.

E - Exhaustion and Exercise

You may not have the kind of energy you are used to during your treatments, but that doesn't mean that your relationship should be put on hold. You may have to make accommodations to your lower energy levels, but that doesn't mean you can't hold each other, kiss and cuddle, and even make love when you feel up to it.

When your recovery allows, you will find that a little exercise as tolerated will actually increase your energy level. So, take a walk, hold hands if you want, and do as much as you can without pain. The more you move, the better you'll feel. The less you move, the less you will be able to move.

F - Fear Factor (yours and your partner's)

Your partner may fear hurting you further, so you will have to talk about what you are capable of enjoying together, and be very frank – this is no time to be shy! Some partners are even afraid that they will be harmed themselves; either by "catching" your illness, or by being made ill by your chemotherapy or other treatments. Male partners can always wear a condom if he is really nervous about it, but hopefully reading this together will give him a sense that he will be okay. Just because you have been getting radiation, doesn't mean that your partner will become radioactive by sharing intimacy with you. Your partner will be safe for both the hanky, and the panky.

using a product such as Luvena which contains a pre-biotic.

E - Elasticity

This is a fancy word that means keeping your tissues elastic or, stretchy. Remember, use it or lose it should be your mantra for elasticity. Tissue atrophy due to reduced estrogen can be minimized by maintaining good blood flow and by stretching the tissues. It is much easier to KEEP your vagina healthy than it is to RETURN it to good health. It's not that easy with cancer treatments, surgical recovery and what not to keep a good handle on your vaginal elasticity. (You don't get up every day and say, "Another day, another chance to keep my vagina elastic!") But it is important. If you haven't been using these tissues in a while, you may need to start small. Literally. A vaginal dilator can be helpful, and is available on line through sites like *Amazon.com*. You can ask your doctor for a prescription if you prefer. A dilator is just a plastic device with tips of various sizes. Used in combination with moisturizers and lubrication, your vaginal opening can gradually be expanded by their use. This can restore natural elasticity and improve comfort in sexual activities. (A place where you really want some comfort!) If you have experienced sexual pain before your diagnosis your body may have developed a pain response that can include spasms of the muscles near

It actually causes your vagina to widen and elongate – which will greatly decrease any discomfort you may experience. An interesting note, most women’s vagina elongates toward your back, but after hysterectomy, it will tend to elongate up more toward your stomach. This may change the angle that feels comfortable to you. The good old missionary position may become uncomfortable. Don’t give up on intimacy, just roll over. You may prefer the angle from the back or even the side. Be adventurous. There is nobody there to see you but your partner, and believe me; they will want to work to make it better for you. You may also want to try a position where you can control the depth and the angle, such as from the top.

F – Flora

Now, a word from our sponsor, Lactobacillus acidophilus. Kidding. That’s the name of the bacteria in “live-culture” yogurt. Did you know that it also plays a starring role in your vagina? That’s the busy little bacterium that keeps yeast infections at bay. It occurs naturally in a healthy vagina, and keeps the environment acidic so that harmful bacteria aren’t happy there. Those little lactobacillus rascals need estrogen too, so menopause can affect the balance of flora in your vagina, which can lead to an increase in urinary tract infections and yeast infections. You can help maintain the acidic environment in your vagina by

Your fear will be greatly reduced if you and your partner have good communication about sexuality, and if you are consistent with your rehabilitation work with your dilators. Even then, it is perfectly normal to feel a little bit apprehensive about getting back to your normal sex life. Give yourself time and talk to your health care practitioner about any difficulties you encounter.

G - Going “Down-town” (alternatives to vaginal intercourse)

While you are working on recovering your vaginal health, you can still be intimate with your partner. If you have never explored options like oral lovemaking (pleasuring each other with your mouths) or manual lovemaking (using your hands to pleasure one another) this may provide the perfect opportunity to branch out. Don’t be afraid to explore. Who knows? You may find something you like so much that you will expand your regular repertoire even after you are healthy again! Wouldn’t it be nice to hear your partner bragging that you used to have a perfectly normal average sex life before you got cancer, but now it is AMAZING! Why settle for normal, average lovemaking? I say, “Shoot for OUTSTANDING, especially when it comes to lovemaking!”

H - Hot Flashes

Hot flashes can be embarrassing and annoying. If you are facing early menopause you should know that this usually passes after the first few months or so. They can be especially severe in women who have

sudden menopause because of their cancer treatment. (The fun just goes on and on – doesn't it?) You may be able to alleviate them by using a hormone patch or pill, but talk to your doctor to see if this appropriate for you. If not, then a low dose of some anti-depressants may help. Eliminating caffeine, alcohol, and smoking will all help to decrease this symptom, as well as avoiding hot environments. Keep room temps cool, and keep some ice water handy and perhaps a washcloth you can use to bathe your face and neck. Women who exercise regularly have about half as many hot flashes, so there's another great reason to get moving.

Many women find relief in deep breathing and other relaxation techniques. Simply practicing deep breathing can help get you through a hot flash. Practice breathing in for a 10 count, and then out for a 10 count. You might want to find a relaxing word or phrase to say to yourself while inhaling and again while exhaling. Something like "peaceful thinking" or "tranquil waters" or "ice cream sundaes" (okay, that last one works for me; but use what works for you!).

I - Initiating Sex

You may be able to continue making love in all the usual ways depending upon what kind of treatment you are undergoing. (And how acrobatic you normally are!) You may find that you have to make accommodations for equipment, (oxygen, IV lines, and colostomy, whatever), your lower energy level, or other obstacles. Open, frank discussions with your partner will enable you to get back to some level of

Please enjoy your sexual relations! Wait, finish reading first! That's better. Unfortunately, some women suffered from unsatisfying sexual relations before they ever got cancer. If you have been suffering in silence all these years, you just got your get out of jail free card. Look at cancer treatment as an opportunity to make some changes that will make the rest of your life richer, happier, and more rewarding – especially in the orgasm department. (Which is a very nice department.)

If you've been shy about telling your partner what you need or have been afraid of bruising their delicate ego by telling them you've been less than satisfied – this gives you an excuse to open a new dialog, and try some new techniques. Sometimes, since women can participate in sex without actually feeling any desire for sex, lazy partners can forget to give you adequate stimulation for the encounter to be enjoyable for you. If you are using an Eros Therapy Device or a vibrator, you may find yourself already stimulated, and take that opportunity to seek out your partner and initiate things yourself. Some guys need that little blue pill to get in the mood – why shouldn't we have some help if we need it? Don't miss the opportunity to tell your partner what you need in the way of stimulation, where your pleasure spots are, and what makes you feel good. Arousal is very important. We all know it's the key to proper lubrication, but did you know that there are also physical changes to your vagina when you are aroused?

can cause thinning of the tissues, shrinkage and decreased lubrication of the vaginal walls. As if cancer isn't enough fun all in itself, chemotherapy is the gift that keeps on giving, because it can also directly affect your vaginal health. Not only will all this lead to painful intercourse, but it will also make you more vulnerable to yeast infections. All of these things can be improved with one simple idea – keep the blood flow in this area good.

Now, the good news; There are some easy (and even fun) things you can do to help improve your blood flow. Stimulation is a great way to accomplish this. You can use vibrators or even a willing partner if you have one “handy” (no pun intended.) You may want to explore a product called an Eros Therapy device. This little gem was created to treat female sexual dysfunction. It is a gentle vacuum which will help to restore blood flow to the clitoris and genitalia. (Not a Hoover – I said a gentle vacuum!) The byproduct of increased blood flow in this area can be increased orgasms, improved vaginal lubrication, and overall sexual satisfaction. (Let's hear it for overall sexual satisfaction – YEAH!) The Eros Therapy device is available by prescription only. For more information, visit <http://www.eros-therapy.com>

E – Enjoyment

Now with all that increased blood flow, you will be ready to move on to the best advice anyone could give.

intimacy with small accommodations, such as a change of positions. You may want to explore side-by-side lovemaking, or your partner standing beside the bed while you sit at the edge to keep you from having extra weight on you, or tangling oxygen or IV lines. You will be limited here only by your imaginations, and your willingness to experiment.

A lot of the anxiety associated with getting back to love making can come from fear of disappointing your partner if you get started and aren't able to continue. Self-exploration prior to initiating sex can alleviate this fear somewhat. If you are comfortably accommodating your dilators, you shouldn't have too much trouble with your partner. Frank discussion of your capabilities and your willingness to explore just how far you can comfortably go will ease you back into your sexual relations gradually.



J- Join a Support Group

There are many emotional aspects to cancer that you are going to have to deal with. One thing that may make it easier is know that you are not alone. Many women have walked this road ahead of you, and they have dealt with the same fears and anxieties that you are going to face. This can be especially important if you are single. In some ways, being single is easier as you go through this treatment, because you don't have a partner whose needs must also be considered, but in many ways it is harder. You don't have that other person to confide in, to talk to, to share your fears with.

Whatever your relationship status, you are going to have to deal with emotions, including fears of relapse, infertility, and many other anxieties. You have to grieve loss of health, loss of hair, loss of a breast, loss of vitality, loss of desire for intimacy, loss of... Well, you get the picture, there's a lot to deal with. While some women are helped by a therapist, most women find very good practical help from other women who are facing, or have faced, these exact issues before. So, find a support group, join it, and share openly. These ladies will laugh and cry with you, they will see you through the dark times, and celebrate even your small victories.

Some people need more help than can be gotten in a support group. If you feel in need of additional emotional, mental, or even sexual support, you should contact a licensed mental health provider. Your doctor can make a recommendation to a Psychiatrist,

Ways to Help Yourself

There's a lot you can do to take back and maintain your sexual health, even while undergoing active treatment. The biggest thing to remember is to be proactive. Prevention is much easier than treatment down the road. While you may not feel up to activities now, you want to keep your body primed for the future!

*Just Remember **BE-FEMM!***

Blood Flow

Enjoyment

Flora

Elasticity

Muscle Tone

Moisture

B- Blood Flow

All over your body, healthy tissue needs good blood flow. When your body has had medical or surgical interventions, this becomes even more important. Menopause, whether it occurs naturally over time, or surgically, comes with its own challenges. As estrogen declines, your vagina will begin to atrophy. (Yes, the fun of being a woman goes on and on!) This atrophy

Supplementary Information:

Ways to Help Yourself – Page 29

Products to Maintain Vaginal Hydration – Page 36

How to Use a Vaginal Dilator – Page 40



“I think it might have to do with your own attitude about it, too. Because I remember, gosh, I think it was maybe a day or two after my surgery...I still had tube drains hooked up and all that stuff, and I was like, this is how I’m going to make my statement to my husband, that ***I’m not going to let cancer take us over.*** I actually made the moves on him. And he was totally shocked. You know? He wasn’t expecting anything for a really long time.”

- A Cancer Fighter

Psychologist, or even a Sex Therapist. There is no shame in getting treatment or support for an additional aspect of your cancer treatment, the mental and emotional aspects are just as legitimate as the physical aspects of your recovery, and it shouldn’t be embarrassing to seek whatever kind of treatment will help you.

K - Kegel Exercises

Now, I know that diamonds are supposed to be a girl’s best friend, but there is a kind of exercise that will TRULY reap huge benefits for you in terms of your sexual health. You may have done Kegel exercises when you were pregnant, but in any case, they are an indispensable tool in your sexual recovery tool kit. Kegels strengthen the muscles of your pelvic floor (the muscles that support your bladder, bowels and the walls of your vagina). These muscles are vitally important for maintaining bladder and bowel continence as well as your ability to enjoy sexual relations for the rest of your life. Good. Now that I have your attention; let’s try to isolate those pelvic floor muscles.

- Try to tighten the muscles you use to stop urinating, without moving the muscles of your abdomen, legs or buttocks. If you have trouble isolating them, practice stopping and starting your urine flow (hopefully on the toilet). Once you have found the correct muscles, go on to the next step.
- Squeeze these muscles for about 3 seconds. Then relax them for 3 seconds.
- Do 10-15 repetitions at a time, at least 3 times a day. If you have trouble remembering to do them,

associate them with something you do several times a day anyway. Before you start breakfast, lunch and dinner, try a set of Kegels. If you are doing them right, nobody can tell you are doing them (unless you giggle). If you are a giggler, perhaps you should skip them if you are having breakfast at Denny's!

There is a lovely side benefit to doing Kegels. They may actually increase your sexual pleasure. (Whoo-hoo!) Many women find that they have stronger orgasms after training these muscles, due to increased blood flow and stronger muscle contractions. The increased blood flow to your vaginal area not only speeds healing, but also increases sensitivity, and that's GOT to be a good thing. With the return of good blood flow, you will also see an increase in your desire for intimacy. And trust me, your partner will also enjoy the increased muscle tone in your vagina, and if you want to really blow their mind, try doing your Kegel exercises DURING sex. They'll love it.

L - Laughter

A good sense of humor will go a long way toward returning to the best sexual health you are capable of. Okay, you may have scars. Okay, your body may have changed. Okay you might be bloated from your medication or skinny from your chemo. And okay, you might not have any hair – ANYPLACE!! Yikes. All this is going to be true whether you like it or not. Why not take the attitude that if you can laugh at

Z - Za-Za-Za- Zoom!!

Hopefully you have found this information inspiring, informative and helpful. Your future sexual health and function are yours to claim! Empowerment is a wonderful thing, cancer is not in charge of you; YOU are in charge of you. YOU have a tremendous say in what your future sexual health will be. Cancer can take a lot of things from you, but good sexual health doesn't have to be one of them. Now go out and make the rest of your life exciting and sexy!



during this time. The options for this are limited only by your imagination and creativity.

Y - You Are More Than a Cancer Patient!

You are many things. You may be a wife, a mother, a lover, a boss, an employee, a grandma, an aunt, a golfer, a musician, a poet, a princess, a vixen, a prophet, a cyclist, a bowler, a sage, a mentor, a sister, a daughter, a dreamer, a visionary, a pragmatist, a realist, an optimist, a meditator, a mediator, a negotiator, an animal lover, a human rights advocate, a politician, an athlete, or even an athletic supporter! We all have lots of hats, and this cancer patient thing should not define who you are. It is just something you are going through, like a tax audit, only slightly less fun. Through it all it is up to you to be sure that you keep being all the wonderful things you are, despite what you are currently going through. One of the best things you are is a sexually healthy person; you are just going to have to work at that a little bit harder than most people to keep it being true. And if you play your cards right, you just may come out of this challenge with a whole new and awakened sexual life that is more mature and much more satisfying than your pre-cancer sexual experiences.

yourself, you will at least go through all this with a smile on your face. Sexuality is serious business, but it doesn't have to be somber business. Why not let it be monkey business?

M - Moisture

What you may not know about moisture, is that the drop in estrogen after menopause can lead to your vagina becoming dry and less stretchy. (Now, there's a scary concept!) In addition to a lubricant during intimate activity, or when using a dilator or other blood flow enhancing device, you will need to use a vaginal moisturizer, which is a product you will apply at least once a week. Something like Replens or Luvena – some moisturizers have the added benefit of a pre-biotic ingredient which will help to maintain good bacterial balance in your vagina. If your pH balance and good bacteria isn't maintained, you will see an increase in yeast infections and urinary tract infections. (Nobody's idea of fun.) So, in addition to keeping the tissues of your vagina well lubricated during intimacy, you must keep the tissues well moisturized all the time. Just like you use hand cream and face cream to keep your skin from drying out, so you must also consider the tissues of your vaginal walls. You don't ever want someone to say, "She looks young, but she has the vagina of a 90 year old!"

Remember, a moisturizer is not the same as a lubricant; they are two different products that accomplish two very different objectives. You will need a moisturizer to keep your vaginal area moist

and pliable. A lubricant is used to reduce friction during sexual activity.

And now a word about lubricants! In real estate, they say the secret is location, location, location. But in this case, your best friend will be lubrication, lubrication, lubrication. There are plenty of lubricants on the market. Whether you choose KY, or Astroglide, or even a store brand personal lubricant, the important thing to remember is that your discomfort will be greatly reduced with plenty of lubricant. Remember, without it you lubrican't, but with it, you lubri-can! *(Please see the Supplementary Information table which compares various lubricants.)*

N - Night Time is the Right Time?

It doesn't have to be. If your energy is better in the morning, or in the middle of the afternoon – let that be the time that you two make time for intimacy. There is nothing to say that you can only make love after dark. That's why they make curtains! So find the part of the day where you feel best, and let that be when you light the candles, put on the soft music, and make with the snuggling and what-not.

O - Open Communication

You are going to have to tell your partner what you are ready for, and when. Don't expect them to guess, spell it out. I'm not ready for this... But some of that would be nice... If you haven't had an open line of communication about sex it may feel awkward to talk

Cosmopolitan to look just like Samantha! Who hasn't fanatized about having intimate relations with new people? Thanks to wigs, you can offer your partner lots of different people without ever straying! You can be a blonde today, a brunette tomorrow, and a red-head next Tuesday! Play with it, make it work for you, and enjoy the adventure!

X - Explore New Options

If intimacy the way you have always shared is not possible for you right now, be willing to explore other intimacies until you are ready for resuming your normal activities. If you have never showered together or bathed together, now is the time to consider it. Go to a drive-in movie and neck in the back seat. Or just park in the moonlight and kiss. Order a CD on line and surprise your partner with a return to the music from the good old days of your relationship. Slow dance in the living room, play strip poker, hang mistletoe in July, make a rule that every time you hear a bell ring – you have to kiss. It will make a phone call or the doorbell seem suddenly exciting! Pull out the photo album and share reminiscences from the early days of your courtship. Leave naughty notes for your partner in the steam on the bathroom mirror – so that when they shower, it will become visible! Ask your partner to do a strip tease for you. Play footsie during breakfast. Slip a sexy note into the newspaper before your partner leaves for work, so that it will fall out over coffee at their desk. Just take new opportunities to express your love and intimacy to replace the old intimacies

sex toys – there are plenty of reputable websites (such as www.goodvibes.com, www.evesgarden.com, or www.xandria.com) that offer discrete packaging. You can also pick something up at a “passion party” one of your friends may be throwing. Try using a vibrator in conjunction with your medical dilators, to make that whole experience a little more fun, or teach your partner how to pleasure you using a vibrator. Basically, restoring circulation and blood flow to the area is a medical necessity, so don't let the little prude who lives in the back of your head talk you out of maintaining your sexual health. It is just as important for you as good dental health. You need to floss to keep your mouth healthy – and you need to work at recovering your sexual health just as religiously. It's not nasty – it's good sexual health. (Okay, it may feel a bit naughty, but definitely not nasty.) In the end, if you keep your sense of humor, it is just good giggly fun.

W - Wigs, Wigs, Wigs!

Okay, so being bald isn't usually seen as sexy. Especially all the places you can go bald (Oh, my!), but if this is one of the side-effects you are struggling with, it doesn't have to keep you from feeling sexy. Look at the bright side – a lot of women pay a lot of money to become completely hairless in lots of different places. You have the great good fortune to be hairless for free!! That's how I choose to see it. Try a hairless lifestyle, you may even find that you prefer it. The girls on *Sex in the City* did a lot of talking about waxing, shaving, and plucking to get the look you now have. All you need is an Appletini or a

about it. But nobody can fix this for you – except you. Only you are going to know what you are or what you aren't ready for. So you will have to tell your partner because there is no other way for them to know. For example, “I'm not really ready for vaginal stimulation, but I would enjoy some clitoral stimulation.” Now you may feel uncomfortable using the clinical terms. Feel free to use; who-who; vajayjay; wee-wee; or love tunnel for vagina. You might refer to your clitoris as a love button; happy nubbin; muffle truffle, or “that thing that looks like an oyster.” If you don't want to say sex, try; love making; the horizontal mambo; the shimmy sham; the wild monkey dance; knocking boots; or the big yahoo. It doesn't matter what you call it, as long as you find a way to talk to each other about it.

Those of you with breast cancer not only will have changes in your vagina, but you have the double whammy of having lost one or both of your breasts. One benefit is that you can finally have that boob job you always wanted. The down side is that if you previously enjoyed nipple stimulation, that aspect of sexual pleasure is gone. Explore with your partner what things they can do to replace this loss.

P - Patience

You aren't going to get better all in one day. You can't just put your life on hold for cancer, and you can't just put your relationship on hold and wait for a perfect state of recovery to be intimate with your partner. A little bit better every day. That should be your mantra. If you are just up to holding hands

today, aim for a little kissing tomorrow. (Not necessarily French kissing at first, you don't want to rush into anything!!) Before you know it, you will find yourself making progress in the right direction.

Q - Quickies

Until you have all your strength and energy back, you may have to make do with a quickie. If you aren't up to a marathon lovemaking session, perhaps you could manage a quickie. Don't underestimate the intimacy you can share in a shorter period of time. It isn't about taking a long time; it is about making the time, whatever time you can manage. I'm sure if you ask your partner if a quickie is better than nothing – you will get a resounding “You betcha!” You'll work your way back up to your normal routine in time, but for now, enjoy whatever is possible for you, and let that be enough to express your love, your closeness and the fact that even though you may be ill right now, you are still madly in love with your partner.

R - Reaching Orgasm!

Everybody's response to the various treatments for cancer is different. Some women don't notice any difference in their ability to reach orgasm after their treatments have been completed. Some people become non-orgasmic during treatment, and then recover fully. Some people are able to reach clitoral orgasm, but not vaginal, or vice-versa. Some people never recover their orgasm, it's true. But the one thing that is true for everyone is that your recovery is

may be waiting a long time. Some women have a long term lack of desire. Many women have told us that they imagine themselves in a Nike commercial and “Just do it”. Once they get started the experience often becomes very satisfying and they feel closer to their partner. Just don't let a temporary drop in libido evolve into a permanent sexual disability.

As estrogen declines, your vagina will atrophy. Disuse will compound this problem. So you need to maintain blood flow and elasticity in your vagina. If you are a person who has always experienced pain or has sexual trauma or other issues to contend with, don't let cancer be the final nail in the coffin of your sexual health. The time to deal with these issues has come. There is a Supplementary Information section at the end of this guide with a link to resources that may be helpful to you.

V - Vibrators and Sex Toys

If you've never had one, treat yourself. Call it a medical device, and learn to use it. It doesn't have to be a big vibrating dildo for vaginal stimulation. You won't have to shop in the dark of night in a seedy neighborhood. Start with a “medical” vibrator from Walgreens or CVS. They are probably in the “medical equipment” section near bedpans and support stockings. Lube up and use it for clitoral stimulation, and see if it doesn't put a smile on your face. (Obviously not right there in the CVS!) Some people prefer the similar stimulation offered by a handheld massage shower head. After you have rediscovered your orgasms, you may want to branch out to actual

involve any of the naughty bits that may be out of sorts just now. Sometimes the most loving thing your partner can do for you is just to hold you without it having to lead to sex. If cuddling is all you need, don't be afraid to ask for it. If your partner is very giving, they may be willing to massage you. If this isn't something that you have experience with, get a book. Learn how to massage each other. You will be surprised how much of your need for intimacy can be satisfied by just taking the time to touch each other in a loving way. If you aren't in a relationship, hug people. Hug everybody in your life. Hug your friends, hug your kids, hug your dog or your cat, hug your postal carrier – you'll still have to tip them at the holidays, but what the heck?

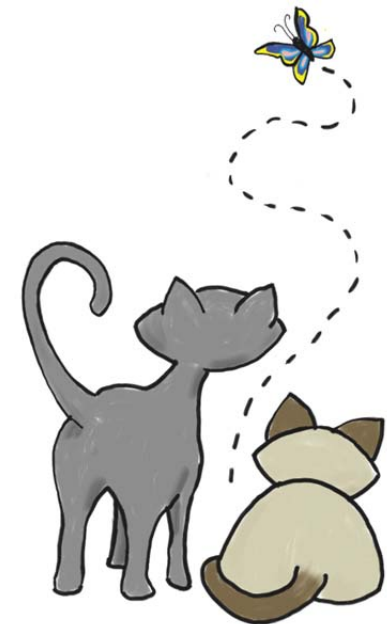
U - Use It or Lose It!

If you take nothing else away from this information, take this: Use it or lose it is VERY real in this case. The worst thing you can do to recover and maintain your sexual health is nothing at all. If you do nothing, you will recover nothing. If you work at nothing, you will achieve nothing. If you talk about nothing, you will get nothing. Whatever age you are at, ask yourself if you are ready to give up being a sexual person for the rest of your life. Because that is really the decision you are making if you don't commit to active sexual maintenance and recovery. Many women experience a loss of interest in sex during treatment, and that's understandable. This is largely due to hormonal changes, and decreased blood flow after surgery. If you think that you are going to wait to be in the mood to make love to your partner you

in your hands. (No pun intended!) Ideally, your partner will be a willing accomplice in this effort, but you are ultimately the one that will have to do the work.

You may find that you have a new normal in terms of your orgasm. Your intensity of orgasm may change, especially if you have experienced vibration of the uterus with your past orgasms. Since your uterus may no longer be there, that component of your orgasm will obviously change.

Don't fall into the trap of "faking it" for your partner. Many women fall into this trap because a woman doesn't really have to be aroused to have sex (only to enjoy it). Arousal becomes very important to your recovery of sexual function. The elasticity of your vagina is actually increased with arousal, which makes penetration much less painful even after a hysterectomy. Some women find that they are more aroused if they spend some time fantasizing before they even suggest a sexual encounter, or self-stimulate before involving their partner. Your partner doesn't need to know why you take such a long bath before lovemaking, all that matters is that you get aroused, which allows your body to be ready for intercourse. Ideally that arousal is a result of foreplay, but that isn't always a workable



solution. The important part is that you not rush into anything before you are aroused, that will lead to increased pain and a longer recovery.

Before surgery, most women's vaginas stretch toward their spine. Afterwards, they tend to elongate up, behind your stomach and this can make the standard missionary position no longer comfortable.

Experiment with new positions, you may find that from behind or beside is more comfortable for you now. Or, a position that allows you complete control of the angle and depth of penetration, such as from above, may make your initial forays into sex less frightening. If so, I say, "ride 'em cowgirl!"

S - Solo Satisfaction or Cancer and the Single Girl

Okay, so this has been focusing on couples. Not everybody is in a couple. If you're single, you should still be concerned with your sexual health. You will want to keep your options open for the future. Even if you don't ever intend to have a sexual relationship with anyone else – you still want to be able to be function for self-satisfaction. Just like all kinds of sexual activity, self-stimulation may seem different after treatment. The same advice goes for you, recovery will take time. Don't get discouraged if you aren't as responsive as you have been in the past, there is a lot you can do to improve that. Treat yourself special, take the time to relax and explore what level of function you are capable of. Remember that you will also need lubrication, time, and practice. Draw yourself a hot bath, light some candles, put on

whatever kind of music makes you feel sexy, and take yourself down to funky town!

A word here to the single woman, you face your own challenges when you consider dating and cancer. When do you tell prospective partners? How much do you tell them? Will they flee upon learning you have (or have had) cancer? There is no one answer for these questions. They vary with each individual. We are all afraid of rejection, and the big C just feeds into these fears. Nobody looks forward to getting naked for the first time, but if you have had a mastectomy, genital scarring or an ostomy, it can be a hurdle that seems almost impossible to face. The truth of the matter is some may reject you because of it. But there are partners who will reject you for much less, so just be brave, honest, and open. If they can't deal with someone who has health problems, they wouldn't be a good partner in the long run anyway. Nobody's continued health is guaranteed. This is one of those topics that make you really glad you have a support group. Talk to them, commiserate with them. I bet you will find someone with a worse situation than your own, and while that doesn't make yours any easier – it does make you feel better about it!

T - Touching

Even if you're not ready for sex, it doesn't mean you can't enjoy being close. Before you are ready for anything else, you may feel closer and keep your intimacy intact by something as simple as holding hands. Cuddling, kissing and even slow dancing are lovely ways to share intimacy without having to