



Understanding Women's Sexuality & Intimacy after Bladder Cancer

With Dr. Daniela Wittmann, PhD, MSW



Tips and Tricks for Regaining Sexual Function

Dr. Wittmann: So what's going to be done? So, I've talked to you about losses and this is something that people don't always realize that, when they lose any aspect of their functioning, it's a loss that has to be grieved. And grief is very different from depression in the sense that, grief can be really motivating and it comes and goes in waves, and there are regular feelings in between. And it can be energizing in a way that depression is not.

Depression is when you can't get out of bed in the morning ever and you lose interest in everything and anything. Grief has a lot of intense emotions, which can be leveraged to cope with the changes and to create a path forward.

So the first task is to recognize that the change has happened and that there's no going back. And

that one has to figure out how to live with the new reality. The part that many people prefer to avoid is the experience of the emotional aspects of the loss, the feelings of pain, the feelings of disappointment, the feelings of anger, the feelings of fear and that things are never going to be the same. Those are difficult emotions. However, if a person can experience it with her partner, then usually that's actually diminished because it's not diminished, the feelings are not diminished, but there's a bonding around having a shared experience which can be actually quite empowering and very loving.

The Tasks of Grief and Mourning

1. Accept the reality of the loss
2. Experience the pain or emotional aspects of the loss
3. Adjust to an environment in which the old sexuality is missing
4. Memorialize old sexuality

Worden, 1996



And I have heard people say that they've been able to bond around this as they try to figure out how to stay intimate. Sometimes they come to the conclusion that their sex is better because they now have an emotional aspect to it that they probably never had before. For lots of people sex is very nonverbal for many years. They learn this through our research. People don't talk about it, they just use the sounds and motions to help each other have a good experience. And so they don't have language for problem solving when cancer happens and treatment happens and something has to be figured out.

And so couples that can learn to talk and problem solve and use the language of loss and grief, tend to better and become quite emotionally intimate in the process. So there is a need to adjust to the fact that sex is not being held the same way that it used to. There may be more of a need for sexual aids and it's just not what it used to be. And that can be quite difficult. So sometimes people really go through this period, where every time they try to make love, they have these intrusive thoughts about what it used to be like, what is it anymore? Is there really going to be satisfaction?

Is my partner enjoying this? And when you start worrying in the middle of love making, what do you think happens to dopamine that is trying to focus you on pleasurable outcomes? It just immediately starts diminishing in the brain. So you'll have trouble enjoying what you're doing. You'll have trouble having an orgasm. You'll have trouble getting through the experience in a positive way. This is not a criticism. It was just normal and it happens often at the beginning of sexual recovery. But because it's a part of grief, it can diminish with time. People become experts of their new body and of their new sexuality and their partners do too.

Dr. Wittmann: And once they know how this new paradigm works, it can be quite satisfying, quite lovely. Sometimes people say they don't even want to think about what sex was like before. I personally discourage that, because I think if you had a good sex life, you had a good sexual body; it's just something to feel really good about. And it probably means that you'll be good at figuring out how to have sex in a new way because you already figured it out once. So there are tools for the problems with vaginal lubrication.

Regular sexual stimulation is important because it brings blood flow and it brings blood flow which then brings lubrication. It can be done through masturbation.

It can be done with vibrators. Vibrators honestly, it's just that it's less work. Sp using a vibrator, always use plenty of lubricant and

Maintenance of Vaginal Health

- Regular sexual stimulation (masturbation, consider vibrators)
- Maintain vaginal health
 - Regular penetration and stretching
 - Regular moisturizing (Replens, KY Liquibeads)
 - Topical lubricants (water or silicon based), Glycerin based lubricants are not recommended** because of danger to men and women who are diabetic
 - Kegels/physical therapy** (stretching, scar tissue massage, strengthening pelvic floor)



it can be extremely helpful. Regular penetration, stretching is important to keep the vaginal walls elastic and comfortable. And I would say that that's true for any post menopausal women anyway. The importance of penetration is critical to that. But for most women, if they've had menopause if they've had a hysterectomy and lost ovaries, whether or not cancer related, vaginal dryness just remains and issue. Some are less or more dry, but many women can't sustain prolonged intercourse.

And so moisturizing with something like Replens can be extremely helpful, so that the vaginal walls are ongoing stretch and elastic as possible. And then when making love then it's good to use lubricants, plenty of lubricants that are both making it comfortable for the woman and make it easy for the man if it's a male partner to slide in and out of the vagina. But even if the partner is a woman, just using hands for stimulation or maybe a dildo or something like that, lubrication is very, very important. Now, we sex therapists are clear about recommending some and not others.

So if the lubricant is water-based, that's perfectly healthy and perfectly good. The water lubricants such as Astroglide for example, tend to dry up fairly quickly and have to be reapplied. So the ones that they tend to last longer are silicon-based, they really can take quite a bit longer. So they can be quite satisfactory. Some people don't like to use them because you actually have to wipe off afterwards, because it just stays on you. So those are pretty good choices. Now, some lubricants have glycerin in them, and we always discouraged women from using them, because they're basically putting sugar into your body and into the body of your partner and nobody wants that, the same way that we don't want to eat too many cookies.

All the things that predisposed us to diabetes or to any metabolic problem, we don't want to do that with lubricants and not realize that we're doing it. I want to talk at some length about pelvic floor physical therapy. I can't tell you how helpful it is to women who are experiencing the problems that I'm talking about, they need a vaginal stretching. They have scar tissue in their vagina or around their vagina that is creating problems and needs releasing. Physical therapists are amazing at both doing the work and teaching the woman to do the work, how to stretch, how to do trigger pointing.

Dr. Wittmann: That's a massage technique, how to massage the tissue to soften it. And then they give exercises that strengthen the pelvic floor. The pelvic floor takes a beating when women have children anyway. And some women have problems with a weak pelvic floor. Anyway, but the pelvic floor holds up all the organs in the pelvis and when it's strong it helps with continents it helps with better functioning of the vagina, and keeping that area nicely toned while stretching and while massaging tissues can be extremely helpful. I'm going to get in a second too dilators and the physical therapist can teach you about how to use vibrators, dilators as can actually sex therapists as well as can gynecologists.

So, dilators can be very, very useful in that way and physical therapists have a lot of expertise in this area. So still talking ... Sorry. Still talking about, how to keep the vaginal walls elastic and moist. There is a topical medications, it's called Vagifem. It's an estrogen for post-menopausal women that helps plump up the vaginal walls. It helps with lubrication. It generally doesn't go into the rest of the body. There are women who have estrogen based cancers such as women with breast cancer, ovarian cancer who would not be recommended to use it. But women with bladder cancer and that have other risks can use it safely, but only after discussion with their gynecologists is by prescription.

Local estrogen

Vagifem—estrogen for post-menopausal women (with exception for women who have estrogen related cancer)



It's a very tiny pellet that is inserted into the vagina, like you would at Tampax. And at first you do it I think three times a week for two weeks and then a couple of times a week ongoingly. It's not messy. It's not unpleasant. And you find yourself then having a little bit of a discharge that you might've had when you were 20. It just nicely lubricates and plumps up the vaginal walls. And some women even report that it helps them with their desire. So, on your left you can see the dilators that I was talking about. They start with a very, very narrow small dilators. And then they increase in size as the woman learns to stretch the vaginal walls. And the great thing is an applicator and they can be quite effective. And women, who have to stretch, unless they're having intercourse with a male partner all the time, generally have to keep a stretching routine a little bit ongoingly, because those tissues really like to shrink back.

Dr. Wittmann: Vibrators are wonderful for blood flow. So I was telling you that you can use them to reach orgasm. You can also use them inside the vagina. And there is A website called A Woman's Touch, which is a website for products that are designed for women with cancer. It is run by a physician, a social worker, both certified sexual ...One is the sexuality counselor and the other one is a sex therapist. They're certified and they have interesting ...

Dilators, vibrators, pelvic floor exerciser



They developed these interesting vibrators. They call them wands that are very, very narrow and if inserted into the vagina, they stimulate blood flow beautifully. But because they're so narrow, they don't hurt anything. They're not uncomfortable to insert. They are probably as thin as the smallest dilator. So that's actually a very nice way to do that. And on the right you see a pelvic floor exerciser,

which helps exercise the pelvic floor. Sometimes it is an attachment that can also do some clitoral stimulation.

So, there are definitely ways in which it's possible to work on sexual capacity, functional capacity. Now after cystectomy, some women opt for vaginal reconstruction. That is when everything has been basically taken out from the pelvis, what is usually done is flaps of muscle and skin from other parts of the body get used. But remember this is, even if it's enervated and has blood flow, it's not the skin that is a mucous membrane. So there's a need to help lubricated, doesn't need to keep it clean and flush it regularly and this is not going to help anyone to have an orgasm.

Dr. Wittmann: But if it's done in such a way that the clitoris is reserved and able to be orgasmic, then it becomes an opportunity to have intercourse, somewhat without the sensitivity of intercourse. Now, we're going to demonstrate to you some clothing that has been developed for people with bladder cancer to facilitate sexual activity.

These are really lovely bands that can both secure the pouch and they can also maintain the ability to be skin to skin it. What you see here is some for men and some for women, but obviously the lacy ones are for women, although the black wants going to be women as well. They're just demonstrated here on a man. So people just should be aware of these kinds of things.

Dr. Wittmann: Okay. Then you can just look at other clothing and other things that are developed for people who I have a stoma to make it less of a daunting thing, more of a fun thing, more of a way to live with it rather than hiding it. So what's really critical is, it's very important for the woman with bladder cancer who wants to be sexually active, to be able to communicate with the partner and the partner to be able to communicate or a potential new partner. It then becomes really critical to make things work. The other thing that becomes important is acceptance of how things are, and recognizing that despite of changes, in spite of changes, sexuality is still available. It's just a new sexuality. The person has to learn new sexual interactions, new techniques for pleasuring and faith in the whole process.

Ostomy clothing

<http://www.stomaatje.com/clothing.html>



New Sexuality

- Learning new sensual interactions
- Learning techniques for pleasuring
- Development of faith in LEARNING new things
- Desensitization to the use of sexual aids



Dr. Wittmann: And then also accept that maybe there's going to be a need for some sexual aids. In sex therapy, we usually assess sexual concerns and we look at sexual function, the individual and the couple, relationship factors. We try to understand other history issues that might impact, and a lot of education, education about what's possible in this new sexual environment, and how to address it within the couple.

Sometimes sex therapy is about addressing old couple issues. But for many people, a lot of it is just education and support for new sexuality.

We hope that people will have better sexual function, which means sometimes using sexual aids that communication will improve. I've already said that's terribly important, learning new sexual interactions, feeling better about oneself. And if a person is feeling depressed about what they've been through, that that be alleviated. So just to go to some take home points, as you know bladder cancer brings about lots of changes. A lot of those changes are actually similar to changes brought about by aging, loss of spontaneity and some sexual sensitivity. If you're a young woman, that must feel completely premature.

So that is a part of the grief process. But if you want to stay sexually active, you just have to design how it's going to be and what you're going to learn to make it work.

Remember that if you have a relationship and emotional intimacy, this would definitely help. Your sensuality is still there and for most orgasmic capacity is there as well. So basically, it's just more work. If you have an emotional connection, it will be helpful.

And, there is a greater need to come communicate about sexual needs. And this is what effective sexuality looks like, when people have come to terms with the changes after bladder cancer treatment.

Sex Therapy

Assessment

- Sexual concerns
- Sexual function of the individual and couple
- Relationships factors and relationship history
- Individual histories' impact on current concerns

Treatment

- Psychoeducation
- Couples' therapy to address relationship as well as sexual issues



Sex Therapy Outcomes

Improved sexual function – may include competency in the use of aids to sexual functioning

Improved communication

Improved sexual interactions, including expansion of sexual repertoire

Improved self-esteem

Alleviation of symptoms of depression or anxiety



Dr. Wittmann: You may or may not have nice spontaneous desire, but you may care about your partner and love having sex with them. So you have a psychological desire. You can approach them for sex. They can approach you. You can have discussion and you can decide. You can arrange for a suitable time and space. And then you can get into it maybe with some help with sexual aids. And you most people when they are able to have an orgasm with their partner naturally, and then they can relax and feel satisfied that they're continuing to have a sex life even in this new setting.

Take Home Points

- Bladder cancer brings about changes similar to changes brought about by aging— loss of spontaneity and some sensitivity
- BUT!
 - You can stay sexually active, your definition of how one has sex will change
 - Much of sexuality remains available:
 - Relationship and emotional intimacy
 - Sensuality and physical intimacy
 - Orgasmic capacity (for most)



Take Home Points

- Sexuality in middle and older age becomes more work because both men and women require more stimulation and sex – but it is great work!
- Emotional connection helps
- After bladder cancer, sexual activities are more intentional, less spontaneous
- There is a greater need to communicate about sexual needs



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