PELVIC HEALTH MATTERS: A WEBINAR SERIES FOR WOMEN WITH MOBILITY IMPAIRMENTS

SESSION 3 OF 4: Bladder and Bowel Issues That Affect Sexuality
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>> RACHEL MARKLEY: Good morning and afternoon to everyone, and welcome to the Pelvic Health Matters Webinar Series for Women with Mobility Impairments. It's exactly 1 p.m. here in Houston, so we are going to begin. We will record this webinar for archiving and I will start that recording now.

My name is Rachel Markley with TIRR Memorial Hermann and the Center for Research for Women with Disabilities at Baylor College of Medicine. I will be serving as the moderator for this session. This program is brought to you as a collaborative effort between TIRR Memorial Hermann's Spinal Cord Injury and Disability Research, Baylor College of Medicine, the American Congress of Rehabilitation Medicine, Spinal Cord Injury Interdisciplinary Special Interest Group Women's Health Task Force and the Christopher and Dana Reeve Foundation. Individuals are joining us today using a variety of media, including the webinar platform, listening via the telephone, and using realtime captioning.

A copy of today's PowerPoint presentations are available at www.bcm.edu/crowd. As I said, this session is being recorded and will be archived on our website very soon.

Our presenters today will provide us with some valuable information and at the conclusion of their presentations; there will be an opportunity for everyone to ask questions. You may submit your questions using the chat area within the webinar platform. We will address them at the end of the session. So feel free to submit them throughout the presentation.

Now, I would like to introduce Dr. Margaret Nosek, director of the Center for Research on Women with Disabilities. Dr. Nosek?

>> MARGARET NOSEK: Thank you, Rachel. Welcome to everyone and thank you for joining us for our third in the webinar series called Pelvic Health Matters. This session will address bowel and bladder issues that affect sexuality.

This is part of a larger series called the Pelvic Health Initiative, and we are undertaking a variety of projects, one of which is to offer this dissemination project called the Pelvic Health Matters Webinar Series. I would like to thank again our funders which are TIRR Memorial Hermann and the Christopher and Dana Reeve Foundation, Quality of Life Grant. Also the support we have gotten from Women's Health Task Force of the American Congress of Rehabilitation Medicine’s Interdisciplinary Spinal Cord Injury Special Interest Group. All of our presenters have reported that they have no financial conflicts of interest to disclose.

I would also like to thank our medical advisors, and also our consumer advisors, who
have been with us over the two years of this project. They have been advising us about
topics that we should address and the ways in which we should address them. We were
advised that a webinar series with archives would be the best way to reach women and
providers in helping remove some of the myths and inform women about these topics
that really have not been addressed adequately in information that exists on the web, in
clinical practice, and other avenues of information available to women with disabilities.

So we're very happy to have LeAnne Beers, soon to be Dr. Beers. She's joining us today
as the facilitator of our panel. LeAnne has been one of our advisors on many different
projects related to all aspects of the health of women with disabilities. Her specialty is
sexuality. LeAnne is pursuing a doctoral degree and her dissertation will be on sexuality
in women with neuromuscular disorders. She's also a board member of the Summit
Independent Living Center in Missoula, Montana.

Meena Outlaw, who is another of our advisors, is an author of many children's books
about disability and Meena is also very much involved in spinal cord injury peer support
organizations. We also have Liza Criswell, who is an occupational therapist and
assistive technology professional at TIRR Memorial Hermann. And Liza is also known
as the “sex lady” because she gives us lots of information about sexuality and she's the
go-to person at TIRR for issues related to sexuality, especially for women with
disabilities.

So I will turn it now over to LeAnne to start our presentation and to introduce our other
panelists. LeAnne.

>> LEANNE BEERS: Thank you, Peg. I'm honored to be amongst all of these wonderful
ladies and excited to hear from both of the panelists on their expertise regarding
sexuality, the bladder, and the bowels. There's so much information that could be
presented and due to our limited time, myself and the panelists will give a brief overview
of a few specific areas.

To get started, sex needs to be addressed. Let me begin by stating although times are
continuously changing, there is still unfortunately some stigma around the word "sex."
Discussions about sex are not always easy for many individuals - and this includes
medical professionals, physical therapists, occupational therapists, counselors,
personal care attendants and, yes, even parents.

Now, we add another twist to the discussion of sex which entails an individual with a
disability. Now the discussion revolving around sex becomes a taboo topic and
individuals, once again don't often like to discuss it, including medical professionals.
Having sex after disability may mean adjusting, innovating, discovering, and inventing
new ways. People need to know relationships and relations are still possible.
People may not give up on their dreams of love, marriage, parenthood, and just typical lives that they would like to live. So what do individuals do when they have questions regarding intimacy, sex, and relationships? Well, let's take a closer look at these bullet points in relationship to these questions on pelvic health. Knowing about sex is extremely important. Of course, I highly recommend individuals talk to their health care providers regarding their sexual needs.

And this can include physical therapists and/or occupational therapists to help figure out adaptations that may be accommodating for the individual in assisting them with fulfilling their sexual desires. But it is just as important to have an understanding of not only sex, but intimacy. Sex can be defined as intercourse or other forms of sexual stimulation. And intimacy can be defined as a state of extreme interpersonal emotional closeness, such that an individual's personal space can be entered without causing discomfort.

Intimacy can be described as an affectionate or loving personal relationship and having a deep understanding of each other: I bring this concept of sex versus intimacy up, because I believe it's important for individuals to have an understanding that just because one's body may not react to sexual intercourse, does not mean that they cannot have an intimate and fulfilling sexual relationship.

Sexual discovery is another aspect, which I believe is extremely important in knowing about sex and intimacy. We all have sexual needs and desires but are not always sure how our body is going to react. Therefore, sexual discovery of our own body will prove to be useful, both in a physical and emotional manner. An individual with a disability, whether it's a spinal cord injury, neuromuscular disorder, autoimmune disease, or any other type of disability, each individual is still going to have erogenous zones. Sexual discovery allows to you know how to react to certain sexual stimuli, which can be done alone or with a trusted partner.

Not knowing how the body will react to intimate touches can cause extreme apprehension. Let me provide you with an example. A woman with a neuromuscular disease will have a loss of sensation in numerous areas of her body. Over time, this loss of sensation will often get worse, therefore, what was once her erogenous zones may no longer exist due to the disability and lack of sensation. Upon some self-discovery and being with a trusted partner, she discovered that her breasts have little to no sensation. Therefore, they will no longer be one of her erogenous zones.

However, through discovering her body, she found that her sides are extremely sensitive to the slightest touch, which arouses her. This discovery was extremely important in terms of intimacy as intercourse was not always successful due to the lack of sensation. But discovering this area on her side made her understand and continue to
have a fulfilling intimate relationship. It just took time and patience to discover this.

Continuing on, each individual is going to be different in terms of their erogenous zones. Despite the type of disability, the brain will continue to send signals of pleasure to areas of the body. It is a matter of self-discovery and finding those new areas. Again, this can cause some apprehension among some people because discovering something new and that they are unfamiliar with may be scary on how their body may react.

So some things to consider. The thought of losing control over one's bowel and bladder is extremely frightening and can cause a great deal of anxiety for an individual who has never been in an intimate relationship or is in a relationship but the injury is now new or a progression of disease has occurred. So what are some things an individual can do to discover how their bowels and bladder will react when their body begins internally reacting to the feelings of touch and pleasure?

The answer to this question is once again one of those that many often feel uncomfortable discussing. But it is natural and very efficient. The ability to discover one's own body and how to please one's self is a great first step. Recognizing how the body will react. This can be done alone or with a trusted partner.

When I say discovering oneself, this does not necessarily mean masturbation, but I would definitely encourage this process when the individuals feel comfortable. The discovery of one's body allows each individual to become more in tune and aware of the body, and how the body will react to certain touches or to a spasm of certain muscles.

Now, if we move forward, into masturbation, there are a wide variety of assistive devices to help with masturbation. The reason I bring this up is it allows the individual to discover what happens to their body as they begin to relax and release themselves, to pleasure, and maybe even orgasm. This allows the individual in their own comfort to discover how their bowels and bladder may react.

There is so much information that can be relayed on this topic and I want to ensure that each panelist gets their time. Therefore, I want to conclude my portion with a few tips of positioning that can assist in bladder and bowel control during sexual activity. The following was provided to me by Dr. Lisa Bakker, an expert in women's health and a physical therapist. Before I go over the tips on position, it's important to have a bit of understanding on what the pelvic floor is and how the pelvic floor will help with bladder and bowel control.

So what is the pelvic floor and how will it help with bladder and bowel control? The pelvic floor supports your bladder at the bottom. The job of the pelvic floor is to lift and stabilize your stomach contents. This includes the bladder, the colon, and the rectum. So if you
look in the picture above, the muscle is hammock-looking. As shown below, the bladder, uterus, and rectum all go through this group of muscle. So when it's contracted it lifts the bladder and rectum, which helps to maintain continence. The stronger your pelvic floor, the more control you will have over your bowel and bladder function.

So helpful tips about positions for intimacy and bowel and bladder. When you sit, your stomach contents rest on your pelvic floor. What this means is that you have more stuff pushing on your bladder and rectum. It's harder to control your bladder and bowel with this pressure. So the ideal position would be lying down with your hips raised slightly. If you look at this picture, it shows with possibly a pillow or something under the hips to raise them. Now, remember, positioning has to be for your comfort. So this may not be the ideal position for you, but if you can put yourself in a position that your hips are slightly raised, or even lying on your side, will help relieve some of that pressure that is being pushed on your bowel and bladder. This picture, as I said, illustrates proper positioning with that pillow.

Here are some other things to think about and recommendations. Lying on your side will help to move the abdominal contents move off your pelvic floor.

Does your chair tilt? If yes, it's a good idea to tilt back slightly and this will help with the pressure on the pelvic floor.

Do you have spasticity? If so, work with pillows to support your legs, arms, and other parts of your body so that you are not fighting that spasticity. This will lead to fatigue and exacerbate the spasticity.

At this time, I would like to go ahead and introduce our two panelists who are going to answer questions that have been provided.

Meena Outlaw is a wife and mother of three children, ages 19, 16, and 4. Since her injury, she has been a passionate advocate for the disabled, especially those who are pregnant or wanting to become pregnant. She has dedicated much of her work to raising awareness and educating others on understanding had the dynamics of the female body after spinal cord injury in terms of pregnancy. Meena was first runner up in 2014 for Miss Wheelchair Texas, whereby her platform was inclusive parenting.

Meena is also the author of three books "A Moment In Time" and "The Maddie Has Wheels Series." She continues to write blogs for NuMotion and J & R Medical. She has been awarded in 2015, the Wallace Bennett Award for Excellence in Journalism for her books and blogs.

Finally, she's established, created, and launched Connections Peer Network and
Connections Peer Network Support Group through United States Spinal Association and currently doing the same for Amazingly Abled, the first support group for all physical disabilities in Sugar Land, Texas.

Liza Criswell is our second panelist. Liza graduated from the University of the Philippines with a Bachelor of Science in Occupational Therapy. She has been a registered occupational therapist for the last 21 years. She's been working for the TIRR system since 1998. She's a senior clinical occupational therapist treating adults and young adults with spinal cord injuries, brain injuries, amputees, and other neurological disorders at TIRR Memorial Hermann Hospital.

Liza also serves as a clinical instructor for level one and level two OT students and mentors to new OT staff and other disciplines. She was awarded employee of the year in 2010. Liza has been a resource person for sexuality and bowel and bladder management for people with spinal cord injury. She has presented the subject of sexuality and the role of occupational therapists and treatment of patients after spinal cord injuries in multiple settings. These include hospitals, OT and PT schools, and local and national stages. Liza also served as an expert reviewer for Spinal Cord Injury Clinical Practice Guideline, Sexuality and Reproductive Health in Adults with Spinal Cord Injury.

Again, I am honored to be amongst these ladies for this webinar. Welcome to both of them.

To start with, our first question is going to go out to Meena, if you would like to answer this. What does the bowel and bladder do as the pregnancy progresses?

>> MEENA OUTLAW: Hi, LeAnne, hi, everybody. Thank you very much. I'm going to go through it by each trimester to make it a little bit more understandable. The first trimester is where all the hormones are starting to increase. You will find that you can see changes in the function of your bladder. You will experience some leakage and discharge. This is where you start to realize you need to tune in more to what your body is telling you.

Your urologist should be well versed in your SCI or neuromuscular condition and they will have evaluated your bladder medicine by now, which by the way, is quite safe to take during the course of pregnancy. As the belly swells, the uterus grows. The stimulation from it will make you probably need to urinate more. Therefore, increasing your bladder regimen will help you prevent accidents.

The second trimester is when you will experience major changes. The uterus will press down and stretch to all organs. Your bowels and bladder will be affected and you will find
that if you just increase your bowel program and bladder voiding, you will again lessen
the chance of accidents; however, your diet has changed by now and you should have
increased your water intake. So all of this will make you continue to notice that you are
no longer holding the normal amount of urine.

The other thing that will start to change is your sensory level. If you have some
sensation, it could decrease or increase. Again, changing the regimen is a key factor.
You also need to be watching for signs of urinary tract infections with the need to
catheterize.

The third trimester is when your baby will change your physical ability to catheterize. If
this happens, you may need to talk to your physician. Possibly a Foley if you are having
trouble getting on the commode or the bed. For me, I changed my program to twice a
day, in the morning and at night. I had frequent attacks of bladder and bowel and
sometimes it would be diarrhea. The only way I could minimize the chances of this
happening unexpectedly was if I made sure that I was even more proactive with my
program.

In addition, wearing disposable underwear or pads would be best at this time. Nutrition is
a huge importance in this too. Increasing fiber roughage and vitamins through natural
food as opposed to processed food, including sugar and sodium, will also help you
immensely during this time.

>> LEANNE BEERS: Thank you, Meena. Moving on, the next question is to Liza. Is it
safe to wear a tampon again after a spinal cord injury? And how can I manage it?

>> LIZA CRISWELL: To answer your question, most of the patients that we see here at
TIRR are really acute. You know, they came from acute hospitals and this their first time
to go to rehab. So most of them are still not quite ready to talk about sexuality or even if
they are thinking about it but they are not that verbal in asking about this.

So it’s our job as therapists or any rehab professionals to actually start the conversation
with them. We have a class here called wrapped classes and each day, there’s different
topics and I teach the sexuality class. So my job is to really just to get basic information
to the patient, especially for women. What are the changes that’s happening in their
body after spinal cord injury? The change of menstruation, sometimes women, they
have a halt in their menstruation period. And it’s sometimes six months to a year before
they regain it. Sometimes patients have no problem regaining their menstruation but we
give information about all of those changes to expect in their body, like the sensation
loss, like what Meena already discussed earlier.

But also, giving them information about pregnancy and intimacy. With pregnancy, it
doesn't necessarily mean that you are not menstruating, that you are pregnant. So it's very important to educate these women, especially on their child bearing years to as early as possible to consult their OBGYN just to guide them what kind of contraceptives are appropriate for them to use.

And even with that, that already opens the conversation about sexuality and intimacy. And another thing that I do with some of my patients, I invite their significant others to listen to how to even navigate the world of sexuality after spinal cord injury. And just giving them some pointers on how to handle bowel and bladder, like what you said earlier, we need to teach them how to be proactive. So most of these patients, if they are able to do their own bowel program, we teach them to be very diligent on performing it because this could really help save their sexual functions. So if they can prevent bowel and bladder accidents during sexual intercourse, then it kind of increases their confidence.

But having them really realize the impacts of being proactive and open to doing their bowel program in a very timely manner can impact their satisfaction and performance during sexual activity.

>> LEANNE BEERS: Meena, how does being pregnant change your mobility and what can you do to help that?

>> MEENA OUTLAW: Yeah, I didn't write anything down for this. I will just go from sheer experience and my own knowledge. The first trimester, you don't see many mobility changes. You are obviously still quite fat in the stomach and the belly doesn't really start growing. The baby doesn't really start growing until the third month.

Now, third month is when you are going to see more physical changes that will affect your mobility. If you are a paraplegic like myself, making plans ahead of time is going to help you the most. If you are normally used to just sliding on a bed or sliding on a commode or sliding on a shower chair, most likely this is probably when you would need to start looking into getting adaptive equipment to help. IE, a transfer board which is number one. If you have more of a higher paralysis or disability level, then you would have more attendant help available.

The other thing to think about is as your belly grows and you are sitting in your wheelchair, most likely you are not able to really bend down as you normally can to pick up things or reach for things. Again adaptive equipment is the key here.

Looking at your home and thinking of possibly getting more of a bar, helping you get on your bed and stopping from pooling and adding some more safety features around your commode so you can easily grab on to things.
Now it is definitely a hazardous when you have a big bulge in you. As the baby grows, it likes to position itself in many different ways and when you are constantly sitting down and most likely it will go to your back. This adds more pressure to you. It will add more pressure to the help you now need to be able to still function, and maybe having a little bit more help in the shower at the time, something that maybe your partner can help you do, or even having attendant help at that time. For me, specifically, I honestly just needed more transfer help which is what I used the adaptive equipment for.

By the third trimester, I was pretty much on and off my bed. It started to get a little uncomfortable sitting in the wheelchair. Just because I felt like I needed to stretch more for the baby's sake and using the standing frame at home was very beneficial for me. Stretching your belly, letting that uterus do what it naturally needs to do. You will also find it's pressing against your liver, your kidney, all of it, and so it's uncomfortable. So the third trimester is when, you know, the added help is going to be a big necessity. Up until the time of delivery.

>> LEANNE BEERS: A question that has come in, are there state and/or national advocacy groups for these medical/women's accessibility issues? If so, how do I get more involved?

>> LIZA CRISWELL: Yes! Well, that's a good question. There are groups, women's groups that you can actually get involved with. So if you go to this website, called United Spinal Association, and National Spinal Cord Injury Association, or the NSCIA, there's a lot of information there. There's the mobilewomen.org, womenshealth.gov. So there's a lot of advocacy out there. So the first thing I usually tell my patients is to go and access this website and we have a gentleman named Rafferty Laredo. We distribute that so they can start like really exploring all of these options out there and all of these advocacy out there that can help them, and by joining the NSCIA, that would open a lot of doors for them and it gives information of anything under the sun regarding spinal cord injury or any kind of advocacy group or health information about women with disabilities.

And if I'm not mistaken, Meena, you can correct me if I'm wrong, but there are some support groups that NSCIA is started.

>> MEENA OUTLAW: Yes, that's the Connection Peer Network. And the Connection Peer Network Group. 2011 is when I gave birth to my baby and there was no support. Trying to find and match yourself with a parent in the same situation or who has had a baby was very difficult for me.

So it does take a lot for the individuals to research or find out. I actually found my support through a rehabilitation system in Atlanta, Georgia. And I matched with a lady who was
actually pregnant at the same time with me and she had a baby. So she was able to explain.

Now, through my association here is where I found another lady who I knew, who also used to be one with the TIRR mentor program who had babies before and they were now grown up and definitely the same level as me. I approached her and she's the one that actually showed me how to prepare myself for the baby.

Now, in regards to the support, there's definitely more support now, thank God. National Spinal Cord Injury Association is a great, great, great resource to have. They have -- if you go on to the website alone, they have a lot of resource information and you will know from there where to go.

The other place to go is to basically try to connect through the peer matching program, whether it's through TIRR or through United Spinal Association or any other programs like that, that can help you connect with the same type of person. That's going to be the key to having a little bit more of a stress-free, worry-free pregnancy. And definitely through discovering yourself. Not everybody wants to talk about sexuality in an open support group.

The group I'm now helping in, in Sugarland, Texas is much more private. It's headed by a behavioral scientist doctor, and she has absolutely dedicated her spare time every Wednesday to coming in and talking to everybody about whatever issues they have. And this is where it's a private, confidential, support group where discussions that we talked about, where you don't feel like you are overexposing yourself or you could have a private conversation over the phone.

So there are definitely other ways to connect with people. I certainly say research online. I found many other resources online that help me. I don't know if anybody ever heard of Judith Rogers. She wrote an amazing book "Disabled Woman's Guide to Pregnancy and Birth" and I believe her organization is called Through the Looking Glass. Speaking with her before and after pregnancy was an amazing amount of advice that she had given me. Take a little bit of time and research your information and you will find that online too.

>> LIZA CRISWELL: Yeah, and just to add to that, here at TIRR, what Meena said, we have a program. I have been here for quite some time. So I have pretty much have information about all the previous patients that, you know, that experienced pregnancy and have children, and the different management that they choose to handle their bowel and bladder. I have a patient that -- well, she was a previous patient but then she decided -- she used to be performing ICP, but after having babies and really getting a very hectic schedule, she managed or decided to choose to have a Mitrofanoff. When
we have a patient would is trying to navigate the name bowel or bladder management, we get them connected to go. Even as simple as just getting a peer to peer connection just to have somebody to talk to, that has been through the same issues in the past, really can help the patient.

And like I said, advocacy is everywhere. It's helpful and I really observe that women, if they can talk to somebody right away, and help them navigate all this different emotions and, you know, different kind of physical information that they want to learn from other women, and it's a lot easier for them to actually understand their situation.

So advocacy can be very local and it can be more on a global scale. It's just easier for a lot of women to talk to people by connecting them to peer to peer, in the beginning. And like what Meena said, the Internet can provide so much information and can link you to different kind of advocacy group for women with disabilities.

>> LEANNE BEERS: Thanks, Liza and Meena. That's some great information and I know extremely valuable, especially as people are looking at starting families. It's nice to know that there's organizations out there that are more than willing to help answer questions.

So we'll go ahead and go on to the next one and this is for Meena. Do spasms become frequent around the bladder and bowels during pregnancy?

>> MEENA OUTLAW: Absolutely. First and foremost, if you have no sensation, you will actually find that your sensory levels change through the course of your pregnancy.

You will also be thinking that you will have to look for where your contractions are. This is where connecting with a doctor who is familiar with your disposition, your condition and having a baby is very, very essential.

Of the first trimester, you will absolutely experience spasms and this is where you start to watch very carefully as to what that is. Me particularly, I had many bladder spasms. At times it was very, very painful. Many times I would call my physician and OBGYN and talking to him and I would go in often to be checked on the monitor. It would be so painful that I often felt like I was contracting.

By the second and the third trimester, as the baby is pressing on down, you will find that it will probably go down to the leg, probably going to go a little bit upwards to your higher level and -- now the interesting thing is, though, when I talk about watching for spasms and what your contractions are, my bladder spasms end up being my contraction in my third trimester.
And I know that sounds very confusing, but what I would like to talk about is being in tune with your body from the moment that you are pregnant. It's really important to start realizing very early on what is different. What feels different than your normal spinal cord injury or neuromuscular situation? And if you don't normally spasm, and you are continually spasming, then you need to be in more contact with your doctor at that point.

When I started spasming and it went down to the third trimester, it go to the point where the spasms turned in contractions so maybe all the way through because my sensory levels were so off that I could not recognize the fact that maybe it was trying to tell me that's probably where I will feel my most contraction.

The other thing that changes is your sensation. During this time of pregnancy, you may feel the same if you have sensation. You may not feel anything if you don't normally. But at some time during the course of the pregnancy, even through delivery, it can change and it did with me which was very surprising.

And it just goes to show that just because you are paralyzed or you have a neuromuscular issue, it doesn't stop your body from still working the way it's supposed to. We're just having to baby-sit it a little bit more during this time.

So from the eighth month on, if most pregnancies can last that long, most can, some actually end up needing induction earlier on by the eighth month because it's pressing too much and maybe at that point, it's going to cause a little bit of problems. But for me personally, by the eighth month, those spasms turned into full contractions and the day after my eighth month is when I delivered.

So definitely something to watch for. If you go through situations like autonomic dysreflexia, it's something that you need to watch even more closely and that's something that you need to be in constant contact with your OBGYN. An able bodied woman would normally have a prenatal checkup once a month through the pregnancy. It starts off with once a month and it starts to go more frequently as the pregnancy grows.

If you are pregnant with a neuromuscular disease or injury, that's off the table. It's now a constant communication with your OBGYN. Mine in particular, I was in contact with him weekly, if not daily. That's actually the type of care that you need.

>> LEANNE BEERS: Thanks, Meena. Again, some great information.

We have one more question and then I would like to see if we have any chat questions that came in. So we'll keep this next question to just a couple minute answer and ensure we answer any questions from the audience if there are any. So Liza, the question is: Can you explain how one could prepare themselves for intimacy so not to have a bowel
or bladder accident?

And I know I briefly discussed it, but maybe you could add a little more to that, if you know some tactics or ways that this could help the individual.

>> LIZA CRISWELL: Yes, definitely. Well, most of the things that I suggest to my patients are actually, suggestions from previous patients, because they experience it and they see what works for them. So what they tell me, it's like when they do their bowel program at night time. So if they do it at night time, their bowel and bladder sometimes they actually don't limit themselves on just having, sexual activities at night time. They said, after that, sometimes they are getting so tired and it limits their ability to participate in sexual activities when they are so tired doing their bowel and bladder, plus bathing at night time. So sometimes they choose their activity in the morning, their sexual activity, where they only have to do cathing and they know they can control it better because they emptied the night before.

And the second thing is it's important to be very cautious of their diet. A lot of patients say that they know if they have plans to go out with their husbands or their significant others in terms of them having sexual intercourse at the end, they limit the amount of dairy. They limit the amount of food that they eat and stuff like that. So they can do their bowel program and knowing that they are not going to have an extra accident.

The second thing is positioning. And, you mentioned that earlier. It's really wonderful for women to understand the importance of the pelvic floor.

The position of women in relation to sexual intercourse can make a big difference on preventing the bowel and bladder accident. I like that you actually put it in your slide show that the patient lay down with a pillow and to actually relax the bowel and the bladder.

If there's no pressure in the pelvic floor, the chances of having a bowel and bladder accident is going to be less. But it's really, in a nutshell, it's knowing your body. The more you know how your body functions and how your body reacts and your system on how to make your bowel and bladder program work, that's the key.

I can't completely guarantee that accidents will not happen. That's why it's called an accident. But in also preparing your partner psychologically and mentally that, hey, it might happen and know what to do? You deal with it and move on.

So I think the less anxiety, the more open your relationship with your partner, the less anxious you become. No matter how you prepare for bowel and bladder management,
sometimes it can still happen because it's in the same area when it's getting stimulated
and your bowel sometimes can get that stimulation and think that, oh, I need to empty
my bowel but really and truly, it's not, but it can happen.

For me, just be vigilant on bowel and bladder and eat a good diet and you know how
cheese can affect your bowel program or any kind of, very oily dish or something like
that. So once you know how your body works, you can prevent this accident to happen
more often and the more successful and pleasurable sexual activity can be.

>> LEANNE BEERS: Thanks, Liza. Again some great information.

At this time, I would like to ask Rachel if there's any chat questions that have come in
before we start to conclude the webinar as we are coming up upon the hour.

>> RACHEL MARKLEY: Thanks, LeAnne and thank you, ladies, for all of your wonderful
answers so far. We do have two chat questions. I'm going to go ahead and read you
both and then I will let you LeAnne, decide how you would like to distribute those
questions.

The first one who is from a woman who has been trying to get pregnant for about a year.
She has spina bifida and she wants to know why she's having difficulties. She's seeing
specialists but everyone thinks that her spina bifida should not be a factor.

Then the second question, Dr. Nosek would like to talk about lubrication and pain
problems during sexual activity. How do you communicate that without turning your
partner off?

>> LEANNE BEERS: Okay, well, if the ladies don't mind, I will go ahead and chime in on
both of those and if they have anything to add just because of our time limit, we will see
how time goes if that's cool.

The question with spina bifida, first and foremost, I'm so glad you are seeing some
specialists about it. I do know individuals with spina bifida, who have had successful
pregnancies. So I do know it's absolutely possible.

I'm glad you are seeing the doctors, because they will be able to eliminate if anything is
happening due to you not being pregnant or getting pregnant due to medical factors.
So I encourage you to continue talking with the doctors. Some things that can happen to
cause pregnancy not to happen is simple things such as stress. If you are so stressed
about becoming pregnant, this can often affect the pregnancy process and this happens
to individuals with and without disabilities. So that is one thing to consider.
Positioning is another thing to consider to ensure proper positioning as being done. And Liza may know a little bit more about that or Meena.

Another factor would be to ensure you are having proper timing of the intercourse.

And so these are just a few things to consider, but good news, because the spina bifida, that should not have any effect. So sometimes it just takes a little time, but I'm sure when you get pregnant, it will be the best thing ever.

And real quick to answer Peg's question with lubrication, I have a neuromuscular disease, and I have found that I don't lubricate on my own for sexual intercourse at all. Dry as a bone! And so I have had to find different things that help with lubrication that don't lead to further issues like yeast infection because of being in a wheelchair so much of the oils and stuff don't go well with the body and causing bacteria.

One thing I have found is coconut oil is a great option to use. It soaks in great. It's easy to clean up, and it smells good and it doesn't leave the greasy residue.

I have found that partners do not mind using any type of lubrication as that's more pleasurable for them as well.

Rachel, how are we doing on time?

>> RACHEL MARKLEY: Well, we do not have any further questions in the chat box. I'm just going to direct people to the last little bit if they have further questions and then if we have an extra few minutes, then I can let Liza and Meena chime in with their responses to those questions.

I would like to thank all three of you so much for your wonderful answers and thank you to the audience for your questions. And if you do still have questions about this or other webinars in the series, you can please feel free contact us. Our number is 832-819-0232. Or you can email us at crowd@bcm.edu.

I would like to remind you that this session was recorded and should be available for viewing on our website within just a few days. The first two sessions are currently archived and are available at our website. And the link is here as you see LeAnne sharing and these slides are available to you can download the slides and get the link.

You will be receiving a link to an evaluation survey via email, we encourage you to participate to help us identify future topics and even if you completed the survey after the April 6th or the April 20th sessions, we would really appreciate it if you would do so again. They are all just slightly different. Unfortunately, it looks about to be right about 2:00.
So if anyone does have any questions, again, email or call. We’ll get those out to our panelists and they can answer those questions.

I would like to thank everyone for your time and enjoy the rest of your afternoon.