Managing Bowel, Bladder, and Sexual Dysfunction

You can listen to the audio of this talk at: https://youtu.be/qOh9U9naKCM

Janet Dean: [00:00:00] Hi, there. Today I'm going to be talking about bladder, bowel, and sexual challenges in rare neuroimmune disorders. Bowel and bladder function, both work kind of the same way.

[00:00:14] So there's two functions. They store waste and they, in the bladder for bladder and in the rectum for bowel, and they release the waste at appropriate times. And each system, as I said, has a muscular storage area, the bladder or the rectum, and an outlet valve or a sphincter. And both these systems have components of voluntary control and also components of involuntary control.

[00:00:45]So when you've had a rare neuroimmune disorder that is caused by an attack on the spinal cord or lesions in the spinal cord that cause interference with communication between the brain and the bowel or bladder you can have lesions at any level that can cause different kinds of issues with your bowel and bladder. If you have an upper-motor neuron lesion, which is an injury actually to the spinal cord itself at about T12 and above, people generally have spastic muscles and a spastic bladder and bowel. If you're injury is lower in the spinal cord, about L1 and below, or a lower motor neuron injury, you generally have a flaccid type paralysis where you have sort of limp or weak muscles in your extremities and you also have weak muscles in your bladder and bowel.

[00:01:52] And I wanted to note that acute flaccid myelitis, because it affects the peripheral nervous system or the anterior horn cell, is a lower motor neuron injury, but it can occur at any level in the spinal cord. Because AFM, acute flaccid myelitis has lesions at all different levels, often people have intact bowel and bladder function, but there can be some issues with acute flaccid myelitis. But it's always a lower motor neuron pattern.

[00:02:30] So for neurogenic bowel and bladder, if you have an upper motor lesion, you have a spastic bladder. So your bladder is contracting and irritable and the urinary sphincter is very tight, and it doesn't relax voluntarily. So you have difficulty with storing and releasing urine. When you have a spastic bowel, you have a decreased GI motility and the rectum will hold stool and the anal sphincter is very tight and doesn't relax voluntarily. So you have difficulty releasing stool as well.

[00:03:05] For the lower motor neuron pattern of injury, for a flaccid bladder, the bladder does not contract well and it's very floppy and it will just fill up and become very full. And the urinary sphincter is loose, and it fails to contract so you'll have difficulty storing urine and have incontinence of urine when the bladder overfills.

[00:03:32] With a flaccid bowel, the rectum holds stool and the anal sphincter does not contract well. And so you again have difficulty storing stool and more issues with incontinence.

[00:03:43] So how do you know which type of a bladder and bowel that you have? Usually it's done by some, either testing or physical exam. For the bladder, urologic evaluation by a urologist that

specializes in neurogenic bladder is important. There are different testing that can be done. Urodynamic studies or systemmetric studies will tell us how your bladder functions. A VCG or a voiding cystourethrogram can tell us whether urine is refluxing back into your kidneys. And renal ultrasound helps to identify whether you have any problems with kidney or bladder stones and gives us some idea of your bladder functioning.

[00:04:30] For the bowel, for the most part, a rectal examination generally by a healthcare professional a digital rectal exam where they use a gloved, lubricated finger to test your rectal sphincter and see whether you have good sensation, whether you're able to voluntary contract or relax your sphincter. And other GI exams are usually not necessary. One other test that we often use to figure kind of out where we are is an X-ray of the abdomen on occasion to see how much stool you have in your GI tract. Without a formal evaluation, your level of lesion and your muscle tone in your lower extremities can give some indication, but it's not 100% accurate.

[00:05:23] So when we're talking about bowel and bladder management, the first thing that we, you know, is really important is to establish healthy habits. You need a healthy diet, which includes fiber which is really helpful for maintaining stool consistency, and you need to drink, drink, drink, drink. And for many people, you need to spread out your fluids over the day, because if you drink a lot of fluids at once, you may have more trouble with incontinence. You want to maintain activity as best as you can. Being moving around helps to facilitate movement through the GI tract and through the kidneys. You want to have good hygiene so that you make sure that you can prevent things like urinary tract infection and also to prevent skin breakdown if you're having problems with incontinence.

[00:06:17] And then as much as you can, to take care of your bladder and bowel programs yourself. And you may need some assistant devices to do that. You may need, equipment so that you can be positioned comfortably on a toilet. And if you can't do your own care, being able to direct your own care.

[00:06:39] And then we want you to establish a good routine. So goals of bowel and bladder management are to prevent incontinence and accidents. We want you to be able to empty your bowel and bladder at predictable times. And we want you to maintain health and prevent complications.

[00:07:01] So what's the significance of bowel and bladder management? Incontinence or loss of continence is very difficult for people to manage. It can cause problems with maintenance of healthy self-image and self-esteem if you're having difficulty. There could be parent-child relationships if there's difficulty with potty training and trying to get kids to manage a bladder program. Having incontinence can interfere with intimate partner relationships and sexual activity. And peer interactions and social participation can be markedly decreased. Even in people who have good bowel and bladder management or function with a bowel and bladder program have a lot of anxiety or fear around having an accident, and this in itself can also keep people from going out and participating. Incontinence can also be a barrier to education or employment. And people with mobility difficulties report that bowel and bladder issues are equally if not more stressful than their impaired motoric function.

[00:08:21] So now talking specifically about bladder management. With a bladder program, we want to prevent urinary tract infection. We want to work to maintain their bladder capacity or how much urine your bladder can hold will make a difference of how long you can go between having to urinate. And ultimately preventing urinary tract infection and maintaining capacity is very important for protecting your kidneys. And then it also can help to prevent kidney stones or bladder stones that can occur if urine is not being emptied completely from your bladder.

[00:09:01] Programs for bladder programs can range from some people have frequent or urgent voluntary urination and that's okay with them. They're not interested in other ways of managing their bladder, so they just, you know, put up with frequent or urgent, having to go to the bathroom frequently. We can help to manage that to some extent with medications that can help relax the bladder if you have a spastic bladder. We can help by having you trying to do timed voids. So instead of waiting until you feel the urge to urinate, you go to the bathroom at specific times. Two hours, every two hours, every three hours. To prevent incontinence. And then if we really want to have predictable voids, we can do that with intermittent catheterization. Intermittent catheterization may be required for some people as it's the only way that we can empty your bladder to protect your kidneys, or some may choose to do intermittent catheterization to achieve social continence. There are also surgical procedures that can be done to facilitate urination.

[00:10:19] So bladder management for a spastic bladder which includes frequent or urgent urination, are medications to relax the bladder such as Oxybutynin is the most common medication, but there are many others. And then intermittent catheterization, and that can range from every four hours, usually for children, up to sometimes every six hours for adults.

[00:10:44] When you have a flaccid bladder and have frequent leaking of urine, medications are often not effective but can be tried depending on your bladder evaluation. I talked about timed voids. you can also try double-voiding, where you void once and then you wait for seconds or minutes and then try and void again to be sure the bladder is empty. And then again intermittent catheterization, to prevent incontinence. And generally if you have a flaccid bladder and a flaccid sphincter, you need to cath more frequently. More like every three to four hours.

[00:11:23] You also may want to catheterize prior to doing any activities that cause Valsalva, that contracts your abdominal muscles. You know, people that do adapted sports often will catheterize right before they are going to play a game, so they don't have to worry.

[00:11:45] Other options for bladder management. Men can use a condom catheter and it's a special catheter that can slide over the penis that has a connector to a tube that goes to a leg bag. You can use an indwelling Foley catheter, also it's not recommended, and those are the type of catheters that you often had during your acute injury that stay in all the time. There is a super pubic tube that can be placed through the abdomen in directly into the bladder. It's a more reversible and minor surgery, but there sometimes can be increased urinary tract infections or potentially bladder cancer. There is a catheterizable stoma that is also placed in the belly button that goes into the bladder, and this is a more permanent and a more major surgery and allows you to actually catheterize the stoma, so in-and-out catheterization.

[00:12:45] And then for people with lower motor neuron, there are some bulking agents that can be injected into the sphincter to try and decrease the amount of incontinence. There are some bladder net surgical procedures that can be done. And Botox is another option that can be used, and this is for people with spastic bladders and it's usually completed about every six months.

[00:13:13] Now I'm going to switch gears to bowel management. Bowel management is important because we want to prevent constipation. And if you have chronic constipation, that can lead to hemorrhoids, anal fissures, impactions and actually rectal prolapse. Also, bowel management is important to prevent UTIs because if your abdomen is full of stool, it presses, can press on the ureter, it can press on your bladder and can cause urinary retention. It also can cause incontinence, bladder incontinence because there's not enough room for your bladder to fill. And so people will have increased incontinence.

[00:13:59] So no matter which rare neurologic disorder you have, it seems like also everybody has constipation because it occurs with any decreased mobility and decreased GI motility. So to try and prevent constipation, we want to manage the frequency of how often you're stooling. And because most people may have some decreased GI motility, the longer stool stays in your GI tract, the harder it gets because the GI tract's job is to suck water out of the waste. And so the longer it stays in, the more water gets sucked out. So we want to promote regular bowel movements and we would like to see people having minimum of three bowel movements per week.

[00:14:52] We'd also like to work on managing the consistency of your stool. Stool that is general is the softness of a ripe banana is soft enough to pass and solid enough to also be able to hold in the rectum without leaking. So management of stool consistency can be done by diet. Eating a diet that's high in fiber and also you can use a fiber supplement if you need. You need to be cautious if you're adding too much fiber into your diet and especially if you're not drinking well, because fiber is kind of a double-edged sword. It can bulk and soften stool, or it can turn it into just like cement if you're not getting enough fluid.

[00:15:42] Medication to soften the stool can be used. Docusate sodium and polyethylene glycol or Miralax or Glycolax can be used at lower doses to help soften stool. And then medications to promote GI motility to help stool move through faster, include Senna, which is an oral tablet that you can take. And again using polyethylene glycol but in higher, more laxative doses. And the dose that you use needs to be just adjusted little by little. And when making changes to bowel programs, you should wait three days about between changes so that you know what's working.

[00:16:30] Also having a good bowel routine is important. We all have what's called a gastrocolic reflux. So when you eat, your GI tract starts to move and move waste through. So if you do your bowel routine about 20 minutes after eating, we can take advantage of that. So we'd like you to sit on the toilet at a regular time because your body can just be retrained.

[00:17:02] Again you need to have good adaptive equipment to be comfortable with positioning. For children, we need to be sure that their feet are on a floor or on a step stool, because you need, everybody needs to be able to use a Valsalva to be able to help, push stool out. I always tell my kids

that they should do a potty dance while they're on the toilet. And that can cause Valsalva, again to help push out stool.

[00:17:33] What do you do for a spastic bowel program? So you're doing a routine bowel program every one to three days. We're working to use medications or diet to get soft-form stool and we want to trigger a reflux evacuation using either digital stimulation, which is using a gloved, lubricated finger in the rectal sphincter, to help relax the rectal sphincter and trigger reflux evacuation of stool. You can also use a rectal suppository or many enemas that can help with triggering reflux evacuation.

[00:18:14] When you have a flaccid bowel, you want to have again a routine bowel management program. Often this program needs to be done one to two times per day, because people have more difficulty with incontinence. With flaccid bowel, you want to have more formed stool and that may be more like a unripe banana to make it easy to remove but not leak. Suppositories generally don't work well in these situations but can be tried. And what works best is manual disimpaction using a gloved, lubricated finger to actually go into the rectum and remove stool manually. And this can often be done one or two times per day and prior to activities that cause Valsalva. So just get stool out of the rectal vault so it doesn't come out when you're doing any Valsalva movements.

[00:19:13] Other options include transanal irrigation system. There's a picture of the Peristeen here. And there's another system that's more recently come out called the Navina. And this uses a bladder catheter with a balloon around the outside of the catheter that helps to hold enema liquid in the bowel just briefly. And then the balloon is released, the catheter comes out, and then waste comes out along with that into the toilet. This can often speed up bowel programs for some people.

[00:19:54] A cecostomy is also being able to do an enema, but the cecostomy is a valve that's often put in through the bowel through the abdomen and it can be done in interventional radiology. It's a reversible procedure and it allows you to do an enema from above. An ACE or an anti-grade continent enema is a more permanent position that allows you to also do an enema from above and often is done if you have a procedure to do like a continent bladder sphincter. Also the procedures are often done in one surgery. You need to be cautious about these procedures that I just talked about if you have a spastic rectal sphincter, because often even with those procedures you will still need to do some digital stimulation to relax the spastic sphincter.

[00:20:51] So no matter how good of a bowel and bladder program you have, accidents are going to happen. So you want to be sure that you have a change of clothes, some toilet paper or wipes and hand sanitizer. If you need to, use briefs or pads or diapers to prevent difficulty. And then have plastic bags for everything that is soiled that you need to put away.

[00:21:20] So now I'm going to switch gears one more time and talk about intimacy and sexual functions in rare neuro immunologic disorders. So these conditions can cause a lot of primary challenges, which are impairments that are caused actually by the lesions to the spinal cord directly caused by the condition. And you can have people can have some or all of these symptoms depending on your level of injury.

[00:21:56] You could have a decreased sex drive. You can have decreased genital sensation or actually genital pain, some people can have. You may have a diminished capacity for orgasm. Men may have difficulty achieving or maintaining erections. They may have decreased ejaculation and may some impaired sperm motility. Fertility may be impaired, but with the help of reproductive endocrinologists or neuro urologists, men with rare neuro immune conditions or spinal cord injury are able to have children. Women may have also decreased lubrication and diminished clitoral engorgement. And for women fertility is maintained.

[00:22:51] There are also secondary challenges that are not sexual related but can also add to difficulty with sexual function. This can include depression and also medications that are used to treat depression can decrease libido and decrease the ability to have an orgasm. Fatigue can interfere with wanting to participate in sexual activity. People may have decreased self-esteem because of changes in their body image. You may have spasms that interfere with the ability to have a comfortable position for having sex. You may have loss of mobility and that may be for either receiving pleasure or giving pleasure to your partner. You may have hypersensitivity or diminished sensitivity, and you may see bowel and bladder issues that can... If you're having trouble with bowel and bladder, that can interfere with sexual function.

[00:23:59] So to manage intimacy and sexual function, it takes an, a team. And it's going to take you and if you have a partner, your partner. Your healthcare professionals are going to be needed. Your neurologist or physiatrist, primary care provider, your neurologist, to help manage a lot of the primary issues and medication management. And then mental health providers can also work to help with changes with mental health. There is a specialty called rehab psychologists that often have training with function following a spinal cord injury. And then there are also sex therapists that can help with cognitive issues regarding sexual function. Occupational therapists sometimes have a specialty in helping patients with sexual function particularly in management of clothing and positioning and things like that.

[00:25:03] And probably the number one thing that can be helpful is peer counseling. People that have injuries similar to yours that have had experience and can help with telling you about the ins and outs. And peer counselors are often - available through your center or through like the Christopher and Dana Reeve Foundation.

[00:25:26] So managing these challenges, erectile dysfunction it occurs frequently in men and many men will respond well to Viagra or the Cialis or Levitra, the typical, erectile dysfunction medications that you see advertised. Women who have decreased libido, there's a relatively new medicine called, Flibanserin that can help with libido. If you're having trouble with engorgement or lower motor neuron injury, there's vacuum pumps that can help men and women for engorgement of the penis or clitoris. For men also, if the oral medications don't work for erectile dysfunction, there's transur- urethral therapy that can be used. There's penile injections and there are also penile prostheses that are available.

[00:26:29] And one of the other things that you want to do is make sure that you look at the medications that you're using, both men and women, because these antidepressants and other medications can decrease erectile dysfunction and the ability to experience an orgasm.

[00:26:48] Overcoming challenges includes also looking at different ways to enable romance. You need to know what your needs are. It means having increased communication with your partner. It also means exploring your own body to figure out what works, what doesn't work, what feels good, what doesn't feel good, and to share what you're learned with your partner. You may need to try new things. You may need to try different positioning that accommodates spasticity or muscle contracture. You may need to use pillows for supporting body parts. Women may need to add extra lubricant. And you may also want to think about experimentation with sex toys, particularly vibrators that can help to increase sensation and even can be used to decrease pain. And sex toys can also be important for people that have limited mobility in their upper extremities and hands. With adaptation, vibrators and such can be adapted for use for giving pleasure.

[00:28:06] You also may want to think about some ways of redefining sex. So focusing more on the sensual experience and less on results. Look at other ways to experience pleasure and intimacy besides sexual intercourse. And you, you know, if you need help with this, you can try, individual and couples' therapy can be quite effective for helping with facilitating communication and thinking about these issues.

[00:28:40] And again, with all things with spinal cord injury, enabling romance, you need to be prepared. You may need to plan ahead to decrease, to be sure that you're going to be feeling like that you're feeling well. You need to take medications, or you may need to hold medications. You need to choose a time of day that's best and you need to be sure that you're managing your bowel and bladder function well.

[00:29:12] So that's all I have for today. I have a lot of different resources here. Here's some books. There's a lot of good web resources. There's some catalogs, discreet catalogs that you can order from for sexually oriented materials. And then the Paralyzed Veterans of America have very good publications and specifically their sexuality and reproductive health for adults with spinal cord injury is very informative and those can come from the PVA. Here is my contact information. I am certainly not an expert, but I know a lot of experts, so if there are questions that you have, I certainly would be happy to facilitate that.

[00:30:01] So next I'd like to introduce to you Dr. Justin Abbatemarco who is a physician in the neurology department at the University of Utah Health. And he's going to be talking about symptom management, types of pain, and how to treat them.