Bladder, bowel, and sexual dysfunction in rare neuro-immune disorders

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Transcription from presentation available at https://youtu.be/4v0b4z2jkUo

00:01 Good afternoon everyone I'm Dr. Cabahug. First of all, I would like to take. I would like to thank the Transverse Myelitis Association for inviting me back again to give this talk so that means I have not traumatized the last group that I gave this talk to. So that's a good sign. Before I begin. Here. I have to give a warning. How many people around here are less than the age of 16. Do I have your parents' permission for you to attend this talk? This is a “PG-13” talk so you guys have been warned. I kept it to “PG-13” I promise. I think anyway. All right.

00:49 So to start as Dr. Greenberg had mentioned earlier not a lot of physicians will talk to our patients about bowel and bladder function and certainly not about sex. So please keep an open mind for this part of the talk later on.

01:06 I do not have any financial disclosures. I wish I did have. But I do not which makes it a good thing. I will be mentioning certain brand names later. I do not have any ties with them. And actually a fight with some of them. So, when I first started studying medical school the my worst subject was physiology. It's gonna bite me in the butt. It's been biting me in the butt since I became a spinal cord doctor because that's all I talk about the autonomic nervous system is basically your body's automatic pilot.

01:39 Things that we think that go on in my body that we do not give second thought to breathing, our heart beating for example, or tummy's happily digesting after a nice lunch we had earlier. We don't think about it because it's all on automatic pilot. Your autonomic nervous system takes care of your bladder filling up and emptying your bladder, your bowels pooping farting, your breathing. And of course, your heart beating like right now my heart is beating so fast. I didn't know if I can keep up with it. But now to go. You're the way that God has designed our body it's actually quite a feat of engineering. All of our systems work together. They have a certain task and they do wonderfully. Until we get sick now our bowels and our bladder have certain functions our bowels and their bladder. Once they've done they store waste and at the appropriate time and socially acceptable an appropriate time if I may stress we empty our bowels in our bladder.

02:52 Now each system has a muscular storage and an outlet valve or sphincter and it's the interplay of storing stuff and then opening up to release your waste. That's what your brain and your spinal cord are responsible for. The brain sends impulses and instructions down your spinal cord it gets to through your nerves it
gets to the organs that it needs to get to. And that's and it's a beautiful ballet if you come in you know if you think of it carefully it is a beautiful work of art.

03:22 Now there is voluntary and involuntary control. When we were babies you know we just did what we had to do. Right.

03:30 And mommy and daddy we're going to take care of us and then we grew older. Social norms come into play and we do things both voluntary and involuntary. Again when we do have anything that injures either our brain or the spinal cord. This normal interplay this normal coordination this gets affected. And this is what we deal with on a day to day basis. So just a picture of the bowel of the bladder and how your brain is brain and spinal cord is connected to your bladder and your bowels. Now as I mentioned earlier when you have anything that in that injures or affects your spinal cord or your brain for that matter you're going to have problems with bowel and bladder function no coordination is lost. You either don't go or you. Soil yourself. So that is the unfortunate thing in our careers as physicians, physiatrist, nurse practitioners, who help people with these problems. This is basically our bread and butter. I did not think this would be my bread and butter when I started medicine but you know what. It is quite satisfying.

04:45 For me the best visit. This is when I ask my patients, “How's your bowel program?”

04:50 “Oh it's fine. You don't have to do anything about that this time.” It's very satisfying for me to hear it. I mean we're all doing a good job. OK. Now when you have bowel and bladder dysfunction it's a whole group of symptoms. You could have urgency. It's like those commercials on TV the adverts.

05:08 I gotta go, I gotta go, I gotta go. You know that little shadow there. I got to go. That's your urgency your frequency as you just came from the bathroom. You have to go to the bathroom again.

05:18 And then. Then other types of bowel and bladder dysfunction is or you have constipation or you can't tell if your bowel or your bladder is full or sometimes you can't even tell if you've completely emptied or not. It's the syndrome of something left behind. So. Anyway sometimes it's it comes to the point that you'll need assistive devices and we'll talk more about that later. You know I will give a very short anatomy lesson. We will have little anatomy lessons throughout this talk. So, these are the Cliff Notes version. I don't know if any of you remember Cliff Notes. I don't know what's the new you know what's the counterpoint of Cliff points and Cliff Notes in this era. But this is the Cliff Notes version. OK. Now your spinal cord and you're vertebra.
We like to classify and give names the things right. So, for reference “C” is cervical. That's your neck. “T” is thoracic. That's her upper back. “L” is lumbar your lower back and “S” is sacrum. Butt.

OK. Now you've probably heard my level is cervical thoracic lumbar. That's basically what you're referring to. Where in your spinal cord or where in your duty to your injury or where your spinal cord has been affected. Human beings like to draw lines as you've seen and politics are being heard over at CNN if you're like me we've been hearing a lot of people drawing red lines.

Today I'll be drawing some red lines as well.

If my oh you so that red line here basically represents the difference between where we call your where we classify as an upper motor neuron or a lower me or in your on spinal cord injuries spinal cord dysfunction. There is a big difference. Now when you say upper motor neuron it's everything above your thoracic are 12 thoracic vertebra. Why is 12 very important. In my world when you are when you say T12 around that level between 12 and L-1 that's where your spinal cord ends. That is where the cord ends your cord is not all the way up to your butt? No. that's T12. From T12 onwards are you want to have like a horse's tail of nerve roots going out and that is that is very important because it differentiates how your bowel and your bladder function is going to be affected when your injuries T12 and up we call it an upper motor neuron injury and usually these upper motoring injuries will present with a spastic bladder or a spastic bowel which I will explain more later.

Lower motor neuron those are your flaccid. Flaccid bladder flaccid bowel. So that's the big difference.

Now in life there are recently two types of people and or some people in between. You have those really really uptight people that will not let anything go grievances says they will not let anything go. Same thing with our bowels and our bladder. That's their spastic bladder. They're so spastic they're so tight you cannot let go you cannot poop. And then there is the other type the loosey-goosey people they'll just flow through life those again.

That's my analogy that's your flaccid bladder or your flaccid bowel. Now with flaccid bowels the good thing is the way our bodies have been designed. We have a sphincter that normally would stay closed until its breaking point reach and then everything flows out OK. All right. So again the reason why I wanted to make sure that you understand the difference between a spastic bladder bowel and a flaccid bowel bladder. It's because the type of injury you have the type of bowel or bladder dysfunction that you have dictates how your physicians and your care providers will address the initial management of your bowel or
bladder dysfunction. It’s not one size fits all. And again it is trial and error. It’s not exactly a big but two big boxes but sometimes we overlap in between but we usually start with differentiating a figure spastic or if you're flaccid upper versus lower.

09:58

Red Balloon. I always like this analogy whenever I talk to my patients about the bladder. I tell them imagine how your bladder is like a red balloon. It's a balloon made out of very thin but very powerful muscle. Now when you fill that balloon the balloon normal becomes big, right? And then when it’s time to let the air out or in case it's the bladder let the urine out you let the urine out and it goes back to its normal size. That is what your bladder does normally. Now again the bladder is made out of muscle. OK. So we know for a fact that if we keep on exercising a muscle what happens to a muscle when we exercise.

10:47

It becomes big. This is one muscle you do not want to become big. OK. The reason is if the walls are too thick.

10:59

There will be less space for you to store urine. And if the walls are too thick the pressures would increase and means two options. Now this is first spastic bladder always working out. It's either you leak out your urethra or this is what I'm always scared off if I don't get to manage my patients properly it will be back up towards the kidneys. And that would put you at risk for more infections and kidney failure. In the 1970s people with paralysis they would usually die from kidney related problems. Over the years we recognize that we need to keep the bladder happy and mortality rate from kidney disease from kidney failure has decreased UTI urinary tract infections is still a very big problem in patients with paralysis. But over the years I'd like to see we've gotten better in managing it.

11:56

Now one thing for sure the bladder even though it's like a balloon I promise you it will not pop. OK. The pressures will increase but it will not pop this again shows you the difference between having a very full bladder. And this one full with urine is just going to increase its size and the pressure will increase and we don't want pressures to increase. And then the other one. Here. If the bladder’s always contrasting again the pressure will always increase and you're going to leak out. When we give medications for this type of bladder the spastic bladder we usually try to give medications that either calm the wall of the bladder or calm the sphincter. Again, it depends on the studies that we order. Some of your doctors for those who have significant bladder issues with a spastic bladder you might have heard of a urodynamic study. urodynamic study gives us information.

12:58

If the pressure is inside your bladder are safe and if it's if it is a problem of the walls of your bladder being too hyperactive or the sphincter being so tight that it's not letting anything out. So that’s when we ordered. That's why we ordered
out because we want to find out what your bladder is doing and it will help us
decide the course of management. Now the goal of having a bowel or a bladder
problem, program, sorry. problem is not the goal. We want to make sure that
you are continent, socially continent, a predictable bowel or bladder program.
We don't want you to be all of the sudden soiling yourself. We want out we
want to give our patients some control over this. We want to prevent
complications not just constipation and impaction or diarrhea.

13:57

We want to make sure that we prevent development of long term
complications. And so what I mentioned earlier with kidney failure. Now with
the bowel sometimes you get so constipated you get impacted and obstructed
and then if it's not caught or recognized early in time you could run into a lot of
whole problems. For those who have really high spinal cord dysfunction that
their blood pressure goes crazy when they're in pain or when they are backed
up. That's a significant issue. We call it Autonomic Dysreflexia. That's an that's a
medical emergency in my world. We do everything to prevent your bladder and
your bowel from being so uncontrollable that if it triggers that you're going to if
it's not recognized it's going to lead to a stroke or death or cardiac arrest. But
then I digress.

14:51

Now you've probably heard this a lot from your providers. It all starts with
Even though it's so counterintuitive that. We ask you to drink. We want you to
drink. We do not want patients to get dehydrated. If you do not drink you'll
become more backed up. So it's trying to balance getting enough fluid and doing
your catheterization program. OK. Now in terms of fiber how much fiber does
one need to take. That's a big question for me.

15:32

When I was training before, a long time ago. I swear it is. It was a long time ago.
Stocks. The stock answer was 30 grams a day. Over the years.

15:42

That has changed. It depends on your sex. It depends on your age. I usually
don't like to give a high amount of fiber because if your body is not used to it
you're going to get really really bloated and then you're going to get mad at me.
OK.

15:57

So start with low fiber. Say you can google this. There is a web site called the
“National Fiber Council”¹. And you could plug in your values and it would give
you recommendations about how many grams of fiber you should take a day. If
you haven't really been taking fiber regularly I would recommend starting the
lower end of the spectrum and build up your tolerance to fiber. Again if you do
too much too soon your body might get mad at you for it. So you start with low
you know gradually easing the fiber into your diet. And then and then you.
Take more fiber regularly. But this starting those I wouldn't recommend 30 right away 15 to 20 grams. The Web site is good because it has like recommendations of how much fiber you're the food you have the food you're taking. OK. Activity.

I always like to take a walk after a heavy meal it calms my mind and it helps me bring my food down. In this case gravity will be your friend. I know it's difficult for a lot of my patients who cannot stand up. Some of my patients are very fortunate that they were able to get standers or wheelchairs in case you are not able to do any standing or support that standing any activity will do. Because the more you don't do you don't move around or you're not being moved around or not exercising. The more your body becomes sluggish activity really will help with your gastrointestinal motility if possible I encourage my patients to try to do your own bowel and bladder program if because of their impairment they are not able to do a bowel and bladder program. I drill it to them.

It's your responsibility to know to tell them how to know to know and tell people how to do your bowel or bladder program. You have to advocate for yourself. Your aids may change. You have to know what to tell them so that they will do it properly. That's one thing I make sure my patients know. And then like everything in life and this age we have to have a routine. Our body likes her routine. I don't know. I know my body likes a routine that evening. I don't know about you guys now when we start with formulating a bowel program for patients I always like to ask, before you got sick or before your accident or before your injury. How often did you go? So, we know that once a week. once a week is not good.

Once you know once a week is not good.

I would be freaking out. once a day, twice a day, after a meal. I don't know if you've noticed after you had your lunch or after you had a good steak dinner with them with an R. What do you want to do.

Go to the bathroom whether it's number one or number two will you decide on what you want to do it. But usually we go to the bathroom.

So whenever our patients do their bowel or bladder program, especially the bowel program, I tell them time it within like 30 minutes to an hour after your meal. It makes more sense because you're utilizing one of your body's reflexes what I mentioned earlier.

Once you're full in the car you want to go to the bathroom. So make use of that reflex that will help.
Now I alluded to this earlier if your bladder is spastic or really tight and if you're if you have that impairment that you need to catheterize it is very important that you catheterize on time and regularly. I also mentioned earlier depending on what and how bad your bladder is. Your physicians will most likely start you on medications like oxybutynin or Ditropan, the tolterodine, these medications relax the bladder. I always tell my patients however to be cognizant of the side effects because some of these medications can cause constipation. It's like on top of everything else right constipation or dry mouth. And we work with our patients because it, believe it or not, there are a whole ton of other medications we try aside from oxybutynin or Ditropan. It's just that insurance likes us to start with this medications because they're older medications they've been proven and they are the cheapest kids on the block.

We have newer medications like Myrbetriq or Mirabegron, but they're a bit on the pricey side. Some of the people I'm not sure if you've run into these issues with your insurances. But before we start you on the other medications they have to say that most of the time anyway. I have to prove that we started you on these medications and that you could not tolerate it. So, one thing that I am careful about in any of my patients on anticholinergic oxybutynin and the rest of her family especially for older it can make them feel a little bit foggy or slower is that there is a possible side effect that it can affect your cognition. So be wary about that and tell your prescriber if you feel like you’re so sleepy from the medicine tell them so we can change.

Now if you're bladders the flaccid bladder This is the bladder that keeps on filling and filling and filling in again I promise the bladder will not pop. It does fill but the pressure will increase. So for that type of bladder we don't have any active contraction. It is all the more important that you do your catheterization on time. OK. All the more important catheterize every four hours at the least three to four hours at least. I put there “prior to doing activities that cause valsalva” up again. Before you do anything that is basically stressful like you have to bear down because if you bear down like you’re trying to push something that will increase your pressure inside your abdomen. And that could either if you're really backed up or your bladder is really full you can leak.

OK. So if you're going to do any of those activities or engage in sports or engage in some, intercourse, for example please don't forget to do your bowel and your bladder program before it.

OK now options for bladder management. And this is where we're going to. Before I begin and this is where I start my PG-13 part of the discussion. Are you guys OK with this. Are we good to go. I'm cleared.
OK. All right. So. Most common is condom catheters and in-dwelling Foley catheters. I am not a fan of long term use of in-dwelling Foley catheters because of the increased risk of urinary tract infections. However, for me that is not completely off the table especially if you know if the situation dictates it like if you don't have anyone who's going to do your catheterization for you or for example if you’re going on an airplane trip for like five hours and you can’t cath. That you can catheterize in an airplane that's OK it's acceptable. But again, there are these risk for people to develop recurrent UTIs. And for example, if you have a suprapubic tube. The area a suprapubic tube which necessitates it's a very minor and reversible surgery you see we have a suprapubic tube. We would survey for you know if it's been there for 10 years or more we would start to do regular cystoscopy surveillance for bladder cancer.

OK. Yeah. And then their rates for bladder cancer in patients with in-dwelling Foley catheters are suprapubic tube differs depending on the study. Anywhere between like two percent to 10 percent. Now if another option for a surgical bladder management is placing a catheter, a cath there are sorry, Catheterizable Stoma

OK. Yeah.

So it is usually see this in our younger kids and some of the things I'll be discussing earlier they use they started before in children with Myelomeningocele. But we are doing them in adults as well. So instead of just having the pubic, a suprapubic tube there hanging from you, the surgeon actually creates a stoma or a hole that you can catheterize in and that is really sometimes more acceptable and it's more practical at times. For me the challenge is always finding a surgeon who has capable, who knows how to do this properly. And then the challenge for me is that because I get a lot of patients from out of town, and not all of you know they don't have all of the resources that we have in Baltimore right now, I don't know if you've heard about this.

Some urologists do Posterior Tibial Nerve Stimulation. bladder function and bowel function, it's a whole lot of interplay of reflexes. So what they do there are two versions of this. It's either they stick the needle just right where your posterior tibial nerve is and they stimulate the tibial nerve. OK. What does it do it helps modulate their reflexes in your sacral plexus So what happens is the impulses from your posterior tibial nerve which is behind the ankle over here it goes up to the lower part of your well lower part of your sacral plexus then to the lower part of your cord. My take on this, it works for some are not so severely affected.
And usually it works really well in women with overactive bladders not necessarily the neurogenic bladders that people with paralysis has but you know sometimes it's worth a try. This one however really necessitates commitment because you have to go to the urologist office once a week for around 12 weeks to get this treatment for 30 minutes. So it's a lot of commitment.

And it doesn't effect if you do respond the effects aren't permanent. You have to go for after that 12 weeks you have to go like every month or so for repeat treatment.

Now if this would work all well all good. Now. The other. Treatment for a bladder is the implantable stimulator. It's called the inter stem. Now your bladder and your bowel the sacral segment of your spinal cord S2 S3 S4 all of your reflexes are mediated in that area in terms of bowel and bladder and what.

The surgeon does.

He implants a stimulator that you can control in term in order to help you facilitate urination. Now again this works better if you have an incomplete injury or involvement of your spinal cord. But if you have what we call a complete involvement, meaning no anal contraction, no sensation nothing below, it won't work as well. Also one thing that I have issues with. But then they came out with a new version before the “InterStem” and that's a brand name I have no ties to that the InterStem if you have one you cannot have an MRI. OK. And that's my problem in patients with your non-traumatic myopathic spinal cord dysfunction. You my patients normally require like an MRI every so often and if you have this you can't. Now. Last year they came out with another version a smaller one that is MRI compatible.

The caveat is it's compatible with a 1.5 Tesla MRI. And they think a lot like some of your neurologists would be ordering at least three tesla MRI so that's one thing to consider. OK. And then again this really works better with incomplete lesions or injuries. But if you really have a severe bladder condition I'm not sure if it's really going to work that well. Now bowel management you've seen the adverse whole mountain loads of medications. You have your stool softeners your laxatives and that's what we usually start with we try to we try to get them a perfect type of stool for either a spastic or a flaccid bowel. But bowel for a spastic bowel we want your stool or your poop soft and formed like a banana. OK it's formed enough and it's soft enough you can push it out and won't develop a hemorrhoid trying to push it out or try to get it out.

Now for if you have a flaccid bowel you do not want to have your poop to be too loose because then you'll be spouting like a geyser.
You do not want that. OK. All right. So when you work with your physicians please remember it is trial and error. We usually start with a certain regimen of medications depending on what your bowel is.

And then we work on an adjustment. It's not going to work immediately. Give it a week or so for us to try to establish what works for you and what does not work for you.

Also timing is important. I always tell my patients if you wish for of you. Has any of you tried Senna? Senokot? Smooth Move tea?

Smooth Move tea is actually quite good. I may say so. It's a lot of Senna.

The trick is if you're going to take something like Senna you have to remember it takes six to 12 hours for that to reach its effect. So if you want to go to the bathroom at night you take it. Lunch time. OK.

And so that would prevent you from going to the bathroom or needing to change in the middle of the day or at the time when you do not want to do it.

All right positioning if possible you have to set up in a toilet or bedside commode is really possible because gravity will help or if you cannot then lie on the left side the low. The last part of your large intestine is on the left so it makes more sense for you to lie on the left if you have children make sure that the feet are up supported on the stool and that they're comfortable it's easier for them to poop. Bowel program again if it's spastic, one to three times, every one to three days.

Not once a week, every one to three days and then if it's a flaccid bowel you have to do your bowel program at least once to two times a day. All right. I mentioned earlier you have to we have to find the balance with the stool consistency.

If it's a flaccid bowel you sometimes you really have to go in and do some digital manual evacuation. You have to really bring it out. OK. It's part of, unfortunately, it's part of what we have to do to make sure that you completely empty. During the workshop, I'll be talking more in-depth about manual evacuation and digital stimulation just for time's sake. Right.

Again we like pyramids we like hierarchies. Same thing with bowel management. We start with the most conservative thing. Diet changes, lifestyle, activity, medications. But then what if that doesn't work. What's the next step? Over two years we have several interventions. The first is your transanal irrigation or the brand name is “Peristeen”. Has anyone of you heard about transanal irrigation or Peristeen?
OK so basically it is giving it's basically giving yourself an enema. So the nice thing about this if you have hand function and you have balance you can insert the catheter into your anus discretely.

You can do this independent thing a toilet in you know the toilet stall and then you pump the water. And then once you're done pumping the water in it there's a certain volume between like 500 to 600 ml. And then once you've reached that volume you're seated on the toilet right. You release it and everything goes out with the water. So. It is in a way practical and discrete. If you are appropriate for it you do have to go for training.

You will not get this immediately because insurance takes quite some time to approve. Do you approve this one. It will take anywhere between like a month to a couple of months to get it and then you still have to go for training. Medicare doesn't completely cover for supplies. Unfortunately.

Right now I'm moving to the surgical aspect though the Antegrade Colonic Enema or we call it the MACE, Malone Antegrade Colonic Enema. So basically you have surgery in order to make the hole that you can give yourself an enema that will clean you from top from the start of your large intestine to the end of your large intestine. OK. You lead that they take a piece of your appendix in order to make that whole that you can catheterize. OK. So this started in in children. They used to do it a lot for children with spina bifida. And it's has of course gradually expanded to people with spinal cord injuries and not just in children but also an adult. So that's one thing. Again for me the big factor is finding a center where you can have this done.

Now. A Cecostomy. So it's basically the same concept. You are able to give yourself an enema that will cover your entire. That will clear out your entire large intestine but instead of having just a hole there are a stoma there they put a button that you can actually close and actually, if you google online, you could see that they sell these cute little Cecostomy covers for a button especially for children with different designs. So that's also another option.

Like any surgical procedure there are possible complications with the MACE, the one earlier because it's a stoma. There's a possibility that it can become smaller over time. And then with the Cecostomy the C-tube, sometimes it gets the tube gets dislodged.

Right now Sacral Root Anterior Stimulator. I'm not sure if you're familiar with this it's.

I had mentioned earlier that your whole bowel and bladder that reflex center is S3 S2 S3 S4 now in the 1950s to the 1970s they've developed this technology we're in through surgery. They implant a stimulator over those nerve roots. OK.
This is the only one that will make your bladder contract. This is the only one. Unfortunately it is for me at least. I am. I have not really found a center close to us in Baltimore that does this so it might be a challenge to find a surgeon who can do this also for males, also for males, if they, if you have this done, and usually this is done with upper mobility people, if you have this stimulator done, they'll have to cut off or enervate the sensory part of the nerve root system.

Why is that important in males? Because if you do that, if ever they had any reflex erection that might be gone.

OK. So that's one thing to consider. All right. But so far this is. This is the only technology that I know that can give you a bladder or bowel contraction.

It's approved in Europe and here it's known as VOCARE² system. Unfortunately I don't have any information right now about which centers do this on a regular basis. Now.

Do I still have time still good. OK.

Last few minutes for sex and intimacy sex is a very very important part of being human. We will not be here today if our parents didn't think of us or did this right. So challenge us.

Whenever you have anything that happens to your spinal cord. You have decreased libido, sex drive, sensation down there.

Is going to be off. If it's pressing at all and orgasm.

Is a big issue also unfortunately right now there is nothing that we can give or take to for people to recover full orgasm. Some people are lucky enough that if they get enough stimulation in their genitals, genital area they will have some semblance of orgasm. Right now.

Whoever said females are complicated have not studied them male sex will function. Males are complicated. I swear even their management is complicated in terms of sexual function. So in a nutshell whenever I see my male patients I asked them, “Do you have erections?” And it's not because I'm a nosy busybody. I ask them because it tells me how affected the lower part of their spinal cord is. Now if they have erections but in order to get erections they really have to stimulate their penises. Or for example if the catheterize that's when you have an erection that's called a reflex erection. So it means the lower part of their spinal cord S2 S3 S4 nerve roots. There's something still going on there. OK. Now if they don't have any reflex erections whatsoever it means that S2 S3 S4 that pathway.

Has been affected.
Now look for some people who are lucky if they have a higher level of injury. Some of the men can get some psychogenic erections.

These are directions under excite that appear not just down there. OK. All right.

Now for females what's affected is basically lubrication and arousal. now we're not that complicated.

For fertility.

So for males what happens is the sperm motility slows down so it's harder for them if they want to have children down the line it’s harder for them to have kids.

So for our younger male participants I would recommend if you are interested in having children please talk with a urologist who is also a fertility specialist to consider your options for sperm banking because like over time sperm motility normally over time this you know sperms also have a shelf life. Believe it or not sperms do have a shelf life. It is a little bit faster when you have anything that's injuring your spinal cord. Now for females we're a little bit lucky. I mean we don't have a period for like around six to 12 months and then it comes back. So, we are still able to get pregnant OK. Across the board for both male and female if you're sexually active if you're not careful you will still out you're still going to be at risk for an STD So please practice safe sex. OK.

Right now medication strategies.

Again as I said males are complicated and it's also quite unfair because they have a whole lot of things at their disposal in terms of trying to improve their sexual function. Of course, everyone has heard of Viagra and Cialis. Just remember please do not take it with any of your heart medications unless you want to pass out right. Then you have your penile injections, vacuum pumps.

Please be careful because again your sensation in that area is decreased if you do not check afterwards. Please just check because I don't know you don't want to have a wound in that area. Right. So please check afterwards.

Transurethral therapy. So instead of taking something like Viagra you people get to inject pellets to help with their erections. MUSE is the brand name perhaps some of you’re familiar with addicts or Caverject. So, there's a pellet that is inserted into the penile urethra which releases medication that makes the penis erect.

OK. And then penile prosthesis. So that's a penile prosthesis. I'm not a fan of.
I have not. To be perfectly upfront managed anyone with that. But just the side effects if you're going to consider having that please really go to someone who's done a lot of this because skin breakdown is an issue. Surgical. Re-surgery is an issue. OK. For females again you're not complicated really. You know there is self-stimulation and vibration. For males who are interested in having children in the future we have to harvest the sperm. Ejaculation, unfortunately, is affected in a lot of patients with spinal cord dysfunction. So, well, when I was first studying this again I never looked at my flat iron in the same way again.

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For ladies. You understood for ladies to flat iron you understand where I'm coming from.

Yeah.

So they use this in order to help stimulate ejaculation and hopefully they could harvest ejaculation provided that you don't have retrograde ejaculation. Retrograde ejaculation is when the guy ejaculates the semen takes a detour and it doesn't go out to the urethra, it goes to the bladder. OK. And that's the case you really have to see a urologist.

Urologist also do a sperm retrieval too. So. All right.

Yeah. So this is done in a sterile setting. Yeah. Again retrieved the sperm. Either you bank it or use it for in-vitro fertilization. OK. And again, I've never looked my flat iron in the same way again. Alright. Now there's also rectal probe ejaculation and the only analogy I have for this is that.

It kind of reminds me of a cattle prod. Sorry.

But yeah basically it has to be done in a clinic or in the O.R. especially, for example, if you have a high spinal cord injury. Again, the risk of your blood pressure going crazy or having autonomic dysreflexia is a real consideration.

So this has to be done in O.R. room or in a clinic. So basically, that's what the rectal probe is, where direct probe is inserted. And when they turn the electricity on it shocks and then.

Alright. So I talked about this earlier. AD The that's my medical emergency in my population for both males and females after intercourse. Please make sure you check your skin. Make sure you didn't develop any new wounds from all of the friction involved. We are going to be at risk for STDs if you don't practice safe sex. And then again for females we can get pregnant. So be careful. Secondary challenges so this is the last part of my talk. The next few slides are courtesy of Ms. Janet Dean. Thank you very much for adding to my slide collection. Now we. What is basic it's all of us more of like the physical aspects. The important thing
also that not a lot of people address is the emotion. I mean sex is not just an act. It's basically being with another person and enjoying that act with another person. And sometimes.

46:57 Because of the impairment and because of the stress of trying to perform it gets to be more frustrating it leads to more depression more and more anger more miscommunication between you and your loved one. It's hard for people to talk about this. You can't sometimes you can't talk about it with your partner. So I would recommend if you cannot talk about it with your partner. Try your physician. We also have rehabilitation psychologists and sexual therapists who are trained to listen to you and to help you come up with the plan. OK. Oh let's see.

47:44 Again because of your impairments do not let your impairments limit what you can do or cannot. You know just don't let that be the final end all of everything.

47:56 There are other ways to “skin a cat”, right? That's the saying in this country. There are other ways to enjoy sex with your partner. It's not just penile vaginal penetration.

48:07 It is the intimacy it is the hugging, it is the stroking it’s the kissing just being in near proximity with each other. Sex has more than penetration sex being with that person that to love and care for. And it's something we really have to understand.

48:25 Use your impairment in training in terms of trying to explore what you and your partner can feel. Be creative OK be creative try positions and never thought you'd tried before, aside from missionary. Try doing different strokes. Explore sex toys but before you try and just make sure that it's OK with your physician okay? the sex toy not the position and sex toys.

48:52 All right.

48:55 Oh and don't forget lube. But then again, it's same for whole lot of older abled persons, right? Don't forget the lube. All right. And then plan ahead if you're going to be intimate. And I think this is true for a lot of people without disability. Sometimes you have to like really make an effort to make time for this. So plan ahead. Do your bowel and bladder program before. OK. You don't want any accidents. Okay. Alright, time your medications as well. For the guys usually take the Viagra. Between one to four hours before sexual intercourse. OK. OK. And again, redefine sex, again as what I said earlier do not limit your concept of sex to penetration, sex has more than that. Redefine your rules, redefined the way you explore and enjoy each other's company. And there are lots of resources.
I have my slides in the handout. Again, there are the web sites that we consult. The PVA has excellent guidelines about bowel, bladder and sex. There is good book. There are actually two good books here, “Enabling Romance” and then “Disability & The Art of Kissing” and do not be afraid to explore other resources.

We live in a time that everything is discreet, even delivery of sexual assistive devices. OK.

So we are lucky we are living in a time that we have a lot of things at our disposal. OK with that I end my talk. I do hope that you learn something today and I'm opening the floor for any questions. If we have or.

Resources:

- “Neurogenic Bowel: What You Should Know”
  [http://www.pva.org/CMSPages/GetFile.aspx?guid=89d45479-1126-4c43-ac6f-d1d2469ee0e](http://www.pva.org/CMSPages/GetFile.aspx?guid=89d45479-1126-4c43-ac6f-d1d2469ee0e)
- “Bladder Management Following Spinal Cord Injury: What You Should Know”
- “Sexuality and Reproductive Health in Adults with Spinal Cord Injury”
  [http://www.pva.org/publications](http://www.pva.org/publications)
- [https://facingdisability.com/](https://facingdisability.com/)
- Yes, You Can! A Guide to Self-Care for Persons with Spinal Cord Injury; 2009: Paralyzed Veterans of America (PVA)
- Catalogue services (discrete, anonymous)
  - Good Vibrations, Inc. 938 Howard Street, San Francisco, CA 94103, Phone: 415-974-8990; Phone: 800-289-8423.