

GG: 00:00:00 Hello everyone and welcome to the TMA ask the expert podcast series. Today's podcast is entitled Managing Adult Urological Issues. My name is GG deFiebre and I will be moderating this podcast along with Kristin Smith. The TMA is a nonprofit focused on support, education and research of rare neuro-immune disorders. You can learn more about us on our website at myelitis.org. This podcast is being recorded and will be made available on the TMA website for download and via iTunes. During the call if you have any additional questions, you can send a message through the chat option available with GotoWebinar. For today's podcast, we are pleased to be joined by Dr. Gary Lemack and Dr. Cristina Sadowsky. Dr. Gary Lemack graduated from Cornell University Medical College in 1991 and completed a residency at the New York Hospital, Cornell Medical Center from 1991 to 1997. Dr. Lemack completed a fellowship in incontinence, urodynamics and neuro urology at the University of Texas Southwestern Medical Center from 1997 to 1999 Dr Lemack is professor of Urology at the University of Texas Southwestern Medical Center in Dallas. He is a secondary appointment in the department of Neurology.

GG: 00:01:15 He has board certification and urology and female pelvic medicine and reconstructive surgery. He's the program director for the urology residency at UT Southwestern, a position he has held since 2004 and was the Director of the Fellowship in FPMRS from 2014 to 2019. He is past president of the Society of Urodynamics, Female Pelvic Medicine and Urogenital Reconstruction. He's currently a trustee of the American board of Urology and the chair of the Certification Examination Committee for the board. He has authored over 160 peer reviewed articles and over 25 book chapters. He has authored urinary continence guidelines for the American Urological Association and the European Association of Urology. He's also a coauthor on the neurogenic bladder guidelines currently in development by the American Urological Association. He's a member of the American Association of Genital Urinary Surgeons. His interests, clinical interests include caring for women with incontinence, pelvic orbit, organ prolapse, and other pelvic disorders. He also has a strong interest in caring for patients with bladder dysfunction in the setting of neurological disease and has authored numerous articles and chapters on this topic. His research has focused on improving the care for patients with neurogenic bladder disorders. And he's a frequent national and international lecturer on this topic.

Kristin: 00:02:36 Good afternoon. Evening. As GG mentioned, my name is Kristin Smith. and I am co-moderating the podcast with her. Just a little bit about myself. When I was in my late twenties, I became

paralyzed due to transverse myelitis, and since then I've been trying to navigate my way back to a new normal, especially with all of the secondary issues caused by the paralysis in TM. So our second panelist this evening is Dr. Sadowsky. She was born in Romania and attended the Institute of Medicine and Pharmacy in Bucharest. She completed an internship and residency in internal medicine at Meridia Huron Hospital/Case Western Reserve University in Cleveland, Ohio. From there she began a residency in physical medicine and rehabilitation at Barnes-Jewish Hospital/Washington University School of Medicine in St. Louis, Missouri. Immediately following the completion of her second residency, she began a fellowship in spinal cord injury medicine at Barnes Jewish Hospital Washington University School of Medicine. At the same time, she became a clinical instructor in the school's Department of Neurology and later assumed an assistant professorship in neurology in the Division of Rehabilitation Spinal Cord Injury Unit. In October 2004 she moved to Baltimore joining the Kennedy Krieger Institute as Director of the Paralysis Restoration Clinic, and the International Center for Spinal Cord Injury. In March 2005 she became an assistant professor of Physical Medicine and Rehabilitation at Johns Hopkins School of medicine. She frequently serves as an invited clinical scientific peer reviewer for the American Journal of Physical Medicine and Rehabilitation Archives of Physical Medicine and Rehabilitation, Journal of Rehabilitation, Research and Development, the Journal of Spinal Cord Medicine Translational Research. She also serves as a section editor for physical medicine and rehabilitation reports.

GG: 00:04:51 So welcome and thank you both and Kristin for joining us today. To start, we've gotten a lot of questions. But just to start off with Dr. Sadowsky, there is a brief PowerPoint, kind of giving you an overview on the topic, so I'm going to hand it over to you Dr. Sadowsky.

Dr. Sadowsky: 00:05:08 Good afternoon I am Dr. Sadowsky, and my interest in bladder function and neurologic injury started about 20 years ago. I became interested in paralysis related to spinal cord injury and disease. I am going to just go over a couple of basic functional and anatomic main functional information related to bladder dysfunction in transverse myelitis and other spinal cord injury related diseases. So the bladder function in itself, has two specific elimination and storage type of activity. So, storage requires for the bladder to be stretchy and the sphincter that prevents leaking – it's basically a kind of like a balloon that gets filled with water and that gets tied down by the sphincter to stop leaking. The elimination part is when the balloon gets untied and requires the bladder muscles to contract efficiently.

So the balloon to get smaller and the sphincters to open at the time when that is needed. There are two sphincters, one of them is under volitional control and I believe that there are some questions about that a little bit later in the podcast and yes, then there is one that is not under volitional control. It just acts in synergy with the bladder, or should act in synergy with the bladder muscle. The problems with the bladder in transverse myelitis are related from muscle spasms or uninhibited muscle contraction in the bladder muscle, and the lack of coordination between the squeezing activity of the bladder muscle and the opening activity of the sphincter, which is called the detrusor sphincter dyssynergia. In clinics, and in your case, this will manifest as either urgency, frequency of urination incontinence with accidents, sometimes inability to void on your own, or having inability to empty completely having as a consequence, recurring urinary tract infection. The general treatment from a pharmacologic part, I'm going to leave the surgical part, to Dr. Lemack, but the pharmacologic part, uh, the treatment, works to either decrease the bladder spasm, or increase the bladder compliance or help with the opening of the sphincter, one of the sphincters, using medications. And I'm not going to go through the specific medications because obviously this is a decision that is being made between the provider and the patient. But those are the principles. I understand that there is an interest in urinary tract infections because there is a problem with recurrent UTI. We treat the individuals, or the clinicians that deal with the urinary tract infections in neurogenic bladder, we only treat the symptomatic ones, because if you manage your bladder using a catheter, chances are that at any time if we do a culture, we would find some sort of a bug. So we only treat the bugs that are creating, that have a pathophysiologic consequence, meaning they give a disease. Discomfort or pain, uh, new onset of urinary incontinence or you are continent, and then somehow the frequency and incontinence increases. You might have increased spasticity, and you might feel lethargic, have this stiffness, sense of unease. Um, you might have problems with the labs, either blood pressure is too high or too low with the goosebumps and facial flushing and sweating and stuff like that. The diagnosis and um, and treatments in, and this is very personal. I, I'm going to talk only about what I do.

Dr. Sadowsky:

00:10:11

I never treat just empirically, I ask my patients to please get a urine specimen, send it out to the lab. I was doing empiric treatment based on previous cultures, with antibiotics. And then when I get the results of the culture, I will tailor the treatments specifically and narrowly to the bug. Because if we use, uh, the big guns antibiotics, we end up creating more

troubles by creating resistant bugs. The treatment for a complicated UTI, which is the definition of a UTI in a neurogenic bladder is seven to 10 days. I actually do the full 10 days. It is not the three days, one to three days, which is done in non-neurogenic bladders. Okay. Recurrent urinary tract infections are related to risk factors and being a female and having a short urethra, I have been sexually active, having preexisting condition like anatomic abnormalities in the lower urinary tract, having problems with immunity, kidney or bladder stones, swollen kidneys, a thickened bladder wall, the fact that the person uses catheterization to empty the bladder. These are all of the factors that increase the risk for urinary tract infection. So I look for each one of them and try to minimize them. First things of the, bladder function is being done with blood work with renal ultrasound to look at the kidney, if it has any stones or if it is swollen, bladder ultrasound or to look at post void residual to make sure that the bladder is emptying, then do the gold standard urodynamic testing, which I'm sure Dr. Lemack, will talk about, um, CT or MRI of the abdomen and more specialized tests, a radiology test and then cystoscopy and cystometrography, in which the urologist takes an actual look inside the bladder and looks for causes and consequences of the disease.

GG: 00:13:10 Great. That was great. And I know we'll get into more detail about kind of each of those issues that you talked about with more specific questions. So for the first question, Dr. Lemack, this came in from, from one of our listeners: Since my diagnosis of neuromyelitis optica, I lost bladder and bowel control. Will I ever regain control? I still do have weakness three months now since they were hospitalized and diagnosed and they've had steroids, plasmapheresis and Rituximab is, you know, and also just more generally kind of like how does regaining control of bladder function maybe occur over time in these conditions?

Dr. Lemack: 00:13:54 Yeah, it's certainly too early to know if it's really only three months as to when or if you'll gain control. There's certainly reason to think that with proper treatment of the NMO, appropriate diagnosis and management, that bladder function certainly can improve with time. Um, and so it's hard to know, you know each case is different. It depends on the location of the lesions and, and the severity of the disease process. But in general, there certainly can be improvement with time. A lot of that has to do with um, you know, evaluating you more fully, seeing exactly what the nature of the problem is. Cause everybody's problem might be slightly different. And even if there continues to be ongoing problems with bladder, most of these bladder problems in most of these situations really can be

effectively managed either with medications or other types of treatments, surgeries and so forth. So I wouldn't lose hope. I think there's certainly plenty of time to work that out. And even if we can't make it completely better, I suspect in most situations you'll certainly be able to get things much better with the appropriate treatment.

Kristin: 00:15:06 Thank you. So, Dr. Sadowsky, we also had another question regarding muscle control and the bladder being full from one of the listeners. They wanted to know if it's possible to regain muscle strength so you could eliminate the need for cathing. And if so, what kind of exercise would be helpful to strengthen the bladder?

Dr. Sadowsky: 00:15:29 Number one, it depends what time in the disease, this question arises. As Dr. Lemack said a little bit earlier, if you are early in the disease and the neurologic deficits we can wait and see. and how the bladder, how to retrain the bladder. If we're talking about being unable to void on your own, three to five years after the injury, I can't say that the bladder needs to be strengthened, the muscle needs to be strengthened, because that's not what the problem in the typical transverse myelitis situation is, the one in which you have muscle spasms in the legs. So if you have muscle spasms in the legs, then you probably have muscle spasms in the bladder. Muscle spasms are working in themselves to strengthen the bladder muscle. So it's not an issue of not being able to void, it's not an issue of not having enough strength. It's an issue of coordinating that ability of the muscle bladder to squeeze and to contract and the sphincter to open in the opportune moment. So it might be that this is the detrusor sphincter, this inability to coordinate the mechanism. It can also be, if you've been for three to 5 more years, if you have, have a neurogenic bladder that you have been started already on a medication. Mostly the medications that we're using now are anticholinergics or a beta-adrenergic medication that actually weakens the bladder contraction because you have the spasms. So the medication is used to weaken those spasms to ensure continence. And that in itself makes it harder to void on your own. So, again, without doing a specific evaluation of the individual, it's hard to say which of the condition is the case, but there is always a good idea to see a neurourologist or a spinal cord injury medicine specialist with the knowledge of neurogenic bladder dysfunction to characterize what type of a bladder dysfunction you have as a consequence of the neurologic injury in order to do the proper treatment.

GG: 00:18:20 Got It and thank you. So a lot of the next few questions are about self-catheterization. As you know, this is obviously a common thing that people with rare neuroimmune disorders have to do. So Dr. Lemack, are there any long term effects from self-catheterization?

Dr. Lemack: 00:18:45 No, in general, the answer is no. I mean, I have patients that I take care of, and probably many who care for these types of patients that are catheterizing since the age of three and four, and Spinal Bifida patients are catheterizing their entire lives, 40 50, 60, 70 years and nobody would really know that they're catheterizing. They just go into the bathroom, do their business and nobody would know. Yes, there are risks for bladder infections, obviously true symptomatic bladder infections. But in general, those risks are higher if you're not catheterizing, and you're leaving excess urine in there. So it is important to pay attention to details, to do it appropriately, to do this cleanly as possible, to do it as frequently as you're being recommended to do it. All those things are quite important. But in terms of other effects, no. Indwelling catheters? Yeah. There's higher risks of infections. There's slightly, I say slightly higher risk of bladder tumors in long term indwelling catheters but those aren't necessarily true for patients on intermittent catheterization. So yeah, bottom line is, yeah, I don't think that is what anybody ever really wanted to do. And in an all perfect world wouldn't be doing it. But if you're doing it correctly and you're doing it the right interval, you certainly can do it safely and without really any untoward effects.

GG: 00:20:02 Great. And just a follow up question for Dr. Lemack, is there potential for damage to the urethra or sphincter from a lifetime of cathing?

Dr. Lemack: 00:20:11 That risk seems to be very low. There is a significant risk of damage to the sphincter and urethra in indwelling catheter and that is something that may not be easily reversible and from a surgery standpoint as some things that we have patients come in that have been inappropriately treated and had catheters in for years and years and years. And the next thing you know, if it's a woman, they've completely eroded their bladder neck or if it's a man they've developed damage to their penis and then that requires surgery to fix. So we try to avoid that. And in general, if you have an indwelling catheter, we prefer a suprapubic catheter, which is not perfect but better. But as far as in and out capitalization itself, or self-intermittent catheterization damage to the urethra is rare. I mean, you can get damaged and a man with scar tissue and those kinds of things. And that's something that can happen to anybody with

catheterization. But it's much less common than with indwelling catheters.

- Kristin: 00:21:04 Dr. Lemack, we talked a little earlier about how much the bladder could hold volume wise. And we had several more questions along the same topic. How much should a person typically be out putting when they cath or how often should they be cathing and how do you stay hydrated without overcathing?
- Dr. Lemack: 00:21:28 So, you know, bladder volume and capacity certainly can vary individual to individual, but in general is somewhere between 200 to 400 CC's. It can be higher. Uh, but that's on average with normal bladder capacity is mmm. And if somebody's not voiding at all on their own, then on average they're catheterize in somewhere between four and six times a day. Again, depending on their fluid intake and so forth. On average, we'd like to have a patient make at least 1500 cc's of urine a day. That's what we consider reasonably well hydrated. In some cases we'll push for more, in some cases we'll accept less. But in general, we want to see at least 1500 cc's of urine a day. And you know, that really shouldn't be impacted whether you're catheterizing or not. That's the urine volume we'd like. You happen to notice it more probably when you're catheterizing because you pay more attention to it, but that's kind of the volume that we're looking for. And so you can gauge the frequency of catheterization based on that total urine output for 24 hours. On average, in somebody who's not voiding at all on their own, on the average, somebody's catheterizing typically four to six times a day.
- GG: 00:22:37 Thank you Dr. Lemack. Dr. Sadowsky, about catheterization, what are the best products to use? There's different types of lubricants and catheters, and we've heard questions about, concern about cancer-causing products. So if you could just talk a little bit about what's out there and what the best products might be.
- Dr. Sadowsky: 00:22:56 I'm going to say that probably the best answer for this is going to be a nurse. But I did ask my nurses and they gave me a list of products that they really love. So MTG Closed System is the favorite. It's pre-lubricated, it has the right amount of stiffness, provides smoother catheterization. It's just that it is not always covered by insurance because it's a one use, single time use, fully inclusive system. So it's more expensive. But. I'm starting with, with, you know, the top shelf here. For single catheters, not the all-inclusive system, the Hollister or LoFric hydrophilic catheters are a good selection. They are pre-lubricated and

most times they come with a gripper to help guide the catheter and reduce the need to touch it. So it ensures cleaner catheterization. For females with good finger dexterity, Coloplast SpeediCath Compact. It's a small little thing that looks like, really a tampon or like a lipstick. There are the Speedi-Cath Flex Coude Pro. It's also nice. It's used more frequently in males that have a little bit of a trouble packing the catheters. I personally don't have a favorite for a lubricant because most of the products that I just spoke about, are pre-lubricated. So, I don't have the need for extra lubrication.

Kristin: 00:25:04 Okay. Thank you. Dr. Lemack, another question for you regarding the best method for cathing, specifically how sanitary should someone be, specific washing, and what's the best way for cleaning the area before Cathing?

Dr. Lemack: 00:25:26 These are the kind of questions where you kind of have to take a step back and have to sort of say, well, what's realistic and appropriate for something that somebody may have to do for the rest of their lives? And balancing that with wanting to try to avoid infections as much as possible. And so it's hard to really answer that question except to say, I will say the people who in general are as fastidious as they can be, seem to do better with infections. That's not to say I recommend that you need to be completely sterile by any means or even use special precautions. I think the most important thing honestly, is using adequate lubrication to get the technique right, Not to reinsert if you've not got it in the right place, not to traumatize and avoiding those kinds of things. So, you know, if you use a wipe beforehand, any type of wipe frankly, then that's great. I mean, but I think the key is to just keep it as clean as possible. Do it the same way each time, and to do it atraumatically, just to do it on the first try. Those are the most relevant and important things. Beyond that, you know, you have to be realistic with what you can do on a regular basis to try to do it in a clean setting. Trying to do it in a controlled setting, realizing that that's just not always possible when you live your life.

GG: 00:26:47 Right, right. That makes sense. So moving on kind of from cathing - we'll talk more about it, but we did get a lot of questions about controlling leaking, or you know, the urge to go to the bathroom. And so specifically, we actually got a lot about this issue at night during sleep. For example, someone said, you know, what can be done to eliminate the need to get up at night to urinate, limiting fluids, doesn't work, getting up to cath disturbs my sleep and often I can't go back to sleep. This person is also taking Oxybutynin or Ditropan. And also someone else has gotten botox treatments and is also still having issues. at

night, um, Dr. Lemack and then Dr. Sadowsky, If you could add as well.

Dr. Lemack:	00:27:33	It's a difficult thing because nocturia or nighttime waking to void is a multidimensional process. Yes. Sometimes it's about the bladder. In men, sometimes it's about the prostate. Many times it's about urine production. Many times it's about sleep disturbances, sometimes about other medications. So there's a lot of different things involved. In general, as we get older and as we get into our 50s, 60s and 70s, we start making more urine at night compared to when we were in our twenties or thirties. In fact, when you're in your 20s, you make about 20% of your urine overnight. When you're in your 60s, 70s and 80s, you make about 35% of your urine overnight. So you have to add that increase your urine production on top of a bladder that maybe is not holding as much and you end up getting sort of this nocturia. So if the medications haven't worked or the botox hasn't worked, it is possible although not necessarily always the case, but it is possible, that nocturnal urine production is increased and that's an easy as nothing to figure out by doing a voiding diary, seeing how much urine you make overnight. If you in fact have increase in your nocturnal urine production and if taking the fluids at night does not helped, then it is possible that you might be a candidate for medication which will decrease how much urine you make overnight. This doesn't have to do with your bladder. It works on your kidneys and there are some new products out there that might help with that. Having said that, it's not everybody that benefits from that. And certainly there are some risks with taking those types of medications. And so you need to be careful and watch your electrolytes closely and have that monitored. But there are a subset of patients, especially younger patients who have this, what we call a nocturnal polyuria that might benefit from that. Otherwise absolutely get a sleep study, be evaluated for that to make sure that, you know, it's not a sleep disturbance that could be contributing, but in fact it's the bladder. If it is the bladder and if it is urine production overnight, then something like Desmopressin, or those types of medications may be helpful.
Kristin:	00:29:29	Okay, thank you. Dr. Sadowsky, do you have anything that you wanted to add?
Dr. Sadowsky:	00:29:34	I wanted to talk a little bit about the DDAVP , the Desmopressin as a pharmacologic intervention. And I can tell you that in patients with, uh, severe overnight, nocturia, I actually ended up putting a Foley Catheter overnight in order to ensure sleep.

Kristin: 00:29:58 Thank you. And, Dr. Lemack, we had another question from someone. Their son had ADEM at age 19. He's about to turn 21 and still has to use the catheter. He currently takes Menitra and Oxybutinan but they don't really help. Uh, are there any other treatments? He believes he won't recover if he hasn't by now.

Dr. Lemack: 00:30:23 So just to be clear, he's using self intermittent catheterization and he's not, so is the question, is he going to void again? Or just try to clarify for me.

Kristin: 00:30:32 Okay. It doesn't specify. It says he still uses a catheter himself. It sounds like Intermittent?

Dr. Lemack: 00:30:41 The reason it's confusing a little bit to me is because the Myrbetriq and Oxybutynin are primarily to help hold more and to help stop urge incontinence, not necessarily to restore voiding. So if the question is will you have a restoration of his voiding function? That's a hard thing to estimate. But in general, the longer you're out from this diagnosis, the less likely that is to occur. And of course there's exceptions of every rule, but in general, the longer you're out from it, then the less like it is to occur. The question is he's using the Oxybutynin then Myrbetriq and he's still leaking between catheterizations. Yeah. Then there certainly may be some other options to try to improve his quality of life, whether it's Botox or other types of surgical interventions. There may be some options, uh, for that type of thing.

GG: 00:31:28 Thank you. So in general, what is used to prevent accidents or leakage? We've heard about Botox, you know, is it safe? What are the options out there? Dr. Sadowsky?

Dr. Sadowsky: 00:31:47 I alluded during the opening statement that there are medications that can be used, one to decrease the bladder spasms and those some of the names out there are Enablex, Ditropan, Vesicare, onabotulinumtoxinA definitely, uh, um, and then there are some older drugs that act centrally, like Amitriptyline, Hyoscyamine, Bentyl, so forth. If the problem with the urgency and incontinence the bladder accident is related to the fact that the bladder is not stretchy enough there are other medications that can be used like Santura, Myrbetriq and Botox again. And if the urgency incontinence is related to this dyssinergia between the bladder and the sphincter then medications that affect the internal sphincter like Flomax or Cardura or Hytrin can be used to ease that dysserginic dysfunction. Again, the decision on what type of medication to use is done based on individual assessment and most of the cases performing urodynamic studies will be able to tell the

provider, which of the phenomena is responsible for generating the incontinence and the leakage.

- Kristin: 00:33:34 Okay. Thank you. Dr. Lemack, we have another question regarding Botox therapy. The question is due to urine backing back into the kidney and that I leak urine somewhat regularly during the night, I had botox therapy done. My doctor said the injections will be effective between three to 14 months averaging six months. Will this be a lifetime recurring procedure, or will there be a time when urine will not back into the kidneys and or leakage will stop on its own?
- Dr. Lemack: 00:34:08 The primary indication for Botox, is urgency and urge leakage. And with regard to that, yes. When it helps you, uh, unless there's some other neurological change, it's not anticipated that you wouldn't need it. In other words, on average, you're going to need it two or three times a year. Um, yeah, correct. On average it's about five to six months, sometimes longer can be up to nine or 10 months. Uh, but that's very dependent on patient's expectations, how often they want it and so forth. Yeah. Um, so I would say yes, it certainly could be a lifetime benefit if you still see a benefit. As far as the backing up to the kidneys go, that's a more complicated question and if in fact this patient does have what's called the vesicle uretal reflux, which is urine that's truly backing up, and I'm not sure that's really what's going on here, but if it is, that's not necessarily, uh, an expectation of Botox treatment. If that's happening because there are high pressures in the bladder and the Botox is addressing those pressures and then subsequently the reflux gets better, than then. yes, I guess that's a possibility. I'm not sure if that's really what's going on here or not, but again, that's not the primary indication for Botox. It may be something they'd like to see with Botox injections to see that improve. But, um, I wouldn't say it's a reliable thing that you would see after botox treatments.
- GG: 00:35:34 Thank you. And then just briefly talking about, we haven't talked too much about kind of these surgical options. But this question says I had some Mitrofanoff procedures done without a bladder augmentation. I never leaked before surgery, but now leak out of the stoma when I get bladder spasms, despite being on every type of bladder medication. My doctor recommended a bladder augmentation and a revision of the stoma to tighten it to prevent leakage with this guarantee. I don't get leakage. What about, uh, the potential cancer risks that I've heard of with augmentation? Dr. Lemack?

Dr. Lemack: 00:36:09 So the first thing I'd say is there's no guarantees with any surgical procedures. Sol wouldn't go into any type of procedure thinking that there's no risk for ongoing leakage because there always is. Having said that, if you've tried the medications, um, by the way, Mitrofanoff essentially means that there's typically an appendix that's used, and directly placed into the bladder and then brought out to the skin so that you can catheterize through the appendix, through the skin and into the bladder. We try to do that without an augment in some situations because yeah, adding the augment, adds some other risks - adds mucus, increase infections and so forth. And there is this tumor risk with an augment. Having said that, if you're leaking now, first thing to do would be to get studied and hopefully that's already done, but usually get a video urodynamic study to ensure that the leakage is, is due to the bladder having spasms, and not due to some sort of anatomical problem with the Mitrofanoff. If it's due to spasms and the medications haven't worked and Botox hasn't worked, then yeah, I think an augment would probably make the most sense. If it's not due to spasms but it's just leaking out passively through the Mitrofanoff, then maybe some type of revision of the Mitrofanoff alone would be helpful. Lastly, in terms of the risk of tumors, yes, there's a risk of developing tumors when you're using a segment of bowel and putting it in continuity with the bladder in the case of an augment. However that risk is very remote, very low, and I think with adequate and appropriate surveillance, meaning repeat cystoscopy every year or two to watch for the development of those tumors, I think it's probably overall an acceptable risk. And again, it's quite a low risk in general.

Kristin: 00:38:01 Thank you Dr. Lemack. Changing gears now. We had a lot of questions about urinary tract actions and one of the first questions that we had had to do with what are the best methods that someone can follow to prevent UTI. For example, are there essential oils, maybe a daily low dose antibiotic? Dr. Sadowsky, do you want to give us your opinion.

Dr. Sadowsky: 00:38:31 Sure. So, the prevention of urinary tract infections, if you do not use the intermittent catheterization or an indwelling catheter, is being done differently than if you do use the catheter. I'll start with, I personally don't know of any supplements or essential oils that can prevent urinary tract infections. Good hydration, adequate hydration, good healthy eating. If you docatherization, adequate catherization technique as Dr. Lemack detailed previously are good enough methods to prevent urinary tract infections. Daily low dose antibiotics is a definite no. This just leads to development of a recurrence of urinary tract infections with resistant organisms. So that is a

definite no. So again, hydration, good hydration, good hygiene, good healthy eating and exercise.

GG: 00:39:54 Thank you Dr. Sadowsky. And then, so we talked about preventing UTI, but then what if one does have a UTI, what are the best methods to treat. I know Dr. Sadowsky you talked a little bit at the beginning about kind of your protocol. Dr. Lemack do you have anything to add? Do you always treat if someone comes in with symptoms of a UTI or is it based on urine culture and analysis? Um, Dr. Lemack?

Dr. Lemack: 00:40:18 Yeah, as Dr. Sadowsky mentioned, I totally agree. The problem is generally speaking, that urine cultures are sent routinely by kind of well meaning other providers. And then you get back a urine culture and it's positive and you don't know whether to treat or not. And I think probably most people listening to this podcast and certainly the both of us do this all the time. And then, you know, the counter argument is that many people in this situation don't have the typical symptoms that, that most of us would have if you have a UTI. And so, you know, it's a slippery slope. But the bottom line is, uh, I think the most important thing that Dr. Sadowsky mentioned earlier is to treat only when appropriate, meaning some other symptoms. And that symptom may be spasms. It may be lethargy, it may be fever and maybe back pain and maybe something subtle that only that patient knows. But in the absence of those things, in the presence of a urine culture that's sent without any obvious symptoms, the worst thing you can do is treat that. Having said all that, yeah, we don't treat blindly. If we're convinced that they're truly having a symptomatic UTI, we would base it on a culture, we do not empirically treat. I think that just leads to resistances. And probably more often than not, it's not really going to work in many of these patients because they do have resistant bugs anyways. Uh, so I would encourage them if they are having symptoms that they truly think are related to UTI, I'd get appropriate culture sent, uh, get it to the physician and get it to who treats or takes cares of these patients. Because as also as mentioned earlier, typically it takes a longer course of therapy then sort of your community acquired UTI. So you've got to be careful about that.

Kristin: 00:41:52 Thank you. and following up on that, there is a question about chronic UTI. So, we've mentioned some of the tests like the cultures that can be done to identify if someone has a UTI, but are there any other tests that a urologist could order if somebody is experiencing chronic UTI's? And what if those tests don't show anything abnormal and you're still experiencing those symptoms? Doctor Sadowsky?

Dr. Sadowsky: 00:42:19 I kind of mentioned, that's why I had that one slide saying "testing". And so for a recurrent UTI, imaging - adrenal ultrasound or CT of the abdomen to look to look at, if there are anatomic abnormalities or if there are stones, um, or if there are consequences of a neurogenic bladder like the swollen kidney I was talking about, which is hydronephrosis, which is related to the physical urethral reflux that we -- backing up into the kidneys that we talked to previously, checking post void residuals, which looks at the function of the bladder. Because the more, um, the bigger the volume, that space in the bladder, the more likely that, uh, a urinary tract infection will recur, and there are some numbers, uh, in traumatic spinal cord injury, uh, studies have shown that oppose where the residual higher than 50 milliliters, which is an ounce and a half of urine, um, eh actually predisposes to, to a recurrent urinary tract infection. So checking what that residual is and performing a cystoscopy to look on the inside to locate that are, as I said before, signs of inflammation. And I think Dr. Lemack can actually comment because he does the cystoscopy, I don't, I just read the reports so maybe he can comment on what he sees when he looks on the inside. Um, and that could predispose to recurrent urinary tract infections.

Dr. Lemack: 00:44:06 The only thing I would add is that, so yes, I think it's certainly appropriate in these situations to do those workups, and we, and the main thing is to make sure we're not missing something that would have an actual treatment besides just empiric therapy. So, yeah, occasionally on cystoscopy, we'll see foreign bodies like stones, uh, we'll see diverticula or cellules or areas in the bladder that don't drain very well, we'll see areas in the bladder that are inflamed and what we call cystitis, you know, trigonitis or other areas in the bladder that may be amenable to other types of treatments. Um, with regard to the kidneys, we may see kidneys that don't drain very well, with hydronephrosis or kidney stones or other various types of kidney or renal abnormalities. Um, and so all those things are uncommon, but, um, I think we be kicking ourselves if we say, oh, we missed something that really could have had a treatment besides just doing empiric therapy. So yeah, I would agree with all that. Certainly upper tract imaging and patients who have recurrent UTIs that we can't get a handle on the reason why it's there and cystoscopy in the appropriate patients are relatively simple, straightforward procedures in the office, literally takes, you know, 10 minutes or so. And so you can just reassure the patient and yourself as a physician that we're not missing something that might really have a very easily and readily available treatment that might make things better.

Kristin: 00:45:25 Okay. Thank you. And this is a similar question, but what about those instances for some individuals where, they have tried educating themselves, changing the technique for their cathing approach, even changing the types of catheters or brands and antibiotics just don't seem to be working where they come off of an antibiotic for treatment and then the UTI, all the symptoms come back within a week. So for those individuals that are at their wits' end with what they should do next. Do you have any other suggestions for how these individuals can get through their recurrent UTIs? Dr. Sadowsky?

Dr. Sadowsky: 00:46:10 So when it comes to me, I go through a progressive catheterization protocol. I start first with clean intermittent catheterization, which does not require much except washing, and reusing the catheter but with proper care of the catheter, usually the patient will have about six to 10 catheters, that they will rotate throughout the day. And will keep in soapy water in between usage. Once they have recurrent urinary tract infections, then I am progressing to a clean technique, but sterile catheters. So I'm using one-time use catheters that are sterile, with a clean catheterization technique, meaning just washing the hands, and using that one time catheter. The highest urological intervention is using sterile catheterization with sterile technique. Um, I don't think I have more than probably 10 patients in my 20 years of practice that reach, that level that is the technique in which you wash your hands and put on sterile gloves. This is not exactly something that requires to be done. Uh, but if you are at the wits' end, I would definitely resort to using sterile catheters, with sterile technique. I'm coming back to the sterile catheters. I do have this preference that if you have recurrent urinary tract infections, and I do believe that insurance companies are looking at, documentation of two or more urinary tract infections per year, they have to have documentation with culture and sensitivity. And most of the insurance companies, if you meet that requirement, they will pay for sterile systems, which my favorite is the closed, the MTG system, which is easy to use and also sterile. That's limiting the possibility of recurrence.

Kristin: 00:48:48 Thank you. And Dr. Lemack, do you have anything to add to that?

Dr. Lemack: 00:48:51 No, I think all those things are perfectly appropriate. I will say that particularly in the non-neurogenic community for recurrent UTIs, truly some dramatic recurrent UTIs, I will say that at least in my practice, and again, it's not necessarily this particular group of patients, but I would say that there is a role for controlled low dose specific antibiotic use daily or on a self start

basis. And they have to be careful with it. You have to monitor it. But I will say that in the appropriate selected patient it may be of some benefit. And I know we talked about this earlier and some feel very strongly about it and I certainly understand that, but I will say that in a select group of patients it may be appropriate. And I would say after that, you know, I do take, I would say I do about, uh, perhaps five or so a year patients with either MS or other neurologic conditions who have just such fulminant UTIs and recurrent pyelonephritis that they just can't get past that, we do have to go onto other surgical procedures, to address that, even types of urinary diversion, which again thankfully are very uncommon, but once in a while we have to do that. And I will tell you that once we do that and take that out of the picture, then these patients just can sort of go on with their lives. So there are other options and you know, luckily we don't have to do that very often, but on occasion, especially when it's leading to exacerbations of their underlying neurological condition, you know, you need to consider some of these other more advanced surgical options.

GG: 00:50:25 Got it, thanks. And then talking a little bit more about surgery as well, or surgical things related to this. We did get a question from someone. Her husband has transverse myelitis and currently has a suprapubic catheter. He developed a wound near his groin area on the left buttocks and then another one on the right. And so his wound doctor closed one of the wounds and was going to do a surgery on the other one. But he was diagnosed with having a fistula and so the urine was actually leaking through the wound. And so the urologist attempted a bladder neck closure but then it opened back up again, and failed. And he stated that there was too much scar tissue from the first surgery for him to close it, and suggested an outside bladder. So her husband still has this wound that won't close, and so the wound doctor, she's wondering, you know, the wound doctor, if she, if they closed the wound, how would this impact the fistula or the urinary issues that this person is experiencing? Dr. Lemack?

Dr. Lemack: 00:51:28 It's a pretty complex and specialized problem, and I would suggest getting to a higher level of care and making sure that it's appropriately treated, diagnosed and managed. But yeah, from the sound of it, without knowing the full details, it sounds like this person's headed to what's called an ileal conduit or urostomy. The only way to get this thing to dry up, in my opinion, would be to just go ahead and do what's called a urostomy, which essentially is to divert all the urine away from the bladder probably, or possibly remove the bladder. But yeah, build what's called a stoma to the skin and divert the urine

there. Again, if it's just the fistula involving the urinary tract and not involving the GI tract, then that, yeah. That should take care of it. It may take some time, but it should take care of it.

- Kristin: 00:52:21 Thank you, Dr. Lemack. We have another question regarding stem cells from an individual who has had TM since 2005 and is experiencing incontinence. And they're wondering if stem cells is an option at some point to help alleviate that condition.
- Dr. Sadowsky: 00:52:42 Oh, um, I'm going to say that I can't say that there is a stem cell procedure that I know about that will help alleviate with bladder incontinence. Um, and that's, at least in the United States. Stem cells are still at the phase in which we're just figuring out what they can do. We're not yet using stem cells for specific treatment of urologic dysfunction. With that said, I know that stem cells are being looked upon to improve neurologic functions and there several different types of cells that are being tested. The clinical trials take a bit of a time, and we just have to wait to see if they do impact neurologic function including the bladder function. But for now I'm going to say that we have quite effective treatments to deal with incontinence and neurogenic bladder that don't require stem cells. So being evaluated by a neurourologist or a spinal cord injury medicine specialist with a knowledge in bladder management is a very effective way of improving your quality of life when it comes to bladder incontinence.
- GG: 00:54:32 And um, you know, just thinking about, you know, all of our listeners who use a catheter or have, you know, neurogenic bladder issues, are there any sort of long-term kind of monitoring that needs to be done? I know we talked about renal or kidney ultrasounds or cystoscopy. Is there anything, um, that's recommended, you know, their yearly or at certain intervals to just make sure everything is working okay? Dr. Lemack?
- Dr. Lemack: 00:55:00 So that's actually a bit of a controversial issue which we've written about here at UT Southwestern in terms of monitoring upper track and used to be advocated that every single person has neurological diagnosis, had some bladder problems. They need to get their kidneys evaluated every six months, every year and so forth in it probably is true that for years and years this was just over done. We didn't really need to do it as much, so yeah. MMM. The bottom line is that they're not, every neurological patient is the same. Not every neurological patient has the same, uh, risk factors. And so it has to be sort of investigated on one on one, you know, each patient and visual. I would render to say that at the most getting imaging of the

kidneys every other year with a renal ultrasound, just adequate and that most patients with either MS or transverse myelitis probably don't even require that. As far as cystoscopy goes, yes. If you have an indwelling suprapubic or urethral catheter that has been in for awhile, monitoring that every year or two, to look for foreign bodies, stones or other tumors, which again are very unusual, is probably reasonable if you've had an augment. Yeah, absolutely. Monitoring cystoscopy every couple of years after the first five to 10 years appropriate to look for tumors. As far as urodynamics or bladder function tests, if in the past it was advocated this needs to be done every year or every two years. That's probably not the case for most patients with TM or MS, but it might be for patients with specific, previous urodynamic diagnoses that are worrisome, and certainly patients for example with spinal cord injury and those kinds of things may be more appropriate to do on a regular basis. Uh, but the bottom line is these patients would have to be individualized and there's no set pattern, with the exception of those two things I mentioned.

- GG: 00:56:37 Got it, and so Dr. Sadowsky, do you have anything to add to that?
- Dr. Sadowsky: 00:56:39 Uh, no. I do annual lab work to look at the abdomen, not only because I do it for the neurogenic bladder and the majority of the patients I've had on pharmacologic management of other conditions including neuropathic pain and spasticity that I take a look at the bladder and kidney and liver function doing a CMP (comprehensive metabolic panel). I also, when it comes to urodynamics, I only check them if the bladder function changes. So if there is a new onset of a new pattern and how the bladder elimination of course, then I will check urodynamics. Otherwise I do not check the baseline urine or ongoing yearly, annual or every other year urodynamics. I do, if I have a urodynamic diagnosis, so if they have an abnormality that I correct with a pharmacologic agent. I would like to, uh, repeat the urodynamic testing in two to three to four months after using the medication or whatever intervention I use to make sure that I actually achieved what I intended with the medication.
- Kristin: 00:58:05 Okay. Thank you. And just to finish things up, we're near the end of our podcast. Dr. Lemack and Dr. Sadowsky, is there anything that we didn't get a chance to talk about during the podcast today that you wanted to bring up to the listeners?
- Dr. Lemack: 00:58:23 No, from my standpoint, that was a very thorough discussion. And again, the bottom line is, you know, every patient is different. There's different issues. Even though there's some

things that are certainly common between patients and we've covered a lot of those. You know, if you're not getting the help you need from your provider, then, you know, try to seek out specialists, whether it's in physical medicine and neurology and you know, these people who have more familiarity with it. And you know, you can't generally cure these problems, but you certainly can address quality of life issues and make things a lot better. And I think finding somebody to help you with that, probably the most important thing.

Kristin: 00:58:55

Great! And Dr. Sadowsky?

Dr. Sadowsky: 00:58:56

I second that. I do believe that exercise activity has an important role in maintaining a physiologic integrity of bowel and bladder function. So being active, helps. Sometimes the bladder issues are related to bowel issues. So keeping active is important. If the neurogenic bladder is from a traumatic spinal cord injury, which is not the case that with the majority of the individuals that were on the podcast today. But transcutaneous spinal stimulation is a technological area, meditative intervention that has been utilized in the last eight to 10 years and it seems to modulate the autonomic nervous function, including bowel and bladder and sexual function. So, um, you know, checking in with a center that specializes in innovative, technological or rehabilitative activity based interventions is probably a good idea.

GG: 01:00:09

Great. Thank you. And thank you both so much for joining us today. I know it's a complicated topic and we got through as many questions as we could. We really appreciate you taking the time and, and Kristin for joining us as well today. So thank you.

Dr. Sadowsky: 01:00:22

Sure. Our pleasure.