

# Dealing with Bowel and Bladder Issues Can be Mind-Boggling

For sure! Managing your neurogenic bowel and bladder after Spinal Cord Injury (SCI) can be a most challenging and frustrating task. Information is hard to find. Not everyone is able to provide you with the right answers. Studies in this area are not geared to provide consumers with practical clinical information on how to best manage issues associated with bowel and bladder.

We, at the University of Michigan (U-M) with funding from the US Department of Defense (DOD), have been doing the research on how people, both veterans and civilians with SCI, are finding their own answers to the difficult questions. And we are here to share new knowledge that can help inform your future decisions.

**This newsletter is our report to you.**

The information in it will not tell you exactly what you should do if you are faced with bowel and bladder challenges, but it will reveal how others have made those tough decisions. This new information, in turn, may influence your own decision making process when the time is right.

The newsletter will be published in three consecutive monthly issues, July-September. This first issue will describe the factors that drive people to certain decisions. Are your symptoms getting worse, for example? The second newsletter, in August, will focus on how people think through and decide upon each of their choices. Who might you first ask for advice?

The final issue in September will be about our study participants' perceptions of how these decisions have impacted their health, wellbeing and quality of life. Which medical choices will make life better?

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# DECISION MAKING ABOUT SCI

## How to Best Manage Bowel and Bladder Issues After Spinal Cord Injury

### How Your Decisions Can Affect Your Bowel and Bladder Functioning and Your Overall Quality of Life

By: Denise G Tate PhD, Professor of Physical Medicine and Rehabilitation and Project Director



Denise G. Tate PhD, is a Professor and Psychologist in the U-M Department of PMR with years of experience in SCI.

As living with Spinal Cord Injury (SCI) becomes a lifelong process, different sets of problems are likely to occur at various times during your life.

Most people with SCI and neurological impairment will have associated bowel and bladder problems making this an important management issue. Thus, living with SCI requires extensive decision making over time to address the many associated health issues and complications.

On a daily basis, decisions about your care directly and indirectly impact your success in avoiding bowel and bladder complications.

These decisions are particularly complex in that neurogenic bowel and bladder affect multiple areas of life. They can affect your ability to participate in society--at home, in your community and beyond.

Complications such as recurrent urinary tract infections (UTIs), bowel and bladder leakage, incontinence, constipation and persistent hemorrhoids can affect physical functioning, sexuality, and pain levels. Such new medical difficulties can also degrade both mental and emotional wellbeing, including your sense of control, and feelings of competence.

Because the ability to make effective and informed decisions about your health and lifestyle is of vital importance, we decided to study how these decisions are made, and how they impact the care and the lives of those with SCI. We spoke to 61 people with SCI who disclosed very personal information and insights with our research team in order to help others who may be facing the same issues. It is our privilege to share this new knowledge here.

## Study Participants and their Characteristics: *Who Were They?*

Our participants included a mix of 30 veterans and 31 civilians with SCI. Civilians were recruited in the State of Michigan through medical facilities, The Ann Arbor Center for Independent Living (AACIL), and registries.

Veterans were recruited through the Ann Arbor VA Medical Center, Michigan Paralyzed Veterans of America (MPVA) and from other states with assistance from the Paralyzed Veterans of America (PVA).

### **We wish to thank all who participated in this study for sharing their stories about complications with neurogenic bowel and bladder issues.**

Men with SCI made up the majority of participants (93.3%), most were white (92%) and most were injured through vehicular accidents (36.7%). Most were married (70%), had bachelors' degrees (40%) and most were retired (76.7%). The majority had complete paraplegia (46.7%). Veterans were on average 60 years old, while civilians averaged 49 years of age. Time since injury ranged from 22 to 23 years.

Their main method of bladder management was self-intermittent catheterization (55%) while digital stimulation (19%) was the most frequent method of bowel management.

Bladder incontinence, urinary tract infections, bowel incontinence and constipation were the main complications requiring decision making and changes.

*"Well, bladder's the thing that is threatening to my health and wellbeing...Urinary tract infections are increasingly a problem. And you know, I'm having to take stronger antibiotics. I was in the hospital in September and had to do about four weeks of IV antibiotics... after the fact I found out that Medicare part B does not cover supplies for when you're home getting IV meds..."*

--Study Participant

## Up-Close and Personal: A Conversation with MPVA President, Mike Harris

Interviewed by: Denise G. Tate, PhD



### **Interviewer: What do you see are the major barriers to successful management of bladder and bowel after SCI?**

Information overload from shorter rehabilitation stays, because of insurance limitations, and the difficulty of accessing SCI specialists in a timely manner represent barriers that have ripple effects. These ripples create further hurdles to successful SCI management, including that of bladder and bowel care. It is important to remember that many secondary conditions can be prevented or diminished through appropriate self-care and/or self-management

These barriers, however, require patients and family members to absorb self-care information quickly while in the hospital and to be proactive in finding health information once they are discharged. Individuals with SCI need timely, high-quality information about health and medical issues after discharge, as well as throughout their lifetime, to reduce secondary conditions, stay healthy, and maximize quality of life.

### **Interviewer: How do you personally make decisions about managing your bladder and bowel and related complications?**

As a person with a SCI, I know that living successfully with a disability entails being aware of one's health needs and resources. Also, coping effectively with the stress and difficulties often associated with having a physical disability is supremely important. Individuals who adjust well to unexpected events generally lead healthy, active, and fulfilling lives after their injury.

Most people with a spinal cord injury would probably tell you that after the loss of mobility, loss of bowel/bladder control is the next most distressing aspect of SCI. Bladder/bowel accidents can lead to isolation and depression. It certainly affects quality of life, as it can interrupt moving forward with plans and activities. Fear of even a potential bladder/bowel accident can be just as powerful; for example, I will not eat anything the day I'm flying somewhere because of the fear of having a bowel accident.

I was once told that rehabilitation doesn't really start until discharged from the hospital. This was true when it came to managing my bladder/bowel care. When suffering from bowel dysfunction, bowel management can be the most frustrating, embarrassing, and time-consuming challenge of the day!

Someone living with a SCI learns that their bladder/bowel delivery of care routine changes throughout their lifetime. What I learned in 1986 no longer applies now! From time-to-time, I encounter problems with my bladder/bowel program. If I'm having a problem and not sure what to do, I try getting a better understanding of what may be causing the problem and of different solutions. This may involve doing research on the internet or consulting with my PMR doctor. I've found it very helpful to speak with peers who have had similar experiences.

I have always viewed the peer mentoring program as an extension of rehabilitation. Peer mentorship often provides a level of credibility that non-peer relationships lack because they offer a perspective from their own personal experiences on the realities of day-to-day living with a spinal cord injury. I've found this to be especially true when dealing with bladder/bowel dysfunction. Some of my best outcomes have come from conversations with peers living with SCI. These friends have recommended changes that have had a positive impact on my bladder/bowel care.

**Interviewer: What recommendations do you have for those facing similar decisions?**

- Make sure you evaluate the reliability of the information you find and try not to rely on information from only one source.
- It's important to make only one change at a time so you can tell whether it works or not.
- Make sure you keep track of what you do and what the results are.
- If you don't solve the problem, you may want to choose another option. Problem-solving can involve lots of trial and error! Regrettably, there is no shortcut to find what works for you.

Following SCI, patients will require active management of their bladder/bowel care throughout their lives. Effective bladder/bowel management is fundamental to quality of life after SCI and is maintained by education and the ability of the individual to make changes when necessary.

Unfortunately, you can do everything "by the book" and you may still have a bladder/bowel accident. The spinal cord injury team at U-M are dedicated in helping patients and families ensure that they have access to the care and resources required to maximize recovery. However, after discharge, there are questions that go unanswered; new questions that will periodically come to mind.

**Interviewer: Would you consider surgical procedures as an alternative, if needed?**

If a surgical procedure could enhance my quality of life, I would consider it after exploring all other credible options. It is important to realize that solving one problem might lead to other problems; for example, to control my spastic bladder, I was prescribed Imipramine and Oxybutynin thirty years ago. I was recently informed by my dentist that taking these medications had a negative impact on my dental hygiene because my mouth is constantly dry from the medication.

Sometimes, your injury or other health issues may limit your ability to use traditional bladder/bowel care management methods, or the traditional methods are not working as well as you may like. There is no single reliable method to suit everyone, you may need to experiment quite a bit to find a method to suit your own needs and lifestyle.



Mike Harris, right, chats with fellow MPVA member

# Which Factors Influence Decisions About Bladder and Bowel Problems After Spinal Cord Injury the Most?

We asked participants, veterans and civilians with SCI, which factors influenced their decisions regarding the problems they faced in relation to bladder and bowel function.

First, almost everyone (96.7%) said that the worsening of complications such as incontinence, leakage, constipation, and recurrent urinary tract infections (UTIs), and the increased frequency and intensity of related symptoms was the most important factor in deciding what needed to be done to address the issue.

Second, continued issues in managing these problems, including methods of emptying bladder or bowel were noted by 95.1% of study participants as important factors in their decision making.

Third, ineffective treatments was another reason 91.8% of participants would make new, perhaps different decisions about their bowel and bladder management activity.

Fourth, negative impact on quality of life was also a critical factor impacting decisions, with 88.5% of participants endorsing it.

Other factors influencing decisions were access to resources such as health care facilities, insurance coverage, caregivers, personal finances; relationships with doctors.

Many felt they could trust their doctors in providing good advice while others felt neglected and ignored. Participants additionally cited that the need for emotional and social support; and their own personal style, characteristics, skills, and preferences were important factors to consider.

Below is a quote by someone with recurrent UTIs and bladder leakages who ultimately decided to have bladder augmentation surgery:

*"Like the more I think about it (leakage), the more of an inconvenience it is and the more stressful it can be. These are things that I would like to avoid having to do. Again, I am asking for my options. This medication is not working as well. Botox isn't working. The doctor did suggest that I try Botox again, which I did and it didn't work. It's expensive too. Some of these procedures have a pretty substantial co-pay. Apparently, that's another factor that enters into the situation--the cost."*

**These decisions are complex when considering all issues that need to be evaluated, as they can seriously impact your quality of life forever.**

## Reasons for Making Decisions to Change Bladder and Bowel Care

By: Denise G. Tate, Ph.D. and Edward Rohn, Ph.D.

Study participants shared their perceptions of what ultimately motivated them to change their current bladder and bowel care to address problems. We analyzed what they said and grouped them according to their answers. We found that reasons given could be grouped into six different categories. Those categories included those that primarily discussed:

- **Recurrent symptoms and complications** – almost everyone spoke about their symptoms or complications as motivating their decisions.

*"Immediate urgency to go and leakage, and not a lot of volume. So, it was like just every hour or two, I feel like I had to go and I wouldn't – I couldn't avoid it because then, I was leaking."*

- **Balancing dissatisfaction between current treatments and decisions to change treatments** – those with a positive outlook (34.4%) focused on convenience, ease management, and seeking less invasive or dramatic management changes. Those with negative outlook (37.7%) spoke about ineffectiveness of treatment options, exhausting all their options, etc.

# Meet the Study Team and Collaborators

## *A Diverse Group of Experts*



**Lisa DiPonio, M.D.** is the VA site Principal Investigator of this project. She is an Associate Professor in the Department of Physical Medicine and Rehabilitation (PMR) at Michigan Medicine and the Service Chief in PMR at the Ann Arbor VA Medical Center. She is also the Service Chief for the SCI and Disorders Unit at the VA in Ann Arbor.

**Edward Rohn, Ph.D.** is a medical anthropologist, co-investigator and lead on qualitative data analysis for this study. His research has focused on the lived experiences of chronic pain for persons with SCI, as well as shared decision-making with healthcare providers.

**Marty Forchheimer, MPP** has led the analysis of quantitative data for this study. He has engaged in disability research since 1989, primarily concerning the wellbeing of people with SCI.



Additional collaborators include Drs. Anne P Cameron from the Department of Urology and Gianna M Rodriguez from the Department of PMR. Both are clinical experts in treating patients with SCI at Michigan Medicine. A special thanks to Michael Harris, President of the Michigan Paralyzed Veterans of America (MPVA) and Cheryl Vines, Director of Research and Education of Paralyzed Veterans of America (PVA) for allowing us to reach out to veterans in the United States interested in participating in this study.

**And, again, we extend a very special thanks to all who volunteered their time to become study participants.**

## *Our Personal Sources of Inspiration*

The open-hearted testimonials and ideas for this study came, most of all, from two people in our community who each shared their deep, personal understanding of SCI and how life with SCI evolves on a daily basis. Their gracious insights enlightened each stage of our research.



Marva Ways



Tom Hoatlin

To watch their video **Don't Let Your Bowels Control You** go to:

[https://msktc.org/sci/Hot-Topics/Bowel\\_Function/Bowels-Control-You](https://msktc.org/sci/Hot-Topics/Bowel_Function/Bowels-Control-You)

*"I was traveling ... a lot, so I wanted to get an easy way to cath and quick as well as cut down on UTIs and get off antibiotics and stuff."*

• **Life adjustment: achieving independence, avoiding dependence** – Many spoke about seeking a sense of normalcy in their lives, fitting into their communities, and being able to do what they enjoy the most.

*"Independence was a very key issue... We did not want either of our parents in their 70s...trying to cath me. That's when ... they recommended ... getting a suprapubic catheter, so once they explained that to me, it sounds like a huge win and my kind of thing, and I knew it would gain me some independence."*

• **Behaviors or personality factors** – Many spoke about the impact of their emotions or self-identity as contributing factors to make certain decisions. Some spoke about their military training involving discipline and organizational principles assisting them with decisions.

*"Your body is telling you that. And so I've learned to listen to my body, because my body is smarter than I am."*

• **Support, guidance, and communication with doctors and other clinical providers, friends and family as well as peers** – Most (52.5%) highlighted the positive impact of these factors in helping them make good decisions. Trust in the doctor was also described as critical to make decisions.

*"You know between the doctor/patient. It should be a relationship that you feel confident in expressing issues... because you know you feel confident that the answers you hear back are gonna resolve the issue at hand."*

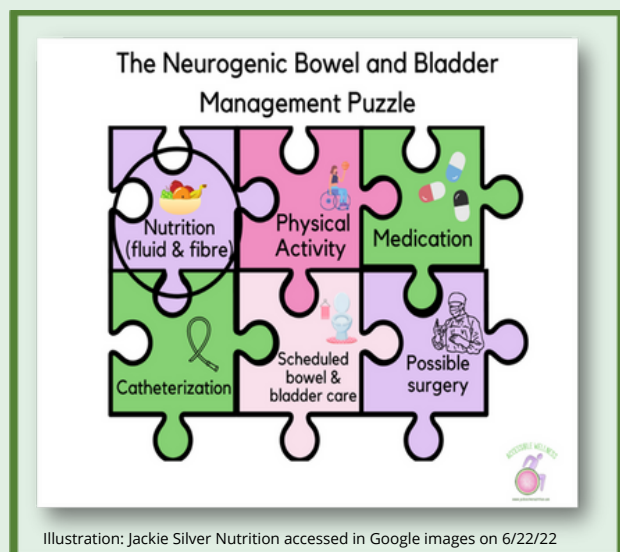
## Findings of Earlier Studies

Only a few studies previous to ours have explored decision making among persons with SCI and bladder and bowel dysfunction. Here are four of those prior findings:

- ✓ One study by Katsumi et al. (2010), suggested that bladder management methods for veterans with SCI should be selected on the basis of long-term comfort for the person; asking for physician's flexibility in bladder management.
- ✓ Another study by Engkasan and Low (2015), focused on civilians and the role of patients, caregivers and physicians in bladder drainage revealed a paternalistic model of physician control, challenging patients' decision making.
- ✓ A study of veterans' primary care, by Weiner et al. (2013), showed a direct association between active patient decision making and improved health care outcomes.
- ✓ Last, a study by Locatelli et al. (2016) emphasized the benefits of shared decision making in producing effective solutions to health problems while promoting patient autonomy in relation to self-care. Greater effectiveness in decision making was achieved by those who were more involved in their own care.

## Bottom Line:

***What are the factors in your life that would influence your decisions about future bowel and bladder management?***



Editors:  
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Sunny Roller

**Watch for the next newsletter coming in August!**