Decisions about your health and life consequences are hard for anyone to make. Decisions in healthcare can be particularly difficult, involving sorting through complex diagnostic and treatment options and uncertainties, personal preferences and values, and availability of resources and benefits.

Appraising each situation that requires a solution, a change, and a decision can be overwhelming. We discussed in our study how this is done and the need for assistance and support from health providers, family, friends or peers, combined with our own self-direction, motivation, and ability to engage in decision making.

A few tips can be helpful:

1. Try to define and understand your problem and its consequences for your lifestyle, health, and wellbeing

2. Divide the problem into logical steps and components so they can be evaluated separately and then jointly. When does bladder leakage occur, for example? What factors seem to influence its occurrence? How does it occur? What happens because of these leakages? What are the solutions or treatment options?

3. Integrate the information you just obtained from your doctor or your own research with your personal values and expectations and ask yourself the question, “what is most important to me?”

4. Explore and evaluate these options by talking with others who have spinal cord injury (SCI), your doctor, therapists, and caregivers, as you are doing your own research. You need to think through the sequence of consequences of each decision option, both short-term and long-term. Search for the best evidence available, which is often explained in clinical practice guidelines, such as those published by the Paralyzed Veterans of America (PVA) as consumer guides at https://pva.org/research-resources/publications/consumer-guides/
Putting the Puzzle Pieces Together

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

Making decisions about health and wellbeing after SCI can be harrowing—filled with puzzling alternatives. Decision making is complex because SCI can affect almost all organs and all bodily systems. In our study, we heard several concerns expressed by SCI veterans and civilian participants.

“Um, hemorrhoids have been pretty bad… a lot of them, they're angry. They've become less of a problem for some reason since I've stopped using the ROHO cushion. But, uh, at their worst, I mean, it was like every day, I lost a fair amount of blood just doing my bowels.”

Persons with SCI experience many changes in their health care needs and must frequently consider multiple treatment options to address complications associated with loss of bladder and bowel functions.

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“You know, the doctors pretty much were in control. Once I got the right diagnosis and got a doctor that was willing to listen to me and willing to send me off to see other doctors... I knew I was, you know, in good enough hands. I just followed their advice. They made more of the decisions for me. I just made the decision to trust them.”

But ultimately, it's up to the individual. Our findings show that those with strong communication skills, and good social and cognitive skills tend to be self-directed and able to manage their problems successfully. These skills, in turn, promote self-confidence and a sense of self-efficacy—having an "I can do it" and "I know what matters the most to me" approach. That personal confidence leads to a more positive view of problems, which are seen as a set of challenges, rather than a threat or loss. With all these empowering factors in play, anyone can expect greater satisfaction with the results of one's decisions.
As part of recruiting for our current decision making study, we went back to talk to some people who had participated in our previous project from 2012. In that earlier project, we explored the QOL for people with SCI and how living with bladder and bowel challenges affected their daily lives. As a reminder, we now wanted to explore decision making for changes in bladder or bowel management. Talking again to these past participants was a great way to reconnect!

We were able to include 21 people from our 2012 study into the new project (which started in 2017). Checking in five years later revealed some hopeful improvements and continuity in QOL. In general, the health of those 21 people stayed very stable. Some had seen an increase in UTIs or hemorrhoids, while others saw a decrease in leakages and accidents.

Overall, there were some changes in how people managed their bladder or bowel, with people trying new approaches or moving towards more intensive management methods. More importantly, physical health and involvement with social activities improved over the five years for most of these participants, suggesting better well-being and participation in the community and with family. Also, overall QOL was significantly higher over time.

When we looked at what people said at these two different points, some interesting patterns emerged. Nearly half the group showed increased acceptance and hope around their bladder and bowel health and management, and the impact these had on their lives.

For example, in 2012, one participant commented about his relatively lower QOL:

"Because I can’t do everything that I once did. I remember what it’s like not to necessarily live on a schedule... overall if I wanted to jump in the car and run someplace I did. And now I don’t do those things."

Granted, no one can control all of these factors, but our findings show that the stronger the decision making skills a person exerts, the better the results will be.

Ultimately, anyone can have the power over those medical puzzle pieces. And making the right healthcare decisions—while considering what really matters in the long run—can absolutely improve quality of life (QOL).
And five years later, his sense of the same issues had improved:

"Um, because I can jump in my car, I can go. I can jump on a bike with some help, and I can ride by myself. Um, I can go to dinner with my wife, go to movies. We can go visit friends."

Acceptance and changing circumstances led this man to see his opportunities change and get better. Other participants, again nearly half, noted how their lives were consistent over the intervening five years.

For example, one of our veteran participants commented in 2012:

"I like what I'm doing, I like my life. Everything would be great if I didn't have bladder and bowel problems. But I'm not going to let that affect what I do and who I am."

And five years later:

"I think my life is going well. There's a few problems, a few issues, but nothing that I can't deal with or handle..."

For the most part, between both civilians and veterans, there were no major differences in complications, or management methods over the years.

This group of 21 was resilient with a strong sense of identity and self-confidence. This led most of them to problem-solve their health concerns over time and surmount many of the obstacles they faced as a result of their SCI.

We hope this small selection of people who candidly shared their experiences will inspire you to find and look forward to all of the day-to-day joys that your life promises to bring.

What our Veterans with SCI Said about Decisions and Quality of Life

By: Denise G. Tate

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

Our study team members spoke with 30 veterans with SCI about decisions they made regarding their bladder and bowel issues. In general, the veterans seemed quite resilient in response to changes due to bladder and bowel function. They were resourceful in terms of finding ways to solve their problems and made decisions without much reservation, often being self-directed, showing good social and interpersonal skills. They also displayed an organized way of addressing issues.

When evaluating the effectiveness and impact of their decisions on QOL, veterans were more likely than civilians to describe both positive and negative aspects of each decision made, weighing benefits and risks carefully, and showing a detailed evaluative approach to decision making.

Here are a few examples of what they said about their satisfaction with decisions and the impact of these on QOL. Each veteran provided a rating from 0-10 (worst-best) about their satisfaction with their decision and QOL. These are noted in parentheses.

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<table>
<thead>
<tr>
<th>Veteran Characteristics</th>
<th>Problem/Solution</th>
<th>Satisfaction with Decisions &amp; (Rating)</th>
<th>Satisfaction with QOL and (Rating)</th>
</tr>
</thead>
<tbody>
<tr>
<td>70-year-old male, married, paraplegia complete; indwelling catheter, transurethral</td>
<td>Bladder leakages, accidents, wounds/colostomy, ileostomy</td>
<td>I am extremely happy...with care and I've been very happy with care...and support I've gotten from the VA (10)</td>
<td>I'm very happy. I volunteer...4-5 days a week...enjoy being with my wife (7.5) Frustrated with leakages; uses pads.</td>
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<tr>
<td>68-year-old male, married, paraplegia complete, suprapubic, laxatives</td>
<td>Bladder leakages, accidents, wounds/colostomy, diet</td>
<td>I think it has simplified my life...made it much easier on my wife...it enabled me to heal...I don't have to worry about the embarrassment part of it (9)</td>
<td>...we always hope that this never happens to you...so that weighs on you a little bit...I guess the 7 takes into account my wife and how much labor she has to go through... (7)</td>
</tr>
<tr>
<td>57-year-old male, divorced, paraplegia complete, urinary diversion/ostomy, ileostomy</td>
<td>Sacral wounds, bowel accidents, bowel collapse, colostomy and ileostomy</td>
<td>Because I'm not happy with it but there's nothing, I can do about it (5)</td>
<td>...my body is going downhill. I lost the use of my left arm so it's harder to transfer now, and I have increased the risk of falls... (4)</td>
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<tr>
<td>56-year-old female, divorced, complete tetraplegia, IC through stoma</td>
<td>Difficulty catheterizing due to stoma bulge/Modified Indiana pouch; re-do stoma</td>
<td>Because I'm treading water about my bladder (8.5)</td>
<td>But things have started to turn around...And that's wonderful...and as soon as I can get some of my debt paid off...then I'll have the quality test. (10)</td>
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<tr>
<td>49-year-old male, married, tetraplegia complete, Foley</td>
<td>Unable to self-catheterize; needs more independence /suprapubic</td>
<td>Well, I think I'm in a pretty good spot, other than 1-off bowel accident that really ticks me off when it happens (9)</td>
<td>I got a great relationship with my wife...and I have a strong family and support group...I think I am in a really good position (9)</td>
</tr>
<tr>
<td>55-year-old male, married, tetraplegia incomplete, IC</td>
<td>Unable to self-catheterize, constant UTIs, kidney failure/ileal conduit urostomy (drainage)</td>
<td>I think if I had paid a little more attention when I was younger...I should have made different decisions...I should have had that early ileostomy done...it would have prevented me from being where I am right now (8)</td>
<td>...things are getting tougher now...I'm getting older, everything hurts, I'm having all these medical issues, you know? (7)</td>
</tr>
<tr>
<td>71-year-old male, widowed, paraplegia incomplete, self- IC</td>
<td>Unable to void due to intense spasms; urine backs up to kidneys/ileal conduit urostomy</td>
<td>...it's probably as good as it is going to get...The only regret I have with my bladder is I didn't do it 20 years sooner (9)</td>
<td>Altogether...I'm satisfied...but socially, I'm not...I'm living alone...my grandkids are scattered all over the country... (7)</td>
</tr>
<tr>
<td>67-year-old male, married, paraplegia incomplete, in-dwelling (transurethral); digit stim (wife does it)</td>
<td>Bowel accidents, collapsing spine, wounds/colostomy</td>
<td>Well, I'm not absolutely 100% happy, but...I'm happier than I would be, I think, the other way (8)</td>
<td>Well, I can do pretty much anything I want to do...it's just a matter of planning and doing it... (8.5)</td>
</tr>
<tr>
<td>61-year-old male, married, tetraplegia complete, condom catheterization</td>
<td>Recurrent UTIs, leakages, bladder wall thickening, AD /Suprapubic</td>
<td>I'm very satisfied with it...just because it's a convenience. It's just easier. (8.5) Still gets UTIs</td>
<td>Because my QOL is very high at the moment...I just got married...I got a place in (state) so right now, It's good (8.5)</td>
</tr>
<tr>
<td>48-year-old male, divorced, paraplegia complete, digit stim</td>
<td>Hemorrhoids /Hemorrhoidectomy</td>
<td>I'd say overall right now everything is going great...the past two months I haven't had any issues (10)</td>
<td>Because there is always room for improvement...if we would have done this 2 years ago when all this crap was going on...it probably would have been a 10 (9)</td>
</tr>
</tbody>
</table>
Overall, this group of veterans (men and women) exhibited very positive attitudes toward both their decisions and the impact of these on their QOL. All decisions shown here involved surgery to address bladder and bowel problems. As a rule, QOL ratings were slightly lower than decision ratings to account for the many complex factors that influence the experience of living with SCI.

Concerns about lack of independence and autonomy, being a burden to others, the aging process, opportunities for social support, and expected roles and responsibilities all weighed in when evaluating satisfaction. Satisfaction with surgery was high, with perhaps one or two exceptions, when other consequences upon overall functioning negatively impacted life and independence.

Veterans spoke highly of the Veterans Administration (VA) and benefits, such as access to resources, clinics, and hospitals offered through the VA network. They also mentioned how being a veteran helped the way they perceived bladder and bowel problems, their sense of self-efficacy, self-management, organization skills and action-prone behaviors as well as their ability to find and participate in activities involving social and emotional support throughout their journeys.

When faced with major changes in life as the result of SCI, having the opportunity to receive services through a comprehensive health care system like the VA can make a real difference, especially when one enters this system with his/her own toolbox of valuable skills and knowledge. Difficult decisions become easier to make, significantly impacting QOL.

Making Decisions for Bladder and Bowel Management: Your Personal Toolbox

In review, the findings of this U.S. Department of Defense-sponsored study show that a combination of skills and knowledge can be very helpful in making important decisions regarding bladder and bowel issues after SCI.

Your toolbox should include a good amount of:
- Self-efficacy (feeling reassured that you have the right skills and knowledge to make the best decisions);
- Effective interpersonal skills to establish good communication with doctors and other health providers as well as family, friends and peers which can provide you with social and emotional support needed for these decisions;
- Self-direction abilities to seek information about new treatments and
- Self-management skills to provide you with the autonomy and independence needed to meet your personal goals.

In review, the findings of this U.S. Department of Defense-sponsored study show that a combination of skills and knowledge can be very helpful in making important decisions regarding bladder and bowel issues after SCI.

A Message to Our Participants

Thank you for giving back so much of your lives by sharing your thoughts, concerns, and impressions with us during this study. We will be publishing our findings in professional journals soon, so just keep an eye on our website or google us at the University of Michigan, Michigan Medicine.

We Wish You the Best Always,
Your Project Research Team
A Final Word from our Project Director, Dr. Denise Tate

Many Thanks to our study team and all who have helped us complete the work of this project:

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