# Matters

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# Spring/Summer 2017



Shirley Ryan AbilityLab

Welcome to the spring issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS). We have officially moved into the new hospital, the Shirley Ryan AbilityLab (formerly Rehabilitation Institute of Chicago). In this issue you will read about our new collaboration with **FacingDisability.com**, "Sexuality & Sexual Functioning after Spinal Cord Injury", and "Adjusting to Life after Spinal Cord Injury". Enjoy!

# New SCI Video Series Coming Soon

**FacingDisability.com** was designed to connect families who suddenly have to manage a spinal cord injury (SCI). Currently, the website has over 2,000 videos of interviews with people who sustained SCI and their family members answering real-life questions about how they cope as well as SCI experts on important medical and rehabilitation topics. They have joined efforts with the Model Systems Knowledge Translation Center (MSKTC) and the Shirley Ryan AbilityLab to create a 10-part series of video packages, 8-11 minutes in length, to be distributed to all Mod-System in-hospital television networks, as well as online and made available to other healthcare institutions.



Nova and Don Langtree are featured on FacingDisability.com

The videos will focus on questions, issues, and concerns most important to patients in the early days after spinal cord injury, such as sensitive topics that are difficult to discuss. Topics will be determined using statistics from Google Analytics and Ooyala (a video platform) for finding the most-watched videos on **FacingDisability.com**, and consulting with patients, healthcare professionals, the SCI Model System Knowledge Translation committee, and the MSKTC. Rough-cuts will be evaluted by the MSKTC team and the final video effectiveness will be evaluated via an online survey.

### Are You Due For a National SCI Database Follow-Up Interview?

Are you approaching your 1, 5, 10, 15, 20, 25, 30, 35, or 40 year anniversary of injury? You may be due for your next follow-up interview. Don't want to wait for us to contact you? Please call or email **Kayla Jones** at 312-238-1624 or **kjones05@sralab.org** to schedule your interview. Your interview can be completed by phone, mail, or in-person.

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is a national leader in sponsoring research. NIDILRR is located in Washington, D.C., and is part of the Administration for Community Living at the U.S. Department of Health and Human Services.



# Adjusting to Life after Spinal Cord Injury

#### What is adjustment?

Everyone experiences changes in their life. Adjustment is how you adapt to, or become used to those new situations. A few examples of exciting changes in life are starting a new job, getting married, and having children. Losing a job, getting divorced, and losing a loved one are examples of changes that can be challenging.

Having a spinal cord injury (SCI) is without doubt a new and challenging situation. SCI affects almost every aspect of your life when it happens, and it can be hard to put yingour life back in order and adjust to living with SCI. This initial adjustment period may be hard, but most people adjust well in time. Then, they continue to adjust to ongoing changes in life similar to those that everyone experiences.

#### What is it like when you first go home after injury?

Going home is a major step in adjusting to life after SCI. It can be exciting to get back to the comforts of home. It can also be scary if you are unsure of what to expect once you get there.

Like most life-changing events, it takes time to adjust to a new "normal" after injury. For example, you were probably used to a daily routine before your injury. You may have gotten up each morning to go to school or work, taken care of your children, or had regular household chores. Whatever the routine was, the day seemed normal because you had some idea of what to expect.

After injury, you will establish a new "normal" routine. People who are newly injured often say it feels like they are doing things for the first time as they learn how to do activities differently. That feeling usually fades as you work through problems and learn how best to manage your daily routine.

- Chances are you will have outpatient rehabilitation for a while after inpatient rehabilitation. Your strength and stamina usually improves. Your ability to do daily activities usually improves. The time you spend out of bed and up in your wheelchair usually increases. At first, you may depend on medical equipment, such as a hospital bed or assistive devices, but not need them later.
- You usually learn to manage some of your activities during inpatient rehabilitation. However, you may change the way you manage things at home. For example, you showered or have done your bowel program at night during rehabilitation. You might find that doing these activities in the morning better fits your daily routine.

#### How people adjust to SCI?

People have different expectations for life after injury. It may be feeling happy. It may be doing meaningful and enjoyable activities. It may be preventing stress, depression, or anxiety. It may be any or all of these things or something else, but most people adjust by setting and meeting their own expectations for life after injury.

- Your personality and the way that you adjust to changes in your life do not usually change after injury. Therefore, you will adjust to life after SCI in your own way and in your own time frame.
- You may feel "different" in your body in the early weeks and months after injury. This feeling usually fades as you become comfortable with your self-image, learn to manage self-care,gain a better understanding of your body, and come to realize you are still the same person.
- You may re-think some of your personal values and what you think of as most important in your life after injury. For example, you may focus your attention more on your relationships with family and friends than you did before your injury.

#### **Adjusting Well**

There is no "one way" to adjust to life after SCI. However, research can offer some insight into what adjusting well looks like. People who adjust well:

Do not experience depression, or if they are depressed soon after injury, they feel better again within a few weeks.

Have an effective coping strategy.

- Have a "fighting spirit" and use every means necessary to overcome challenges and setbacks.
- View their injury as a challenge and see the potential for personal growth to make their life better.
- Accept that their injury has happened and decide to live with it.

Are resilient, meaning they bounce back when they experience difficult times or changes in life. You can make use of some common traits that people who are resilient have.

Seek purpose and meaning. Think about what you want in life. Is it a job? Family? You can have a job, a family and most anything else that you want in life.

The key is to set the goals you want to achieve and relentlessly strive to reach those goals.

Stay connected with your support network. Your family, friends, faith, and others in your community can be a great resource to help you adjust to life after injury and reach your goals.

Use resources to make your life better. There are many organizations, agencies and community resources that offer help to people with SCI. Here are a few.

Job Accommodation Network (www.askjan.org) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. The Network website also has a list of State Vocational.

Rehabilitation Agencies that can help you return to work. Independent Living Research Utilization (www. ilru.org) has a list of Centers for Independent Living and Statewide Independent Living Councils throughout the United States. These Centers are in every State. Your local Center can provide you with information and direct you to local resources. You can work one-onone with an independent living skills trainer. You can get connected with others in your community if you need support and tips from a role model who is living independently. Your local Center can also help with accessibility and equal access to community services as well as transition from nursing homes to communitybased living.

www.Disability.gov is the federal government website for information on disability programs and services in communities nationwide. Search "spinal cord injury." Stay flexible. When you set goals, you may not reach them exactly as planned. Setbacks are common, but you can adjust your efforts to reach your goals. Solve problems. You cannot avoid problems, and people with SCI who have good problem solving skills tend to have a higher quality of life and fewer medical complications. Here's how you might approach solving problems:

- Figure out what the problem or challenge is. Break big issues down into smaller, more manageable parts if needed and tackle one problem at a time.
- Brainstorm— Think about all possible solutions and get input from family and friends. If another person is involved in the problem, make sure that person helps to brainstorm for solutions.
- Choose the solution you think will work best. Make sure the solution is acceptable for everyone involved.
- Try your solution to learn if it works.
- Evaluate results— You have solved your problem if your solution works. If not, brainstorm, choose another solution and try it. Most solutions do not work perfectly the first time. Trying again and adjusting plans are keys to success.

#### Difficulty with adjustment

It is normal to have days when you feel down or bad after SCI. However, people who have continuing depression tend to have difficulty adjusting after SCI. Sometimes depression happens soon after injury. In a few cases, depression begins some time later.

People who become depressed usually fall into thinking and behavior traps. Talking with peers, professionals, family or friends may help you see these traps and find solutions. Here are some examples of thinking and behavior traps.

Believe they have no control over their life, rather than focusing on what they can control.

Depend on others more than they need to, rather than seeking ways to become more independent.

Focus on the bad thing that might happen, rather than on the good things that "could" happen.

Give up trying to deal with difficulties caused by SCI rather than working out these difficulties over time.

Focus on what they cannot do rather than on the meaningful or enjoyable activities that they are still able to do.

More than 25% of people with SCI had difficulties with depression before they were injured. Being prone to depression, anxiety or other mental health problems can make it harder to adjust to SCI. If you are in this situation, it may serve you well to have regular mental health services during and after rehabilitation.

Pain is a common risk factor for depression. Learn more about the types of pain and treatment options by reading "Pain after Spinal Cord Injury" at www.msktc. org/sci/factsheets/pain. However, not all people who have pain after injury become depressed.

Talk to a professional if you think you might be depressed. Depression is treatable with medication and counseling. Learn moreabout depression and treatment options by reading "*Depression and Spinal Cord Injury*" at www.msktc.org/sci/factsheets/Depression.

#### Does family life change after injury?

#### Relationships

Changes in family roles and relationships can be stressful for couples after SCI. It can take time for couples to find a new "normal" in their relationships. However, couples can work together to adjust over time and have a healthy relationship.

Read "Sexuality and Sexual Functioning after Spinal Cord Injury" to learn more about managing relationships, sex, and havingchildren after SCI at http://www. msktc.org/sci/factsheets/sexuality.

#### Parenting

For any parent, raising a child is both challenging and rewarding. It is an ongoing learning process to determine what approaches are and are not effective for each child.

The fact that you have limited mobility does not mean you are less able to parent. Parenting is much more about supporting your child with love, devotion, and guidance rather than what you can do physically. Be fully involved in making decisions about your children's day-to-day activities, including discipline. Children are naturally curious and will likely ask many questions about your injury. They usually adjust quickly when their questions are answered in terms they can understand.

Unless you have a preexisting condition, having SCI does not prevent you from having children. In fact, people with all levels of SCI have children after injury. You can too if you choose.

# How can I be independent if I have to rely on others for help?

During rehabilitation, you learn how to do as much as you can on your own. While these skills help to lessen your reliance on help from others, you may need to ask for help to do the things that you cannot do. If asking for help is sometimes difficult to accept, here are two questions to consider.

How do you view independence? It is common to think of independence as being able to do everything on your own. However,most people depend on others, and you can probably think of many examples when you relied on others before your injury. You may have depended on a mechanic for car repairs or a friend or relative for picking the kids up from school. After SCI, it is helpful to think of independence as actually being in control of your life. Being in control means making decisions for yourself, learning how to best care for yourself and direct your personal care, and being an active voice in the decisions that affect you and your family. Do you feel like you are a "burden" on those who help you? It is common to feel like a burden to a spouse or caregiver who does the physical tasks that you may no longer be able to do. You may hesitate to ask for help or speak up for something you want or need. However, you can help limit their stress by making decisions together.

Open communication is one of the best ways to solve problems and reduce stress for everyone. Back to top

## What adjustments do I need to make to manage my health?

All aspects of your health and wellness are important. If you stay healthy, you are more likely to stay active, reach your life goals, and maintain a high quality of life. Although people who help with your care need to know about your medical needs, you are responsible for managing your health and directing your care.

Learn about your risks for secondary medical conditions, how to prevent them from occurring, and what to do if you have a medical problem.

It is important to have a healthy diet and stay active. Think about the activities you enjoyed before your injury.

Those same activities can still be enjoyable even though you may need to make adjustments in the way you do them. You can also find new ways to stay active.

The National Center on Health, Physical Activity and Disability (www.nchpad.org) is a great resource for lifestyle information.

Schedule annual follow-up visits with your SCI-specialist and your Primary Care Provider.

Your SCI-specialist is well trained to manage the unique medical issues of SCI but does not usually provide primary care services.

Your Primary Care Provider is not trained in SCI issues but is trained to provide the healthcare services that everyone needs, such as treatment of common sicknesses and preventive medicine. They watch for early signs of medical problems and refer patients for specialized care when needed.

#### Who can I talk to if I have problems or questions?

It is common to have problems with no easy solutions or questions with no easy answers. If so, you are not beyond help and do not have to be on your own.

You can seek input from multiple sources to help you with important issues. Family, friends, spiritual advisors, mental health professionals and people with SCI can be very helpful and supportive. There are a lot of good resources on the internet. However, be mindful that some websites and social media contain incorrect information.

Few people are well informed enough about SCI to provide the best advice, so your best sources for advice and information are usually professionals who are experienced with SCI issues.

A physical or occupational therapist can help with activities of daily living.

A doctor or nurse who is an SCI-specialist can help with medical needs.

A counselor, psychologist, or social worker can help with concerns about mood, anxiety, relationships, substance use and getting back into enjoyable and meaningful activities. They can help with couples and family issues, too.

When searching the internet for information, start your search by going to websites managed by a Spinal Cord Injury Model System.You can find a directory of SCI Model Systems at http://www.msktc.org/sci/model-system-centers.

If you are searching for peer support, you might start with two of the most reputable online support websites. www.spinalcord.org provides information and resources to meet the needs of people with SCI and their families and friends.

**www.facingdisability.com** provides Internet-based information and support for people with SCI and their families. The website has more than 1,000 videos of family members answering real-life questions about how they cope with SCI.

#### Aurhorship

Adjusting to Life after Spinal Cord Injury was developed by Phil Klebine, M.A., Charles Bombardier, Ph.D., and Elizabeth Richardson, Ph.D. in collaboration with the SCI Model Systems Knowledge Translation Center.

http://www.msktc.org/sci/factsheets/adjusting\_to\_life

# Sexuality & Sexual Functioning after SCI

#### What is sexuality?

Your sexuality is what guides your natural desire to bond with others through love, affection, and intimacy. Here are a few ways you might express your sexuality.

Emotional connections— feeling close to someone. Physical contact— acts of touching such as holding hands, hugging, kissing, cuddling, and sexual activity.

Sexual identity—how you think and feel about yourself and your desires for the opposite sex, same sex, or both.

Gender identity—the gender you feel you are "inside" (your body may or may not match the gender you feel you are).

#### How does spinal cord injury impact sexuality?

Loss of muscle movement, sense of touch, and sexual reflexes often occurs after spinal cord injury (SCI). How this loss effects arousal, orgasm, and fertility depends on your level of injury and whether your injury is complete or incomplete.

To learn more on the nervous system and about complete and incomplete injuries, please see "Understanding Spinal Cord Injury: Part 1—The Body Before and After Injury" at http://www.msktc. org/lib/docs/Factsheets/SCI\_Understand\_Spin\_ Crd\_Inj\_Prt1.pdf.

You may not have a strong desire for sex when first injured, but your desire will likely increase over time as you learn to manage self-care and understand your body after injury. If not, talk to your doctor. It is possible your medications are interfering with sexual desire. Changing medications may help.

SCI may also impact how you think and feel about yourself. Some people may not feel desirable after SCI. However, loss of movement or sensation does not change the fact that you are a desirable sexual being. You are more likely to feel desirable and want to fully express your sexuality if you understand your body and feel comfortable with yourself and your personal identity. This factsheet will help you.

#### Is dating different after injury?

Here are a few ways dating is usually the same as before your injury.

- You increase your opportunities to meet people by making yourself available to meet them. This might be online dating or getting out and meeting people.
- You have to ask for a date to know if he or she will go out on a date with you.
- It is just as important after injury as it was before your injury to practice safe sex to prevent pregnancy and contracting sexually transmitted infections/diseases.

Here are a few ways dating may be different.

- You will probably be asked about your injury and how you manage daily activities. Be ready to respond in a way that is comfortable for you.
- You have to ask for a date to know if he or she will go out on a date with you.
- You may need to balance your dating schedule with a caregiver's schedule.
- You may be living with a family member or someone else after your injury. If so, you may need to talk with them about setting up guidelines for bringing a date home, privacy, and personal space.

#### **Understanding Sexual Arousal**

#### What is sexual arousal?

Sexual arousal is the body's response to your desire for sex. This includes an increase in heart rate, blood pressure, and breathing rate, and can include an increase in blood flow to the genitals to ready your body for sex.

- Women have an increase in vaginal lubrication to ready the vagina for easier, safer penetration.
- Men get an erection.

People without SCI are usually aroused through two pathways.

Reflex pathway—Arousal that occurs in response to sensual touching. Psychogenic pathway—Arousal that occurs from psychological sexual sensations such as sexual thoughts, sights, smells, or sounds that turn you on sexually.

#### Sexual arousal after injury

One or both of your pathways for arousal may be blocked.

- Most people with SCI can be aroused by sensual touching. Try stimulating your body in sexual ways to find out if you become aroused. Does masturbation feel good? Does oral sex? You might also enjoy touching in areas like your neck, ears, nipples, and inner thighs.
- Some people with SCI, mainly those with an incomplete injury, may be aroused by psychological sexual sensations.
- The more sensation you have in the area between your belly button and front pant pocket areas (upper outer thigh), the more likely you are to be aroused in your genitals by sexual thoughts, sights, smells, or sounds.

# What can I do if I cannot get aroused after injury?

Talk to your doctor. Changing your medications may help with the problem. Often times, spasticity medications, pain medications, or antidepressants are contributing factors. If not, here are other actions that might help address the problem.

Women—having your partner perform oral sex may help increase vaginal lubrication enough for penetration. Using a water-based lubricant is another option.

Men—most men can get an erection with sensual touching after you take a medication like sildenafil, tadalafil or vardenafil. If cannot, talk to your health professional about other options, which might include a constricting ring, vacuum suction device, injection of medications into the penis, or a surgically implanted penile prosthesis.

#### **Understanding Orgasm and SCI**

#### What is orgasm?

An orgasm is a reflex response of the nervous system that feels good and relaxes you.

#### Orgasm after injury

Most people with SCI can still have orgasms. Here are some important facts to know.

- Stimulation to the genitals is usually a good way to achieve orgasm.
- Sensual touching in the area where your sensation changes (at your injury level) may help to achieve orgasm.

- Achieving an orgasm generally takes longer and may feel "different" than it did before your injury.
- Women—using a vibrator is helpful for achieving an orgasm.
- Men—often have orgasms where the semen goes back into the bladder instead of coming out through the penis (also known as retrograde ejaculation).
- Orgasms are often followed by a decrease in spasticity.

# What can I do if I cannot have an orgasm after injury?

Remember, sexual activity can be great fun with or without orgasm, but here are some potential options.

It is important that you and your partner not give up too soon. Sometimes it just takes time and practice.

Try masturbating with or without a vibrator.

If your injury is at or above T6, you should be careful and watch out for headaches and other signs and symptom of Autonomic Dysreflexia (AD). If that happens, stop activity, check your blood pressure, and ask your doctor to review your medications to see if they can be adjusted. For more information about AD, please read "*Autonomic Dysreflexia*" (Coming Soon).

Talk to your doctor about using medical devices.

Men—a high amplitude vibrator held against the head of the penis may stimulate ejaculation. Women—a gentle suction device can help increase the ability of the clitoris to respond so you can achieve orgasm.

#### **Understanding Fertility and SCI**

#### What is fertility?

Women become pregnant when sperm, which is in semen, fertilizes an egg.

#### Can I have children after injury?

Yes! You decide to have children in much the same way as anyone else. You consider the demands and challenges of parenting and how you might manage them. Here are other facts to consider when deciding whether or not you want to have children.

- Men and women of all levels of injury have had children after their injury. You can too if you choose.
- The positive aspects of parenting usually outweigh the difficulties.
- http://www.lookingglass.org/ and http://www. disabledparents.net/ are good online resources for people with SCI who are or want to be parents.
- You need to practice safe sex if you want to prevent pregnancy. Condoms are considered the best choice for both men and women with SCI.
- Women—talk to your doctor if you are interested in birth control options other than condoms. Intrauterine devices and diaphragms are generally not ideal if you have problems with sensation and insertion. The pill is not usually recommended because it increases your risk for developing a blood clot (deep vein thrombosis).

# Do women have problems getting pregnant after injury?

There is usually a brief pause in your period when you are first injured. You can naturally become pregnant, carry, and deliver a baby once your period returns. Contact your doctor if your period does not return with a few months after injury.

You are at higher risk for common secondary complications of SCI during pregnancy, but you can prevent problems or mange problems if they develop. It is best that you have an obstetrician who understands, or is willing to learn, the facts about pregnancy, labor and delivery for women with SCI.

For more information on pregnancy, labor and delivery, please read "*Pregnancy and Women with Spinal Cord Injury*" at http://www.msktc.org/sci/factsheets/Pregnancy.

# Do men have problems getting their partner pregnant after injury?

Some men with SCI can get their partners pregnant through sexual intercourse, but many men cannot.

- May be unable to ejaculate into the vagina during intercourse.
- Sperm may be unable to swim to fertilize the egg (also known as poor sperm motility).

Urologists who are experienced in SCI can offer treatment options.

- In-Home Insemination—if a high amplitude vibrator can stimulate ejaculation, the semen can be collected in a clean cup. The semen can be drawn from the cup into a syringe. The syringe can be inserted into your partner's vagina, and the semen is slowly injected.
- Retrograde ejaculation may be treated with medications.
- Vibratory stimulation may cause Autonomic
- Dysreflexia if your injury level is T6 or above.
- Medically assisted procedures—doctors may use methods such as electroejaculation, intrauterine insemination, or in vitro fertilization.

# How can I help my partner adjust to changes with my body after injury?

Here are some tips for both you and your partner.

Understand your body. This fact sheet is only a starting point to begin to understand how your body might change after injury. Your body is unique, so your issues are unique, too. It can take time to understand how your body works and manage problem issues.

Take the time to figure out what each of you finds pleasing and exciting. What you did before your injury may work for you. If not, you and your partner can be creative and open to exploring new ways to find sexual satisfaction.

Have fun. Using humor and being playful are keys to having a more interesting, enjoyable and mutually pleasurable experience.

Keep an open mind along with an honest and open line of communication. Below are some helpful suggestions:

Know what you want to communicate. This involves self-awareness and possibly self-exploration to get a clear sense of what you want or need sexually.

#### Communicate your needs to each other. Talking about sex can be difficult, so you will want to communicate in a way that makes both you and your partner feel comfortable. Some couples find it helpful to write down their needs. The goal is to talk about any issues or concerns and work together to solve problems and resolve concerns.

Listen to each other. Healthy communication requires give and take. Listen and be open to your

partner's response, just as you would like your partner to do for you. Listening to your partner can help resolve issues in a way that satisfies both partners. This includes paying attention to body language.

Be flexible. Couples commonly need time to get comfortable with each other. You will likely experience a few setbacks. For example, there may be issues with bowel, bladder, and spasticity. However, you and your partner should be able to manage issues as you continue to communicate, listen, and remain flexible.

#### How do I keep the romance alive if my partner is also my caregiver?

Do everything you can to keep the role of the caregiver separate from that of a ro-mantic partner. This will better allow you to enjoy each other when you are feeling romantic. Here are some tips.

- Be as independent as possible. Learn to do as much as you can with your selfcare and other daily living activities. This will limit the amount of help you need from a caregiver.
- Have set times when caregiving tasks are needed and set other times, like a date night, when there is romance without caregiving. Keeping these roles separate will help you to avoid confusing and blurring the two roles.
- Hire a personal care attendant (PCA) to take on some caregiving tasks if you can. You may qualify for programs that

can help if you cannot pay for one. Some agencies that you might contact are your state's Vocational Rehabilitation Services, your local Independent Living Center, or the Department of Veteran's Affairs if you are a veteran.

#### Who can I talk to if I have problems or questions?

Most problems have a solution, and professionals who know about sexuality and issues of SCI are your best option to find solutions. They can provide you with accurate information, treat you with respectful, and ensure confidentiality answering your questions.

- Talk to a doctor or nurse about medical needs.
- An occupational therapist or physical therapist can be helpful in suggesting equipment needs.
- An experienced counselor, psychologist, social worker, or sex therapist can usually help individuals and couples work through relationship problems and identify other helpful resources.

#### Authorship

Sexuality & Sexual Functioning After Spinal Cord Injury was developed by Marcalee Alexander, M.D., Trisha Hicks, MSW, LSW, M.Ed., Mindy Aisen, M.D., and Phil Klebine, M.A., in collaboration with the Model Systems Knowledge Translation Center.

http://www.msktc.org/sci/factsheets/sexuality

## We want to hear from you!

Interested in other SCI topics? Want more info? Need to update your contact information? Want to receive this newsletter by email?

Let us know, contact Allison Todd at 312-238-2264 or atodd@sralab.org

## Want to get involved in more research at RIC?

Contact Dian'Ella Ramsey at 312-238-1624 or dramsey@sralab.org to learn about the Center for Rehabilitation Outcomes Research's (CROR) registry. After you enroll in this registry, we will contact you about CROR's upcoming studies.

Visit https://www.sralab.org/search?content\_type=clinical\_trial for a list of Shirley Ryan AbilityLab's research studies and clinical trials.

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