

LIVING WITH PARALYSIS

Women's Mental Health After Paralysis



**CHRISTOPHER & DANA
REEVE FOUNDATION**

TODAY'S CARE. TOMORROW'S CURE.®

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INTRODUCTION: IMPORTANCE OF MENTAL HEALTH



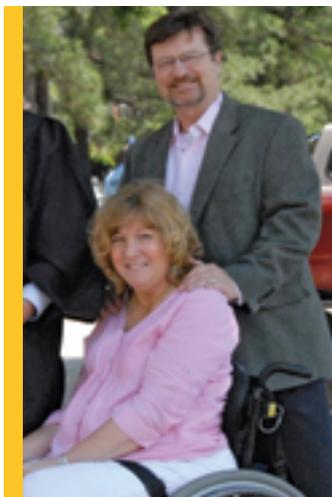
According to the Centers for Disease Control and Prevention (CDC), about 27 million women in the U.S. have disabilities and the number is growing. When an illness or injury occurs, particularly paralysis caused by a spinal cord injury (SCI), spina bifida, or multiple sclerosis, your mental health is at risk since you're likely incapable of executing some tasks in your daily routine. This is particularly true for those who experience severe spinal cord injuries that result in paraplegia or quadriplegia since your condition can affect how you think and feel.

Mental health is made up of your emotional and social well-being – or satisfaction with life – and affects how you think, feel and behave. Having good mental health is vital in order to lead a rewarding and well-balanced life as it promotes productivity and success in activities and relationships both in and out of the home.

ADJUSTMENT TO SPINAL CORD INJURY OR ONSET OF PARALYSIS

An injury to your spinal cord or experiencing a loss of muscle function significantly changes all aspects of your life and body; proper mental care is vital for helping you to manage the adjustment. Everyday activities, such as bowel and bladder routines, grooming, using the phone and computer, cooking, and traveling to and from work, will need to be altered. With so many changes in your day-to-day life and abilities, it's not surprising that so many women with paralysis experience mental health difficulties.

According to a SCI Forum report by The University of Washington, there are about 27 million women living with a physical disability in the U.S., of which approximately 39,000 have a spinal cord injury. A study by Monash University Centre for Developmental Psychology and Psychiatry found that spinal cord injuries doubled the risk of mental health problems, with 48.5 percent of survivors experiencing depression, 37 percent coping with anxiety, 8.4 percent facing post-traumatic stress disorder (PTSD), and 25 percent feeling significant levels of clinical-level stress. Women with disabilities are twice as likely to experience depression as men due to being disabled and female. This is largely due to facing obstacles to health care, unemployment, lower wages and increased time and effort to complete everyday activities.



First year post-injury, I struggled very profoundly with anxiety. I was sad, but I was also worried about the 'what ifs' that may occur in my marriage, my family life, my profession, and our financial status. My husband and I had just purchased our new home on two salaries, my income was cut permanently, and our new home now had to be retrofitted to accommodate me and my new way of living. The anxiety was suddenly deafening and very overwhelming. What I found to help me was to create an all-encompassing list of 'to-dos'. As each item was completed, I marked it off and moved on to the next." Patty, T-3/T-4, injured in 2009

STAGES OF CHANGE AND REDISCOVERY

There are approximately 17,000 new spinal cord injuries reported each year in the United States and, as of 2016, 1.4 million people are living with a spinal cord injury. Additionally, there are nearly 5.4 million Americans living with some form of paralysis (stroke, SCI, MS, ALS, etc.).

The stages you may go through following a SCI or the onset of paralysis are similar to the stages of grief. Some people may experience a few or all of the stages of change and rediscovery, which include the following:

- Confusion and Agitation
- Denial
- Anger and Depression
- Testing
- Acceptance

Having difficulty understanding why or how the injury occurred is common. Your world has changed dramatically which often results in feeling confused and upset, usually shortly after the injury. During this time, you may start to act outside of your normal temperament or behavior. For instance, if you are typically calm and can easily take steps to overcome an issue, your personality shifts and you now feel anxious or upset. This change is completely natural considering people often act out of character when faced with a challenge.

This stage often segues into feelings of confusion or even disbelief about having to deal with your new reality. Not knowing the next course of action to take or what will happen in the future may bring on such anxiety that you deny your current state, shut people out and try to convince yourself that nothing is wrong. This perspective is essentially a defense mechanism to help you avoid the pain and sadness you're feeling about the injury.



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Find your driving force to get out of your dark place. It's important not to get stuck in one stage for long periods of time.” Keyonna, T-4/T-5, injured in 2005

Anger and depression are common reactions to paralysis. You may feel like it's unfair that you became injured if it was beyond your control and want to lash out and take it out on others or become extremely mad at yourself. Some even report wanting to stay angry because it helps them realize that they are at least feeling something. Depression can come on weeks, months or even years following a SCI as you grieve the loss of your abilities. The adjustment process of changing how you think and feel takes time.



Making improvements in your functionality often leads to a period of testing your limits to determine what you can and can't do. It might be difficult at first as you learn new ways of completing daily tasks and when you realize you can't do some things at all. However, this stage will help you to determine what you need to achieve a high quality of life and discover your new normal.

Acceptance is a crucial step in your adjustment to living with a SCI. It's being able to accept what happened in the past and develop new

ways to cope. You will know and be able to set your limitations but also learn how best to enjoy new experiences to achieve a fulfilling life. This may not be the final stage in your adjustment process as you may go through these stages at additional times in life, especially when experiencing major change or transition including starting a new job, dealing with relationship issues or becoming a mom. But as you work through the steps when faced with a challenge, you will ultimately become happier and more fulfilled.

SIGNS OF HEALTHY & UNHEALTHY ADJUSTMENT

Adjustment to paralysis takes time. As with all change, you have to be realistic in your goals and be ready and willing to transform how you think and act in order to alter your perception of your circumstances. Everyone has different expectations, from feeling happy and attempting to engage in fun and meaningful activities to preventing stress, depression, or anxiety and everything in between. Largely, how you adjust after your injury is directed by your personality and how you typically adapt to change when faced with adversity.

There is no definitive way to accomplish it, but research offers some indications of healthy and unhealthy adjustment. Healthy signs include having an effective coping strategy, similar to finding ways to overcome challenges or seeing the injury as a test to improve one's self and life. Women with a healthy adjustment are resilient and can quickly recover from setbacks by finding personal fulfillment and engaging with friends, family, community groups and organizations. Being flexible and adaptable are key when you run into roadblocks as well as having the ability to problem-solve to accomplish your goal. People with SCI – especially women – typically can break down, brainstorm and manage problems, which equates to acquiring a higher quality of life and fewer medical issues.

It is completely normal and expected to feel sad after experiencing a spinal cord injury. However, if you continue to feel down, you are susceptible to becoming depressed, especially if you allow yourself to feel helpless. Examples of unhealthy behaviors include focusing on negative aspects of your situation, what you can't do and potential scenarios that might happen, becoming dependent on others and giving up when experiencing obstacles. More than 25 percent of people with SCI experienced depression before they were injured. This may make it harder to adjust. If you think you have become depressed, you should talk to a mental health professional to discuss treatments that may include medication and counseling. Also consider speaking with friends, family or trusted community members to help you manage your emotions and find solutions.

FINDING A NEW NORMAL

The time when you start to adjust to a SCI or the onset of paralysis both mentally and physically varies for each person; some can improve in a few weeks whereas others need months. Your acceptance of your new normal will occur as you start to become comfortable with yourself and your care needs and when you realize that your personality and values haven't changed, just your circumstances.

Managing your relationships with others is an important part of finding a new normal. Whether it's defining new roles and responsibilities as a couple, a mom, employee, etc., you need to work together with family members or your employer to determine how to best accommodate everyone and return to your normal bond. Be sure to listen to each other's wants and needs and be an active participant in your relationship.

Understanding your abilities and asking for help when you need it are certainly a large part of being able to achieve normalcy. However, it's important that you take action as opposed to allowing others to do things you are capable of completing. Being an active participant in your rehabilitation is also vital to learning how to care for yourself.

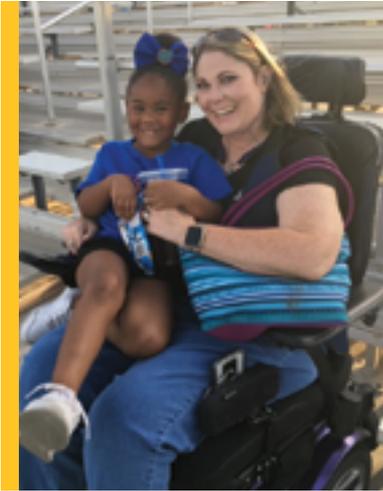


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My family is a huge support, but I always try something three times before I ask for help. The only way to improve is to practice.” Sarah, C-7, injured in 2015

DEVELOPING A SUPPORT SYSTEM

There are many ways that you will need help in the days, months and even years after your injury. As you adjust to life with paralysis, you will see how important it is to have a strong network of friends, family, neighbors, peers and community support groups by your side. Staying connected to your friends, family and community and nurturing the relationships you have formed are as valuable as ever. It's common to want to shut people out and hide but spending time with family and friends will help you stay positive, healthy, and hopeful. And when you are feeling down or frustrated, you can turn to your support system to get you through it.



Things aren't going to be easy, but don't give up. Enlist the help of others to be able to do everything possible you want to do. Brandy, C-4 to T-8, injured in 2014

DEFINING A SUPPORT SYSTEM

Having a support system is an essential element for your new lifestyle. As you explore how you will need assistance and care from your family and friends, consider their position as most likely it is foreign territory for them too. Everyone will respond in different ways depending on their comfort level, how close they are to you and their confidence that they are acting in the right way. It's helpful if you are knowledgeable about your injury and are willing to educate and train them on how they can best support you.

Start by explaining the extent of your injury and how it affects your abilities so they have a clear understanding of what they can do to help. It will be a learning process, so don't hesitate to jump in to correct wrong actions or to simply let them know if they're helping too much. While it might be uncomfortable in the beginning, being open about your paralysis and your needs will ultimately lead to healthy and strong relationships.

Defining the roles of those in your support system is crucial to ease your transition and ensure there aren't any holes in your care needs. You will require a fully encompassing environment of love, care and trust which needs to be achieved at multiple levels, including physically, mentally, emotionally and spiritually. These are vital components to maintaining your positivity and self-esteem, which are needed to overcome the obstacles that often arise following paralysis.

Not everyone will be suited to assist you in the same ways, so talk to each willing member of your support system to determine his/her availability and comfort level with certain tasks. If someone isn't able to help you physically, perhaps they are able to support you emotionally and mentally. This is a great way to include those both young and old as active participants in your adjustment to a new life after paralysis. You will also need to continue to challenge yourself intellectually, which may mean returning to work or adapting so you can work remotely. Enlist your colleagues or seek out peers living with the same disability to help guide you.

As you will experience a rollercoaster of emotions, the people around you are necessary to help identify and address the stages of your emotional adjustment to a SCI. Confide in trusted individuals about how you're feeling; you may find that they are experiencing the same feelings, only on a different level. As you work together to manage your worries and concerns, little by little you will determine ways to accept and solve challenges.



You have to reach out to your network. It might be difficult at first, but if you continue to work on yourself it will become easier to get past your feelings. Surround yourself with people of all abilities. Those who are able-bodied have the most compassion, but peers in chairs have actually been through it, so their advice is invaluable.” Brandy, C-4 to T-8, injured in 2014

STRATEGIES FOR BUILDING & MAINTAINING A SUPPORT SYSTEM

It's common for friends and family to come together to offer support when you are newly injured. After some time has passed, it's also typical that the level of support tends to decrease for one reason or another. Don't be afraid to reach out if you haven't connected with someone in a while. Everyone leads very busy lives and it's easy for a friend or family member to get distracted with their daily responsibilities. It's helpful to connect when you just want to say hi and invite them over for coffee or if you are able to help them with a task. Maintaining your connections and upholding your end of the relationship are necessary to make your bonds flourish.



Stay connected. Keep relationships with your community, both in-chairs and those who are able-bodied. Call, text, meet for coffee and do your best to accept invitations to meet peers. Even if you're experiencing a bad day or had an issue, brush yourself off, tell them you need a little more time and keep the connection." Ashley, T-10, injured in 2014

This is especially true for your spouse or partner as his/her life will also be significantly impacted as a result of your injury. Take the time to discuss your needs as individuals, but also your needs as a couple. A study conducted by the Department of Physical Medicine and Rehabilitation at the University of Michigan found that couples were 1.3 to 2.5 percent more likely to divorce than the general population in the first three years after a SCI; in the years following, the divorce rate was approximately 40 percent. However, the same study also found that the more time couples spent communicating and engaging

in activities they both enjoy outside the home, the better their relationship was, which decreased the likelihood of divorce. Like any relationship, you need to make an effort to enjoy time together and show gratitude, love, and affection every day. Every strong relationship maintains its success when both people are treated as equals, respected and cared for. If you both are committed in the long-term, your relationship can survive and may even evolve and grow stronger by overcoming adversity together.



Experiencing a little bit of normalcy when everything else is not the same makes you realize that you're still okay." Brandy, C-4 to T-8, injured in 2014

There will be times that you need help from people outside your circle who are more in tune with what you're going through. Psychologists and doctors are good options for clinical support, but if you want to connect with others who are living with a spinal cord injury and can speak to the experience firsthand, peer support groups are a great resource for forming a sense of community. These groups (often found in hospitals, rehab centers, online forums and community events) can offer understanding, perspective and guidance to help you create and maintain a positive outlook.

Reaching out and finding SCI peer mentors after an injury is one of the best things you can do. They can provide you with key health-related facts linked to living with paralysis that your doctors and rehab nurses may forget to relay, including how to handle urinary tract infections and solving problems with bowel management. Peer mentors can also provide strategies and tips for leading an active life and increasing independence, such as recommendations for travel, exercise, diet and nutrition and advice on driving, returning to work or school and managing your finances. The Christopher & Dana Reeve Foundation's Peer & Family Support Program offers one-on-one peer mentoring [ChristopherReeve.org/peer](https://www.ChristopherReeve.org/peer).



It's incredibly important to find a mentor who's been in a similar situation and can offer you support and guidance. If you're in a funk, sometimes you need the perspective of someone who's been in your shoes to pull you out of it." Sarah, C-7, injured in 2015



Online magazines and websites are also full of information and articles from those who have experienced a similar injury and can provide a new perspective and resources; they can also help you to stay in the know about new products, news and research developments. Look into joining online forums and social media groups related to living with a spinal cord injury on Facebook and Instagram. They will give you the opportunity to search for past topics and to post your own questions for the community to answer. Often through these groups, you may find opportunities to attend topical, informative and fun events to give you the chance to network with new peers. One highly-attended event is the series of Abilities Expos (www.abilities.com) held around the country that offer workshops, product demos, and activities that can enhance your quality of life.



I use social media to my advantage. Rather than focusing on what I can't do, I use it to find people doing amazing things with what they can do. I was always active in sports and came across paraplegic swimming. I looked into it and, after five months, I swam in the U.S. Paralympics National Para Swimming Championships and won third place. I set a personal best and ranked 18th in the world. Now my goal is to compete in the 2024 Paralympics in Paris.” Sarah, C-7, injured in 2015

STRESS

Stress can have a detrimental impact on your physical, mental and emotional health. For example, high stress levels are associated with high levels of depression. If you experience stress, you may have physical signs which can include pain and nausea, chest pain, rapid heart rate and frequent colds. Mental and emotional symptoms consist of memory problems, inability to concentrate, a negative viewpoint, feeling anxious or constantly worrying as well as depression, irritability and feeling overwhelmed.

Some may also experience changes in their behavior like eating less or more, sleeping too much or too little, procrastinating or neglecting responsibilities, removing themselves from social situations, dulling pain or anxiety with drugs and alcohol as well as an increase of nervous habits like nail biting.

One study found that high levels of stress were directly related to architectural obstacles in homes and at work, issues with personal assistance, and problems with transportation services. According to one analysis, women tend to struggle more with stress when they encounter more functional limitations. It's helpful to research resources in your area that can advise you on appropriate accommodations to achieve independence including returning to work.

MANAGING STRESS

One source of stress for people living with spinal cord injuries is pain. The majority of people with a SCI report continual, unpleasant feelings or pain. About a third describe the pain as severe, which can be very difficult to live with. Unfortunately, constant pain related to spinal cord injuries tends to exist at various points of the body and typically does not improve with time. It can interfere with normal life activities thus causing depression. Only a few pain medications are helpful and some may provide slight relief but with potentially dangerous side effects. For this reason, most people need alternative methods of pain management like hypnosis, relaxation, imagery, meditation or yoga. Sleep is often improved as a result of hypnosis as it helps to dull the pain.

Exercise provides benefits including more flexibility, improved muscle tone, increased stamina and energy, and stress management. Regular aerobic activity also increases the functioning of the heart and lungs,

improves daily living activities and independence, decreases the chances of developing chronic diseases and improves mental health. All adults can benefit from being physically active, especially those with disabilities. It's best to talk to your doctor to determine what kind of physical activities are appropriate for your ability as well as a recommended length of time per week.

When you are ready to return to work, you can eliminate some of the associated stress by consulting resources that provide help with making this transition. The Job Accommodation Network (www.askjan.org) provides free, expert, and confidential guidance on workplace modifications and disability employment issues. The website has a list of state vocational rehabilitation agencies that can help you return to work. In addition, Independent Living Research Utilization (www.ilru.org) has a list of centers for independent living and statewide independent living councils in every state which can provide you with information and local resources, including finding an independent living skills trainer.

Attending rehabilitation to learn new skills and problem-solve is vital to managing stress. A team of professionals will be involved in your rehab to maximize learning how to manage your spinal cord injury. You will also gain an understanding of the tools required to make your day-to-day life easier and more controllable.



It's okay to tell people you're having a bad day. Take time to self-care and evaluate your circumstances and needs. Accept your bad day and decide tomorrow will be a better day. Write it on a sticky note and put it on your mirror: Today was a bad day, tomorrow won't be. If your bad day continues to a week or longer, speak to a clinical health professional. Mental health is not talked about enough. Don't be afraid to get help." Ashley, T-10, injured in 2014

PREVENTING STRESS

The way you respond to your injury or circumstances will be highly unpredictable and your emotional adjustment may take some time — months even. However, there are ways to help yourself through this time by confiding in a friend, loved one, or doctor and by keeping a journal of your challenges and successes as well as how you feel about

your journey. Speaking with others about their spinal cord injury or paralysis will help to reveal ideas and experiences to work from. This can also help you meet other individuals living with paralysis in your community. Setting realistic goals and reaching them will also help you to move forward.



Keep moving, stay busy and active. Get involved with organizations and nonprofits that interest you. Your instinct may be to rollover, but there are so many resources available to improve your well-being. Look to your community, groups or friends that have been through a similar situation to find a mentor or help someone else.” Ashley, T-10, injured in 2014

Scheduling annual visits with your specialist(s) and primary care provider will help to treat medical issues as well as prevent potential illnesses you may be susceptible to. A full check-up should include a complete annual physical and influenza vaccine once per year. Additional medical examinations and tests will vary according to your age and health history. Be sure to speak with your insurance provider to be able to visit doctors who have the accommodations and facilities to execute your yearly mammogram and Pap smear. Visiting your physician annually is also a good idea as spinal cord injuries have been associated with an increased risk of heart disease and stroke. Avoiding the use of alcohol, drugs, or smoking will also help you keep a clear head and will serve as a great way to keep your body strong to put you on the path of an active lifestyle.

It is important to have a healthy diet and to remain active to prevent stress. Just because you have a spinal cord injury or paralysis doesn't mean you can't enjoy activities you love. By adapting and learning about how you can participate in a modified way, you can be active and excel in your hobbies and interests. If you are unsure how to start, the National Center on Health, Physical Activity and Disability (www.nchpad.org) is a great resource for lifestyle information.

Travel is always a great way to take a step back and live life to the fullest. It takes a bit more planning, but in the end it will be worth it. Be sure to contact your airline carrier, hotel and cruise line to ensure they will meet your requests for special accommodations. Carry your

medications and supplies for catheterization and other self-care regimens in your carry-on luggage and get as much rest as possible so you can maintain your usual care routines. When traveling for the first time, enlist family and friends to accompany you until you become comfortable.

DEPRESSION, ANXIETY AND POST-TRAUMATIC STRESS DISORDER

The emotional impact of a spinal cord injury or the onset of paralysis can be overwhelming. Being in charge of your own day-to-day routine is taken away. Your body doesn't move or respond like before. You become dependent on other people. This injury will most definitely have an impact on your mental health. When it does, is it even conceivable to get it all back in check?? The answer is YES.

Physical health and mental health are extremely closely linked. When physical health is affected by illness or injury, mental health is more vulnerable and when women experience a spinal cord injury resulting in paraplegia or quadriplegia, both the injury and side effects from treatment can affect the way they think and feel.

DEPRESSION

Many women have experienced depression in some form either before a SCI or definitely after a SCI. Depression is common and can affect anyone, yet women are believed to suffer from depression at twice the rate as men. About one in 20 Americans (over 11 million people) get depressed every year. Depression is even more common in the SCI population — about one in five people. Estimated rates of depression among people with SCI range from 11% to 47%. Depression is one of the most common psychological problems in people with SCI. In a study completed by the National Institutes of Health, it found of the participants studied, the frequency of depression was 49.3%. A period of sadness is normal and expected after a loss such as losing the ability to walk, the control of upper muscles or the ability to breathe independently. Overall, women lose the independence they once knew. Being diagnosed with a SCI initially is challenging emotionally, and of course physically, but depression can and does improve as independence takes over.



I was dealing with depression when I was first released from the hospital, but I knew I wanted something better for myself. I had to keep telling myself, things can always be worse — at least I'm here. I didn't want to be sad anymore and pushed myself to find the light at the end of the tunnel.” Keyonna, T-4/T-5, injured in 2005

PHYSICAL SIGNS OF DEPRESSION

- **Chronic pain.** Any kind of chronic pain may get worse. Any pain you may be experiencing may intensify due to feelings of depression.
- **Digestive problems.** You might feel queasy or nauseated. You might have diarrhea or become constipated. This is a difficult symptom with a SCI because you may not even realize bouts of depression are causing your diarrhea or constipation, yet it plays a key role.
- **Exhaustion and fatigue.** No matter how much you sleep, you may still feel tired or worn out. Pushing a wheelchair can be extremely exhausting. Getting out of the bed in the morning may seem very difficult, even impossible.

- **Sleeping problems.** Many people with depression can't sleep well anymore. They wake up too early or may have difficulty in falling asleep when they go to bed. Others sleep much more than normal.
- **Change in appetite or weight.** Some people with depression lose interest in food and drop weight. Weight loss immediately after your SCI is a normal event and should not be confused with depression. You certainly will not have the appetite you once did pre-SCI. Others find they crave certain foods, like carbohydrates, and weigh more.
- **Loss of interest and motivation.** Loss of pleasure in doing the things you once found enjoyable.
- **Persistently feeling extremely sad or tearful.** It's normal to feel sad or have some crying episodes following the loss that comes with paralysis. However, it's another story when it's continuous and extreme.
- **Difficulty thinking or concentrating.** Feeling like you're in a "brain fog".
- **Feeling worthless or guilty.** With a new SCI, one can feel helpless and dependent which only increases this problem.
- **Loss of sexual interest.** Loss of sexual interest is not to be confused with loss of sexual function. Yes, you have lost some or all sensation of the sexual act but that doesn't mean you've lost sexual interest. Loss of sexual interest means you have no desire to be sexual in any way, whether the act or any other form of showing loving emotions.

COMBATING FEELINGS OF DEPRESSION

Share your symptoms, feelings, and emotional state. If you are still in rehab, a psychologist will be available for immediate intervention. This is important too because treatment for depression can improve your capacity to manage rehab. But what happens if depression begins after discharge? Coming back home for the first time after a SCI is a game changer. It's usually the first time you discover what it's like to live life from a wheelchair in the outside world and your own home. You are no longer the relatively carefree, abled body that lived there before. That's a big pill to swallow. While in rehab or the hospital setting, there was constant activity and therapy. No time to really be quiet with your own thoughts. Going home is just the opposite. You finally have time to

absorb the reality of your situation and the ramifications that go with it. That's when depression can really get a foothold.



Realize that there's nothing wrong with talking about your feelings. If you're struggling, you must take the steps to seek help from someone you trust: a colleague, friend, pastor, peer or family member.” Keyonna, T-4/T-5, injured in 2005

When this happens, whether it's you or someone else that recognizes it, it's very important to notify your physician or your psychologist from rehab. Treatment may include a combination of psychological or “talking” therapies, medication, community support programs and education and support for families. Don't shy away from asking your potential therapist plenty of questions. Finding a provider you feel comfortable with is your key to success as is knowing that not every therapist is a good match for each patient.

Fit in some exercise and physical activity. Exercising may help to ease symptoms of depression by releasing feel-good endorphins that can enhance your sense of well-being. Exercising also takes your mind off of negative thoughts that feed into depression.



Antidepressant medications may include duloxetine (Cymbalta), venlafaxine (Effexor), and older tricyclic antidepressants like amitriptyline (Elavil) or desipramine (Norpramin). Your doctor will discuss the best options for you, but be sure to mention ALL drugs, including herbal and over the counter medications, you are taking to ensure safe drug interactions.

Get outside into the sunshine. Exposure to sunlight is thought to increase the brain's release of a hormone called serotonin, which is associated with boosting mood and helping a person feel calm and focused. Place battery-operated remote-control candles around for some instant brightness enhancement, especially during winter months.

Seasonal affective disorder (SAD) is a type of depression that typically occurs each year during fall and winter. The use of a light therapy box can offer relief as it mimics outdoor light. Researchers believe this type of light causes a chemical change in the brain that lifts your mood and eases other symptoms of SAD. Light boxes are designed to be safe and effective, but they aren't approved or regulated by the Food and Drug Administration (FDA) for SAD treatment, so it's important to understand your options. Ask your healthcare provider if this treatment may be of benefit.

Some other suggestions that may help battle depression: volunteer, help others, socialize, listen to enjoyable music, get involved at church, take up a hobby, get outdoors, phone a friend, but stay busy.

ANXIETY

Everyone has experienced times when they feel anxious. But what occurs when the emotions of anxiety are so overwhelming that they interfere with the ability to function? Anxiety disorders come in many different forms: constant worry, uncontrollable obsessions or urges, social anxiety, and panic attacks—and the distinction between an official diagnosis and “normal” anxiety isn't always clear. Feeling anxious after a devastating diagnosis like paralysis is not uncommon. Anxiety over your physical health, the financial burden, your family dynamics, and your employment are very normal and you will work through each, but what occurs when you have relentless worry after a SCI or the onset of paralysis?

SIGNS AND SYMPTOMS OF AN ANXIETY DISORDER

The following is a list of signs and symptoms of anxiety disorders. After an initial diagnosis of paralysis, it is difficult not to fall into this mental state but the disorder occurs when you find yourself here and you can't climb out. The anxiety is completely overwhelming and affecting your daily routines.

- **Difficulty performing simple tasks.** Being newly injured, simple tasks become challenging at the beginning. But if you're constantly procrastinating because you can't concentrate or can't stay focused, then it's time to get some professional assistance.
- **Difficulty in finding others who understand.** When you find yourself getting frustrated and anxious because those around you just don't/can't understand what it's like living with a SCI, it's time to get some help. Support groups are excellent. Another place to find others who understand is the Christopher & Dana Reeve Foundation's Peer & Family Support Program. Facebook has several SCI groups that are extremely supportive and you will soon realize you are not alone.



When I was newly injured following a car accident, I looked at my support system, my family and dear friends, but they could all walk. I received the love I needed from my family and friends but I craved others who understood my physical and emotional limitations. Approximately a year after my injury, I created a Facebook profile and started searching for others who were also spinal cord injured. I joined several Facebook groups, because none of my friends or family could truly understand the pain and emotions I was experiencing with such a huge lifestyle change.” Patty, T-3/T-4, injured in 2009

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- **Trouble focusing on the good.** When you are newly diagnosed with paralysis, it is extremely difficult to see “the good” in anything. Your life is turned totally upside down but when the dust settles and you still have difficulty focusing on the good in your life, it may be time to seek professional assistance.
 - **Anxious feelings come on, with no explanation.** Anxiety can come and go while performing new routines but when an anxious feeling comes on with no reason and doesn't go away, it may need some investigation.

- **Obsessive compulsive disorder (OCD) and depression.** If you find yourself with OCD tendencies and/or a depressed state along with anxiety, you should share this with a professional to assist with symptoms.
- **Panic attacks.** When anxiety turns into full-blown panic attacks, this may be the time to consult a professional. Panic attacks involve sudden feelings of terror that strike without warning. People experiencing a panic attack may believe they are having a heart attack, dying or going crazy. Most people with panic attacks experience several of the following symptoms: “racing” heart; feeling weak, faint or dizzy; tingling or numbness in the hands and fingers; a sense of terror, impending doom or death; feeling sweaty; having chills, chest pains or breathing difficulties; or feeling a loss of control.
- **Often backing out of social invitations.** This is a difficult symptom of anxiety. Doing anything for the first time causes anxiety for those of us with a SCI. Will that restaurant accommodate my wheelchair? Can I move around freely without rolling over toes? Will people stare at me? Having a SCI and needing to have a wheelchair in tow is difficult for any situation. With time, going out without fear should become the norm again. When it doesn't and you find yourself still avoiding social situations, it is time to see your healthcare professional.
- **Avoidance of specific situations and things.** The above symptom leads right into this. Backing out of situations often leads to avoidance of specific situations also. The following are some examples of why people with anxiety actually cancel plans last minute:
 - They're too exhausted to face the world and pretend to be “okay”.
 - They're struggling and don't want to burden others with their problems.
 - They're “on edge” and can't cope with being in a situation that's not “in their control”.
 - They're overwhelmed.

But with a SCI there are other anxiety producers:

- They're afraid they might have a "poop accident" while out.
- They're afraid the venue won't be accessible.
- They can't deal with people staring at them.



I had this happen to me when my son got married. Not only was I the mother of the groom, but I felt like even more attention would be drawn to me because I was in a wheelchair. My wheelchair pushed my anxiety through the roof. I didn't want to go. But I couldn't allow my anxiety to interfere with my son's wedding. So, I rolled forward, held my head up high, and rolled along with the festivities of the weekend. You know the saying, 'It is what it is'? That was and is my motto."
Patty, T-3/T-4, injured in 2009

COPING WITH ANXIETY

If anxiety is just beginning as you are dealing with a newly diagnosed SCI, you may be able to work through it with family and friends by your side but what if you are unable to break free?

Learn to relax. Do yoga, meditation or get some exercise. Exercise is a terrific outlet for anxiety. This suggestion can be a bit tricky for women living with paralysis due to their unique individual limitations. So, keep in mind there are several adaptive forms of yoga, meditation, and exercise that are available to try out. More importantly, find an outlet to relieve anxiety that works for you. Read a book, listen to music, volunteer, find a hobby, whatever YOU ENJOY, do it. Distraction will ease the anxiety you are feeling.

Find someone to talk to. A good listener can go a long way. Very often, it's possible to get past an anxiety cycle with the help of friends or family -- someone who can help you sort out your problems. This may be all it takes but if not, it is time to meet with a trained professional.

Grounding is a set of simple strategies meant to distract. Distraction works by focusing outward on the external world rather than inward toward yourself. When you are overwhelmed, you need a way to decompress so you can gain control over your feelings and stay safe.

Grounding “anchors” you to the present and to reality. Below is an example of an exercise in grounding. It can help you when you feel like you’ve lost all control of your surroundings.

STOP! LOOK AROUND YOU AND FIND...

5 THINGS YOU CAN **SEE** 

4 THINGS YOU CAN **TOUCH** 

3 THINGS YOU CAN **HEAR** 

2 THINGS YOU CAN **SMELL** 

1 THING YOU CAN **TASTE** 

Talk to your physician regarding medication and discuss your options. Create a plan of attack. Medication will not cure an anxiety disorder, but it will help keep it under control. Antidepressants, particularly the SSRIs (selective serotonin reuptake inhibitors), may be effective in treating many types of anxiety disorders. Some common SSRIs include Celexa, Prozac, and Zoloft. Other treatment includes benzodiazepines, such as Valium, Ativan and Xanax alone or in combination with SSRI medication. These drugs do carry a risk of addiction so they are not as desirable for long-term use. Other possible side effects include drowsiness, poor concentration, and irritability.

Change what you can and accept the rest. Separate out the real risks and dangers that a situation presents and those your imagination is making worse.



You can't live your life being scared about what might happen. Instead focus on how your life can improve if you try something. Your injury will open up new doors you never thought you would experience." Sarah, C-7, injured in 2015

POST-TRAUMATIC STRESS DISORDER

Post-traumatic stress disorder (PTSD) develops in some people who have experienced a shocking, scary, or dangerous event. Any experience that threatens your life or someone else's can cause PTSD. These types of events are sometimes called trauma. Nearly everyone will experience a range of reactions after trauma, yet most people recover from initial symptoms naturally. Those who continue to experience problems may be diagnosed with PTSD. People who have PTSD may feel stressed or frightened, even when they are not in danger. When a SCI results in the development of PTSD, it may be due to the traumatic event that a survivor may relive in his/her mind for years to come. Another reason for PTSD is that a SCI can affect virtually every aspect of your life — everything from the sensory and motor functions of your body to your ability to use the restroom, eat, or live independently. This life-altering change can result in a negative impact on your mental health.

SIGNS AND SYMPTOMS OF PTSD

PTSD can be difficult to explain or diagnose. Not every traumatized person develops ongoing (chronic) or even short-term (acute) PTSD. Not everyone with PTSD has been through a dangerous event. Some experiences, like the sudden, unexpected death of a loved one, can also cause PTSD. Symptoms usually begin early, within three months of the traumatic incident, but sometimes they begin years afterward. At least half of Americans have had a traumatic event in their lives. Of people who have had trauma, two in 10 women will develop PTSD.

There are four types of PTSD symptoms:

- **Reliving the event.** People with PTSD repeatedly relive the ordeal through thoughts and memories of the trauma. These may include flashbacks, hallucinations, and/or nightmares. They may also feel great distress when certain things remind them of the trauma – a trigger. Even an anniversary date of the event can become a trigger.
- **Avoiding things that remind you of the event.** Avoiding situations that remind you of the trauma leading to your SCI is understandable. But with PTSD this can lead to feelings of detachment and isolation from family and friends as well as the loss of interest in activities that you once enjoyed.

- **Having more negative thoughts and feelings than before.** The key word here is “more”. This includes having negative thoughts about yourself or the world or distorted feelings about guilt and blame.
- **Arousal and reactivity.** These symptoms are usually constant instead of being triggered by things that remind you of your traumatic event. You may feel easily startled, tense, “on edge” or even angry. These feelings may make it difficult to perform daily tasks such as sleeping, eating or concentrating.

SEEKING PROFESSIONAL SUPPORT

If you have been experiencing any of the above symptoms nearly every day for more than two weeks, then it’s time to seek assistance, especially if these symptoms are interfering with your daily life or if they are causing you to think about or plan to commit suicide.

Your primary care provider or a mental health professional is a great place to start. Your health care professionals will screen your mental health and discuss the best course of action. The goal of PTSD treatment is to reduce the emotional and physical symptoms, to improve daily functioning, and to help you cope better with the event that triggered the disorder. Treatment may involve therapy, medication, or both.

Therapy and psychotherapy are both a type of counseling. The goal of therapy is to teach the person affected as well as his/her family about the disorder and how to work through the fears associated with the traumatic event. Psychotherapy focuses on teaching the skills to manage symptoms and to develop ways of coping. The most common type of medication for treating PTSD is antidepressants, which may help control PTSD symptoms such as sadness, worry, anger, and feeling numb inside. Other medications may be helpful for treating specific PTSD symptoms, such as sleep problems and nightmares.

PROFESSIONAL SUPPORT SOURCES

There are many, many directions to turn for encouragement. Don’t be shy and don’t try to go it alone. Each of these professionals will maintain your confidentiality.

- Family doctor
- Mental health specialists, including:
 - Psychiatrists
 - Clinical psychologists
 - Social workers
 - Licensed mental health counselors
- Employer-provided Employee Assistance Programs (EAPs)
- Nearby university or medical school-affiliated mental health clinics
- Local hospitals
- Community mental health centers
- Clergy
- Health maintenance organization (HMO) or health insurance company
- National Suicide Prevention Lifeline 1-800-273-8255

OVERCOMING THE STIGMA

Stigma is a mark of disgrace that sets a person apart from others. When a person is labeled by their illness, they are no longer seen as an individual but as part of a stereotyped group. Negative attitudes and beliefs toward this group create prejudice, which leads to negative actions and discrimination. Three out of four people with a mental health illness report that they have experienced stigma.

Finding yourself a woman with paralysis will include physical, emotional, and mental labor. There can be stigma directed towards you for any one of these reasons. Don't ever be afraid to share your thoughts and feelings with family and/or friends. Stigma is almost always based on a lack of understanding rather than the facts. Learning to accept your condition and recognize what you need to do to treat it, seeking support, and helping to educate others can make a big difference in getting you back to being in charge of your own life!

BODY IMAGE

How women view their bodies has and always will be a sensitive yet empowering topic. Women are often their own worst critic, analyzing their shape, size, weight and flaws and comparing them against influences in their daily lives and so-called standards in society. Maintaining a positive body image after experiencing a trauma or injury is more challenging if you were previously struggling to see your body in a positive way.

Having a disability or injury brings an additional challenge as you may be perceived as atypical and possibly even incompetent. Many times this view stems from conjured up images the media projects throughout our culture depicting individuals with disabilities as ill or weak. These images are the total opposite of what their vision of a smart, strong and attractive woman looks like, which can cause you to see your body in a negative way.



You're here. It doesn't matter what you look like. You can still live your life. This is just a detour on your journey, your path is not over." Sarah, C-7, injured in 2015

IMPACT OF PARALYSIS/DISABILITY ON BODY IMAGE

As more studies and research surface, they confirm the challenges people with paralysis – women in particular – face regarding their self-esteem and body image. While each person experiences different situations, there are common patterns that exist. For instance, women with disabilities may not fit the narrow definition of the ideal female body or what is considered beautiful, which is often white, thin, and tall with a full bust, large eyes and full lips. Images in movies, television shows and commercials rarely include women with paralysis and disabilities. And when they do, they are often portrayed as angry, helpless and without a partner. Even though giving in to these flawed views is a challenge that both disabled and able-bodied women face, many women living with a disability will fixate on their negative body image to the degree that if not explored, it may result in a genuine psychological and emotional issue.



For some women, how you see your body directly relates to how attractive or sexual you believe you can be. And as women frequently compare themselves to those inside and outside their circle, it's easy to feel like you don't measure up to how the ideal woman is portrayed throughout pop culture due to

your distinct disability. Adding on to the pressure of meeting society's expectations of beauty, women also feel the burden of wanting to be seen as an attractive partner and able to fulfill the traditional roles of women which include motherhood.

Not all women, however, suffer from negative body image concerns and rise above societal expectations. Many actively work to fight the harmful perceptions the world disseminates to others as well as within themselves. By challenging these ideals of beauty and the narrow thoughts of femininity, women with disabilities can begin to accept their bodies and achieve higher self-esteem.

SIGNS OF AN UNHEALTHY BODY IMAGE

Viewing your body in a positive way is challenging for any woman. While you may not like certain aspects of your body, it may be difficult to decipher if you have a negative body image or if you simply recognize your flaws. When you have a negative body image, you typically have a pessimistic inner voice which fixates on your body's imperfections. This includes, but is not limited to, the color, shape and perceived abnormality or body part.

If you are having trouble accepting your level of disability or injury, it may complicate your body image issues. And unfortunately, if you experience having a negative body image, you may become prone to mental health issues including depression, eating disorders, isolation and low self-esteem.



One sign of having an unhealthy body image is only taking pictures of yourself that don't show your injury. Be confident and be in charge of your own narrative. You're in charge of your own story." Sarah, C-7, injured in 2015

STRATEGIES FOR ATTAINING A HEALTHY BODY IMAGE

Developing a positive body image can be difficult, but with support from friends and family and, if needed, professional help, it is achievable. Don't be afraid to talk about your issues and concerns and have a real conversation about your thoughts and outlook. It's hard to see yourself as you truly are and the people who know you most will reinforce how beautiful you are. Talking to peers and community support groups may be especially helpful to receive tips on how to view yourself in a healthy way and to learn from each other by sharing and listening to each other's stories.

Having a supportive environment is a piece of the puzzle needed to achieve a positive body image, but the majority of the work has to come from you. In order to help yourself, consider the following:

- **Start pinpointing any sources of negative messages.** They often come from the media you consume, including television and movies as well as social media platforms showcasing people "living their best life," which most of the time is altered. Do your best to stay away from these mediums whenever possible and replace them with versions that deliver positive body messages.
- **Think carefully and honestly to determine if your injury is interfering with the acceptance of your body.** If this is the case, make it a point to work on appreciating your body as it will be difficult to tackle other issues until that is complete.



You can still dress in the same style, you just may need to make some modifications. I loved wearing cowboy boots but it was difficult to pull them on and off. I didn't want my injury to define my appearance so I took them to a shoe repairman and had him put a zipper in the back of the boots so I could keep my style and my confidence." Sarah, C-7, injured in 2015

- **Keep a journal or diary of your thoughts.** This includes negative and positive viewpoints. As you record your feelings, you will start to become more aware of your negative inner voice and what prompts your feelings.
- **Stay on top of news and events regarding negative and positive body image.** By reading books and articles, watching online talks and presentations or attending events and expos, you can learn more about how body image is formed and how it impacts you. It's also helpful to continue to examine your emotions and your ways of thinking.



- **Develop new and old hobbies – where possible – to continue to push your limits and learn new skills.**

There is a whole world of activities and entertainment options available to explore that can help you go beyond how your body looks to realize what you can do. If you're unsure where to start, connect with your local support group and online communities to get some suggestions.

- **How you dress and present yourself also has an impact on your body image.** Buy clothes that make you feel confident. Sometimes a new hair style can drastically change how you look and feel, so take charge and change it up.
- **It's also important to take care of your body by eating healthy and exercising.** Enlist the help of a friend, family member or peer mentor to explore different activities and fitness regimens where you safely can be healthy and have fun.
- **If you are dismissive of the thought of having romantic and sexual relations, it can lead to or reinforce negative body images.** Remind yourself that you are attractive and deserve love and affection. Take pride in your appearance, reaffirm positive thoughts and your body image will become healthier.



People who haven't faced adversity in their life before may struggle. You have to get up and continue to do the things that make you happy. Dress up, sing, get your hair done, go swimming. Find groups available to you to make it happen. And if it doesn't exist, create it." Keyonna, T-4/T-5, injured in 2005

If you are still having trouble attaining a positive body image, speak with a mental health professional. They can work with you to determine successful techniques to help you in your journey to seeing yourself in a positive light and working through your concerns. As you start to feel comfortable with yourself and understand how to care for and keep your body healthy, it will help you to feel better overall. Continue to challenge the norms of ideal concepts of beauty and femininity and you will be able to accept your body and have higher self-esteem.

SIGNS OF A HEALTHY BODY IMAGE

Having a healthy body image means you have a high sense of self-worth and can accept your flaws without obsessing over them. This includes acknowledging your weight, while taking the necessary steps to remain at a healthy weight – or clothing size – for your body type.



When you eat, you do so for energy and nutrition, not as an emotional clutch. We all indulge from time to time, but you make the best choices for you and your body to meet your physical needs. And you're able to enjoy a cheat meal without beating yourself up or setting yourself up to indulge too much.

Your inner thoughts about you and your body are positive. We all have an imperfection or two, but for the most part you don't judge yourself harshly and are able to encourage and compliment yourself. And you don't hesitate to put your needs ahead of others. It's so easy to always

think about your parents, siblings, children or partners first but, in order to be healthy, you know you need to carve out time for your wants and desires to ultimately make yourself happier and healthier. This includes enjoying outings with friends as well as exercising and participating in physical activities. You can recognize your beauty and it leads you to love your whole self.



Track your progress. Keep a diary, videos or pictures of yourself so you can look back and see how far you've come.” Sarah, C-7, injured in 2015

SELF-ESTEEM

Self-esteem involves your sense of worth, competence, and self-respect. Some women find that their level of self-esteem is based on their mutual relationships, caring for others, being able to influence people, and their belief that they are truly being seen and heard by their community. While many women with disabilities have positive self-esteem, overall their confidence tends to be lower than able-bodied women.

IMPACT OF PARALYSIS/DISABILITY ON SELF-ESTEEM

An added challenge you may have as a woman with a disability may be viewing yourself as a person first. Your disability is only one aspect of who you are, so it's important to allow yourself to view your disability as one component of your life, not the only component.

Another issue you may experience is dealing with discrimination and stereotypes from society based on looks and being different from everyone else. It's understandable that so many women put added pressure on themselves to try to meet society's impossible standards. Some studies also suggest that certain factors have been found to decrease self-esteem, including experiences with pain and fatigue, dependency on others, the development of secondary conditions, or loss of stability in life, including employment and benefits.

SIGNS OF LOW SELF-ESTEEM

Based on your life experiences, your self-esteem will change over time. It's common to go through rough patches when you feel bad

about yourself as well as phases when you are content. However, if you recognize that you are constantly degrading yourself and your abilities without being able to identify positive qualities, you need to increase your self-esteem.

Knowing the signs of having low self-esteem is helpful to curb potential long-term effects. While it is not widely studied in the disability field, there is evidence that shows an illness or disability can negatively impact self-esteem, which can intensify stress levels and negative moods. Therefore, it's important to be able to recognize the various components of having low self-esteem.

When you have negative or low self-esteem, you don't believe in your thoughts, beliefs and actions and feel you contribute little to society. You might find it difficult to accept compliments and positive feedback. If you have low self-esteem, you give little recognition to your skills, accomplishments and assets and choose to focus on your perceived weaknesses and faults. Some believe they are incapable of having an impact on their community and believe that others are more competent and successful. The fear of failure could also prevent you from succeeding in many areas of life, including in relationships, at work or in school.

BENEFITS OF POSITIVE SELF-ESTEEM

It goes without saying that having a positive self-esteem is a good thing. No one wants to feel negatively or badly about themselves, but without knowing the benefits of a healthy self-esteem, you might not be inclined to actively attain it.



When you have positive self-esteem, you will find that life overall becomes simpler and lighter. Life's issues don't seem as big and when you do face challenges, you'll be able to see how to address them. You will have more inner stability. When you like yourself more, your opinion of yourself naturally increases, which eliminates

the need for validation from others. As you become less needy, you won't be experiencing so many emotional ups and downs based on what others may think about you.



Everyone's journey to acceptance is different. Slowly, I realized that I didn't take time to smell the roses and enjoy life before my injury. It forced me to get off the hamster wheel of my life and allowed me to be so much more my authentic self than I ever was on my feet. Now I'm a mentor and Ms. Wheelchair Maryland 2017."
Keyonna, T-4/T-5, injured in 2005

Self-sabotage will decrease. By maintaining your self-esteem, you'll feel more deserving of experiencing good things in life and will chase them more and with a newfound enthusiasm. Once attained, you'll be less likely to give in to self-doubt. You'll be more attractive in your relationships. By living more simply, having more inner stability, being less needy and loving yourself more, you will create a more enjoyable experience with less fighting and arguments. This is true for all relationships, not just with your partner. And with all things considered, you will be happier.

SIGNS OF HEALTHY SELF-ESTEEM

Having healthy or positive self-esteem does not mean that you have an inflated or arrogant view of yourself. It simply means that you are able to accept yourself as is and can acknowledge your strengths and weaknesses. When you have healthy self-esteem, you are kind and are able to create positive, secure and honest relationships. It gives you the skills needed to identify what you want and what you deserve and the strength and knowledge to know when to leave an unhealthy relationship.

Having realistic expectations of yourself and the people around you leads you to be more sympathetic and less critical. If something goes wrong or you fail at a task, you are able to brush it off, discover why you failed and try again. You feel confident in your abilities and decision-making skills, which allows you to be assertive, express your needs and opinions, and do what's best for you. Rather than finding a way to belong, you are confident in your beliefs and carve your own path to lead you to success. Resilience is the key to managing stress and any obstacles you meet.

STRATEGIES FOR RAISING SELF-ESTEEM

It's easy for someone to say, "look on the bright side" or "believe in yourself," but it's quite another to change your mindset – especially when faced with an injury. If you are struggling with negative self-esteem, there are multiple ways to try to boost your sense of worth.

- **Maximize the positive and minimize the negative.** That doesn't mean that you should pretend you don't have paralysis, but you should find ways to highlight and develop your abilities as opposed to focusing on your restrictions. Tell yourself that you are smart and capable and take pride in your accomplishments.



Focus on what works, things you can do versus things you can't. You have to find the positive or you won't be able to get through it." Ashley, T-10, injured in 2014

- **Avoid unrealistic comparisons.** With people boasting on social media of how great and perfect their life is, it's hard not to get wrapped up in it. However, it's not fair – or healthy – to compare yourself to someone who doesn't have the same challenges as you so there's no sense in being so hard on yourself.
- **Set realistic goals for yourself.** While you may want to exceed your expectations, if you go too far, it may backfire and result in you feeling worse. Think about what and how you ideally want to accomplish something but be sure to factor in the extra time you may need to succeed. As you meet your goals, you will boost your confidence and strive to continue to excel.
- **Don't jump to negative conclusions.** There are and will be challenges and tasks you aren't able to do. Don't automatically decide that you are incapable or a failure. This will dramatically decrease your self-worth and hinder you from attempting that task in the future. Instead, analyze the situation to determine what you did wrong and how you can find a resolution.
- **Eliminate "should" statements from your vocabulary.** While you may think you ought to have the ability to accomplish something, the reality is that you may require accommodations that others

don't. This concept ties back to setting practical goals to eliminate unfair comparisons.

- **Appreciate your entire self – disability and all.** Believe that you are worthy and focus on what makes you special and unique, while allowing yourself to acknowledge the benefits of your injury. It may sound clichéd, but it's helpful to make a list of your strengths to empower you to overcome any challenges.



Be the best you can be and know who you are. Don't let your injury dictate how you act, look or feel. You are a person, not an injury. This doesn't define who you are." Ashley, T-10, injured in 2014

All in all, remember why you are looking to change your life for the better. You are facing challenges, but you are strong, resilient and capable of much more than you may think. By focusing on your mental health, you will start to see improvements in many areas of your life.



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