

Adjusting to Life After Spinal Cord Injury

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<https://msktc.org/sci/factsheets>

SCI Factsheet

It is important that rehabilitation is your main focus in the early weeks and months after injury. You can learn more about expectations for recovery, your role in rehabilitation, and find other suggestions to guide your recovery in “Understanding Spinal Cord Injury: Part 2—Recovery and Rehabilitation” at www.msktc.org/sci/factsheets/Understanding_SCI

The Model Systems Knowledge Translation Center works with Spinal Cord Injury Model System (SCIMS) centers to provide free research-based rehabilitation resources for people living with spinal cord injury (see <https://msktc.org/sci> for more information). This factsheet has been approved by experts from the SCIMS centers.

What is adjustment?

Adjustment is how you adapt to or become used to changes in your life. 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.



Experiencing 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 your 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 SCI?

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 SCI. 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.

People who are newly injured adjust to a “new normal.” They 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 they work through problems and learn how best to manage daily routines.

- You usually begin learning how to manage your self-care and daily activities during inpatient rehabilitation.
- 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. You may first depend on medical equipment, such as a hospital bed or assistive devices but not need them later.
- Over time, you may change the way you manage things at home. For example, you may have showered or did your bowel program at night during rehabilitation. You might find that doing these activities in the morning better fits your daily routine.



How do people adjust to SCI?

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



- Your personality and the way that you adjust to changes in your life do not usually change after SCI. This means you will likely adjust after SCI in your own way and in your own timeframe.
- You may feel “different” in your body in the early weeks and months after SCI. 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 find important in your life. For example, you may focus your attention more on your relationships with family and friends than you did before your SCI.

Adjusting Well

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

- Do not experience depression, or if they are depressed soon after SCI, 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 SCI as a challenge and see the potential for personal growth to make their life better.
 - Accept that their SCI 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? A 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 SCI 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:
 - The Job Accommodation Network (JAN; www.askjan.org) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. The JAN website also has a list of State Vocational Rehabilitation Agencies that can help you return to work.
 - The Independent Living Research Utilization (www.ilru.org) program 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-on-one 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 community-based living.

- The Disability Services webpage on the USA.gov web site (<https://www.usa.gov/disability-services>) offers information on disability programs and services available from the government and in local communities nationwide.
- ✓ 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 is 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 the 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 SCI. 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 SCI become depressed.
- Talk to a professional if you think you might be depressed. Depression is treatable with medication and counseling. Learn more about depression and treatment options by reading “Depression and Spinal Cord Injury” at www.msktc.org/sci/factsheets/Depression.

Does family life change after SCI?

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 find the “new normal” in their relationship.



- Read “Sexuality and Sexual Functioning After SCI” to learn more about managing relationships, sex, and having children after SCI at <http://www.msktc.org/sci/factsheets/sexuality>.

Parenting

For any parent, raising a child is a learning process that is challenging and rewarding. 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 SCI. 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 SCI. 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. These skills help to lessen your reliance on help from others.



Still, you will likely need some type of help to do the things that you cannot do. Asking for help is sometimes difficult to accept. Here are two questions to consider if you are hesitant to ask for help.

1. 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. You can probably think of many examples when you relied on others before your SCI. 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.



2. 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.

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 SCI. 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 health care services that everyone needs, such as treating common illnesses and providing 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 sites may 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 couples and with 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.
 1. The United Spinal Association (www.unitedspinal.org) provides information and resources to meet the needs of people with SCI and their families and friends.
 2. FacingDisability.com (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 people discussing real-life issues they faced after SCI.



Authorship

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