

Better Together: Spinal Cord Injury Support Groups

A spinal cord injury is a highly personal condition, but that doesn't mean you have to go it alone. Spinal cord injury support groups can connect you to the SCI community and help you learn practical skills.

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Michael Henley sustained a spinal cord injury that paralyzed him when he was 18 years old. While he was a patient at the University of Maryland Rehabilitation and Orthopaedic Institute, he was invited to join their spinal cord injury support group. Little did he know then that it would change nearly every aspect of his life.

Twenty-two years later, Henley is now the senior recreational therapist who runs that support group, and he's not the only long-time member. Some of those who mentored him when he began still attend regularly today.

If you or a loved one have had a spinal cord injury, here's what you need to know about support groups.

Benefits of Support Groups

"Two of the guys in the group had injuries very similar to mine, and they'd both been injured at 17," Henley says. "Talking with them was awesome."

The help group members provided was often practical, says Henley. They told him about vocational rehab, which helped him to pay for college and get accommodations he needed to be successful. But there were less tangible benefits, too, in the hope they provided for his future.

"One of the guys always had his beautiful girlfriend with him at the support group. At first, after an injury, you think, 'Nobody's going to want me like this.' But he was paralyzed like me. They showed me it was all about attitude and personality."

Attending a support group can help you feel less alone and more connected to others who can relate to your challenges, fears, and triumphs. Often, it's reassuring to find out that your feelings are common and that others have been able to thrive after a life-changing injury.

Groups can also help people band together to find solutions to problems. For instance, members of Henley's group are joining forces to advocate for more accessible sidewalks for people who use wheelchairs, and better transportation support so that those who use paratransit services are not kept waiting for hours.

What to Expect from a Support Group

Most spinal injury support groups meet either monthly or twice a month, usually between one and two hours per meeting. For the [Baltimore Spinal Cord Injury Support Group](#), COVID-19 changed that—when they decided to move things to Zoom, they also agreed to meet more frequently. Currently, they meet for one hour every week.

One benefit was that they saw several new faces—people who lived too far to make it to their in-person meetings or who lacked transportation. As a result, they've decided that even when they're able to resume regular meetings in person, they'll also continue Zoom meetings in between.

Many groups meet at rehabilitation centers or other medical institutions. There is generally no cost involved to attend, except for special events they may host. Sponsors may also pay for meals or snacks at meetings.

Check with the group leader ahead of time about bringing family members or caregivers. In some organizations, there are also separate caregiver support groups.

Topics and Structure of a Spinal Cord Injury Support Group

Coordinators generally lead meetings to make sure conversations stay on track and that everyone has a chance to speak. That leader may or may not be a mental health professional.

In some cases, guest speakers give presentations and do Q&As to start each meeting. Often the group's discussion afterwards will be an offshoot of the speaker's topic.

Other groups rely entirely on peer-to-peer chats, either with a formal topic and structure in mind, or a more free-flowing conversation that can center around whatever issues have come up for people in the group that month.

Some of the common topics discussed include:

- Intimacy and sex
- Mental health
- Coping skills
- Pain management
- Going back to work or college
- Adaptive sports and exercise

- Driving
- Caregivers' roles
- Managing bowel and bladder complications
- Alcohol and substance abuse

Forming Friendships and Finding Mentors

It's OK to hang back and watch and listen in the beginning in most support groups. You may be expected to introduce yourself briefly, but don't worry about needing to get too personal too quickly. Each group has a different dynamic and different leadership style, and you may find that you need to try more than one before you figure out where you fit in.

Some groups also offer peer mentors, generally those who've been in the group for at least a year and have experience dealing with a variety of spinal cord injury-related challenges. Mentors may attend the support group meetings, or may stick to checking in on their mentees outside of the group.

It's also not at all unusual for friendships to form that go beyond the confines of the meetings.

"One friend I met in the group is lending me his off-road power chair to take to the beach on my family vacation at the end of the month," Henley says. "Another guy just invited 10 people in the group over to his house for dinner. We're talking about long-term friendships."

There may also be a networking aspect. In Henley's case, he was recently able to help a member find a new job because employers contact him with opportunities to share with the group. In other cases, members can tell each other about jobs they've held that have been good in terms of accessibility and working environment.

Who Needs a SCI Support Group?

The bottom line is that anyone who's been through a spinal cord injury can benefit from a support group, both for the camaraderie it provides by connecting you with others in the SCI community and for the education and practical help. To find support groups in your area in the United States, visit the [United Spinal Association](#) or call your local rehab center. You might find out that it's an essential part of your care.

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