

Title of Document: **Tips for Spouses who Have Become Caregivers**

Overview: When someone sustains a spinal cord injury, there are supports in our healthcare system for rehabilitation. On the other hand, when one becomes a caregiver, there are fewer resources available. Spinal Cord Injury BC does provide support services for members as well as family. This document is a summary of the top 10 tips that are available online for spouses who have become caregivers for their partners.

Tips: **10) Know who your trusted supports are and get them involved as soon as possible.** Even if you don't tell them about your daily life, a quick update every now and then will suffice. This way, if you require their assistance at some crucial point, they are not clueless.

9) Do not let the expectations of others guide you. It is common for people to ask you questions like "does (s)he take sugar with that?" or "why aren't you pushing him/ her?" Over time, you will find a way to collectively respond to such remarks and be with each other as you deem fit.

8) Contrary to popular belief, your sex life does not have to come to an end after SCI.

There may be challenges, and it will be different. Yet, intimacy post-injury is possible. Have a look at the sexual health resources on our database for ideas. Expect that people will ask you about your sex life but you do not have to answer.

7) Be sure to have a life aside from your partner's life.

This shouldn't be any different than what you did before the SCI. It is not selfish to indulge in self care and put yourself first at times. You are more than your partner's caregiver. You cannot be an effective caregiver unless you take care of yourself too.

6) You will have to fight for your relationship.

At times, you'll be up against those closest to you – remember that they don't live your daily life and will take time to understand why you choose to be with your partner. You may also have to remind yourself at times that your fight isn't with your partner, but that you are fighting together against your barriers.

5) Needless to say, you will need to adjust to your new life, new roles, and the presence of new people and professionals in your life.

Care aides, physiotherapists, occupational therapists, doctors, nurses, and maybe even lawyers will become a part of your team in caring for your partner. They are there to help you so reach out to them when you feel the need to do so.

For further information on SCI BC programs and services check out our website at www.sci-bc.ca

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4) Be prepared to answer lots of questions.

People will ask you questions out of ignorance, a sheer will to help, curiosity, and other reasons. You don't have to answer them all –in fact, the perfect response to the rude questions might just be the silence that does not dignify the question with an answer. Nevertheless, be prepared.

3) It is quite common to feel guilty when one is a caregiver, especially initially.

This could be amplified if you, as the caregiver, are able-bodied and your partner isn't. It's imperative that you don't let the guilt taint your decision making process. Ask yourself: would I act this way if my partner didn't have SCI? If it helps, there are online forums and Facebook groups that you can join (search using keywords like SCI, caregiver, spouse, etc.) where you will find people in the same boat as yourself. They have been through similar experiences and emotions and can help support you during this process.

2) In relation to the previous point, join a support group if there is one available near you and you are able.

The power of peer networking can be immensely helpful for some people. Connecting with a Peer staff member at SCI BC might be helpful. Not only are the Peer staff members experienced in matters specific to SCI, they can connect you with other staff and community members with whom you can relate, whether online/by phone or in person, depending on your location.

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1) Do not become your partner's caregiver first—BE his or her partner first.

While it is recommended that the roles of caregiver and partner be fulfilled by two different people, the reality is that most spouses do become caregivers of their partners. This is especially true in rural communities. Be mindful of your roles and prioritize them. If you want more information about how to access caregivers in the community, call InfoLine.

Useful References:

Spinal Cord Injury BC Peer Program.

Runs events to connect people with SCI. Contact your local coordinator for details or call InfoLine to find out more.

<http://sci-bc.ca/about-us/our-staff/>

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