



CHAPTER TWO

Family Members





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Though my husband's support was important to my recovery, it was even more important for me to take the lead on it.

- Lubna Aslam, SCIO Peer Program Manager

THE VITAL ROLE OF FAMILY: ONE FAMILY MEMBER TO ANOTHER

Did this book land in your hands because you are the partner/parent/family/friend of someone with a new SCI? If so, read on. You have a lot to learn. This is most likely the first time you have known someone with an SCI and there's a chance you feel quite lost. Although we won't have all the answers for you, as every SCI is different, we hope that you will learn a lot here and that it will help the person in your life with an SCI get on the road to recovery.

In this section, you will discover important things to know and you will read advice from people who have found themselves in the complex role of a family member of a person with an SCI .

Family member is how we will refer to the *primary* person supporting a person who is newly injured. This is the one who finds themselves right at the bedside. The family member may not actually be family, but most often is. It could be a partner, parent, adult child, family friend — someone who loves the person with an SCI and wants to see them recover as much and as soon as possible; you are attached to them! Rather than “caregiver,” which may not be accurate for this role, we'll use *family member* throughout this publication (except where stated by those being interviewed). Family members will be called upon to make decisions until the person who is newly injured is able to do so for themselves. They will also help out, when needed, with therapy and other tasks as required. Each case is different.

Your new role as family member

This was never something you guessed would happen and now you need to be on your “A Game.” The person who is newly injured will be relying on you for help until they are able to help themselves. How long that takes depends on the level of SCI and severity of other injuries.

If you have not realized it yet, your main job is to listen. Listen to everything every doctor and nurse says and, as much as possible, write it down. Keeping a notebook as you go will help you when you can't recall details because your brain is in a fog.

A Family Member's Story

A HUSBAND'S PERSPECTIVE, PART 1

At first (until after a couple of months), I didn't realize that I was now "the caregiver" to my wife. All I was doing was reacting to situations, answering questions that were asked by the professionals, communicating to friends and family and trying to look after our kids. I was just husband and father. But then, as time went on, I realized — especially as the nurses talked to me — I had become her caregiver.

After the accident, my life went sideways. I was a stay-at-home dad with two kids and a small farm on the side. We live an hour and a half from the hospital where she would be for four months. I had to ask for help. This was hard for me because I was the one who looked after everything and, usually, on my own. So asking and accepting offers of help was difficult.

One thing that I figured out, as the weeks went on, was to accept help and be specific. When someone offered to drop off a meal, I would say which evening of the week would be best. The same went for offers to drive the kids to their activities. Even more helpful was when people asked to help with specific things (like the gardens) and would say which day they would come.

My advice is to accept help. It won't come around forever, and it may feel uncomfortable or inconvenient at the time, but it will be worth it. What it means is you get a little bit of relief, a meal and one less taxi ride to give your kids.

Ask for help

Now is the time to ask for help. Call for favours from family, friends, neighbours, colleagues or people from your place of worship. What you need now is for someone to “keep the home fires burning” and look after whoever is there, keeping life as normal as possible. You will also need to get in touch with the injured person’s place of work and let them know that they will not be back, likely for many months. Find out about any work or auto-related insurance your person may have.

But most of all, be by their side. They need to know you are there. It’s a scary place, being in a hospital. Seeing you will help them feel less alone and a little less scared.

A Family Member’s Story

A HUSBAND’S PERSPECTIVE, PART 2

We live in a small community and my wife had a lot of concerned family and friends. Her accident had been on the local radio station and in the newspaper. People wanted to know how she was and what they could do to help.

Some email and most Facebook communications had been picked up by our friend, Selena. Melissa was helping organize food drop-offs and the kids were with my parents. Farm tasks had been picked up by other friends; most things were being done without my involvement.

What I wish I had done was assigned a “point person,” someone who would get an update from me and then send the word to all the others. I was still communicating with some family and my wife’s friends via text. If you are tech savvy, use an app; if not, get someone who is. They can answer all the follow-up questions that will inevitably come from the community.

I found it all overwhelming, but connecting with my people did distract me from thinking about it all, all of the time.

If you spend your time answering the same questions from many different people (over and over), you will start to wear out. It may feel comfortable at the time, but what you don't know are all the other communications that are yet to come. You already have to keep track of what the doctors are saying, but soon enough it will be insurance or WSIB (if it applies), then will come the lawyers, case managers, therapists, home care specialists, SCIO Regional Services Co-ordinator and the list goes on. Pace yourself.

Other things you might need to ask for help with are groceries, bringing coffee to the hospital and visiting relief at the hospital to allow you some time to go home (or to a hotel) to shower and have a nap. Are there kids who need looking after, pets to walk and feed, clients to notify? Ask someone at the hospital (like the social worker) to help you brainstorm the people that need to be contacted and list the everyday-life activities that you are going to need help with. Then, ask people to help with specific things, because people will offer and it's best to be specific — it helps you and them.

Find a peer

As the newly-injured person moves from the ICU to acute care to rehab, you are likely feeling in over your head. Take a minute to find someone else who is in the same boat as you. They are a family member too, perhaps in the same situation, but likely not identical. They are the partner or parent of someone with an SCI. Reach out to that person, even for a moment, and you will find that you have a lot in common. It will be helpful for you both. SCIO can help you find a match, too, through their peer support program.

Your newly-injured person will have a different type of SCI or other injuries and will have spent a different amount of time in hospital than your peer's person, but you can still compare notes, talk about the support you have had (or have not had) and the concerns that you have as you look ahead.

It's important for you, the family member, to find a peer because *you need help too* and you can't minimize your own situation just because someone else's is worse. You need to talk, because on top of what you already were dealing with in your life, you now have a loved one with an SCI.

Now is the time when *you don't know what you don't know* and talking to someone who is going or has gone through the same thing will help. It will feel comfortable and it will help you get through, because you WILL get through; it just may not feel like it right now. You are in a one-foot-in-front-

of-the-other place.

Although you will be able to find an online forum for SCI supporters once you get home, take the time to seek out someone else to speak with face-to-face before leaving the hospital. Once you are home, you will lose constant contact with all the other in-hospital experts. Talking to someone now will give you the opportunity to stay in touch as they continue their journey, too. As the newly-injured person transfers to rehab, you will see more people who have sustained an SCI. It may be too soon for your loved one to talk to a peer, but you can be on the look-out or let SCIO know they may be ready.

A Family Member's Story

A MOTHER'S PERSPECTIVE, PART I

My daughter sustained her SCI when she was age 20. Being a young woman, she did not fit into the "SCI norm" and therefore there wasn't anyone in rehab who fell into that age/sex bracket. But we have muddled through and learned a lot along the way. Number one: you (as the caregiver) did not train for this and are learning as you go, just like your child is, so cut yourself some slack.

However, you have an adult's perspective. So be patient and don't take their criticism of the job you're doing to heart. You are doing the best job you can. Seek out other supporters and talk with them; we all share the same problems and triumphs and it really helps to talk to someone who is living the same life

Remember that your child feels they have lost control of a lot in their life, so trying to control you and what you do is all they can do — don't take it personally! If you have other children, remember to make time for them, too. They could be feeling alone and it's easy to let your relationship with them slide with so much going on. Even if they are grown up, try to make a conscious effort to spend time with them, too.

Step back, just a little bit

Rehab has the potential to go on for a very long time. It's even more time away for the one you love and a huge learning curve for both of you. Your job is to *let them learn*. Of course it is important to support them, show them love and be there to cheer them through therapy, but you have to give them space to learn (and do) on their own.



Julie's Journey

A DORM ROOM

When I went to the rehab hospital, I was grateful to be in a private room. It turned out that I was only in that room because there were no ward rooms available at the time I "checked in." I was not at all keen to be in a room with anyone else; I wanted privacy and not to have to hear others suffer like I was.

In the end, being moved to a room of four (right outside the nurses' station) allowed me to ask more questions, hear more information (often too much), talk to fellow SCI survivors and get help when others could not reach their call buttons. My husband didn't feel supremely comfortable being a visitor there; he felt he was invading others' privacy, which made him go home earlier than I wanted each visit. It meant that he wasn't there every time I wanted his help. Maybe, in the end, it forced me to be a little bit more independent?

A MOTHER'S PERSPECTIVE, PART 2

Give your child space! If they hadn't been injured, would they want to be around you 24/7? Not likely! And think about this: Have their interests changed just because they have an SCI? If they were not interested in playing sports, that likely has not changed. Not to say you can't give some encouragement to try something new, but back off a bit on the "you should try..." Even if they were into sports, trying it again for the first time will not go as planned, and this can cause sadness, depression and discouragement. Some things are just never going to be the same.

People young and old often feel uncomfortable seeing someone who has been injured for the first time. Tell your child's friends that they can still be friends and include them in their plans. It's tricky, but you can help by having an open and honest conversation with them about it.

Nothing you can say or do will make your child do anything they don't want to. For the most part, it will be their decision and it will take time. If you push, they will just push back. Remember: they will ask for your opinion if they want it.

Seek Professional help

Returning home from rehab means that you, the family member, are really *it*. Hopefully you have some help coming to your home, like another family member, a professional home care nurse or a personal support worker (PSW). *You will need it*. Not because you aren't capable, but because you will need a break. A break from your new situation, that is, because all the other things in your life are still happening on top of what you are doing to provide care: work, kids, home, life and now a family member with an SCI.

You are going to be doing things that you never, in a million years, would have dreamed up. If you are married and said the "in sickness and in health" bit in your vows, never did you picture this. It will be scary, exhausting, uncomfortable and sometimes just plain gross.

A Family Member's Story

A HUSBAND'S PERSPECTIVE, PART 3

When I met with our family lawyer, after Julie had been home for a while, he said, "Good for you." As in, "good for you for sticking around." In his line of work, he sees a lot of situations where this is not the case, because not all are able to. I am in no way condoning you leaving your partner, but know that you may struggle. In saying that, it was a long time before I realized that not only did I need someone to help with Julie, but I needed help for myself. It was more than a year before I started seeing a social worker to talk about me and my life. I should have found one sooner.

A Family Member's Story

A MOTHER'S PERSPECTIVE, PART 3

Try to see things from a teenager's perspective. What may not bother us as adults can be mortifying and embarrassing to a child. Insist that they meet regularly with a psychologist or therapist from the very start. Although it may not appear as fear, your child is afraid. They think that people will see them as different, that they will not be attractive to potential love interests and will not be accepted by their peers.

Mostly, they are afraid about the future. Everything looks so different now – aging, health, their fragile body and their potential for independence. Talking about it, about what they can deal with in the here and now, that is how to find a way through. Seeking professional help is the best way to start this healing process.

Talk about it

Everyone recovers differently. That is why writing a resource is so difficult — because everyone's situation is different (injury, geographical location, availability of resources, etc.), as is their approach to accommodation. Some people install lift tracks, ramps and roll-in showers; others decide to make very few changes to their home and others still go with their friends to theme parks and just tape their hands to the bars on a rollercoaster ride (true story).

How newly-injured people recover is up to them. You can provide support and encouragement. You can tell them that the hard recovery work they are doing is visibly making a difference. But you can't do it for them. The more *you* try, the more frustrated you *both* will become.

If you are concerned about progress, talk to them about it. Likely they are feeling frustrated too and it's better to have it all out in the open. This type of communication is one thing that will keep your relationship from falling apart.

A Family Member's Story

A CHILD'S PERSPECTIVE

It was a while after my mom's accident when I learned something that really helped me understand her situation. One day we were going out and she told us (my sister and me) that we needed to be more helpful than usual. Then she talked about "energy points," how she only had so many available in a day and, once they were used up, she would have to steal from the future. She said it's called "spoon theory." Now I get it; it's just like health points (HP) in a video game — except it's real. Understanding it makes a difference because now all my mom has to say is: "I'm running out of HP" and I know that I have to be more helpful, push her chair for her on hills or rough surfaces or help in other ways. She's not just being bossy or lazy, she actually is running out of HP.

Communicate with your people

Everyone will want to know how your loved one is doing. Once they are in rehab, the improvements are not that easy to spot day-by-day, so your response will be something like “they are getting better.” Most people have no way of relating to what “SCI better” means and they will likely think that the person is learning to walk again!

One thing people will not ask is how *you* are doing. It will take time before you notice this — at first you’re just glad that people are inquiring about the recovery and are offering “to help if you need anything.” This, actually, is not helpful because it puts the onus on you to reach back out and ask for help. So try to act on the offer while it is still hanging in the air — have a little list ready (in your head) of things that you need help with, like picking up a car from an oil change, clearing the driveway on a day when you know you won’t be home, getting your kids on the bus in the morning or picking up a short list of groceries. Don’t be afraid to ask; most people really *do* want to help, they just don’t know how.



Julie’s Journey

A POST-RECOVERY PERSPECTIVE

Something that I learned more than a year after my injury was how my husband was feeling about his role in my recovery. As my number one, he really kept my life and our family going — no pressure there! One day, he told me how only two people asked him how he was doing. Only two — one friend and his therapist. That’s all. Although he didn’t realize it at the time, this hurt. So as you go about caring for your loved one, try to remember yourself in all of this. See a therapist, too, and try to be open with your friends and your family — you can even ask them to check in on you from time to time. Your energy and emotional bank is not bottomless, after all.

You cannot do this alone

As the transition happens from acute care to rehab, the health care team is still doing most of the heavy lifting. However, this will change once the transition to home occurs. Be as prepared for this as possible. Have help lined up before the discharge date. Interview people so they are in place and ready to start that first week back at home. Homecare will not do everything, so you will need backup. Family and friends will only be able (or willing) to do so much. You cannot do this alone.

As you provide care and support, you may have to do things you never dreamed of. Bowel care, for one, was not in the “marriage contract” but here you are, anyway. (See Skills To Know Before You Go Home in Chapter Four). You may have thought that learning about SCI was just about over... Sorry, but you still have a long way to go.

A Family Member's Story

A MOTHER'S PERSPECTIVE, PART 4

We knew immediately that our life was changed forever, but what we didn't know was that it would get better than it was in the beginning. It's so important to get into a good routine right from the start (when you get home), but it will take a lot of patience and a lot of trial and error before you find what works for your loved one. Even with a good routine (mostly bladder and bowel I'm talking about) anything can upset it, at any given time. No matter how you try, sometimes their body is in (or out of) control, no matter what you do!