

Module 11 – SCI 101 for Researchers

A Day in the Life

A spinal cord injury affects many aspects of functioning besides movement, including many things you cannot see when you first look at someone, such as:

- Sensation,
- Bowel and bladder function,
- Sexual function,
- Temperature regulation,
- Blood pressure regulation, and
- Many other functions.

Because of the many ways an SCI affects daily life, it takes someone with an SCI more planning, time, and energy to get things done.

Some people require a personal care assistant, sometimes called a personal support worker (or “PCA” or “PSW”) to help attend to personal hygiene and household needs. People with spinal cord injury may also choose to have help with certain tasks to save time or energy to do other things, such as going to work, caring for family members, volunteering, or other important activities.

Those *without* a PCA or PSW may spend even *more* time on everyday activities, depending on how much loss of function they have.

SCI also affects the families, friends, and loved ones of people who are injured.

Let’s listen to some advocates as they describe the ways their injury affects their daily lives.

Josh Forbes – So a day in the life for me starts at 9 a.m. every day when I have a PSW that enters my apartment. They come in, they help me use the washroom, transfer onto a commode chair then I transport into the bathroom, and whether it’s a bowel treatment day or not I’ll use a suppository, poop, and get into the shower. After the shower they help me to bathe, almost like a sponge bath type of deal in the bathroom and transfer back into bed where they help get me dressed. From getting dressed, back into my actual wheelchair, I’ll have breakfast, which they’ll help me prepare. Back into the washroom, brush teeth, do another catheter, so pee again, and my day basically starts three hours after it began. From there, 3:00, another PSW will come to my door, they’ll help me use the washroom, eat lunch. Then at 6:00, same thing, use

the washroom, eat dinner. At 11:00 I have a PSW come up and they will help me to use the washroom, get into bed, position me properly, get undressed, then at 5:00 a.m. will come back up, help me use the washroom and turn to the other side to prevent pressure sores, and I go to sleep for a few hours until the next PSW comes in. So in total, there's six PSWs that come to my house during the day, or six times, and that's probably three and a half to five hours a day of daily care just to live. That's without going out or doing anything.

Anita Kaiser – So I've had a spinal cord injury for 25 years now and I'm classified as a C6/7 tetraplegic and I'm complete injury, so no sensory or motor function from my chest down. I have a lot of function in my arms, although it's not full strength and I just have a flicker and a few fingers, so I really rely on caregivers every morning for my personal care. That alone is a challenge, because I have three different caregiver agencies that I'm coordinating between in the morning, as well as I have another agency that comes in the evening to help me with prepping for dinner so it's it's a it's a lot of scheduling to work out. Outside of those times I'm fairly independent during the day. I do work, I go to school I'm able to drive my own vehicle. I'm married, so I have a family, I have a husband and a 14-year-old child.

April – I'm pretty independent on a regular basis, so I don't need anyone all day anymore. I did in the beginning, but on a typical day right now, I have someone who comes in the morning. They help me get up. They also help me shower, bathe. They help me with my bowel management. I'm able to independently manage my bladder. I also get help typically with basic housekeeping work. – April, an individual with SCI

Garret Frey – I use what is called a sip and puff and that's a power electric wheelchair. So I can drive around. I have an automatic, uh, door opener to get in out of my own house. And then I have, um, different Alexa devices. So I use those Alexa devices to turn on and off the, the TV, the lights, a fan, heater, um, anything that I need to do.

Claudia Garofalo – One of the biggest complications for me right now, where I am, is that I have no support. I mean I have support from friends, and I work with a therapist, but I don't have anybody that comes into my house to help me manage my house, help me do laundry, or clean my house or just help change my sheets—which is really impossible for me to do. And so I've gotten to the point where that is the hardest thing for me to deal with because it seems like the older I get, the less I can do by myself.

JD – Spinal cord injury really makes us, it's made me plan a lot more. It required a whole lot of focus on what does it take to get things done, considering I have to use personal care attendants to do everything, to get me rolling, even though I can do some things by myself now.

Josh Forbes – There's also things, events that you miss because you're not prepared to go. There's no more last-minute just jump in the car and go, so there's all kinds of mental things that play on with that as well, on top of the physical stuff.

Later in this module, we will talk about the implications of the lived experience for research, including:

- Developing research questions that are important to people living with SCI
- Practical factors to consider when designing clinical research, and
- How to collaborate with people living with SCI to gain insights into your own work.

But first, let's take a more comprehensive look at the physical effects of SCI, beyond paralysis.