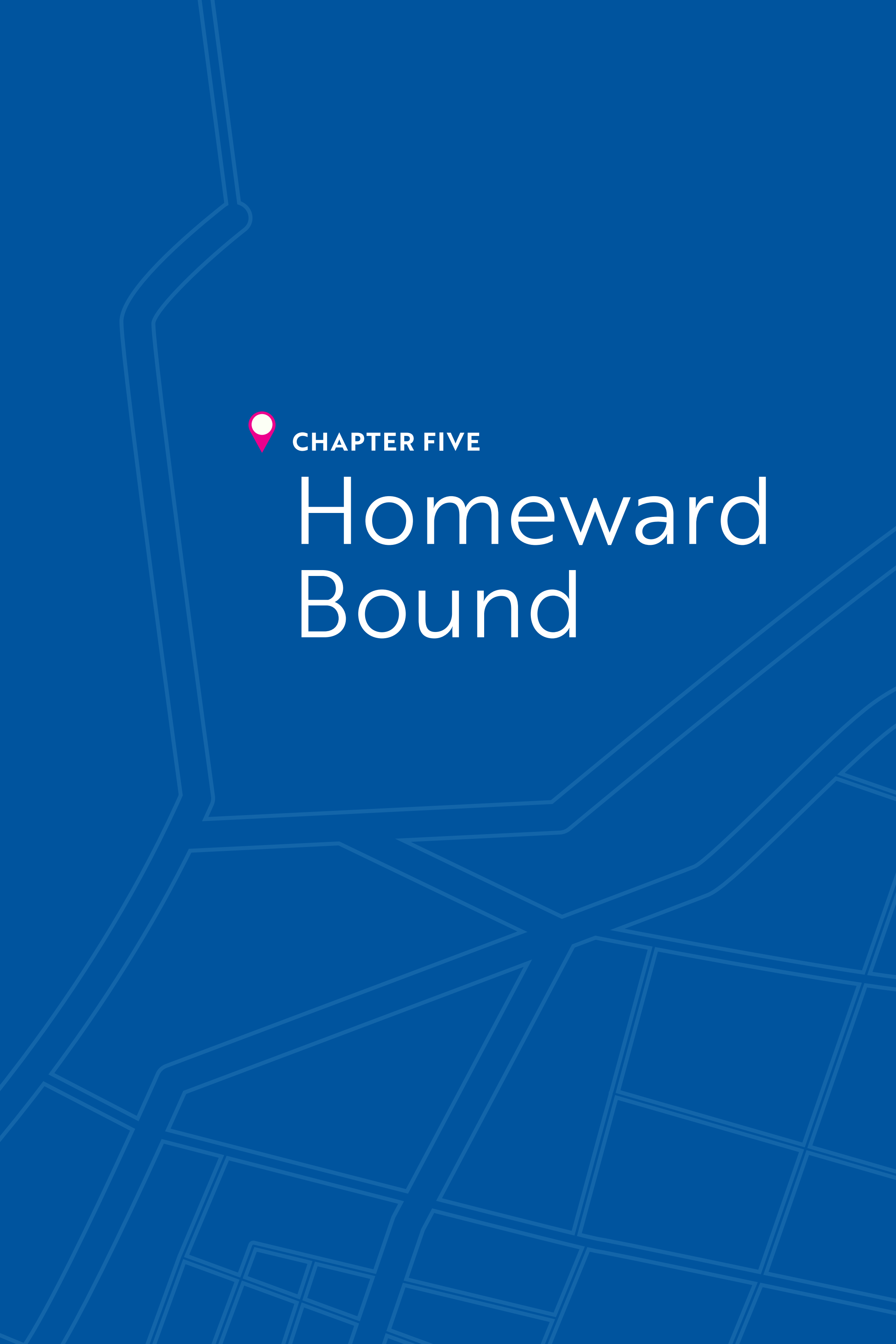
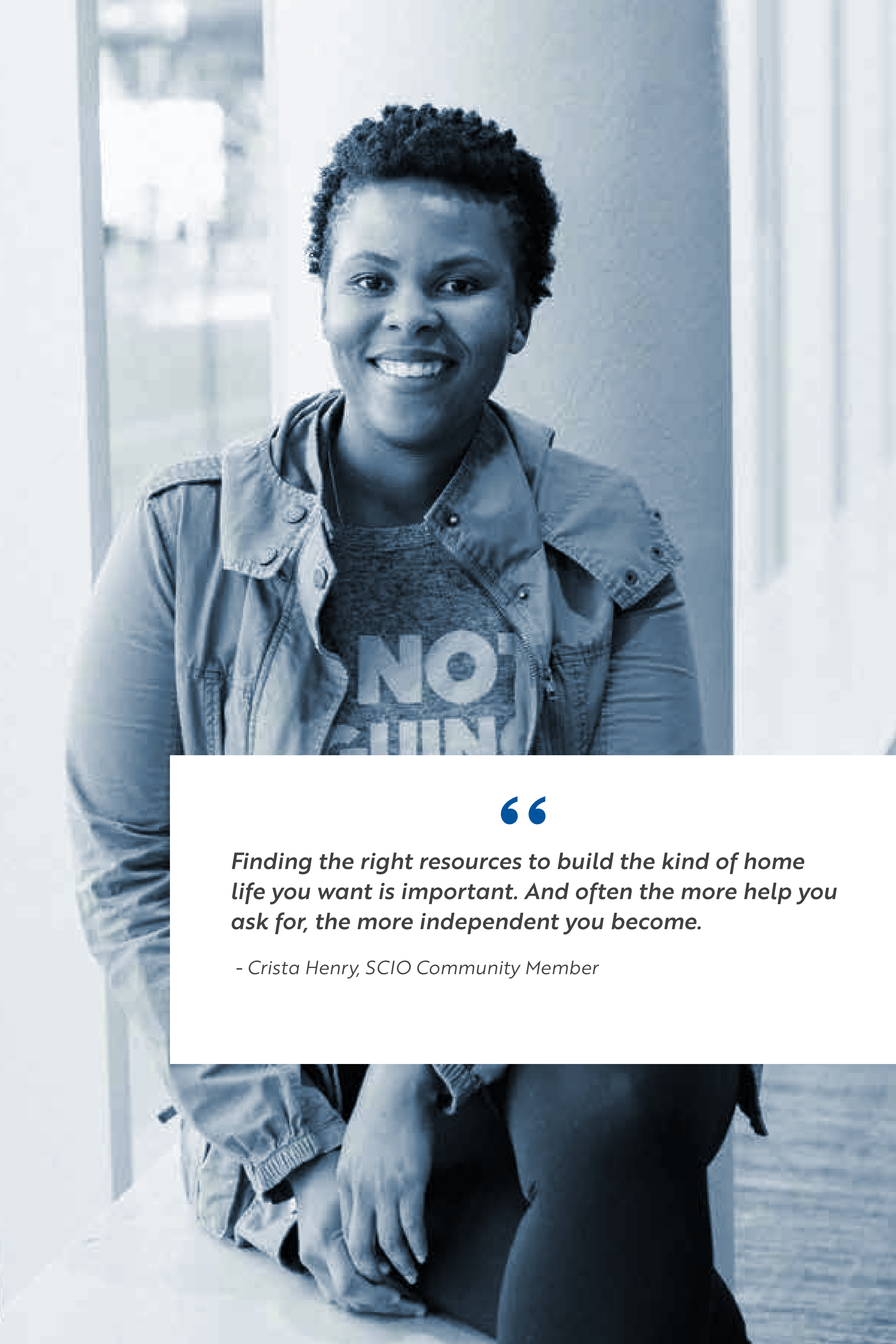


CHAPTER FIVE

Homeward Bound



> “
>
> *Finding the right resources to build the kind of home life you want is important. And often the more help you ask for, the more independent you become.*

- Crista Henry, SCIO Community Member

GOING HOME – OR MAKING A NEW ONE

Being Home

Moving home will evoke a huge range of emotions from happiness to fear. Planning to return home needs to start well in advance. Have a partner, family member or friend help out with this planning. You may have an OT or social worker on your team who will be able to assess your needs for managing in your current space or finding a new one. An SCIO Regional Services Co-ordinator can also help you plan for what you need. Getting your physical space set up and ready for your return is one thing, but remember that returning home will take a toll on your emotions.

How do I start planning for going home?

There are several options that you will need to consider before going home. Do you need to renovate? These may be big (long-term) or small changes just to get you comfortable in your current home. But big or small, both take time, so be sure to plan for that.

Maybe you need to consider moving? If your current home is not going to work, you'll have to look elsewhere. Options include a rental space (apartment) or something like a long-term care facility or supportive housing.

Julie's Journey

SLEEPING IN THE DINING ROOM

Because I was living in a 110-year-old two-storey farmhouse at the time of my accident, installing an elevator or stair lift was not very practical. All the bedrooms were upstairs, so we made some changes to our living arrangements. The dining room was large enough to become a bedroom for my husband and me, so we put the dining table into the kitchen. We left the piano to act as a divider, so looking through the door you saw it instead of our bed. Our bookshelves were emptied and became closet shelves — open, mind you! We put lights up on either side of the bed and placed pull-down curtains in the windows. For hanging clothes, we put a small clothing rod on the wall to add to our "open concept" closet. We made do — but how I missed being able to tuck my kids in at night.

If building a new home is on the radar, you have A LOT to think about, but you'll still have to look at the first two options because you will be *told* by your rehab team that you are going home and there is not much you can do to stop or delay that discharge date. So go back to thinking about making some changes to your current location for the short term.

What are the essentials for moving home?

1. **Access:** First priority is the obvious one — getting in. But the not-so-obvious thing is being able to get out in an emergency. If you are building a ramp or installing a lift to access your home, this means you have elevation to consider at more than one entry. If a fire were to block that exit, you can't exactly crawl out the window. Plan for an alternate door, such as a lift through the garage or out onto a deck. You can get an escape chair to use down a set of stairs, but keep in mind that you may not be able to operate it on your own. Before you start, measure the width of your chair so you can compare it to your doorways. Add a couple of inches on either side to give room for your knuckles.

2. **Bathroom:** There is a lot to consider for one small room. Door width and clear floor space — is there enough for you to manoeuvre your chair (and a showerchair) *and* close the door? You will need to install a grab bar or two but, before you do, make sure you have solid backing to screw them into. You need a minimum of two attachment points into each wall stud or ¾ inch plywood or it will not be safe.

   Consider all the showering options before you start to renovate. Is it possible to make your current shower accessible — can it be changed to a roll-in? Is there room for a commode or shower bench across the tub?

   Is there room to store the commode/shower bench when not in use? In an ideal situation, you should be able to get your knees under the sink and your chin over the sink. "Side saddle" can be done, but over the long term it's annoying, uncomfortable and energy consuming.

   There are also a lot of safety aspects to consider when planning a bathroom. Temperature-controlled water, wrapped pipes and the possibility for slippery floors are also important.

3. **The rest of the house:** Of course you will also have to consider where you are going to sleep and eat. If there are multiple levels (even one step), small

ramps can be installed. Create access to the kitchen by taking off doors under the sink so you can roll under. Make a lower workspace from a desk, leave some dishes on the counter where you can reach and lower the microwave. Ask your OT for suggestions. Bigger changes can be made down the road but, for now, all your energy should go into recovery.

4. **Outdoor space:** As you think about your home, try to focus on what you will be able to do when you get there. It is really important that you are able to get outside. Maybe it means getting out on your veranda, driveway or just out onto your front step; in any case, you will welcome some fresh air and sunshine.

What will going home really be like?

It's best to just come out and say it. Going home is going to be challenging. In some ways, you will be excited about being home, but in many ways you will realize that being home could be hard. Very hard.

Peer Perspective

A CONVERSATION WITH MIKE (T11-T12) AND KAREN

When Mike was ready to leave rehab, his home was not ready for him. Multiple sets of stairs prevented him from moving back to the house he shared with his wife Karen. The option they decided on (supported by WSIB) was for Mike to get a private room at a residential care facility. Their plan was for Mike to stay there while they sold their house, bought and renovated another.

Mike lived with people who were 30 to 40 years older than him and he enjoyed their company. He is, after all, a pretty social guy! Mike was able to access the pool for fitness and physio. He wheeled downtown in minutes to get to all the places and appointments he needed to go to. Karen and Mike have since purchased a home and are making plans to renovate. After that, they will be able to find a new normal of being a couple again!

Peer Perspective

MICHELLE (C6-C7 INCOMPLETE) ON GOING HOME

When I came home from rehab, I felt really vulnerable. In the beginning, my quadriplegia left me without the use of my hands. I remember being at home when there was a spider crawling on my leg. I didn't have the ability to sweep it away or squish it. I couldn't get the spider off my leg. It took so much time for me to realize that it was okay that I was alive. Little by little, all the effort that I put into my recovery started to show, but it's a slow process. Nerve pain may not go away but you get used to it, you learn to tolerate it. I take medication sometimes to take the edge off when it is bad. Nerve pain used to preoccupy me, but now I can think over top of it. It took two and a half years to get that far.

The importance of SCIO Regional Services

No matter where you are on your journey or what plans you have, the experience and expertise of SCIO Regional Services Co-ordinators can help you move closer to your goals. Staff members — many of whom have a spinal cord injury — are in your community providing practical help, advocacy and assistance, from injury right through rehabilitation and into the community. Regional Services Co-ordinators are located across the province to provide highly individualized services by phone, email and in person in SCIO offices, in your home or at a mutually convenient location. These services are free to registered clients of SCIO.

You don't know what you don't know. Every person and situation is unique, so a Regional Service Co-ordinator will help you determine your needs and support you in finding the best path to living independently. They will work with you to navigate the system in your area, help you advocate for change, adjust to life with a physical disability and guide you to achieve your recovery goals.

SCIO provides information and education on a wide range of topics and can be your first stop when you need support. Because the Province of Ontario is so large and varied when it comes to medical and rehabilitation services, the Co-ordinator in your area will have the "inside scoop" on what is happening. For example, there may be a local physiotherapy clinic that has university students run rehab clinic days. They will also be able to tell you about local accessible transportation options and means of accessing equipment that has been donated or is for rent.

Medical Home Team

Keep in touch with your rehab physiatrist, find a psychologist and/or social worker, PT and OT in your area, but most importantly get access to the following:

Family Health Team General Practitioner

You need a GP — your family doctor. If you don't have one, *find one*. They often have experience working with people with SCI but, if they don't, it is your job to help them learn everything that you have learned about your new body. Your biggest issues will likely be continued pain management, as well as bowel and bladder issues. When you speak to the receptionist, clearly identify what your needs are and how soon you need to see/speak to someone. You can ask to speak with the nurse; sometimes problems can be solved over the phone. Family Health Teams also may have a Nurse Practitioner who can help you. Ask for them if you can't get to see your doctor.

The nurse will need to know all of your symptoms and all the questions that you have for that visit. They will keep tabs on your blood pressure/heart rate and medications; keep a list at all times. Be sure you tell your nurse/GP if you have stopped taking any of your medications. When you suspect that you are fighting an infection, you likely are. You know your body best — you have to convey that in order to get the help that you need.

Julie's Journey

PAIN MANAGEMENT

After four years, I have yet to figure out how to turn off my pain. Certainly it is less than it was at the beginning and I have learned some triggers, but unfortunately what works for some does not work for others. I have tried meditation, massage, medication (including narcotics), medical marijuana and acupuncture. I seem to have found a balance now, but I also have identified some things that intensify pain. First — infection. UTIs cause pain to be unbearable, like, go-to-bed-and-stay-there pain. Second — fatigue. Overdoing it never helps. Third — diet. Some foods seem to trigger more pain events. My advice? Keep track of when your pain rating is high; if you can pay attention, maybe you will learn what your triggers are.

Professional Points: Personal Support Worker (PSW)

This person (or these people) may very well become the most helpful in your new life. Depending on your needs and who you hire (either privately or through a public health care company), they may be able to help you with everything from stretching and bathing to laundry and cooking. It is their job to help you do the things that you used to do, but are not able to do yourself, yet.

What is Attendant Care?

The OT assigned to your case will assess your need for attendant care, which includes assistance from a trained Personal Support Worker (PSW) or "Attendant" for Activities of Daily Living, such as showering, getting out of bed and bowel routine.

If you have insurance (from a Motor Vehicle Accident, for example), this will be referred to as attendant care. Insurance will pay the wages of this person so long as you have been assessed as needing this type of care. At this time, the insurance company may send their own OT to reassess. If you do not have insurance, there are agencies in Ontario that provide attendant services on a government-funded or a fee-for-service basis, which you can register for.

How do I make the best of PSW time?

In matters of care, YOU are in charge. This does not mean that you have to be bossy, but you do need to establish what is expected of the PSW in terms of responsibilities and timing; for example, if they are there to help you with your personal care and showering, make sure they understand other things that they can be doing while you are in the bathroom (e.g., making lunch, changing sheets, doing laundry). Be honest and upfront right away about your expectations. This makes it easier for the PSW to know what you want and need. Prioritize your day by listing (in writing) what is most important to have done that day.

How do I find a PSW?

There are a few options for finding the right PSW for you. It is easiest to start with a government-funded program. This way you should be able to start with a PSW right away. You will receive an assessment and create a schedule/plan of what the booking will entail. The emphasis is on directing your own care and being very specific around your needs, such as saying, "Place a dime-size amount of shampoo on your hand and massage it into my scalp." Government-funded PSWs will not perform many homemaking duties as the focus is on personal care.

If you have insurance or other means, you can also hire someone privately — this means that they are their own boss; they do not work for a larger company. This will give you the most flexibility in terms of time and the type of work that they can do for you. They will have hours that are more flexible and, once you establish your needs, they will work with you to help you accomplish them.

It is also possible to hire a PSW through a firm where you say which hours you need help and they will send someone. It may or may not be the same person each time, depending on availability. Rates will vary depending on a private hire or through a company. Word of mouth is the best way to find a good private PSW; ask your other therapists, as some keep a file of PSWs available to help. Remember, not all people are the right fit. Don't feel bad if you don't "click" or are not comfortable with who is sent to work with you; call and ask for someone different to be sent next time.

Insights from the PSW: Elaine Delisle

"Remember — it is your body, your family, your home. Never be afraid or ashamed to ask for anything you like or do not like. The PSW is there to work for you and you deserve the best care possible."

Peer Perspective

JULIE (C4-C5) — PSW SUPPORT MEANS INDEPENDENCE

I have PSWs that come in the morning to help me get up and at night for about an hour, to help me get into bed. I used community agencies for the first 5-6 years and then started hiring privately. If I can't find anyone through word of mouth, I'll put an ad on a website.

I don't drive so, if I'm not with friends, sometimes my PSWs will drive me places or I have a full-time person that takes me where I need to go. This person has always been hired privately.

I'm not much of a cook, so I often go to a little market that has pre-made meals. I have also ordered from a company that delivers individually portioned, pre-made frozen meals.

I am very fortunate that I was able to build my own home. It suits my needs and I think that really helps me live as independently as I can.

DRIVING

Why did they take my licence away?

Upon injury, your medical team is required by law to complete the paperwork that revokes your driver's licence. It's a process, but if you have enough manual dexterity and upper body strength, you will be able to get your licence back and drive again.

What do I need to do to get my licence back?

The first step is having your rehab doctor write a "prescription" for you to be assessed. The assessment will be done by an OT with specific driver-training qualifications. You will need to choose the location where you will do your assessment, lessons and final test. Most places will have wait-lists, so get your name on it as fast as you can.

The assessment looks at your cognitive (brain) function, your knowledge of road safety, upper body strength and ability to control your hands. If you pass the assessment, then a report will be sent to the Ministry of Transportation to get a temporary driver's permit. You will then be able to take lessons in a modified car (e.g., with hand controls or other modifications), provided by the driving instructor.

Those with higher levels of injury will require a more in-depth driving assessment at a specialized driving assessment centre. It is still possible to drive with a "zero effort" steering wheel and a joystick style gas/brake.

After completing your lessons in a modified vehicle, you will need to be tested by an MTO (Ministry of Transportation Ontario) assessor. When you pass the road test, the paperwork will be completed by the assessor and sent to the Ministry. In time, you will receive a new licence (class G restriction 2C) in the mail. Once this is completed, the OT will write you a prescription for hand controls. Be patient — the medical review and re-licensing process is not fast.

Take your hand controls prescription to a business that installs them. If you need to purchase a new car, be sure to ask around or attend a "modified car" event at your rehab hospital so you can see what most people in your situation are using.

The wheels you choose — well, that is personal! Do you want a truck or a van? Or maybe you prefer a small car? All your decisions should be based on where your chair is going to go. Are you driving yourself places or will someone take you in your car? Can you transfer from your wheelchair to the driver's seat? You will progress with your abilities as you recover and, therefore, your ability to get your chair in and out will also change. No matter what, if you were driving before, you will want to drive again. And it feels great!

EQUIPMENT & SUPPLIES

While you are in rehab, it will seem like there is an overwhelming amount of equipment that you may use during your recovery. Take a deep breath and do not rush to make purchases, as most equipment can be rented (even hospital beds). Renting or using second-hand equipment is a great way to give yourself the time to decide what kind of equipment you need. In time, you may have more and more function. You may find that as you recover some strength, core stability and your blood pressure stabilizes, things like lifts or elaborate commode chairs may not be necessary. If you have the means, you can rent, see how you like it and then go from there.

There are other medical supplies, such as catheters, that you may require on an ongoing basis. You'll get an understanding of your needs and options in rehab, with samples to determine what works best for you.

Julie's Journey

ON THE ROAD AGAIN

It took me a full six months to get back behind the wheel. Both of our cars were manual, so we had to buy an automatic. We purchased a Mazda 5 — it was by far the most popular vehicle driven by people with the same type of injury as mine (T4). What is great about it is the sliding back door and the height of the driver's seat — no need for a lift, just a transfer board. I opted not to have the robot arm that puts your chair into the car; it takes up space and is permanent. I wanted the option of putting that bucket seat back in and I needed space for my two kids and their friends.

Learning to drive with hand controls was pretty easy. After my cognitive assessment, the instructor showed me how the controls worked. I transferred into the driver's side of an instruction car and off we went! Get on a list as soon as you can; this means getting permission from your doctor to begin the process. There was a wait list for driving lessons at my rehab facility, so that, combined with winter weather and the MTO wait time, meant it took me six months!

Mobility devices

By far, the most important piece of equipment (potentially for the rest of your life) is your wheelchair. Your chair becomes your legs. Your wheelchair assessment (done by an OT and PT combined) will look at your strength, mobility, balance, posture, blood pressure and dexterity. You will look into a power or manual model and you will talk about where the money will come from — it is a big expense! You may have good arm movement, but longevity also needs to be considered; it is a fine line. Your doctors will be consulted to help with the decision, but ultimately you decide.

While in rehab, you will start the process by being measured by your OT/PT. Those measurements will determine the size of your wheelchair — body position, shoulder issues, need for pressure relief, type of seat cushion, backrest, foot placement and angle, size of front casters, with or without armrests, type of brakes, push rims, colour — there is an extensive list of decisions to be made.

How do I choose my "vendor"?

You will need to decide where your chair will be purchased and maintained; hopefully, they will give you the option of trying different types of chairs before you have to place an order. For both of these decisions (vendor and chair type), ask around. Those who have been at your rehab hospital as outpatients will be a good place to start. Your OT/PT can give you advice and they can suggest people that you should talk to about their experiences, but they cannot make that decision for you. These are important decisions to make because it will be another five years before you will be eligible for ADP funding for a new chair. The better your chair fits, the greater your manoeuvrability will be. Small front casters mean tighter corners, but they also get stuck in bumps more easily. How your chair folds (or doesn't fold) will be something to think about when it comes to getting it in and out of your car. The more gadgets you have on your chair, the heavier it will be to push around.

How do I choose seating?

There are several options for seating (cushion and backrest); hopefully you are able to try them out. There is also custom seating available. Ask around about people's experience with custom seating and you will get lots of different answers. Some say it works for them and others say that they wished they had waited. Custom seating is made by molding the materials to your exact shape. Some people find that their shape (posture, muscle tone) changes as they recover, making custom seating not the best option. Custom is also quite a bit more expensive than an "off the shelf" option.

Shower chair, shower bench or commode

What you choose will depend on your bathroom situation and posture. You may start with a shower commode and later on decide that a fold-down shower bench is more convenient. Ask your OT what will work best in your bathroom. What you need to think about is your ability to transfer safely and protect your naked skin. Be sure that the surface you choose is well padded and has no rough edges. When you have a new piece of equipment, like a shower bench, practice using it with help from someone else — be comfortable with it before you try to go it alone. Of course your equipment and processes will be determined by your level of injury and whether you have help in the home, among other factors.

Lifts and transfer boards

Your needs will change as you recover. At the beginning, getting in and out of bed and into the shower will be the biggest challenge. A lift on a ceiling track can be installed, but will require proper reinforcement to the ceiling joists. Other lifts are portable (like a Hoyer) and can be taken while travelling.

A wooden transfer board is a convenient tool. It allows the person to transfer their weight from one surface (bed) and slide across the board to the other (chair). The length of the board depends on how far you need to travel from one seat to another. There are many different styles, materials and shapes of transfer boards to fit specific uses. Have several in strategic locations in the house and always keep one in the car.

Do your research

Other types of mobility equipment exist, like hand bikes and attachments that turn your manual chair into an electric motorbike! Ask your vendor to help you try them out to see if they are right for you. Hand bikes are a great way to get back outside and there are several types of offroad devices. Again, ask around and see what others in your area use and take them for a spin. Travel commodes are essential if you want to be comfortable when you leave home. Pool chairs and lifts are available too — varying in expense — so do your research.

Supplies

While in hospital/rehab, all of your supplies are managed for you. When you return home, you will need to order and pay for them yourself; Ontario Disability Support Program (ODSP) can be an important source of funding. If you have a nurse/case manager, this may be one of their responsibilities. You will need some or all of the following:

- bed pads to protect your mattress (washable or disposable); at least 4 (if you are washing them) — sometimes laundry cannot happen fast enough
- urine collection bottles, 2 - 4
- adult diapers (aka "fancypants")
- gloves, lubricant and suppositories for bowel care
- catheters (you should be able to try a variety of catheters while in hospital)
- leg bag, elastic straps and in-dwelling catheters (for travelling); make sure you learn how to do this before you leave rehab
- baby wipes — convenient for bowel care and other clean ups
- Voltaren (or another brand of pain relief cream)
- antifungal cream (for dealing with athlete's foot when/if it appears)

These are just a few supplies and you may find your situation requires others. What's most important is that you understand what you need for your care and ensure you have a plan/vendor in place and a way to fund these things before discharge.

Julie's Journey

FANCYPANTS

A fact of your new life is that your bowels and bladder will not always co-operate. While in rehab, I had the experience of rolling from the cafeteria all the way back up to the 4th floor with a trail of urine behind me — little did I know I was sitting on a very wet seat cushion. When you get home, this type of event becomes even more inconvenient. The best way to make sure you keep your pants dry and clean is what I call "fancypants." They are really just adult-size diapers, but my husband came up with the term fancypants because I was not at all happy calling them diapers. It won't just be your bladder that doesn't co-operate — your bowels will turn against you at times as well. Developing a routine takes patience. Don't be afraid to wear fancypants. It will give you peace of mind and maybe there's a bit of Murphy's Law involved — if you are wearing them, then you won't have an accident; it's when you are not that you will. It won't be for the rest of your life and everyone is different, but you'll need to be patient with yourself sometimes.

Medications

Even if you are only taking one medication, using a pill sorter is a good idea. They allow you to check and make sure you have taken your meds for that time/day. Not taking them can cause spikes in pain or plunges of mood, neither of which you want. Be sure you renew your prescriptions well in advance of running out — being caught without (especially if you live far from your pharmacy or it's a long weekend) is never a good thing.

As you progress through your recovery, you will find that you change medications or stop using them. Never throw them out. Take them back to the pharmacy where they will dispose of them properly. Keep records of the prescriptions you take, especially antibiotics, and be sure to take that list with you every time you see a doctor.