

**Making Equipment Decisions
after Spinal Cord Injury:**

**A Peer Support
Discussion Guide**



Spinal Cord Injury
Peer Information Library
on Technology

www.scipilot.com

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A resource describing the assistive technology experiences of individuals with spinal cord injury told from their own perspective



This peer support discussion guide was developed as part of the Spinal Cord Injury Peer Information Library on Technology (SCI PILOT). The overall goal of SCI PILOT is to present assistive technology from the consumer perspective. Experienced consumers have a wealth of practical knowledge about assistive technology that is rarely tapped in a systematic way. SCI PILOT aims to fill that gap.

For the most up-to-date information on the project, please visit our website:
<http://www.scipilot.com>.

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Introduction

Why a Discussion Guide?

Making decisions about assistive devices and technology, such as choice of wheelchair, home renovations, computers, environmental controls and vehicle adaptations, can be challenging, confusing and overwhelming - especially when a person is new to the world of spinal cord injury.

Sometimes decisions and choices must be made quickly, pushed along by many people with diverse, sometimes conflicting, perspectives and interests (e.g., therapists, vendors, insurance, family members). How does a newly injured person with no previous SCI experience know what he or she might need or want? How does she/he know what factors to consider or what benefits and limitations might be associated with each choice?

One of the best ways to get informed, according to those with SCI, is by talking to more experienced peers living in the community who have used a variety of assistive devices over time and are willing to share their opinions and ideas.

This guide is designed to facilitate just such information sharing by providing group discussion material as well as facilitator notes. The guide is a tool to get people started, to assist people who are new to SCI in talking, questioning, and seeking advice from those who “really know.” The scenarios in this guide present issues and choices as a “starting point” from which opinions and decisions can be debated and discussed in an informal interactive way. It won’t provide answers or solutions but it should get people started down the path to arriving at their own.

How to Use this Guide:

1. Handouts

Six discussion topics, familiar to most people with spinal cord injuries, are presented as “scenarios” of individuals using various assistive technologies. Each topic (e.g. wheelchairs, home renovations, vehicles etc.) presents two contrasting scenarios of fictitious individuals in imagined situations that have been derived from the composite opinions and experiences of individuals living with SCI. Suggested resources for obtaining further information relative to each topic follow the scenarios. These materials are intended to be copied and used as handouts at the beginning of each group discussion session.

2. Facilitator Notes

General facilitator’s notes for all group discussion sessions are provided, as well as facilitator notes specific to each discussion topic. These include suggested “conversation starters” as well as a list of “issues” embedded within each scenario, that could also be used to promote or enrich ongoing discussion.

General Facilitator Notes (for all discussion topics)

Discussion Group Guidelines

- Discussion works best with 4 to 12 individuals. At least 1/3 of the group should be experienced in living in the community for several years with SCI.
- One to one and a half hours is a comfortable length of time for a group session.
- Only one topic should be discussed per session.
- Depending on the time of day and available time, some light refreshments could be served. (e.g., drinks, pizza).
- Make sure attendant are available, if necessary (e.g., for help with food, coats).
- A flip chart with markers and a designated writer should be available

About Groups

- Some discussion groups take longer than others to get going. Don't worry, this is normal.
- Don't be concerned if the discussion goes off on tangents, with group members describing their own experiences. That's the whole point! This guide is meant to provide a starting point for informal, spontaneous peer support.

Facilitator Materials

- Some "conversation starters" are suggested in the Facilitator Notes that accompany each discussion topic. These can be useful for triggering conversation at the beginning, or when people seem to have nothing more to say. They are in no particular order. Use any or several "starters" – or none at all! It's up to you.
- A list of the "issues" within each topic scenario is also included. These issues might be spontaneously identified by participants during discussion. Alternatively, a group participatory exercise might be to identify and note these issues on a flip chart.

Suggested Group Discussion Process

- Introduction of Group Participants
- Explanation of Group Purpose (as described in "Why a Discussion Guide")

- Introduction of session Discussion Topic
- Handouts of session Discussion Topic to all participants
- First Scenario to be read by all participants
- Comments and Questions invited (5 – 15 minutes)
- Second Scenario to be read by all participants
- Comments and Questions invited (5 – 15 minutes)
- Discussion regarding both scenarios (20 – 30 minutes)
- Wind-up

NOTE: The above suggestions regarding group composition, format, process and timing are suggestions only and certainly may be varied at the facilitator's discretion.

Choosing Chairs (Manual vs. Power)

Scenario 1: Jim

Jim, an incomplete C5-7 quad, switched from a manual to power chair several years ago. He has lived in a downtown high rise apartment ever since he got out of rehab. some 15 years ago. He teaches high school science and has been lucky enough to work at a large city high school only 6 blocks from his home. Both Jim and his wife enjoy living so close to the stores, theatres and sports events. Although Jim has an adapted van he seldom uses it, finding it much more convenient and energy saving to “just whip down the elevator and out the door” in his power chair. “I go very fast and the chair handles long distances, even in bad weather,” he says. “It saves so much time and energy when I don’t have to get in and out of the van, let alone the hassles and expenses of parking.”

It wasn’t always this way. After the injury Jim realized the importance of keeping his arms strong and knew that one of the best ways to do this was by pushing himself everywhere in his manual chair. He liked the challenge of uneven sidewalks and surfaces and felt much less disabled pushing himself places, like down the street to his neighbour’s for a beer. At that time Jim and his wife liked to travel and go to cottages in the summer. “You can’t throw a power chair in someone’s car or get hauled up steps or through rough ground in a power chair,” Jim said, and during those early days especially, he didn’t want to miss any opportunities for recreation and adventure.

Jim got through college and the first five years of teaching with a manual chair. He figures he marathoned thousands of miles before “his arms and energy level started yelling back.” Jim finally agreed to a power chair only after several episodes of missed work because of severe shoulder pain. The new chair was hard to get used to. Jim was initially frustrated by its size and lack of manoeuvrability and the damage it did in his small apartment, as well as by the total dependence on his van for long-distance transportation.

As time went by however, Jim got used to it. He appreciated the chair’s energy saving potential and the speed with which he could get to practically anywhere downtown and in his school. “Now I can outrace my wife and students anytime I want,” he says. “My mobility’s not as versatile as before, maybe, but I’m healthier and more productive and finally I’m no longer struggling to keep things on my lap!”

Yet, there are days when Jim gets really down and wonders if he did the right thing. He misses the versatility of his manual chair, especially in the summer when he thinks about cottage country. He also worries about getting weaker because his arms no longer get the great workout they once did.

Scenario 2: Pete

Pete lives with his wife and teenage sons in a small village an hour away from a mid-size city where most of the amenities he needs can be found. He already owned his home when he was injured some 12 years ago. Fortunately, it was a single story house so it wasn't too difficult or costly to gradually make it accessible. Pete's injury was incomplete at the C5-6 level so he has some use of his arms and is able to push himself around the house as well as shift his weight to relieve pressure.

Pete has seriously thought about getting a power chair. He knows it would be much easier than pushing himself manually, especially when it comes to getting around the village, but his accident wasn't covered by insurance and he didn't have any health care benefits because he was unemployed at the time. Even though government assistance would cover up to three quarters of the cost, he simply couldn't afford a power chair. Pete also worries about the specialized maintenance of a power chair and reasons that "dependence on such high tech just gets you into a whole new set of problems. With a basic chair, any local garage can fix a spoke or put air in a tire – even do simple welding if the frame breaks, but they couldn't deal with the high tech electronics inside the chair. I'd be held up for days waiting for someone to come out from the city to fix it," he says, "not to mention the cost."

The size and weight of a power chair would be another problem. Many village stores have a single step and no one could haul a heavy power chair up and down. Pete points out that "everyone in the village knows me by now and there's always someone on the street jumping to open a door or haul me up a step or two. I've met tons of neighbours this way. I don't mind and it's like, they're all my family now."

Although Pete realizes his disability is significant, it's important to him to look "as least disabled as possible." "That's another reason for staying manual," he says. He likes the versatility of his manual chair, which can easily be folded and thrown in the trunk of any car as soon as he's transferred into the passenger seat via his transfer board. Pete's not ready to let his muscles "go soft" and has no intention of limiting the summer and winter vacations he and his wife take on a regular basis.

Still, there are times when Pete gets sick and tired of always smiling and being nice to people and having to wait until someone comes along. "It'd be nice to just take off totally on my own once in a while for a long hike beyond the village," he says. He wonders if he should lobby the store owners to get ramps or search out some old abandoned power chairs and ask his auto-mechanic friends at the garage to put something simple together for him.

Some Internet Resources

SCI PILOT

<http://www.scipilot.com>

At this website the following personal stories discuss people's decisions to use manual and/or power wheelchairs:

- [Anna](#)
Provides a good description of the feelings related to manual vs power chair and how during rehab power chair represented a higher degree of disability.
- [Jason](#)
Describes difficulty in going from crutches to a manual chair but not going from manual to power later.
- [Jonathan](#)
Describes living in a small inaccessible town where it was easier to use a manual chair, then moving to a city where independence was gained by using a power chair.
- [Paul](#)
Explains why manual chair (which he used for 31 years) was preferred even though it was difficult, over the power chair he now uses because of shoulder problems.
- [Monica](#)
Power chair allows her to get things done more quickly.
- [John](#)
Uses a manual chair - doesn't want to lose the freedom of throwing a chair in a car.
- [Alex](#)
Used a power chair in rehab, then went to manual, then returned to power chair because of rotator cuff injury. Discusses image and how he can do more in a power chair.
- [James](#)
Doesn't care anymore about people thinking he is lazy because he uses power chair, he has more energy when using power chair.
- [Bruce](#)
Uses a manual chair when traveling due to the damage airlines do to power chairs.
- [Matt](#)
Had an electric chair in rehab but his first goal was to get out of it and into a manual chair.

Wheelchairnet

<http://www.wheelchairnet.org>

This website contains resources for lifestyles that include wheelchairs, wheelchair technology and research, mobility products and services, funding, and opportunities for discussion. There are good links to other resources and an active moderated discussion forum where questions can be posted.

Abledata

<http://www.abledata.com>

This website contains information on specific products, a discussion forum and a resource section related to spinal cord injuries.

Spinal Cord Injury Information Network

<http://www.spinalcord.uab.edu>

This website focuses on wheelchairs and seating. There are good links and articles available under the wheelchair section.

Sports and Spokes & Paraplegia News

<http://www.pn-magazine.com/sns/default.asp>

<http://www.pn-magazine.com/PN?NewVersion/Frames/>

Sports and Spokes is a magazine that highlights information related to sports and leisure activities. Paraplegia News features topics related to SCI. Back issues are listed by topic and can be ordered online through the online article library.

One article from Sports and Spokes magazine (April 2002) presents the magazine's 20th annual survey of wheelchair manufacturers and provides information about wheelchair selection, chair accessories and wheelchair cushions.

<http://www.pn-magazine.com/sns/Articles/03.02/20YearsAndStillRollingStrong.htm>

Spinlife.com

<http://www.spinlife.com>

This website sells wheelchairs, parts and accessories on-line. Articles, resources and links to other sites are also provided.

Wheelchairjunkie

<http://www.wheelchairjunkie.com>

This website features information about wheelchairs and related issues.

Facilitator Notes

Some general guidelines and tips for running a successful group, as well as suggestions for getting conversation going, by using the following “starters” and “issues” can be found under General Facilitator Notes in the Introduction.

Some Conversation Starters

1. Has Jim made the right decision? What were the pros and cons for him with respect to health, work and leisure?
2. Are there other options he hasn't considered?
3. What would you do in Jim's situation?
4. What are the key issues for Pete?
5. Are the compromises Pete made appropriate?
6. What is your opinion of Pete's proposed “do-it-yourself” plan?
7. How would you weigh the importance of work, leisure and health in choosing a chair?
8. How important are “psychological” issues, such as image, independence and freedom, in choosing a chair?
9. If Jim quit his job and he and Pete swapped homes for a six month vacation, what do you think might happen?
10. Are there other limitations Jim and Pete probably experience but haven't mentioned?
(e.g. power tilt chairs are higher - a problem getting knees under tables)

Scenario Issues

1. Health
 - a) Strength & Fitness
 - b) Comfort & Function
 - c) Energy Conservation
 - d) Independence & Self-reliance
 - e) Self Image & Cosmetics
 - f) Skin
2. Mobility
 - a) Flexibility & Spontaneity

- b) Accessibility
 - c) Function in a variety of settings
 - d) Ease & Convenience for other people
 - e) Venue Choices
 - f) Distance & Travel
 - g) Vehicle
3. Environment
- a) Home (size, storage, manoeuvrability)
 - b) Village streets
 - c) Rural vs City
 - d) Workplace
4. Costs
- a) Purchase Costs
 - b) Maintenance Costs & Complexity
 - c) Related Costs (e.g. van, bigger home)
5. Employment
- a) Improved efficiency
 - b) Energy Conservation
 - c) Loss of Work
6. Environment
- a) Home
 - b) Storage & Manoeuvrability
 - c) Workplace
 - d) City vs Country

A Home of My Own (Custom Built Condominium Apartments vs. Home Renovation)

Scenario 1: June

June decided to buy her own place when she saw the sign go up for a proposed condominium development. She had a good relationship with her insurance company following the car accident which left her an incomplete paraplegic at the T1-2 level, as well as her own savings to draw on, so she was sure she was making the right move. Since the accident two years ago June had been living with her parents in their minimally accessible farmhouse. Because of this, June felt she now knew what she really needed to be able to live on her own. She met with the developer months before the building was even a hole in the ground to discuss possibilities such as wider doors, lower light switches and a no threshold balcony that she could wheel herself over. They promised that the common areas (e.g. pool, party room, lobby, underground parking) would be accessible and agreed to “consider” custom changes. June discussed her dream with her rehabilitation consultant as well as an architect friend and began to explore the possibilities by talking to people with disabilities, searching the Internet, and incorporating ideas from various accessibility guides – such as the CSA Building Code Standards. She was encouraged to hire an occupational therapist, paid for by her insurance, and was very impressed with the knowledge, ideas and dedication that the therapist contributed throughout.

Negotiating

When June knew for sure what she wanted, her therapist and rehabilitation consultant joined her in re-approaching the developer with some blueprints her architect friend had drafted, to discuss the possibilities and potential costs. June’s initial excitement turned to months of delay and frustration as many negotiating meetings took place between her therapist, rehab consultant, condominium developer, lawyers and other insurance personnel. Although there were differences of opinion, they all agreed with June’s plan for knee cut outs under one lowered kitchen counter as well as the kitchen and bathroom sinks. The insurance wouldn’t approve June’s plan for reclaiming lost cupboard space by mounting half deep half height cupboards on the wall under the lower kitchen counter. They argued, “Well, you can’t access those cupboards yourself anyway,” so June paid for these costs herself.

The Kitchen

June’s kitchen was made wider by moving one wall a foot into the living room area. The counter opposite the sink and stove side of the kitchen was lowered so that a seated person could work comfortably there. At the suggestion of the therapist, a “pass through” opening was made in the wall so June could slide food through from the counter. “I like to entertain a lot,” said June, “so that was a great idea!” Deep, easy-to-open drawers were built under the lowered counter, beside the fridge. Because June uses appliances like a rice steamer and a crock pot, she had an extra electrical outlet installed within reach on the facing edge of this accessible counter.

Bathroom & Bedroom

June rejected the idea of a wheel-in shower for several reasons. She has some sensation as well as painful spasms that are relieved by soaking in a fragrant bubble bath. This was one of June's most relaxing pre-injury pleasures and she was not about to give this up. She had a ceiling track lift installed over her Jacuzzi tub, which also travels between bathtub, toilet and bedroom. June realized she would always require some personal care assistance and wanted to make her transfers as easy as possible. "Installing a multipurpose track lift not only saves floor space," she says. "It looks and is less intrusive than a floor lift, which is always in the way, and it means that even a child could help me get to bed."

In Retrospect

June is happy with her custom adapted condominium and plans to "stay there forever, although it was pretty bad in the beginning," she says, when "there were no guarantee about how things would turn out and she worried constantly about the time delays - construction was already proceeding" and she didn't want to lose such a great opportunity to have a condo she liked in such an ideal location. "It was only by luck, faith, and persistence - especially my therapist's, that I eventually got most of what I wanted," June says.

There were some goofs that had to be changed – "like my bathroom sink counter was installed 2" higher than normal instead of 2" lower and the developer's bulk purchased deep pile carpet with foam underlay was installed instead of the commercial grade cemented to the floor I'd requested," June explains. "The biggest challenge of all, which actually took weeks to resolve, was getting the electric door opener to my apartment activated. No one would do anything until one day, in **TOTAL** exasperation, I phoned the local alderman for help. Within 30 minutes the building contractor was at my door. Apparently the problem was some territorial jurisdiction between the different trade unions involved – the electrician, the carpenters and so on. I didn't understand it, but it could only be resolved at a very high level. Obviously I'd finally hit on the right political button because, after three frustrating months of phone call after phone call, the door was working by the end of that day."

June never misses an opportunity to advise others about what to expect if they're planning to go the route she did. "What would really be helpful," she stresses, "is a resource and information guide for people with disabilities, something to help you understand how a building gets built, who you have to talk to, when to go in, and how to resolve the inevitable issues. And then, of course, there's the insurance. Now, that's another whole topic!"

Scenario 2: Denzel

Denzel co-owned a single story house with two friends for the first few years following his SCI at the C6-T1 level. They ramped the front step and changed the bathroom door to one with two-way swing hinges, but other than that made no other changes because they planned to sell the house. Denzel was content with these arrangements at the time. He used the bathroom sink sideways, and met his hygiene and treatment needs by transferring to a commode chair in the bedroom and then getting pushed into the bathroom. At the time, Denzel didn't feel any other accommodations were necessary because he went out to work every day. "As long as the basics are covered," he explained, "I'm okay—Someone else gets the food and as long as my knees can slide under the kitchen table for eating, I'm happy."

Designing it yourself – the “mainstream” route

When the house was sold Denzel bought a small bungalow in the same area—a 15 year old subdivision with shopping, library and many other services within pushing distance. Because Denzel would now be living on his own he wanted to make the bungalow as accessible as possible, as well as “normal looking,” without spending a lot of money. Unlike his roommates at the rehab hospital, Denzel had no insurance to help with costs and had to watch his budget carefully when it came to buying the extra things he needed because of his disability.

In the past Denzel hadn't been impressed with the “I know best” attitude of some therapists and vendors, so he deliberately decided to go the “mainstream” consumer route. He used to work in electronics and knew that some of the specialized rehabilitation products, particularly in the area of environmental controls, cost far more than they needed to, and for sure more than he could afford. Denzel talked to many people before deciding what he wanted, including a peer mentor who had a similar injury and lived in an accessible home. He went to home shows and browsed through a variety of electronics catalogues and home renovation books that he found at his nearby library.

Before moving in, Denzel had a second hand vertical platform lift installed at the front porch and had the interior walls of the bedroom beside the living room removed, so as to open up the living space. He also had the kitchen door and part of the kitchen wall at the far end removed, thus creating an open “through” route in his kitchen. Denzel bought large lazy Susans for the kitchen cupboard corners, as well a heavy duty TV turntable from an electronics store which he keeps on his dining room table. Denzel increased the surface size of this by mounting a 2_ ft. plywood circle on top. This turntable, which Denzel now calls his “office,” keeps all his files, binders, pens and so on, within easy reach.

Denzel purchased a fridge with the freezer compartment below and special deep custom fridge door shelves that extended far into the fridge. These shelves provided quick and easy access to items once the fridge door was opened. Getting the door open, though, was tough because of the extra weight on it. Denzil solved that problem by taping a paper match across the rubber around the door, so as to weaken the vacuum seal.

Denzel saved space and also solved the dilemma of opening and manoeuvring around doors by installing sliding pocket doors that had a hole big enough to thrust his fingers into for opening and closing. He didn't like the institutional look or cost of the adjustable electric beds available from specialized vendors so he ordered one that he saw on a television commercial. Denzel was disappointed when the bed arrived because, although the head and foot were adjustable, the height was not.

Going remote

Denzel had discovered quite a few remote controls, some with large buttons even, during his search for accessibility ideas and home automation. Because of his electronics background he was able to successfully incorporate many of these throughout his home. These remotes enabled him to turn lights off and on, open and close his front and patio doors, raise the blinds, activate the electric fireplace, his coffee maker, CD Player, TV and DVD. Denzel has heard about some commercially available computer software through which he can activate everything in his house and is currently looking into this. Just recently a friend even found him a voice-operated clock/radio. "Very useful for those sleepless nights," he laughs, "My home is becoming an automation showcase!"

Denzel is generally pleased with the way he's set up his home. He believes he's got what he wanted. just by taking his time and doing it "his way." Still, there are times when he does wonder what he might have missed by not consulting with the rehab professionals. "After all," he acknowledges, "there are some good therapists and architects out there who are specialized and experienced in things like ergonomic design and building accessibility. " I'd expect them to be far more on top of things than the average person like me who's been going it alone."

Some Internet Resources

SCI PILOT

<http://www.scipilot.com>

At this website the following personal stories discuss people's decisions and solutions for making their homes accessible. Some have chosen to custom build an entirely new home, or to purchase a condominium before building starts and negotiate with the developers to have custom accessibility adaptations made. Others have chosen to renovate existing structures. The following individuals describe their choices, frustrations, disappointments and successes, as well as offering advice for others who may be considering an accessible home of their own.

The following stories discuss people's experiences with home modifications:

- [Charlotte](#)
Discusses the challenges and joys of purchasing a condominium before construction starts, making accessibility decisions and negotiating for individualized custom changes with the developers, rehab consultants and insurance personnel is discussed.
- [Francois](#)
Renovated the basement of his home to be a self contained apartment. He did much of the work himself.
- [Joan](#)
Lives in a studio apartment that was formerly a garage attached to her two-storey home. She describes the process of modifying her home and the importance of the layout of her physical space.
- [Sam](#)
Sam has experienced a number of living situations since his injury. He currently lives in a building that does not meet his needs. This story chronicles what it means to not have what you need.
- [Paul](#)
Paul is an older gentleman who purchased a one-storey home with his wife and did modifications to make it accessible. He describes the various features of his home.
- [Max](#)
After his injury Max and his wife decided to sell their three-storey home and buy a bungalow. He describes the complications and frustrations involved in retrofitting his new home while he was still in rehabilitation.
- [Marilyn](#)
Marilyn lives on the first floor of a duplex with her young son. She moved in before any modifications had been made and describes what it was like to live there before and after.

Center for Universal Design

<http://www.design.ncsu.edu/cud/index.html>

Look under resources for an excellent collection of links to other sites that provide information, floor plans and information on funding for home modifications.

Abledata

<http://www.abledata.com>

Abledata contains information on specific products, a discussion forum and a resource section related to SCI.

Spinal Cord Injury Information Network

<http://www.spinalcord.uab.edu/>

Look under home modifications for good links and relevant articles..

National Resource Center on Supportive Housing and Home Modification

<http://www.homemods.org>

This site has current news items relating to accessible housing. Also look under links and products sections.

Idea Center

<http://www.ap.buffalo.edu/idea>

Look at resource and publication sections for information on residential remodeling and accessible design

Canada Mortgage and Housing

<http://www.cmhc-schl.gc.ca>

Information is available on obtaining a home modification grant for low income Canadians (RRAP). A publication titled "Housing for Persons with disabilities" can also be ordered from this site.

Concrete Change

<http://www.concretechange.org>

This site focuses on the concept of visitability, i.e., changes and modifications that can be made to residential homes to allow people to enter and interact with one another.

Wheelchair Accessible Home Clearinghouse

<http://www.waccess.org>

This site publishes listings of accommodations to purchase or rent that are wheelchair accessible.

Facilitator Notes

Some general guidelines and tips for running a successful group, as well as suggestions for getting conversation going, by using the following “starters” and “issues,” can be found under General Facilitator Notes in the Introduction.

Some Conversation Starters

1. What advantages and disadvantages do you see with insurance company involvement?
2. What were the key issues for June and/or Denzel?
3. What are the advantages and disadvantages of involving rehabilitation consultants?
4. Is a person “missing out” by not consulting with professional accessibility experts?
5. What risks, if any, is Denzel taking by going “mainstream?”
6. What advantages has Denzel gained by doing it himself?
7. Did June and/or Denzel do sufficient research and investigation before making their decisions? Are there other resources they could or should have used?
8. Could June and/or Denzel have avoided some of the frustrations and disappointments they encountered? How?
9. What other accommodations might have been made but not mentioned? (e.g. parking location, landscaping, floor covering, storage, size, exits and entrances.)
10. If you were about to move into June or Denzel’s home, which of their accessibility features would you keep, add to or remove? (e.g. replace carpet with tiles or hardwood flooring)

Scenario Issues

1. Post-Injury prior living experiences
2. Process & Time Issues
 - a) Research & investigation of options
 - b) Meetings & negotiations
 - c) Aggravation & Stress Factors
 - d) Complexity of multi-player involvement
3. Money & Costs
 - a) Insurance
 - b) Purchase & Modification Costs

- c) Ongoing Maintenance
 - d) Consultants
 - e) Appliances & specialized technology
4. Independence
- a) Physical Functional
 - b) Decision making
 - c) Self-reliance
 - d) Involvement of rehab professionals
 - e) Long term planning (e.g. overhead lift, able-bodied convenience)
5. Life-style, interests & abilities
(e.g. entertaining, cooking, electronics, creative problem solver, handy-man interests)
6. Re-sale Marketability & Value
- a) Cosmetics
 - b) Re-sale Value
 - c) Able-bodied person convenience

Other Relevant Issues – not mentioned in scenarios

1. Location (e.g. close to work, rural/urban, terrain, costs, weather factor)
Size of Home (e.g. manoeuvrability, storage, costs, function, energy conservation)

Bringing Up the Kids

Scenario 1: Marissa

Marissa was dismayed when her doctor said she shouldn't even think about having a child and then, absolutely furious when her parents agreed with the comment, "How could you possibly look after children when you can't even take care of yourself?"

Marissa and her husband Ken had been childhood sweethearts who shared a deep common bond in their mutual love of children. During the teen years they often found themselves working together with local community youth sports teams or other kids groups. "Having kids, lots of them, was just a fact of life," so obvious to both of them that they never really talked much about the details. That changed, however, when Marissa had a spinal cord injury at the C7 level, just 10 months after they got married.

Marissa completely rejected her parent's advice, believing that they were just concerned for her health, and simply didn't know that many people in wheelchairs became parents and successfully raised children. As for the doctor's advice, Marissa and Ken tried to understand his reasons for concern by learning everything she could about spinal cord injuries and pregnancy. During rehab Marissa realized that doctors have different opinions about many things. Often there are no right or wrong answers. "You have to find an obstetrician who is knowledgeable and experienced with your situation," said Marissa, "someone you trust and communicate well with, someone who will be comfortable working with the rest of your medical team."

Marissa and Ken found useful peer information through her local Independent Living Centre and discovered a Parenting with Disability Network. This strengthened their determination to go ahead and have children. The Network was a wonderful resource for finding recommended and experienced physicians, accessible medical facilities, adapted childcare equipment and ideas. "Not only did we get ideas, support and knowledge from other people's experiences," Marissa said, "Someone lent us an accessible crib made by a volunteer engineer, where the side slid under the crib as it lowered—that way I could get my knees under and reach the baby. The Independent Living Centre told me how to get extra hours of attendant help, called "nurturing assistance." Ken says, "Those extra attendant hours for physical help with infant and child care really made a difference, especially during those first few months. I didn't have to take time off work or worry about how Marissa was managing when I wasn't there." Through resources such as these, Marissa discovered ways to safely carry her babies at different ages and stages. She and Ken also learned how to find and modify standard baby equipment so that it was accessible, such as a padded desk top she could wheel under for a diapering surface and a playpen on legs with a side zipper so she didn't have to lift the baby up and over to get him out. One of her children turned out to be a very active toddler and on a few occasions wandered away and came close to getting lost. "We got through this stage," Marissa said, "by using a wrist tether whenever we went out and sometimes a harness which we attached to the clothes line in the back yard for a while – until we were able to fence in the yard and get a childproof gate.

Marissa and Ken just smile when Marissa is asked about discipline. "How can anyone in a wheelchair control their kid when you can't run after them or pull them away from things,

even rescue them from danger?" they ask. Marissa points out how amazing it is that children sense, even from a very young age, what you cannot do and just accommodate to it. "For example," says Marissa, "if they misbehave or don't listen to me I just give them 'the look' and it stops them in their tracks!" When Eric was little he'd just run to the bedroom crying and stay there until I told him to come out. You wouldn't believe it!" Another example she cites is that when the kids were still in their cribs, she had a remote device which triggered the crib side to lower half way. Both Brenda and Eric would just sit there until she moved closer. Then they would climb over the crib rail onto her lap. "Both kids did this," she said. "They had plenty of opportunities to climb out of the crib on their own, but they never did."

Before the accident, Marissa and Ken might have wanted lots of children, but now they are content with the two happy, well-adjusted children that they have. Although Marissa's pregnancies were trouble-free and raising the children has brought no particular health or management challenges that they haven't been able to overcome (in spite of what the so-called experts said), Marissa and Ken have now decided that two children are enough. "Looking after my daily disability needs and having to do things in different ways, takes extra time and requires extra planning and consideration" Marissa says. "It wouldn't be fair to Brenda and Eric—more kids would just dilute the time and attention we're able to give them now. Besides, there are always new unexpected wrinkles that you have to deal with."

She and Ken are thinking specifically about the fact that Brenda, now aged 8, is being teased and ostracized at school because her mummy is a "cripple weirdo" who can't take care of children like a "real mum." Brenda has come home crying on a few occasions and it is becoming a real battle to get her off to school each morning. It's been hard for Marissa to suppress the tears and terrible hurt she feels when trying to comfort her daughter. Thank goodness for Ken, who has been a wonderful shoulder to cry on and seems to totally understand the devastation of being the unwitting "cause" of her daughter's pain. As a family, they have been discussing the issue and supporting Brenda in her attempts to deal with this. Marissa and Ken have met with the teacher and the principal and plans are now underway for Marissa to talk at the school and become a classroom volunteer. Marissa is worried about the extra time and energy this added commitment will take.

As for Marissa's doubting parents, they are thrilled that Marissa didn't listen to them. They've proven to be wonderful, doting, involved and totally supportive grandparents who simply can't imagine a world without Eric and Brenda. "Marissa's disability is an important positive factor not a negative one," says Marissa's dad. "It's simply added to the closeness and caring of our entire family in ways we could never ever have imagined."

Scenario 2: Trevor

Simon was two when Trevor had the accident which left him quadriplegic at the C4/5 level. It didn't matter to Simon that his dad couldn't walk. He loved his dad anyway and soon learned how to step on the footrest and claim his rightful lap space for a story and sat there as "King of the Charioteers," whenever they went out for a walk. Simon, of course, was fascinated by the power chair. He wanted to grab the controls, but right from the start Trevor laid down the rules that the controls were "out of bounds" and Simon always respected this. When Simon was small, he also liked to stand on the battery box at the back of the chair. This was allowed, as long as an adult was there to supervise. Simon got bolder of course, as he got older and by the time he started school you'd often see him standing on the tip wheels of the chair with his arms around his daddy's neck, yelling "faster, faster, faster" as they hurtled through the park.

When it came time to shop for a new chair, Trevor was hoping he'd find one that would still allow Simon to stand on at the back, but whenever he mentioned this to a vendor they were horrified and actively discouraged him from even thinking about it.

From the time Simon was born, Trevor had always shared in every aspect of his care with his wife, Emma, so when Carla came along, Trevor wanted to be just as involved. He hadn't been able to return to his construction job since the accident and was content to be a stay-at-home dad while his wife went out to work. However, he spent many nights worrying about how well he'd be able to manage.

There would be attendants in and out to assist with infant and child care but Trevor was concerned about what could happen when nobody was there except him and the baby. He worried about safely picking up, holding, carrying, feeding and even changing the baby. As Emma's pregnancy progressed, Emma and Trevor asked lots of questions and discussed their concerns with other parents who had disabilities. "We learned that there are a lot of parent pioneers out there already," said Trevor, "we're not the first, there's lots of resources, peer support, good ideas, adapted baby equipment – even regular baby equipment on the market that you wouldn't even have thought about until someone told you – baby monitors, safety gates, electrical outlet covers, devices so kids can't strangle themselves on the cords of window blinds, and so on."

When the time came, Trevor drove Emma to the hospital and was her labour coach during the delivery. Emma's mother moved in for a month to care for Simon and helped to ease the transition of managing with a new baby in the home. As time went by, Trevor and Emma developed several kinds of slings and harnesses so Trevor could hold and carry the baby securely on his lap. Once Carla developed some sitting balance, he used an extended lap belt which fastened around the chair and secured the baby on his lap. Trevor worried that Simon might feel "deposed from the throne" so to speak, but Simon simply moved to the back of the chair and acted like a "royal footman," responsible for the safety of the little princess now in the "baby" seat – as well as his dad.

Trevor discovered he could feed the baby by using a Velcro cuff on his hand which attached to a Velcro sleeve around the baby bottle. As the weeks went by, feeding Carla

solids became possible too, simply by attaching Velcro to a bent spoon handle. The real trick here was trying to hit a messy moving target – Carla’s mouth!

Now that Simon and Carla are 10 and 6 years old, Trevor reflects back with pride on what his role as a father. “Dad’s often feel left out,” he says, “’cause child care is traditionally a woman’s role – what with breastfeeding and all, but I’ve never felt like that. I’ve been involved right from the beginning. After my injury, we just problem-solved all the issues as they came up. For example, when Carla started crawling and toddling around on her own, I closed in the back deck with narrow pickets so she couldn’t crawl through and had a gate put across the steps. That way, I could be out there with her, kinda like in a big play pen together, you might say.”

Trevor believes that child care is equally shared between Emma and himself. He does most of the driving in the family, helping with shopping and taking the children to appointments and various activities, such as sports and boy scouts. He’s also become the designated “homework” helper. “It is easier as kids get older and more physically independent,” Trevor says. “You can work with language now and that’s a huge benefit.”

Simon and Carla especially enjoy sports and have become important members of their local soccer team. They are now competing with other teams in their junior league and soon will be entering competitions at the provincial level. Over time, Trevor has taken on more and more responsibilities for organizing these events and driving kids, coaches and equipment. In fact his van now proudly displays the official team colors and logo. Everyone counts on Trevor and he loves doing it.

However, Trevor has been having increasing difficulty with pressure sores. He’s had to stay down for weeks at a time this past year, which wasn’t a problem during the winter but could be a big problem now the summer season is starting. Trevor’s doctor wants him to undergo extensive plastic surgery as soon as possible, rather than risk infection and further deterioration. Trevor doesn’t know what to do. He can’t let his kids down, let alone the rest of the team or the organization—but he doesn’t want to jeopardize his health either. He’s thinking of waiting until the soccer season is over.

Some Internet Resources

SCI PILOT

<http://www.scipilot.com>

At this website the following personal stories discuss people's experiences with parenting.

Sandra

Describes the experiences of raising a son, now age 20, from infancy to adulthood, including initial medical discouragement, the search for information and the childcare equipment adaptations and devices they developed as various needs arose.

Jeannie

Discusses the importance of her power chair in being able to take her daughter places as a pre-schooler and now being able to keep up with her daughter in various activities, such as rollerblading.

Sarah

Describes the physical and psychological experiences of raising two daughters and how various infant care functions were met by adapting equipment, such as a crib, changing table and playpen. Notes the responsiveness of children to what you can and can't do from a very early age.

Parenting with a Disability Network (CILT)

<http://www.cilt.ca>

Housed within the CILT Web site The Parenting with a Disability Network (PDN) is a peer support and information-sharing network for parents and prospective parents with a disability. Look under Parenting with Disability Link and Online Resources Link > parenting.

Through the Looking Glass

<http://www.lookingglass.org/>

TLC mission is, "To create, demonstrate and encourage non-pathological and empowering resources and model early intervention services for families with disability issues in parent or child which integrate expertise derived from personal disability experience and disability culture."

This site is home to a number of forums as well as an extensive list of publications, resources and Online links.

Parents with Disabilities Online

<http://www.disabledparents.net/>

This site provides articles written by parents with disabilities on various aspects of parenting as well as information on adaptive parenting aids.

Parents with Disabilities Program (project star)

<http://trfn.clpgh.org/star/>

Parenting tips, links and references.

Disabled Parents Network

<http://www.disabledparentsnetwork.org.uk/>

This is a UK based organization whose online resources include publications and a moderated forum for parents with disabilities. Disability, Pregnancy & Parenthood International is a sister organization that produces a journal and online ideas forum.

AbleData

http://www.abledata.com/Site_2/parentin.htm

Follow links for Resource Centres, then parenting with a disability. Includes resources and publications on parenting and disabilities

Facilitator Notes

Some general guidelines and tips for running a successful group, as well as suggestions for getting conversation going, by using the following “starters” and “issues,” can be found under General Facilitator Notes in the Introduction.

Some Conversation Starters

1. What risks did Marissa and Ken take in deciding to go ahead and have children?
2. Did they focus too much (too narrowly) on “disability” in their search for parenting resources?
3. Do you agree with Marissa that children accommodate to your disability so discipline isn’t the problem that people expect it to be?
4. Do you agree with Marissa & Ken’s decision not to have more children because of all the extra work of a disability?
5. How would you handle the situation with Brenda? What would you say to her?
6. Simon wasn’t jealous when his sister came along. How might Trevor have handled this if Simon did feel “dethroned”?
7. Do vendors have the right to advise you about children riding on the back of the chair?
8. Is letting your kids ride on the back of your chair a safe thing to do?
9. Is the care of Carla and Simon really “equally” shared between Trevor and his wife?
10. How should Trevor handle the issue of surgery versus soccer team responsibilities?

Scenario Issues

1. Health
 - a) Pregnancy and SCI
 - b) Skin Care vs Responsibilities
 - c) Energy Conservation
 - d) Independence & Self-reliance
 - e) Emotional & Psychological Health
2. Research and Education
 - a) Discovering Resources
 - b) Parent Peers
 - c) Medical Issues
 - d) Childcare equipment & adaptations

3. Function & Mobility
 - a) Adapting equipment
 - b) Modifying the environment
 - c) Child Safety Issues
 - d) Accessibility
4. Childcare Support
 - a) Nurturing assistance
 - b) Grandparent & other supports
 - c) Shared care duties
5. Child Life Issues
 - a) Discipline & behaviour
 - b) School
 - c) Sports, recreation etc.
 - d) Peer/public attitudes

Getting Around (Cars, Vans, Public Transit, etc.)

Scenario 1: Nasir

The dream of driving again kept 25-year-old Nasir going during his months of rehab. He accepted that he'd be always be in a chair because of his injury at the T2/3 incomplete level, but getting behind the wheel again would at least be "some kind of equalizer." At the rehab centre, he met many paras and quads who drove, he'd seen some driving ideas and even had a driving assessment, so he knew it was possible. However, actually getting his own vehicle and the set-up he required took far longer than Nasir ever imagined.

First of all, there were so many choices. There were cars, vans and trucks. Then there were full-size vans versus mini-vans, lifts versus ramps, side versus rear openings, raised roofs versus lowered floors, transferring to the driver's seat versus power tie downs (which enable you to drive from your own chair). There was even a new power driver's seat that swivelled in and out of a pick-up truck so you could transfer more easily, and electro-mechanical hoists that could pick your chair up and stow it in the back. Every kind of vehicle, it seemed, could now be converted and there were so many conversion companies out there, just waiting for your business. "Twenty years ago," one of Nasir's friends told him, "There were only a few choices, mostly just hand controls. Now you can pretty well get whatever you want. Just take your time though, don't be in a hurry... get to know what's out there... and save your money cause you're gonna need lotsa dough."

Nasir's insurance company would pay for driver assessment and re-training as well as some selected conversions and devices, but not for the vehicle itself. The government vocational employment program would also provide some money towards the purchase of a vehicle because this was essential for Nasir to be able to return to his previous job as a software engineer. There were other perks to think about too, such as a sales tax rebate on a new vehicle after conversions were done.

As if these choices and considerations weren't daunting enough, an even bigger dilemma was trying to figure out what kind of vehicle and what kind of adaptations were going to work best. "How can anyone possibly know what they want or need without trying all the options first," Nasir frequently moaned during moments of frustration. The driver assessment and retraining program at Nasir's rehab centre was very helpful in this regard. The therapist knew what assistive technology was out there and after assessing Nasir, was able to narrow down the choices and recommend to Nasir the devices that would work best for his particular situation. Because she worked so closely with the vendors, she was able to arrange opportunities for Nasir to see and try out different kinds of controls.

Nasir's dream was to drive around in a flashy red two door sports car with wide doors and hand controls. After all, he could transfer without too much difficulty and he thought he'd be able to pull his manual chair into the back seat behind him. He'd seen so many others do this at the rehab centre. But the more Nasir talked to people, the more he thought about the energy that would take. Sports cars were very low, and hauling himself back up to his chair each time could take a toll on his shoulders. He even thought about the fact that he likely wouldn't be able to do as much when he got older. He realized that a car would not transport a power chair, should he ever decide to get one. Also, the financial support he

was getting from his insurance company and the government might be only a one time deal so perhaps it was better to aim high at this point in time.

Nasir finally decided on a minivan with a lowered floor, power side door opening and ramp. He chose permanent hand controls and had power lock downs installed to secure his manual chair, from which he drove. Having the floor lowered was very costly. It would have been quicker and cheaper to install a raised roof instead, but Nasir needed to park underground sometimes and he also didn't like the eyelevel visual barrier the added roof imposed on friends in chairs who might be riding in the back. Nasir heard that minivans with lowered floors went through at least a muffler a year because of the limited clearance from the road but the newer minivan conversion designs like his, rode higher in the back with an automatic lowering system that begins to operate as soon as the door opens and the ramp starts to deploy. Knowing this, he wasn't worried.

Nasir had also looked at full size vans but quickly dismissed that option because of the size, poorer manoeuvrability, higher gas and maintenance costs as well as the fact that you'd need a lift to get into it. He was scared of those lifts and "felt out of control that far above the ground." He'd even heard of someone who rolled off the end of a lift and had a bad injury.

Nasir chose a remote starter with an auto alarm that a technician had modified to perform multiple functions, such as operating the doors and ramp as well. Nasir believes that every driver should have a combined function remote. "It saved my life once," he said. "It was freezing outside and my chair wouldn't work so I was trapped in my van. I just pressed on that auto alarm and before long a car slowed down and people came over to help."

It took over a year before Nasir's dream of driving again actually happened. Assessments, negotiations between his insurance, rehabilitation team and government voc rehab program personnel, as well as confusion about who was responsible for what, caused considerable delay even at the approval stage. Several weeks of learning how to drive again with hand controls, then waiting for the appointment to take his driving test and finally get his licence back – it all took time.

However, the time was not really wasted as Nasir was becoming more and more knowledgeable about his needs and the options available which would work for him. As a result, he was able to have a lot of choice in the adaptations eventually decided upon.

In the end, Nasir's goal of driving – his rehab "beacon of hope," as he called it, has been met and has proven to be everything he thought. "Driving your own vehicle is amazing, liberating, exciting," he says. "I can go anywhere, anytime, whenever I like. It's my ticket to freedom. Absolutely everyone should get back up and drive again, no matter what – just put your mind to the dream and it'll happen."

Scenario 2: Karen

Karen is a single mum with two children, a 16-year-old boy and an 8-year-old girl. After the accident, which left her quadriplegic at the C3/4/5 level, Karen never pursued the possibility of driving again, even with the sophisticated hi-tech controls she would require. She had been at fault in the accident five years ago which also left her children with multiple fractures and some internal injuries. Although “the kids” have completely recovered and want their mum to “get back in the driver’s seat” again, Karen is terrified it could happen again and refuses to even consider it. Also, the expense of custom adaptations, even the cost of gas and maintenance, would make a dent in Karen’s limited income, which she knows she simply couldn’t afford.

Karen lives in a large city where there is a Paratransit system for persons with disabilities, as well as an increasing number of accessible regular city buses, light rail transit and subway stations. In fact, there is a strong commitment to make all public transportation services totally accessible by the year 2025. “I’m fortunate to live here,” Karen says. “I can get around this city pretty easily really, and with a bit of planning I can even connect with the accessible regional, provincial and national train and bus services, taking one of my kids or my PCA as a “free” escort. The spontaneity of using the buses and subways, like everyone else does, is wonderful and the cost suits me just fine.”

Nothing is perfect, however. The closest accessible bus route is three blocks from Karen’s home. She doesn’t mind this in good weather but when it’s raining or very cold, she would have to plan in advance to take the paratransit to an accessible route or the subway. Paratransit requires three days advance booking and has no evening or weekend service. “This can be a problem, especially in an emergency,” says Karen, recalling a time when she had severe abdominal pain and went to hospital by ambulance. The ambulance could not accommodate her wheelchair, so she had to go on a stretcher, only to be examined, treated and released within a few hours. “I couldn’t get a ride back home with Para-Trans—unless I wanted to wait three days because of their advance booking requirement, lying on a stretcher, of course, because I didn’t have my chair. Even if I could have got a Para-Trans bus home that day, I wouldn’t be able to go in it because I had no chair to sit in. I was no longer sick or in pain, but the only way I could get home that time was to wait for hours for a non-priority ambulance and then go home on a stretcher. As soon as I was home they wanted payment right away. I don’t keep that kind of money in the house. I don’t even have it, for Pete’s sake!” It was this situation and several episodes of being stranded for hours in a broken down Para-Trans bus that prompted Karen’s parents to buy a second-hand van for her.

Although Karen was surprised and thrilled about the van, she still has no intention of learning how to drive. She does feel more secure now with a vehicle of her own that her attendant (and perhaps her son) could drive in an emergency or unexpected situation, but she is firm in her resolve to rely primarily on Para-Trans and the accessible public transit system—in spite of its limitations.

For example, Karen doesn’t use public transit in rush hour because of the mad rush of people. She usually telephones the transit company before going out to check which

subway elevators are out of operation, so she can allow the time to make a detour, if necessary. Some of the elevator buttons or doors are difficult to manage. Although passersby are usually willing to help, Karen generally finds it less stressful to take someone with her when she can. She has to be vigilant in watching for platforms that are inch or so lower than the train and also in protecting her neck against the rough side to side jostling of the subway trains. In spite of these challenges, Karen much prefers taking the regular transit to Para-Trans. "I love the spontaneity of it," she says, "It's wonderful to be able to come and go as you please, any time of the day or night without having to book three days ahead. It's so nice not to arrive hours too early, or be late for appointments, or to be taken on a milk run all over the city, or have to leave a concert or a great party before it's over. Who wants a life like that?"

Karen does not want to use her new second-hand van any more than she has to, because she worries about the costs of gas and maintenance. However she's grateful to have it, especially as the van also gives her a way to visit her parents who live out of town. Karen believes she now has "the best combination of personal transportation options." She plans to carry on as she is doing, relying primarily on the regular and Para-Trans systems and using the van only for emergencies or when she goes out of town to places that an accessible train cannot take her.

Some Internet Resources

SCI PILOT

<http://www.scipilot.com>

There are many personal stories on this website that discuss transportation choices. These include cars, vans, trucks, paratransit services and public transit. The following are a few examples.

Ken

Ken cannot drive himself but has a minivan that his attendant drives for him. He discusses his preference for sitting up front and choosing a ramp versus a lift. Ken also has a motorcycle with an adapted sidecar, which his attendant also drives.

Marilyn

Marilyn uses public transit and paratransit without much difficulty. She has recently purchased a van with a lift and tie-downs that family members drive for her, thus providing greater spontaneity.

Steven:

Steven has a minivan with lowered floor and ramp but no adaptations for driving yet due to the recentness of injury and possibility of further recovery. He discusses his hope that insurance company will pay for required modification when it is determined what will be needed.

Monica

Monica used local paratransit service for work but she eventually purchased her own minivan with hand controls, due to lack of weekend and evening service. She discusses researching her options, government funding, contingencies and delays, as well as the reasons for her choice.

Paul

Paul describes a loss of physical function over the years, which necessitated a transition from driving a car to a full size van to driving from his wheelchair.

Jeannie

A family member or an attendant drives her full size converted van because of Jeannie's discomfort in driving following her accident, as well as driving fatigue. She discusses feelings of safety in a larger van and describes accessible environmental controls within the van (lights, fan), as well as funding resources.

John

John used to drive a full size van with a lift operated by a remote control which was problematic difficult to operate, but he now has an older model two door car with wide doors and hand controls. He discusses how he enters the car and accesses the controls as well as his next plan to buy another car, rather than a van, when the time comes, because he cannot afford the high cost of van modifications.

Steve

Steve has had a variety of vehicles, including a cargo van and truck which he used to lift his chair in and out of many times a day. He now drives a 4x4 pick-up truck with hand controls and an electric remote controlled arm which hoists his chair into the back of the truck and lowers a camper shell to cover it.

For more stories go to <http://www.scipilot.com>

**National Highway Traffic Administration
United States Department of Transportation**

<http://www.nhtsa.dot.gov/>

<http://www.nhtsa.dot.gov/cars/rules/adaptive/>

NHTSA is the federal government agency with the authority to regulate the manufacture of automotive adaptive equipment and modified vehicles used by persons with disabilities. Consumer information, regulations and standards, and research reports are provided.

US Federal Transit Administration

<http://www.fta.dot.gov/ada/>

This site provides links to information on the Americans with Disabilities Act of 1990 (ADA) as it applies to transportation.

Wheelchairnet

<http://www.wheelchairnet.org>

http://www.wheelchairnet.org/WCN_Living/transport.html

Under Community Living and Transportation, resources are provided about adaptive driving evaluation and equipment. This site includes an extensive collection of articles and links relating to public and private transportation including, vehicle conversion, driver's education, safety, buses, airplanes and rail. There is also a moderated discussion group where you can submit questions and comments.

Abledata

<http://www.abledata.com>

Articles and specific product information related to transportation. Information can be found under Reading Room, AT Library and Product Information.

Easter Seals Project ACTION

<http://projectaction.easter-seals.org>

Easter Seals Project ACTION promotes cooperation between the transportation industry and the disability community. This site includes a searchable database of information on accessible transportation options in cities across the U.S. The Information Clearinghouse and newsletter also offer information on accessible transportation.

Access-Able Travel Source

<http://www.access-able.com>

Facilitator Notes

Some general guidelines and tips for running a successful group, as well as suggestions for getting conversation going, by using the following “starters” and “issues,” can be found under General Facilitator Notes in the Introduction.

Some Conversation Starters

1. Has Karen made the right decision, given her circumstances and past experience?
2. Did Karen give up the idea of driving too quickly?
3. Are there other options Karen might have considered?
4. Should Karen be more strongly encouraged to drive?
5. What are the pros and cons of Karen’s transportation choice versus Nasir’s?
6. What other advantages and/or limitations do you see for Karen and Nasir that they might not be aware of?
7. Do you agree with Nasir that absolutely everyone can and should get back up driving again, regardless of injury or circumstances?
8. How could Nasir have speeded up the process of getting his vehicle?
9. Did Nasir make a mistake he’ll regret by not buying his dream car with hand controls?
10. Do you agree with Nasir’s “thinking-ahead, what-if” approach to decision making? (e.g., aging, shoulder injury).

Scenario Issues

1. Home & Work Location
 - a) Urban vs Rural
 - b) Distance Travel
 - c) Parking
2. Past Experiences
 - a) Driving History
 - b) Traumatic Events
3. Costs
 - a) Vehicle Purchase
 - b) Vehicle Adaptions & Conversions
 - c) Ongoing Costs (licence, gas, insurance, maintenance)

- d) Financial Assistance (insurance, govt. rebates, subsidies etc.)
- 4. Vehicle Conversion/Adaptions
 - a) Researching the options
 - b) Energy
 - c) Age
 - d) Size & manoeuvrability
 - e) Parking requirements
 - f) Security & Safety
- 5. Personality & Lifestyle
 - a) Independence
 - b) Flexibility, spontaneity & freedom
 - c) Responsibilities

Having Fun (Recreation and Leisure)

Scenario 1: Nick

Pushing the Limits (Excitement and Challenge)

Nick's idea of fun was pushing the limits, challenging the impossible, setting goals for himself and going way beyond. Bikes, car racing, power boats – adrenalin was the fuel that kept Nick going. But all that changed in an instant when an accident rendered Nick paraplegic at the T10 level. Nick was angry. Never being able to walk again was more than he could bear. "It's like being forced to watch a slow motion video," he used to say, "watching my own life playing out in front of me, taunting me with reminders of a life that is gone." It was difficult for Nick to cope with having to think about his body and organize his time to care for it. Before the accident Nick never thought about skin, hygiene, wheelchairs, bowel and bladder care, and the organization involved. "It's like I'm held hostage," he says, "in a foreign country—Planet Para—new language, strange culture—I don't wanna be here."

Nick's friends, fiancé and family were supportive. The rehab staff tried to understand and provided some personal counselling but nothing really helped. "What do able-bodied know about all this shit?" Nick complained. "They've never been in a chair—how do they know what it's like? Being in a chair should be a basic requirement for a counsellor in a place like this."

The recreation staff introduced Nick to wheelchair sports: rugby, tennis, basketball, sailing, archery, swimming, and sledge hockey. His rehab centre had a close relationship with a sports equipment vendor so Nick had many opportunities to try out sports chairs and discover the differences between them. The basketball chair, for example, was the same height as his regular chair but the camber (angle of the wheels) was wider to make for greater stability and ease of turning. The tennis chair was lower and very lightweight with a greater dump (bucket seat).

Nick went to some games and participated in a few events but discovered that his heart wasn't really in it. One of his cousins had been paraplegic since birth and had excelled in swimming and basketball, winning many medals and even getting to the Paralympics. Nick had never been close to his cousin and really resented the inevitable family comments, "– if John can do it, so can you." Nick felt that such competitive "cripple sports" were embarrassing, second class and not something he wanted to be part of. "I'm a solitary kind of guy," he explained to others, "I like my own space, competing against myself, not with or against others."

Nick's quadriplegic roommate John lived in a remote rural area and loved the solitude of nature he experienced while fishing. Nick found it hard to believe that such quiet "boring" activities could bring pleasure and relaxation and was amazed at John's persistence in developing a hoist for getting in and out of his boat, thus enabling him to get back into the wilderness. Nick tried fishing with John and had a great time, but decided that this wasn't what he wanted to do with his time either. "It's too much work just getting through the woods, lugging stuff around. The payoff isn't worth it. Fishing's too slow for me. I get enough peace and quiet playing Spider Solitaire on the computer."

Recently, Nick heard about bi-skiing. "It involves sitting in a seat like a bucket which is mounted on two skis and using two outriggers, short ski poles on little skis of their own, for balance and steering," he explains. "Before my accident, I was into extreme skiing – and maybe this is something close to that. I'm really excited."

Nick has also just met someone who has signed up for a trail expedition in the mountains. "Two muscular guys haul you in on a special lightweight, low-slung cart type of thing, which they can lift, lower and pull depending on the terrain. You sleep on the trail, bear repellent and all. I could get excited about that. I know I'd be totally dependent, especially in that environment, but the adrenalin of it – well..." Nick also describes some specialized safaris and wilderness expeditions in Africa and South America that he recently read about.

Nick is starting to think a person might be able to change their interests as time goes by. He's wondering if some of his negative attitude might have been because he doesn't like being a paraplegic. He now sees a way to get back to doing some of the things he enjoyed. He's worried though because his basic living and medical expenses are high, he's unemployed and his only source of income is public support. How could he possibly hope to afford such sports and adventures?

Another, even more basic problem is transportation. Nick doesn't own a car and can't afford to take taxis. The public paratransit service in his town, although the same cost as a bus ticket, isn't always dependable and has to be booked several days in advance. The pre-planning and lack of spontaneity saps the pleasure out of going out. Sometimes Nick wonders if getting out and doing things is really worth it.

Scenario 2: Laura

Sewing, Designing, Creating, Travel

Laura's career in fashion design came to a crashing halt when an accident left her quadriplegic at the C6 level. Some early acute health crises, long months of rehab and making decisions about assistive technology such as wheelchair, van and home renovations kept Laura and her husband Roy busy for a long time. Gradually, as these issues got sorted out and Roy returned to his international sales job, Laura found herself with time on her hands and an urge to "do something."

She hoped to eventually work again but had no idea what she could do or how to go about it. "I've got to get used to my new life," she explained. "I've never had time to explore my interests in art, so now's the time to do it."

With a universal cuff and Velcro tabs to hold pencils and paintbrushes, a specially constructed easel that fit over her wheelchair, and careful positioning of paint supplies, Laura found she was able to paint without too much difficulty. Oils were easier to work with than watercolours—she could paint over mistakes and the thicker oil paint didn't run down the easel. With the help of her attendant and teenage son (when he was home) as well as some creative problem solving, such as taping the paper onto a movable piece of wood, Laura discovered she could also work with watercolours on a flat surface. Laura was happy when she was painting. She was especially pleased with some of her designs, which she thought she'd someday like to see printed on fabrics.

Laura usually painted flowers and landscapes from magazines or from photos that she and Roy had taken in the garden or on past vacations. She hadn't worked out a way to paint outside or on location—such as in the garden—but her son came up with a plan to mount a camera on a gooseneck on her wheelchair which, with a screw on cable plunger trigger, she was able to activate herself.

Photography generated a whole new area of interest, which in turn, provided new opportunities for generating both realistic and impressionistic material that Laura could work with, especially during the winter months when it was more difficult to get outside.

Because Laura's insurance company would provide her with whatever voice-operated computer set-up she required, Laura was involved with an Assistive Technology and Training Centre in her town in order to determine what computer components would best suit her needs. She was in no hurry, taking the time to try out different set-ups and adaptations and even taking some training on voice dictation systems. It was at this Centre that Laura discovered digital cameras and scanners, as well as a wide variety of exciting software that she could use to extend her artistic interests further. "With a digital camera and a scanner there is no end to what I could do," Laura enthused. "The only problem I can see would be not having enough hours in the day!"

Laura's painting and photography, weekly swimming and adapted fitness classes at the local community centre kept her busy and satisfied for a long time. But, as time went by she

missed the travel that she used to do and began to think about how she could travel again. Roy was enthusiastic and encouraged her to join him on his next business trip to Europe, especially as he would be spending five days at a comfortable hotel in Paris.

Laura researched the possibilities with her classmates at the fitness centre. She also found some comprehensive resources on the Internet and several travel agents who specialized in this area. Her friends gave her tips on challenges to expect and watch out for, such as airline damage to or loss of her wheelchair, airport protocols and questions to ask hotels before booking, such as bed heights, door widths and clearance under the beds so the legs of a mechanical lift could go under the bed. Laura was especially concerned about bathroom accessibility and toileting needs. She was willing to use an indwelling catheter for convenience during air travel but did not want to jeopardize the successful intermittent catheterization routine she had established by leaving the indwelling in for too long.

Laura had three months to explore the options while developing and practising strategies for managing without the conveniences of home. She wanted to travel as lightly as she could, leaving her Hoyer lift and commode at home, if possible.

Laura customized her clothes by having zippers sewn in the crotch of her pants. She used the recline feature on her power chair to lean back and have her attendant position her legs on the side of a bed or a chair for IC procedures. Through an Internet search she located a transfer board that incorporated a sliding disk on a track which could be positioned under one buttock and then, when she was on it, the attendant could easily slide her across the transfer board. Laura thought about the efficiency of her packing and found a bag with many compartments that she could carry on the back of her chair and bring with her onto the plane for in flight use.

Laura's careful planning paid off. She and Roy had a wonderful trip. While Roy was attending his conference, she and her attendant roamed the streets, enjoying the sights and taking enough photos to keep Laura painting the rest of the winter. As soon as they were home, discussions began about planning another "family holiday" trip.

Meanwhile, Laura's busy mind has taken off on yet another direction. She wants to be able to sew some of her fabric designs into cushions and other home décor items. She has tried using her sewing machine, but it took ages and was extremely slow and difficult because of Laura's limited hand function as well as the fact that one hand had to be used to operate the foot pedal. Nevertheless, Laura has an idea for an adaptation that would enable her to run the sewing machine's foot control with her elbow, thus freeing both hands to handle the fabric. She is hoping to find an engineer or a technical person who could help her develop such a device.

Laura is also getting itchy about returning to work. Her confidence and self-esteem have soared as a result of her accomplishments so far and she's beginning to believe that anything's possible. She knows she can't do the same job as before but she's wondering if her artistic interests and ideas are marketable. She's scared about the practical logistics involved – attendant help, travel, costs of set-up, administration headaches and the cut-throat pressures of the real working world. "Am I crazy?" she asks. "Maybe I'm better off to just keep doing all these things I love for my own recreation and leisure?"

Some Internet Resources

SCI PILOT

<http://www.scipilot.com>

There are many personal stories on this website that discuss choices for leisure and recreation activities. These include a wide variety of sports activities and equipment as well as activities such as painting and travel. The following are a few examples.

Helena

Discusses the three different wheelchairs she uses for playing tennis, basketball and everyday use, as well as an attachment which turns her everyday chair into a hand cycle for exercise purposes.

Sandra

An elite swimmer at the Paralympic level as well as a downhill skier, rower, sailor, water-skier and kayaker, Sandra discusses the importance of exercise in keeping mentally and physically fit. She describes the equipment she uses and adaptations she has made which enable her to maintain mobility and toileting independence in the community as well as save energy, now that she is getting older.

Brenda

In spite of the time it takes, Brenda puts her creative energy into sewing with a sewing machine and painting. She discusses the adapted easel which makes this possible, as well as her idea for a device, which a local volunteer agency may make at cost, that will enable her to operate the sewing machine with her elbow.

Mike

Mike stays in touch with his computer, which he also uses for advocacy work. He discusses the adaptations he uses for painting and photography, such as a beanbag lap table, hand splint and a gooseneck camera holder attached to his wheelchair. He also describes his experiences with airline travel and makes suggestions for travelling, such as reserving ahead and requesting a bulkhead seat. He also discusses his experiences with accessible hotel rooms and cruise vacations.

Francois

Describes the exercise bike he uses to keep his muscles in shape, in case future research finds a cure for his spinal cord injury. He discusses his experiences with air travel and the equipment used by his local adapted sailing program that lifts him in and out of the boat and enables him to sail. As a one time engineer in the Navy, Francois discusses his plans for adapting and outfitting a boat so as to get himself back on the ocean again.

Pascal

Describes the technology used when travelling, particularly a portable combination toilet seat/bath bench which fits and tub or shower and disassembles to fit in a suitcase.

Jerry

Power wheelchair soccer is described as well as the excitement, social opportunities and team camaraderie this sport provides.

Ken

Having high-level quadriplegia and being dependent on a ventilator full-time hasn't stopped Ken from coaching and playing power wheelchair soccer, bowling, target shooting and operating remote controlled gliders and cars. As the first quadriplegic ever to go tandem skydiving with an air supply strapped to his chest, Ken believes that all it takes is some thinking and adapting of available technology.

Rich

Rich is, in his words, an "active guy." In fact, he is a skilled athlete who competes at very high levels. He says that early in his rehab, "Sports was the question I needed answers to."

Dan

Since leaving the rehab centre, Dan has tried numerous sports including wheelchair rugby, tennis, snow skiing, jet skiing and hand cycling. He feels that participating in sports helps you spiritually, emotionally, functionally and with your personal relationships, and helps you to believe in yourself—to realize that you can do more than you think you can.

For more stories go to <http://www.scipilot.com>

Wheelchairnet

<http://www.wheelchairnet.org>

http://www.wheelchairnet.org/WCN_Living/recreate.html

Under Community Living Sports and Recreation, an extensive collection of articles and links relating to sports and recreation are provided. There is also a moderated discussion group where you can submit questions and comments.

Abledata

<http://www.abledata.com>

Articles and specific product information related to recreation are provided. Information can be found under Reading Room, AT Library and Product information.

National Centre on Physical Activity and Disability

<http://www.ncpad.org>

The National Center on Physical Activity and Disability (NCPAD) promotes the health benefits that can be gained from participating in regular physical activity. This site provides information and resources that can enable people with disabilities to become as physically active as they choose to be.

A Celebration of Wheels

<http://lenmac.tripod.com>

This site includes many sports images and contacts to further information.

PALAESTRA: Forum of Sport, Physical Education & Recreation for Those with Disabilities

<http://www.palaestra.com/>

This is the online site for quarterly publication. It provides resources and contacts on adapted physical activity.

Tools for Play

<http://guide.stanford.edu/toolsforplay/activities.html>

Tools for Play is a multimedia program that was presented at the Opening Session of the 1996 Paralympic Congress. This site provides information for contacting individuals and organizations that support various kinds of recreation and leisure activities.

Sports 'n Spokes Magazine

<http://www.sns-magazine.com/sns/wheelcha.htm>

This is the online site for a magazine that focuses on wheelchair sports. Back issues can be ordered online. An online directory of wheelchair sports associations is provided.

Society for Accessible Travel and Hospitality

<http://www.sath.org>

The Society for Accessible Travel & Hospitality (SATH) is a non-profit educational organization that promotes awareness, respect and accessibility for travelers with disabilities and the mature individual. Information and tips and advice on travel for those with mobility impairments are provided.

Moss Rehabilitation Resource Net

<http://www.mossresourcenet.org>

<http://www.mossresourcenet.org/travel.htm>

Information and resources for the disabled traveler..... Including airlines, trains, buses, cruise lines, driving, travel agents, tourism offices and more.

Canadian Wheelchair Sports Association

<http://www.cwsa.ca/home.html>

This site provides links to other Sporting Associations as well as a Buy and Sell for used sporting model wheelchairs.

Facilitator Notes

Some general guidelines and tips for running a successful group, as well as suggestions for getting conversation going, by using the following “starters” and “issues,” can be found under General Facilitator Notes in the Introduction.

Some Conversation Starters

1. How easy would it be to change your interests or adapt to different kinds of recreation and leisure following a SCI?
2. How important is it to get out and do recreational activities again? By yourself? With others?
3. What opinions do you have of the various ways that staff, family and friends took trying to support Nick?
4. How essential is money in the pursuit of recreational and leisure interests?
5. Are there recreation and leisure options where cost is not an issue?
6. Is Laura’s approach to recreational and leisure pursuits typical?
7. Is it easier for someone “born with a disability” to get involved?
8. What is your opinion of Laura’s plan to transform her recreational interests into employment?
9. How important is recreation, leisure or sports to a person with spinal cord injury?
10. What are some of the barriers to getting involved?

Scenario Issues

1. Support
 - a) Family
 - b) Friends
 - c) Rehab personnel
 - d) Attendant assistance
 - e) Recreation equipment Availability
 - f) Getting equipment adapted & customized
2. Experiences
 - a) Opportunities for try-out
 - b) Past interests and activities
 - c) Availability and convenience of options, programs & equipment
3. Costs
 - a) Leisure pursuits, supplies

- b) Travel
- c) Special Equipment
- d) Income & expenses
- 4. Employment Possibilities
- 5. Research and Getting Information
- 6. Transportation
 - a) Availability of public transit
 - b) Own vehicle
 - c) Costs
- 7. Personality, Interests & Life Style
 - a) Independence
 - b) Flexibility, spontaneity & freedom
 - c) Competitive, loner versus high social needs
 - d) Creative, highly active, risk taker