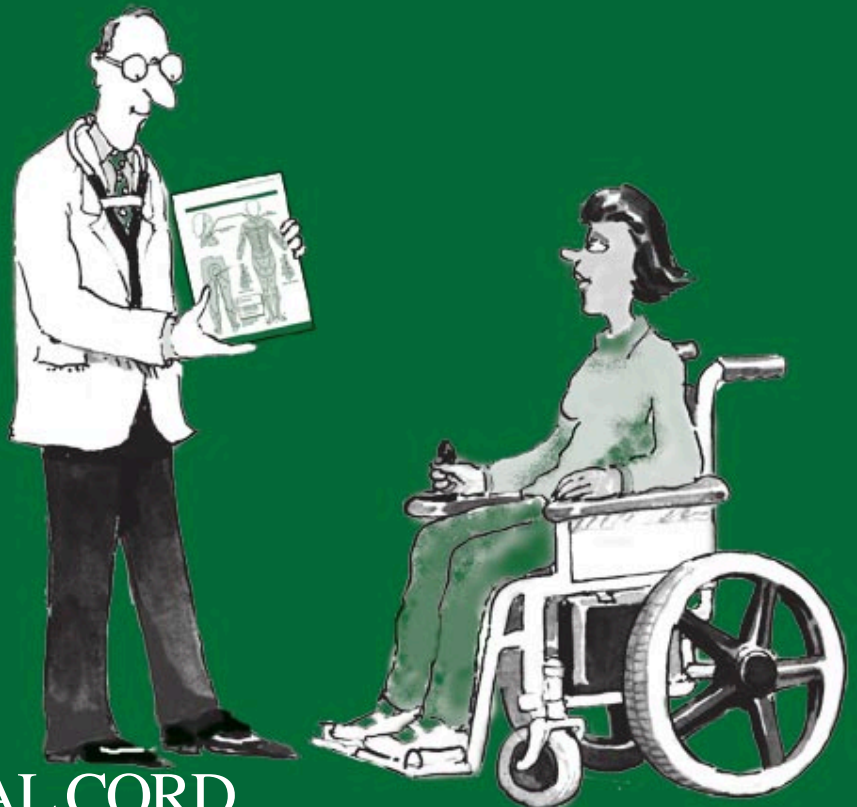


Expected Outcomes: What You Should Know

A Guide for People with **C1-3 Spinal Cord Injury**



Consumer Guide Panel Members

Gale Whiteneck, PhD (Chair)

(Research)
Craig Hospital
Englewood, CO

Carole Adler, BA, OTR

(Occupational Therapy, Spinal Cord Injury)
Santa Clara Valley Medical Center
San Jose, CA

Sharon Blackburn, PT

(Physical Therapy, Spinal Cord Injury)
Craig Hospital
Englewood, CO

Robert D. Hendricks, PhD

(Health Systems Specialist)
VA Puget Sound Health Care System
National Spinal Cord Injury and Disorders Strategic
Health Group
Seattle, WA

Kelly Johnson, RN, MSN, CFNP, CRRN

(Nursing, Spinal Cord Injury)
Craig Hospital
Englewood, CO

Harley Thomas

(Consumer)
Paralyzed Veterans of America
Washington, DC

Consumer Focus Group Members

J. Fred Cowell (Chair)

Paralyzed Veterans of America
Washington, DC

Ronald P. Amador

California Paralyzed Veterans Association, Inc.
Long Beach, CA

Craig Bash, MD

PVA Member
Bethesda, MD

Robert Herman

Paralyzed Veterans of America
Washington, DC

Ronald P. Hoskins

PVA Delaware-Maryland Chapter
Christiana, DE

Kenneth C. Huber

PVA Michigan Chapter
Novi, MI

John T. Jackson

PVA Virginia Mid-Atlantic Chapter
Richmond, VA

Consortium Member Organizations

American Academy of Orthopedic Surgeons
American Academy of Physical Medicine and
Rehabilitation
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Association of Rehabilitation Nurses
Congress of Neurological Surgeons
Eastern Paralyzed Veterans Association
Insurance Rehabilitation Study Group
Paralyzed Veterans of America
U.S. Department of Veterans Affairs

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This guide has been prepared based on scientific and professional information found in *Outcomes Following Spinal Cord Injury: Clinical Practice Guidelines for Health-Care Professionals* published September 1999. Users of this guide should periodically review this material to ensure that the advice herein is consistent with current reasonable clinical practice.

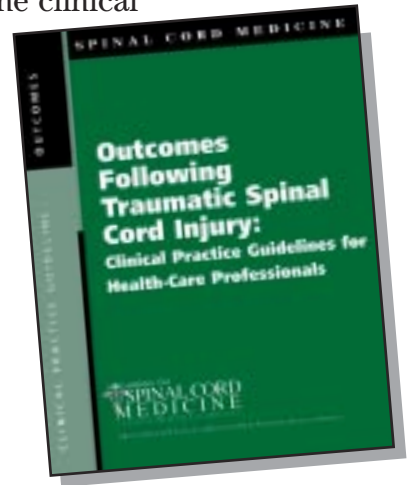
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Who Should Read This Guide?

- People with C1–3 complete spinal cord injury (SCI).
- Family, friends, personal care attendants, and other caregivers.
- Health-care professionals, especially rehabilitation staff.
- Case managers and payers of services and equipment.

This consumer guide is based on the clinical practice guideline about outcomes following traumatic SCI currently available for health-care professionals. Tell your health-care team to contact the Paralyzed Veterans of America (PVA) Distribution Center toll-free at **(888) 860-7244** to purchase any guideline or consumer guide, or visit the Consortium for Spinal Cord Medicine's web site for a free download at **www.scicpg.org**.



Why Is This Guide Important?

This is one in a series of eight guides that describe outcomes according to level of injury. **This Guide deals with a complete C1–3 SCI**—injury between the first and third cervical spinal cord segments with complete paralysis below the level of injury. The purpose of this series of guides is to describe what people with different levels of SCI can reasonably expect for daily functions.

This information can help people with SCI and those who care for and about them to understand the present and plan for the future. It explains important information that can be useful to you, like:

- What can a person with SCI expect to do one year after injury?
- What help will be needed with daily life tasks at home, at work, and in the community?
- What equipment can help make a person with SCI more independent?

A spinal cord injury (SCI) is damage to the spinal cord resulting in a loss of movement or feeling. The spinal cord is a bundle of nerves that runs through the bones making up the spinal column. The spinal cord does not have to be totally cut or torn for a loss of functioning to occur. On the other hand, a person can “break their back or neck,” and not have a spinal cord injury if only the bones around the spinal cord (vertebrae) were damaged and the spinal cord was not affected. In these situations, the individual may not have paralysis after the bones are stabilized.

Rings of bone called vertebra surround the spinal cord. These “back bones” make up the spinal column. The higher the injury to the spinal cord, the more the individual usually experiences activity limitations. The vertebrae in the neck are called cervical vertebrae. The top vertebra is C1; the next is C2, and so on. Cervical spinal cord injuries usually cause loss of function in both arms and legs. This is called tetraplegia, sometimes referred to as quadriplegia.

What Are “Outcomes”?

When we talk about “outcomes” after SCI, we mean many things:

- Movement/sensory recovery
- Ability to perform common daily functions
- Social life in the community
- Overall quality of life

An outcome is a change that happens to you because of an event, such as a spinal cord injury. These can be described in the following ways:

- **Impairment outcomes**—health problems or illnesses.
- **Activity outcomes**—basic tasks you do for self-care (breathing, eating, dressing, and moving around). These activities can be done with or without help from special medical equipment or another person.
- **Participation outcomes**—ways you connect with others in the community like being a friend, partner, parent, student, employee, or volunteer.

- **Life satisfaction outcomes**—reports from you of how you see yourself and your quality of life.

This Guide focuses mostly on **activity outcomes**. The other outcomes described above are difficult to explain for each person. You should think about ways to pursue your own interests following your injury. Ways you can participate may include:

- Connecting with other people (in person, by telephone, or by email).
- Changing your physical environment and lifestyle to allow you to do your job, go to school, and have fun.
- Asking your friends, family, and others for suggestions.
- Planning to stay healthy, active, and satisfied (ask your health-care team).
- Going back to school and continuing your education.

This Guide is an educational tool!

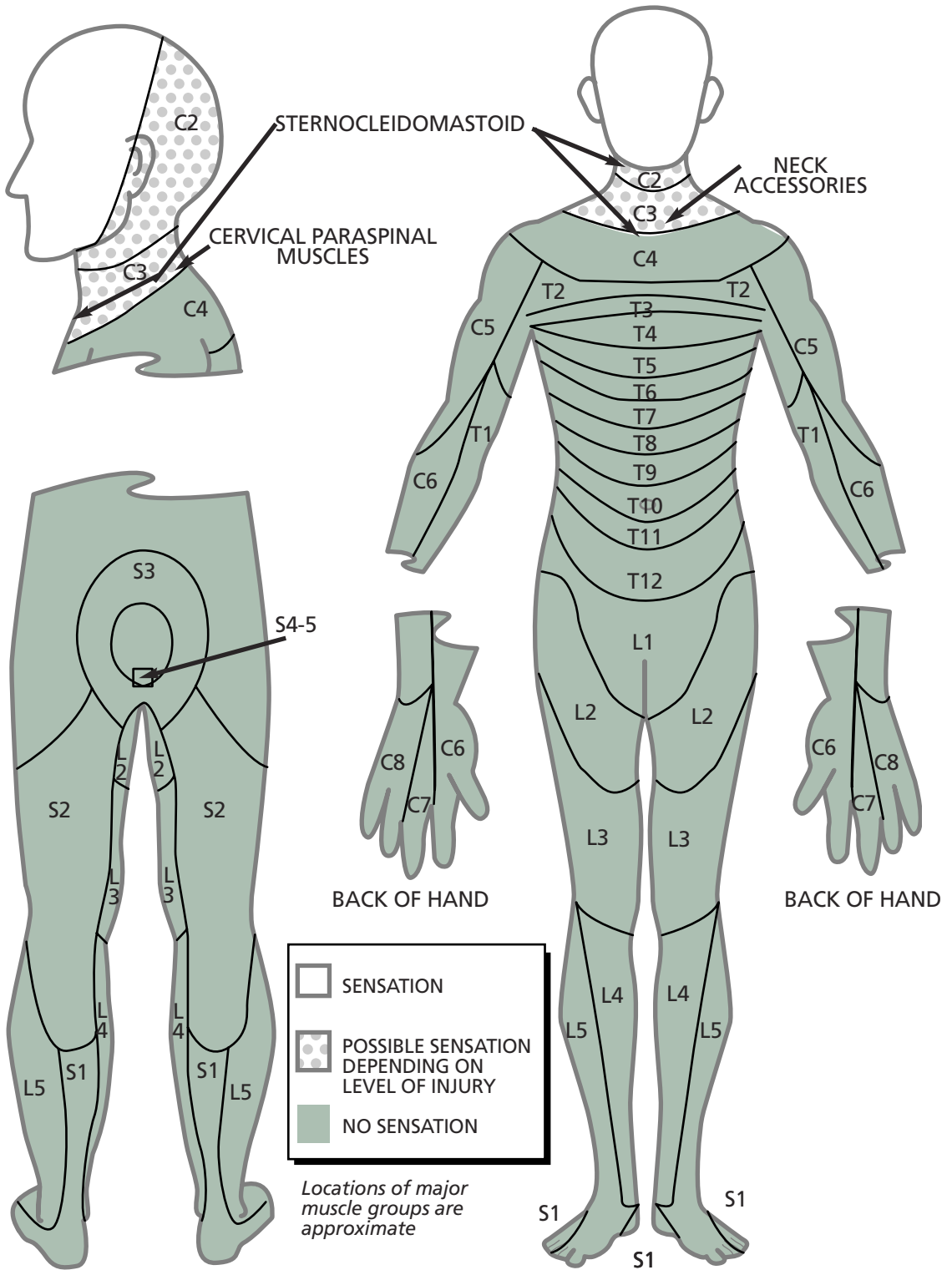
Feel free to share it with your health-care providers when you discuss what activities you may expect to do one year after injury. The recommendations within this consumer guide are based on scientific research used in the Consortium's clinical practice guideline (CPG) *Outcomes Following Traumatic Spinal Cord Injury: Clinical Practice Guidelines for Health-Care Professionals* published in September 1999. Order your copy by calling the PVA Distribution Center toll-free at **(888) 860-7244** or download a free copy by visiting the Consortium for Spinal Cord Medicine web site at www.scicpg.org.

What Influences Outcomes after SCI?

A spinal cord injury changes many things. Those changes depend on many factors. Each part of the bundle of nerves called the spinal cord controls different parts of the body.

By now, you know what “C1–3” means, but friends and family members may find some explanation helpful. The spine has four sections: cervical (C), thoracic (T), lumbar (L), and sacral (S). It also has 33 bones, called vertebrae. Each vertebra is associated with a spinal nerve. A simple system of one letter and one number acts as shorthand for the SCI (Figure 1). The letter shows the section, and the number shows

FIGURE 1—LEVEL C1-3 SENSATION DIAGRAM



the injured nerves. The level of injury determines what parts of the body lose muscle and sensory function. The severity or completeness of the injury determines whether some or all motor and sensory function is lost. This guide is intended for someone with complete paralysis below C1–3.

Cervical (neck) injuries usually result in four-limb paralysis called tetraplegia. People with complete C1–3 SCI are able to speak, swallow, and control head movement, but do not have the ability to move their arms or legs. They will lose the ability to cough and breathe. Injuries at the C1–3 level require mechanical ventilation.

The position of key muscle groups still working after a C1–3 spinal cord injury are indicated in Figure 1. They may include:

- Sternocleidomastoid (rotates and flexes neck)
- Cervical paraspinal muscles (extend neck)
- Neck accessories (assist with speech and swallowing)

Other factors affect outcomes. They include:

- Health before injury
- Current general health status and body build
- Age
- Associated injuries
- Secondary complications
- Support network of family and friends
- Financial situation
- Home and work environment (accessibility; attitudes)
- Access to and availability of healthcare and rehabilitation services
- Participation in community activities

What Activity Outcomes Can I Expect after a C1–3 Spinal Cord Injury?

Table 1 lists life activities, such as breathing, eating, dressing, and moving around. For each activity, it explains what many people with a C1–3 SCI can reasonably expect one year after injury. This table can help you and your health-care team set short- and long-term goals.

It is important to understand what “reasonably expect” means. **Table 1 uses averages.** In the real world, outcomes vary from person to person for the same level of injury. Your health-care team can help to set goals for you since outcomes are very specific to each person.

Important:

Table 1 is a general guide for expected outcomes for a C1–3 complete spinal cord injury. **It’s a goal to work toward, not a guarantee!** For every activity listed, some will not be appropriate or achievable for everyone with a C1–3 SCI. Your outcomes may not match table 1 within the timeframe suggested or you may exceed the goals listed. The expected outcomes listed here are based on research and clinical experience, but they’re based on other people with SCI—not on you.

The outcomes in table 1 are described in terms of the need for help with specific activities. The table has three categories: independent (I), some assist (S), or total assist (T). Activities including mobility and communication have more than one category marked. It may be possible to have some movement of your neck with a C1–3 spinal cord injury. However, outcomes vary from person to person. Most C1–3 injured people need a ventilator to assist in breathing. Individuals will require the total assistance of a caregiver to transfer from surface to surface. Depending upon what equipment is available to the individual and the accessibility of their environment, their level of assistance will vary. For instance, a person with a chin-driven power wheelchair or high-tech computer access may be independent in their mobility and communications, but will require assistance for set up.

Special equipment you may need or want is also listed. Your rehabilitation treatment team may have different suggestions. Equipment needs, like outcomes, may change over time.

Availability of personal care assistance for individuals with C1–3 SCI is expected to be 24-hour care, which includes homemaking. With a C1–3 injury, you should be able to explain everything an assistant needs to know about your care. But, you will require assistance to perform all of your activities of daily living and to meet basic care and safety requirements.

TABLE 1.**Expected Outcomes—Level C1–3 Complete Spinal Cord Injury****ASSISTANCE TYPE:**

I=Independent

S=Some Assist

T=Total Assist

Name: _____ Date: _____

Individual Goals recommended by: _____

Activity	Assistance Type	Equipment*/Comments	Individual Goals
Breathing	T	<ul style="list-style-type: none"> -1 bedside ventilator -1 portable ventilator -Device for suction -Backup for power failure (generator or batteries) -Vent tray for wheelchair 	
Eating	T		
Bathroom Functions: -Bowel care -Bladder care	T T	If roll-in shower available: <ul style="list-style-type: none"> -padded reclining shower commode chair 	
Personal care: -Dressing -Grooming -Bathing	T T T	Bathing equipment: <ul style="list-style-type: none"> -Shampoo tray If roll-in shower available: <ul style="list-style-type: none"> -Handheld shower -Padded reclining shower commode chair 	
Positioning/ Pressure Relief	I/S	Wheelchair: <ul style="list-style-type: none"> -Power recline, and /or tilt function -Pressure-relief cushion -Postural support and head control devices as needed 	

*Use the Equipment Diary on Page 15 to keep track.

<p>Positioning/ Pressure Relief <i>cont.</i></p>	<p>T</p>	<p>May be needed –Hand splints Bed: –Specialty bed or pressure-relief mattress</p>	
<p>Mobility: –Bed</p>	<p>T</p>	<p>Bed: –Full electric hospital bed with Trendelenburg feature and side rails Transfers: –Transfer board –Power or mechanical lift with sling Wheelchair use: –Power recline and/or tilt wheelchair with head, chin, or breath control –Manual recline wheelchair Standing: –Tilt table –hydraulic standing table Transportation: –Attendant-operated van (e.g., lifts, tie-downs) or –Accessible public transit</p>	
<p>–Transfers</p>	<p>T</p>		
<p>–Wheelchair use</p>	<p>I</p>		
<p>–Standing</p>	<p>T</p>		
<p>–Transportation</p>	<p>T</p>		
<p>Communication (Handwriting and keyboard and telephone use)</p>	<p>I/S/T</p>	<p>–Mouth stick –High-tech computer access –Environmental control unit –Adapted equipment</p>	
<p>Homemaking</p>	<p>T</p>		

It's a good idea for you and your health-care team to check your equipment from time to time to make sure it's in good shape and working well for you. As you age, your equipment needs may change. Rehabilitation staff can keep you up-to-date about new designs and products that may fit your changing needs.

Modifications to your home and workplace will be needed for you to do as much as possible. **Safety and accessibility are significant considerations.** Ask your rehabilitation staff for referrals to rehabilitation therapists who specialize in accessibility for an evaluation of your home and work environments. This should provide you with helpful architectural and other changes that may help you accomplish as much as possible.

Activities can change over time. They can improve, lessen, or both. Keep in touch with your health-care team for regular reviews of how you are doing. They may be able to help meet your needs with different services, assistance, equipment, or repairs.

It is important to know that changes and improvements in function will not happen all at once. **Rehabilitation is a lifetime process...**it does not end when you leave the rehabilitation facility. In order to master your life after a spinal cord injury, you will need courage, commitment, and a sense of challenge.

A spinal cord injury does not necessarily lessen satisfaction with life. Life satisfaction is your answer to the question, "Is my life going well, according to the standards that I choose to use?" Your degree of life satisfaction is **not** strongly related to your type or your level of SCI. For example, some people with C1–3 spinal cord injury can be more satisfied with their lives than people without a spinal cord injury or with other types of SCI. You will notice that your perspective on life will change with time. As one individual noted, "The person I am after a spinal cord injury is different, but improved from the way I used to be. I still wouldn't mind visiting the old me, however." Satisfied people have been found to take better care of themselves, maintain their health, and prevent medical complications.

Your personal satisfaction is more related to ways you connect with others in the community. Therefore, your ability to

form friendships or be a partner, student, employee, or volunteer is very important. For people with high cervical injuries, it requires effort to manage personal care, get out in the community, and make productive uses of time. Sometimes a brief review of participation outcomes (social life in the community) can help you stretch your imagination and think of ways to improve things (see **table 2** below).

TABLE 2:

Questions and Actions

<i>Questions</i>	<i>Actions</i>
Is there adequate money to meet housing, food, and health-care needs?	<ul style="list-style-type: none"> • Review benefits. • Budget with your financial planner, social worker, or case manager.
How do I make and keep friendships and relationships?	<ul style="list-style-type: none"> • Review your skills with your counselor or psychologist. • Join a peer group.
How can I best organize and manage my care?	<ul style="list-style-type: none"> • Discuss personal care management with your health educator.
How can I feel useful and productive?	<ul style="list-style-type: none"> • Discuss vocational, volunteer, and education options with your vocational counselor. • Work, go back to school, or volunteer.
How do I get around in my community?	<ul style="list-style-type: none"> • Discuss transportation and community mobility with your case manager, rehabilitation therapist, social worker, independent living center, or local PVA chapter.

Meaningful activities are available to people with even the more physically limiting spinal cord injuries. During rehabilitation, you learned the need to become an expert on spinal cord injury so you could educate your family, friends, partners, and personal care attendants. In addition to education, it is important to advocate assertively for your needs. This is sometimes difficult to do, but is important if you are to succeed in developing a satisfying life in which you make meaningful contributions to your community and achieve important things you want.

Appendix A

Resources for People with SCI

Look in your local phone book to find federal, state, county, and local government agencies. For information on local resources, call the National Council on Independent Living at **(703) 525-3406** or check the Internet at www.spinalcord.uab.edu.

Housing

Assisted living; personal care homes; return to own home; independent living centers; state veterans homes; nursing home placement; housing authority for subsidized housing and rental aid programs; local realtor; U.S. Department of Housing and Urban Development.

Finances

Supplement Security Income (SSI); Social Security Disability Income (SSDI); VA* for veterans who served in wartime or are connected to a branch of military service; workers' compensation; food stamps; Aid to Families with Dependent Children (AFDC); State department of rehabilitation services.

Transportation

Local public transit authority; area agency on aging; state division of rehabilitation services; Medicaid taxi services; VA*; independent living centers; places of worship (churches, synagogues, mosques); rental van services.

Caregiver support

VA* for respite for veterans; respite care through local hospitals and nursing homes; homemaker services through VA* or state funding; local support groups; mental health center or professional; the National Caregivers Association.

Personal care assistance

Home health agencies; independent living centers; family members; training of people who can hire and manage their own employees; Medicaid waiver programs; state funding options; VA*.

Peer support

Independent living centers; local rehabilitation hospitals; PVA*; National Spinal Cord Injury Association; local SCI or PVA* chapters; disability-specific support groups.

Home access

Independent living centers; civic groups; houses of worship; state department rehabilitation services; Medicaid waiver programs; VA*; PVA* Architecture; workers' compensation.

Adaptive equipment

VA*; independent living centers; PVA*; National Spinal Cord Injury Association; Medicare; private insurance.

Leisure, sports, and recreation

Independent living centers; PVA*; National Spinal Cord Injury Association; houses of worship; YMCA/YWCA; local fitness centers; county parks and recreation service; Chamber of Commerce; state sports associations; senior citizen centers.

Individual, family, and caregiver support

Independent living centers; local rehabilitation hospitals; mental health center or professional; local SCI or PVA* chapters; disability-specific support groups.

Jobs, vocational help

State employment agency; independent living centers; state division of rehabilitation services; VA*.

**VA = Department of Veterans Affairs; PVA = Paralyzed Veterans of America. References to VA are appropriate for veterans only.*

Medical History

Name _____

Date of birth: ___/___/___ Sex: M or F

Date of spinal cord injury: ___/___/___

Level of injury: Complete Incomplete

Allergies, including medications:

List medications taken regularly (prescription and over-the-counter):

- | | |
|----------|-----------|
| 1. _____ | 7. _____ |
| 2. _____ | 8. _____ |
| 3. _____ | 9. _____ |
| 4. _____ | 10. _____ |
| 5. _____ | 11. _____ |
| 6. _____ | 12. _____ |

List medications taken as needed (prescription and over-the-counter):

- | | |
|----------|-----------|
| 1. _____ | 7. _____ |
| 2. _____ | 8. _____ |
| 3. _____ | 9. _____ |
| 4. _____ | 10. _____ |
| 5. _____ | 11. _____ |
| 6. _____ | 12. _____ |

Emergency Information

In Case of Emergency, Call: _____

Relationship: _____

Phone Number: (_____) _____

Alternative Phone Number: (_____) _____

Insurance Information

Name of Insurance Company: _____

Identification Number: _____

Group Number: _____

Phone Number: (_____) _____

Attendant/Caregiver Information

Name: _____ Date Hired: _____

Address: _____

City: _____ State: _____ Zip: _____

Home Phone: (_____) _____

Cell Phone: (_____) _____

Pager Number: (_____) _____

Email Address: _____

Acknowledgements

The Consortium for Spinal Cord Medicine Clinical Practice Guidelines is composed of 19 organizations committed to improving spinal cord injury (SCI) care and treatment. The Consortium Steering Committee established a clinical guideline development (CPG) panel to make recommendations on expected outcomes following SCI. The recommendations within this consumer guide are based on scientific research compiled from 1966 to 1999 and used in the Consortium's CPG *Outcomes Following Traumatic Spinal Cord Injury: Clinical Practice Guidelines for Health-Care Professionals*. The CPG development panel was assisted by an expert team from the University of North Carolina at Chapel Hill who reviewed the literature and determined the quality of the research. Paralyzed Veterans of America provided financial support and administrative resources for all aspects of guideline and consumer guide development.

The consumer guide panel was chaired by Gale Whiteneck and consisted of five members with experience in assessment of functional outcomes following spinal cord injury—Carole Adler, Sharon Blackburn, Robert Hendricks, Kelly Johnson, and Harley Thomas. Meeting life's demands in spite of a spinal cord injury requires much adaptation. For many with SCI, limitations in

activities of daily living are a major life-limiting problem. Creation of this series of consumer guides required a diverse, experienced, and sensitive panel. The Consortium would like to thank all members of the consumer guide panel for providing the essential ingredients of knowledge, experience, empathy, and practicality.

The Consortium is also appreciative of the outstanding work of the entire PVA publications support staff. In particular, the Consortium would like to recognize graphic designer and illustrator Sarah Ornstein, PVA Senior Editor Patricia E. Scully, Project Administrator Dawn M. Sexton, and Consortium Coordinator J. Paul Thomas. Also, we would like to recognize professional writer Barbara Shapiro for her work on the initial draft document.

In the end, it is those with SCI who are continually living with their injury are the best evaluators of a teaching tool such as this consumer guide. The Consortium would like to thank the consumer focus group for their critical review and comments on the manuscript, including Chairman Fred Cowell, Ronald Amador, Craig Bash, Robert Herman, Ronald Hoskins, Kenneth Huber, and John Jackson. Their varied life experiences with SCI provided wise perspectives that refined and improved the consumer guide.

Finally, it is essential to recognize all investigators studying the measurement of functional outcomes following SCI. Research is the source of solutions; there is still much to be done in the future. This field continues to be a fertile area for research!


The Consortium will continue to develop clinical practice guidelines and consumer guides on topics in spinal cord injury care. Look for consumer guides on other topics in spinal cord injury at www.scicpg.org.

Notes

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Notes

(This space can be used to record additional medical history details.)

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