

# ACADEMY OF NEUROLOGIC PHYSICAL THERAPY

## **Bridging the Gap Between Physical Therapy and Long-Term Physical Activity and Training in People with Spinal Cord Injury (SCI): Recommendations from the SCI Special Interest Group**

### Introduction:

People with spinal cord injury (SCI) have varied options for physical activity after their formal rehabilitation ends based on their interests, ability, community resources, and personal resources. However, there is limited information available to guide individuals with SCI in choosing the best options based on their goals and resources. These guidelines provide information and recommendations to people with SCI and to physical therapists, in order to guide their decision-making in determining their plans for continued physical activity.

### Objectives:

1. Describe reasons for completing formal post-SCI rehabilitation including maximizing recovery and future planning for health and wellness.
2. Outline recommendations for a long-term relationship with rehabilitation professionals, including check-ups and reasons to re-initiate care.
3. Describe potential goals of post-rehabilitation physical activity, including fitness, wellness, continued recovery of physical function, and maintenance of physical function.
4. Provide recommendations for achieving goals, including providing criteria and considerations for evaluating resources and activity plans.

The following sections provide a broad overview of the recommendations for decision-making during the transition from physical therapy (PT) to a long-term physical activity and training program (**the *Brief Summary of Recommendations* section, page 2**) and a more detailed description of this process (**the *Detailed Recommendations* section, page 3**).

Target audience: The primary target audience for the *Brief Summary of Recommendations* section is people with SCI. The target audiences for the *Detailed Recommendations Section* are people with SCI, physical therapists, other clinicians who care for people with SCI.

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## **Brief Summary of Recommendations:**

Long-term physical activity and exercise helps recovery from a spinal cord injury (SCI). If you have sustained a SCI, you will likely have rehabilitation, including physical therapy (PT). This PT usually lasts as long as you make gains in your abilities and function.

Once you complete your first bout of PT, you have many options for exercise and recovery. These options range from exercising on your own at home to hiring a trainer at a local gym to assist you. These recommendations provide guidance for how to come up with the best plan for you. Your physical therapist can also help you decide the best plan for you.

### Making a Plan for Long-Term Exercise:

The first step is to decide what your goals are. These goals may be to:

- Increase your independence
- Improve your ability to move
- Increase your strength
- Improve your fitness
- Improve your health
- Make friends and meet other people with SCI
- Improve your mental health

The second step is to make a general plan to achieve those goals. For instance, if your priority goals are to a) improve your fitness and b) promote recovery for walking, your general plan might be to practice walking and do aerobic exercise.

The third step is to figure out what resources you have available to you in terms of people, facilities, and services. Links to programs and facilities across the United States are listed in the Detailed Recommendations section along with questions that you may want to ask of these programs and facilities. If you are unable to access people or programs to help you with your long-term exercise plan (e.g., due to lack of transportation or such programs in your area), there are still many ways to incorporate physical activity and training into your life. You and your physical therapist should work together to find a plan that will work for you.

Once you know what you would like to do and what resources you have available to you for continued exercise and training, you are ready to finalize your exercise plan and put it into action.

### Additional Physical Therapy Later On

Your needs may change over time. You can continue to see your rehabilitation team (including your physical therapist and your doctor) occasionally to get input and assistance in addressing your needs, including for exercise and continued physical recovery. You may also return to your rehabilitation team at times when new problems arise – for instance, if you have shoulder pain from using your arms more or if you lose function or endurance after being on bed rest for a pressure sore.

## **Detailed Recommendations:**

**Objective 1:** Describe reasons for completing formal post-SCI rehabilitation including maximizing recovery and future planning for health and wellness.

### Formal Rehabilitation/Physical Therapy After a Spinal Cord Injury (SCI)

Rehabilitation for a spinal cord injury (SCI) typically includes intensive care, acute care, inpatient, and outpatient physical therapy (PT). Home PT is sometimes included as well. During a PT episode of care, people with SCI will undergo treatment to address the following areas:

- Maximizing recovery of motor function
- Improved ability and independence with functional activities and walking
- Return to previous home and community roles, as well as return to leisure time physical activity
- Minimizing risk of future injury/medical problems
- Maximizing health, wellness, and adjustment to changes in abilities.

The typical duration of outpatient PT varies widely from several weeks to many months. The length of stay for outpatient PT in each individual person with SCI should be determined as a team by the person with the SCI, the physical therapist, any involved family, other health care professionals, and the physician. These team members should decide how long outpatient or home PT will last based on 1) objective measurements of each person's goal areas (e.g., transfers, walking, wheelchair propulsion) and 2) the person's performance of those activities in day-to-day life. A person with SCI should consider continuing in outpatient PT as long as he or she is making meaningful and measureable gains in function or motor recovery and the necessary resources are available (e.g., funding, transportation, time and effort required to participate in therapy).

The initial bout of formal PT may be discontinued for several reasons:

- Lack of improvement: The trajectory of a person's recovery should be assessed with objective measurements (for instance, with the ISNCSCI, the SCIM or FIM, and/or gait measures)<sup>1,2</sup> as well as by changes in the person's ability to perform functional activities in day-to-day life. Typically, people will see most improvement early in SCI rehabilitation with more gradual improvement over time.<sup>3-7</sup> Discharge from ongoing skilled PT is appropriate once rehabilitation has addressed all areas of impairment and limitation and there is not meaningful improvement in measures of recovery or functional abilities despite having trialed all appropriate PT interventions.
- Limitations in funding: Different payers have varying levels of coverage for PT. The duration of PT may be limited based on a person's available funding resources. Any limitations in funding should be explored and discussed as early in the rehabilitation stay as possible to optimize the person's abilities despite potential limitations in funding. Strategies to prioritize and optimize use of limited resources, such as early referral to

community programs and development of comprehensive home exercise programs, should be utilized as well.

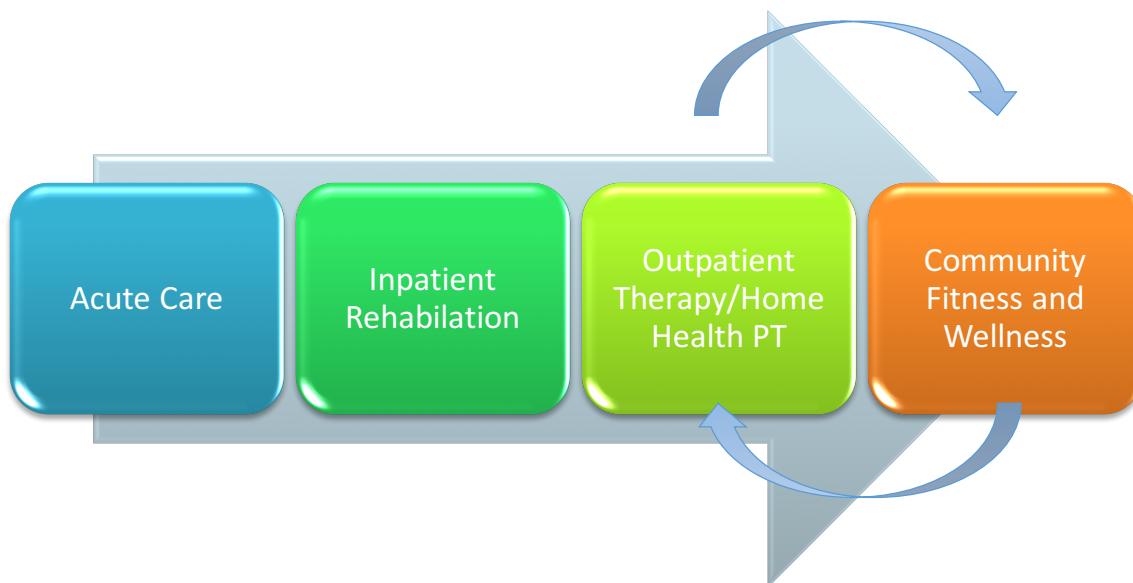
- Personal circumstances or priorities: People with SCI may have personal circumstances, such as medical, family, or transportation issues, that may lead them to discharge from PT prior to achieving optimal recovery from the SCI. In addition, people with SCI may decide to discontinue PT services due to personal preferences or priorities.

**Objective 2:** Outline recommendations for a long-term relationship with rehabilitation professionals, including reassessments and reasons to re-initiate care.

### Rehabilitation After the Initial Episode of PT Care Is Completed

It is appropriate for people with SCI to maintain long-term, intermittent relationships and communication with rehabilitation professionals (including physical therapists) even after the initial episode of rehabilitation has been completed. These intermittent relationships and communications may occur in multiple formats, including: 1) additional bouts of care to address specific problems that arise or to upgrade the person's functional activities or exercise programs based on changes in the person's abilities, 2) reassessments, and/or 3) consultation for a second opinion. (See Figure 1) Insurance coverage for these types of visits may vary and should be checked on an individual basis. People with SCI and their rehabilitation team should discuss a plan for future interactions and follow-ups prior to discharge from the initial episode of care, including potential indications for additional bouts of care or reassessments in the future. With open discussion of this nature, people with SCI can have a better understanding of when they should consider re-initiating contact with and care from their rehabilitation team in the future.

**Figure 1: Continuum of Rehabilitation after SCI**



People with SCI will typically progress through the levels of rehabilitation shown in a linear fashion initially, and return to outpatient therapy intermittently once the first bout of rehabilitation is completed.

At times, an improvement or a decline in function or ability may make it necessary for someone with a SCI to undergo an additional episode of skilled PT. For instance, people with SCI have a high incidence of shoulder pain<sup>8</sup> due to heavy shoulder use, and physical therapy may be appropriate to address this shoulder pain.<sup>9</sup> Another example is if a person with SCI has a decline in function; for instance, someone who has more difficulty with transfers after a period of time not performing lateral transfers due to a pressure sore. In general, the need for a return to PT should be considered whenever someone with a SCI experiences a significant, measurable improvement or decline in motor function or functional mobility.

It may also be appropriate for people with SCI to follow-up with rehabilitation professionals for reassessment related to their SCI. These reassessments can occur from quarterly to annually. A reassessment with a PT should be individualized to each person's needs and may include:

- Reassessment to determine progression or decline
- Reassessment to determine need for further PT care
- Modification to functional mobility strategies
- Equipment assessment and modification
- Review/modification to exercise programs.

Some people with SCI may elect to pursue a consultation for a second opinion about their rehabilitation plan of care at a facility that specializes in SCI Rehabilitation. Such a consultation typically consists of a single visit with one or more rehabilitation team members, including a physical therapist, occupational therapist, and/or a physiatrist (a physician who specializes in physical medicine and rehabilitation). Such visits are typically most successful when the person with SCI is prepared with specific questions and concerns. Areas that could be addressed in such a consultation include, but are not limited to:

- Appropriateness of current rehabilitation plan of care in terms of content, duration, and frequency
- Any additional interventions that may be beneficial
- Equipment recommendations
- Prognosis for further recovery
- Recommendations related to return to daily life functions such as driving, school, work, family responsibilities, and/or household management.

A plan for follow-up care of these types can be determined by people with SCI in coordination with their rehabilitation team. Ultimately, it is the responsibility of each person with SCI to determine their goals and needs for rehabilitation throughout their lifetime. It is the responsibility of the rehabilitation team to assist the person with SCI to determine and implement an appropriate plan related to those goals and needs. Therefore, people with SCI should initiate contact with their rehabilitation team any time they believe that their rehabilitation team can be of assistance. This contact may occur at pre-determined times or on an ad hoc basis.

**Objective #3:** Describe potential goals of post-rehabilitation physical activity, including fitness, wellness, continued recovery of physical function, and maintenance of physical function.

### Potential Goals of Post-Rehabilitation Physical Activity

Physical activity beyond activities of daily living is critical for people with SCI for: fitness, wellness, continued recovery of physical function, and/or maintenance of physical function. Recommendations related to specific parameters for exercise after a spinal cord injury are available elsewhere.<sup>10</sup> A physical activity regimen may occur at home or in the community, with or without assistance from other people. Physical activity regimens are often most successful when they are goal-directed.

People with SCI may choose to participate in post-rehab programs/community fitness and wellness centers for the following reasons:

- ❑ Promote functional independence through continued practice of compensatory and restorative based interventions.
- ❑ Promote recovery of function and neurologic status.
- ❑ Optimize physical and mental health and wellness throughout the lifespan
  - ❑ Maintain adequate range of motion and strength, with consideration of secondary medical conditions associated with spinal cord injury.
  - ❑ Decrease cardiovascular risk factors. Regular exercise may help to improve cholesterol levels,<sup>11-14</sup> exercise capacity,<sup>14-17</sup> and blood pressure control,<sup>18</sup> as well as prevent obesity.<sup>19,20</sup>
  - ❑ Slow the decline in bone density.<sup>21</sup> After spinal cord injury, bone density decreases rapidly, increasing the risk of fracture and osteoporosis.
  - ❑ Exercise promotes adequate insulin uptake and release to reduce the risk and consequences of diabetes mellitus.<sup>22,23</sup>
  - ❑ Prevention of secondary injury and health compromise
    - ❑ Participating in a wellness program can enable participants who are wheelchair users to be out of their wheelchairs more hours of the day. Remaining active and reducing sedentary behaviors can reduce risk of skin breakdown<sup>24,25</sup> and joint contractures or tightness.<sup>26</sup> More specific strengthening and stretching may also prevent overuse injuries such as bicep tendinopathy or other shoulder pathologies associated with full-time wheelchair use.<sup>27-29</sup>
- ❑ Develop and maintain social support through building community with peers and professionals. Regular participation in a community fitness and wellness center provides unique opportunities to learn from and share with peers with similar injuries and ability levels.
  - ❑ Peer mentorship-sharing successful tips, exercises, methods.
- ❑ Participating in ongoing wellness opportunities post rehab can improve one's quality of life and reduce the reliance or level of physical assistance needed from others.<sup>30-33</sup>
- ❑ Maintain mental health and/or reduce the risk of anxiety and depression.<sup>34</sup>

When establishing goals related to the areas above, consider making S.M.A.R.T. goals. S.M.A.R.T. goals are **S**pecific, **M**easurable, **A**chievable, **R**esponsible, and **T**ime-related. For instance:

- In six months, I will propel my wheelchair for 1 mile in 20 minutes without a rest break and with no shoulder muscle soreness.
- In one month, I will complete my 15-minute leg strengthening routine at least 3 days/week consistently.
- I will perform FES cycling 3 times per week for 8 weeks to slow muscle atrophy and improve circulation.

For more information about setting S.M.A.R.T goals, see

<https://www.cdc.gov/healthyyouth/evaluation/pdf/brief3b.pdf>

**Objective #4:** Provide recommendations for achieving goals, including providing criteria and considerations for evaluating resources and activity plans.

Recommendations For Achieving “After Initial Physical Therapy” Goals:

(including providing criteria and considerations for evaluating resources and activity plans)

Once a person with SCI has decided on their goals or areas to be addressed in post-rehabilitation care, a specific plan can be developed. This plan should be realistic, safe, and an effective use of time, effort, and resources. Ideally, this plan will be developed prior to completing traditional rehabilitation, which will allow the therapy team to help generate an effective and safe plan and will also avoid a lapse in training. In addition, a physical therapist can help with the initial implementation of this plan by assisting with the development of specific training activities and by helping the person with SCI to educate any providers about SCI and the person’s individual needs. For example, a physical therapist may train a caregiver or a personal trainer in how to set-up and/or assist the person with SCI with transfers, walking, or exercises. It is highly recommended that you, your physical therapist, and any post-rehabilitation providers (such as personal trainers) collaborate to create an individualized, optimally effective, and safe program. At a minimum, people with SCI should discuss their plans for exercise with an appropriate healthcare provider (such as a physician or physical therapist) to determine any guidelines or limits from a medical standpoint, including vital sign targets and limits, weight-bearing precautions, appropriate or inappropriate types of exercise, procedures in the event of medical emergencies such as autonomic dysreflexia.

When developing a plan for post-rehabilitation physical activity, the following steps are recommended for a person with SCI:

1. Identify your goals. Which of the above goals feel most important to you?
2. Determine a general plan to achieve those goals. For instance, if your priority goals are to a) improve your cardiovascular fitness and b) promote neurological recovery for walking, your general plan might be to practice walking and do aerobic exercise. Your physical therapist can collaborate with you to determine an appropriate plan to achieve your goals as effectively, efficiently, and safely as possible.

3. Determine what resources you need to implement that plan. Again, your physical therapist can collaborate with you to determine what resources you will need to safely and effectively implement your plan. In the example above, the resources you need to practice walking and do aerobic exercise will depend on your level of function and preferences. For instance:
  - a. Someone who is able to walk with a rolling walker independently may be able to achieve both walking training and aerobic training by walking intensively with a rolling walker or by using a treadmill if safe to do so.
  - b. Someone who needs physical assistance to practice walking, may need a person/trainer and special equipment to assist with walking training. In either scenario, this person may elect to use other aerobic training equipment (e.g., an arm bike, recumbent cross-trainer, recumbent bike) to work toward the goal of improved cardiovascular fitness.
4. Assess the resources that you have available to you, including people, facilities, and services. Consider programs such as local gyms, YMCAs, and community programs as well as support personnel at those locations. People that you need to help you may include caregivers, personal assistants, family members, or personal trainers. In some areas, specialized programs such as adaptive sports programs and fitness centers are available that have facilities, programs, and activities that are targeted to people with spinal cord injuries and other diagnoses. Your physical therapist can also be a resource in helping to identify what resources are available in your area. In the Appendices, you will also find the following resources:
  - a. Links to lists of programs and facilities (See Appendix A)
  - b. Questions to ask programs and facilities to help determine appropriateness (see Appendix B)
  - c. Links to information about developing an appropriate exercise program (see Appendix C)
5. Determine whether there is a good match between your goals, general plan, and available resources. If yes, continue to #6. If no, return to #2 and assess whether you can modify your general plan to match the resources that you have available.
6. Determine your specific plan for achieving your goals. If you find that you have a good match between your general plan and your resources, you are now ready to decide exactly what you will do.



## **Appendix A:** **Listings of Facilities and Programs:**

See if there is a facility or trainer near you:

1. National Center on Health, Physical Activity and Disability (NCHPAD) has a national directory of programs, facilities, and organizations that are available for people with health conditions and disabilities:

<http://www.nchpad.org/Directories>

2. Certified Inclusive Fitness Trainers (CIFTs) who have undergone certification through the American College of Sports Medicine (ACSM) and NCHPAD are able to provide personal training services to people with health conditions and disabilities. While this is not training exclusive to SCI, these trainers are more likely to have experience and training in exercise for people with disabilities. A directory is available here:

<https://certification.acsm.org/pro-finder>

## **Appendix B.**

### **Questions for Individuals with SCI to Ask About Post-Rehabilitation Facilities:**

#### **What are the goals for your participants? Purpose of facility?**

- Health & Wellness
- Weight training or strengthening intact muscles above level of the injury
- Recovery or strengthening below the level of the injury
- Improve cardiopulmonary function
- Improve endurance
- Improve flexibility
- Weight management
- Practice functional activities (mat/bed activities, transfers, balance, etc.)
- Multi-purpose

#### **Facility: Is this facility accessible?**

- Access to medical assistance (on site or call 911)
- Enough room between equipment to maneuver wheelchairs
- Water (hydration is important!)
- Towels
- Wheelchair accessible exercise equipment (e.g., weight training equipment with movable seats)
- Wheelchair accessible restrooms
- Wheelchair accessible locker rooms
  - Is there an available mat in the locker room for dressing, if needed?
  - Is there assistance available for dressing or undressing?
- Wheelchair accessible showers
- Grab bars in restrooms and showers
- Clean and well-maintained facilities
- Handicap parking
- Distance from parking to facility entrance
- Ramp – entry in/out of building
- Working elevators if multiple floors
- Is the facility near your home? You are more likely to go exercise if the location is convenient.
- What are the open hours? Some facilities are open 24 hours, while others have limited hours? When is the facility busiest?
- Are participants required to have medical clearance or a health history?
- Can you take a tour?

### SCI-Specific Concerns:

- Accommodate people with tetraplegia: Do you have equipment to adapt exercise equipment as needed for limitations in hand function, such as adaptive gloves or ace wraps.

### Staff Background and Training

Who is available onsite to assist an individual with SCI?

- Personal trainer with or without certification, such as:
  - Certified Inclusive Fitness Trainers (CIFT):
    - <https://certification.acsm.org/acsm-inclusive-fitness-trainer>
    - [http://certification2.acsm.org/profinder?\\_ga=2.254101768.1286397395.1495148201-581199747.1495147925](http://certification2.acsm.org/profinder?_ga=2.254101768.1286397395.1495148201-581199747.1495147925)
  - Certified Special Populations Specialist (CSPS):
    - <https://www.nasca.com/Certification/CSPS/>
- Athletic Trainer (ATC)
- Exercise Physiologist
- Physical Therapist (PT)
- Occupational Therapist (OT)
- Pre-PT/OT or PT/OT students
- Nutritionist or dietitian
- Pilates or other specialized training
- Other \_\_\_\_\_

What training does the staff have?

- Does the center have you fill out a health questionnaire to determine your risk factors and the most suitable activities to meet your needs and interests?
- How does the facility handle emergency situations? Has staff been trained in cardiopulmonary resuscitation (CPR) and first aid?
- If the staff are not licensed in the area of working with people with SCI (e.g., are not PTs or OTs), are they trained to:
- Work with people with disabilities (such as with Certified Inclusive Fitness Trainers)
- Work with individuals with SCI
- Pass competencies to be able to work with individuals with SCI or other neurologic dysfunction
- Monitor blood pressure and/or heart rate
- Monitor pulse oximetry
- Recognize and address orthostatic hypotension and autonomic dysreflexia
- Implement an exercise prescription
- Appropriately progress exercises or decrease frequency/intensity when needed
- Perform skin checks after exercise, when appropriate

### Extent of assistance

- One-time tour of facility
- One-time orientation to equipment
- One-on-one personal trainer
- One trainer for \_\_\_ (number of people)
- Group workouts or classes? (what type?)
- Monitor every session, weekly, monthly
- Assist with set-up on each piece of equipment
- Assist with transfers on/off equipment
- If no assistance...
  - Can a family member, or personal assistant attend to help me?
  - Can the above individual also exercise? If so, what is the cost?

**List the equipment that is available at your facility.** (*While having all of the “latest and greatest” equipment available may not be needed to obtain your personal goals, you will want to find out if equipment that you need is available.*)

- Automated External Defibrillator (AED)
- Weight-training equipment (chest press, biceps curls, triceps, etc.)
  - With or without ability to move seat out of the way for wheelchair access
- Free weights
- Elastic bands or tubing
- Arm ergometers /arm bikes
- Recumbent bikes
- Inclined plane bodyweight devices
- Standing frames
- Treadmills
  - With or without overhead harness system or other support system for safety and/or body weight support during training
- Overhead harness suspension systems
- Sturdy rolling walkers (Second Step, Rifton Pacer (adult, and tall/heavy duty), platform walkers, etc.)
- Parallel bars
- Pool
  - Lift for entry/exit
  - Ramp for entry/exit
- Underwater treadmill
- Equipment for balance training (foam, Swiss balls, bolsters, etc.)
- Pedometers and/or accelerometers
- Slings with overhead suspension
- Functional electric stimulation (FES) cycling
- Electric stimulation for individual muscles
- Whole body vibration
- Robotic or powered exoskeletons

## Finances

- Approximate cost \_\_\_\_\_ (per session, per week, per month, annual)
- Private pay or accept any insurances
- Scholarships
- Reduced rates for fitness centers that have equipment with limited access for disabled individuals
- Can I obtain a temporary pass for a small daily fee or at no cost to try out the facility?

## Communication with Healthcare Providers

Open communication amongst your team is critical for developing, implementing and progressing your training program in a way that is safe and effective. Questions to ask a post-rehabilitation program or provider include:

- Is the program or provider willing to communicate with your rehabilitation team or PT?
- How will they communicate with your rehabilitation team or PT?
  - One or more meetings face-to-face with therapist for communication and training
  - Email
  - Phone
  - Other: \_\_\_\_\_
- When will they communicate with your rehabilitation team or PT?
  - To alert therapists of potential or actual medical status changes (e.g., fractures, major illness) and seek input for appropriate physical activity modifications
  - To seek assistance of therapist if need to update program
  - To alert therapist to when a patient increases or decrease function to the point of need of re-entry into therapy
  - At regularly scheduled intervals
  - Other: \_\_\_\_\_

## Other Resources to Consider:

From NCHPAD:

Choosing a Fitness Center:

<http://www.nchpad.org/308/1909/Choosing~a~Fitness~Center>

## **Appendix C.** **Information about Developing an Appropriate Exercise Program:**

From NCHPAD:

- Exercise Guidelines for People with Disabilities  
<http://www.nchpad.org/14/73/Exercise~Guidelines~for~People~with~Disabilities>
- Discover Accessible Fitness: booklet that serves as a guide for individuals using wheelchairs for using fitness equipment.  
<http://www.nchpad.org/discoverfitness/index.html>
- Life on Wheels: “a guide for living a healthy, active life with a spinal cord injury” <http://www.nchpad.org/1200/5830/Life~on~Wheels>

From the Model Systems Knowledge Translation Center  
Fact sheet about SCI and Exercise:

<http://www.msktc.org/sci/factsheets/exercise>

Fact sheet about SCI and Adaptive Sports and Recreation:

[http://www.msktc.org/sci/factsheets/adaptive\\_sports](http://www.msktc.org/sci/factsheets/adaptive_sports)

From the U.S. Department of Health and Human Services:

Physical Activity Guidelines for Americans:

<https://health.gov/paguidelines/pdf/paguide.pdf>

From Exercise and Sports Science Australia (ESSA):

Position Statement on Exercise and Spinal Cord Injury:<sup>10</sup>

<https://www.essa.org.au/wp-content/uploads/2015/10/ESSA-Position-Statement-on-Exercise-and-Spinal-Cord-Injury.pdf>

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