Webinar title: What rehab is appropriate for SCI and when?

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http://restorefunction.org/

The Institute for Functional Restoration has the mission to restore function to people with neurologic disorders by creating a sustainable commercial model for neuromodulation technologies. Founded in 2013, the IFR is a non-profit based at Case Western Reserve University (Cleveland, OH).

www.NeurotechNetwork.org

Helping people regain life thru neurotechnology

Focusing on education of and advocacy to access neurotechnology devices, therapies and treatments for people living with impairments, their care-givers and medical professionals.

https://unitedspinal.org/

United Spinal Association is dedicated to enhancing the quality of life of people living with spinal cord injuries and disorders (SCI/D).
Want to Ask a Question?
Disclaimer

The information presented in this webinar is not meant to replace the advice from a medical professional. You should consult a healthcare professional familiar with your specific case, concerns and condition.

Neurotech Network and its representatives do not endorse, rate, sell, distribute, prescribe, administer or recommend any products, procedures or services. We highly suggest for you to take information to a trained medical professional familiar with your case to discuss options that are best for you.
Webinar Agenda

▪ What are the components of rehab?
▪ How to advocate for yourself/your family?
▪ Preparing for the kick-out
▪ Rehab doesn’t end at discharge
▪ Reasons for denials that are not valid
▪ Tips & Tricks for getting what you need
▪ Resources to learn more
Question: Where did you go for your acute (initial) rehab post injury?

Answer choices (pick one):
• Model SCI system
• General rehab hospital (like Healthsouth)
• Nursing home or skilled nursing facility
• Didn’t do rehab
WHAT ARE THE COMPONENTS OF REHAB?
Terms to know

- Acute Rehabilitation
- Subacute Rehabilitation
- Home Care
- Outpatient Rehabilitation
- Nursing Home or Skilled Nursing Facility
Primary Goals

■ Enable you to perform activities of daily living as independently as possible
  - Ex. Physical therapy to improve strength and balance
  - Ex. Assistive equipment demos and trials
  - Ex. Establish a bowel and bladder management program
  - Ex. Wheelchair use skills

■ Teach you how to cope with barriers in the physical environment
  - Ex. Navigate public transportation
  - Ex. Modify your house
Important Points About Securing Appropriate Rehab

- There are many different types of rehabilitation programs offered in different rehabilitation settings.

- The type of program you choose should depend on both your rehabilitation needs \textit{and} your health insurance coverage (not just geographic proximity)

- You may progress through more than one type of rehabilitation program during your recovery.
  - Advocate aggressively for appropriate SCI rehabilitation (don’t take no as a final answer)
  - Enlist support from legislative offices and SCI advocates such as United Spinal Association
Potential members of your rehab team

- Physical therapist
- Occupational therapist
- Physiatrist
- Respiratory therapist
- Rehabilitation nurse
- Clinical psychologist
- Dietician
- Alternative therapists
- Urologist
- Chaplain
- Orthotist/Prosthetist
- Rehab technician/DME rep
- Social worker
- Rehabilitation care manager
- Speech-language therapist
- Recreation therapist
- Vocational rehab specialist
- Peer mentor
- Sexuality educator
### Steps for Choosing a High-Quality Rehabilitation Program

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
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<tr>
<td><strong>STEP 1</strong></td>
<td>Your Needs&lt;br&gt;What are your current rehabilitation needs?&lt;br&gt;• How healthy are you?&lt;br&gt;• How intense do you need rehabilitation to be?&lt;br&gt;• How severe is your condition?</td>
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<td><strong>STEP 2</strong></td>
<td>Insurance&lt;br&gt;What kind of health insurance do you have? Does your health insurance plan limit the amount and type of therapy or other services you can have?</td>
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<td><strong>STEP 3</strong></td>
<td>Setting&lt;br&gt;What rehabilitation setting will best suit your needs?&lt;br&gt;• Acute rehabilitation facility&lt;br&gt;• Subacute rehabilitation facility&lt;br&gt;• Day rehabilitation&lt;br&gt;• Home&lt;br&gt;• Outpatient&lt;br&gt;• Nursing Home&lt;br&gt;• Skilled nursing facility</td>
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<td><strong>STEP 4</strong></td>
<td>Quality Outcomes&lt;br&gt;Do the outcomes of programs you are considering reflect high-quality care?&lt;br&gt;• FIM scores&lt;br&gt;• Where past patients were discharged to (home, nursing home, or assisted living)&lt;br&gt;• Patient and family satisfaction&lt;br&gt;• JCAHO accreditation&lt;br&gt;• CARF accreditation</td>
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New Beginning Back Pack Program
Question: What are the elements that you received in rehab?

Check all that apply
• Physical therapy
• Occupational therapy
• Recreational therapy
• Nutrition resources
• Psychology/clinical counseling
• Vocational rehab
• Alternative therapy (i.e. massage, acupuncture)
• Peer support
• Speech-language therapy
• Sexuality education
• Bowel and bladder management program
How to advocate for yourself and/or your family?

- Know and understand your medical condition
- Know your rights – you can appeal denials of reimbursement for services
- Self-Determination – you can control your own life
- Assertive vs Aggressive

Sources:
- https://www.christopherreeve.org/blog/daily-dose/advocating-for-your-medical-needs
- https://facingdisability.com/resources/advocacy
Preparing for the kick-out

- It’s going to stir up emotions
- Prepare yourself to develop a new routine, things will be different from the hospital
- Be adaptable, it’s OK to try new things, new techniques
- Take it one day at a time
- Talk with other people with SCI/D, you’re not alone
- Ask for help if you need it
- Stay active, including through adaptive sports groups
Preparing for the kick-out

https://facingdisability.com/spinal-cord-injury-videos/going-home
REHAB ISN’T OVER AFTER DISCHARGE
Inpatient & Outpatient stays getting shorter...

The Human Body only heals so fast...
Rehabilitation vs Fitness

- **Definition**: Rehabilitation is a program of interventions designed to facilitate the process of maximizing an individual’s ability to live, work, and learn to their highest potential.

- **Focus is**
  - Restoration/recovery
  - Compensation
  - Limitations/adjustment
  - Independence

- **Definition**: Fitness is physical activity that is planned, structured, and repetitive for the purpose of conditioning any part of the body.

- **Focus is**
  - Improve health condition,
  - Maintain or improve fitness, and
  - Prevention/performance

*Wellness: An active process of becoming aware of and making choices toward a more successful existence*
Types of Programs

- Clinical Programs
- Stand Alone Programs
- Public Access & Private Gym Programs
Clinical Programs

- **Locations:**
  - Rehabilitation Facility

- **Gives You Access to:**
  - Trained Rehabilitation Therapists

- **Guidance**
  - Rehabilitation Equipment

- **Program Structure:**
  - Goal-Oriented

- **Financial Commitment:**
  - Typically not covered under insurance. Payment plans available
Clinical Program Access to Services
Examples of Programs

■ Beyond Therapy - Atlanta, GA: http://www.beyond-therapy.org/

■ Brooks Rehab Neuro-Recovery Center - Jacksonville, FL: https://brooksrehab.org/services/neuro-recovery-center/


■ PEAK Center – Englewood, CO: https://craighospital.org/programs/the-peak-center

■ Precision Rehabilitation – Long Beach, CA: http://precisionrehabilitation.com/

■ Courage Kenny Rehabilitation Institute – Minneapolis, MN: http://www.couragecenter.org/
Stand Alone Programs

■ Locations:
  - Specialized Facility

■ Gives You Access to:
  - Personal Trainers/Exercise Physiologists
  - Specialized Equipment

■ Program Structure:
  - Goal-Oriented & Self-Motivated

■ Financial Commitment:
  - Membership fees or up-front payment
Stand Alone Program Access to Services
■ Beyond the Chair – San Antonio, TX: http://www.beyondthechair.org
■ Buckeye Wellness Center – Valley View, OH: http://www.buckeyewellnesscenter.com
■ CORE FLORIDA – Longwood, FL: http://www.coreflorida.com
■ Journey Forward – Canton, MA: http://www.journey-forward.org/
■ Mobility Fitness Institute – Tucson, AZ: www.mobilityfitnessinstitute.com
■ NeuAbility – Denver, CO: https://neuability.org
■ NeuroFit360- Pembroke Pines, FL: http://neurofit360.com/
■ NextSteps Chicago-Willow Springs, IL: http://www.nextstepschicago.org
■ Next Step Fitness – Several Locations: http://www.nextstepfitness.org
■ Project Walk – Several Locations: http://projectwalknj.com
■ Push to Walk- Riverdale, NJ: http://www.push2walknj.org
■ Pushing Boundaries- Redmond, WA: http://pushing-boundaries.org
■ Race to Walk- Mooresville, NC: http://racetowalk.org
■ REACT – Dallas, TX: http://www.neuroreaction.org
■ SCI Total Fitness – online: http://www.scitotalfitness.com
■ STAR Rehab – Grand Blanc, MI: http://www nghịta into rehab.com
■ Stay In Step – Tampa, FL: https://stayinstep.org
■ The Recovery Project - Two Locations in MI: http://www.therecoveryproject.net/
■ TheraFit Gym, New Lutherville, MD: http://www.therafitgym.com
■ Walk The Line – Southfield, MI: http://walkthelinetoscirecovery.com/
Public Access/Private Gyms

■ Locations:
  - Gyms, Wellness Centers, Parks, Swimming Pools

■ Gives You Access to:
  - Limited or No Supervision (self-directed)
  - Fitness Equipment

■ Program Structure:
  - Limited or None

■ Financial Commitment:
  - Low cost fees or Free
Public Access and Private Gyms
Questions to Ask

- What should I expect from a typical program?
- Is it a rehabilitation program or a fitness program?
- Will there be a trained professional monitoring my program? If so, what are his/her qualifications and what are his/her experiences working with people with SCI?
- What type of equipment will I have access to?
- What is the length of the program?
- How much will this cost me?
Where to Find These?

- National Center on Health Physical Activity & Disability: [https://www.nchpad.org/Directories](https://www.nchpad.org/Directories)
- Wellness Center/YMCA
- Therapeutic Recreation
- Parks & Recreation
- Shepherd Center App – SCI-Ex
HOW UNITED SPINAL CAN HELP YOU/UPDATE ON UNITED SPINAL REHAB ADVOCACY
Maximizing Rehabilitation Outcomes

- United Spinal Association has the policy and advocacy staff, resource center and chapters/support groups structure in place to ensure people who leave institutional settings have an improved quality of life back in their communities.

- United Spinal Association is leading an education and awareness campaign, entitled Maximizing Rehabilitation Outcomes, to improve rehabilitation outcomes for people living with spinal cord injuries and disorders (SCI/D). United Spinal is working with leading rehabilitation facilities and hospitals across the country including National Institute on Disability, Independent Living and Rehabilitation Research’s Model Systems Knowledge Translations Centers.

- The project is four-fold: Education, Expertise, Research, Community Integration.
  - Writing clear guidelines on policy and available benefits – Medicare, Medicaid etc.
  - Preparing rehab education toolkits/guidelines needed for Consumers, Case Managers, Directors of Nursing, Physicians, Clinicians
  - Defining criteria for SCI Centers of Excellence to define what SCI, other specialty rehab is, what it should be
  - Researching/Collecting Rehab Outcomes and Health Economics data
Roadblocks to Rehabilitation

- Lack of rehab reimbursement / Medicaid or Medicare or other insurance

- Eligibility in question: collateral injuries, broken bones, vent weaning or TBI resulting in intervening care in a SNF or long-term facility in lieu of SCI rehab - delaying factor in getting the right rehab therapy

- Pressure ulcer preventing or delaying SCI rehabilitation

- Not initially able to participate in a minimum of 3 hours of therapy

- Transitioning to different levels of rehabilitation (difficult to go back to in-patient level). Continually receive stories about being discharged to home from SNF or LTAC after wound healing without receiving SCI rehab
Reasons for Denial = Not valid!

Chris is a 43 year-old male, on ventilator, in ICU for 10 months and no rehab prospects due to no appropriate SCI rehab in Maine…

Many hospitals, in Maine and throughout New England: “We are not able to take patients on ventilators” and “We don’t accept Maine Care”.

Conclusion & next steps:

- Enlisted legislative offices, ME Governor's Office and ME Dept of Protection & Advocacy support to demand care that had been denied in ICU

- Orchestrated single-patient Medicaid contract for out-of-state SCI rehab.
Reasons for Denial = Not Valid!

Sean is a male in his 20s with a cervical injury, from Illinois. He was initially denied rehab reimbursement as his insurer falsely claimed: “He is unlikely to improve so we’re not paying for SCI rehab.”

His parents successfully fought for therapy reimbursement with intervention by United Spinal Information Specialists.

What is the Improvement Standard anyway?
Tips & Tricks: For getting the rehab you need

- Obtain a copy of the full (not abbreviated or summarized) explanation of insurance benefits. Read your policy carefully and thoroughly.

- Determine the rehabilitation benefits: inquire about the number of allowed days of coverage for inpatient acute and sub-acute rehabilitation, outpatient and home health rehabilitation; is there an annual maximum number of days; is there a lifetime maximum number of days (these need to be differentiated according to the above categories of service).

- Inquire about rehabilitation in a SCI/D-accredited rehabilitation facility; does this include both an in-state or out-of-state facility?
Tips & Tricks: For getting the rehab you need

- Submit an appeal if you're denied services!
- Realize that insurers will typically only pay for one episode of inpatient rehabilitation so it's important to attend a facility that can provide high quality SCI specific services to maximize your stay.
- Many acute care facilities will not accept patients that have first attended a long term care facility. Before transferring to any facility, be certain that the long term plan is in place and agreed upon by all parties.
- If you are denied out of state services, contact your legislators office(s) and seek support.
Resources on Our Website

https://www.unitedspinal.org/ask-us/

- Seek guidance from our Information Specialists askus@unitedspinal.org
- In the search field, type in ‘Rehab guidelines’ to find the link to United Spinal Association Guidelines for Selecting a Rehabilitation Facility: https://askus-resource-center.unitedspinal.org/index.php?pg=kb.page&id=1717
- In the search field, type in ‘Rehabilitation, New Injury & Recovery Programs’ to find the link to United Spinal Association’s Rehabilitation Knowledge Book: https://askus-resource-center.unitedspinal.org/index.php?pg=kb.book&id=11
- Find your Members of Congress: https://unitedspinal.org/advocacy-action/resources/
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