

New England Spinal Cord Injury Toolkit Standards

1. Patient/Family/Caregiver Education

1.1.STANDARD: Individuals, their family members and caregivers taking part in inpatient rehabilitation for spinal cord injury (SCI) will receive appropriate education to maximize functional independence and minimize secondary health conditions. Education will encompass all areas of SCI rehabilitation and will be included in all standards listed.

Minimum Requirements:

- Core educational areas: autonomic dysreflexia, bowel/bladder, SCI anatomy & physiology, skin care, respiratory care, sexuality, medical complications, psychosocial, home modifications, equipment needs, rehabilitation team roles, community reentry (including accessibility), medications, discharge planning, nutrition & lifestyle (exercise), spasticity management and contracture prevention, pain, driving, recreation, community and educational resources, assistive technology, vocational rehabilitation, mobility, self-care, self-advocacy, circulatory (DVT, etc.), heterotopic ossification (HO), health care maintenance (preventative care, follow up with outpatient appointments, etc.)
- Patient and/or caregiver competency established via verbal recall and/or demonstration

Recommended Resources:

- Yes, You Can! A Guide to Self-Care for Persons with Spinal Cord Injury published by the Paralyzed Veterans Association (PVA). The book can be ordered online at <http://tinyurl.com/ksa3z5e>
- PVA Consumer Guidelines* are available on multiple topics and are free downloads at <http://tinyurl.com/mfgnnj2>
- PVA Clinical Practice Guidelines* are available on multiple topics and are free downloads at <http://tinyurl.com/oxozdtm>
- Paralysis Resource Center, Christopher and Dana Reeve Foundation <http://www.christopherreeve.org> and toll-free 1-800-225-0292. Information is offered in multiple languages
- Connecticut Resource Directory & patient packet by CT Chapter of National Spinal Cord Injury Association at www.sciact.org
- Peer mentor programming offered through National Spinal Cord Injury Association, call 203-284-2910 in Connecticut or 781-933-8666 in Massachusetts
- Stepping Forward Staying Informed Consumer Education Program and Knowledge in Motion webcasts (available on NERSCIC website) <http://tinyurl.com/NERSCICvids>
- SCI Guide www.sciguide.org – including Top Sites for Newly Injured and Best of the Best sites
- Inpatient and outpatient support groups including family/caregiver support groups
- Patient Education Manual(site-specific – to obtain a copy from Gaylord Hospital, contact Diana Pernigotti at DPernigotti@gaylord.org and contact Joanne Morello at Jmorello@northeastrehab.com for a copy from Northeast Rehabilitation)
- National Institute of Health Physical Exam Recommendations <http://tinyurl.com/335k9n>
- Model Systems Knowledge Translation Center SCI Factsheets (available online from NERSCIC website and the MSKTC website as a complete booklet <http://tinyurl.com/mrxqju6> or separate topics at www.MSKTC.org)

THIS TOOL DOES NOT PROVIDE MEDICAL ADVICE. It is intended for informational purposes only. It is not a substitute for professional medical advice, diagnosis, or treatment. Never ignore professional medical advice in seeking treatment because of something you have read in the Toolkit. If you think you may have a medical emergency, immediately dial 911.