

# New England SCI Toolkit

## 1. Patient/Family/Caregiver Education

**1.1. STANDARD:** Individuals, their family members and caregivers taking part in inpatient rehabilitation after 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/mfqnnj2>
- 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 Spinal Cord Injury Association of Connecticut, a Chapter of United Spinal at [www.sciact.org](http://www.sciact.org)
- Peer mentor programming offered through United Spinal local chapters, 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](http://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 – contact Diana at [DPernigotti@gaylord.org](mailto:DPernigotti@gaylord.org) for a Gaylord copy and Joanne Morello at [jmorello@northeastrehab.com](mailto: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 as a complete booklet <http://tinyurl.com/pth9kky> or separate topics at [www.MSKTC.org](http://www.MSKTC.org) )
- If injury is T8 or above, poster on AD education from the PVA and Reeve Foundation partnership <http://tinyurl.com/j7sw6kj>

\* To access, Adobe must be installed on your device

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## 2. Autonomic Dysreflexia

**2.1 STANDARD:** All care providers will identify episodes of autonomic dysreflexia (AD) and provide appropriate intervention. Intervention will include identifying and removing noxious stimuli, providing medical care as indicated, and monitoring patient's status.

### Minimum Requirements:

- Facility has an AD policy and procedure or guideline in place
- All care providers are trained to identify signs and symptoms of AD
- All care providers are trained to follow facility policy and procedure on AD
- All care providers will understand the causes of AD for prevention
- Staff competency conducted for all care providers

### Recommended Resources:

- Poster on AD education from Paralyzed Veterans Association (PVA) and Reeve Foundation partnership <http://tinyurl.com/j7sw6kj>
- Yes, You Can! A Guide to Self-Care for Persons with Spinal Cord Injury published by the PVA. The book can be ordered online at <http://tinyurl.com/ksa3z5e>
- Patient Education Manual (site-specific – to obtain a copy from Gaylord Hospital, contact Diana Pernigotti at [DPernigotti@gaylord.org](mailto:DPernigotti@gaylord.org) and contact Joanne Morello at [Jmorello@northeastrehab.com](mailto:Jmorello@northeastrehab.com) for a copy from Northeast Rehabilitation)
- Specialized courses offered through NESCI facilities on SCI – available to outside caregivers with CEUs. The SCI Specialist course is periodically offered at Gaylord Hospital. Contact Janine Clarkson at [Jclarkson@gaylord.org](mailto:Jclarkson@gaylord.org) for more information.
- Christopher and Dana Reeve Foundation Paralysis Resource Guide (available in many languages for free) <http://tinyurl.com/qzll2gq>
- PVA Clinical Practice Guideline Acute Management of Autonomic Dysreflexia\* <http://tinyurl.com/p36sff6>
- General SCI Competency at Northeast Rehabilitation Contact Joanne Morello at [Jmorello@northeastrehab.com](mailto:Jmorello@northeastrehab.com) for more information
- MSKTC SCI Factsheet Autonomic Dysreflexia <http://tinyurl.com/hc558eo>

**2.2 STANDARD:** Refer to STANDARD 1: Patient/Family/Caregiver Teaching

### Recommended Resources:

- Credit card-style AD education cards for patients from the PVA available to download at <http://tinyurl.com/qh6gmoj>
- Education cards in Yes, You Can! book The book can be ordered online at <http://tinyurl.com/ksa3z5e>
- PVA Consumer Guideline Autonomic Dysreflexia: What You Should Know\* <http://tinyurl.com/kfrobkd>
- MSKTC SCI Factsheet Autonomic Dysreflexia <http://tinyurl.com/hc558eo>

## 3. Skin Care

**3.1 STANDARD:** Patients taking part in inpatient rehabilitation will be free from new pressure ulcers throughout their stay. All disciplines involved in patient care will take part in the education and prevention of pressure ulcers.

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### Minimum Requirements:

- Facility has a skin care policy and procedure or guideline in place
- Staff competency conducted for appropriate providers for prevention and standardized assessment of risk
- All care providers are trained to follow facility policy and procedure/guidelines on skin care
- Site-specific skin management program encompassing assessment, prevention and treatment
- Access to certified wound care specialist (WOCN) (for most up-to-date evidence-based care)
- Process in place for measuring outcomes

### Recommended Resources:

- PVA Clinical Practice Guide Pressure Ulcer Prevention and Treatment Following Spinal Cord Injury\* <http://tinyurl.com/m6xubgd>
- PVA Consumer Guide Pressure Ulcers: What you Should Know\* <http://tinyurl.com/lqff2kv>
- MSKTC SCI Factsheet Skin Care and Pressure Sores in Spinal Cord Injury 6 Part Series <http://tinyurl.com/k9orwb7>
- Clinical Practice Guidelines for Prevention and Management of Pressure Ulcers available to purchase at <http://tinyurl.com/kaadnqs> from the Wound Ostomy and Continence Nursing Society at <http://www.wocn.org/>

**3.2 STANDARD:** Patients with existing pressure ulcers will receive appropriate treatment to decrease severity of existing ulcers and prevent the development of new ulcers.

### Minimum Requirements:

- Facility follows professional standards of care for treatment of existing ulcers, such as Clinical Practice Guidelines for Prevention and Management of Pressure Ulcers per WOCN Society
- Staff competency conducted for appropriate providers for standardized assessment regarding identification and treatment of pressure ulcers

**3.3 STANDARD:** Refer to STANDARD 1: Patient/Family/Caregiver Education

### Recommended Resources for 3.2 and 3.3 (in addition to Standard 1 resources):

- Online lecture from Lauren Harney, RN, BSN, CWON “The Skin You’re In: An Overview of Maintaining Skin Integrity for Individuals with Spinal Cord Injury” <http://tinyurl.com/ku45awt>
- If injury is T8 or above, poster on AD education from the PVA and Reeve Foundation partnership <http://tinyurl.com/j7sw6kj>

## 4. Bladder Management

**4.1 STANDARD:** Upon admission, each patient will have an assessment of bladder function. A bladder management program will be initiated and followed for all patients taking part in rehabilitation in order to resume regular and complete emptying of the bladder for urinary system health.

### Minimum Requirements:

- Facility has a bladder management policy and procedure/guidelines in place
- All appropriate care providers are trained to follow facility policy and procedure/guidelines on bladder management

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- All pertinent care providers are trained in appropriate technique and use of adaptive equipment for bladder emptying
- Site-specific bladder management program in place encompassing assessment, intervention and ongoing management
- Staff competency conducted for all direct care providers
- Access to urologic assessment and monitoring as needed

**Recommended Resources:**

- PVA Consumer Guide Bladder Management Following Spinal Cord Injury: What You Should Know\* available for free download <http://tinyurl.com/n67wb8b>
- PVA Clinical Practice Guideline Bladder Management for Adults with Spinal Cord Injury\* available for free download <http://tinyurl.com/mqljq3>
- University of Alabama SCI InfoSheets Bladder Care and Management <http://tinyurl.com/jl34flg>

**4.2 STANDARD:** Staff members will be able to identify urinary complications and provide appropriate intervention.

**Minimum Requirements:**

- All appropriate care providers are trained to identify signs and symptoms of urinary complications
- Access to ongoing urologic assessment and monitoring to diagnose and develop treatment plans for urinary complications
- Facility has a process in place for measuring and managing outcomes

**Recommended Resources**

- Institute for Healthcare Improvement: How-to Guide: Prevent Catheter-Associated Urinary Tract Infection\* available for free download at <http://tinyurl.com/lwkunag>
- PVA Clinical Practice Guideline Bladder Management for Adults with Spinal Cord Injury\* available for free download <http://tinyurl.com/mqljq3>
- University of Alabama SCI InfoSheets: Bladder Care and Management <http://tinyurl.com/jl34flg>
- MSKTC Factsheet Surgical Alternatives for Bladder Management Following SCI available at <http://tinyurl.com/pqzjoqr>

**4.3 STANDARD:** Individuals, their family members and caregivers taking part in inpatient rehabilitation for SCI will receive appropriate education in bladder management techniques to maximize functional independence and minimize secondary health conditions.

**Minimum Requirements:**

- Family/caregiver/patient training on bladder management techniques and use of adaptive equipment during inpatient rehabilitation
- Family/caregiver/patient training on identification of signs and/or symptoms of urinary complications and possible interventions, including seeking medical attention
- Family/caregiver/patient competency established via verbal recall and/or demonstration

**Recommended Resources**

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- Institute for Healthcare Improvement: How-to Guide: Prevent Catheter-Associated Urinary Tract Infection\* <http://tinyurl.com/lwkunag>
- PVA Consumer Guide Bladder Management Following Spinal Cord Injury: What You Should Know\* <http://tinyurl.com/n67wb8b>
- PVA Clinical Practice Guideline Bladder Management for Adults with Spinal Cord Injury\* <http://tinyurl.com/mqldj3>
- University of Alabama SCI InfoSheets: Bladder Care and Management <http://tinyurl.com/jl34flg>
- MSKTC Factsheet Bladder Management Options Following SCI available at <http://tinyurl.com/pgdr5fw>
- If injury is T8 or above, poster on AD education from the PVA and Reeve Foundation partnership <http://tinyurl.com/j7sw6kj>

## 5. Bowel Management

**5.1 STANDARD:** Each patient will have an assessment of bowel function. A bowel program will be initiated and followed for all patients in order to strive for regular and complete emptying of bowels.

### Minimum Requirements:

- Facility has bowel management policy and procedures/guidelines in place
- All appropriate care providers trained to follow policy and procedure/guidelines on bowel management
- All pertinent care providers are trained in appropriate technique and use of adaptive equipment for bowel emptying
- Site-specific bowel management program in place encompassing assessment, intervention, and ongoing management
- Access to bowel management assessment and monitoring as needed

### Recommended Resources:

- PVA Consumer Guide Neurogenic Bowel: What You Should Know\* available for free download <http://tinyurl.com/n3qfaxl>
- PVA Clinical Practice Guideline Neurogenic Bowel Management in Adults with Spinal Cord Injury\* available for free download <http://tinyurl.com/kzkbfwe>
- University of Alabama InfoSheets Bowel Management following Spinal Cord Injury <http://tinyurl.com/nbvzfxs>
- Spinal Cord Injury Rehabilitation Evidence (SCIRE) Project factsheet Bowel Dysfunction and Management <http://tinyurl.com/nypud95> Canadian sourced
- Kessler Rehab video (29 minutes) Bowel Management (Managing Medical Complications After Spinal Cord Injury – Part 1 of 3) <http://tinyurl.com/gmxxa5e>

**5.2 STANDARD:** Staff members will be able to identify complications of ineffective bowel management and provide appropriate intervention.

### Minimum Requirements:

- All appropriate care providers trained to identify signs and symptoms of bowel dysfunction
- Ongoing bowel monitoring and assessment to diagnose and develop treatment plans for bowel complications

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- Process in place for measuring outcomes

**Recommended Resources:**

- One page information sheet plus extra notes for each individual patient being discharged from acute rehabilitation with specific comments regarding their bowel program
- PVA Consumer Guide Neurogenic Bowel: What You Should Know\* available for free download <http://tinyurl.com/n3qfaxl>
- PVA Clinical Practice Guideline Neurogenic Bowel Management in Adults with Spinal Cord Injury\* available for free download <http://tinyurl.com/kzkbwfe>
- University of Alabama InfoSheets: Bowel Management following Spinal Cord Injury <http://tinyurl.com/nbvzfxs>
- Spinal Cord Injury Rehabilitation Evidence (SCIRE) Project factsheet <http://tinyurl.com/nypud95> Canadian sourced
- If injury is T8 or above, poster on AD education from the PVA and Reeve Foundation partnership <http://tinyurl.com/j7sw6kj>

**5.3 STANDARD:** Individuals, family members and caregivers taking part in inpatient rehabilitation after spinal cord injury will receive appropriate education in bowel management techniques to maximize functional independence and minimize secondary health conditions.

**Minimum Requirements:**

- Patient and/or caregiver competency established via verbal recall and/or demonstration

**Recommended Resources:**

- PVA Clinical Practice Guideline Neurogenic Bowel Management in Adults with Spinal Cord Injury\* available for free download <http://tinyurl.com/kzkbwfe> specifically pp. 29-31

**6. Sexual Health and Fertility**

**6.1 STANDARD:** Individuals and their appropriate family member(s) or partner(s) will be offered age specific education and counseling regarding medical and psychosocial issues related to sexual health and function after an SCI.

**Minimum Requirements:**

- Facility has a process to assess/educate re: sexual health in SCI- “Who says what when?”
- Maintain an open discussion and provide access to education about sex in both formal and informal settings throughout the treatment continuum
- Care providers may offer referral to the appropriate rehabilitation professional in collaboration with the medical provider

**Recommended Resources:**

- PVA Consumer Guide Sexuality and Reproductive Health for Adults with Spinal Cord Injury: What You Should Know\* available for free download <http://tinyurl.com/kfnvtby>
- PVA Clinical Practice Guideline Sexuality and Reproductive Health in Adults with Spinal Cord Injury\* available for free download <http://tinyurl.com/mnmwhfv>

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- Christopher and Dana Reeve Foundation Paralysis Resource Guide pp. 188-197  
<http://tinyurl.com/m5w3yo3>
- MSKTC SCI Factsheet Sexuality & Sexual Functioning After Spinal Cord Injury  
<http://tinyurl.com/zo7nb7r>
- Online lecture from Marcalee Alexander, MD from the VA Sexuality After Spinal Cord Injury  
<http://tinyurl.com/jnct5ch>

**Additional Resources:**

- Dr. Stan Ducharme [www.stanleyducharme.com](http://www.stanleyducharme.com)
- Mitchell S. Tepper, PhD, MPH <http://mitchelltepper.com>

**6.2 STANDARD:** Care providers will be able to identify common physical and emotional challenges related to sexual functioning and provide appropriate intervention, resources, and/or referrals.

**Minimum Requirements:**

- Care providers will offer general information and resources on the impact of SCI on sexual functioning, as well as safety considerations e.g., autonomic dysreflexia
- Provide individualized recommendations and/or referral for diagnosis and treatment of sexual health challenges/dysfunction in SCI

**Recommended Resources:**

- PVA Consumer Guide Sexuality and Reproductive Health for Adults with Spinal Cord Injury: What You Should Know\* available for free download <http://tinyurl.com/kfnvtby>
- PVA Clinical Practice Guideline Sexuality and Reproductive Health in Adults with Spinal Cord Injury\* available for free download <http://tinyurl.com/mnmwhfv>
- Christopher and Dana Reeve Foundation Paralysis Resource Guide pp. 188-197  
<http://tinyurl.com/m5w3yo3>
- University of Alabama InfoSheets:
  - Sexual Function for Men with SCI <http://tinyurl.com/cbg92ot>
  - Sexuality for Women with Spinal Cord Injury <http://tinyurl.com/l28pouk>
- MSKTC SCI Factsheet Sexuality & Sexual Functioning After Spinal Cord Injury  
<http://tinyurl.com/zo7nb7r>
- Online lecture from Marcalee Alexander, MD from the VA Sexuality After Spinal Cord Injury  
<http://tinyurl.com/jnct5ch>
- If injury is T8 or above, poster on AD education from PVA and Reeve Foundation partnership  
<http://tinyurl.com/i7sw6kj>

**Additional Resources:**

- Dr. Stan Ducharme [www.stanleyducharme.com](http://www.stanleyducharme.com)
- Mitchell S. Tepper, PhD, MPH <http://mitchelltepper.com>

**6.3 STANDARD:** Individuals and their appropriate family members or partner will be offered information and resources to help educate them on fertility options.

**Minimum Requirements:**

- Appropriate care providers will provide general information and resources re: reproductive health and fertility

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- Provide medical referrals to people interested in further options

#### Recommended Resources:

- PVA Consumer Guide Sexuality and Reproductive Health for Adults with Spinal Cord Injury: What You Should Know\* available for free download <http://tinyurl.com/kfnvtby>
- PVA Clinical Practice Guideline Sexuality and Reproductive Health in Adults with Spinal Cord Injury\* available for free download <http://tinyurl.com/mnmwhfv>
- Christopher and Dana Reeve Foundation Paralysis Resource Guide pp. 188-197 <http://tinyurl.com/m5w3yo3>
- Miami Project- Male Fertility Following Spinal Cord Injury: A Guide For Patients <http://tinyurl.com/ztapp3l>
- MSKTC Factsheet Pregnancy and Women with Spinal Cord Injury available for free at <http://tinyurl.com/pnyab2h>

## 7. Spasticity

**7.1 STANDARD** Staff members will identify spasticity and provide intervention as appropriate. Intervention will include identifying and addressing potential triggers, providing medical and therapeutic care as needed and monitoring patient's status.

#### Minimum Requirements:

- Facility has a process to educate staff members re: the identification, evaluation and management of spasticity using an inter-disciplinary approach
- Staff competency conducted for all care providers
- Maintain an open discussion and provide access to education about spasticity in both formal and informal settings throughout the treatment continuum
- Care providers may offer referral to the appropriate rehabilitation professional in collaboration with the medical provider

#### Recommended Resources:

- Christopher and Dana Reeve Foundation Paralysis Resource Guide <http://tinyurl.com/m5w3yo3>
- MSKTC SCI Factsheet Spasticity and Spinal Cord Injury <http://tinyurl.com/lsqbezq>
- FacingDisability.com <http://tinyurl.com/mxc3azy>
- eLearn A web-based teaching and educational resource <http://tinyurl.com/kv8qu4b>

**7.2 STANDARD** Patient/Family/Caregivers Teaching: Individuals, their family members, and caregivers will receive appropriate spasticity education to maximize functional independence and minimize secondary health conditions

#### Minimum Requirements

- Care providers trained to educate patient, family members and caregivers re: spasticity
- Ongoing spasticity education

#### Recommended Resources:

- Christopher and Dana Reeve Foundation Managing Spasticity <http://tinyurl.com/mjd6p76>

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- Northwest Regional SCI Model System Consumer Information Factsheet-Spasticity and SCI <http://tinyurl.com/kwgrymc>
- Online lecture from Marika Hess, MD from the VA Get a Jump on Spasticity <http://tinyurl.com/lu9opf6>
- Spasticity and Movement Disorder Checklist <http://tinyurl.com/khtgbqb>
- Daily Diary <http://tinyurl.com/n5hvzpb>

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