



## **Clinical Practice Guidelines for Paralysis Bibliography**

**March 2024**

## Amyotrophic Lateral Sclerosis

**Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: Multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review)** Miller, RG, et al. Report of the Quality Standards Subcommittee of the American Academy of Neurology. Published in *Neurology* Oct 2009, 73 (15) 1227-1233.

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**Practice parameter update: The care of the patient with amyotrophic lateral sclerosis: Drug, nutritional, and respiratory therapies (an evidence-based review)** Miller, RG et al. Report of the Quality Standards Subcommittee of the American Academy of Neurology. Published in *Neurology* Oct 2009, 73 (15) 1218-1226.

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**EFNS guidelines on the Clinical Management of Amyotrophic Lateral Sclerosis – revised report of an EFNS task force.** Andersen PM et al EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis. *Eur J Neurol* 2012 Mar;19(3):360-375.

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## Autonomic Dysreflexia

**Evaluation and management of autonomic dysreflexia and other autonomic dysfunctions: Preventing the highs and lows:** / Consortium for Spinal Cord Medicine. Washington, DC: Paralyzed Veterans of America, 2020.

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## Bladder Management

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**Clinical Practice Guidelines: Insertion of an Indwelling Urethral Catheter in the Adult Female.** Pittman, NJ: Society of Urologic Nurses and Associates, 2021.

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Click on Urinary Catheter Care, see Clinical Practice Procedures and select the relevant title.

**Clinical Practice Guidelines: Insertion of an Indwelling Urethral Catheter in the Adult Male.** Pittman, NJ: Society of Urologic Nurses and Associates, 2021.

<https://www.sunu.org/resources/clinical-practice>

Click on Urinary Catheter Care, see Clinical Practice Procedures and select the relevant title.

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**Clinical Practice Guidelines: Methods and Types of Urinary Catheters used for Indwelling and Intermittent Catheterization:** / Pittman, NJ: Society of Urologic Nurses and Associates, 2021.

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**Clinical Practice Guidelines: Urinary Catheterization of the Adult Female.** Pittman, NJ: Society of Urologic Nurses and Associates, 2021.

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**Clinical Practice Guidelines: Urinary Catheterization of the Adult Male.** Pittman, NJ: Society of Urologic Nurses and Associates, 2021.

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**Urinary dysfunction and multiple sclerosis: Evidence-based management strategies for urinary dysfunction in multiple sclerosis/Multiple Sclerosis Council for Clinical Practice Guidelines.** Washington, DC: Paralyzed Veterans of America, 1999.

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**Guidelines for the Treatment of Severe Traumatic Brain Injury, Fourth Edition.** Brain Trauma Foundation. 2016.

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**Guidelines for the Field Management of Combat-Related Head Trauma.** Brain Trauma Foundation. 2005.

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**Guidelines for the Surgical Management of Traumatic Brain Injury.** Brain Trauma Foundation. 2006.

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**Head injury: Assessment and early management.** London (UK): National Institute for Clinical Excellence (NICE); 2014 (updated 2019)

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## **Cerebral Palsy**

### **Cerebral Palsy- Critical Elements of Care**

**Providing a Primary Care Medical Home for Children and Youth with Cerebral Palsy** (clinical report) Gregory S. Liptak, MD, MDH; Nancy A. Murphy, MD; the Council on Children with Disabilities Pediatrics Vol. 128 No. 5 October 2011, pp. 1321-1329

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### **Practical Oral Care for People with Cerebral Palsy**

From the National Institute on Dental and Craniofacial Research. Part of the series: Practical Oral Care for People with Mild or Moderate Developmental Disabilities.

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## Duchenne Muscular Dystrophy

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**Practice guideline update summary: Corticosteroid treatment of Duchenne dystrophy.** Report of the Guidelines Development Subcommittee of the American

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**Prevention and treatment of pressure ulcers/injuries: Clinical Practice Guideline.** European Pressure Ulcer Advisory Panel, National Pressure Injury Advisory Panel and Pan Pacific Pressure Injury Alliance. Prevention and Treatment of Pressure Ulcers/Injuries: Quick Reference Guide. Emily Haesler (Ed.). EPUAP/NPIAP/PPPIA:2019.  
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[https://pva.org/wp-content/uploads/2021/09/consumer-guides\\_outcomes\\_t1-t9.pdf](https://pva.org/wp-content/uploads/2021/09/consumer-guides_outcomes_t1-t9.pdf)

**Expected Outcomes T10-L1: What You Should Know** / Consortium for Spinal Cord Medicine. Washington, DC: Paralyzed Veterans of America 2002.

[https://pva.org/wp-content/uploads/2021/09/consumer-guides\\_outcomes\\_t10-11.pdf](https://pva.org/wp-content/uploads/2021/09/consumer-guides_outcomes_t10-11.pdf)

**Neurogenic Bowel: What You Should Know**/ Consortium for Spinal Cord Medicine. Washington, DC: Paralyzed Veterans of America, 1999.

[https://pva.org/wp-content/uploads/2021/09/consumer-guide\\_neurogenic-bowel.pdf](https://pva.org/wp-content/uploads/2021/09/consumer-guide_neurogenic-bowel.pdf)

**Pressure Ulcers: What You Should Know**/ Consortium for Spinal Cord Medicine. Washington, DC: Paralyzed Veterans of America, 2002.

[https://pva.org/wp-content/uploads/2021/09/consumer-guide\\_pressure-ulcers.pdf](https://pva.org/wp-content/uploads/2021/09/consumer-guide_pressure-ulcers.pdf)

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[Spinal Cord Injury from Sources other than PVA](#)

**SCIRE: Spinal Cord Injury Rehabilitation Evidence Modules**

<https://scireproject.com/evidence/>

## **SCIRE: Spinal Cord Injury Rehabilitation Evidence: Outcome Measures**

<https://scireproject.com/outcome-measures/>

**American Dietetic Association's Spinal cord injury (SCI). Evidence-based nutrition practice guideline. 2009.**

<https://www.andeal.org/vault/pqnew88.pdf>

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## **Spinal Muscular Atrophy**

**Diagnosis and management of spinal muscular atrophy: Part 1: Recommendations for diagnosis, rehabilitation, orthopedic and nutritional care.** Eugenio Mercuri et al for the SMA Care Group, *Neuromuscular Disorders*

Volume 28, Issue 2, February 2018, Pages 103-115

[https://www.nmd-journal.com/article/S0960-8966\(17\)31284-1/fulltext](https://www.nmd-journal.com/article/S0960-8966(17)31284-1/fulltext)

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## **Stroke**

**2021 Guideline for the Prevention of Stroke in Patients with Stroke and Transient Ischemic Attack: A Guideline From the American Heart Association/American Stroke Association.** *Stroke*, July 2021, Vol. 52, No. 7

<https://www.ahajournals.org/doi/10.1161/STR.0000000000000375>

**Canadian Stroke Best Practices Acute Stroke Management 2018.**

<https://www.strokebestpractices.ca/recommendations/acute-stroke-management>

**Clinical Guidelines for Acute Stroke Management. Melbourne, Australia: Stroke Foundation, 2022.**

<https://informme.org.au/Guidelines/Clinical-Guidelines-for-Stroke-Management>

**Royal College of Physician's National Clinical Guidelines for Stroke**

<https://www.rcplondon.ac.uk/guidelines-policy/stroke-guidelines>

**Royal College of Paediatrics and Child Health: Stroke in Childhood**

<https://www.rcpch.ac.uk/resources/stroke-in-childhood-clinical-guideline>

**VHA/DoD Clinical Practice Guideline for Management of Stroke Rehabilitation**

<https://www.healthquality.va.gov/guidelines/Rehab/stroke/>

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## **Syringomyelia**

No Clinical Guidelines located.

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## Tracheostomy

**Practice Management Guidelines for the Timing of Tracheostomy: The EAST** Practice Management Guidelines Group. Holevar M, Dunham JC, Clancy TV, Como JJ, Ebert JB, Griffen MM, Hoff WS, Kurek SJ Jr, Talbert SM, Tisherman SA. Eastern Association for the Surgery of Trauma (EAST); *The Journal of Trauma: Injury, Infection, and Critical Care*: October 2009 - Volume 67 - Issue 4 - p 870-874. [https://journals.lww.com/jtrauma/Fulltext/2009/10000/Practice\\_Management\\_Guidelines\\_for\\_Timing\\_of.32.aspx](https://journals.lww.com/jtrauma/Fulltext/2009/10000/Practice_Management_Guidelines_for_Timing_of.32.aspx)

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## Transverse Myelitis

The Siegel Rare Neuroimmune Association supplied the following section on TM.

**Proposed diagnostic criteria and nosology of acute transverse myelitis.** *Neurology*. 2002 Aug 27;59(4):499-505. <https://n.neurology.org/content/59/4/499.long>

- **History and Diagnosis - Transverse Myelitis**

**Transverse Myelitis: Pathogenesis, Diagnosis and Treatment.** Chitra Krishnan, Adam I Kaplin, Deepa M Deshpande, Carlos A Pardo, Douglas A Kerr. *Frontiers in Bioscience. (Landmark Ed)* 2004, 9(2), 1483–1499. <https://doi.org/10.2741/1351>

**Transverse Myelitis: Symptoms, Causes and Diagnosis.** Siegel Rare Neuroimmune Association.

**Demyelinating Disorders: Update on Transverse Myelitis.** Chitra Krishnan, MHS, Adam I. Kaplin, MD, PhD, Carlos A. Pardo, MD, Douglas A. Kerr, MD, PhD, and Sanjay C. Keswani, MBBS, MRCP. *Current Neurology and Neuroscience Reports* 2006, 6:236–243  
<https://wearesrna.org/resources/demyelinating-disorders-update-on-transverse-myelitis/>

- **Other Neuroimmunologic Diseases**

Diagnosis and Management of Acute Myelopathies  
<http://www.theneurologist.org>

**Diseases Associated with Transverse Myelitis.** Johns Hopkins Medicine, Neurology and Neurosurgery.  
[https://www.hopkinsmedicine.org/neurology\\_neurosurgery/centers\\_clinics/transverse\\_myelitis/about-tm/related-diseases.html](https://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/transverse_myelitis/about-tm/related-diseases.html)

**Neuromyelitis Optica.** National Institute of Neurological Disorders and Strokes  
<https://www.ninds.nih.gov/health-information/disorders/neuromyelitis-optica>

**Acute Disseminated Encephalomyelitis**

National Institute of Neurological Disorders and Strokes

<https://www.ninds.nih.gov/health-information/disorders/acute-disseminated-encephalomyelitis>

**Multiple Sclerosis.** National Institute of Neurological Disorders and Strokes.

<https://www.ninds.nih.gov/health-information/patient-caregiver-education/hope-through-research/multiple-sclerosis-hope-through-research>

### **Acute Therapies for Transverse Myelitis**

<https://wearesrna.org/living-with-myelitis/disease-information/transverse-myelitis/acute-treatments/>

- **Symptom Management**

**A Comprehensive Algorithm for the Management of Neuropathic Pain.** Pain Medicine, Volume 20, Issue Supplement\_1, June 2019, Pages S2–S12. Daniel Bates, MD, B Carsten Schultheis, MD, PhD, Michael C Hanes, MD, Suneil M Jolly, MD, Krishnan V Chakravarthy, MD, PhD, Timothy R Deer, MD, Robert M Levy, MD, PhD, Corey W Hunter, MD.

doi: [https://academic.oup.com/painmedicine/article/20/Supplement\\_1/S2/5509427](https://academic.oup.com/painmedicine/article/20/Supplement_1/S2/5509427)

**Long term Transverse Myelitis Care.** Johns Hopkins Medicine, Neurology and Neurosurgery.

[https://www.hopkinsmedicine.org/neurology\\_neurosurgery/centers\\_clinics/transverse\\_myelitis/about-tm/long-term-care.html](https://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/transverse_myelitis/about-tm/long-term-care.html)

**Transverse Myelitis; A guide for patients and carers.** Brain and Spine Foundation UK [https://www.brainandspine.org.uk/wp-content/uploads/2018/02/BSF\\_Transverse-myelitis-A5-booklet.pdf](https://www.brainandspine.org.uk/wp-content/uploads/2018/02/BSF_Transverse-myelitis-A5-booklet.pdf)

- **Neuropsychiatric Implications**

**Demoralization and Depression in Multiple Sclerosis and Transverse Myelitis.** Adam Kaplin, MD PhD, Johns Hopkins University School of Medicine; Departments of Psychiatry and Neurology; Johns Hopkins TM and MS Centers; The Transverse Myelitis Association Medical Advisory Board. Transverse Myelitis Association, Volume 8 Issue 1 Fall 2007.

<http://files.wearesrna.org/newsletters/v8n1/newsletter8-1-02.htm>

- **Neurology Overview**

**Brain, Spinal Cord and Cells: A Neuro-primer for non-neurologists.** Carlos A. Pardo, M.D. Johns Hopkins Transverse Myelitis Center; Johns Hopkins University School of Medicine. Transverse Myelitis Association Journal, Vol. 1, January 2006.

<http://files.wearesrna.org/newsletters/j1/journal-1-08.htm>

### **Rare Neuroimmune Disorders**

Siegel Rare Neuroimmune Association

<https://wearesrna.org/living-with-myelitis/disease-information/rare-neuroimmune-disorders/>

## **Rehabilitation**

### **Body Weight Suspended Treadmill Training or Locomotor Training**

<http://files.wearesrna.org/newsletters/v4n2/newsletter4-2-04.htm>

### **Why a Person with TM Should Consider Physical Therapy**

<https://wearesrna.org/resources/why-a-person-with-tm-should-consider-physical-therapy/>

### **Why a Person with TM Should Consider Occupational Therapy**

[https://files.wearesrna.org/resources/Newsletter\\_Articles/2000\\_07\\_15\\_Why\\_A\\_Person\\_With.pdf?\\_gl=1\\*16oc617\\*\\_ga\\*MTcyNDc3MDkwNC4xNzEwODA3MDY5\\*\\_ga\\_J9YYCV6PSN\\*MTcxMDgwNzA2OC4xLjEuMTcxMDgwNzA4MS40Ny4wLjA](https://files.wearesrna.org/resources/Newsletter_Articles/2000_07_15_Why_A_Person_With.pdf?_gl=1*16oc617*_ga*MTcyNDc3MDkwNC4xNzEwODA3MDY5*_ga_J9YYCV6PSN*MTcxMDgwNzA2OC4xLjEuMTcxMDgwNzA4MS40Ny4wLjA).

## **Additional Resources:**

### **Johns Hopkins Transverse Myelitis Center**

[https://www.hopkinsmedicine.org/neurology\\_neurosurgery/centers\\_clinics/transverse\\_myelitis/](https://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/transverse_myelitis/)

### **Project RESTORE at Johns Hopkins Medicine**

[https://www.hopkinsmedicine.org/neurology\\_neurosurgery/centers\\_clinics/project\\_restore/index.html](https://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/project_restore/index.html)

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## **Databases to search for clinical guidelines related to paralysis and its secondary conditions:**

National Library of Medicine's Pubmed/Medline

<http://www.ncbi.nlm.nih.gov/sites/entrez>

National Guidelines Clearinghouse (U.S.)

[www.guideline.gov](http://www.guideline.gov)

NHS's National Institute for Health and Clinical Excellence (NICE) (UK)

<http://www.nice.org.uk/>

Scottish Intercollegiate Guidelines Network (SIGN)

<http://www.sign.ac.uk/>

Best Practice Advocacy Centre New Zealand Guidelines Group

<https://bpac.org.nz/guidelines/about.html>

Guidelines International Network

<http://www.g-i-n.net/>



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