Aging with Spinal Cord Injury and Disability

The life expectancy of people living with spinal cord injuries has increased thanks to decades of progress in treatment and care. At the same time, a growing number of people are acquiring disabilities later in life. As a result, more seniors are living with disabilities, including paralysis, than ever before.

Everyone ages differently, and needs will vary based on individual factors like severity of injury, family health history, lifestyle and the age at which the disability was acquired. For people who become paralyzed later in life due to strokes or falls, the challenge will be learning to manage a new disability in
addition to other health issues associated with aging. People who acquire spinal cord injuries at birth or an early age will find the aging process itself accelerated by the injury and face a greater number of secondary conditions, including muscle and bone deterioration, endocrine-related issues such as diabetes, chronic pain, pressure sores, and kidney and bladder stones.

There are many resources available to help anticipate how aging may impact physical and mental health. Support services and outreach efforts promoting the importance of exercise, social engagement, and strong community networks can benefit all individuals living with spinal cord injuries as they age.

Sources: Model Systems Knowledge Translation Center, Craig Hospital, Department of Rehabilitation Medicine at the University of Washington Medical Center.

Websites

https://www.n4a.org/adrcs
https://www.acl.gov/node/413
Aging and Disability Resource Centers/ No Wrong Door
Call Eldercare Locator Toll-free 1-800-677-1116 to find the ADRC in your area.

The No Wrong Door (NWD) System initiative is a collaborative effort of the ACL, the Centers for Medicare & Medicaid Services (CMS), and the Veterans Health Administration (VHA). The NWD System initiative builds upon the Aging and Disability Resource Center (ADRC) program and CMS’ Balancing Incentive Program No Wrong Door requirements that support state efforts to streamline access to long-term services and support (LTSS) options for older adults and individuals with disabilities. NWD Systems simplify access to LTSS, and are a key component of LTSS systems reform.

The Aging and Disability Resource Center Program (ADRC) is a collaborative effort of the U.S. Administration for Community Living (including AoA as of April 2012) and the Centers for Medicare & Medicaid Services (CMS). ADRCs serve as single points of entry into the long-term supports and services system for older adults and people with disabilities. Sometimes referred to as a “one-stop shops” or "no wrong door" systems, ADRCs address many of the frustrations consumers and their families experience when trying to find needed information, services, and supports. Through integration or coordination of existing aging and disability service systems, ADRC programs raise visibility about the full range of options that are available, provide objective information, advice, counseling and assistance, empower people to make informed decisions about their long term supports, and help people more easily access public and private long term supports and services programs. Click on your state to find state and local ADRCs.
The core functions of an ADRC are 1) information, referral and awareness, 2) options counseling, advice and assistance, 3) streamlined eligibility determination for public programs, 4) person-centered transitions, 5) quality assurance and continuous improvement. ADRCs perform these functions by integrating, coordinating, and strengthening different pieces of the existing long term supports and services systems, including Area Agencies on Aging, Centers for Independent Living, state and local Medicaid offices, and other community-based organizations.

http://www.advancingstates.org/about-advancing-states

ADvancing States (formerly National Association of States United for Aging and Disabilities (NASUAD))
241 18th St. S., Suite 403
Arlington, VA 22202
Phone: 202-898-2578
Email: info@advancingstates.org
ADvancing States represents the nation’s 56 state and territorial agencies on aging and disabilities and supports visionary state leadership, the advancement of state systems innovation and the articulation of national policies that support home and community-based services for older adults and individuals with disabilities.

Christopher & Dana Reeve Foundation: Nurse Linda webcast on aging and spinal cord injury

https://craighospital.org/resources/topics/aging
Craig Hospital: Aging Resources

https://craighospital.org/resources/aging-and-spinal-cord-injury
Craig Hospital: Aging and Spinal Cord Injury

https://eldercare.acl.gov/Public/Index.aspx/
Eldercare Locator from ACL
Phone: 800-677-1116
Provides info on aging programs and resources.

Medscape: Spinal Cord Injury and Aging
This page has information on the aging process in people with spinal cord injury, including musculoskeletal, cardiovascular, gastrointestinal, pulmonary and integumentary, and endocrine changes.

http://www.ncba-aged.org
National Caucus and Center on Black Aging Inc. (NCBA)
1220 L Street NW, Suite 800
Washington, DC 20005
NCBA has helped protect and improve the quality of life for elderly populations, making certain that legislators, policy makers, philanthropists, advocacy groups, service organizations, thought leaders and the public at-large include minority seniors in their programs, policy- and law-making, and giving. NCBA is one of the country's oldest organizations dedicated to aging issues and the only national non-profit organization devoted to minority and low-income aging.


**NCHPAD: Resistance Training for Persons with Physical Disabilities**

This page has information on how exercise can help people with physical disabilities maintain physical function and independence, particularly as they age. The document discusses resistance training guidelines for persons with physical disabilities, focus on associated conditions and general resistance training guidelines. There are also guidelines for specific disability groups – wheelchair users and people with spinal cord injury, multiple sclerosis, post-polio syndrome, cerebral palsy, and stroke.

http://nicoa.org/

**National Indian Council on Aging (NICOA)**

8500 Menaul Blvd., NE, Suite B-470
Albuquerque, NM 87112
Phone: 505-292-2001

NICOA is a non-profit organization founded in 1976 which advocates for improved comprehensive health, social services and economic well-being for American Indian and Alaska Native Elders.

http://www.nia.nih.gov

**National Institute on Aging (NIA)**

Building 31, Room 5C27
31 Center Drive, MSC 2292
Bethesda, MD 20892
Phone: 800-222-2225 (Toll-free), 800-222-4225 (TTY/toll-free)
Email: niaic@nia.nih.gov


NIA: Clinical Trials and Older People

https://www.nia.nih.gov/health

NIA: Health Info


NIA: Why Participate in a Clinical Trial?

Northwest Regional Spinal Cord Injury System: Aging with a Spinal Cord Injury
This page has an 81-minute streaming video and a report of the June 9, 2009, presentation by Rina Reyes, MD, and Ivan Molton, PhD, of the University of Washington, Department of Rehabilitation Medicine.


Northwest Regional Spinal Cord Injury System: Everybody’s Doing It! Aging with a Spinal Cord Injury
A 78 minute streaming video presented on October 9, 2012 at the University of Washington Medical Center, Seattle, WA.

https://www.youtube.com/watch?v=INXDJikEAE&feature=youtu.be

Northwest Regional Spinal Cord Injury System: Profiles of Aging with a Spinal Cord—Elaine’s Story
Elaine Stefanowicz was injured in a car accident as a teenager. She is now an academic adviser at a two-year college and former Miss Wheelchair America. She talks with UW clinical psychologist Jeanne Hoffman about her injury, the ways it shaped her life and career over 30-plus years, and how she stays healthy and independent as she ages with her disability.

https://www.youtube.com/watch?v=BAc0vOWrUE&feature=youtu.be

Northwest Regional Spinal Cord Injury System: Profiles of Aging with a Spinal Cord—Clark’s Story
Clark sustained a cervical spinal cord injury from a diving accident 35 years ago and went on to an active life, including college, career, sports, marriage, and fatherhood. He talks with Dr. Jeanne Hoffman about his life, aging, and staying healthy after more than three decades in a wheelchair.

www.agerrtc.washington.edu
http://agerrtc.washington.edu/info/factsheets

Northwest Regional Spinal Cord Injury System: Rehabilitation Research and Training Center (RRTC) on Aging with a Physical Disability
University of Washington
Box 356490
Seattle, WA 98195
Phone: 866-928-2114
They have factsheets on depression, sleep, exercise, getting the most out of a health care visit for people aging with disabilities.

http://usm.maine.edu/muskie/cutler/da

University of Southern Maine: Cutler Institute’s Disability and Aging Program
PO Box 9300
Portland, ME 04104
Phone: 207-780-4430
The Cutler Institute’s Disability and Aging program is a team of multi-disciplinary professionals with extensive experience working in close collaboration with states to
provide technical assistance, conduct evaluations, identify best practices, and perform policy analysis work.

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