



NDSS Webinar Series

March 19th, 2013

Aging and Down Syndrome with Dr. Julie Moran

**An NDSS Webinar in conjunction with the
release of *Aging and Down Syndrome: A
Health & Well-Being Guidebook***

Aging and Down Syndrome

A HEALTH & WELL-BEING GUIDEBOOK



National Down Syndrome Society
ndss.

Goals of the Booklet

- Provide guidance, education and support to families and caregivers of older adults with Down syndrome
- Prepare families and caregivers of adults with Down syndrome for medical issues commonly encountered in adulthood
- Empower families and caregivers with accurate information so that they can take positive action over the course of the lifespan of adults with Down syndrome
- Provide an advocacy framework for medical and psychosocial needs commonly encountered by individuals affected by Down syndrome as they age

Overview of Aging with Down Syndrome



“Accelerated Aging”



Common Medical Conditions



Sensory Loss

- *Screen for vision and hearing impairment and get regular exams to assess overall eye and ear health.*
- *Check for ear wax impactions and request formal audiology testing to detect hearing loss.*

Hypothyroidism

- *Test for thyroid abnormalities periodically through screenings and blood tests.*
- *Discuss screening with the primary care doctor and consider checking for thyroid dysfunction if new symptoms of sleepiness, confusion or mood changes occur.*

Obstructive Sleep Apnea

- *Sleep apnea is common and can frequently go undetected in adults with Down syndrome.*
- *Monitor sleep patterns, particularly if there is a change in mood, behavior or ability to concentrate.*
- *Discuss concerns with a primary care doctor to see if a sleep study is necessary.*

Osteoarthritis

- *Pay attention to changes in walking or activity level, looking for signs of stiffness or discomfort.*
- *Keep in mind that many adults with Down syndrome may under-report pain or appear to have a high pain tolerance. If pain is suspected, discuss the possibility of underlying arthritis with the primary care doctor.*

Atlantoaxial Instability and Cervical Spine Concerns

- *Remain mindful that the bones of the neck are more vulnerable as adults with Down syndrome grow older.*
- *Further imaging or referral to a specialist may be necessary if new symptoms occur.*
- *A screening cervical spine x-ray is generally recommended at least once during adulthood.*

Osteoporosis

- Osteoporosis causes a thinning of bone mass that leads to risk of fracture.
- People with Down syndrome are at higher risk for disease, especially if there is immobility, low body mass, family history of osteoporosis, early menopause or longtime exposure to certain anti-seizure medications.
- Osteoporosis is screened for via a bone density test and can be treated through medication, as well as other exercise and lifestyle modifications.

Celiac Disease

- *Consider the possibility of celiac disease when there is weight loss, poor nutrition or persistent changes in bowel habits.*
- *Talk to the primary care doctor about the increased risk of celiac disease and, if it was never performed in adulthood, consider a screening blood test.*

Medication and Prescription Considerations

- *A periodic review of the medication list is essential.*
- *When reviewing the medication list, consider: Is each medication necessary? Do the benefits of each medication outweigh the risks of side effects? Is there room to simplify?*
- *Always think of medications when observing a new change in mood, behavior or physical symptoms. Was a new prescription just started? A dose increased? A medication suddenly discontinued?*

Emotional and Psychiatric Well-Being



- *People with Down syndrome can have psychiatric illness (depression, anxiety, etc.) just like anyone else.*
- *Monitor closely when there is a significant change in mood or behavior and seek attention from a primary care doctor or mental health specialist if features persist or interfere with day-to-day life.*
- *Don't overlook other new medical or physical issues that may be contributing to these changes.*
- *Pay attention to any other situational changes that may also trigger or exacerbate sadness, anxiety, etc.*

Alzheimer's Disease and Down Syndrome

- *There is an increased risk of Alzheimer's disease (dementia) in adults with Down syndrome.*
- *The risk increases with age.*
- *However, Alzheimer's disease is not inevitable in people with Down syndrome.*

The Span of Alzheimer's Disease

- Early Stage
- Middle Stage
- Advanced Stage



Recognizing Alzheimer's Disease

- *Regular screening for memory impairment is important. Look for symptoms of confusion or memory loss, as well as changes in skills and daily functions that are declining from previous "baseline" abilities.*
- *When dementia is suspected, it is important to pursue a comprehensive evaluation that takes into consideration other common medical conditions that could be contributing to the individual's symptoms. Psychiatric or emotional contributors should be considered as well.*
- *If Alzheimer's disease is diagnosed, become familiar with the general features of the disease across the lifespan to help plan proactively and set proper expectations.*
- *Create formal (physicians, social workers, case managers, support staff) and informal (extended family, caregivers, respite workers) support networks to help cope with the progression of the disease.*

A Caregiver's Guide to Down Syndrome and Alzheimer's Disease

- Common Behavioral Pitfalls
- Emphasizing a Positive Approach
- First Steps to Improved Communication
- General Verbal Communication Tips
- The Art of Redirecting the Conversation
- Intervening on Behaviors

Steps to Successful Communication

GETTING STARTED	FACIAL EXPRESSION	tone of voice	BODY LANGUAGE
<ul style="list-style-type: none">• Approach from the front• Smile• Identify yourself• Use the person's name• If possible, be at eye level	<ul style="list-style-type: none">• Establish & maintain eye contact• Be friendly & relaxed• Always remember humor: smiles & laughter go a long way• Be patient and supportive	<ul style="list-style-type: none">• Speak slowly & clearly• Use a gentle & relaxed tone of voice• Convey an easy-going manner	<ul style="list-style-type: none">• Avoid sudden movement• Be open & relaxed with your stance• Remain calm & confident to provide reassurance• Use gestures such as pointing• Give visual cues

Planning for Old Age

- *Maintaining social connectedness is a priority throughout every stage of life.*
- *Thinking proactively is the key to maintaining a successful and sustainable living situation.*
- *Adults with Down syndrome are routinely living into older age. Transition out of the family home or into other types of living arrangements is a common situation. Start these discussions early to avoid the need to make any arrangements during crisis.*
- *Just like the general population, some adults with Down syndrome will want to reduce the demands and expectations placed on them as they age. Consider exploring ways in which retirement could be a reality.*

Coordination of Care



- *It is common for individual needs to become more complex with aging. Providing care to an older adult with Down syndrome becomes an increasingly collaborative effort that requires both teamwork and leadership.*
- *Keep lines of communication open and seek opinions and input of other members of the team that participates in the day-to-day life and care of the individual.*
- *Maintain the individual with Down syndrome as the focal point to foster a collaboration that*
- *enables the individual to thrive and succeed throughout the lifespan.*
- *Seek legal consultation for health care proxy, power of attorney and a living will.*

Topics to Consider in Care Coordination

ABILITIES & CAPABILITIES	ENVIRONMENT & ACTIVITIES	CONDITIONS	RESOURCES
<ul style="list-style-type: none"> • Physical • Psychological/ Behavioral • Cognitive • Functional Abilities (activities of daily living) • Sensory (vision, hearing, touch, smell) • Communication 	<ul style="list-style-type: none"> • Living Arrangement • Employment/ Retirement • Social Engagement/ Activities • Day Program Activity • Daily Routines • Spiritual Support • Likes/Dislikes • Safety Risks 	<ul style="list-style-type: none"> • Nutrition • Oral/Dental • Elimination Pattern • Sleep Pattern • Medical Conditions • Allergies & Intolerances • Medications • Prevention Care • Treatment & Services • Palliative & End of Life Care Needs 	<ul style="list-style-type: none"> • Community Services & Support • Funding • Staffing Requirements • Transportation Needs • Legal

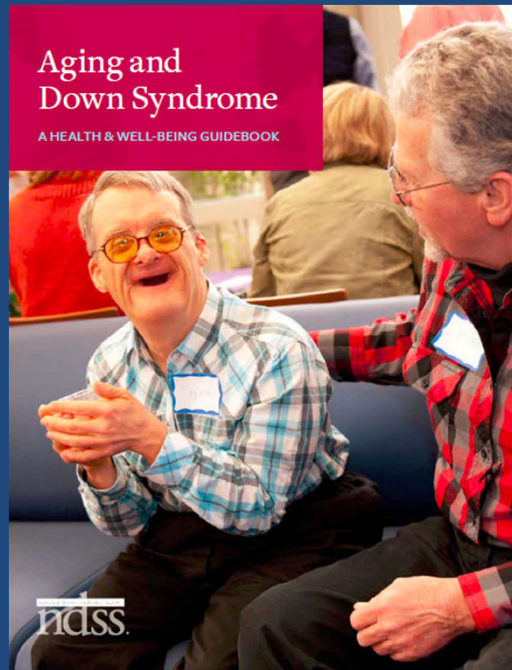
End-of-Life Considerations

- *Identify who the medical decision-maker is: the center person, a family member, a court appointed guardian?*
- *Engage the decision-maker proactively regarding end-of-life wishes. Have a discussion with the primary care doctor to help clarify any unfamiliar terms and to formally document any wishes or goals.*
- *Tackle the tough discussions at a time when there is no crisis, when decisions can be made in a relaxed fashion so that all aspects can be properly considered and explored.*



Image Courtesy of Jamie Kaplan

Be proactive!



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Q&A with Dr. Moran



Type your questions into the box on the lower left-hand side of your screen



Thank you!