Aging and Alzheimer’s Disease in Adults with Down Syndrome

Adult Down Syndrome Center
November 10, 2020

Resource Library: adscresources.advocatehealth.com
Reminders

• This webinar is being recorded.
  – Available within two weeks in our Resource Library and on Facebook.
    • https://adscresources.advocatehealth.com
    • www.facebook.com/adultdownsyndromecenter

• Q&A
  – Please submit questions using the Q&A option.
Disclaimer

This information is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health or behavioral evaluation, diagnosis or treatment plan by a qualified professional.
Adult Down Syndrome Center
Park Ridge, IL

Our mission is to enhance the well-being of people with Down syndrome who are 12 and older by using a team approach to provide comprehensive, holistic, community-based health care services.
Adult Down Syndrome Center
Park Ridge, IL
Online Resource Library

• Contains videos, articles, and booklets on a variety of topics, including aging and Alzheimer’s disease.

• Resources are continually being updated.

adscresources.advocatehealth.com
1. Select an audience
2. Scroll to the Narrow Results section

3. Use the checkboxes to select a topic or the search bar to find resources on a topic
Agenda

• Describe healthy aging and challenges associated with aging
• Provide an overview of Alzheimer’s disease
• Discuss management of aging issues and Alzheimer’s disease
• Share lessons learned from families and caregivers
• Describe resources to learn more and get support
Today, people with Down syndrome are living *longer* and *healthier* than any other time in the past.

- Life expectancy
  - 1907: 9 years
  - 1984: 28 years
  - Today: 60 years

Source: Centers for Disease Control and Prevention and Global Down Syndrome Foundation
Graphic by Amanda Falvey and Hedley Mocnik/Coverite News
Healthy aging

- Eat healthy food
- Get good sleep
- Feel relaxed
- Drink water
- Be active
Health screening

• Healthcare guidelines for adults with Down syndrome

• Cancer screening?
  – Colonoscopies, mammograms

https://www.globaldownsyndrome.org/global-adult-guidelines/
Aging in people with Down syndrome

• Earlier aging
• Onset of certain health conditions
  – Cataracts
  – Osteoarthritis
  – Hearing impairment
  – Alzheimer’s disease
Alzheimer’s disease
What is Alzheimer’s disease (AD)?

• Progressive neurological condition
• Affects the brain
• Is a type of dementia
• Plaques and tangles = the microscopic changes of the brain consistent with AD
  – Also referred to as neuropathologic changes
Association between DS and AD

• Nearly all people with Down syndrome (DS) have plaques and tangles by age 40.
• All people with DS over age 60.

Mann 1997
Does everyone with Down syndrome get Alzheimer’s disease?

• Eventually, everyone with DS gets the neuropathologic changes.

• BUT NOT everyone gets symptoms of Alzheimer’s disease.
Why is AD more common in DS?

• One of the genes associated with AD is on the 21\textsuperscript{st} chromosome.
  –Amyloid precursor protein (APP)

• Since people with DS have an extra full or partial copy of the 21\textsuperscript{st} chromosome, they have more of the gene.
What is the incidence of clinical Alzheimer’s disease?

- AD thought to be uncommon before age 40.
- Incidence estimated to be 55% in those between ages 50-59.
- Incidence estimated to be greater than 75% in those 60 years of age and older.

Mann et al. 1984, McCarron et al. 2014, Coppus et al. 2006, Strydom et al. 2018
Symptoms

- Memory deterioration
- Loss of previously mastered skills
- Incontinence
- Unsteady gait
- Dysphagia (swallowing)
- Seizures
  - Higher rate (77% vs 2-25%)
- Weight loss
- Psychological changes
Diagnosis

• Look for the pattern of decline.
• Rule out other causes.
  – Examples:
    • Vitamin B12 deficiency
    • Depression
    • Sleep apnea
    • Hypothyroidism
    • Cataracts
    • Regression syndrome
# Regression syndrome vs. Alzheimer’s disease

<table>
<thead>
<tr>
<th>Regression syndrome</th>
<th>BOTH</th>
<th>Alzheimer’s disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of onset = teens, early 20s</td>
<td>Decline in skills</td>
<td>Age of onset = &gt; 40</td>
</tr>
<tr>
<td>Sometimes reversible</td>
<td></td>
<td>Not reversible</td>
</tr>
</tbody>
</table>

**Link to webinar on Regression and Loss of Skills**
Progression of Alzheimer’s disease

• Rate of decline varies from person-to-person and over time

• Plateaus, sudden drops, etc.
Possible causes of sudden drops

- Stroke
- Infection
- Depression
- New onset or change in metabolic condition (e.g. diabetes)
- Dehydration
- Inadequate sleep
- Pain
Quality of life

• Doing what can still be done
• Friends and family
• Physical exercise
• Healthy eating
• Ideal body weight

• Social engagement
• Creative arts
• Sensory stimulation
• “Bingo Pace”
• (Prevention)
Managing aging issues and Alzheimer’s disease
Non-medicinal strategies
Non-medicinal strategies

• Environmental modifications
• Adaptive equipment recommendations
• Sensory needs
• Visual supports
• Communication
Home safety

- Contrasting colors in the bathroom
- Adequate lighting in rooms and hallways
- Remove unnecessary furniture and mirrors
- Add handrails and ramps
- Add reflective tape on stairs
Home safety

• Ensure chairs have arm rests to help with sitting and standing
• Remove throw rugs and door sills
• Add a deadbolt out of reach or alarm on main doors
• Lock up medications and cleaning supplies
• Remove locks on interior doors to prevent person from locking themselves in
Adaptive equipment

- Weighted utensils
- Adapted plates
- Contrasting colors
- Consider a shower chair and handheld shower head
- Grab bars
- Raised toilet seat or rails for the toilet
Our sensory system
Our sensory system
Sensory and behavior

• The kink may impact behavior

• We may see...
  – Verbal outbursts
  – Physical aggression
  – Slowing down
  – Shutting down
Proprioceptive Input

Many individuals with Down syndrome experience difficulty with their proprioceptive system. The proprioceptive sensors in our body are responsible for providing feedback so we know where our body is in space. When these sensors aren’t working like they should, someone may experience difficulty with motor coordination, meaning they appear clumsy. This could also impact a person’s ability to actually carry out a movement even though they know how to do it; this is called motor planning. They may carry out activities and have difficulty grading their movements, perhaps they do things too hard or too soft. Another feature is the person may have difficulty with postural stability so they often appear slumped over or lethargic.

In order to activate these receptors and improve a person’s proprioceptive system, the following activities can be encouraged throughout the day to get natural input into a person’s joints. These activities can be done in preparation for a transition or when you start to see a person’s body becoming worked up. For instance, they need to complete a series of self-care tasks in the bathroom but often require verbal prompts to initiate the activity. Provide proprioceptive input to see if it helps them stay alert and engaged. Do you ever need to leave the house and your loved one with DS doesn’t want to go? Try some proprioceptive input to see if it helps them transition. These activities may not be effective once a person is having a tantrum or melt-down.

- Animal walking (like bear or crab, even crawling like a cat or dog, or hopping like a bunny)
- Jumping up and down, maybe even on a trampoline
- Dancing
- Jumping Jacks
- Push-ups on the floor or against the wall
- Bouncing on a therapy ball
- Sitting on a sit-disc
- Riding a bike/scooter
- Sports like swimming, yoga, Pilates and martial arts
- Completing an obstacle course
- Carrying a heavy backpack
- Moving furniture
- Pushing a cart/puller wagon
- Rolling up in a blanket like a burrito
- Bear hugs or being squeezed between pillows or cushions
- Using play-doh or playdough
- Log rolling
- Vibration
- Weighted blankets
- Sitting in a beanbag chair
- Rocking in a rocking chair or on a glider
- Strength training activities with a theraband or light weights
- Throwing a weighted ball
- Joint compression (see handout on how to complete joint compression)
- Massage
- Yard work like raking and shoveling
- House work like vacuuming, sweeping, mopping, washing windows, and wiping down the counter
- Eating chewy or crunchy foods
- Sucking through a straw

https://adscresources.advocatehealth.com/resources/proprioceptive-input/
Joint compression is a form of proprioceptive input. It occurs when there is compression, push, or weight bearing placed on a joint. It is important for developing body awareness and body in space, as well as for joint stability and strength. It also promotes self-regulation and can be very calming, regulating, and organizing for the brain and nervous system. This is a technique that seems to be effective for individuals with Down syndrome.

It can be used to help with transitions as well as to help calm the body. Therefore, complete this quick activity prior to an event that can be stressful for your loved one with Down syndrome. It should only take a few minutes.

For any questions, please contact Katie Frank, PhD, OTR/L at 847-318-2331 or
Katherine.Frank@AdvocateHealth.com

1. Have the individual sit down in a chair or on the floor. If they want or need to stand, joint compression can still take place.

2. Ask the individual if it is alright that you touch him/her. Once joint compression becomes part of the routine, you can just announce that it’s time for joint compression.

3. You can start on either the right or left side and you will plan on doing joint compression to both sides.

4. Place one of your hands on top of his/her shoulder and your other hand on his/her upper arm. Gently press your two hands toward one another to provide compression at the shoulder joint. Do this 10 times.
Affordable Sensory Equipment Recommendations

Weighted products:
Key points to remember: Please consult with an occupational therapist to help you determine the best size and weight. It is typically recommended to have a blanket be 7-10% of a person's body weight. It is NOT recommended to sleep under weighted blankets.

Weighted blankets and lap pads: Prices vary, but range from $30 - $100+ depending on size and weight.
  - Custom weighted blankets and lap pads:
    - http://www.seesawalm.com/weighted_blankets/
    - http://www.mamasweightedblankets.com/ (They even offer DUV kits)
    - Amazon, Bed Bath & Beyond, and Ilizzy even carry weighted products

Weighted snake: Prices range from $25 - $50+
  - Amazon has a few versions. They vary in weight.

Alternative ideas to expensive weighted objects
  - Door stoppers and neck wraps and warmers (priced $10 and up)

  - Available at drug stores and websites like Amazon, Bed Bath and Beyond and Amazon carry a brand called Bed Buddy.
  - Talk with your dentist as you may be able to get an old lead vest used for x-rays.

Vibrating products:
  - Hand held massager: Amazon as well as drug stores, Target, Walmart etc. (priced under $10)

  - Vibrating cushion: Amazon carries a brand by Dr. Scholl's (priced under $30)

  - Vibrating neck massager or vibrating cushion (priced $20 - $50)
Somewear’s Weighted Blankets provide deep touch pressure which promotes relaxation and restful night sleep.

- Gentle pressure: Feel the same as the experience as swaddling
- 100% Cotton Cover
- Polyester insert with glass beads and pellets
- Suitable for all ages
- 5 lb. blanket fits users up to 80 lbs.
- 8 lb. blanket fits up to 110 lbs.
- 12 lb. blanket fits up to 140 lbs.
- 16 lb. blanket fits up to 160 lbs., measures 48” x 60”
- 25 lb. blanket fits users 200 lbs. +, measures 48” x 70”
- Made in USA and imported materials

Sleep Tight Weighted Blanket Sold Separately.
## Calming and Alerting Sensory Strategies to Use with People with Down Syndrome and Alzheimer’s Disease

<table>
<thead>
<tr>
<th>Calming</th>
<th>Alerting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hot shower or bath</td>
<td>Cool shower or bath</td>
</tr>
<tr>
<td>Holding or stroking a pet</td>
<td>Holding ice or a cold washcloth in hand or to face</td>
</tr>
<tr>
<td>Sitting in front of a fireplace</td>
<td>Being in a cool room</td>
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<tr>
<td>Wrapping in a heavy blanket</td>
<td>Wrapping in cold bed sheets</td>
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<tr>
<td>Massage/deep pressure touch</td>
<td>Fast-paced, upbeat music</td>
</tr>
<tr>
<td>Isometric exercises/yoga</td>
<td>Alerting nature sounds (birds chirping)</td>
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<tr>
<td>Leisurely walks</td>
<td>Strong scents (peppermint)</td>
</tr>
<tr>
<td>Slow/rhythmic music</td>
<td>Light touch</td>
</tr>
<tr>
<td>Calming nature sounds (waterfalls, oceans)</td>
<td>Aerobic exercise</td>
</tr>
<tr>
<td>Humming/singing</td>
<td>Power walks</td>
</tr>
<tr>
<td>Soothing scents (lavender)</td>
<td>Rough or prickly materials or textures</td>
</tr>
<tr>
<td>Soft materials or textures</td>
<td>Fast or bumpy car ride</td>
</tr>
<tr>
<td>Rocking in a rocking chair or glider</td>
<td>Spinning on a swing</td>
</tr>
<tr>
<td>Swinging on a swing</td>
<td>Fast and/or jerky movements</td>
</tr>
<tr>
<td>Slow rhythmic motions (swaying to music)</td>
<td>Bright or flashing lights</td>
</tr>
<tr>
<td>Soft/low lighting</td>
<td>Drinking tea or coffee</td>
</tr>
<tr>
<td>Decaffeinated and herbal teas</td>
<td>Biting into a popsicle</td>
</tr>
<tr>
<td>Chewing gum or sucking on candy</td>
<td>Sour or hot foods/candy</td>
</tr>
</tbody>
</table>

Adapted from Champagne, 2011
Use of visual supports

• Pictures, words, or other images that are used to...
  – Share or manage expectations
  – Provide reminders
  – Maintain skills & independence
  – Help communicate
First / Then boards

- Help to manage expectations
  - Typically “first” is a non-preferred task and “then” is a preferred task
Share or manage expectations

My bathing routine

- Sunday
- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday

My Weekly Schedule

- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday

Checklist Before Going Downstairs

- Get dressed
- Go to bathroom
- Wash face
- Brush teeth
- Brush hair

Advocate Health Care
Provide reminders
Maintain skills & independence

Using the Restroom

1. pull down underwear
2. go to the bathroom
3. get toilet paper
4. sit down
5. pull pants up
6. flush
7. wash hands

'Ss Shower Routine

Get wet
Wash face and head
Rinse
Wash back, chest, arms
Rinse
Wash privates
Rinse
Wash legs and feet
Turn water off
Dry off
Help facilitate communication
Additional communication strategies

• Provide simple instructions
• Do not argue, you will not win
• Avoid asking them if they remember
• Smile
• Try not to raise your voice - speak calmly with a slow pace
• Get down on their level (eye-to-eye)
Medicinal strategies
Treat associated symptoms

• Depression
• Anxiety
• Agitation
• Sleep challenges
  – E.g. day/night reversals

• Medication choices are influenced by a patient’s particular symptoms and the particular effects and side effects of the medication.
• Observation and report of symptoms are key to assisting with medication selection.
Medications for Alzheimer’s disease

• Cholinesterase inhibitors (e.g. donepezil / Aricept)
• NMDA receptor antagonist (memantine / Namenda)

Cochrane Database of Systematic Reviews, Livingstone et al. 2015
Lessons Learned from Families and Caregivers
Changing expectations

• A challenge for family members is accepting the diagnosis and the behavior changes, loss of skills, and diminished interaction with the outside world.

• Family members often have to make changes to their loved one’s living situation.
Caregiver roles

**siblings**

- They were sometimes the primary caregiver for their brother or sister or were providing a lot of help for their parents.
- Many wished they had been better prepared for this new role.
Care for the caregivers

Everyone needs help and support when caring for a loved one with Alzheimer’s disease.

Sources of Support:

– Family members, friends and neighbors
– Adult Day Care Programs
– Respite Programs
– Home Health Agencies
– Support Groups
Resources for additional information and support
Aging Resources

https://adscresources.advocatehealth.com/resources/?category=Aging

Aging and Down Syndrome: A Health & Well-Being Guidebook
Author: National Down Syndrome Society - Resource
The resource linked below is a guidebook from the National Down Syndrome Society. According to the introduction, "Adults with Down syndrome, along with their families and caregivers, need accurate information and education about what to anticipate as a part of growing older, so they can se

Today & Tomorrow: A Guide to Aging with Down Syndrome
Author: Canadian Down Syndrome Society - Resource
The resource linked below is a guidebook on aging from the Canadian Down Syndrome Society. While some of the information and recommendations are specific to Canada, the resource contains helpful information about health concerns, life and behavior changes, Alzheimer's disease, and other topi
Aging Resources

https://adsresources.advocatehealth.com/resources/?category=Aging

Tips for Going Up and Down Stairs Safely

Author: Katie Frank, PhD, OTR/L - Occupational Therapist, Adult Down Syndrome Center

Going up and down stairs can be challenging for some people with Down syndrome. Aging, differences in depth perception, unsteady gait, and other issues may contribute to difficulty with navigating stairs. The suggestions below may help with going up and down stairs safely. Make sure there

Healthy Aging Toolkit: Promoting Healthy Aging While You Are Stuck at Home

Author: Mary Stephens, MD & E. Adel Herge, OTD, OTR/L, FAOTA

This list of resources for promoting healthy aging while you are stuck at home was developed by Mary Stephens, MD and E. Adel Herge, OTD, OTR/L, FAOTA.
Alzheimer’s Disease & Down Syndrome: A Practical Guidebook for Caregivers
Author: National Down Syndrome Society - Resource
The guidebook linked below was published by the National Down Syndrome Society "to help empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease, suggestions about how to carefully and thoughtfully evaluate changes that may be

Seizures in People with Down Syndrome and Alzheimer's Disease
Author: Brian Chicoine, MD - Medical Director, Adult Down Syndrome Center
We were sent a question about seizures in a person with Down syndrome who developed Alzheimer's disease. The individual continues to experience seizures despite being treated with levetiracetam (Keppra). We have provided some information below. Please note that this information is for educ
Alzheimer’s Disease Video Journal Segment 1

Author: Adult Down Syndrome Center - Video Journal
The video below is the first segment of our Alzheimer’s Disease Video Journal, which consists of interviews with Colleen Buffington, a woman with Down syndrome who was diagnosed with Alzheimer's disease in December 2016, and Bo Thompson, Colleen's sister and caregiver. Collee

Alzheimer's Disease Video Journal Segment 5b

Author: Adult Down Syndrome Center - Video Journal
The video below is the fifth segment of our Alzheimer's Disease Video Journal, which consists of interviews with Colleen Buffington, a woman with Down syndrome who was diagnosed with Alzheimer's disease in December 2016, and Bo Thompson, Colleen's sister and caregiver. Collee
Alzheimer’s Disease Resources

https://adsresources.advocatehealth.com/resources/?category=Alzheimer%27s%20Disease%20and%20Dementia

Let's Talk about Dementia
Author: Down's Syndrome Scotland
This booklet for individuals with Down syndrome explains dementia using easy-to-read language. It is provided by Down's Syndrome Scotland (www.dsscotland.org.uk/resources/publications/).

Living with Dementia
Author: Down's Syndrome Scotland
This booklet for families and caregivers of individuals with Down syndrome discusses dementia. It is provided by Down's Syndrome Scotland (www.dsscotland.org.uk/resources/publications/).
Other organizations

• Down Syndrome Organizations
  – The National Down Syndrome Congress website contains an affiliate directory of local Down syndrome support groups. Local groups can connect families to available resources and to other families. [https://www.ndsccenter.org/programs-resources/affiliate-organizations/local-and-national-support-networks](https://www.ndsccenter.org/programs-resources/affiliate-organizations/local-and-national-support-networks)

• Alzheimer’s Association
  – The Alzheimer’s Association has local chapters throughout the United States that can connect families to available resources.
  – They also have a 24/7 hotline: 800-272-3900
  – [https://www.alz.org/](https://www.alz.org/)
Online/phone support

- The National Task Group on Intellectual Disabilities and Dementia Practices
  - Offers an online support group. More information can be found at: [https://aadmd.org/ntg/onlinesupportgroup](https://aadmd.org/ntg/onlinesupportgroup)

- Down Syndrome and Dementia Family Caregiver Telephone Support Group
  - 3rd Thursday of every month, 6:00-7:00 pm (Pacific Time)
  - To join please contact Marianne Iversen at [Marianne@dscba.org](mailto:Marianne@dscba.org)
Online/phone support

• Facebook groups
  – Down Syndrome and Alzheimer’s Disease Support Group
    • [https://www.facebook.com/groups/1683973878347586/](https://www.facebook.com/groups/1683973878347586/)
    • Moderated by the Down Syndrome Association of Wisconsin
  – Down Syndrome and Alzheimer’s/Down Syndrome Regression Support
    • [https://www.facebook.com/groups/DSALZ/](https://www.facebook.com/groups/DSALZ/)
    – These are private groups. You need to request to join the groups.
State services

• Varies from state to state

• Illinois Department of Human Services
  – Developmental Disabilities Service System
    • Independent Service Coordination Agencies (ISC) can help families access services and make changes to their loved one’s living arrangements. To find a local ISC: http://www.dhs.state.il.us/page.aspx?module=12&officetype=3&county or 1-888-337-5267
  – Rehabilitation Services
    • The Home Services Program provides services for individuals under age 60 with severe disabilities so they can remain in their home. http://www.dhs.state.il.us/page.aspx?module=12&officetype=7&county= or 1-800-843-6154
Questions?

Resource Library
adscresources.advocatehealth.com

Facebook
www.facebook.com/adultdownsyndromecenter

E-mail Newsletter
http://eepurl.com/c7uV1v