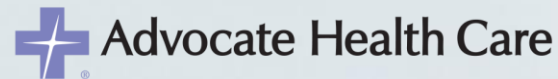


# Aging and Alzheimer's Disease in Adults with Down Syndrome

Adult Down Syndrome Center

November 10, 2020

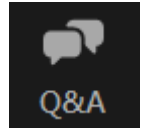
*Resource Library:* [adscresources.advocatehealth.com](https://adscresources.advocatehealth.com)



We are  AdvocateAuroraHealth

# 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](http://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

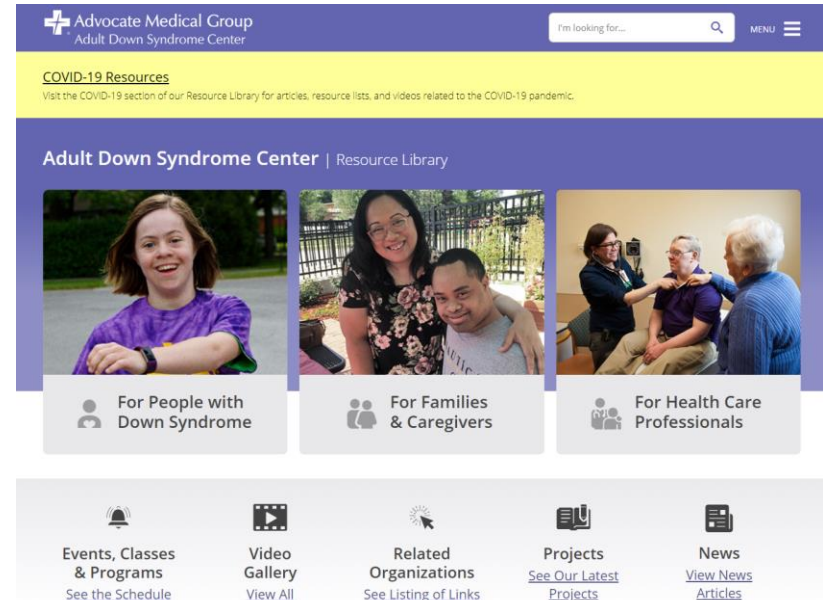
Park Ridge, IL





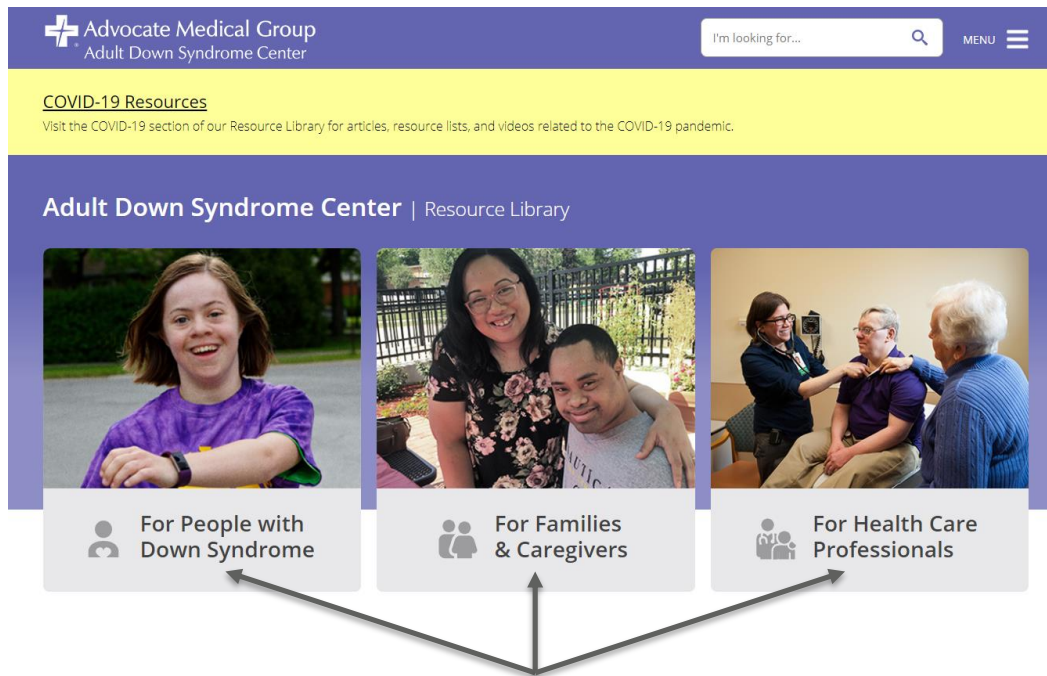
# Online Resource Library

- Contains videos, articles, and booklets on a variety of topics, including aging and Alzheimer's disease.
- Resources are continually being updated.




[adsresources.advocatehealth.com](https://adsresources.advocatehealth.com)


# Resource Library - [adscresources.advocatehealth.com](https://adscresources.advocatehealth.com)



Advocate Medical Group  
Adult Down Syndrome Center

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I'm looking for... 

MENU 

Resources Media Gallery Events, Classes & Programs Related Organizations Projects About the Center

Home > Resources > Families and Caregivers

**Navigate**


Use these links to see **all** resources for an audience

People With Down Syndrome

**Families and Caregivers**

Health Care Professionals

**Narrow Results**


Search Within 

**Review our COVID-19 Resources**

Showing 1 - 24 of 220


Sort By **Title (A to Z)**

1 2 3 4 5 > Page 1 of 10

 **"Self-Talk" in Adults with Down Syndrome**  
Author: Dennis McGuire, PhD; Brian Chicoine, MD; & Elaine Greenbaum, PhD - Disability Solutions (July/August 1997)  
The article linked below was published in the July/August 1997 edition of Disability Solutions and describes "self-talk" in adults with Down syndrome.  
<http://downsyndromenutrition.com/images/stories/dsolnsvol2/2-2.pdf>

## 2. Scroll to the Narrow Results section

**Narrow Results**

Search Within 

**Topic**

- ☐ Aging (14)
- ☐ Alzheimer's Disease and Dementia (20)
- ☐ Anesthesiology (1)
- ☐ Autism Spectrum Disorder (1)
- ☐ Cancer (4)

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





**Brian Chicoine, MD**



**Katie Frank, PhD, OTR/L**

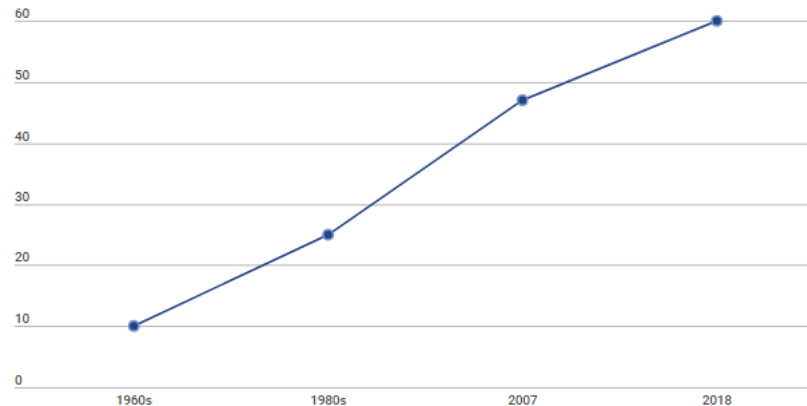
# Agenda

- 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

# Aging

# 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 Fahey and Hailey Mensik/Cronkite News

# Healthy aging





# Health screening

- Healthcare guidelines for adults with Down syndrome
- Cancer screening?
  - Colonoscopies, mammograms

## GLOBAL MEDICAL CARE GUIDELINES for Adults with Down Syndrome Checklist



This checklist is intended to support the health of adults with Down syndrome directly or through their caregivers. We encourage this checklist to be shared with your medical professionals. Statements in blue represent our recommended, periodic health screening/assessments that should begin at a specific age. Below each blue screening/assessment recommendation, there are blank boxes. Caregivers or individuals with Down syndrome can check off, date, or initial each blank box when the screening/assessment is completed. For screening/assessment recommendations with a time range (e.g. 1-2 years), the box size represents the longer possible time frame, such as 2 years versus 1. Statements in gray represent advisory recommendations that individuals with Down syndrome and caregivers should follow throughout adulthood.

	21-29 Years	30-39 Years	40-49 Years	50-59 Years	60+ Years
	A review of behavioral, functional, adaptive, and psychosocial factors should be performed as part of an annual history that clinicians obtain from all adults with Down syndrome, their families, and caregivers. (Boxes below represent 1 year increments)				
Behavior					
	When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should: a) Evaluate for medical conditions that may present with psychiatric and behavioral symptoms and b) Refer to a clinician knowledgeable about the medical, mental health disorders, and common behavioral characteristics of adults with Down syndrome.				
	When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should follow guidelines for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The Diagnostic Manual-Intellectual Disability 2 (DM-ID-2) also may be used to adapt diagnostic criteria from the DSM-5.				
Dementia					
	Medical professionals should assess adults with Down syndrome and interview their primary caregivers about changes from baseline function annually beginning at age 40. Decline in the six domains as per the National Task Group - Early Detection Screen for Dementia (NTG-EDSD) should be used to identify early-onset age-related Alzheimer's type dementia and/or a potentially reversible medical condition. (Boxes below represent 1 year increments)				
Diabetes					
		For asymptomatic adults with Down syndrome, screening for type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 30. (Boxes below represent 3 year increments)			
		For any adult with Down syndrome and comorbid obesity, screening for type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 2-3 years beginning at age 21. (Boxes below represent 3 year increments)			
Cardiac					
	For adults with Down syndrome without a history of atherosclerotic cardiovascular disease, the appropriateness of statin therapy should be assessed every 5 years starting at age 40 and using a 10-year risk calculator as recommended for adults without Down syndrome by the U.S. Preventive Services Task Force. (Boxes below represent 5 year increments)				
	For adults with Down syndrome, risk factors for stroke should be managed as specified by the American Heart Association/American Stroke Association's Guidelines for the Primary Prevention of Stroke.				
	In adults with Down syndrome with a history of congenital heart disease, given the elevated risk of cardiovascular stroke, a periodic cardiac evaluation and a corresponding monitoring plan should be reviewed by a cardiologist.				
Obesity					
	Healthy diet, regular exercise, and calorie management should be followed by all adults with Down syndrome as part of a comprehensive approach to weight management, appetite control, and enhancement of quality of life.				
	Monitoring for weight change and obesity should be performed annually by calculating Body Mass Index in adults with Down syndrome. The U.S. Preventive Services Task Force Behavioral Weight Loss Interventions to Prevent Obesity-Related Morbidity and Mortality in Adults should be followed. (Boxes below represent 1 year increments)				
Atlantoaxial Instability					
	In adults with Down syndrome, routine cervical spine x-rays should not be used to screen for risk of spinal cord injury in asymptomatic individuals.				
	Annual screening for adults with Down syndrome should be based on a review of signs and symptoms of cervical instability using targeted history and physical exam. (Boxes below represent 1 year increments)				
Osteoporosis					
	For primary prevention of osteoporotic fractures in adults with Down syndrome, there is insufficient evidence to recommend for or against applying established osteoporosis screening guidelines, including fracture risk estimation; thus, good clinical practice would support a shared decision-making approach to this issue would support a shared decision-making approach to this issue.				
	All adults with Down syndrome who sustain a fragility fracture should be evaluated for secondary causes of osteoporosis, including screening for hyperthyroidism, celiac disease, vitamin D deficiency, hypoparathyroidism and medications associated with adverse effects on bone health.				
Thyroid					
	Screening adults with Down syndrome for hypothyroidism should be performed every 1-2 years using a serum thyroid-stimulating hormone (TSH) test beginning at age 21. (Boxes below represent 2 year increments)				
Celiac Disease					
	Adults with Down syndrome should receive an annual assessment for gastrointestinal and non-gastrointestinal signs and symptoms of celiac disease using targeted history, physical examination and clinical judgement of good practice. (Boxes below represent 1 year increments)				

This checklist is not intended to be diagnostic. Presentation of medical and mental health conditions for people with Down syndrome may be atypical. Similar signs and symptoms may be a consequence of multiple reasons, including different disease processes. Thus, the patient evaluation should include considerations of additional causes for any detected signs or symptoms. The development of new and/or changes in signs or symptoms should prompt a comprehensive evaluation with your clinician.

© 2020 Global Down Syndrome Foundation

<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<sup>st</sup> chromosome.
  - Amyloid precursor protein (APP)
- Since people with DS have an extra full or partial copy of the 21<sup>st</sup> 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

Regression syndrome	BOTH	Alzheimer's disease
Age of onset = teens, early 20s	Decline in skills	Age of onset = > 40
Sometimes reversible		Not reversible

[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



A toilet or bath may not be seen or used appropriately if the bathroom is white.



Adding colour as shown here makes the toilet easier to see.

[LINK TO RESOURCE](#)



## Tips for Going Up and Down Stairs Safely

Author: Katie Frank, PhD, OTR/L - Occupational Therapist,  
Going up and down stairs can be challenging for some people with  
in depth perception, unsteady gait, and other issues may contribute.  
The suggestions below may help with going up and down stairs safely.

[LINK TO RESOURCE](#)



# 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



[LINK TO RESOURCE](#)

# 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



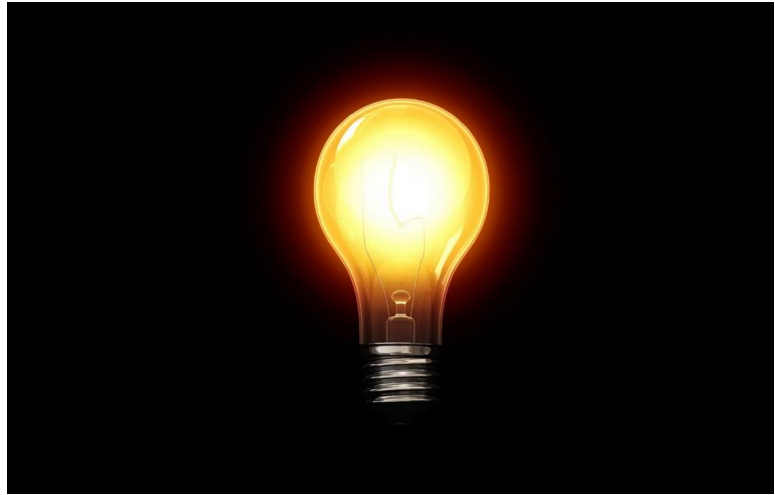
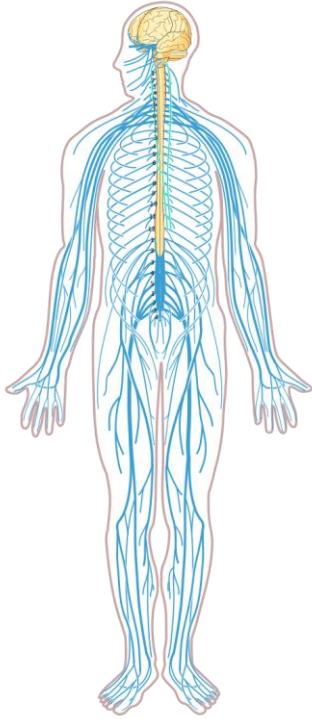
*This shows how a white plate may become lost against a white table or cloth.*



*By adding a coloured background the plate is easier to identify.*



# 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 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 restart their body and prepare to complete the required task. This also goes for transitions. 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/stroller/wagon
- Rolling up in a blanket like a burrito
- Bear hugs or being squeezed between pillows or cushions
- Using play-doh or theraputty
- 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://adsresources.advocatehealth.com/resources/proprioceptive-input/>

## Joint compression-Upper body

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](mailto: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.



[https://adsresources.advocatehealth.com/assets/1/13/Upper\\_Body\\_Joint\\_Compression.pdf?55](https://adsresources.advocatehealth.com/assets/1/13/Upper_Body_Joint_Compression.pdf?55)

## 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.sensacalm.com/weighted-blankets/>
- <http://www.mosaicweightedblankets.com/> (they even offer DIY kits)
- Amazon, Bed Bath & Beyond, and Etsy 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)

[https://adscresources.advocatehealth.com/assets/1/13/Affordable\\_Sensory\\_Equipment\\_Recommendations.pdf?33](https://adscresources.advocatehealth.com/assets/1/13/Affordable_Sensory_Equipment_Recommendations.pdf?33)





D

Somme... Tight Weighted Blankets provide... pressure which  
promotes... restful night sleep

- Gentle pressure... experience as swaddling
- 100% Cotton Cover
- Polyester insert with... pellets
- Suitable for all ages
- 5 lb. blanket fits users...
- 8 lb. blanket fits u...
- 12 lb. blanket...
- 16 lb. blanket... lb, meas...
- 25 lb. blanket... lbs. +, measures...
- Made...
- ...and imported materials

by Sleep Tight Weighted Blanket Sold Sep

# Calming and Alerting Sensory Strategies to Use with People with Down Syndrome and Alzheimer's Disease

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

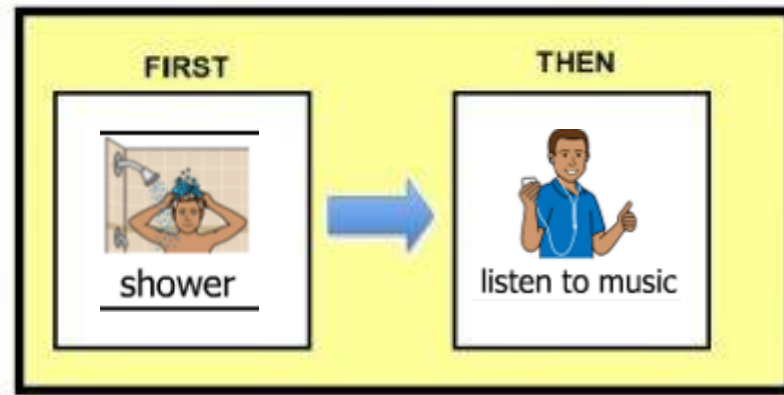
Adapted from Champagne, 2011

# 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

## Checklist Before Going Downstairs

Get dressed



Go to bathroom



Wash face



Brush teeth



Brush hair



## My bathing routine

Sunday

Monday

Tuesday

Wednesday

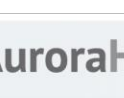
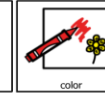
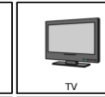
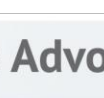
Thursday

Friday

Saturday







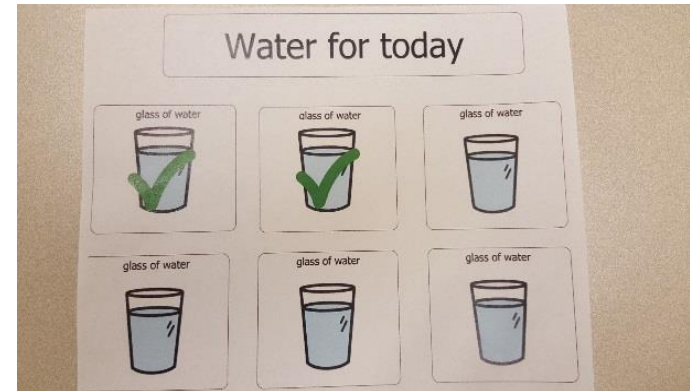
## My Weekly Schedule



# Provide reminders



Phone Call Schedule						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
						
call at 8PM	call at 8PM		call at 8PM			call at 8PM



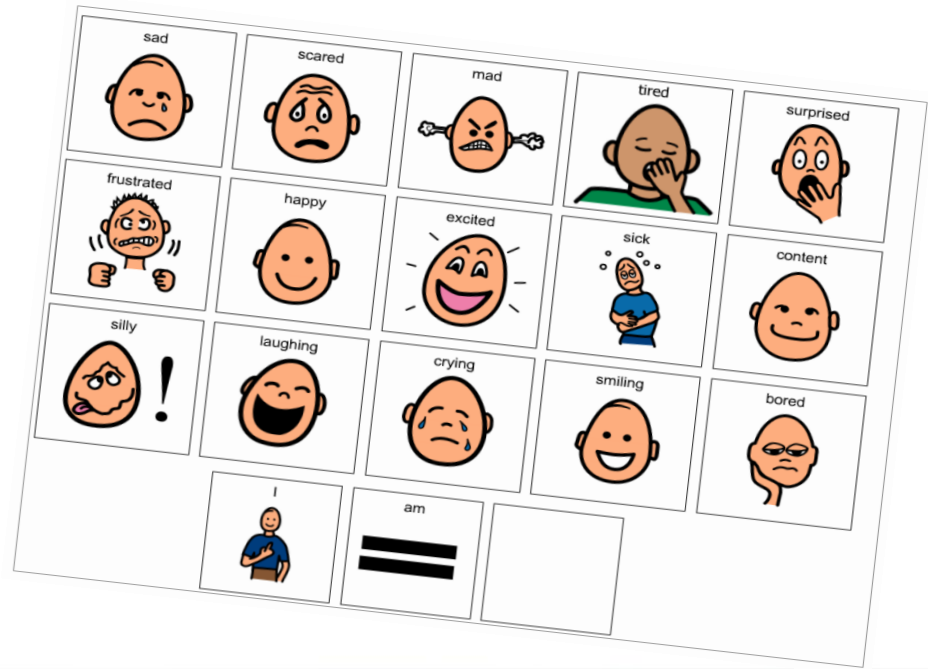
# Maintain skills & independence



## █'s Shower Routine



# 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

We are **AdvocateAuroraHealth™**

# 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://adsresources.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

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 is at least one handrail. Having two handrails is best (one on each side or side when possible).
- Keep handrails well lit. When possible, include lights on the walls adjacent the stairway.
- Remove plants and other obstructions from the walls of the stairway to minimize distractions.
- Use a slip-resistant tape on the tread of the steps.



## 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

## Promoting Healthy Aging While You Are Stuck at Home

May 25, 2020

By Mary Stephens, MD MPH, and E. Adel Herge, OTD, OTR/L, FAOTA

Healthy Aging Toolkit

Download the toolkit

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Download the toolkit

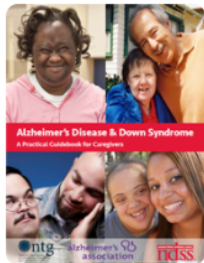
## Healthy Aging Toolkit: Promoting Healthy Aging While You Are Stuck at Home

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 Resources

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



## 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

Advocate Health Care - Medical Director, Adult Down Syndrome Center

We were sent a question about seizures in people 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 educational purposes only.

- Seizures are more common in people who develop Alzheimer's disease - both people with and without Down syndrome - than in people who do not develop Alzheimer's disease. However, the incidence of seizures as a symptom of Alzheimer's disease is greater in people with Down syndrome than in people without Down syndrome.
- For people with Down syndrome the seizures usually have been in the context of another health problem. For people with Down syndrome, seizures are usually associated with another health problem.
- Seizures may range from mild to severe. Seizures may be treated with medication. However, seizures are not always treatable with medication. Some cases of seizures in people with Down syndrome are not treatable with medication.

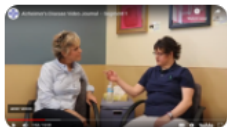
## Seizures in People with Down Syndrome and Alzheimer's Disease

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 educational purposes only.

# Alzheimer's Disease Resources

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## 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://adscresources.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/](http://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/](http://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>
- 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/>

# 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>
- 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/>
    - Moderated by the Down Syndrome Association of Wisconsin
  - Down Syndrome and Alzheimer's/Down Syndrome Regression Support
    - <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](https://adscresources.advocatehealth.com)

Facebook

[www.facebook.com/adultdownsyndromecenter](https://www.facebook.com/adultdownsyndromecenter)

E-mail Newsletter

<http://eepurl.com/c7uV1v>