

Adapting Activities for Individuals with Down Syndrome as Alzheimer's Disease Progresses

Katie Frank, PhD, OTR/L

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NDSS Mission

NDSS is creating a world where individuals with Down syndrome thrive.

NDSS Core Pillars

NDSS supports and advocates for the Down syndrome community by focusing on four key pillars:



**Resources
& Support**



Research



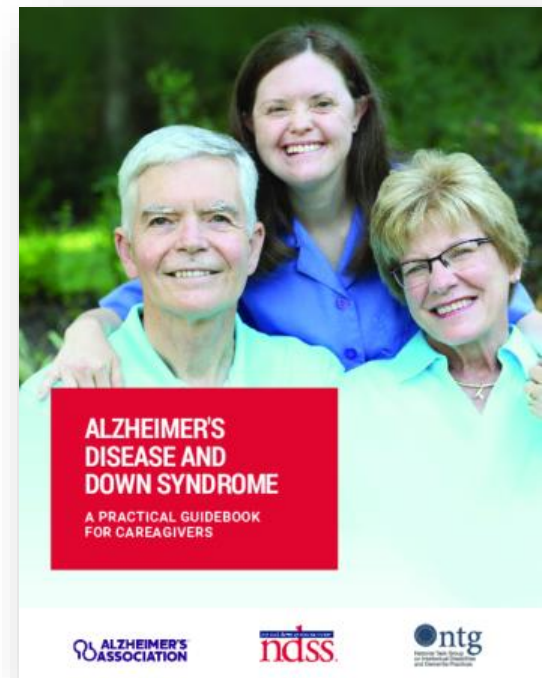
**Advocacy
& Policy**



**Community
Engagement**

Health & Wellness

- [Informative Health & Wellness resources](#)
- [Health-related advocacy and policy](#)
- [Alzheimer's Disease & Down Syndrome: A Practical Guide for Caregivers](#)
- [CARE Down Syndrome](#)
- [Health & Wellness Newsletter](#)



Welcome!

Katie Frank, PhD, OTR/L, Occupational Therapist at Advocate Medical Group

Katie Frank, PhD, OTR/L has worked as an occupational therapist at the Adult Down Syndrome Center since 2016 and in the field of occupational therapy since 2001. She earned her degree in occupational therapy from Saint Louis University and her PhD in Disability Studies from the University of Illinois at Chicago. Most of her work has been with individuals with Down syndrome of all ages. Dr. Frank's experience includes treatment and evaluation as well as facilitating groups for people with Down syndrome, conducting trainings for staff, families, and caregivers, and offering a variety of other educational opportunities across the United States. She is the immediate past President of DSMIG-USA.



Today's objectives

- Describe the progression of assistance.
- Discuss strategies to modify or adapt activities.
- Provide examples of activity modifications.
- Identify equipment that may improve safety.
- Share resources.



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.

Neither Advocate Health nor Katie endorse any products mentioned in this presentation.

Supporting individuals with Down syndrome

How individuals with Down syndrome learn

- Visual learners and do well learning from someone that looks like them.
 - Pair pictures with spoken words.
- Require simple directions.
 - Say what to do instead of what not to do.
- Are not as strong with auditory memory and auditory processing and have difficulty retaining directions or information that is only presented verbally.
 - Allow adequate response time.
- Have fewer short-term memory channels.
 - Break down directions into smaller steps.

Progression of assistance



Progression of assistance

Dependence

Independence



- Able to complete task 100% on their own, even if modifications or adaptations are put into place

**No
assistance**

Progression of assistance

Dependence

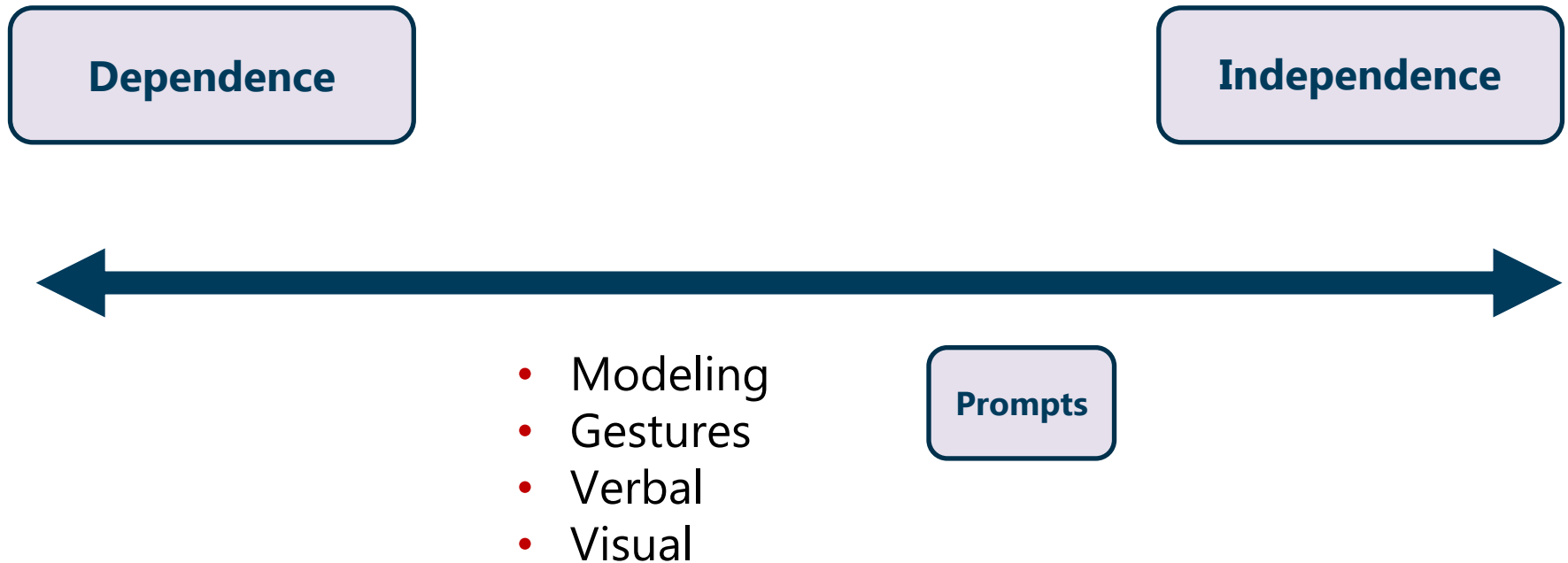
Independence



- Able to complete task on their own but requires supervision for safety.
- May also use modifications or adaptations.

Supervision

Progression of assistance



Progression of assistance

Dependence

Independence



**Minimal
assistance**

- Person requires 25% physical support and can complete 75% of the task on their own.
- Hand over hand or hand under hand assistance.
- Providing set-up.
- May also use modifications or adaptations.

Progression of assistance

Dependence

Independence

**Moderate
assistance**

- Person requires 50% physical support and can complete 50% of the task on their own.
- May use modifications or adaptations.
- Caregiver may need durable medical equipment for safety.

Progression of assistance

Dependence

Independence

**Maximal
assistance**

- Person requires 75% physical support and can complete 25% of the task on their own.
- Adaptive equipment or durable medical equipment may be used by caregiver.

Progression of assistance

Dependence

Independence

**Full
assistance**

- Need 100% physical support

Strategies to modify or adapt activities

Strategies to consider

- Activity/task analysis
- Visual supports
- Sensory system

Activity analysis/Task analysis

- Breaking task down into individual steps.
 - Example- getting dressed
 - Gather new/clean clothes.
 - Remove old/dirty clothes.
 - Put on undergarments.
 - Dress lower body
 - Pants/shorts/skirt.
 - Socks and shoes.
 - Upper body dressing
 - Shirt.

What are visual supports?

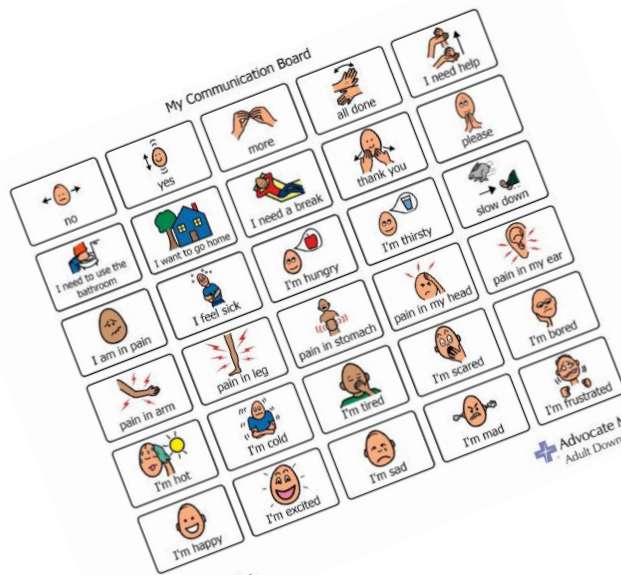
- Pictures, words or other images that are used to...
 - Help communicate.
 - Share or manage expectations.
 - Provide reminders/offer choices.
 - Maintain skills & independence.

Using visual supports to help learn

- Visual supports help to provide/establish structure and routine.
- Provide memory and comprehension strategies.
- Lessen the battle between parent/caregiver and person with I/DD.
- Help teach/show what to do.
- Can provide motivation.
- Provides opportunity to offer choices.
- Eliminates need to process instructions auditorily.

How can visual supports be implemented?

Help communicate

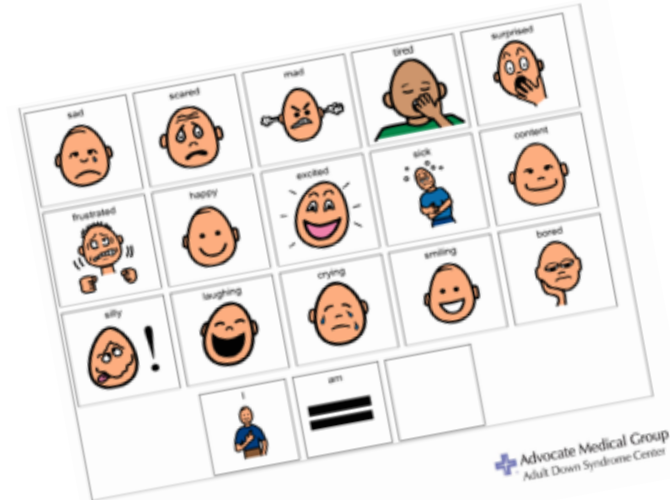


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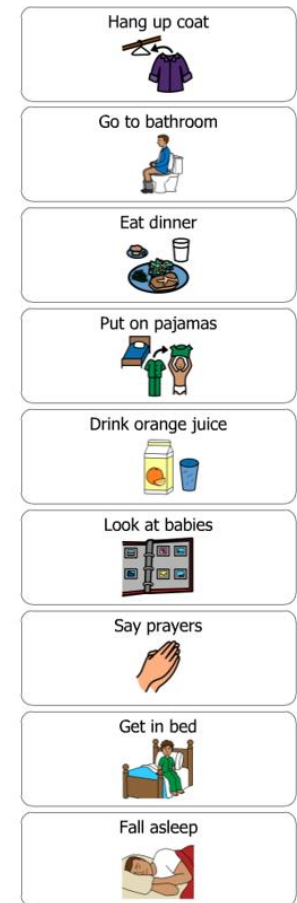
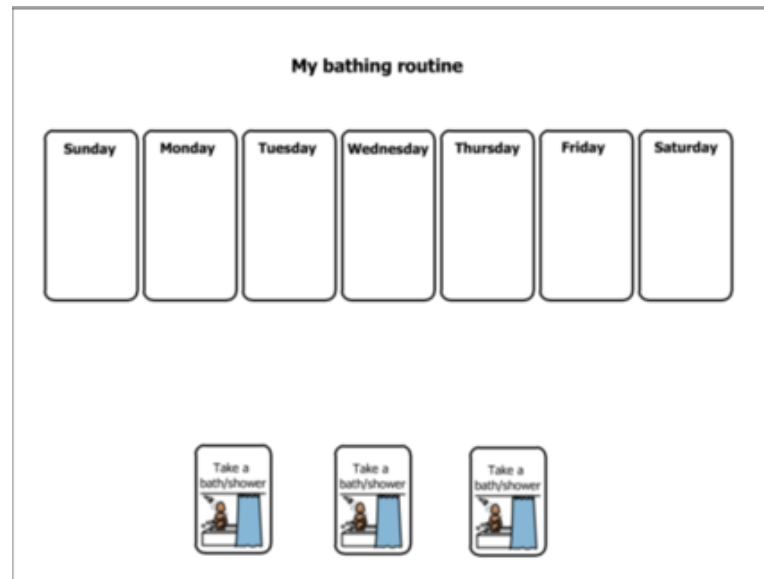
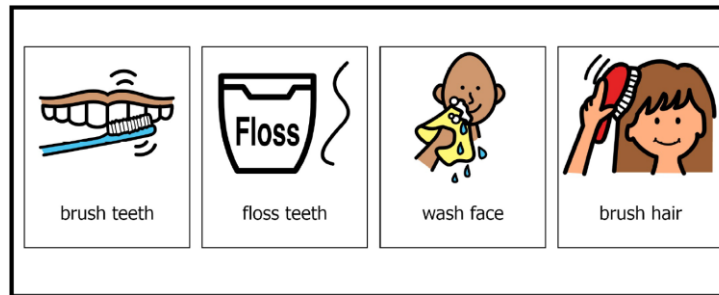
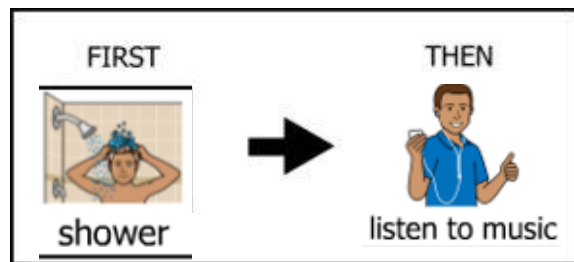
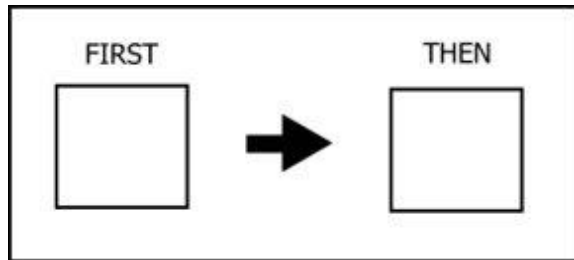
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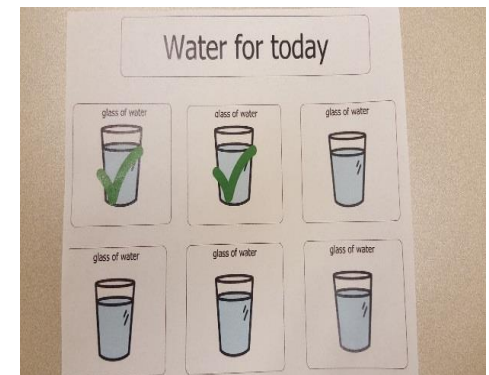
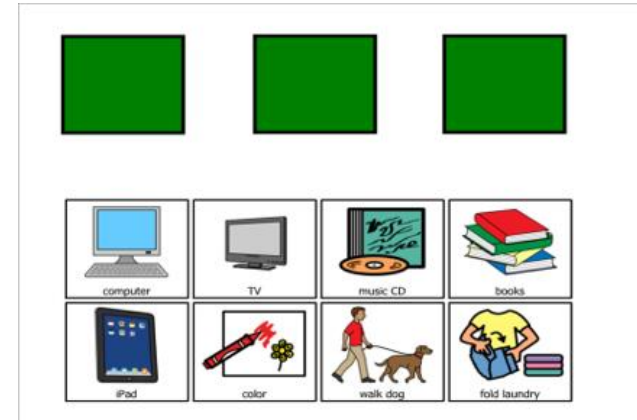
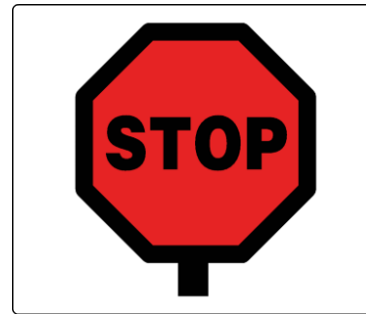
How can visual supports be implemented?

Share or manage expectations



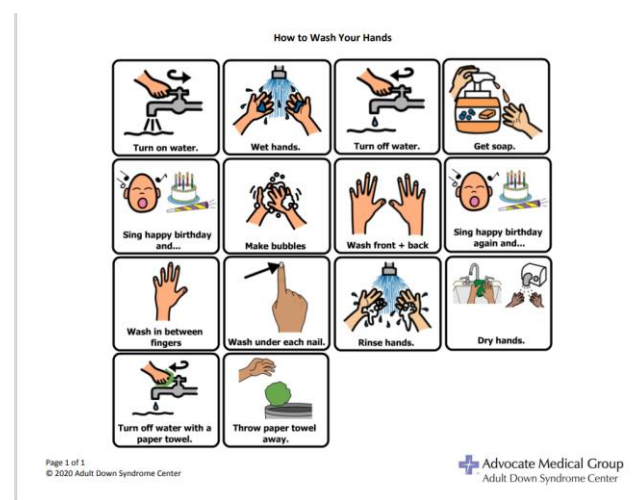
How can visual supports be implemented?

Provide reminders/offer choices

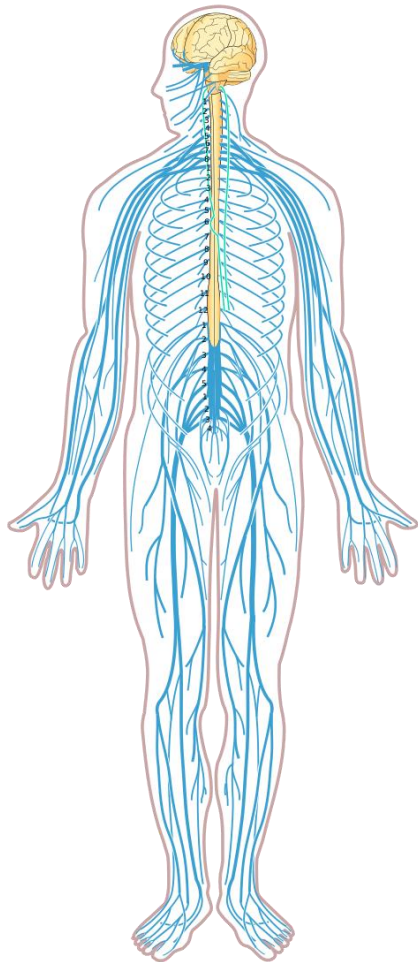


How can visual supports be implemented?

Maintain skills and independence



Our sensory system



Our sensory system



Our sensory system



The kink may impact behavior.

We may see...

- Verbal outbursts
- Physical aggression
- Slowing down
- Shutting down

Calming and alerting strategies

Individuals with 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

<https://adsresources.advocatehealth.com/resources/?category=Sensory>

Examples of activity modification and progression of assistance

Feeding/Eating

- As Alzheimer's disease progresses, it is common to develop difficulty eating or swallowing foods or liquids safely.
 - May not remember
 - that they have or have not eaten.
 - how to properly chew or swallow.
 - recognize thirst or hunger cues.
 - Cough reflex weakens.
 - Takes longer to eat and at risk for weight.

Feeding/Eating strategies

- Allow more time to eat.
- Provide finger foods.
- Cut food into smaller-sized bites.
- Provide smaller portions of food more frequently throughout the day.
- Observe for changes in swallowing such as coughing or gagging while eating.
- Consider using adaptive equipment.
- Avoid extra noise when eating (turn TV off, limit conversation).
- Contrast between plate and table and food and plate.

Feeding/Eating progression

- **Supervision** – watching to make sure they do not eat too fast.
- **Prompts** – verbal prompt to chew before swallowing.
- **Minimal assistance** – you set up the food, but they are able to do everything else.
- **Moderate assistance** – you set up the food and load the utensil, but they are able to bring the loaded utensil to their mouth on their own.
- **Maximal assistance** – you are feeding them, but they are able to chew and swallow on own.
- **Full assistance** – feeding tube.

Bathing

- As Alzheimer's disease progresses, it is common to develop difficulty with bathing.
 - Difficulty stepping into and out of tub/shower.
 - Fear of the water.
 - Preference not to put head back.
 - Unable to follow the steps to wash themselves without assistance.

Bathing strategies

- Use medical equipment like shower chair or transfer tub bench and grab bars.
- Use a handheld shower head.
- Consider visors to keep water off face.
- Sponge bathe as needed.
- Use dry shampoo or shampoo caps.
- Talk to the person and tell them what you are doing while you are assisting.
- Consider the time-of-day task is completed.



Bathing progression

- **Supervision** – supervision for safety or thoroughness
- **Prompts** – verbal prompts for each step or gestural prompt for water temperature
- **Minimal assistance** – turn on the water to correct temperature, washes body on own, assistance with washing hair
- **Moderate assistance** – turn on water to correct temperature, set-up soap, person washes body on own, assistance with washing hair
- **Maximal assistance** – get into bath or shower on own, most likely uses shower chair or bench and handheld shower head, unable to assist with the steps of washing
- **Full assistance** – sponge baths

Dressing

- As Alzheimer's disease progresses, it is common to develop difficulty with dressing.
 - Difficulty stepping into and out of pants/underwear.
 - Sensitivity to textures.
 - Unable to follow the steps to get dressed without assistance.
 - Refusal to complete task because lack understanding of why it needs to occur.

Dressing strategies

- Have person sit when getting dressed.
- Consider clothing without fasteners like buttons and zippers.
- Limit wearing undergarments.
- Tell the person what you are doing while you are assisting.
- Set out clothes for them if selection is an issue.
- Use a visual support for the steps to get dressed.
- Label their dresser or closet.
- Remove clothing that is not in season.

Dressing progression

- **Supervision** – supervision for safety or clothes selection.
- **Prompts** – verbal prompts to select clothes.
- **Minimal assistance** – gets self-dressed, but assistance needed with fasteners.
- **Moderate assistance** – can dress either upper or lower body, but not both.
- **Maximal assistance** – assistance to dress both upper body and lower body. Needs physical assistance to stand but will pull up lower body dressing with prompts.
- **Full assistance** – wearing a hospital gown, if anything, for ease of care.

Mobility

- As Alzheimer's disease progresses, it is common to develop difficulty with walking and balance.
 - difficulty navigating environment.
 - difficulty climbing stairs, stepping on or off curbs, or walking through doorways.
 - decreased strength impacts the ability to walk and get up and down from sitting.
 - hearing and vision may worsen also impacting balance and mobility.
 - medications may cause dizziness.

Mobility strategies

- Provide handheld assistance.
- Use a gait belt.
- Consider walkers or wheelchairs.
- Provide adequate lighting.
- Remove throw rugs and excess furniture.
- Provide supportive well-fitting footwear.
- Use chairs with armrests to help get up and down.
- Use additional lighting in bathroom and stairwells.

Mobility progression

- **Supervision** – monitoring for safety when going up or down stairs.
- **Prompts** – gestural prompts or verbal prompts to use a handrail.
- **Minimal assistance** – handheld assistance when going up or down stairs or rails needed to get up from a chair. If using a walker, needs it set-up for them to use on own.
- **Moderate assistance** – can walk short distances with a walker or rolling walker with a gait belt and handheld assistance. Not using stairs well. May use wheelchair for long distances.
- **Maximal assistance** – can get up and down from a chair with arm rests to transfer to a wheelchair with a gait belt. Uses a wheelchair to get around.
- **Full assistance** – non ambulatory and assistance for all transfers. Uses a wheelchair.

Toileting

- As Alzheimer's disease progresses bowel and bladder functions deteriorate.
 - Memory impairment leads to
 - difficulty interpreting bathroom cues/urge.
 - inability to locate the bathroom.
 - inability to properly ask for help.
 - difficulty sequencing toileting routine.

Toileting strategies

- Provide verbal reminders to use the bathroom.
- Mark the bathroom door so the person can identify that room is the bathroom.
- Use a toileting schedule.
- Add contrast to the toilet in the bathroom.
- Limit fluids before bedtime.
- Consider 3-in-1 toilet or urinal.
- Use chucks when laying in bed.
- Use adult diapers.
- Use flushable wipes when assisting with hygiene.

Toileting progression

- **Supervision** – ensure they go in correct public restroom or close the door for privacy-perhaps wash their hands.
- **Prompts** – verbal prompt to use the toilet or wash hands.
- **Minimal assistance** – can complete the entire task, but assistance with hygiene after a bowel movement.
- **Moderate assistance** – same as minimal assistance, but also wears an adult diaper in case of accidents.
- **Maximal assistance** – wears adult diapers.
- **Full assistance** – uses a catheter.

Hygiene

- As Alzheimer's disease progresses, it is common to develop difficulty with hygiene tasks like brushing teeth, shaving, cutting nails, brushing hair etc.
 - Increased sensitivity to textures and sounds.
 - Unable to follow the steps to complete hygiene without assistance.
 - Refusal to complete task because lack understanding of why it needs to occur.

Hygiene strategies

- Avoid completing hygiene tasks in front of a mirror.
- Use an electric toothbrush or a 3 sided toothbrush.
- Try floss picks.
- Nair or other cream for hair removal.
- Rotating or automatic nail clippers.
- Brush/comb hair when it is wet.
- Pick and choose your battles.
- Consider time of day the tasks are completed.



Sleep

- As Alzheimer's disease progresses sleep may become dysregulated.
 - Mixing days and nights.
 - Napping throughout the day.
 - Refusing to go to sleep.
 - Slow to fall asleep.
 - Waking up in the middle of the night and trouble falling back to sleep.

Sleep strategies

- Dark room, close curtains.
- Sound machine.
- Sleep with a favorite object.
- May need bed rails.
- May need bed alarm.
- Use a sheet placed horizontal under the person to help adjust in bed.
- Label bedroom with a photo of them.

Leisure activities

- Listen to music.
- Watch a favorite tv show.
- Color or do art.
- Create a memory box.
- Look at old photos.
- Take walks or just sit outside.
- Assist with chores like wiping counters or folding laundry.
- Add sensory play.

Leisure strategies

- Offer support, cues, and supervision.
- Allow more time to complete activities than previously.
- Be realistic. Create a mixture of activity and rest.
- Break activities into simple steps and focus on one task at a time.
- Let the individual feel useful and helpful.
- Relax your expectations.
- Don't criticize or correct.
- Involve the person through conversation. Talk to the individual about what you're doing.
- Try again later. If something isn't working, it may be the wrong time of day, or the activity may be too complicated. Try again some other time, or adapt the activity

Home modifications and equipment recommendations

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.
- Walk-in shower vs. tub shower.



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.

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.
- Close curtains at night.
- Turn down the volume on TV before changing channels.

Adaptive equipment

- Weighted utensils.
- Adapted plates.
- Contrasting colors.
- Cups with lids.
- Long handled sponges.
- Automatic soap or toothpaste dispensers.



Medical equipment

- Consider a shower chair and handheld shower head.
- Grab bars.
- Raised toilet seat or rails for the toilet.
- Gait belt.
- Wheelchair.
- Rolling walker or standard walker.
- Patient transfer sheet.
- Hospital bed.
- 3-in-1 commode.



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).

Takeaways

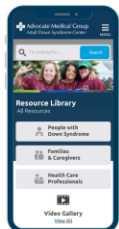
- As an individual ages, a change in functional status occurs.
- More assistance may be needed to help an individual with I/DD as there is a decline in skills.
- It is important to ensure safety of the individual as well as the caregiver when providing care.
- Keep the environment calm, predictable, obvious, familiar, and safe.

Resources

Adult Down Syndrome Center

FREE HEALTH RESOURCES

for people with Down syndrome, families and caregivers, and professionals



Resource Library



Find information on aging, puberty, mental health, self-talk, weight management, Alzheimer's disease, social skills, and more.

adscresources.advocatehealth.com

Facebook & Instagram



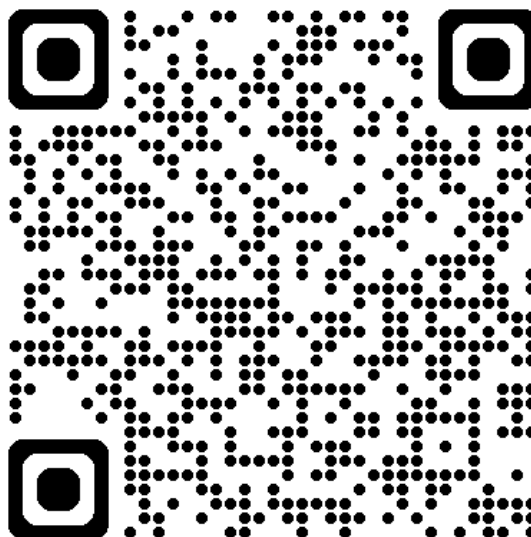
@adultdownsyndromecenter

Email List



www.eepurl.com/c7uV1v

 Advocate Medical Group
Adult Down Syndrome Center



Archiving and Showering Tips

Download a Health Care Resource Center - PDF 10/1/16

Archiving and showering tips and tricks for people with Down syndrome and other disabilities. These tips are meant to help people with Down syndrome and other disabilities live more independently.

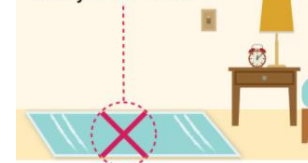
Archiving and showering tips and tricks for people with Down syndrome and other disabilities. These tips are meant to help people with Down syndrome and other disabilities live more independently.



Placing a shower head and a person with Down syndrome can also help them live more independently.



Don't use area rugs and check that all carpets are fixed firmly to the floor.



WHEN I GET DRESSED I WILL PUT ON...



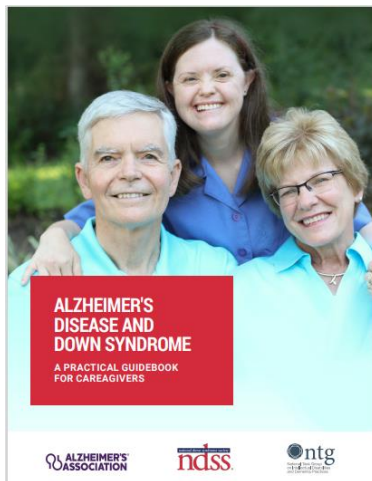
Tips for Going Up and Down Stairs Safely

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.

Additional resources

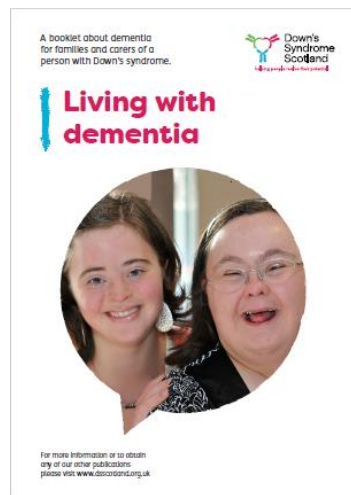
NDSS caregiver guide

[caregiver_guide_eng\(ndss.org\)](http://caregiver_guide_eng(ndss.org))



Down's syndrome Scotland Living with Dementia

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(dsscotland.org.uk)



NDSS Aging Guide

[Aging_and_Down_Syndrome:
A Health & Well-Being
Guidebook | National Down
Syndrome Society \(NDSS\)](http://Aging_and_Down_Syndrome:_A_Health_&_Well-Being_Guidebook_|_National_Down_Syndrome_Society_(NDSS))



Canadian Down Syndrome Society

Aging-Package-APR-2020.pdf



Questions?

Contact information

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Thank you!

Head to www.ndss.org for more
information and additional resources.