

Alzheimer's Disease Prevention & Healthy Aging in People with Down Syndrome

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We are  AdvocateAuroraHealth

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.

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.

Objectives

- Discuss strategies to promote healthy aging
- Provide a brief overview of Alzheimer's disease in people with Down syndrome
- Describe current knowledge of Alzheimer's disease prevention and treatment

Healthy Aging

Healthy aging

- Includes optimizing physical, mental, *and* social health.
- Health promotion
- Medical care

Health promotion

Good sleep

- Sleep hygiene
- Review current medications
- Consider natural products
- Talk with healthcare provider about prescription medications

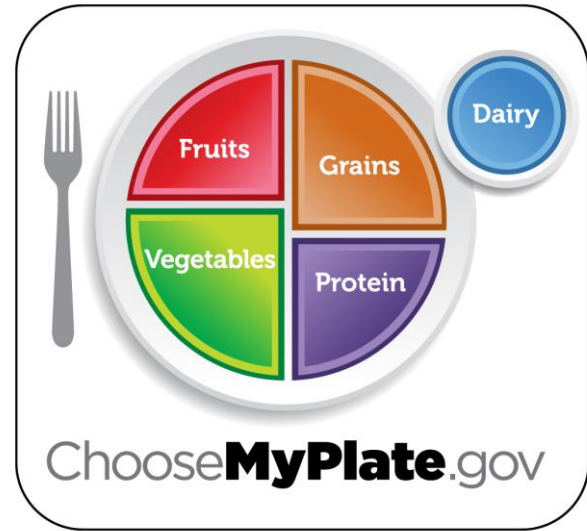


[Link to resource](#)

[Webinar on Sleep in Adolescents and Adults with Down Syndrome](#)

Healthy eating

- Hydration
- Balanced meals (all the food groups)
- Portion size
- Limit processed foods and pop/soda
- Small changes add up



Eat fruits and vegetables with every meal.

Starting your meal with a salad is a good way to do this.



Or fill half your plate with fruits and vegetables.



Choose grilled food instead of fried food.

Eat grilled chicken or fish instead of fried or crispy chicken or fish.



Limit condiments and dressings.

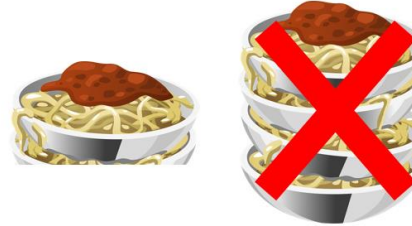
Ask for salad dressing on the side. Only use some of the dressing.



[Link to resource](#)

Be aware of how much food you eat.

Eat your meal. Drink some water. Wait a few minutes. Go back for seconds only if you are still hungry.



Eat slowly. Put your fork down between bites of food. Or take a sip of water between bites of food.



Exercise/physical activity

- Find what works for the individual
- Fun and social
- Incorporate it throughout the day
- Go outdoors

ALPHABET WORKOUT

Create a workout by spelling your name, the day of the week, or another word or phrase of your choosing!

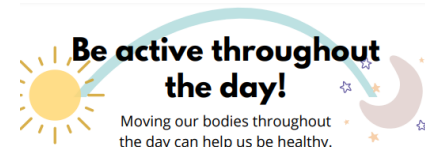
A	10 jumping jacks	N	Run in place for 30 sec.
B	15 crunches	O	10 butt kicks
C	5 squats	P	10 high knees
D	5 push-ups	Q	5 squats
E	Wall sit for 20 sec.	R	10 jumping jacks
F	15 arm circles	S	15 arm punches
G	10 mountain climbers	T	Plank for 20 sec.
H	5 lunges on each leg	U	5 push-ups
I	15 arm punches	V	15 arm circles
J	Plank for 20 sec.	W	10 mountain climbers
K	Wall sit for 20 sec.	X	5 lunges on each leg
L	15 crunches	Y	Run in place for 30 sec.
M	10 high knees	Z	10 butt kicks

The Special Olympics [FIS Cards](#) and [Dynamic Stretches Guide](#) demonstrate these exercises.

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[Link to resource](#)



Be active in the morning



Go for a walk.



Do an exercise video.

Be active in the afternoon



Dance break!



Lift weights.

Be active in the evening



Stretch/do yoga.



Clean.

To be active throughout the day, I can...

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[Link to resource](#)

Manage stress

- Stress is in the eye of the beholder
- Be aware of “empathy radar” or “social sensitivity”
- Provide “in the moment” support when possible
- Work with a mental health provider
 - Consider therapies (e.g., music, art, etc.)

Close your eyes



Take deep breaths



Talk to family or friends



Use a stress ball



Play with a pet



Spend time outside



Dance to a favorite song



Listen to music



Color



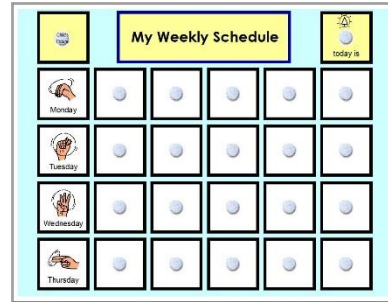
Exercise



[Link to resource](#)

Employment, recreation, and social opportunities

- Involvement promotes physical, mental, and social health
- Find options that match interests and skills
- “Safe” reintroduction



Medical care

Regular health care

- Frequency
- Observe and share history
 - Importance in diagnosis and treatment
- Topics to consider
 - ADSC health questionnaire

ADSC health questionnaire

[LINK](#)



NEW PATIENT HEALTH QUESTIONNAIRE
ADULT DOWN SYNDROME CENTER || ADVOCATE LUTHERAN GENERAL HOSPITAL

Date of Appointment _____

ALL QUESTIONS REFER TO THE PERSON WITH DOWN SYNDROME

Name _____ Date of Birth _____

Person Filling Out the Form: _____

Do you have any specific concerns regarding new or ongoing health/behavioral issues about the Down syndrome? (Please write in the space below. Use another sheet of paper if necessary).

SAFETY ISSUES:

Are there safety issues that have affected or impacted his or her daily routine (i.e. sex, physical abuse, etc.)? **If so, please describe:**

REVIEW OF SYSTEMS:

SAFETY ISSUES:

Are there safety issues that have affected or impacted his or her daily routine (i.e. sex, physical abuse, etc.)? **If so, please describe:**

REVIEW OF SYSTEMS:

BEHAVIOR, FEELINGS AND MEMORY

Has the patient had trouble remembering things or been forgetful? Yes _____ No _____

Can the patient learn to do new things? Yes _____ No _____

Stopped being able to do things he or she used to be able to do? Yes _____ No _____

Had any change in his or her usual behavior or outlook on life? Yes _____ No _____

Had any change in his or her interest in life or activities? Yes _____ No _____

Seemed sad or withdrawn? Yes _____ No _____

Are there concerns about how the patient is acting or feeling? Yes _____ No _____

If yes, please describe:

ENDOCRINE

Has a medical person ever said that the patient has a thyroid problem? Yes _____ No _____

If yes, has the medical person said the thyroid is underactive (working too little) or overactive (working too much)?

Underactive _____ Overactive _____

Ever been diagnosed with diabetes mellitus? Yes _____ No _____

Can the patient drink more liquids recently? Yes _____ No _____

Can the patient urinate more? Yes _____ No _____

Ever had seizures (spasms, convulsions)? Yes _____ No _____

Does the patient have any other neurological issues (epilepsy, multiple sclerosis, stroke, etc)? Yes _____ No _____

Reason: _____

Does the patient seem more tired? Yes _____ No _____

Has the patient been diagnosed with a sleep disorder? Yes _____ No _____

Reason: _____

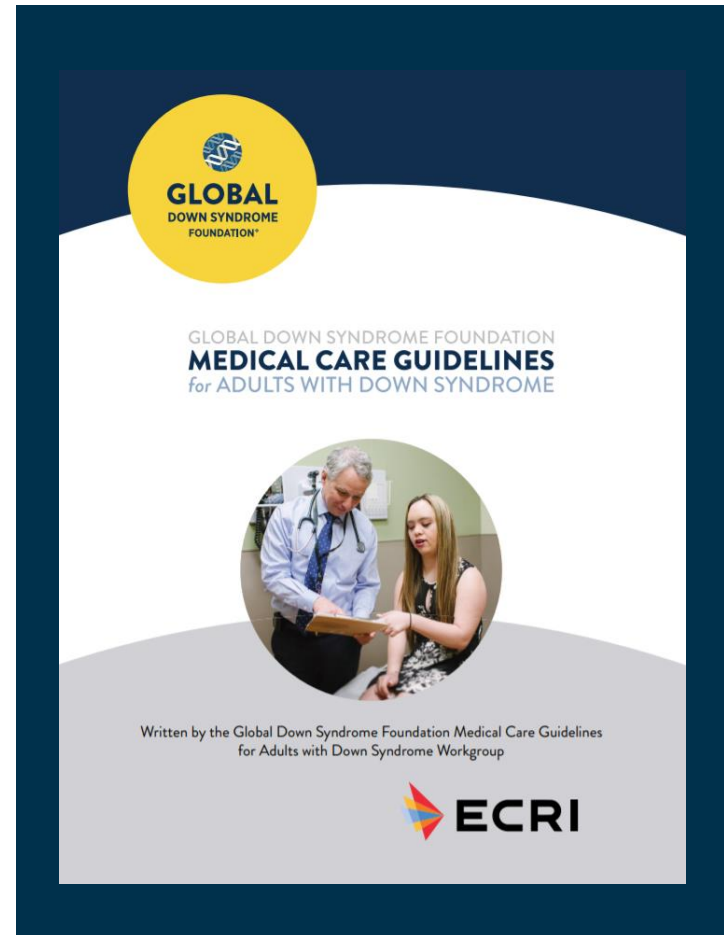
Does the patient go to bed? _____

Does the patient get up? _____

GLOBAL Medical Care Guidelines

- Evidence-based recommendations intended to offer guidance to healthcare providers who see adults with Down syndrome
- Article published in *JAMA*, guidelines document, and checklist

[LINK](#)



Health conditions

More common

- Celiac disease
- Sleep apnea
- Thyroid disorders
- Anxiety
- OCD
- Mood disorders (inc. depression)
- Catatonia
- Pneumonia
- Swallowing dysfunction
- Seizures
- Obesity
- Atlantoaxial instability
- Testicular cancer
- Alzheimer's disease

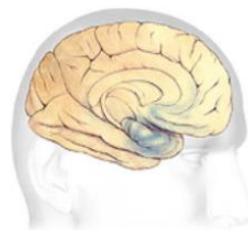
Less common

- Solid tumor cancers
 - Breast cancer
 - Colon cancer
- High blood pressure (hypertension)
- Atherosclerosis
- Diabetes
 - Type II

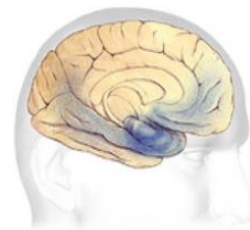
Overview of Alzheimer's Disease

Alzheimer's disease (AD)

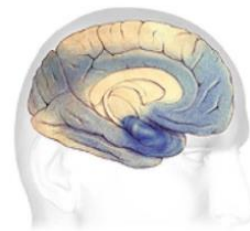
- Progressive neurological condition
- Affects the brain
- Is a type of dementia
- Plaques and tangles = the microscopic changes of the brain consistent with AD
 - Also referred to as neuropathologic changes



Earliest Alzheimer's



Mild to moderate Alzheimer's



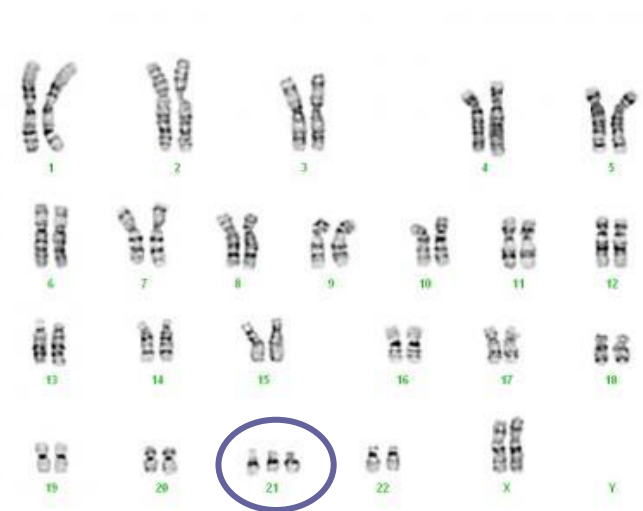
Severe Alzheimer's

Incidence of clinical AD

- Nearly all people with DS have plaques and tangles by age 40.
- **Symptomatic** AD thought to be uncommon before age 40.
- Average age of diagnosis is 50-55 years of age.
- Incidence estimated to be 75-90% in those 60 years of age and older.

Why is AD more common in DS?

- One of the genes associated with AD is on the 21st chromosome.
 - Amyloid precursor protein (APP)
- Since people with DS have an extra full or partial copy of the 21st chromosome, they have more of the gene.



Symptoms


- Behavior changes
- Memory deterioration
- Loss of previously mastered skills
- Incontinence
- Unsteady gait
- Psychological changes
- Weight loss
- Seizures
- Dysphagia (swallowing)

Diagnosis

- Look for symptoms and a pattern of decline.
- Rule out other causes.
 - Vitamin B12 deficiency
 - Depression
 - Sleep apnea
 - Hypothyroidism
 - Cataracts

GLOBAL Medical Care Guidelines

- For adults with Down syndrome younger than age 40, be cautious when diagnosing age-related, Alzheimer's type dementia.
- Assess baseline function each year beginning at age 40.
 - National Task Group Early Detection Screen for Dementia ([NTG-EDSD](#))



NTG-EDSD
NTG-EDSD Manual
© 2010 NTG

NTG-EDSD

v. 1/2020.1

The NTG-Early Detection Screen for Dementia, adapted from the DSQIQ[®], can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.8 of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/screening).

(1) File #: _____ (2) Date: _____

Name of person: (3) First _____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

Female
Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

No discernible intellectual disability
Borderline (IQ 70-75)
Mild ID (IQ 55-69)
Moderate ID (IQ 40-54)
Severe ID (IQ 25-39)
Profound ID (IQ 24 and below)
Unknown

(9) Diagnosed condition (check all that apply)

Autism
Cerebral palsy
Down syndrome
Fragile X syndrome
Intellectual disability
Prader-Willi syndrome
Other: _____

Current living arrangement of person:

Lives alone

Lives with spouse or friends

Lives with parents or other family members

Lives with paid caregiver

Lives in community group home, apartment, supervised housing, etc.

Lives in senior housing

Lives in congregate residential setting

Lives in long term care facility

Lives in other: _____

Prevention

**There are things we can do
that may lower our risk of
developing Alzheimer's
disease or delay it.**

Risk Factors Associated with AD

- A. Midlife Obesity*
- B. Physical Inactivity*~
- C. Midlife Hypertension
- D. Diabetes
- E. Smoking~
- F. Depression~
- G. Low Education*
- H. Hearing Loss

Top 3: * 2018, ~ 2011

Research

JAMA Neurology | **Original Investigation**

Risk Factors Associated With Alzheimer Disease and Related Dementias by Sex and Race and Ethnicity in the US

Roch A. Nianogo, MD, PhD; Amy Rosenwohl-Mack, RN, MS; Kristine Yaffe, MD; Anna Carrasco, MPH; Coles M. Hoffmann, PhD, MC; Deborah E. Barnes, PhD, MPH

IMPORTANCE Previous estimates suggested that 1 in 3 cases of Alzheimer disease and related dementia (ADRDs) in the US are associated with modifiable risk factors, the most prominent being physical inactivity, depression, and smoking. However, these estimates do not account for changes in risk factor prevalence over the past decade and do not consider potential differences by sex or race and ethnicity.

OBJECTIVE To update estimates of the proportion of ADRDs in the US that are associated with modifiable risk factors and to assess for differences by sex and race and ethnicity.

DESIGN, SETTING, AND PARTICIPANTS For this cross-sectional study, risk factor prevalence and communality were obtained from the nationally representative US Behavioral Risk Factor Surveillance Survey data from January 2018 to December 2018, and relative risks for each risk factor were extracted from meta-analyses. Data were analyzed from December 2020 to August 2021. Respondents included 378 615 noninstitutionalized adults older than 18 years. The number before exclusion was 402 410. Approximately 23 795 (-6%) had missing values on at least 1 of the variables of interest.

[Link to article](#)

A. Obesity

- More common in people with Down syndrome
- **Guidelines:**
 - Monitor for weight change and obesity annually by calculating BMI.
 - Follow the U.S. Preventive Services Task Force (USPSTF) Behavioral Weight Loss Intervention to Prevent Obesity-Related Morbidity and Mortality in Adults
 - Use a comprehensive approach to weight management, appetite control, and enhancement of quality of life.
 - Healthy diet, regular exercise, calorie management

Healthy diets and AD

- No one diet is best
- DASH (Dietary Approaches to Stop Hypertension)
 - Vegetables, fruits, fat-free or low-fat dairy products, whole grains, fish, poultry, beans, seeds, nuts, and vegetable oils
 - Limit sodium, added sugars, red meat
- Mediterranean diet
 - Vegetables, fruits, whole grains, nuts, seeds, fish and shellfish, healthy fats like nuts and olive oil
 - Poultry, eggs, cheese, and yogurt in moderation
 - Limit red meat, added sugars, refined grains
- Limit alcohol consumption

B. Physical inactivity

- Physical activity increases blood and oxygen flow in the brain

C. Hypertension

- Hypertension and heart disease are less common in people with Down syndrome
- What's good for the heart is good for the brain?

D. Diabetes

- More common or less common?
- **Guidelines:**
 - For asymptomatic adults with Down syndrome beginning at age 30:
 - Screen for type 2 diabetes mellitus using hemoglobin A1c or fasting plasma glucose every 3 years.
 - For any adult with Down syndrome and comorbid obesity beginning at age 21:
 - Screen for type 2 diabetes mellitus using hemoglobin A1c or fasting plasma glucose every 2-3 years.

E. Smoking

- Less common in our experience

F. Depression

- More common in people with Down syndrome
- **Guidelines:**
 - Perform a review of behavioral, functional, adaptive, and psychosocial factors as part of an annual history.
 - Obtain history from adults with Down syndrome, their families, and caregivers.
 - When concern for a mental health disorder in adults with Down syndrome is present:
 - Medical professionals should evaluate for medical conditions that may present with psychiatric and behavioral symptoms.

G. Low education

- Defined as not graduating high school

Stay active mentally

- Learning throughout life
- Social connections, opportunities to engage with others
- Check vision and hearing
 - They can impact our ability to participate in social settings
 - Isolation may contribute to decline in skills and cognition
- Activities that stimulate the mind

H. Hearing loss

- More common in people with Down syndrome
- **Pediatric Guidelines:**
 - Ages 12 to 21: Obtain annual ear-specific audiologic evaluation
- **Adult Guidelines:**
 - Not addressed
 - Typically recommend a hearing evaluation every 1-2 years

Check hearing and vision

- May impact our ability to participate in social settings.
- May lead to isolation, which can contribute to decline in skills and cognition.

Get good sleep

- Regular sleep
- Sleep apnea

Avoid head trauma

- Wear a seat belt
- Wear a helmet
- Increase safety in the home
 - Remove loose rugs
 - Improve lighting
 - Minimize clutter

Treatment

Treat associated symptoms

- Depression
- Anxiety
- Agitation
- Sleep challenges
 - E.g., day/night reversals

Medications for AD

- Cholinesterase inhibitors (e.g., donepezil/Aricept)
- NMDA receptor antagonist (memantine/Namenda)
- Aducanumab/Aduhelm

Supporting someone with DS & AD

- Focus on what they still enjoy
- “Bingo Pace”
- Communication
 - Get down on their level (eye-to-eye)
 - Provide simple instructions
 - Limit choices
 - Minimize background noise
 - Avoid arguing
 - Avoid asking if they remember

Visit our Resource Library

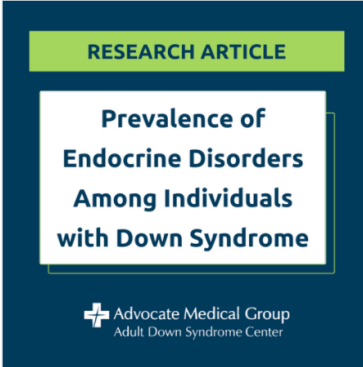
The screenshot shows the website's header with the Advocate Medical Group logo and 'Adult Down Syndrome Center' text. A search bar contains 'I'm looking for...' and a menu icon is on the right. Below the header is a yellow banner for 'COVID-19 Resources' with a subtext: 'Review articles, resource lists, and videos related to COVID-19 and Down syndrome.' The main content area is titled 'Adult Down Syndrome Center | Resource Library' and features three large image-based cards: 'For People with Down Syndrome' (with a photo of a young woman), 'For Families & Caregivers' (with a photo of a woman and a man), and 'For Health Care Professionals' (with a photo of three people in a meeting). Below these cards is a row of five icons with corresponding text: a bell for 'Events, Classes & Programs' (with a link 'See the Schedule'), a play button for 'Video Gallery' (with a link 'View All'), a cursor for 'Related Organizations' (with a link 'See Listing of Links'), a book for 'Projects' (with a link 'See Our Latest Projects'), and a document for 'News' (with a link 'View News Articles').

<https://adsresources.advocatehealth.com>

Follow us on Facebook

Adult Down Syndrome Center
January 31 at 7:00 AM · 🌐

We are excited to share the recent publication of our study on the prevalence of endocrine disorders in individuals with Down syndrome. The Adult Down Syndrome Center collaborated with the Advocate Aurora Research Institute and University of Chicago. Individuals with Down syndrome were more likely to have thyroid disorders, type 1 diabetes, and gout and less likely to have type 2 diabetes than their age- and sex-matched counterparts. The findings highlight the need for health... [See more](#)



RESEARCH ARTICLE

Prevalence of Endocrine Disorders Among Individuals with Down Syndrome

Advocate Medical Group
Adult Down Syndrome Center


👍 60 45 Shares

👍 Like 💬 Comment ➦ Share

Adult Down Syndrome Center
January 25 at 7:00 AM · 🌐

Fear of heights is a common fear identified by individuals with Down syndrome and their families who come to our clinic. The providers at the Adult Down Syndrome Center have observed that many people with Down syndrome seem to have a difference in depth perception which may contribute to this fear. In the article linked below, Dr. Brian Chicoine shares more on this topic, including ways to support a person with Down syndrome who may have a fear of heights.

<https://adsresou...> [See more](#)



Fear of heights in people with Down syndrome

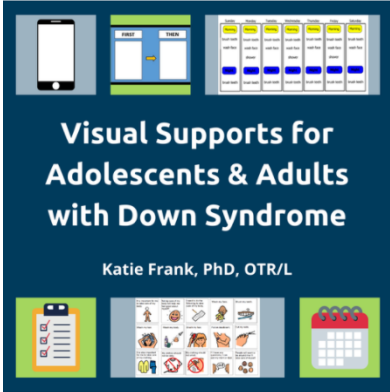
Advocate Medical Group
Adult Down Syndrome Center

👍 95 27 Comments 46 Shares

👍 Like 💬 Comment ➦ Share

Adult Down Syndrome Center
January 20 at 7:00 AM · 🌐

Visuals can assist people with and without Down syndrome in many ways. We do not think that they are something that we "outgrow." In fact, many of us use visual supports (such as apps on our phones, to-do lists, calendars, etc.) on a daily basis! They can be used to set and manage expectations, establish routines, communicate, learn new skills, and more. Our occupational therapist Dr. Katie Frank shares information about the use of visual supports in the article from our Reso... [See more](#)



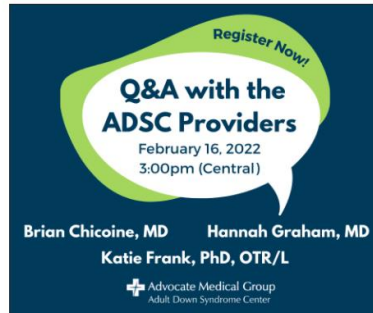
Visual Supports for Adolescents & Adults with Down Syndrome

Katie Frank, PhD, OTR/L

👍 98 9 Comments 52 Shares

<https://www.facebook.com/adultdownsyndromecenter>

Join our email list



Do you have questions about health and wellness of adolescents and adults with Down syndrome? Our next webinar is for you! Join Brian Chicoine, MD, Katie Frank, PhD, OTR/L, and Hannah Graham, MD for a Q&A on Wednesday, February 16, at 3:00pm (Central). Questions may be submitted before the webinar and/or during the webinar. Please click the button below to register and submit a question.

[REGISTER NOW](#)

Resources



Even if the weather outside is frightful, there are many activities we can do at home to fight boredom, stay active, be social, and have fun. We recently updated our "Activities You Can Do at Home" resource. There are ideas for arts and crafts, cooking, education and learning, fitness and physical activity, games, and more.

[Explore activities](#)

<http://eepurl.com/c7uV1v>

Questions?

Resource Library:
adscresources.advocatehealth.com

Facebook:
facebook.com/adultdownsyndromecenter

Email Newsletter:
eepurl.com/c7uV1v

Resources

- Adult Down Syndrome Center
 - [Aging](#)
 - [Alzheimer's Disease and Dementia](#)
 - [Exercise and Physical Activity](#)
 - [Mental Health](#)
 - [Nutrition and Healthy Eating](#)
 - [Sleep](#)
- Alzheimer's Association
 - [Prevention](#)
 - [10 Ways to Love Your Brain](#)

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