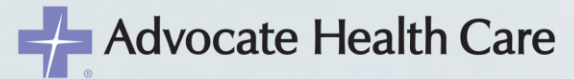


Promoting Health for and with Adults with Down Syndrome

Down Syndrome Alliance of the Midlands

January 19, 2021 | Brian Chicoine, MD



We are  AdvocateAuroraHealth

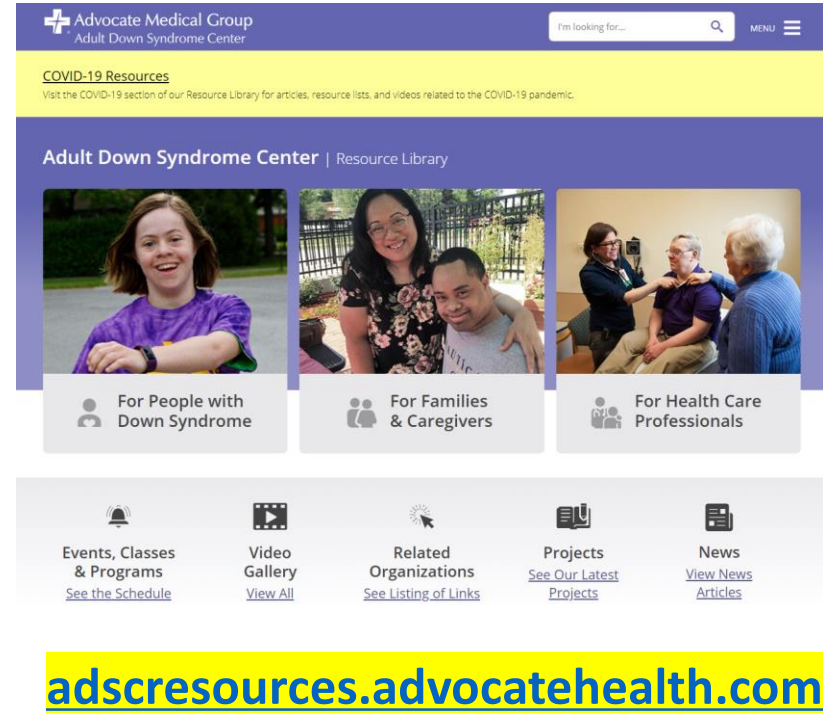
Adult Down Syndrome Center

Park Ridge, IL



Online Resource Library

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



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

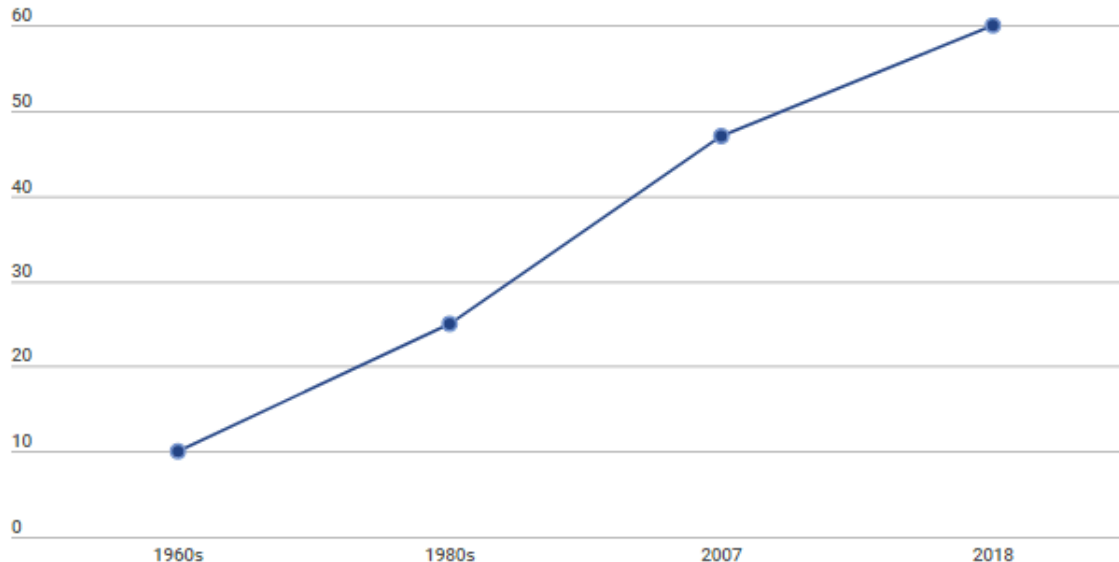
- Provide an overview of health conditions that are more and less common in adults with Down syndrome.
- Describe guidelines and best practices for addressing common health conditions in adults with Down syndrome.
- Identify resources and strategies that individuals with Down syndrome and their families and caregivers can use to promote health and wellness.

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

Life Expectancy of People with Down Syndrome

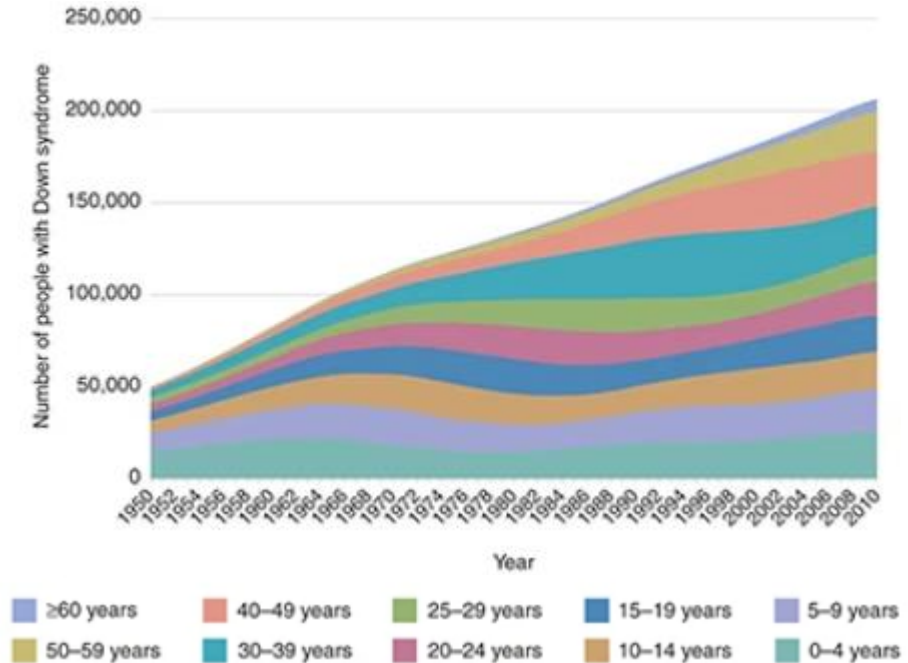


Source: [Centers for Disease Control and Prevention](#) and [Global Down Syndrome Foundation](#)
Graphic by Amanda Fahey and Hailey Mensik/Cronkite News
<https://cronkitenews.azpbs.org/2018/05/25/experts-say-adults-with-down-syndrome-more-independent-but-face-challenges-in-getting-old/>

There are more **adults** with Down syndrome living now than ever before.

People with Down syndrome in the US

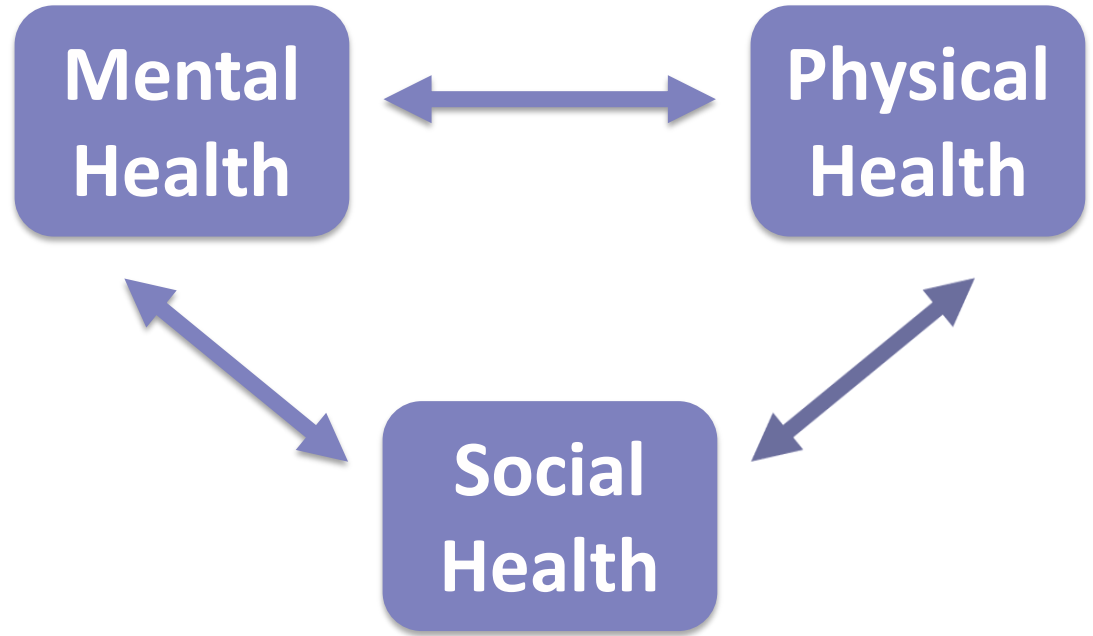
- Estimate of # of adults 20 years of age and older
 - 1950: 13,368
 - About 27% of total # of people with DS
 - 2010: 117,763
 - About 57% of total # of people with DS



Health and well-being

“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”

(World Health Organization)



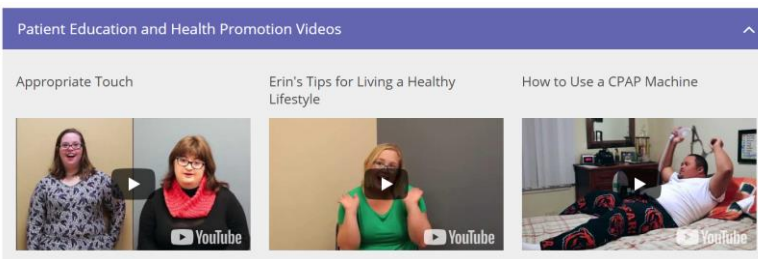
Common characteristics

- The Groove
- Self-talk
- Strong memory and the concept of time

Promoting health and independence

- Provide tools and resources that draw on strengths.
 - Visuals
 - Videos
 - Peer support

Making Healthy Choices



Visual supports

Visual Supports

February 2017 | Katie Frank, PhD, OTR/L | Occupational Therapist, Adult Down Syndrome Center

Copyright 2017

When making a copy of this document, please be sure to include the following information about visual supports: • Name of the person who created the visual support (author) • Name of the person who reviewed the visual support (reviewer) • Date the visual support was created • Date the visual support was reviewed • Date the visual support was revised

When you are creating a visual support, be sure to include the following information about the visual support: • Name of the person who created the visual support (author) • Name of the person who reviewed the visual support (reviewer) • Date the visual support was created • Date the visual support was reviewed • Date the visual support was revised

Use of Visual Supports

Author: Katie Frank, PhD, OTR/L - Occupational Therapist, Adult Down Syndrome Center ... **Visual** supports are pictures, words, or other images utilized to help communicate, share or manage expectations/rules, provide reminders, or teach new skills. **Visual** supports are another way for us to process information. **Visual** supports are also commonly used with individuals on the autism spectrum; ...

There are different types:

1. First/then boards: do their homework and

2. Visual schedules: These can be a list of activities for the entire day, only the morning or evening routine, or even the chores that need to be done. This can be presented as a list of words or as a series of pictures. The use of a calendar naturally provides a visual schedule. Perhaps you already use this with their extra-curricular activities, but you can also do this with self-care tasks. Maybe they don't love to bathe, but you have decided that they need to take a shower every Tuesday, Thursday, and Saturday. There could be a picture of a bathtub or shower or the word "shower" on their calendar for those days. As a parent/caregiver, you can instruct the person to check their calendar/schedule and the person can be responsible for completing the task and you don't have to keep providing verbal prompts to bathe that day.

3. Stories: Stories can be used to teach new skills, ease anxiety about activities like going to give blood or even help change a negative behavior. They can also be used to support positive behavior. How many of you have turned to YouTube or looked at Pinterest to learn how to do something new or ease anxiety about an upcoming event? These stories can be pictures only, a combination of pictures and words, words only, or even videos.

Health conditions

We are **AdvocateAuroraHealth™**

Health issues that are **MORE** common

- Hypothyroidism and hyperthyroidism
- Celiac disease
- Sleep apnea
- Hearing impairment
- Auto-immune conditions
- Vision problems including cataracts and keratoconus
- Leukemia
- Cancer of the testicle
- Alzheimer's disease

Health issues that are MORE common (cont.)

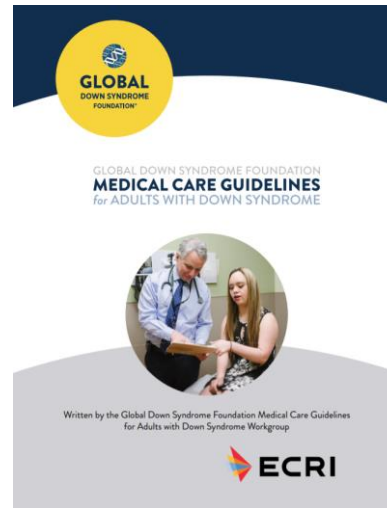
- Cervical subluxation
- Vitamin B12 deficiency
- Gastroesophageal reflux disease (GERD)
- Constipation
- Boils
- Fungal infections
- Osteoarthritis
- Obesity
- Respiratory infections
- Secondary disabilities

Health issues that are LESS common

- Hypertension (high blood pressure)
- Coronary artery disease
- Cancer (solid tumors)
 - E.g. breast, colon

GLOBAL Medical Care Guidelines

- Evidence-based recommendations intended to offer guidance to healthcare providers who see adults with DS
- Newest set published in October 2020



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 not recommended, periodic health screening/instruments that should begin at a specific age. Below each blue screening/instrument recommendation, there are blank boxes. Caregivers or individuals with Down syndrome can check off, date, or initial each blank box when the screening/instrument is completed. For screening/instrument 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.

Legend: ☐ Screening/Instrument ☐ Advisory ☐ Checklist ☐ Not Recommended

	21-29 Years	30-39 Years	40-49 Years	50-59 Years	60+ Years
Behavior					
Dementia					
Diabetes					
Cardiac					
Obesity					
Adolescent Instability					
Osteoporosis					
Thyroid					
Celiac Disease					

© 2020 Global Down Syndrome Foundation

Topics in the GLOBAL Guidelines

Behavioral
Health

Dementia

Diabetes

Obesity

Thyroid

Cardiovascular
Disease

Osteoporosis

Celiac Disease

Atlantoaxial
Instability

Overweight, Obesity, and Diabetes

Overweight and obesity

- More common
 - Estimates vary
 - Review of literature combined results from several studies:
 - 38% of study participants were obese, 34% were overweight
- Associated with other physical, mental, and social health issues
- Guidelines
 - Monitor for weight change and obesity annually
 - Follow a healthy diet, regular exercise, and calorie management

Capone et al. 2018 Tsou et al. 2020

Diabetes

- Type II diabetes is more common (?)
 - Estimates vary
- Guidelines
 - For adults without symptoms:
 - Screen for type 2 diabetes every 3 years beginning at age 30.
 - For adults with comorbid obesity:
 - Screen for type 2 diabetes every 2-3 years beginning at age 21.
 - How? Hemoglobin A1c (HbA1c) or fasting plasma glucose

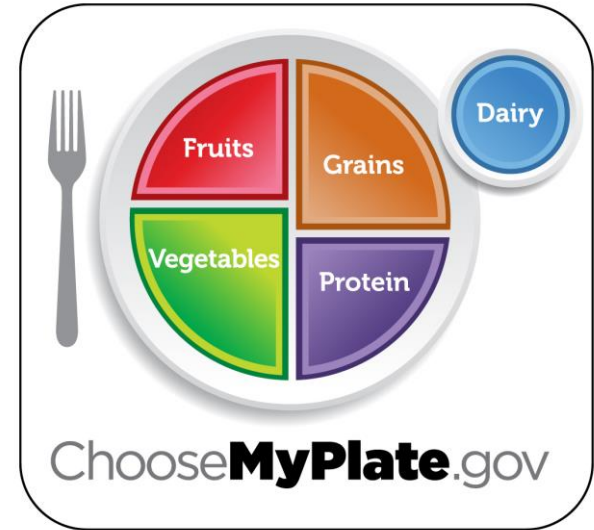
Capone et al. 2018 Tsou et al. 2020

Strategies and Resources

We are **AdvocateAuroraHealth™**

Healthy eating

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



Healthy eating resources



Healthy Pace for Eating Video

Author: Adult Down Syndrome Center - Video

Eating too fast can cause us to get a stomachache, cough, or even choke. We can enjoy our food and be healthier. This video talks about a healthy pace for eating. The corresponding visual handout can be found at this link .



Tips for Eating Healthy Meals

Author: Adult Down Syndrome Center

This handout provides 6 ways to make healthier choices for meals. Eat your best at home, school, work, and in the community.



What to Drink Instead of Pop/Soda

Author: Adult Down Syndrome Center

This visual suggests alternatives to pop/soda.

<https://adsresources.advocatehealth.com/resources/?category=Nutrition%20and%20Healthy%20Eating>

Exercise/physical activity

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

WAYS TO BE ACTIVE!



Play a sport.



Join Special Olympics.



Join Special Rec.



Go for a jog.



Do housework/chores.



Dance.



Do an exercise video.



Stretch



Use exercise equipment.



Walk your dog.



Take the stairs.



Lift weights.

[Link to resource](#)

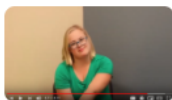
Exercise/physical activity resources



Fit 5 Fitness Cards and Videos

Author: Special Olympics - Resource

The website linked below contains downloadable cards and videos that feature Special Olympics athletes and provide visual demonstrations of endurance, strength, and flexibility exercises. There are exercises for 5 different levels of difficulty so you can select the appropriate exercises for your fi



Erin's Tips for Living a Healthy Lifestyle Video

Author: Adult Down Syndrome Center - Video

In the video below, Erin shares tips for living a healthy lifestyle. As Erin says, "Living a healthy lifestyle can be really hard," but her tips can help make it easier!



Exercises You Can Do at Home

Author: Adult Down Syndrome Center

This visual shows pictures of and describes exercises you can do at home without exercise equipment.

<https://adsresources.advocatehealth.com/resources/?category=Exercise%20and%20Physical%20Activity>

Mental Health

We are **AdvocateAuroraHealth™**

Mental health disorders

- Behavioral and mental health disorders are common in people with Down syndrome.
 - Depression, anxiety, OCD
- Studies have shown that 25-40% of people with Down syndrome experience a behavioral or mental health disorder during their life.

Dykens 2007 Mantry et al. 2008 Alexander 2015 Palumbo & McDougale 2018

Mental health disorders

- Guidelines
 - When concern for a mental health disorder in adults with Down syndrome is present:
 - Refer to a clinician knowledgeable about the medical, mental health disorders, and common behavioral characteristics of adults with Down syndrome.
 - Follow guidelines in the:
 - Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and/or
 - Diagnostic Manual – Intellectual Disability (DM-ID-2)

Mental health disorders

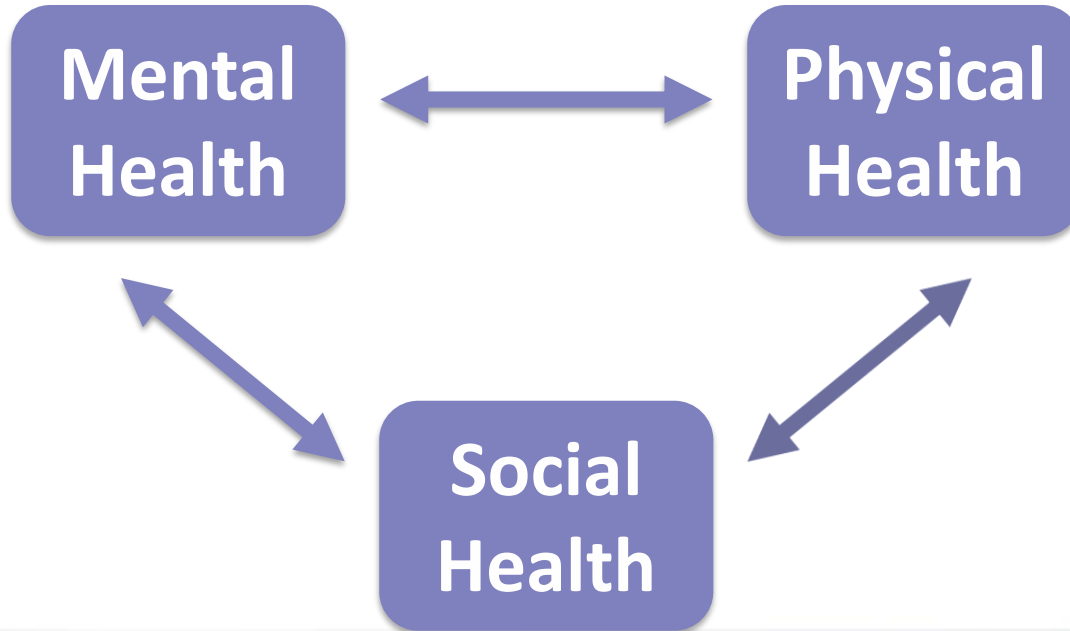
- Guidelines
 - Clinicians should perform a review of behavioral, functional, adaptive, and psychosocial factors on an annual basis.
 - When concern for a mental health disorder in adults with Down syndrome is present:
 - Medical professionals should evaluate for medical conditions that may present with psychiatric and behavioral symptoms.

Strategies and Resources

We are **AdvocateAuroraHealth™**

Promoting mental health

- Connection between physical, mental, and social health



Importance of sleep

Do:

- Set up a healthy sleep space.
- Have a bedtime routine.
- Wake up at the same time each morning and go to bed at the same time each night.

Don't:

- Consume caffeine or sugar before bed.
- Watch TV or use phones or tablets in bed.
- Linger in bed in the morning.

Ways to get good sleep

I should wake up at the same time each day.



I should go to bed at the same time every night.



I should create a good sleep space.



TV



tablet



phone

I should have a bedtime routine.

Hygiene



brush teeth



wash face



go to bathroom

Relaxation



write in journal



pray



read



take deep
breaths



stretch

Remembering this will help me sleep better and be healthy!



Promoting mental health

- 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).

Mental health resources

Topic

- ☐ Aging (14)
- ☐ Alzheimer's Disease and Dementia (20)
- ☐ Anesthesiology (1)
- ☐ Autism Spectrum Disorder (1)
- ☐ Laboratory Findings (4)
- ☒ Mental Health (29)
- ☐ Neurology (5)
- ☐ Decline in Skills (6)
- ☐ Endocrinology (4)
- ☐ Exercise and Physical Activity

Grief - Ways to Help Support Someone with Down Syndrome Who is Grieving

Grief - Ways to Help Support Someone with Down Syndrome Who is Grieving
May 2017 | Shana Sexton, LCSW | Social Worker, Adult Down Syndrome Center

Grief - Ways to Help Support Someone with Down Syndrome Who is Grieving

Author: Shana Sexton, LCSW - Social Worker, Adult Down Syndrome Center

Ways to Help Support Someone with Down Syndrome Who is Grieving: Acknowledge and normalize the person's feelings. It's important for someone to know that their feelings, whatever they are, are normal and they are not alone. It can help just to say "you are sad"



Down Syndrome and Mental Health

Author: Down Syndrome Australia - Resource

The resource found at the link below is an 11-page summary for individuals with Down syndrome and their families on promoting and maintaining good mental health. Dr. Chicoine and Dr. McGuire's book Mental Wellness in Adults with Down Syndrome was used in the development of



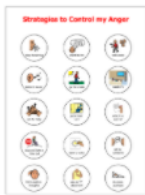
Promoting Mental Health Presentation (9/6/2017)

Author: Adult Down Syndrome Center Staff - Adult Down Syndrome Center

Below is a recording of a presentation given by providers at the Adult Down Syndrome Center on the topic of promoting mental health. Two videos are included below - one contains the presentations and the other contains the question and answer session that followed.

<https://adsresources.advocatehealth.com/search/families-and-caregivers/?category=Mental%20Health>

Mental health resources



Strategies to Control My Anger

Author: Adult Down Syndrome Center

This handout gives examples of things you can do when you get angry.



Managing Emotions

Author: Adult Down Syndrome Center

This visual shares information about managing emotions



Tips for Dealing with Stress Video

Author: Adult Down Syndrome Center - Video

We all experience stress in our lives. What causes stress and how stress is managed varies from person-to-person. In the video below, Cindy and Nora describe stress and share tips on how to manage it. A corresponding visual handout can be found at this link .

<https://adscresources.advocatehealth.com/search/people-with-down-syndrome/?category=Mental%20Health>

Alzheimer's Disease and Dementia

We are **AdvocateAuroraHealth™**

Alzheimer's disease and dementia

- More common in people with Down syndrome
 - 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.
- Why?
 - One of the genes associated with Alzheimer's disease is on the 21st chromosome.
 - Amyloid precursor protein (APP)

Coppus et al. 2006 McCarron et al. 2017 Zis & Strydom 2018

Alzheimer's disease and dementia

- 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.
 - NTG-EDSD: National Task Group – Early Detection Screen for Dementia

Strategies and Resources

Preventing Alzheimer's disease (?)

- Exercise

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)

Livingstone et al. 2015

Supporting an individual with AD

- Quality of life
 - Doing what can still be done
 - “Bingo Pace”
- Communication
 - Simple instructions, do not argue, avoid asking them if they remember, get down on their level
- Home safety and adaptive equipment

Home safety

- Contrasting colors
- Adequate lighting
- Handrails and ramps
- No unnecessary furniture, mirrors, or throw rugs



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 contribut
The suggestions below may help with going up and down stairs sa:

LINK TO RESOURCE

Adaptive equipment

- Weighted utensils
- Adapted plates
- Contrasting colors
- Shower chair and/or handheld shower head
- Raised toilet seat or rails for the toilet



Alzheimer's disease resources



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



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/).

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

Alzheimer's disease resources



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

Seizures in People with Down Syndrome and Alzheimer's Disease

April 2018 | Brian Chicoine, MD - Medical Director, Adult Down Syndrome Center

The following is 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 and is not intended to serve as a substitute for medical guidance or medical advice. Always consult your physician or healthcare provider for medical advice.

- Seizures are more common in people who develop Alzheimer's disease. Both people with and without Down syndrome. Older people who do not develop Alzheimer's disease. However, the number of seizures in a person with Alzheimer's disease is greater in people with Down syndrome than in people without Down syndrome.
- For people without Down syndrome, the seizures usually occur late in the course of Alzheimer's disease. In people with Down syndrome, seizures are common in the early stages.
- Seizures may be more common in people with Down syndrome who have a history of epilepsy. However, seizures may occur in people without a history of epilepsy. Seizures may occur at any time in the course of Alzheimer's disease. Seizures may occur at any time in the course of Alzheimer's disease.

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

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

Healthy Aging

We are **AdvocateAuroraHealth™**

Healthy lifestyle



- Healthy eating
- Exercise
- Hydration
- Sleep

- Stress management
- Social connections
- Social skills

Review the ADSC Resource Library


The screenshot shows the website for the Advocate Medical Group Adult Down Syndrome Center. The header is purple with the center's name and a search bar. A yellow banner highlights 'COVID-19 Resources'. The main section, titled 'Adult Down Syndrome Center | Resource Library', features three image-based categories: 'For People with Down Syndrome', 'For Families & Caregivers', and 'For Health Care Professionals'. Below these are five icons representing different resource types: Events, Classes & Programs; Video Gallery; Related Organizations; Projects; and News. Each icon has a corresponding text label and a link to view more.


Advocate Medical Group
Adult Down Syndrome Center


I'm looking for... MENU


COVID-19 Resources
Visit the COVID-19 section of our Resource Library for articles, resource lists, and videos related to the COVID-19 pandemic.


Adult Down Syndrome Center | Resource Library



For People with Down Syndrome



For Families & Caregivers



For Health Care Professionals

 Events, Classes & Programs
[See the Schedule](#)

 Video Gallery
[View All](#)

 Related Organizations
[See Listing of Links](#)

 Projects
[See Our Latest Projects](#)

 News
[View News Articles](#)

adscresources.advocatehealth.com

Find an adult healthcare provider

- Review lists of clinics compiled by national organizations
 - [National Down Syndrome Congress](#), [Global Down Syndrome Foundation](#), or [National Down Syndrome Society](#)
 - **If a clinic only serves children, ask the clinic if they have adult providers they typically refer to.
- Contact a Down syndrome organization in your area
 - Their staff and/or member families may be able to point you to healthcare providers with experience in caring for individuals with Down syndrome and/or recommend providers with whom they have had good experiences.

Share the Global Medical Care Guidelines



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 screenings/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
	<input type="checkbox"/> Screening/Assessment	<input type="checkbox"/> Advisory	<input type="checkbox"/> Checklist	<input checked="" type="checkbox"/> Recommendations	
Behavior	When concerns for a mental health disorder in adults with Down syndrome prompt medical professionals to evaluate for medical conditions that may present with psychiatric and behavioral symptoms and to refer to a clinician knowledgeable about the medical, nursing, psychiatric, and potential legal and ethical considerations of adults with Down syndrome.	When concerns for a mental health disorder in adults with Down syndrome prompt a primary medical professional should follow guidelines for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) should be used to guide the diagnosis of adults with Down syndrome.	When concerns for a mental health disorder in adults with Down syndrome prompt a primary medical professional should follow guidelines for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) should be used to guide the diagnosis of adults with Down syndrome.	When concerns for a mental health disorder in adults with Down syndrome prompt a primary medical professional should follow guidelines for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) should be used to guide the diagnosis of adults with Down syndrome.	When concerns for a mental health disorder in adults with Down syndrome prompt a primary medical professional should follow guidelines for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) should be used to guide the diagnosis of adults with Down syndrome.
Dementia	Caregivers involved when diagnosing age-related Alzheimer's Type Dementia in adults with Down syndrome less than age 65.	For symptomatic adults with Down syndrome, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 35.	For symptomatic adults with Down syndrome, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 35.	For symptomatic adults with Down syndrome, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 35.	For symptomatic adults with Down syndrome, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 35.
Diabetes	For any adult with Down syndrome and controlled diabetes, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 25.	For any adult with Down syndrome and controlled diabetes, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 25.	For any adult with Down syndrome and controlled diabetes, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 25.	For any adult with Down syndrome and controlled diabetes, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 25.	For any adult with Down syndrome and controlled diabetes, screening for Type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 25.
Cardiac	For adults with Down syndrome, screening for cardiac conditions should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for cardiac conditions should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for cardiac conditions should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for cardiac conditions should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for cardiac conditions should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.
Obesity	For adults with Down syndrome, screening for obesity should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for obesity should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for obesity should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for obesity should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for obesity should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.
Autism/Instability	For adults with Down syndrome, screening for autism/instability should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for autism/instability should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for autism/instability should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for autism/instability should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for autism/instability should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.
Osteoporosis	For adults with Down syndrome, screening for osteoporosis should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for osteoporosis should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for osteoporosis should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for osteoporosis should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for osteoporosis should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.
Thyroid	For adults with Down syndrome, screening for thyroid should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for thyroid should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for thyroid should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for thyroid should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for thyroid should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.
Celiac Disease	For adults with Down syndrome, screening for celiac disease should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for celiac disease should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for celiac disease should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for celiac disease should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.	For adults with Down syndrome, screening for celiac disease should be performed by the American Heart Association/American Society of Human Genetics (ASHG) Guidelines for the Primary Prevention of Disease.

This checklist is not intended to be diagnostic. Prevention of medical and mental health conditions for people with Down syndrome may be delayed. Similar signs and symptoms may be a consequence of multiple conditions. Individuals should consult with their medical professionals. The development of new medical therapies in response to symptoms should prompt a comprehensive evaluation with your physician.

© 2020 Global Down Syndrome Foundation

<https://www.globaldownsyndrome.org/global-adult-guidelines/>

Questions to ask



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 _____

Has been drinking more liquids recently? Yes _____ No _____

Has been urinating more? Yes _____ No _____

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

Has had any other neurological issues (epilepsy, multiple sclerosis, stroke, etc)? Yes _____ No _____

Other: _____

Seems more tired? Yes _____ No _____

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

Other: _____

Does the patient go to bed? _____

Does the patient get up? _____

https://www.advocatehealth.com/assets/documents/subsites/luth/downsyndrome/new_patient/new-patient-health-questionnaire.pdf

Questions?

Resource Library

adscresources.advocatehealth.com

Facebook

www.facebook.com/adultdownsyndromecenter

E-mail Newsletter

<http://eepurl.com/c7uV1v>

References

Alexander M, Petri H, Ding Y, Wandel C, Khwaja O, Fosskett N. Morbidity and medication in a large population of individuals with Down syndrome compared to the general population. *Dev Med Child Neurol*. 2016;58(3):246-254. doi:[10.1111/dmcn.12868](https://doi.org/10.1111/dmcn.12868)

Capone GT, Chicoine B, Bulova P, et al. Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines. *Am J Med Genet A*. 2018;176(1):116-133. doi:[10.1002/ajmg.a.38512](https://doi.org/10.1002/ajmg.a.38512)

Coppus A, Evenhuis H, Verberne GJ, et al. Dementia and mortality in persons with Down's syndrome. *J Intellect Disabil Res*. 2006;50(Pt 10):768-777. doi:[10.1111/j.1365-2788.2006.00842.x](https://doi.org/10.1111/j.1365-2788.2006.00842.x)

Dykens EM. Psychiatric and behavioral disorders in persons with Down syndrome. *Ment Retard Dev Disabil Res Rev*. 2007;13(3):272-278. doi:[10.1002/mrdd.20159](https://doi.org/10.1002/mrdd.20159)

Livingstone N, Hanratty J, McShane R, Macdonald G. Pharmacological interventions for cognitive decline in people with Down syndrome. *Cochrane Database Syst Rev*. 2015;(10):CD011546. Published 2015 Oct 29. doi:[10.1002/14651858.CD011546.pub2](https://doi.org/10.1002/14651858.CD011546.pub2)

References

Mantry D, Cooper SA, Smiley E, et al. The prevalence and incidence of mental ill-health in adults with Down syndrome. *J Intellect Disabil Res*. 2008;52(Pt 2):141-155. doi:[10.1111/j.1365-2788.2007.00985.x](https://doi.org/10.1111/j.1365-2788.2007.00985.x)

McCarron M, McCallion P, Reilly E, Dunne P, Carroll R, Mulryan N. A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *J Intellect Disabil Res*. 2017;61(9):843-852. doi:[10.1111/jir.12390](https://doi.org/10.1111/jir.12390)

Palumbo ML, McDougale CJ. Pharmacotherapy of Down syndrome. *Expert Opin Pharmacother*. 2018;19(17):1875-1889. doi:[10.1080/14656566.2018.1529167](https://doi.org/10.1080/14656566.2018.1529167)

Tsou AY, Bulova P, Capone G, et al. Medical care of adults with Down syndrome: A clinical guideline. *JAMA*. 2020;324(15):1543-1556. doi:[10.1001/jama.2020.17024](https://doi.org/10.1001/jama.2020.17024)

Zis P, Strydom A. Clinical aspects and biomarkers of Alzheimer's disease in Down syndrome. *Free Radic Biol Med*. 2018;114:3-9. doi:[10.1016/j.freeradbiomed.2017.08.024](https://doi.org/10.1016/j.freeradbiomed.2017.08.024)