Health Management with Adults with Down Syndrome

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California Disability Conference

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Medical
Group
Adult Down
Syndrome Center
1610 Luther Lane

Objectives

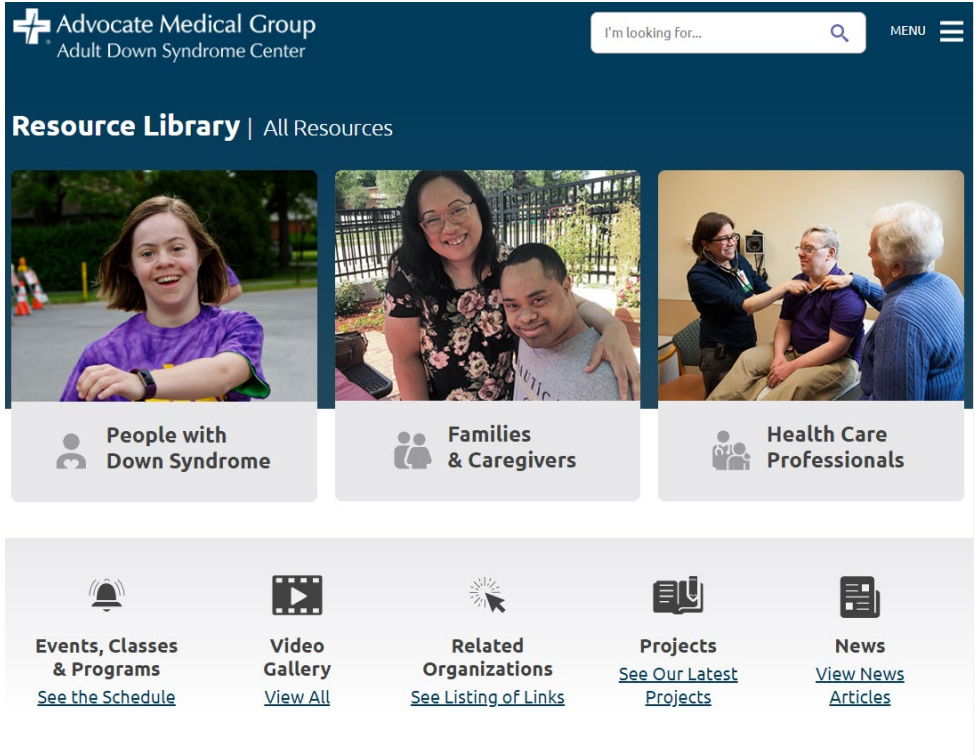
- Identify gaps in healthcare as defined by adults with Down syndrome and their families
- Discuss key concepts paramount to improve the delivery of healthcare to adults with Down syndrome
- Explain the needs of adults with Down syndrome as they transition to adult care and resources to assist in the transition
- Describe resources available for health professionals, families, and caregivers to support people with Down syndrome in their own health promotion

No financial disclosures

Please note:

- This presentation is intended for families, caregivers, health care professionals, and service providers of individuals with Down syndrome.
- The information in this presentation 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.
- We are unable to provide diagnosis or treatment recommendations specific to an individual. We recommend that you bring specific questions about an individual with Down syndrome to their medical and/or therapy professionals.

Resource Library



https://adscresources.advocatehealth.com/

Today, people with Down syndrome are living *longer* and *healthier* than any other time in the past.

Life expectancy in years

Bittles et al. 2004, Coppus et al. 2008, Glasson et al. 2002, Zhu et al. 2013

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

People with DS in the United States

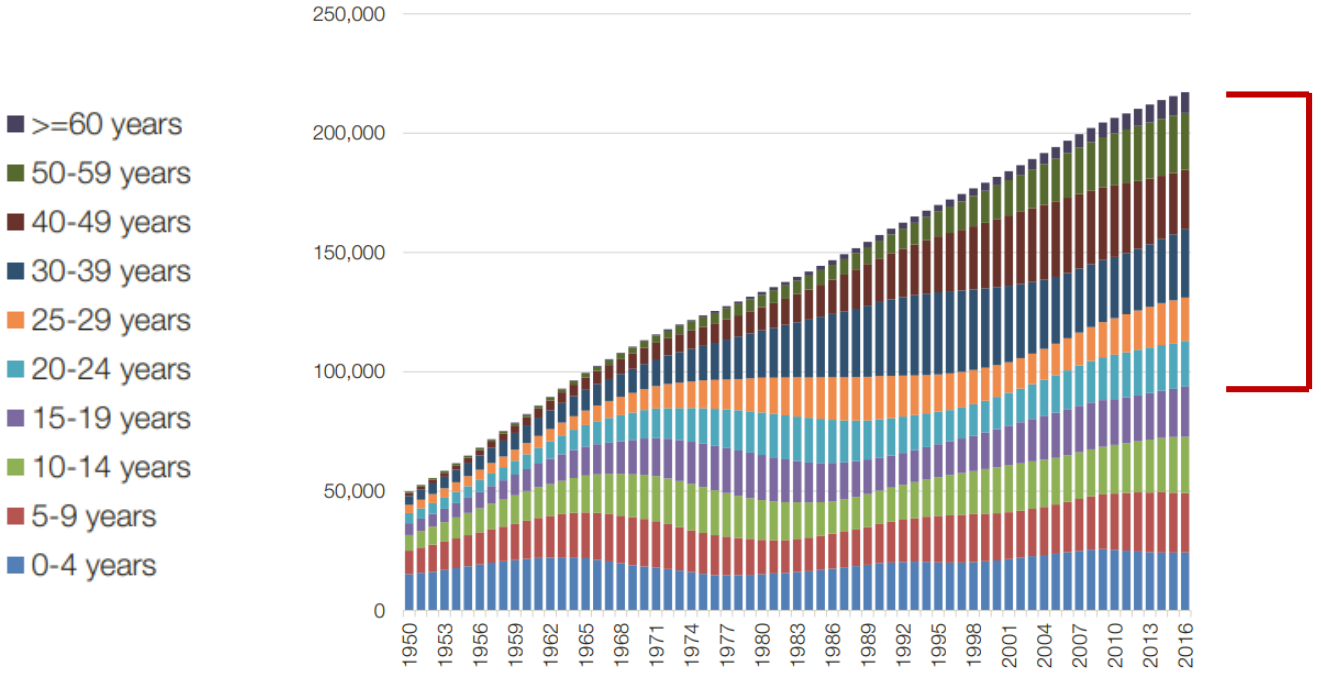


Figure 5. Population of people with Down syndrome in the USA, 1950-2016

Estimated # of people with DS 20 years of age or older

de Graaf et al. 2017

What are these adults looking for in healthcare?

NADS and NDSS

- In 1991, the National Association for Down Syndrome surveyed their members.
- In 2023, the National Down Syndrome Society surveyed their members.

- Expressed clear desire for health professionals who:
  - Were competent in caring for adults with Down syndrome
  - Would treat adults with Down syndrome with dignity and respect

Let’s get to know these individuals


NEVER GIVE UP
BULLS
BULLS


2023
5K RUN
3K WALK


2019
Olympics
Chicago

Each person with Down syndrome is unique.

Many people with Down syndrome share common characteristics.

Common characteristics of many (but not all) people with Down syndrome

Physical

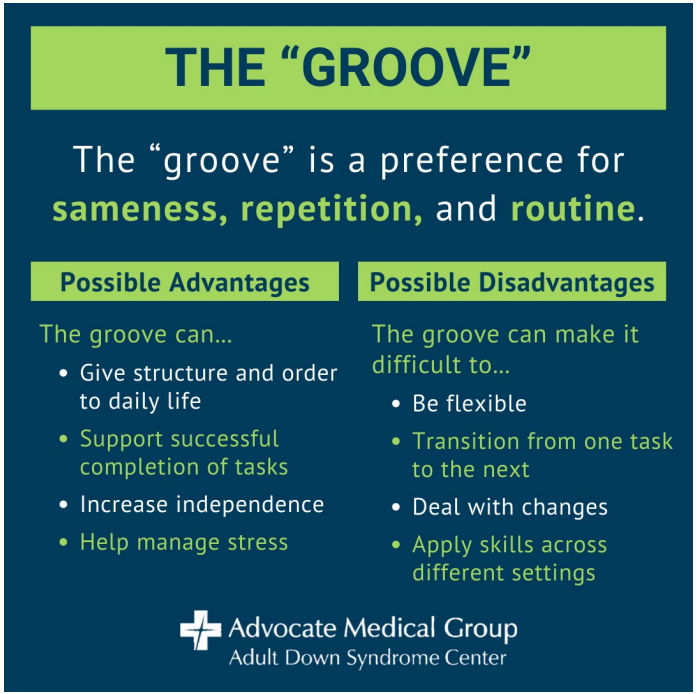
- Almond-shaped eyes that slant up
- Short neck
- Small ears
- Small hands and feet
- A single line across the palm of the hand (palmar crease)
- Shorter in height
- Lower heart rate, lower blood pressure

Cognitive

- Mild to moderate to severe intellectual disability
- Better receptive language than expressive language
- Concrete thinking
  - Difficulty with abstract concepts (e.g., time)
- Visual memory

Behavioral

- Self-talk and imaginary friends
- The “Groove”
- Empathy radar



How do we respond (and not respond) to their request?

Inclusion

- In 1992, health care for people with Down syndrome
- In 2025, health care ***with*** people with Down syndrome

- Not *if* they should be included
- But *how*

Diagnostic overshadowing

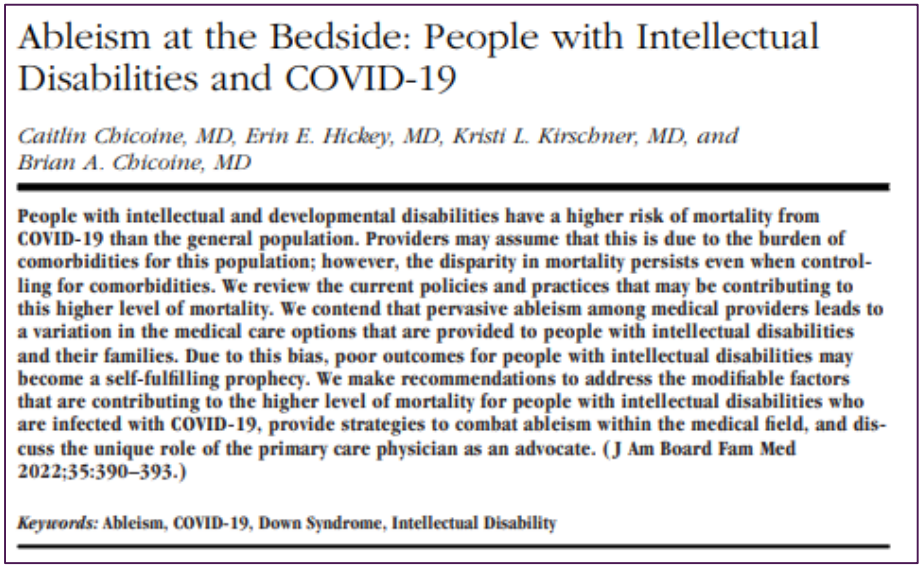
- To cause something to seem less important
- The attribution of symptoms to an existing diagnosis rather than a potential co-morbid condition (The Joint Commission)
- Co-occurring conditions
  - Misdiagnosis
  - Underdiagnosis
  - Overdiagnosis

“It’s just Down syndrome.”

Reiss, 1982

Ableism/disability bias

"The belief that the quality of life or worth of a person with a disability (PWD) is inherently less than that of a nondisabled person"



Ableism at the Bedside: People with Intellectual Disabilities and COVID-19

Caitlin Chicoine, MD, Erin E. Hickey, MD, Kristi L. Kirschner, MD, and Brian A. Chicoine, MD

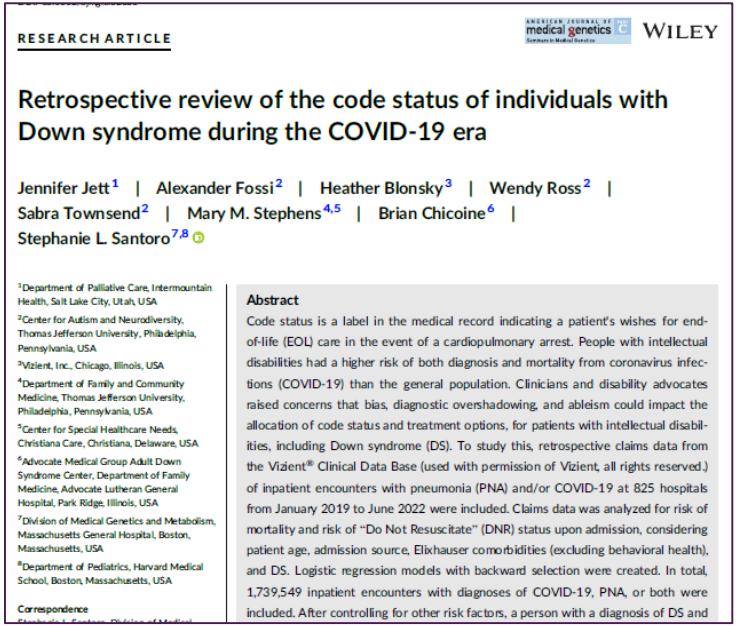
People with intellectual and developmental disabilities have a higher risk of mortality from COVID-19 than the general population. Providers may assume that this is due to the burden of comorbidities for this population; however, the disparity in mortality persists even when controlling for comorbidities. We review the current policies and practices that may be contributing to this higher level of mortality. We contend that pervasive ableism among medical providers leads to a variation in the medical care options that are provided to people with intellectual disabilities and their families. Due to this bias, poor outcomes for people with intellectual disabilities may become a self-fulfilling prophecy. We make recommendations to address the modifiable factors that are contributing to the higher level of mortality for people with intellectual disabilities who are infected with COVID-19, provide strategies to combat ableism within the medical field, and discuss the unique role of the primary care physician as an advocate. (J Am Board Fam Med 2022;35:390–393.)

Keywords: **Ableism, COVID-19, Down Syndrome, Intellectual Disability**

Chicoine et al. 2022

COVID-19 pneumonia & code status

- People with Down syndrome were 6 times more likely to have an order placed for DNR than people without Down syndrome.



RESEARCH ARTICLE

American Journal of Medical Genetics C Seminars in Medical Genetics | WILEY

Retrospective review of the code status of individuals with Down syndrome during the COVID-19 era

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Abstract

Code status is a label in the medical record indicating a patient's wishes for end-of-life (EOL) care in the event of a cardiopulmonary arrest. People with intellectual disabilities had a higher risk of both diagnosis and mortality from coronavirus infections (COVID-19) than the general population. Clinicians and disability advocates raised concerns that bias, diagnostic overshadowing, and ableism could impact the allocation of code status and treatment options, for patients with intellectual disabilities, including Down syndrome (DS). To study this, retrospective claims data from the Vizient® Clinical Data Base (used with permission of Vizient, all rights reserved.) of inpatient encounters with pneumonia (PNA) and/or COVID-19 at 825 hospitals from January 2019 to June 2022 were included. Claims data was analyzed for risk of mortality and risk of "Do Not Resuscitate" (DNR) status upon admission, considering patient age, admission source, Elixhauser comorbidities (excluding behavioral health), and DS. Logistic regression models with backward selection were created. In total, 1,739,549 inpatient encounters with diagnoses of COVID-19, PNA, or both were included. After controlling for other risk factors, a person with a diagnosis of DS and

Physician perceptions

82.4%	18.1%	56.5%
• People with significant disability have worse quality of life than nondisabled people	• Strongly agreed that the health care system often treats patients with a disability unfairly	• Strongly agreed that they welcomed patients with disabilities into their practices.

Iezzoni et al. 2021

Health conditions

More common and/or common

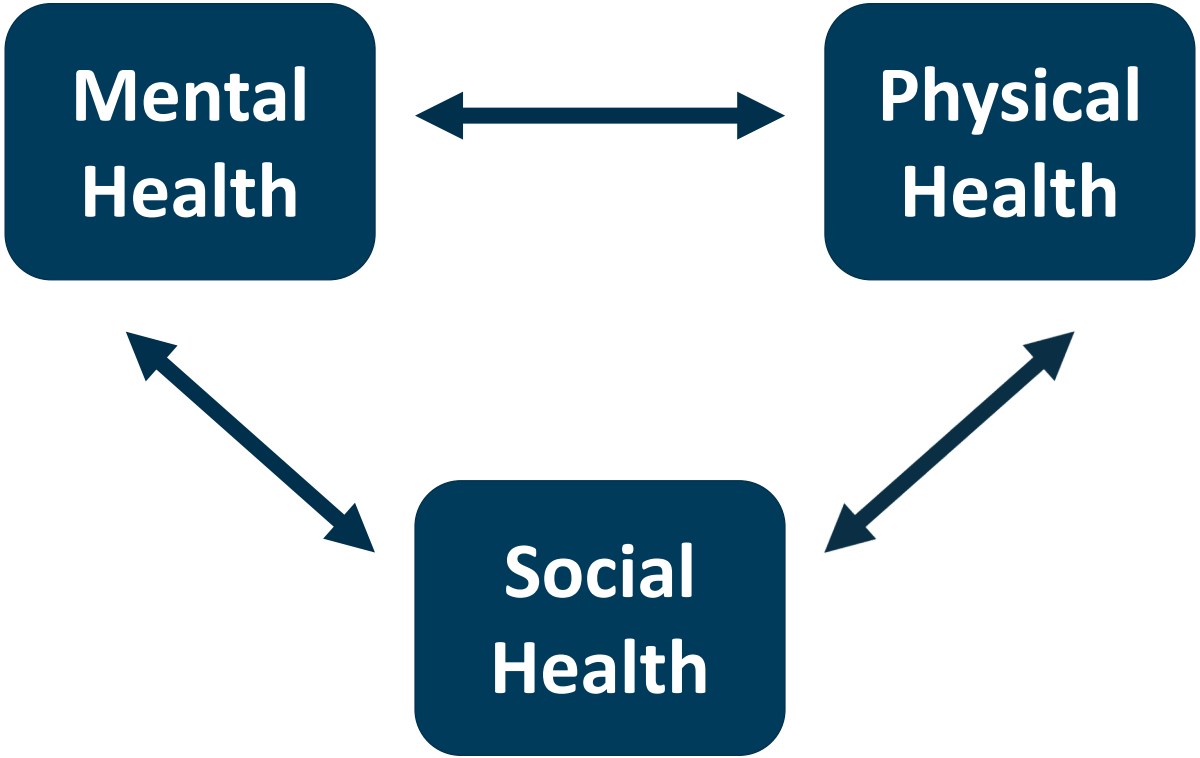
- Thyroid disorders
- Anxiety
- Obsessive-compulsive disorder
- Depression
- Obesity
- Pneumonia
- Swallowing dysfunction
- Skin conditions (e.g., folliculitis)
- Gum disease
- Congenital heart disease
- Gastroesophageal reflux (GERD)
- Celiac disease
- Constipation
- Seizures
- Atlantoaxial instability
- Vision and hearing problems
- Down syndrome regression disorder
- Sleep apnea
- Alzheimer's disease

Less common and/or uncommon

- Many solid tumor cancers
- Atherosclerotic disease (“hardening of the arteries,” plaques in the arteries)
- Myocardial infarctions (heart attacks)
- Hypertension (high blood pressure)

Pain

- People with Down syndrome experience pain.
  - Some people with Down syndrome report it less often than people without Down syndrome.
  - May have difficulty localizing pain.
  - May have delayed response to pain.
- Some people with Down syndrome appear to experience greater pain than people without Down syndrome.
- Certain conditions may increase pain perception (e.g., aging, Alzheimer's disease).


Mental Health
Physical Health
Social Health

Any and all behavior change should be viewed as a possible communication tool.

Health promotion

Dignity of risk

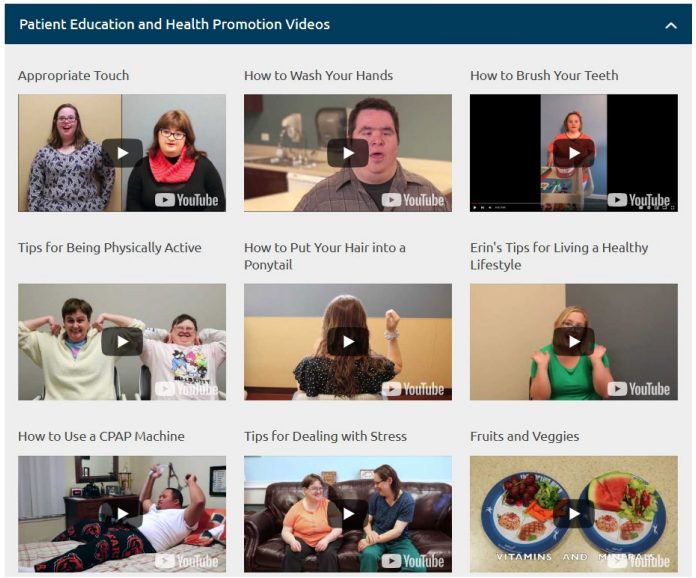
- Respect for an individual's right to:
  - Make their own decisions
  - Participate in a broad range of desired activities
  - Expose themselves to potential consequences or learning opportunities

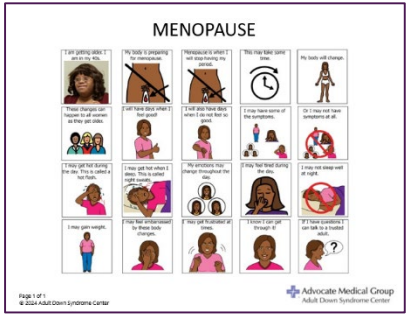
Unrestricted freedom

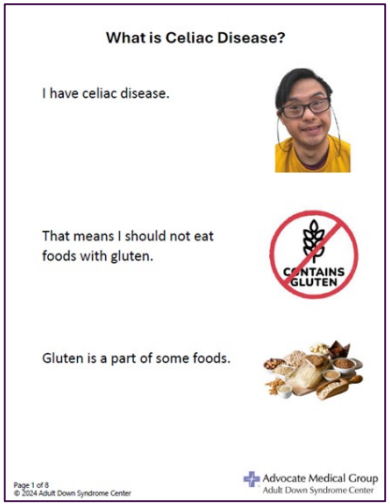
No freedom


Unrestricted freedom
Education
No freedom

“With” instead of “for”







Recipe for health

Ingredients

- Nutritious food
- Physical activity
- Sleep
- Stress management
- Meaningful activities and social connections
- Social skills






Nutritious food

- Involve the person in planning meals and snacks, shopping for foods, and/or preparing meals and snacks.
- Label foods
- Use apps and visuals
- Use portion control products (plates, containers, measuring cups, etc.)
- Discuss which parts of the meal to have seconds of (e.g., fruits or vegetables)

[Guide to Healthy Eating]

[The Traffic Light Eating Plan]

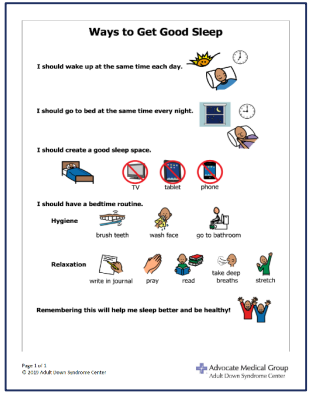
Physical activity

- Build it into the schedule/calendar
- Break it into shorter periods throughout the day
- Make it fun
  - Listen to music
  - Be active with others
  - Turn it into a game

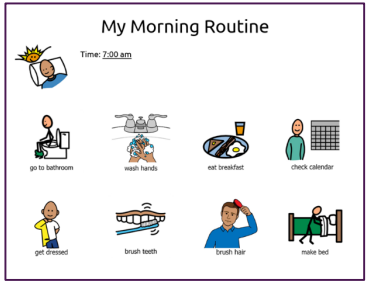
Be Active Throughout the Day

Sleep

- 7-9 hours per night
- Encourage good sleep hygiene
  - Going to bed and waking up at the same time each day
  - Setting up a good sleep space
    - No TV, tablet, or phone
  - Establishing a bedtime routine
    - Hygiene and relaxation
  - Avoiding sugar, caffeine, and alcohol before bed
- Set an alarm for when it is time to start getting ready for bed



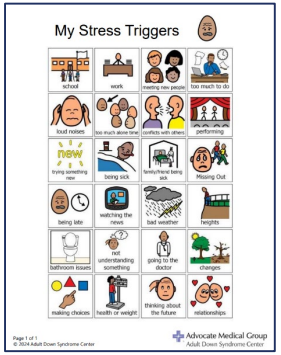
[Ways to Get Good Sleep]



[Create a Morning or Bedtime Routine Visual]

Stress management

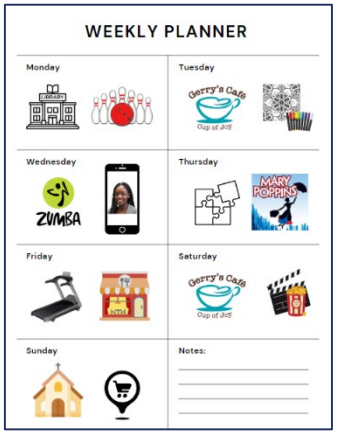
- Identify what stress feels like
- Identify emotions
- Identify “triggers” (causes of stress)
- Calming strategies
  - Counting to 10, taking deep breaths, walking away, coloring
- Coping strategies
  - Reframing thoughts, asking for help, “I” statements
- Anticipate and prepare for life changes
  - Transition out of school, moving, staff changes, siblings going to college, etc.
- Practice during times that are not stressful



How to Cope with Stress Resources

Meaningful activities, social connections

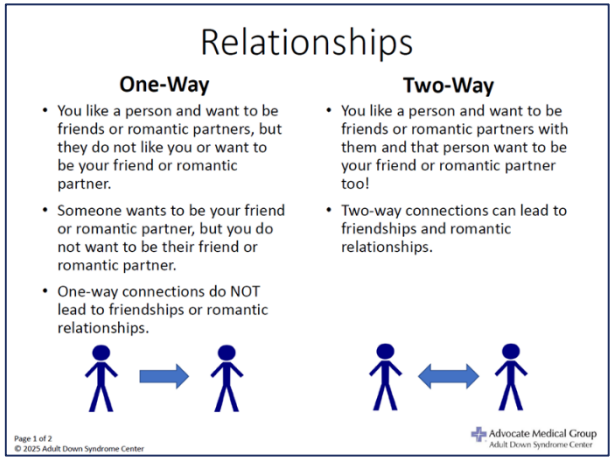
- Building community
  - Down syndrome organizations
  - Next Chapter Book Club
  - Theater program
  - Art program
  - Special Olympics
  - Special recreation associations
  - Best Buddies (Best Buddies Citizens, eBuddies)
  - Religious organizations
- Jobs
- Volunteering
- Hobbies
- Relationships
- Support changing interests
- Use calendars and other visuals



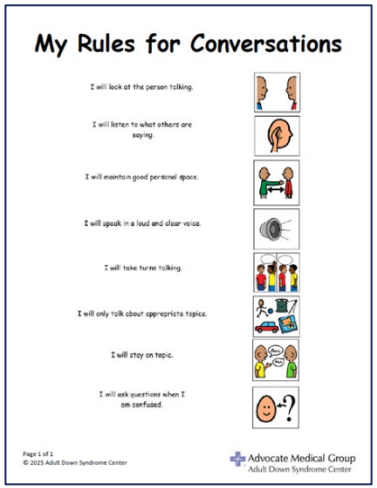
Visual schedule example

Social skills

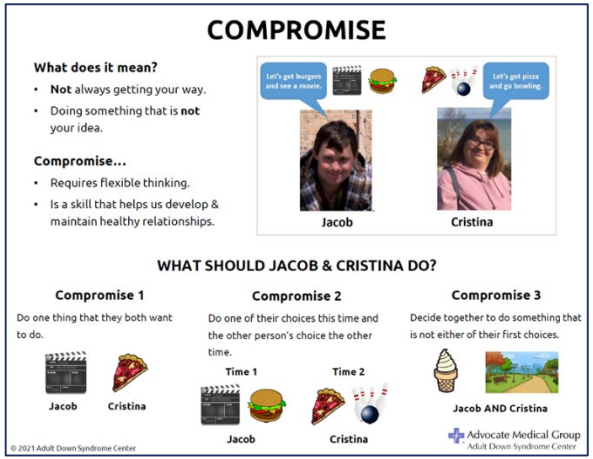
- Ongoing learning and practice



[One-Way and Two-Way Relationships]



[Conversaton Rules]



[Compromise]

A look at the future...

Looking ahead

Life expectancy and health conditions

- Alzheimer's disease
- Inflammation (interferonopathy)
- Metabolic issues (obesity and related health conditions)

Supporting people with Down syndrome

- Exercise
- Nutrition
- Social skills

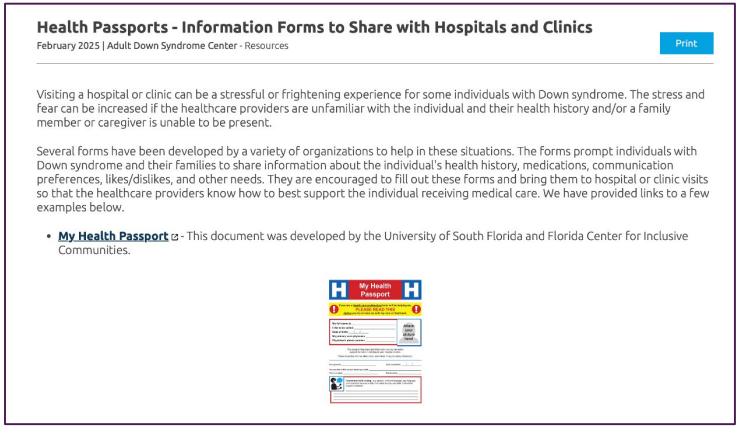
Transition of care

Health professionals

- Educating and supporting health professionals to give the care people with Down syndrome desire and deserve.
  - Knowledgeable
  - Dignity and respect

Resources- bi-directional

- The role of people with Down syndrome and families in sharing resources
- Transition to adulthood
- Who am I?
- What do I need?



Key points

- Each person with Down syndrome deserves to receive healthcare from healthcare professionals who treat them with dignity and respect and are informed about their health needs.
- While each person with Down syndrome is unique, there are some common characteristics.
- Health changes are not "just Down syndrome" and should be evaluated with special attention to the pattern of co-occurring conditions (some more common, some less common).
- People with Down syndrome can and should be involved in their own health promotion.

Resources

Articles

[Alzheimer's Disease Guidebook (NDSS)]

[Atlantoaxial Instability]

[Celiac Disease]

[Constipation]

[Depression]

[Diagnostic Overshadowing]

[Gastroesophageal Reflux Disease]

[Hypothyroidism and Hyperthyroidism]

[Pain]

[Pneumonia]

[Reducing Risk of Getting Alzheimer's Disease]

[Regression (NDSS)]

[Self-Talk]

[Sleep Apnea]

[Swallowing Problems (Dysphagia)]

[The Groove]

[Tips for Staying Hydrated]

[Weight Management in Adults with Down Syndrome]

Webinars

[Adapting Activities for Older Adults]

[Behavior Changes]

[Common and Uncommon Health Conditions]

[Decline in Skills and Regression]

[Gastrointestinal Health]

[Healthy Aging]

[Key Insights from the PCP's Guide to Women's Health and Down Syndrome]

[Personal Hygiene]

[Promoting Mental Health Across the Lifespan]

[Self-Talk]

[The Groove]

[The Recipe for Health]

Videos and visuals

[Boundaries]

[Celiac Disease Visuals]

[Create a Morning/Bedtime Routine Visual]

[Fun Activities for Promoting Health]

[Getting Good Sleep Visuals]

[Guides to Healthy Eating and Drinking]

[Healthy Eating at Buffets Video & Visual]

[Healthy Pace for Eating Video & Visuals]

[How to Cope with Stress Visuals]

[Hydration Video & Visuals]

[Relationships]

[Resources on Phone, Social Media, and Internet Safety and Etiquette]

[Tips for Being Physically Active Video]

[Tips for Eating Health Meals]

[Visuals About the Food Groups]

[What to Drink Instead of Soda]

Adult Down Syndrome Center

Resource Library

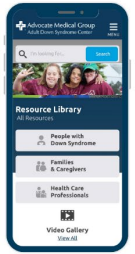
Email List

Facebook

Instagram

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

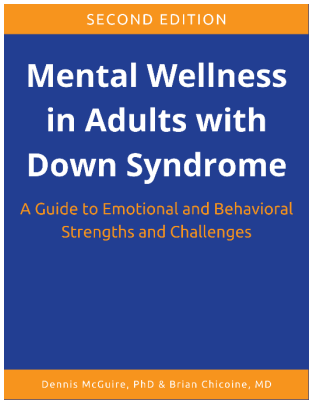
Email List

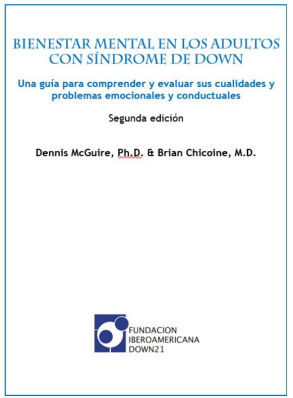
www.eepurl.com/c7uV1v

Advocate Medical Group
Adult Down Syndrome Center

Resources

- Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges
  - Available as a free PDF in English and Spanish



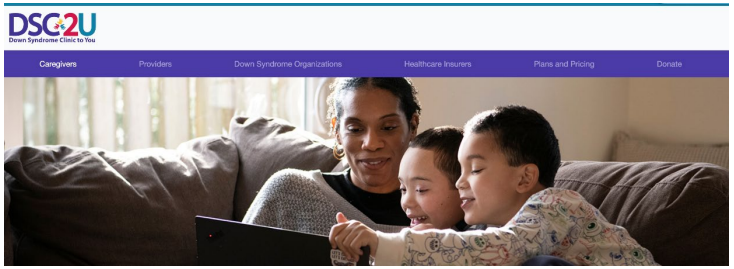


CARE-DS

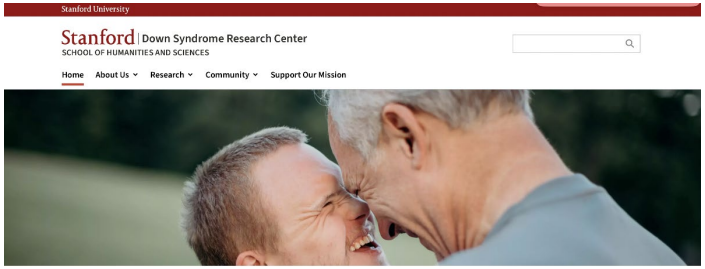
- https://careds.org
- Peer reviewed
- CME available
- 2-hour course
- Reference articles
- Resource materials

DSMIG-USA

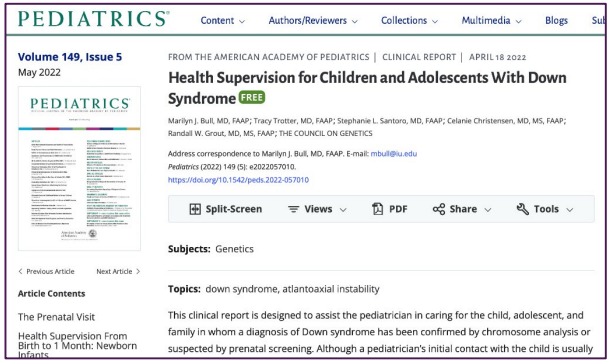
- Down Syndrome Medical Interest Group
  - Membership
  - Speaker Series
  - Project ECHO
  - Webinars



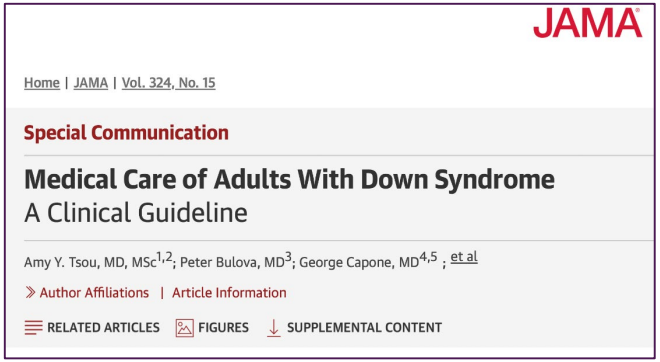
[Down Syndrome Clinic to You]



[Stanford University]



[American Academy of Pediatrics]



[Global Medical Care Guidelines for Adults with Down Syndrome]

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Questions?

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