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# Health Conditions of Adolescents and Adults with Down Syndrome

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Brighter Futures Conference



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# Resource Library



Advocate Medical Group  
Adult Down Syndrome Center

I'm looking for...  MENU

## Resource Library | All Resources



 **People with Down Syndrome**



 **Families & Caregivers**



 **Health Care Professionals**

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<https://adsresources.advocatehealth.com/>

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# 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.

# Objectives

- Identify common and uncommon physical and mental health conditions of adults with Down syndrome.
- Describe unique aspects of diagnosing and treating health conditions of individuals with Down syndrome.
- Share resources on health of individuals with Down syndrome.

# Reminders

**Each person with  
Down syndrome  
is unique.**

**Many people with  
Down syndrome  
share common  
characteristics.**

# Cognitive and behavioral

- Better receptive language than expressive language
- Concrete thinking
- Visual memory
- Self-talk and imaginary friends
  - Change in quality or frequency may be a sign of stress or mental illness
- The "Groove"
- Empathy radar

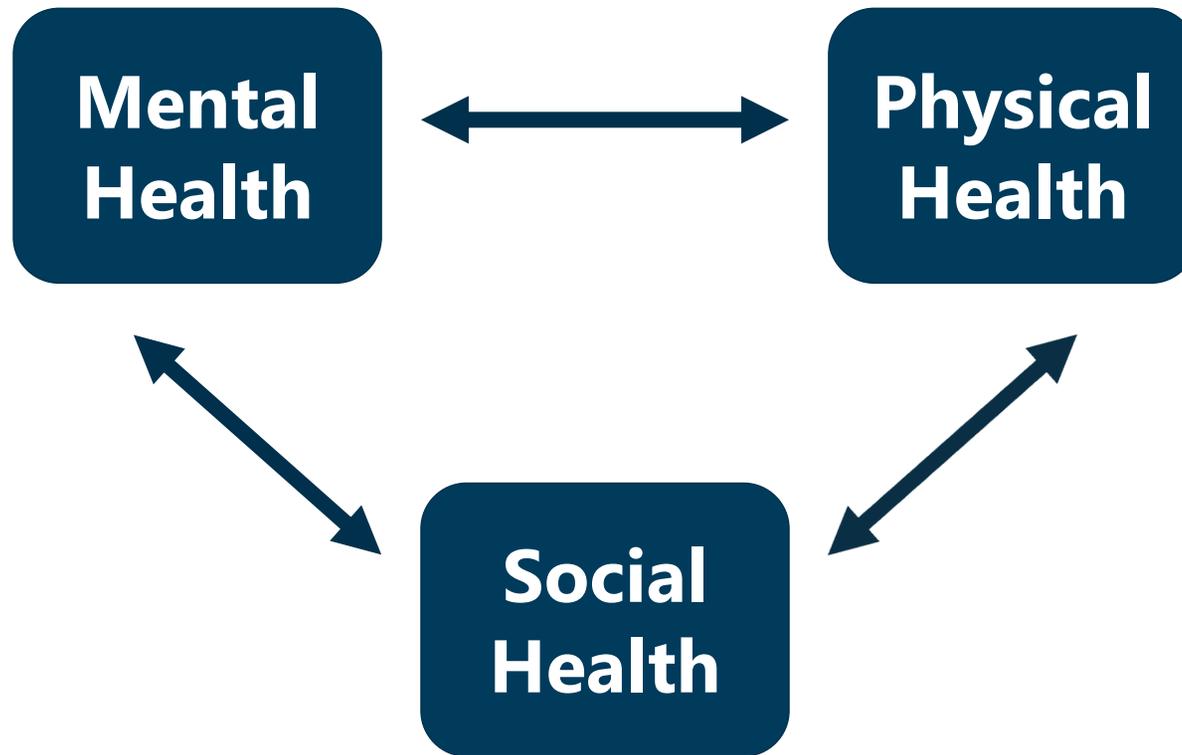
## THE "GROOVE"

The "groove" is a preference for **sameness, repetition, and routine.**

Possible Advantages	Possible Disadvantages
<p>The groove can...</p> <ul style="list-style-type: none"><li>• Give structure and order to daily life</li><li>• Support successful completion of tasks</li><li>• Increase independence</li><li>• Help manage stress</li></ul>	<p>The groove can make it difficult to...</p> <ul style="list-style-type: none"><li>• Be flexible</li><li>• Transition from one task to the next</li><li>• Deal with changes</li><li>• Apply skills across different settings</li></ul>

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



# Rosa

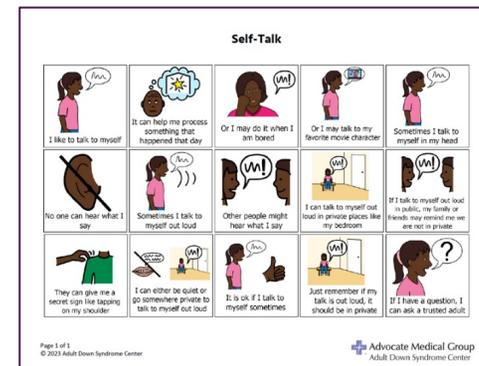
## Age: 43

- Had become mildly aggressive
- Lived in a group home with several other women
- Behavior occurred after dinner during chore time
  - Chores rotated among housemates
  - If Rosa wasn't assigned to sweep, she took the broom from the assigned housemate
- New chore schedule
  - Housemates didn't mind that she wanted to sweep

# Resources



- [Behavior Change](#) (article)
- [Diagnostic Overshadowing](#) (article)
- [Self-Talk](#) (article)
- [Self-Talk](#) (webinar)
- [The Groove](#) (article)
- [The Groove](#) (webinar)
- [Two Syndromes](#) (article)
- [Using Videos](#) (article)



[Self-Talk Visual](#)

# Health conditions

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**Each person with  
Down syndrome  
has a unique  
health history.**

**Many people with  
Down syndrome  
have 1 or more  
common health  
conditions.**

# Data

**CME Accredited** ORIGINAL RESEARCH

## Prevalence of Common Disease Conditions in a Large Cohort of Individuals With Down Syndrome in the United States

Brian Chicoine, MD,<sup>1,3</sup> Anne Rivelli, MPH, MA,<sup>1,2</sup> Veronica Fitzpatrick, DrPH,<sup>1,2</sup> Laura Chicoine, BA,<sup>1,3</sup> Gengjie Jia, PhD,<sup>4,5</sup> Andrey Rzhetsky, PhD<sup>4,5</sup>

<sup>1</sup>Advocate Aurora Health, Downers Grove, IL; <sup>2</sup>Advocate Aurora Research Institute, Downers Grove, IL; <sup>3</sup>Advocate Medical Group Adult Down Syndrome Center, Park Ridge, IL; <sup>4</sup>Department of Medicine, University of Chicago, Chicago, IL; <sup>5</sup>Institute of Genomics and Systems Biology, University of Chicago, Chicago, IL

BRIEF REPORT

## Prevalence of Endocrine Disorders Among 6078 Individuals With Down Syndrome in the United States

Anne Rivelli, MA, MPH,<sup>1,2</sup> Veronica Fitzpatrick, DrPH,<sup>1,2</sup> Danielle Wales, BS,<sup>3</sup> Laura Chicoine, BA,<sup>1,4</sup> Gengjie Jia, PhD,<sup>5</sup> Andrey Rzhetsky, PhD,<sup>5</sup> Brian Chicoine, MD<sup>1,4</sup>

<sup>1</sup>Advocate Aurora Health, Downers Grove, IL; <sup>2</sup>Advocate Aurora Research Institute, Downers Grove, IL; <sup>3</sup>Chicago Medical School, Rosalind Franklin University of Medicine and Science, North Chicago, IL; <sup>4</sup>Advocate Medical Group Adult Down Syndrome Center, Park Ridge, IL; <sup>5</sup>University of Chicago, Chicago, IL

BRIEF REPORT

## Prevalence of Infectious Diseases Among 6078 Individuals With Down Syndrome in the United States

Veronica Fitzpatrick, DrPH,<sup>1,2</sup> Anne Rivelli, MA, MPH,<sup>1,2</sup> Sagar Chaudhari, MA,<sup>3</sup> Laura Chicoine, BA,<sup>1,4</sup> Gengjie Jia, PhD,<sup>5</sup> Andrey Rzhetsky, PhD,<sup>5</sup> Brian Chicoine, MD<sup>1,4</sup>

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BRIEF REPORT

## Prevalence of Mental Health Conditions Among 6078 Individuals With Down Syndrome in the United States

Anne Rivelli, MA, MPH,<sup>1,2</sup> Veronica Fitzpatrick, DrPH,<sup>1,2</sup> Sagar Chaudhari, MA,<sup>3</sup> Laura Chicoine, BA,<sup>1,4</sup> Gengjie Jia, PhD,<sup>5</sup> Andrey Rzhetsky, PhD,<sup>5</sup> Brian Chicoine, MD<sup>1,4</sup>

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Chicoine et al. 2021, Fitzpatrick et al. 2022, Rivelli et al. 2022, Tsou et al. 2020



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# Common health conditions

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

# Less common health conditions

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



# Resources

- [At-Home Treatments for Common Health Conditions of People with Down Syndrome](#) (webinar)
- [Common and Uncommon Health Conditions in Adolescents and Adults with Down Syndrome](#) (webinar)
- [Global Medical Care Guidelines for Adults with Down Syndrome](#) (Global Down Syndrome Foundation)
- [Health Supervision for Children and Adolescents with Down Syndrome](#) (American Academy of Pediatrics)

# GENERAL

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# Vital signs

## Differences

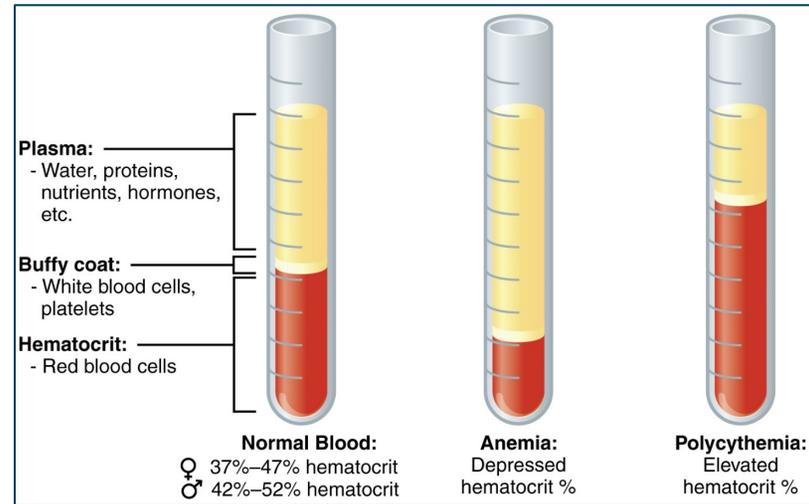
- Lower heart rate (pulse)
- Lower blood pressure
- Body temperature



# Blood

## More common

- Polycythemia (high red blood cell count)
- Macrocytosis (large red blood cells)
- Neutropenia (low white blood cell count)
- Abnormal blood clotting?



Composition of blood

*Anatomy and Physiology, [OpenStax](#)*

# Nutrition

## More common

- Vitamin deficiencies (e.g., vitamin B12)
- Folate metabolism

# 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.

# Joshua

## Age: 28

- Intermittently getting upset
- Can last for a few hours
- Sometimes seems to occur after eating
- Developed episodes of vomiting
- Ultrasound demonstrated gallstones
- Vomiting and behavioral changes resolved after removal of gall bladder



# Resources

- [Differences in Red Blood Cells](#) (article)
- [Fainting](#) (article)
- [Heart Rates and Exercise](#) (article)
- [High and Low Blood Pressure](#) (article)
- [Normal Abnormal Lab Values](#) (article)
- [Pain](#) (article)
- [Polycythemia](#) (article)
- [Temperature Regulation](#) (article)
- [The Recipe for Health](#) (webinar)
- [Vitamin B12 and Folate](#) (article)

# MENTAL HEALTH

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# Mental health

## More common

- Depression
- Obsessive-compulsive disorder
- Impulse control disorder
- Attention deficit disorder

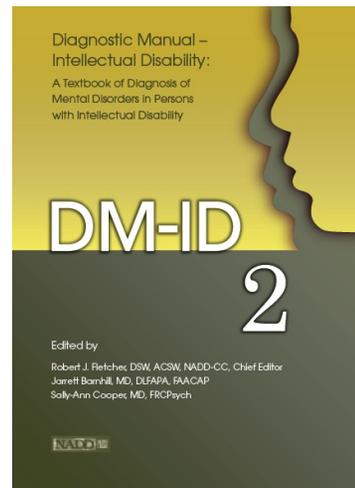
## Less common

- Substance use/abuse
- Anxiety disorder?
- Posttraumatic stress disorder?

# Mental health

## Presentation

- Communication
- Behavior
- Self-report
- Introspection
- Impulse control



[Diagnostic Manual – Intellectual Disability \(DM-ID-2\)](#)

## Screening/diagnosis

- Behavioral changes
- Changes in routines
- Underlying physical health conditions

# Symptoms of depression

- Persistent feelings of sadness and/or decreased interest in things the individual previously enjoyed
- Depressed or irritable mood
- Loss of interest or pleasure in activities
- Weight loss or gain
- Change in sleep patterns
- Slowing down of physical movement or restlessness
- Fatigue
- Feelings of worthlessness
- Decreased concentration
- Recurrent thoughts of death
- Change in self-talk or the groove
- Psychotic features (extreme withdrawal, hallucinatory self-talk, etc.)
- Inappropriate fears or avoidances of people/things
- Strong refusal to leave the home

# Symptoms of anxiety disorder

- Anxiety that interferes with day-to-day life on a long-term basis
- Feeling worried or anxious most days
- Mild self-injurious behavior
- Being easily fatigued
- Difficulty sleeping
- Restlessness
- Difficulty concentrating
- Muscle tension
- Irritability
- Change in self-talk, the groove

# Obsessive-compulsive disorder

- Obsessions – persistent thoughts or thoughts that preoccupy the mind
- Compulsions – repetitive behaviors or acts that one feels compelled to perform
- Individual with Down syndrome often is not upset by the thoughts/behaviors
- May get upset if the behaviors are blocked or prevented
- Impairs function
- Cannot participate in usual activities due to being “stuck”

# Mental health

## Treatment

- Counseling
- Art therapy
- Occupational therapy
- Animal-assisted therapy
- Music therapy
- Medications



# Lexi

Age: 22

- Aged out of school, started to gain weight
- Had a disagreeable mood and difficulty sleeping
- History, physical exam, labs, sleep study (negative)
- Initial diagnosis: adjustment reaction with depressed mood and sleep issues
  - Established new routine, counseling, sleep hygiene
- Didn't respond; diagnosed with depression
  - Bupropion (Wellbutrin) for depression
  - Melatonin for sleep

# Mental Health



- [Behavior Changes](#) (webinar)
- [Depression](#) (article)
- [Finding a Mental Health Professional](#) (article)
- [Generalized Anxiety Disorder](#) (article)
- [How to Cope with Stress](#) (article)
- [Post-Traumatic Stress Disorder](#) (article)
- [Promoting Mental Health Across the Lifespan](#) (webinar)
- [Psychotherapy](#) (article)



[Mental Health Visuals and Videos](#)

# Topics

- **Endocrine & weight**
  - Thyroid conditions, diabetes, obesity
- **Gastrointestinal**
  - Reflux, celiac disease, constipation
- **Musculoskeletal**
  - Joint laxity, flat feet, atlantoaxial instability
- **Nose, mouth & upper airway**
  - Swallowing problems
- **Sensory**
  - Vision and hearing, sensory processing
- **Respiratory**
  - Pneumonia, sleep apnea
- **Down syndrome regression disorder**
- **Neurology**
  - Seizures, Alzheimer's disease
- **Urinary**
  - Urinary retention, UTIs
- **Gynecology**
  - Menstruation, menopause
- **Heart & vascular system**
  - Heart disease, embolic strokes
- **Skin & nail conditions**
  - Alopecia, dry skin, folliculitis/boils
- **Cancer**
  - Solid tumor cancers
- **Wrap-up**

# ENDOCRINE & WEIGHT

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# Endocrine and weight

## More common

- Hypothyroidism – underactive thyroid
- Hyperthyroidism – overactive thyroid
- Type 1 diabetes mellitus
- Obesity and overweight
- Adrenal insufficiency
- Type 2 diabetes mellitus
  - More common age 5 to 34 years of age; less common overall

# Hypothyroidism

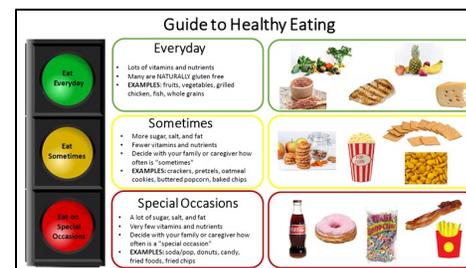
- Underactive thyroid
- Symptoms
  - Weakness, fatigue
  - Dry, pale, and/or cold skin
  - Mood changes, depression
  - Forgetfulness, difficulty with thinking process
  - Puffy eyelids and/or face
  - Constipation
  - Weight gain
  - And others
- Screening/diagnosis
  - Thyroid blood tests of TSH and possibly T4 (less commonly T3)
  - Screen adults with Down syndrome every 1 to 2 years using a TSH test
- Treatment
  - Medication (levothyroxine, Synthroid, Levoxyl), take on empty stomach, first thing in AM, wait 30 minutes to eat and take other meds
  - Check TSH level 6-8 weeks after starting medication or changing dose

# Overweight and obesity

- Weight of adults with Down syndrome in 2020 study
  - 27.3% - BMI in overweight range
  - 53.8% - BMI in obesity range
- Lower resting metabolic rate
- Hormonal differences
- Co-occurring conditions
- Factors that affect weight
  - Genetics
  - Hormones
  - Sleep
  - Physical activity
  - Diet
  - Stress
  - Some medications
  - Life changes

# Overweight and obesity

- Screening/diagnosis
  - Monitor for weight change and obesity annually by calculating BMI
- Treatment
  - Lifestyle (e.g., diet, physical activity, hydration, stress, sleep)
  - Medications
  - Surgery



## Healthy Lifestyle Visuals and Videos

# Lisa

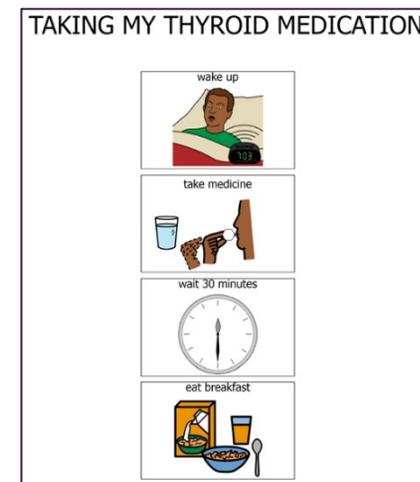
## Age: 31

- “Nervousness” and increasing compulsive behavior - repeatedly straightening objects in her bedroom making it difficult to leave the house
- Labs showed TSH low and T4 high
- Diagnosis: hyperthyroidism
- Improved with treatment
- Six months later
  - Depressed mood
  - High TSH and low T4
  - Diagnosis: hypothyroidism
  - Fluctuation back and forth
  - Radioactive ablation of thyroid and thyroid replacement medication (levothyroxine)

# Resources

- [Diabetes](#) (article)
- [Gout](#) (article)
- [Hypoglycemia](#) (article)
- [Hypothyroidism and Hyperthyroidism](#) (article)
- [Thyroid, Weight, and Metabolism](#) (article)
- [Weight Management](#) (article)

[Topics](#)



[Thyroid Visuals](#)

# GASTROINTESTINAL

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# Gastrointestinal

## More common

- Gastroesophageal reflux disease (GERD, heartburn)
- Celiac disease
- Constipation
- Motility problems
- Achalasia
- Gall bladder disease
- Hernias
- Fatty liver

# Gastroesophageal reflux disease

- GERD, heartburn, reflux
- Backward flow of stomach acid into the esophagus
- Risk factors
  - Obesity
  - Sleep apnea
  - Overeating
  - Consuming caffeine, spicy foods, carbonated beverages
  - Lying down after eating

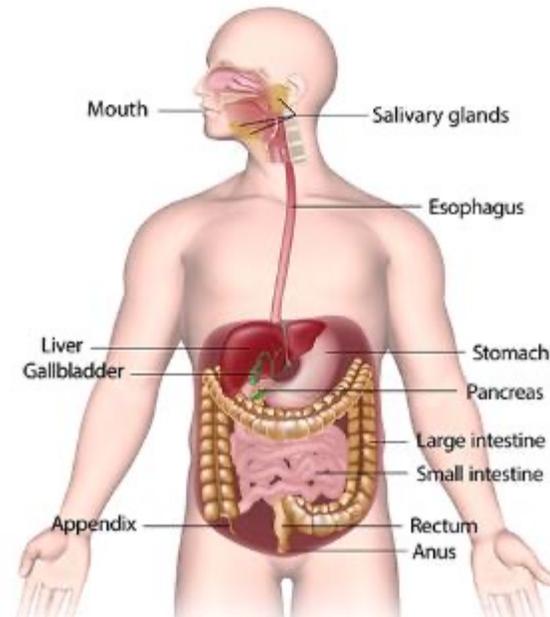


Image from [National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health](#)

# Gastroesophageal reflux disease

- Symptoms
  - Chest pain, abdominal pain
  - Sore throat
  - Regurgitation of digested food
  - Difficulty swallowing
  - Aspiration (breathing food into the lungs)
  - Chronic cough
  - Bronchospasm (asthma)
  - Loss of enamel on the teeth
  - Change in behavior
- Possible complications
  - Barrett's esophagitis
  - Scarring of the esophagus
- Diagnosis
  - Clinical diagnosis
  - Upper endoscopy (EGD)
  - Upper GI (barium)

# Gastroesophageal reflux disease

- Treatment

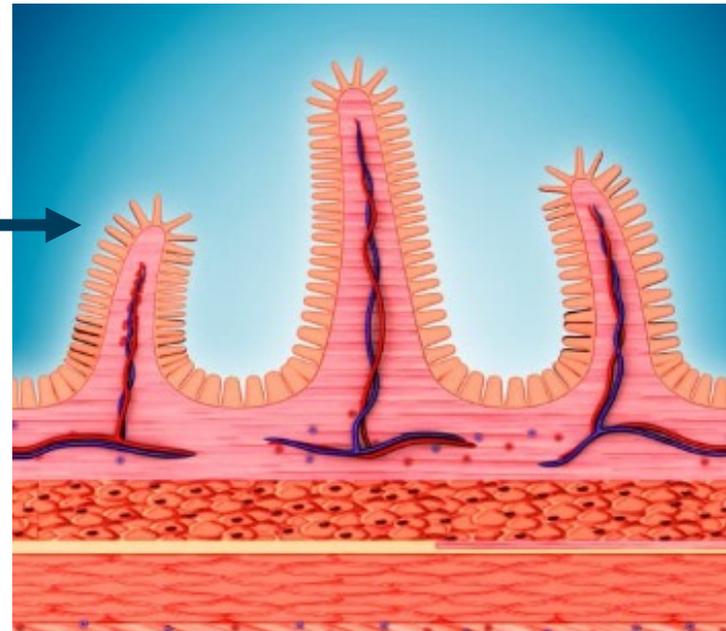
- Avoid overeating
- Reach/maintain ideal body weight
- Limit caffeine and carbonated drinks
- Avoid lying down after a meal
- Avoid clothing that constricts the abdomen
- Elevate the top of the bed
- Treat sleep apnea

- Medications

- Antacids (e.g., Tums)
- H2 blockers (e.g., ranitidine)
- Combination (e.g., Pepcid Complete)
- Proton pump inhibitors (PPI) (e.g., omeprazole)
- Metoclopramide

# Celiac disease

- Sensitivity to gluten that causes an inflammatory response
- Damages villi
- Affects absorption of nutrients
- Symptoms
  - Diarrhea
  - Bloating
  - Weight loss
  - Mood and behavior change



# Celiac disease

- Diagnosis
  - History and physical exam
  - Blood test
    - Anti-tissue transglutaminase IgA
    - Total IgA
    - Genetic testing
  - Endoscopy (EGD) with biopsy
- Treatment
  - Gluten-free diet
  - Supplements
  - Dietician consult
- Screening
  - Guidelines for adults with Down syndrome: annual assessment for GI and non-GI signs and symptoms of celiac disease
  - Guidelines for children with Down syndrome: review for symptoms at each health supervision visit

# Constipation

- Change in the frequency, size, consistency, and/or ease of bowel movements
- Symptoms
  - Infrequent, hard, or difficult to pass bowel movements
  - Diarrhea
  - Bloating
  - Abdominal discomfort
  - Pain with having a bowel movement
  - Fecal impaction
- Diagnosis
  - History and physical
  - X-ray
  - Colonoscopy
  - Celiac testing
- Treatment and prevention
  - Fluids
  - Exercise
  - Fiber
  - Medications

# Jim

Age: 35

- Depressed mood, reduced verbal abilities, change in his ability to complete ADLs
- History and physical exam, lab testing, OT assessment
- “Does he have Alzheimer’s disease?”
- Diagnosed with celiac disease, vitamin B12 deficiency, and depression
- Treatment
  - Gluten-free diet
  - Occupational therapy
  - Medications

# Resources

- [Celiac Disease](#) (article)
- [Constipation](#) (article)
- [Gallstones](#) (article)
- [Gastroesophageal Reflux Disease](#) (article)
- [Gastrointestinal Bleeding](#) (article)
- [Gastrointestinal Health](#) (webinar)
- [Hernias](#) (article)
- [Ulcers](#) (article)

[Topics](#)



**Eating Gluten-Free**

Usually Gluten-Free I can usually eat these foods!	Might Have Gluten I should check before eating these foods.	Usually Have Gluten I should only eat these if they say gluten-free.

Page 1 of 1  
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**Before Going Out to Eat**

- I can look for a restaurant that has gluten-free options.
- I can use my computer or phone to look for restaurants.
- I can use apps such as [Find Me Gluten Free](#) to find restaurants with gluten-free options.

Page 2 of 6  
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[Celiac Disease Visuals](#)

# MUSCULOSKELETAL

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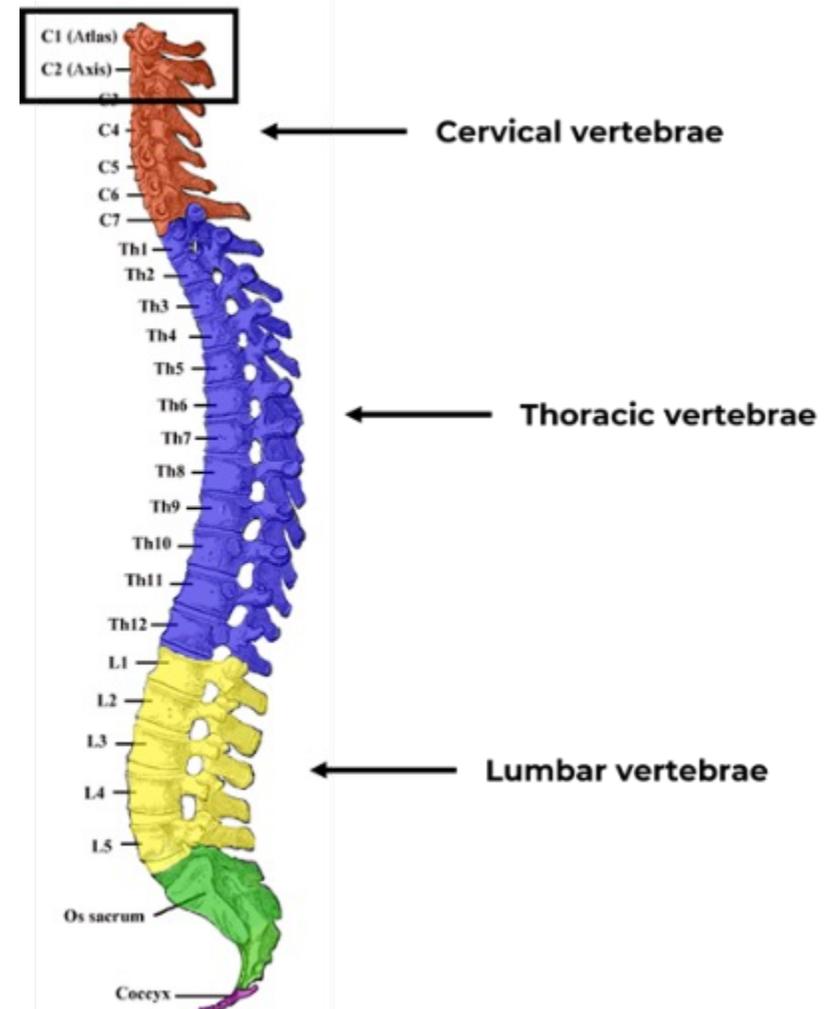
# Musculoskeletal

## More common

- Atlantoaxial instability (AAI), cervical myelopathy
- Autoimmune arthritis
- Joint laxity and subluxation
- Flat feet and overpronation
- Gout
- Osteoarthritis?

# AAI

- Atlantoaxial instability
- Abnormal movement between the 1<sup>st</sup> and 2<sup>nd</sup> vertebrae in the neck
- Symptoms
  - Pain in the neck or head
  - Holding the head in unusual positions
  - Difficulty holding the head up
  - Weakness of the arms and/or legs
  - Incontinence (urine or stool)
  - Not wanting to participate in activities



# AAI

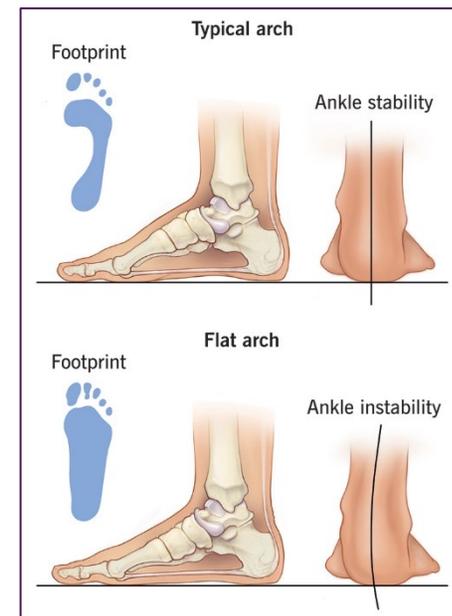
- Screening
  - Annual assessment for symptoms and physical findings for spine and nerve compression
    - Increased deep tendon reflexes
    - Clonus
    - Abnormal plantar reflex
    - Muscle weakness
  - Period neck x-rays are NOT recommended unless a person has symptoms

# AAI

- Diagnosis
  - Neck x-rays
  - MRI
  - CT scan
  - Electromyogram (EMG)
- Prevention
  - Avoid trampolines
  - Teach methods to reduce injury when playing contact sports
  - Anesthesia – do not use posterior extension for placement of breathing tube
- Treatment
  - Observation through regular exams and possibly imaging
  - Surgery

# Overpronation & flat feet

- Overpronation: feet/ankle roll inward too far
- Flat feet: fallen arches of the feet
- Symptoms
  - Foot/ankle pain
  - Bunions
  - Plantar fasciitis
  - Shin splints
  - Knee, hip, and/or back pain



[Image from Cleveland Clinic](#)

# Overpronation & flat feet

- Diagnosis
  - Physical exam
- Treatment
  - Treat associated symptoms – icing, nonsteroidal anti-inflammatory medications (e.g., ibuprofen, naproxen, aspirin)
  - Supportive shoes
  - Orthotics/inserts
    - Superfeet, Sole, Spenco, etc.
    - Custom
  - Physical therapy



Image from [Superfeet](#)

# John

Age: 17

- Teachers and parents concerned that he might be depressed
- Would put his head on the desk and not participate in class (more as the day progressed)
- Physical exam found increased reflexes
- Imaging of neck demonstrated AAI
- Surgery to correct
- With physical therapy, his strength improved, and symptoms thought to be depression resolved

[Topics](#)



# Resources

- [Anesthesia](#) (article)
- [Atlantoaxial Instability](#) (article)
- [Changes in Gait](#) (article)
- [Connective Tissue](#) (article)
- [Ligamentous Laxity](#) (article)
- [Osteoporosis and Osteopenia](#) (article)
- [Overpronation](#) (article)

# SENSORY

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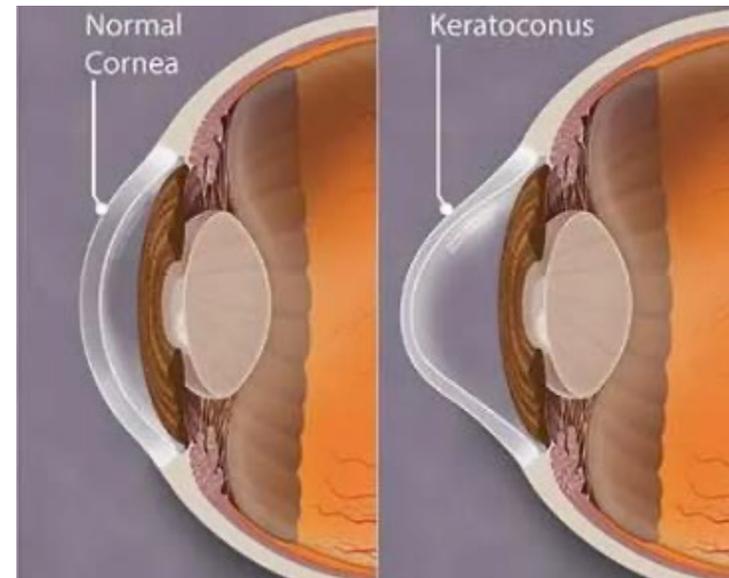
# Sensory

## More common

- Vision impairment
- Cerebral vision impairment
- Depth perception differences
- Hearing impairment
- Sensory processing differences

# Vision

- Myopia – near-sightedness
- Hyperopia – far-sightedness
- Keratoconus
- Cataracts
- Blepharitis
- Conjunctivitis
- Cerebral vision impairment
  - Depth perception differences



[Image from American Academy of Ophthalmology](#)

# Hearing

- Hearing impairment
- Cerumen impaction
- Recurrent infections
- Middle ear complications
  - Cholesteatomas
  - Otosclerosis (abnormal bone growth)
  - Persistent fluid

# Sensory processing

- “Problems with the ability to process information received through the senses which impact the ability for a person to function in their daily life” (Katie Frank, PhD, OTR/L)
- 8 senses
  - Touch, sight, smell, sound, taste
  - Vestibular, proprioception, interoception

## Sensory Activities & Accommodations



### Examples

- Headphones
- Air purifiers
- Weighted objects
- Vibration
- Joint compression
- Physical activity
- TheraPutty
- Massage

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[Sensory Resources](#)

# Lisa

Age: 27

- Needs blood drawing and is afraid
- Gets hot and sweats when just discussing blood drawing
- Discussed calming strategies but still having difficulty allowing blood to be drawn
- A few appointments with OT to learn sensory strategies
- Doing better with blood drawing

# Mohammed

Age: 41

- Concern about cognitive decline
  - "I think he has developed Alzheimer's disease."
- Not following directions, seems confused
- On exam, ear canals were completely occluded with cerumen (ear wax)
- Ear wax removed
- Referred to audiology for hearing test, hearing was only slight decreased
- Noted to be following directions again

# Resources

- [Balance](#) (article)
- [Cerumen Impaction](#) (article)
- [Down Syndrome EyeWiki](#) (American Academy of Ophthalmology)
- [Hearing Loss](#) (article)
- [Proprioceptive Input](#) (article)
- [Sensory Processing](#) (article)
- [Sensory Processing](#) (webinar)

[Topics](#)



[Wearing My Hearing Aids Story](#)

# NOSE, MOUTH, AND UPPER AIRWAY

 Advocate Health Care

Now part of  **ADVOCATEHEALTH**

# Nose, mouth, & upper airway

## More common

- Chronic rhinitis
- Chronic sinusitis
- Gum disease
- Malocclusions
- Dysphagia (swallowing problems)

# Dysphagia (swallowing problems)

- Why is it more common?
  - Differences in anatomy and physiology
  - Eating too fast, not chewing well
  - GERD, esophageal conditions
- Symptoms
  - Choking
  - Gagging
  - Eating refusal or eating selectivity
  - Aspiration pneumonia
- Diagnosis
  - Speech therapy
  - Video swallow study
  - Esophagram
  - Upper endoscopy (EGD)
- Treatment
  - Eat slower, chew thoroughly
  - Swallowing therapy
  - Diet change
  - Feeding tube (e.g., PEG)

# Elisha

Age: 38

- Concern about his eating becoming “picky”
- Eating less solid food
- Coughing after eating sometimes
- Video swallow study normal
- Esophagram demonstrated abnormal contractions in the esophagus
- Further evaluation by GI with EGD
- Diagnosis: Achalasia
- Treated with Peroral Endoscopic Myotomy (POEM)

# Resources

- [Brushing Teeth](#) (visuals and video)
- [Healthy Pace for Eating](#) (visuals and video)
- [Swallowing Problems](#) (article)

[Topics](#)



# RESPIRATORY

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# Respiratory

## More common

- Smaller airways
- Obstructive sleep apnea
- Pneumonia
- Infections
- Pulmonary hypertension (high blood pressure in the lungs)
- COVID-19

## Less common (more severe?)

- Influenza?
- Upper respiratory infection?

# Obstructive sleep apnea

- Temporary stoppage of breathing while sleeping
- Symptoms
  - Daytime sleepiness
  - Snoring
  - Pauses in breathing
  - Nighttime arousal and/or awakening
  - Headaches
  - Changes in behavior and mood

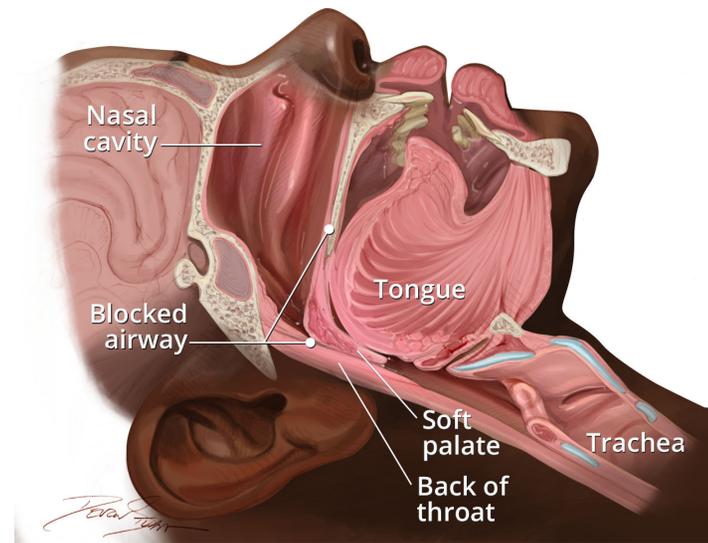


Image from the [National Heart, Lung, and Blood Institute, National Institutes of Health](#)

# Obstructive sleep apnea

- Screening/diagnosis
  - Sleep study in a sleep lab
  - Home sleep study
  - Hand or wrist devices
- Treatment
  - CPAP or BiPAP
  - Positional treatment
  - Oral appliances
  - Surgery
  - Medications



The Inspire implant keeps your airway open while you sleep, so you can breathe regularly and sleep soundly.



The handheld Inspire™ remote simply turns on your therapy when you're ready to sleep. No mask or hose required.



The Inspire® app tracks your sleep goals and allows you to share data directly with your doctor.

Images from [Inspire Therapy](#)

# Pneumonia

- Infection of the lungs
- Symptoms
  - Cough
  - Fever, sweating, and/or chills
  - Fatigue
  - Confusion
  - Shortness of breath, low oxygen level
  - Lower than normal body temperature
  - Low blood pressure
- Increased risk
  - Abnormal swallowing
  - GERD
  - Sleep apnea
  - Immune dysfunction
  - Tooth and gum disease
  - AAI
  - Alzheimer's disease
- Prevention
  - Pneumococcal vaccines

# Omar

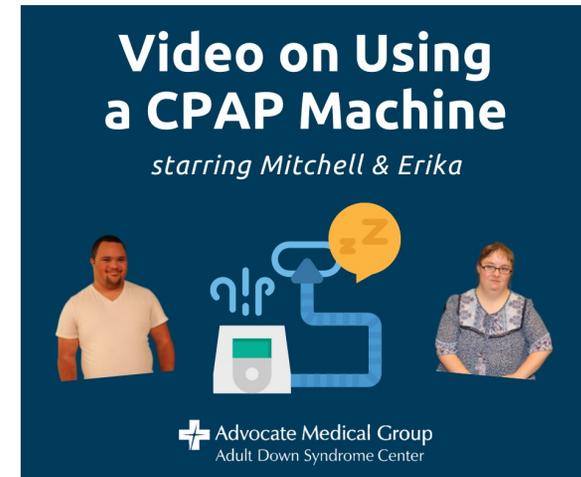
Age: 27

- Psychoses and more rigid adherence to “grooves”
- History and physical, lab tests
- Diagnosed with sleep apnea and obsessive-compulsive disorder
- Treatment
  - Continuous positive airway pressure (CPAP)
  - Anti-depressant
  - Did not require anti-psychotic medication

# Resources

- [Chronic Cough](#) (article)
- [COVID-19](#) (article)
- [Pneumococcal Vaccines](#) (article)
- [Pneumonia](#) (article)
- [Respiratory Syncytial Virus \(RSV\) Vaccination](#) (article)
- [Sleep apnea](#) (article)

[Topics](#)



[How to Use a CPAP Machine Video](#)

# DOWN SYNDROME REGRESSION DISORDER

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# DSRD

- Has also been referred to as:
  - Down syndrome disintegrative disorder
  - Regression
  - Adult regression syndrome
  - Catatonia
- Limited data on prevalence
- Continues to be studied and discussed

# Expert consensus

- Paper published in July 2022
- 27 panelists who previously published on regression in Down syndrome or were involved in national or international working groups
- Name, diagnostic work up, diagnostic criteria



Santoro et al. 2022

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# Diagnostic criteria

- **Symptom onset:** New neurologic, psychiatric, or mixed symptoms over a period of <12 weeks in previously healthy individual with Down syndrome
- **Exclusion of other causes**

## Symptoms

- Altered mental status or behavioral dysregulation
- Cognitive decline
- Developmental regression with/without new autistic features
- New focal neurologic deficits on examination and/or seizure
- Insomnia or circadian rhythm disruption
- Language deficits
- Movement disorder (excluding tics)
- Psychiatric symptoms

# Catatonia

- Abnormality of movement and behavior
- Can (but may not) be associated with a mental illness
- Various presentations
  - Repetitive or purposeless overactivity
  - Resistance to movement

Health Condition	Prevalence (6,078)	Prevalence %	Prevalence (30,326)	Prevalence %	More or less common?	Odds Ratio
	Down Syndrome		Controls			
Catatonia	73	1.20%	70	0.23%	More	5.25*

Chicoine et al. 2021 | \*p<0.0001

# Naya

Age: 16

- Developed rash and treated with oral steroids for poison ivy
- Over next few weeks, severe decline in ADLs, eating refusal, exceedingly slow moving
- Initially diagnosed with depression
- Limited response to anti-depressant
- Diagnosed with catatonia
- Treated very successfully with ECT

Topics



# Resources

- [Decline in Skills and Regression](#) (webinar)
- [Eating Refusal](#) (article)
- [Regression & Down Syndrome](#) (National Down Syndrome Society)
- [Selective Mutism and Other Causes of Loss of Speech](#) (article)

# NEUROLOGY

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# Neurology

## Common

- Epilepsy/seizures
- Alzheimer's disease
- Autism

## Uncommon

- Atherosclerotic strokes
- Multiple sclerosis??
- Parkinson's??

# Seizures

- Wide variety of causes and types
  - Seizure – usually not recurrent
    - Due to infection, electrolyte abnormalities, etc.
  - Epileptic seizures – recurrent
    - Variety of types – e.g., tonic-clonic (grand mal), absence (petit-mal), etc.
    - Two peaks of onset – childhood and later adulthood (Alzheimer's)
  - Psychogenic non-epileptic seizures (PNES)
- Diagnosis
  - EEG (electroencephalogram)
- Treatment
  - Depends on the cause and type

# Alzheimer's disease

- By age 40, nearly all people with Down syndrome have the brain pathology (plaques and tangles) of Alzheimer's disease.
  - HOWEVER, symptoms of Alzheimer's disease are uncommon before age 40.
  - Average age at diagnosis: 54 to 55 years old
- Symptoms
    - Changes in self-talk, routines
    - Psychological changes
    - Memory impairment
    - Loss of previously mastered skills
    - Incontinence
    - Weight loss
    - Seizures
    - Unsteady gait
    - Swallowing difficulties

McCarron et al. 2017, Sinai et al. 2018, Fortea et al. 2021, Tsou et al. 2020, Rubenstein et al. 2024., Ballard et al. 2016, Altuna et al. 2021, Menendez 2005

# Alzheimer's disease

## 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 \(NTG-EDSD\)](#)

# Alzheimer's disease

- Diagnosis
  - Rule out other causes
    - History and physical exam
    - Tests – CBC, metabolic panel, TSH/T4, vitamin B12 and folic acid, celiac, sleep study
  - Neuropsychological testing
    - Limitations
  - Imaging
- Treatment
  - Treat associated symptoms
    - Depression, anxiety
    - Behavior change
    - Seizures
    - Sleep challenges
    - Pain
  - Cholinesterase inhibitor
  - NMDA receptor antagonist
  - Amyloid-beta therapy

# Research



[Understanding key differences among the current and emerging Alzheimer's clinical trials in Down syndrome](#) (National Down Syndrome Society)

# Seamus

## Age: 51

- Sister noted he was no longer sending birthday cards to the family members
- Upon further evaluation at home, discovered their parents had been doing more for Seamus –he was much less independent with his ADLs
- Physical exam and labs did not find an alternative cause
- Diagnosed with Alzheimer’s disease
- Had his first ever seizure



# Resources

- [Aging in Adults with Down Syndrome](#) (webinar)
- [Change in Behavior in a Person with DS and AD](#) (article)
- [How is Alzheimer's Disease Diagnosed in a Person with Down Syndrome?](#) (article)
- [Loss of Skills and Alzheimer's Disease](#) (article)
- [Psychogenic Non-Epileptic Seizure](#) (article)
- [Reducing Risk of Getting Alzheimer's Disease](#) (article)
- [Seizures in People with Down Syndrome and Alzheimer's Disease](#) (article)

# URINARY

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# Urinary

## More common

- Urinary retention
- Impairment of kidney function
- Urinary incontinence
- Urinary tract infections

# Urinary retention

- Build-up of excessive urine in the bladder
- Possible complications
  - Urinary tract infections
  - Urinary incontinence
  - Abdominal pain/discomfort
  - Kidney damage
- Diagnosis
  - Urine sample
  - Ultrasound, catheter, voiding study
  - Cystoscope
  - CT scan
- Treatment
  - Urinating regularly (2-3 hours)
  - Catheters
  - Medications
  - Surgery

# Impairment of kidney function

- Decreased kidney function
- Contributing factors
  - Genetic differences
  - Dehydration
  - Urinary retention
  - Gout
- Labs
  - Blood urea nitrogen (BUN)
  - Creatinine

# José

## Age: 37

- He is non-verbal, has impaired vision
- Intermittent yelling and pushing on his abdomen
- No loss of skills
- Participating in activities
- Wakes at night sometimes yelling
- Bladder scan revealed 600 ml in his bladder before he voided and about 400 ml after he voided
- Diagnosed with urinary retention; referred to Urology

[Topics](#)



# Resources

- [Kidney Function](#) (article)
- [Urinary Incontinence](#) (article)
- [Urinary Retention](#) (article)
- [Urinary Tract Infections](#) (article)

# GYNECOLOGY

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# Gynecology

## More common

- Earlier onset of menstruation and menopause

## Less common

- Sexually transmitted infections (STIs)
- Breast cancer
- Cervical cancer

# Menstruation

- Period hygiene
- Birth control
  - Oral hormonal contraceptive pills
  - Injections
  - IUDs

## Menstrual Hygiene Strategies



Try out different types of pads (length, with/without wings, etc.)



Wear period panties instead of or in addition to pads/tampons.



Pack a period bag with all necessary supplies (pads, wipes, underwear, etc.).



Use visual supports. Check out our Resource Library!



Advocate Medical Group  
Adult Down Syndrome Center

# Li

## Age: 15

- Having difficulty managing her period hygiene
  - Missing out on opportunities, impeding her independence
- “Can we make her periods stop?”
- Reviewed options
  - Supporting her in using pads and tampons
  - Period underwear
  - Medication

# Resources

- [Birth Control](#) (article)
- [Enhancing Women's Health](#) (webinar)
- [Hormone Replacement Therapy](#) (article)
- [Menopause](#) (article)
- [Menopause](#) (visuals)
- [Menstrual Hygiene](#) (article)
- [Menstruation \(Period\)](#) (visuals)
- [PMS and PMDD](#) (article)

[Topics](#)



[National Down Syndrome Society](#)

# HEART & VASCULAR SYSTEM

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# Heart and vascular system

## More common

- Congenital heart disease
- Valvular heart disease
- Embolic strokes
- Moyamoya
- Varicose veins

## Less common

- Hypertension (high blood pressure)
- Coronary artery disease/ myocardial infarctions\*

# History of congenital heart disease

- “In adults with Down syndrome with a history of congenital heart disease, given the elevated risk of cardioembolic stroke, a periodic cardiac evaluation and a corresponding monitoring plan should be reviewed by a cardiologist.” ([Global Medical Care Guidelines for Adults with Down Syndrome](#))

# Joan

Age: 45

- Went to the emergency room because of chest pain
- History, physical exam
- Normal EKG, blood work negative for myocardial infarction (heart attack)
- Treatment
  - Antacids resolved the chest pain
  - Is there need for additional evaluation and treatment?

[Topics](#)



# Resources

- [Heart Disease](#) (article)
- [High and Low Blood Pressure](#) (article)
- [Strokes](#) (article)
- [Venous Disease](#) (article)

# SKIN & NAIL CONDITIONS

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# Skin and nail conditions

## More common

- Alopecia
- Folliculitis and boils
- Hidradenitis suppurativa
- Seborrhea
- Psoriasis
- Infections
- Dry skin
- Onychomycosis (fungal infection of the nails)

# Folliculitis and boils

- Folliculitis – infection or inflammation of the hair follicles
- Boils – painful, pus-filled bumps that can form under the skin if infections around the hair follicles spread deeper
- Prevention and treatment
  - Antibacterial soaps such as Lever 2000 or Dial Soap
  - Antibacterial and antimicrobial skin cleanser such as Hibiclens
  - Dry well after bathing, baby powder
  - Zinc supplement?
  - Antibiotic
  - Boils – heat, triple antibiotic cream, topical cream (e.g., Boil-Ease)

# Alopecia areata

- Sudden loss of hair
- Autoimmune condition
- Treatment
  - Steroids
  - Topical minoxidil (Rogaine)
  - JAK inhibitors

# Veronica

Age: 19

- Has become very distraught due to hair loss
- Multiple bald patches
- Labs unremarkable
- Referred to Dermatology
- Treatment options discussed
- Started on baricitinib (JAK inhibitor)
- Marked improvement in hair loss
- Mood improved

# Resources

- [Alopecia Areata](#) (article)
- [Down Syndrome and Hidradenitis Suppurativa](#) (handout from the Society for Pediatric Dermatology)
- [Dry Skin](#) (article)
- [Folliculitis and Boils](#) (article)
- [Onychomycosis](#) (article)
- [Skin Conditions in Down Syndrome](#) (podcast episodes)

[Topics](#)



**DRY SKIN TIPS**

*Learn more tips in our dry skin video!*

Advocate Medical Group  
Adult Down Syndrome Center

The video thumbnail features a woman sitting at a table, holding a small white bottle of skin cream. The background is a simple indoor setting with a table and chairs. The video player interface includes a play button, a progress bar, and a volume icon.

[Tips for Dealing with Dry Skin Video](#)

# CANCER

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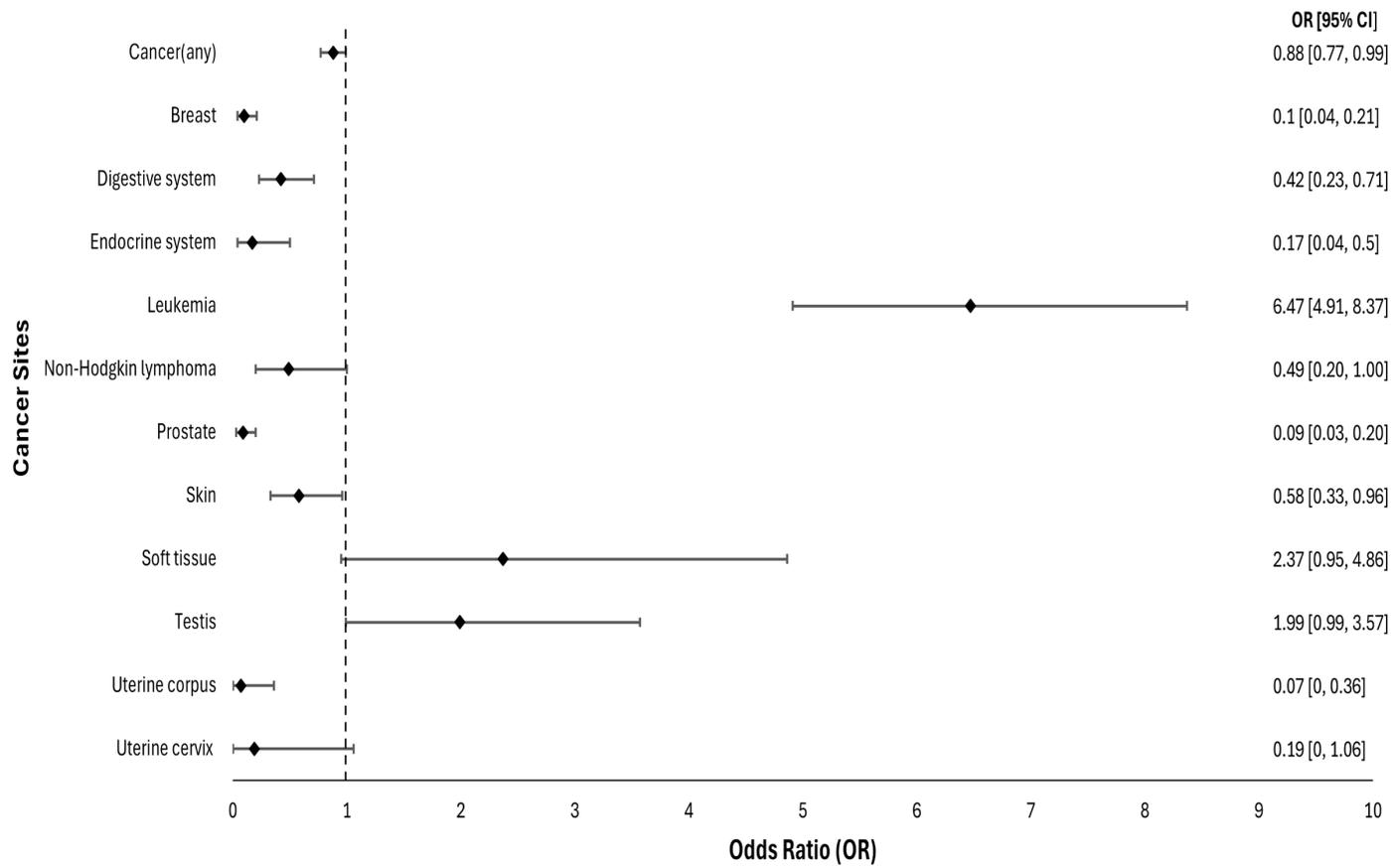
# Cancer

## More common

- Leukemia (childhood)
- Testicular cancer
- Lymphoma?

## Less common

- Many solid tumor cancers
  - Breast cancer
  - Cervical cancer
  - Colorectal cancer



\*Chicoine et al. 2025, unpublished data



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# Cancer

## Presentation

- Lack of self-report
- May present later due to lack of report of sense of ill health
- Behavioral change
- Mostly similar
- Limited experience

## Screening/treatment

- Treatment recommendations generally not different
  - AML (leukemia) – lower doses
- Screening
  - Mammograms
  - Colonoscopies
  - Pap smears
  - Etc.

# Vivian

Age: 45

- Came in for an annual appointment
- No concerns
- History, physical exam, labs
- Asked about mammography



# Resources

- [Breast Cancer and Breast Cancer Screening](#) (article)
- [Colon Cancer Screening](#) (article)
- [Dysgerminomas](#) (article)
- [Primary Care Provider's Guide to Women's Health and Down Syndrome](#) (guidebook from National Down Syndrome Society)
  - Includes information about breast, cervical, endometrial, and ovarian cancer
- [Prostate Cancer Screening](#) (article)
- [Testicular Cancer](#) (article)

# Wrap-up



# Takeaways

- People with Down syndrome are living longer and healthier than ever before.
- Some health conditions are more common in people with Down syndrome, and some are less common.
- Thorough evaluations are recommended to assess for conditions that may present as behavioral change.
- Ongoing research and review of the literature will help us decide on appropriate screening, diagnosis, and treatment of co-occurring conditions in people with Down syndrome.

# Resources

 Advocate Health Care

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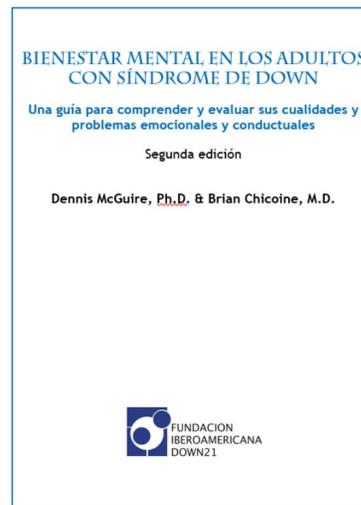
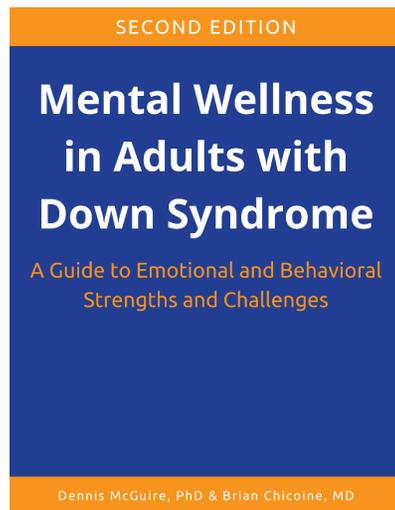
# DSMIG-USA

## Down Syndrome Medical Interest Group-USA

- Speaker Series
- Project ECHO

A promotional graphic for DSMIG-USA. It features a dark blue background with a green and orange banner in the top left that says "FREE RESOURCES". The DSMIG-USA logo is in the top right, with the text "Down Syndrome Medical Interest Group" below it. The main text reads "SHARE WITH YOUR HEALTH CARE PROVIDER". Below this is a bulleted list of three items: 1. Down Syndrome Project ECHO is a monthly virtual meeting for health care providers to learn and seek input from expert providers. 2. The DSMIG Speaker Series consists of webinars and enduring materials designed to share knowledge and experience related to the care of people with Down syndrome and clinical research related to Down syndrome. 3. DSMIG vetted resources including articles and important guidelines related to child and adult health issues, and health utilization by people with Down syndrome. At the bottom left, it says "find out more at: DSMIG-USA.ORG". On the right side, there is a graphic of a megaphone.

# Mental Wellness book



**Available as a free  
PDF in English  
and Spanish**

<https://adsresources.advocatehealth.com/mental-wellness-in-adults-with-down-syndrome-2nd-edition/>

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# 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](https://adscresources.advocatehealth.com)

### Facebook & Instagram



[@adultdownsyntaxromecenter](https://www.facebook.com/adultdownsyntaxromecenter)

### Email List



[www.eepurl.com/c7uV1v](http://www.eepurl.com/c7uV1v)

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# Questions?

## Adult Down Syndrome Center



[Resource Library](#)



[@adultdownsyndromecenter](#)



[Email List](#)

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