

Welcome!
Down Syndrome Day with the Experts
March 7, 2026



Waisman Center
University of Wisconsin-Madison



Waisman Center

University of Wisconsin-Madison



Dedicated to the advancement of knowledge about human development, developmental disabilities, and neurodegenerative diseases throughout the lifespan.

The Waisman Center's Overarching Goal – to Discover the 3 “Cs”

Causes

genetic, environmental

Consequences

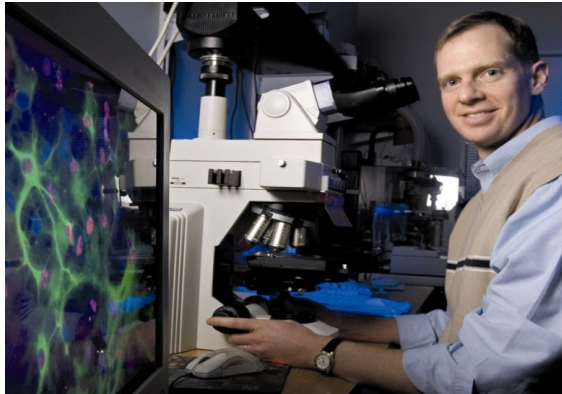
for the individual,
the family, and society

Cures and treatments



The Waisman Center's Four Major Activities

Research



Outreach



Training



Service





Down Syndrome Hub

More than 400,000 individuals in the United States have Down syndrome, or trisomy 21—a chromosomal condition caused by an extra 21st chromosome. Down syndrome is the most commonly occurring chromosomal condition. Approximately one in every 733 babies is born with Down syndrome each year.

- [Waisman Down Syndrome Activities](#)
- [Studies Recruiting](#)
- [Events](#)
- [Researchers](#)
- [News](#)
- [Partners](#)
- [Additional Resources](#)



Down syndrome Studies



[METabolic Health, Lifestyle, and Risk of Co-Occurring Health Conditions in Down Syndrome \(MET-DS\) – \(Hartley\)](#)

The METabolic Health, Lifestyle, and Risk of Co-Occurring Health Conditions in Down Syndrome (MET-DS) study is part of the NIH INCLUDE Project (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome) and its ...



[Exploring Menopause and Caregiving Experiences of Mothers of Children with and Without developmental disabilities \(Columa\)](#)

Are you a mother between 35 and 65 years old who is the primary caregiver of a child (with or without a developmental disability such as autism, Down syndrome, or other conditions)?



[BuILD Study \(Brain Imaging and Language Development in Infants with Down Syndrome\) \(Dean\)](#)

Recruiting parents of children with Down Syndrome who are between 1 and 24 months old.



[Are you a young adult with Down syndrome looking to make brain waves for science? \(Litovsky\)](#)

Our Goals: We hope you will be a part of the first study for young adults with Down syndrome to combine: Who can help? Young adults with Down syndrome who are: 18 to 24 years ...



[Leveraging Technology to Identify Outcome Measures for Young Children with Down Syndrome \(Sterling\)](#)

Our study aims to learn more about how language samples collected in the home can be used to measure the language development of children with Down syndrome.



[Alzheimer's Biomarkers Consortium – Down Syndrome: ABC-DS \(Christian & Hartley\)](#)

The National Institutes of Health-funded Alzheimer's Biomarkers Consortium – Down Syndrome (ABC-DS), a large multi-center research initiative to find biomarkers to track Alzheimer's disease in Down syndrome. The Waisman Center is part of this multi-site ...



[Waisman BioLibrary: Down Syndrome Study \(Chang\)](#)

Be included! Families of children with Down syndrome are invited to participate in our new study about genetics and health. The Waisman BioLibrary is recruiting youth with Down syndrome ages 0 – 17 years. Families ...





Thank You!!!!!!

Small Bites: Nutrition Needs and Sensory Preferences for People with Down syndrome (DS)



Jaclyn Bender, OTR/L
Down Syndrome Clinic
LEND Faculty

Maria A. Stanley, MD, FAAP
Clinical Professor of Pediatrics
University of Wisconsin School of
Medicine and Public Health
Medical Director, Waisman Center

Mary Walters, MS, RD
Down Syndrome Clinic
LEND Faculty

UWHealthKids



**School of Medicine
and Public Health**
UNIVERSITY OF WISCONSIN-MADISON



Department of Pediatrics
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH



WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON

Swallowing differences

What you might see:

coughing and choking
slower feeding/feeding refusal
frequent pauses in feeding/prolonged feeding times,
difficulty gaining weight
wheezing/pneumonia

Why it happens:

airway issues
neurologic differences

Next steps:

Alert your medical provider who may recommend a clinical feeding evaluation, feeding therapy, and/or a swallow study

Alert caregivers to the individual's safety needs





GI Differences

People with DS are at risk for a range of GI issues

What you might see:

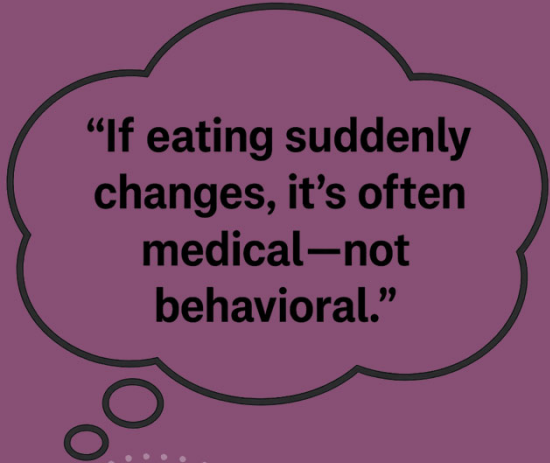
- Pain during/after eating
- Excessive or painful spitting up or vomiting
- Poor growth/appetite
- Excessively loose stools or constipation
- Behavior changes

Next steps:

Work with your medical team: if symptoms are persistent, specialty care may be needed

Other health issues that affect feeding and nutrition

A range of medical conditions and medications can also interact with feeding and nutrition



**“If eating suddenly
changes, it’s often
medical—not
behavioral.”**

- Respiratory issues, congenital heart disease, thyroid disease, obstructive sleep apnea, kidney disease can contribute to feeding difficulties, GI symptoms and/or metabolic changes
- Some medications used to treat serious health and mental health issues can contribute to excessive weight gain or loss

Food preferences

Looks like:

Preference for softer/easier to manage textures, highly processed foods, higher carbs, higher calorie density foods

Inadequate vegetable, fruit intake

Inadequate meat intake in younger kids

Risk for nutritional deficits

Causes:

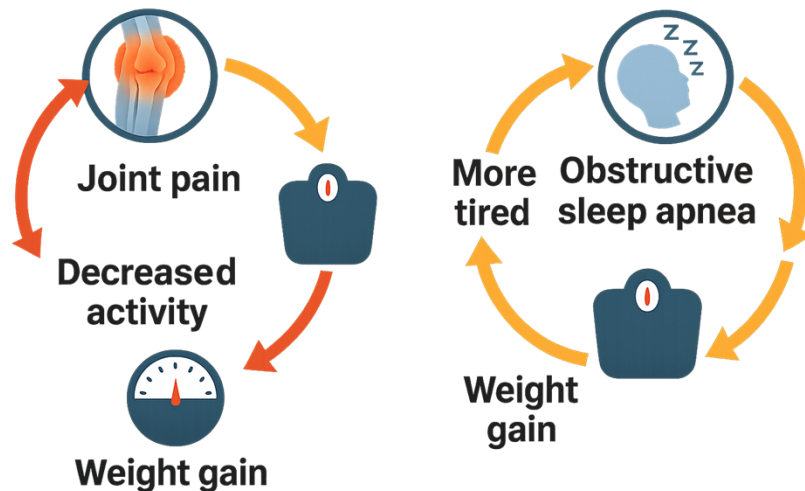
- Low muscle tone
- Oromotor and fine motor delays,
- Sensory differences
- Craniofacial (facial and oral structure)
- Dental differences

“It’s not ‘picky eating’—it’s about comfort, safety, and skill building.”



Metabolism and Weight

- Metabolic rates are **lower**: leading to increased risk for overweight and obesity
- Obesity can set up vicious cycles:



- Obesity in adolescence may increase **inflammation**, increasing risk for other disease processes (A. Gutierrez-Hervas, et al 2020)



Metabolism and Weight

Where to start:

- Be proactive, emphasize healthy choices for the whole family
- Make time for family meals
- Limit sweetened beverages, including juice
- Eat a rainbow of foods
- Find physical activities that are fun for individual or the whole family—aim for 30-60 minutes every day



If more help is needed, ask your team(s) for support.

How does aging affect the bodies of people with DS?

With aging, people with DS typically experience:

- Lower lean mass
- Lower bone density and faster decline with age
- Higher fat mass
- Higher body mass index
- Higher waist to hip ratio

(A Carfi et al, 2016 and L Herrera Quintana, et al, 2024)



What do we know about diet and Alzheimers disease?

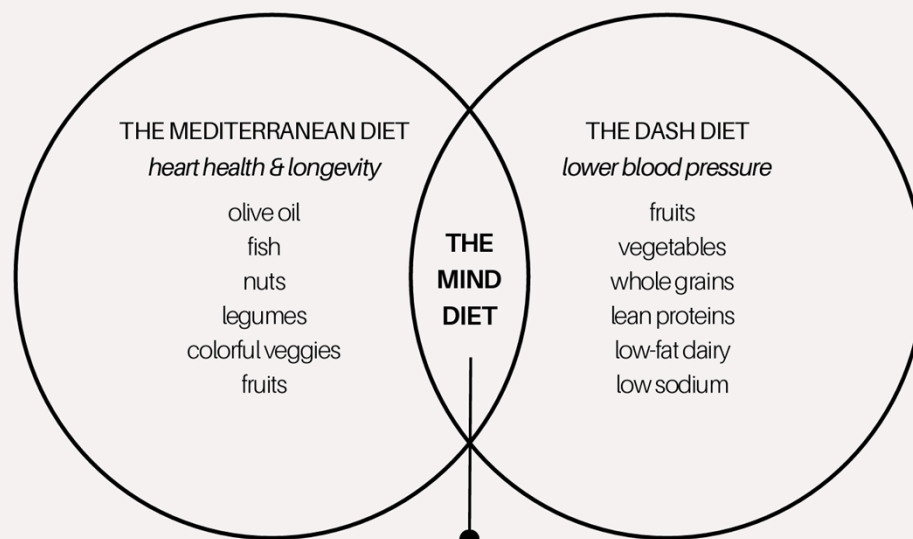
Little data specifically available for people with DS. For the general population, the following are associated with slower rates of cognitive decline with aging:

Diet: Growing evidence to support MIND (Mediterranean-DASH diet Intervention for Neurodegenerative Delay) diet

Cognitive stimulation

Social Activity

Physical activity



Mediterranean-Dash Intervention for Neurodegenerative Delay

cognitive health

leafy greens | berries | whole grains | beans | nuts | fatty fish | olive oil

(Graphic from B. Boules, Alz.org)



How do inadequate nutrients affect a person's health and functioning?

Iron: affects cognition, sleep, energy level, mood

- Sources: meat, fish, dark green leafy vegetables

Vitamin D: affects bone health and sleep

- Sources: fortified dairy, fatty fish, egg yolks, sunlight on skin

Zinc: affects skin/hair, immune health, can cause chronic diarrhea

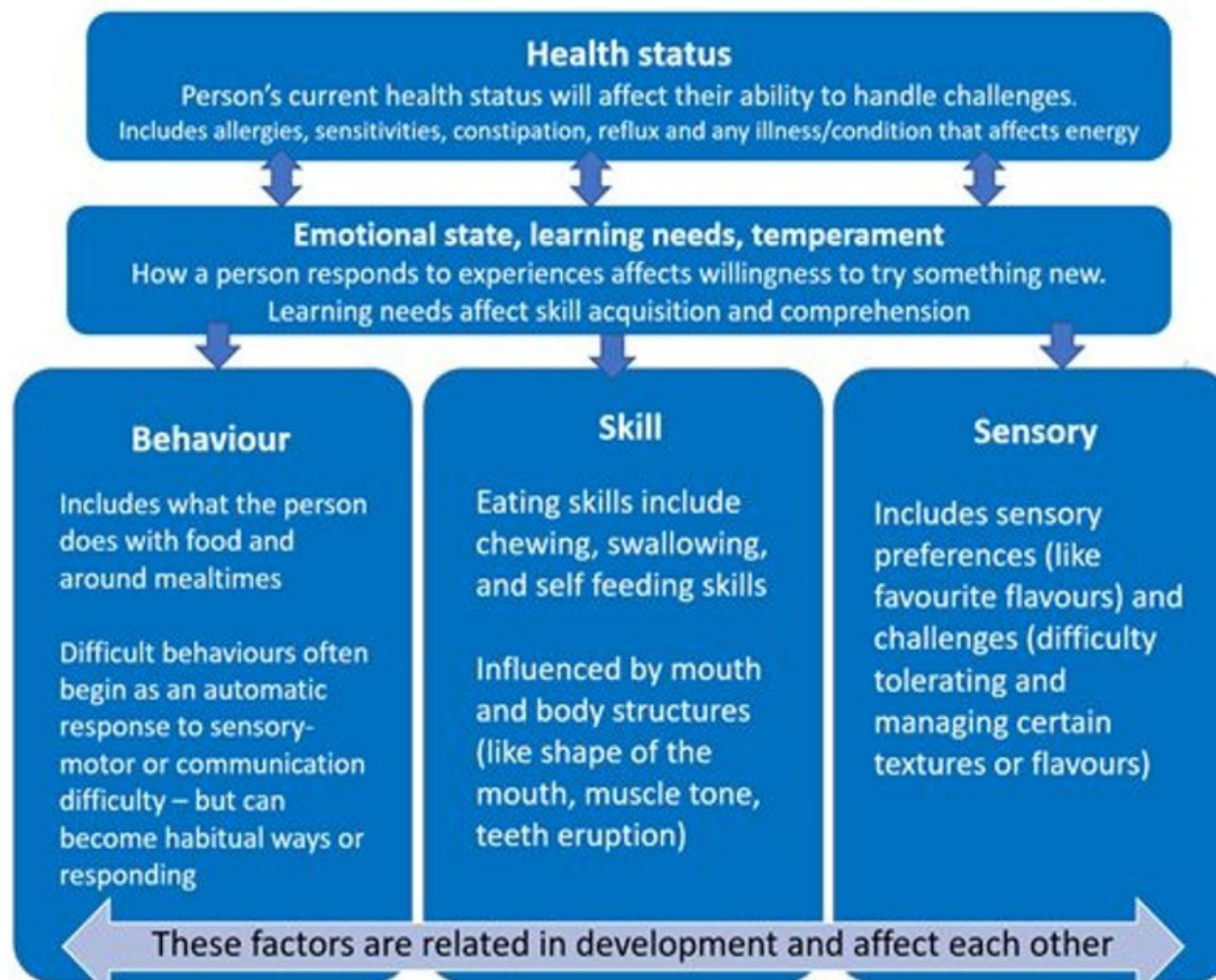
- Sources: shellfish, meat, fortified cereals, nuts/legumes, eggs

Selenium: affects immune health, thyroid function

- Sources: fish, nuts, eggs

Fiber: affects bowel health (constipation), feeling full

- Sources: legumes (beans/peas/lentils), whole grains, fruits, vegetables



<https://dsrf.org/resources/blog/lets-eat-together-navigating-feeding-development-for-your-child-with-down-syndrome/>

Functional differences with feeding and swallowing

- **Physical Factors Influencing Sensory Response:** Low muscle tone and a high/narrow palate can make managing food difficult and can exacerbate sensory aversions or difficulties with foods.
- **Delayed Oral Motor Skills:** Challenges with chewing, sucking, and swallowing are common, due to anatomy, sensory processing differences, and coordination
- **Self-feeding difficulties:** With inexperience, coordination difficulties, endurance and fatigue, this can be a challenging area and contribute to choosing easier foods and/or sensory sensitivities
- **Sensory Processing Differences:** Children may be **hypersensitive** (over-responsive) to tastes, smells, sight, temperatures, or textures, leading to gagging or refusal of certain foods. Conversely, some may be **hyposensitive** (under-responsive), causing difficulty in locating food within the mouth. **Interoception differences** (sensing internal cues) may lead to difficulty recognizing and responding to bodily sensations including fullness, thirst, hunger



How do these differences impact what people eat?

- Sensory processing differences may lead to preferences of foods that are predictable, processed, the same, and soft or crunchy.
- This omits foods that look different than expected, homemade foods, fruits and vegetables, mixed textures
- Oral sensory skills may lead to overstuffing, gagging, difficulty managing foods in the mouth. This might lead to wanting predictability in foods
- Over time, less successful practice with challenging foods decreases skills to manage, leading to more difficulty and less acceptance of challenging foods
- Decreased ability to self-monitor intake when kids are independent (making healthy choices, recognizing fullness)





Take Home Points

- Address feeding/eating/GI concerns early with individual's medical team
- Seek out extra support from Speech Language Pathology, Occupational Therapy, or a Registered Dietitian if needed
- Safety plan if needed at school/work and with all caregivers
- Regular monitoring of nutrition labs, especially if diet is limited
- Consider vitamin supplements if needed
- Encourage a **RAINBOW** of foods every day
- Encourage 30-60 minutes of **enjoyable** physical activity daily
- Consider the MIND diet for adults of any age

Take Home Points

- Exposure to foods through grocery shopping, meal prep, family-style meals through scooping and serving
- Place less preferred foods on plate in modified ways along with preferred foods alongside (dips, purees, sauces, cut up, mashed)
- Explore alternate forms of fruits/veggies- smoothies, frozen fruit, freeze dried, dried fruit, pouches/purees
- Explore different textures, temperatures, flavors when kids might lose foods in their mouths.
- Make swaps in recipes, such as applesauce/purees for oil
- Pre-portion foods out in containers for grab-and-go snacks to promote independence and healthy options



Resources

- **Down Syndrome Resource Foundation:** Let's Eat Together: Navigating Feeding Development for your Child with Down Syndrome (<https://dsrf.org/resources/blog/lets-eat-together-navigating-feeding-development-for-your-child-with-down-syndrome/>)
- **Alzheimers Association** (alz.org): Info on the MIND diet/home tip sheets, plus much other information for individuals/families/caregivers
- **Anxious Eaters, Anxious Mealtimes: Practical and Compassionate Strategies for Mealtime Peace** by Marsha Dunn Klein OTR/L MED FAOTA
- **Feeding Matters** (feedingmatters.org): education and support for families of children with Pediatric Feeding Disorder
- **OLEY Foundation** (oley.org) : education and support for families of individuals who are tube or IV fed
- **Autism Speaks** (autismspeaks.org): Exploring Feeding Behavior in Autism: A Parent's Guide

