

NDSS Caregiver Resources Overview

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Introduction



Jessica Kuss, M.Ed.
Director of
Community Programs

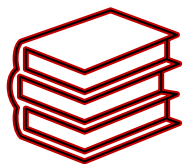


Charlotte Woodward
Programs Associate

*NDSS is creating a world where individuals with
Down syndrome thrive.*

NDSS Core Pillars

NDSS supports and advocates for the Down syndrome community by focusing on four key pillars:



**Resources
& Support**



Research



**Advocacy
& Policy**

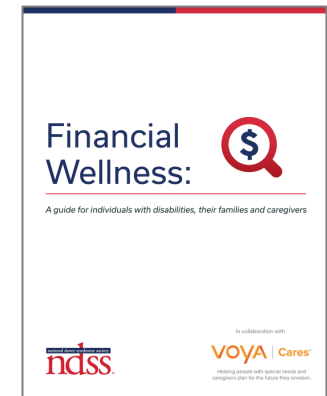
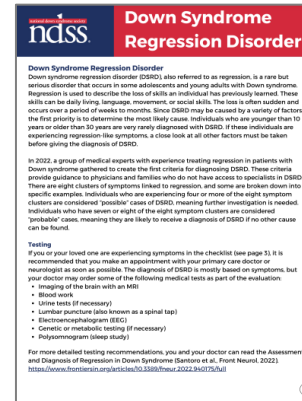


**Community
Engagement**

NDSS Core Pillars

Resources & Support

- 1-800 helpline and info email
- Resources and information from birth to end of life
- Education, employment, health and wellness, aging, caregiving, research, and more



NDSS Core Pillars

Research

- Bridge between research and our community
- Sharing research opportunities
- Expanding clinical trials and access



NDSS Core Pillars

Advocacy & Public Policy

- Federal, state, and local advocacy
- Develop and improve laws to positively impact people with Down syndrome across the country and affirm their human rights
- Legislative agenda spans the life experience of individuals with Down syndrome



NDSS Core Pillars

Community Engagement

- Scholarships, grants, and awards
- National Buddy Walk® Program
- Times Square Video Presentation
- Athlete Ambassador Program
- Virtual Racing for 3.21 for World Down Syndrome Day
- Gala, golf, and more!



Resources for Caregivers

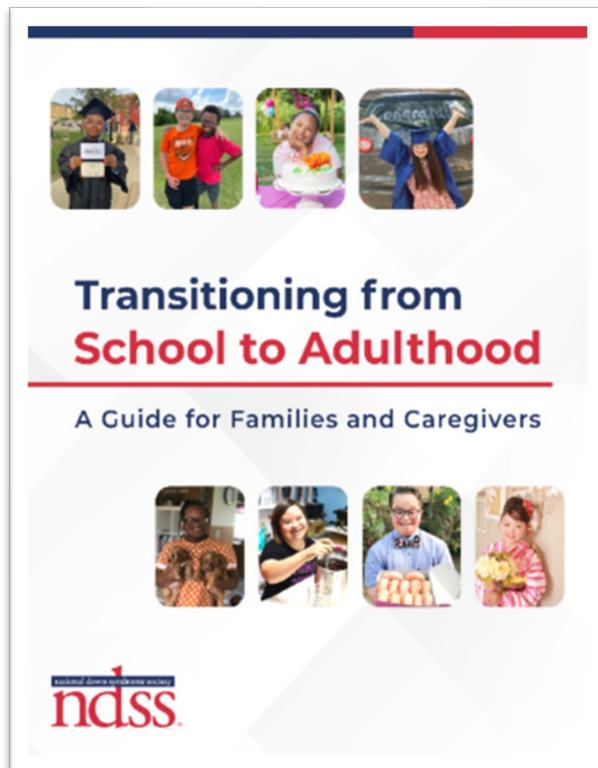
Today's topics include:

- Education
- Employment
- Volunteering
- Financial Wellness
- Aging & Caregiving
- Alzheimer's Disease
- Regression
- End of Life Care



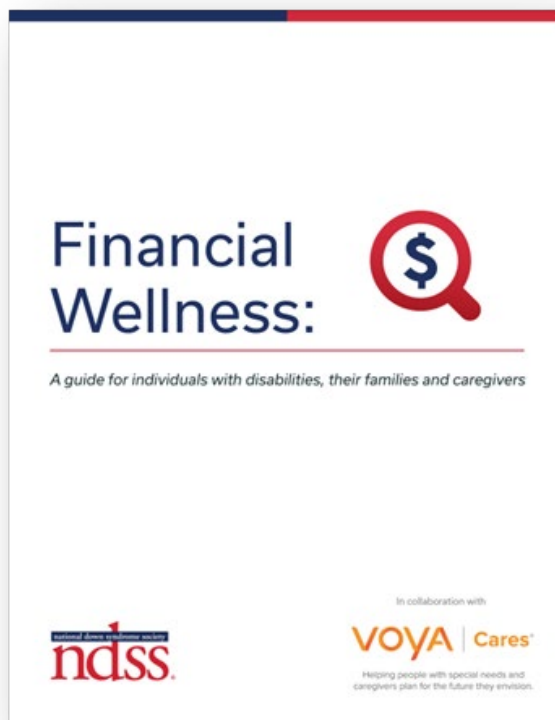
Education

- Transition Guide
- Volunteering



Employment

- Financial Wellness
- Entrepreneurship Guide



Aging

Aging and Down Syndrome: A Health and Well-Being Guidebook

- Created by NDSS in partnership with The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and the Alzheimer's Association
- Emphasizes healthy lifestyle and coordinating medical care and support.
- Includes descriptions of common medical conditions in older adults
- Overall, it outlines how to plan for “successful” aging



ALZHEIMER'S
ASSOCIATION

national down syndrome society
ndss.

ntg
National Task Group on
Intellectual Disabilities and
Dementia Practices

Caregiving

Caregiving and Down Syndrome: A Companion Guide to Aging and Down Syndrome

- Created by NDSS in partnership with The NTG and the National Alliance for Caregiving
- High-level overview of
 - Guardianship
 - Creating a support plan
 - Housing
 - Self-care for caregivers
- Helpful tool for older siblings or family friends who have recently become caregivers



Caregiving

Caregiving Toolkit: Supplemental Worksheets for Caregiving & Down Syndrome

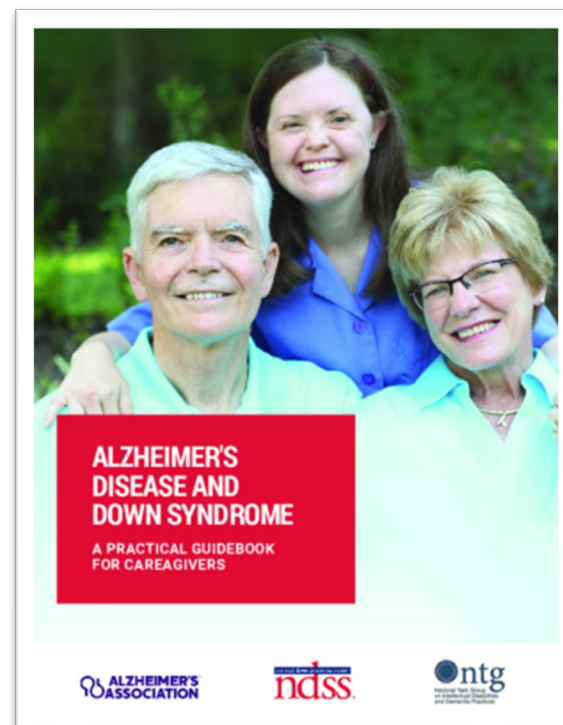
- Emergency Planning
- Support Planning
- Self-Care for Caregivers



Alzheimer's Disease

Alzheimer's Disease and Down Syndrome: A Practical Guidebook for Caregivers

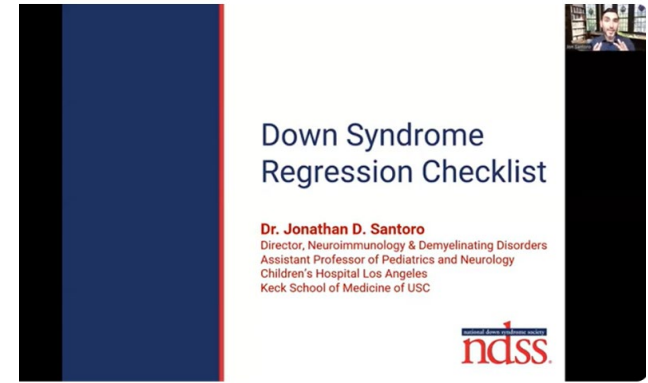
- Created by NDSS in partnership with NTG, and the Alzheimer's Association
- Discusses biological connection between Down syndrome & Alzheimer's disease
- Arriving at a diagnosis
- Treatment options
- Communication and behavior strategies
- Planning for the future



Regression

Down Syndrome Regression Disorder

- Regression is a growing topic within the adolescent and young adult community
- Created by NDSS in partnership with leading expert, Dr. Jonathan Santoro
- Short video resource

The image shows the "Down Syndrome Regression Disorder Symptoms Checklist" form. It features the NDSS logo and title at the top. Below the title, it says "Down Syndrome Regression Disorder Symptoms Checklist" and "Date: _____". A note states: "Symptoms occurring more frequently within the last three months (check all that apply)". The form is divided into eight numbered sections, each with a title and a list of symptoms to be checked. 1. Behavioral Changes: Date symptom(s) began: _____, Eating much more or less than usual, Confusion or disorientation, Laughing or crying at inappropriate times, Frequent changes in mood or rapid fluctuations between happiness, sadness, or anger. 2. Changes in Thinking and Processing of Information: Date symptom(s) began: _____, Decreased visible emotions and empathy, Lack of motivation or lack of engagement, Difficulty starting or finishing tasks, Worsening memory. 3. Loss of Functional and Social Skills: Date symptom(s) began: _____, Loss/worsening of previously learned skills (self-feeding, toileting, dressing, etc.), Decreased social interaction with friends, family, classmates, or coworkers, Decreased eye contact, Repetitive hand or body movements with no clear purpose. 4. New seizures or neurological deficits (weakness, slurring of speech, etc.) determined by a physician: Date symptom(s) began: _____. 5. Difficulty sleeping or sleeping at irregular times: Date symptom(s) began: _____. 6. Language Difficulties: Date symptom(s) began: _____, Difficulty producing speech or trouble reading and understanding speech, No longer using speech or speaking only in a whisper. 7. Irregular Movements: Date symptom(s) began: _____, Lack of movement sometimes with stiff and rigid muscles, Moving very slowly or using an unusual walk or run-gait pattern. 8. Mental Health Symptoms: Date symptom(s) began: _____, New or worsened anxiety, Delusions (false beliefs) or hallucinations (seeing things that are not there), Derealization (feeling detached from surroundings) or depersonalization (feeling of observing oneself from outside of the body), Obsessive compulsive tendencies like living up items, only talking about specific topics of interest, and difficulty tolerating changes in routine, Aggression or agitation toward others. A small circle with the number 1 is at the bottom right.

End-of-Life

End-of-Life and Down Syndrome

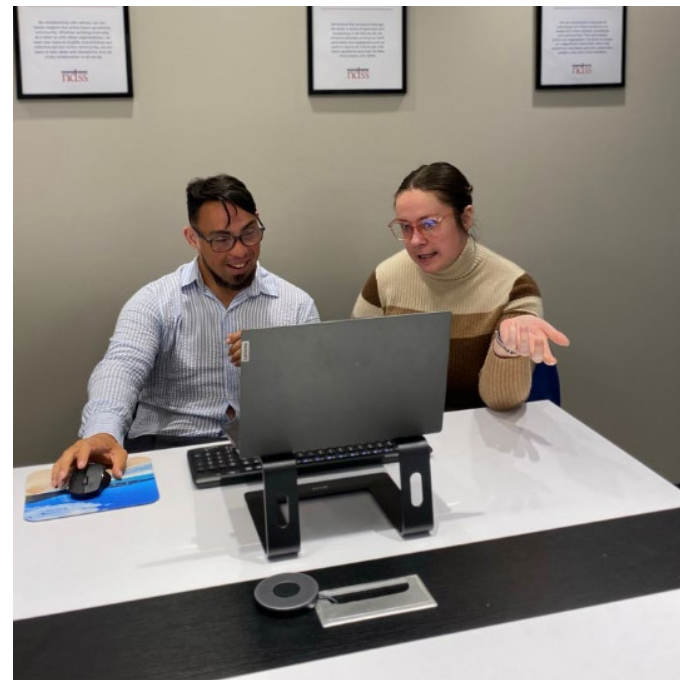
- Created by NDSS in partnership with NTG and the Alzheimer's Association
- Discusses crossroads and decisions that arise in late life and at the end of life
- Proactive guidance for difficult discussions and situations



Recap

Resource Links:

- [Transition Guide](#)
- [Volunteer Resource](#)
- [Financial Wellness Guide](#)
- [Entrepreneurship Guide](#)
- [Aging & Down Syndrome: A Health & Wellbeing Guidebook](#)
- [Alzheimer's Webinar with Dr. Rafii](#)
- [Caregiving and Down Syndrome](#)
- [Caregiving Toolkit](#)
- [Down Syndrome Regression Disorder Checklist](#)
- [Down Syndrome Regression Disorder Webinar with Dr. Santoro](#)
- [End of Life and Down Syndrome](#)



[NDSS Webinars](#)

Questions?



Coming Soon!

BRIGHTER
Futures
Conference

March 27 & 28, 2026

DCU Center in Worcester, Massachusetts

In Partnership with the Massachusetts Down Syndrome Congress

Webinar Series

Coming Up Next:

OCT 07

1:00 PM ET

A Caregiver's Guide to Supporting Career Development for Adults with Down Syndrome

Amanda Myers, Down Syndrome Innovations

OCT 09

1:00 PM ET

Workplace Accommodations for Adults with Down Syndrome: What Caregivers Need to Know

Lisa DeMoss, Job Accommodation Network

OCT 16

1:00 PM ET

From Overwhelmed to Empowered: Thriving While you Care

Shatanese Reese, Shatanese Reese, LLC

OCT 21

1:00 PM ET

Understanding and Supporting Trauma in Adults with Down Syndrome

Ruth Brown, PhD, HOPE Lab at Virginia Commonwealth University

OCT 23

12:00 PM ET

Optimizing ABLE Accounts and Special Needs Trusts

Mike Walther, Oak Wealth Advisors

OCT 30

1:00 PM ET

Adapting Activities for Individuals with Down Syndrome as Alzheimer's Disease Progresses

Katie Frank, PhD, OTR/L, Advocate Medical Group

Thank you!

Email health@ndss.org