



National Task Group on Intellectual
Disabilities and Dementia Practices

When Memory Changes: Guidance for Families of Adults with Down Syndrome

PPT Slides: <https://app.box.com/s/uxgfptgknd69em65ci1rena9c6nh8sv>

Resources:

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities. Excellent resource to print and take to a physician's visit along with a completed NTG-EDSD when changes in memory and functioning are observed.

[https://www.mayoclinicproceedings.org/article/S0025-6196\(13\)00371-6/pdf](https://www.mayoclinicproceedings.org/article/S0025-6196(13)00371-6/pdf)

Adult Down Syndrome Center Resource Library. Wonderful resource for families, healthcare professionals, and individuals with Down syndrome covering numerous topics.

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

NTG-EDSD. The specialized information provided by the NTG-EDSD can aid community practitioners when examining and assessing adults with intellectual disability who are exhibiting changes in memory and functioning. The NTG-EDSD is designed to be completed by family caregivers and staff at local agencies and organizations. The NTG-EDSD has been recognized as a useful dementia symptoms or indicators screening tool in the guidelines issued by the Medical Care Guidelines for Adults with Down Syndrome Workgroup and published in JAMA [2020, 324(15),1543-1556]. <https://www.the-ntg.org/ntg-edsd>

Capturing Observations of Change Using the NTG-EDSD (webinar recording). During this webinar, the presenter will walk participants through the use of the National Task Group-Early Detection Screen for Dementia (NTG-EDSD) using two case examples of individuals with suspected dementia. One example will involve a person with Down syndrome and probable dementia, and one example will involve a person with Intellectual Disability and mental health concerns. The presenter will emphasize the value of the NTG-EDSD as a way of capturing observations of change. Members of the person's team can use findings from the EDSD to promote advocacy, team decision-making, discussions with healthcare providers, and service and care planning. <https://youtu.be/72GXtdjXeyU>

Assessment and Diagnosis of Down Syndrome Regression Disorder: International Expert

Consensus. The authors present international consensus agreement on the nomenclature, diagnostic work up, and diagnostic criteria for DSRD, providing an initial practical framework that can advance both research and clinical practices for this condition.

<https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2022.940175/full>

Planning for the Future: Advance Care Planning for Adults with IDD (webinar recording). Too often, adults with intellectual and developmental disabilities (IDD) are left out of conversations about aging, health changes, and end-of-life planning. This webinar empowers families, caregivers, and professionals to change that. <https://youtu.be/PdzkxyTGXqk>

UPDATES ON BIOMARKERS, THERAPEUTICS, BIOETHICS & DEMENTIA. (webinar recording).

Research on biomarkers and anti-amyloid treatments has advanced rapidly since our last NTG webinar in 2021. This updated panel will share the latest findings, practical applications, and ethical considerations across the lifespan for people with Down syndrome who may face Alzheimer's disease. With perspectives from clinicians, researchers, and a bioethicist, the discussion will offer clear guidance for decision-making and care. This session is designed for clinicians, families, providers, advocates, and all who are committed to improving the future of individuals with Down syndrome.

<https://youtu.be/qaeokHr6hfg>

Actions Speak Louder Than Words: Understanding medical conditions that can present as behaviors (webinar recording). <https://youtu.be/29Ac-fPIEJ0>

Over-Medication and Older Adults with Intellectual Disability: Risks for Brain Health. This document is issued jointly by the NTG and the HealthMattersTM Program as part of an advisory series on risk reduction in adults with intellectual disability and promoting healthy brain outcomes. <https://healthmattersprogram.org/wp-content/uploads/2024/06/Over-Medication-and-Older-Adults-with-Intellectual-Disability-Risks-for-Brain-Health.pdf>

Holidays and Cognitive Loss (webinar recording). How to navigate the holidays with someone living with ID and dementia. <https://youtu.be/ULrsnDZIRSA>

NTG YouTube Channel. Videos covering a range of topics affecting aging adults with intellectual disabilities and dementia. <https://youtube.com/@the-ntg?si=ofjtuAMAs6zxXlrM>

NTG Family Support (website page). <https://www.the-ntg.org/family-caregivers>

Risky Rx: Webinar Recording <https://youtu.be/oXDaOOof0ZFs>

