

## **The Impact of Dementia on the Lives of Individuals with Intellectual Disabilities and their Caregivers**

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### **Key Facts**

- Individuals with Down syndrome are a high risk for dementia.
- Dementia risk increases with age. (McCarron et al., 2017)
- Mean age of diagnosis in individuals with Down syndrome is 54-55 years. (McCarron, et al., 2017)
- Mean survival time post diagnosis in this population is 4.6 years. (McCarron, et al., 2017)

### **Best Practices**

- Establish baseline of function at age 35-40.
- Do early screening to identify functional change, support caregivers, identify interventions/supports and plan future programming.
- An available tool is the EDSD <https://www.the-ntg.org/ntg-edsd>
- Differential diagnosis is important to rule out other causes for behavior.

### **Challenges**

- Individuals with ID/dementia live in a variety of settings-family homes, group homes, supported living, independent living, life sharing.
- Direct support personnel may be providing majority of support and care.
- Parents and siblings are providing direct care so their experience and benefit from understanding the condition so they can make informed decisions about care.

### **Best Practices Post Diagnosis**

- Activity engagement can help reinforce personal identify, sense of belonging and value and can mitigate behavioral upset.
- Activities should be familiar, reflect past interests, simple and repetitive.
- Relax the rules!
- Modify the environment and make it safe, easy to understand.
- Caregiver training and support should include strategies to manage stress.
- Interprofessional team approach is beneficial.

## Rules for Dementia

- Less is more.
- Never argue with dementia; you will never win.
- Dementia is here and now.
- “No” doesn’t always mean no.
- Keep what you have now. (Herge, 2025)

## Resources

American Academy of Developmental Medicine & Dentistry <https://www.aadmd.org>

American Association on Intellectual and Developmental Disabilities [www.aaidd.org](http://www.aaidd.org)

Jefferson Elder Care <http://www.jefferson.edu/university/health-professions/jefferson-elder-care.html>

Jenny’s Diary <https://www.learningdisabilityanddementia.org/jennys-diary.html>

Resources to support conversations with people with intellectual disability

Kennedy Willis Center on Down Syndrome <https://kwcdownsyndrome.org/>

Provides continuing education to families and community about best practice in dementia care for persons with Down syndrome

Learning Disabilities and Dementia <https://www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia>

National Task Group on Intellectual Disabilities and Dementia Practices (NTG) <https://www.the-ntg.org/>

## References

Herge, E. A. (2025). *Best Practice in Dementia Care Training Workbook*. Thomas Jefferson University, Philadelphia, PA.

McCarron, M., McCallion, P., Reilly, E., Dunne, P., Carroll, R., & Mulryan, N. (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research*, 61(9), 843–852. <https://doi.org/10.1111/jir.12390>

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