



RESOURCE GUIDE

Greater Cincinnati Down Syndrome Association
Family Caregiver Conference - April 27, 2024

Dementia-Capable
Care of Adults with
Intellectual
Disabilities and
Dementia.

www.the-ntg.org

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National Task Group on Intellectual
Disabilities and Dementia Practices

NTG Dementia Capable Care of Adults with ID and Dementia Foundation Workshop Resource Guide

Join the NTG...Become a Member and help support our mission

<https://www.the-ntg.org/membership-1>

Please visit the NTG's website for more information on ID and dementia: www.the-ntg.org

NTG Support for Family Caregivers, including online support group. <https://www.the-ntg.org/family-caregivers>

The NTG FAQ: Some Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias

https://www.the-ntg.org/files/ugd/8c1d0a_b3774807d86549c5ba35969814fbcaad.pdf

Advocate Medical Group Adult Down Syndrome Clinic Resource Library (Brian Chicoine, MD): This resource library is an excellent compendium of helpful articles on Down syndrome and medical conditions associated with Down syndrome generally and Down syndrome and dementia specifically. Many webinars featuring Dr. Brian Chicoine are available for viewing.

<https://adscresources.advocatehealth.com/resources/>

Supporting Derek Video

Supporting Derek video: <https://vimeo.com/130775062/2ca596dbaa> Excellent tool to get a sense of how the environment, and especially overstimulation, can impact a person with DS and dementia.



This training film, commissioned by the staff of The University of Edinburgh's Centre for Research into Families and Relationships, is to be used to train staff working in care homes how to better care for patients who have both learning difficulties and dementia.

It was funded by the Joseph Rowntree Foundation. A training pack including the DVD is available to buy from the Joseph Rowntree Foundation at a subsidized cost of £15 at the

following address: <http://www.jrf.org.uk/publications/su...> The pack, which contains the DVD plus training materials covers many of the key issues related to diagnosing and responding to dementia in people with learning difficulties. Catch up with the blog about this DVD and the accompanying training resources here: <http://www.jrf.org.uk/blog/2010/12/su...>

NEW RESOURCE → HELEN JOURNAL

HELEN is the ONLY journal created for ALL disabilities that is endorsed by three nationally recognized professional health organizations. The journal represents the many champions in the field of disability, with high-caliber content created by patients, parents and caregivers, clinicians, educators, and other professionals. <https://helenjournal.org/>

Down Syndrome and Regression.

Variety of studies posted on NTG website: <https://www.the-ntg.org/down-syndrome-regression>

Assessment and Diagnosis of Down Syndrome Regression Disorder: International Expert Consensus.

Front. Neurol., 15 July 2022. Sec. Dementia and Neurodegenerative Diseases.

<https://doi.org/10.3389/fneur.2022.940175>. **Conclusions:** 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/articles/10.3389/fneur.2022.940175/full>

Jonathan Santoro, MD <https://www.chla.org/profile/jonathan-d-santoro-md> Dr. Santoro is a pediatric neurologist with special training in inflammatory and demyelinating disorders of the brain, spinal cord, and peripheral nervous system. His clinical research is in Down syndrome and the association between autoimmunity and the development of cerebrovascular disease. [A Family Finds Hope for Down Syndrome Regression Disorder](#)

NDSS Down Syndrome and Regression Checklist: <https://ndss.org/resources/regression-down-syndrome>

Down Syndrome and Alzheimer's [Down Syndrome and Dementia | NTG 2022 \(the-ntg.org\)](#)

Autism and Dementia

Multiple articles available on the NTG website. <https://www.the-ntg.org/autism-and-dementia>

Cerebral Palsy and Dementia

<https://www.the-ntg.org/cerebral-palsy-and-dementia>

Books of Interest

Dancing with Rose: Finding Life in the Land of Alzheimer: One Daughter's Hopeful Story

<https://www.amazon.com/Dancing-Rose-Finding-Alzheimer-Daughters-ebook/dp/B000QCTPNK>

In The Shadow of Fame: A Memoir by the Daughter of Erik H. Erikson.

[https://www.amazon.com/Shadow-Fame-Memoir-Daughter-](https://www.amazon.com/Shadow-Fame-Memoir-Daughter-Erikson/dp/067003374X/ref=sr_1_2?crid=2UJR2X9MDM5R9&keywords=In+The+Shadow+of+Fame&qid=1643382196&s=books&srefix=in+the+shadow+of+fame%2Cstripbooks%2C386&sr=1-2)

[Erikson/dp/067003374X/ref=sr_1_2?crid=2UJR2X9MDM5R9&keywords=In+The+Shadow+of+Fame&qid=1643382196&s=books&srefix=in+the+shadow+of+fame%2Cstripbooks%2C386&sr=1-2](https://www.amazon.com/Shadow-Fame-Memoir-Daughter-Erikson/dp/067003374X/ref=sr_1_2?crid=2UJR2X9MDM5R9&keywords=In+The+Shadow+of+Fame&qid=1643382196&s=books&srefix=in+the+shadow+of+fame%2Cstripbooks%2C386&sr=1-2)

Shut Away: When Down Syndrome Was A Life Sentence by Catherine McKercher. Available on Amazon. <https://www.amazon.com/Shut-Away-When-Syndrome-Sentence/dp/177310098X>

Screening and Assessment



Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive Impairment Assessments: Report of the Neuroatypical Conditions Expert Consultative Panel.

The NTG and the Lumind IDSC Foundation have issued a comprehensive report on the barriers to determining MCI and dementia in adults with neuroatypical conditions, such as acquired brain injury, autism, cerebral palsy, Down syndrome, intellectual disability, serious mental illness, and significant sensory impairments. Developed by an Expert Panel, the report concludes that current federal guidelines for assessing for MCI or dementia do not provide sufficient information to assess such adults. The Panel recommended broadening federal guidance to include adaptations of assessment practices; expanding training for clinicians about such conditions; and undertaking research to produce more evidence-based information on assessing neuroatypical adults.

https://www.the-ntg.org/files/ugd/8c1d0a_c7ab8e7c49104bca8bc677ac880a3e55.pdf

NTG-Early Detection Screen for Dementia (NTG-EDSD)

The NTG released the NTG-Early Detection Screen for Dementia (NTG-EDSD) which was developed in response to requests by family caregivers and agencies for a tool useful to record observations of changes in function.

The NTG-EDSD is used in starting that critical conversation with (and among) clinical personnel as to whether their observations merit more explicit assessment for MCI or dementia or -- alternatively -- signal behaviors that may be amenable to intervention and remediation.

The EDSD is free and available for download from the NTG website: <https://www.the-ntg.org/ntg-edsd>

NTG-EDSD: PHYSICIAN'S QUICK GUIDE FOR USING THE NTG EDSD



A new informative guide sheet is now available for primary care physicians who may be seeing an adult with an intellectual disability with possible cognitive decline. The guide explains what the NTG-EDSD is and what information it contains. https://www.the-ntg.org/files/ugd/8c1d0a_ddeaed76f098462191e2dea25f3ef50d.pdf

“Possible” Sources of Dementia Assessment/Consultation

Massachusetts General Hospital Down Syndrome Clinic. MGH DS clinic is not accepting new patients; however, they will do a remote second opinion and it costs \$950. . . Alas: Patients are responsible for all charges, and payment is due at the time of request. “Our team cannot file a claim with your insurance carrier or provide a procedure (CPT) code for this service.”

<https://www.massgeneral.org/children/down-syndrome/adult-clinic>

Down Syndrome Medical Interest Group (DSMIG). Mostly pediatric clinics but worth a look.

[Down Syndrome Medical Interest Group - USA - DSMIG-USA Clinic Directory Map](#)

Global Down Syndrome. <https://www.globaldownsyndrome.org/research-medical-care/medical-care-providers/>

National Down Syndrome Congress. Clinic listings by state. <https://www.ndscenter.org/programs-resources/health-care/down-syndrome-clinics/>

Differential Diagnosis

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities.

<https://www.mayoclinicproceedings.org/action/showPdf?pii=S0025-6196%2813%2900371-6>

The following two articles are not specific to intellectual disabilities but give an excellent overview of the steps to establishing a correct differential diagnosis and tests that should be considered and why.

PRACTICE PARAMETER: DIAGNOSIS OF DEMENTIA (AN EVIDENCE-BASED REVIEW).

<https://n.neurology.org/content/neurology/56/9/1143.full.pdf>

Early Diagnosis of Dementia.

KAREN S. SANTACRUZ, M.D., and DANIEL SWAGERTY, M.D., M.P.H. University of Kansas Medical Center, Kansas City, Kansas. Distinguishing among age-related cognitive decline, mild cognitive impairment and Alzheimer’s disease may be difficult and requires evaluation of cognitive and functional status. Careful medical evaluation to exclude treatable causes of cognitive impairment is important.

<https://www.aafp.org/afp/2001/0215/afp20010215p703.pdf>

B12 Deficiency in Down Syndrome

Vitamin B12 Deficiency by Dr. Brian Chicoine.

<https://adscresources.advocatehealth.com/vitamin-b12-deficiency/>

Celiac Disease

What You Should Know About Celiac and Down Syndrome.

<https://www.globaldownsyndrome.org/what-you-should-know-about-celiac-disease-down-syndrome/>

Clinical Guidelines for Medical Care

Clinical Guidelines for Medical Care of Adults with Down Syndrome

The Global Down Syndrome Foundation underwrote and led a broad interdisciplinary effort to create guidelines for medical care of adults with Down syndrome, including considerations for assessing and treating dementia. <https://www.globaldownsyndrome.org/wp-content/uploads/2020/10/Global-Down-Syndrome-Foundation-Medical-Care-Guidelines-for-Adults-with-Down-Syndrome-v.1-10-20-2020.pdf>

Over-Medication and Older Adults with Intellectual Disability: Risks for Brain Health (Statement)

This document, released on February 21, 2023, was issued jointly by the NTG and the Health Matters Program as part of an advisory series on risk reduction in adults with intellectual disability and promoting healthy brain outcomes. The advisory recognizes that in some instances overmedicating can have negative effects on physical and brain health, as well as potentially increase the risk for mild cognitive impairment or dementia. The intent of the advisory is that the information provided will lead

to constructive scrutiny of medication use, avoid “medication harm’, and result in positive health outcomes. https://www.the-ntg.org/files/ugd/8c1d0a_4f34eb50cccb4e398b521764716c756c.pdf

Medications that Can Cause the Symptoms of Dementia

Anticholinergics (commonly prescribed medications that can cause cognitive impairment in older adults).

List of Anticholinergic Drugs and Why Some of Them are Dangerous for Seniors.

<https://www.theselectorlist.com/medication/anticholinergic-drugs/>

Anticholinergic Burden Scale.

A simple to use tool used to determine if an individual is taking 1 or more anticholinergic medications developed by the Aging Brain Program of the Indiana University Center for Aging Research .

<https://corumpharmacy.com/wp-content/uploads/2020/08/Anticholinergic-cognitive-burden-scale.pdf>

Anticholinergic Calculator.

Use this calculator to work out the Anticholinergic Burden for your clients. A score of 3+ is associated with an increased cognitive impairment and mortality. <http://www.acbcalc.com/>

Anticholinergic Drugs in Geriatric Psychopharmacology.

Front. Neurosci., 06 December 2019. Sec. Neuropharmacology.

<https://doi.org/10.3389/fnins.2019.01309>. Drugs with anticholinergic action are widely prescribed in the elderly population due to their potential clinical benefits. However, these benefits are limited by adverse effects which may be serious circumstances. This review presents different aspects of the use of anticholinergics in old age with a focus in psychogeriatric patients. We critically review published data on benefits and disadvantages of anticholinergics, which are often controversial. Prevalence, pathophysiology and measurement methods of the anticholinergic action of drugs are discussed. We also present the most important drawbacks resulting from its use, including effects on cognition in healthy and cognitively impaired people, in aged schizophrenia patients, emergence of delirium and psychiatric symptoms, influence in functionality, hospitalization, institutionalization and mortality, and the potential benefits and limitations of their discontinuation. Finally, we suggest practical recommendations for the safe use of anticholinergics in clinical conditions affecting elderly patients, such as dementia, schizophrenia and acute hallucinatory episodes, depression, anxiety, Parkinson’s disease, cardiovascular conditions and urinary incontinence.

<https://www.frontiersin.org/articles/10.3389/fnins.2019.01309/full>

Anticholinergic Burden Scale.

Used to estimate the anticholinergic burden of medications prescribed to a patient.

<https://corumpharmacy.com/wp-content/uploads/2020/08/Anticholinergic-cognitive-burden-scale.pdf>

Do Certain Medications Increase Dementia Risk? A Q&A to help you understand the research — and how to protect you and your loved ones. <https://health.clevelandclinic.org/do-certain-medications-increase-dementia-risk/>

Medications – Tools

Medscape

Drug interaction checker. <https://reference.medscape.com/drug-interactionchecker>

Beers List

Potentially harmful medications for elderly. [https://www.pharmacytoday.org/article/S1042-0991\(19\)31235-6/pdf](https://www.pharmacytoday.org/article/S1042-0991(19)31235-6/pdf)

Physician's Desk Reference

<https://www.pdr.net/>

Drugs.com

<https://www.drugs.com/>

Jenny's Diary

<https://www.learningdisabilityanddementia.org/jennys-diary.html> Jenny's Diary is a free downloadable booklet and set of postcards. It is aimed at supporting conversations about dementia with people who have a learning disability.

Video: What is Alzheimer's Disease?

https://youtu.be/7_kO6c2NfmE

End-of-Life

Recommended Books

That Good Night: Life and Medicine in the Eleventh Hour. **Sunita Puri, MD.** Thoughtful read on end-of-life care and aggressive treatment written by a palliative care physician. Available on Amazon.

https://www.amazon.com/That-Good-Night-Medicine-eleventh/dp/0735223327/ref=sr_1_1?crid=280K4VBJPHIOF&keywords=That+Good+Life+Sunita+Puri&qid=1643381160&s=books&sprefix=that+good+life+sunita+puri%2Cstripbooks%2C711&sr=1-1

Being Mortal: Medicine and What Matters in the End. In his bestselling books, Atul Gawande, a practicing surgeon, has fearlessly revealed the struggles of his profession. Now he examines its ultimate limitations and failures – in his own practices as well as others' – as life draws to a close. And he discovers how we can do better. He follows a hospice nurse on her rounds, a geriatrician in his clinic, and reformers turning nursing homes upside down. He finds people who show us how to have the hard conversations and how to ensure we never sacrifice what people really care about.

<http://atulgawande.com/book/being-mortal/>

Knowing the Person and Their Wishes.

Introduction to One-Page Descriptions – a Person-Centered tool. One-page description is a brief overview of “what is important to a person” and “how they need to be supported”. It can be used as an introduction to a person in many settings when that individual isn’t able to adequately communicate for themselves, including hospitalization. It creates a person-centered foundation for supporting needs and offering comfort as instructed by the family or caregiver. It is also referred to as a one-page profile.

<https://www.php.com/elearning/introduction-to-one-page-profiles/#:~:text=A%20one%2Dpage%20description%20is,they%20need%20to%20be%20supported%E2%80%9D.&text=It%20creates%20a%20person%2Dcentered,as%20a%20one%2Dpage%20profile.>

Advance Care Planning: Workbook and Video

The following resources were developed by the California Coalition for Compassionate Care to address the needs of the intellectual and developmentally disabled community when preparing for the end of life. Many of the conversations that surround end-of-life care include concepts and language that are challenging to follow, especially for people with developmental disabilities. The CCCC created a guide that enables people with developmental disabilities to advocate for themselves and stay in control of their lives through the very end.

Thinking Ahead: My Life at the End (PDF)

Contains words, symbols and pictures that facilitate discussion with and decision-making by persons with developmental disabilities regarding their values, goals and treatment preferences at the end of life. The video serves as an instruction manual, containing vignettes that illustrate in simple, graphic format the purpose and use of the materials. <https://coalitionccc.org/CCCC/Resources/Resources-for-People-with-Developmental-Disabilities/CCCC/Resources/People-With-Developmental-Disabilities-Resources.aspx?hkey=7db2eeb5-41a4-4bdd-86b1-2c6bb85ac1ff>

H-CARDD Health Care Access Research and Developmental Disabilities

<https://www.porticonetwork.ca/web/hcardd/healthcareresources/people-with-developmental-disabilities-and-caregivers>

Recommended Reading by Prior Workshop Attendees

Grief and its Complications in Individuals with Intellectual Disability.

Brickell, C., & Munir, K. (2008). Grief and its complications in individuals with intellectual disability. *Harvard review of psychiatry*, 16(1), 1–12. <https://doi.org/10.1080/10673220801929786>. Bereavement and loss have significant impact on the lives of individuals with intellectual disability (ID). Although there is a growing impetus to define the symptoms of grief that predict long-term functional impairment, little

is known about maladaptive grieving among individuals with ID. We examine the literature concerning the phenomenology of traumatic grief (TG) in the general population, along with what is known about the manifestations of grief in individuals with ID.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3166634/>

Helping People with Intellectual Disabilities Cope With Loss: Tips and Resources.

<https://vkc.vumc.org/assets/files/tipsheets/copinglosstips.pdf>

Managing Grief Better: People with Intellectual Disabilities.

<http://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities>

Health Care Advocacy

Guidelines for Dementia-related Health Advocacy for Adults with ID and Dementia



These NTG guidelines were developed to help caregivers, whether family members or staff, to prepare for and advocate during health visits. The NTG developed these guidelines and recommendations for dementia-related health advocacy preparation and assistance that can be undertaken by provider and advocacy organizations. <https://www.the-ntg.org/publications-2/guidelines-for-dementia-related-health-advocacy-for-adults-with-id-and-dementia>

Understanding the Experience of Dementia.

Lisa Ghent-Fuller, RN.

This is a really well done, albeit lengthy, explanation of the changes a person with dementia experiences and how it will impact their ability to function and behavior.

http://www.dementiacarestrategies.com/12_pt_Understanding_the_Dementia_Experience.pdf

Pain Assessment Tools

Pain Assessment of Adults With Intellectual and Developmental Disabilities

<https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/06/3.8-Pain-Assessment.pdf>

PAINAD

<https://pediatric-pain.ca/wp-content/uploads/2013/04/CPSNAID.pdf>

Dis-Dat:

<https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/disability-distress-assessment-tool-disdat/>

Pain Perception in People with Down Syndrome.

Pain perception in people with Down syndrome: a synthesis of clinical and experimental research. McGuire, B. E., & Defrin, R. (2015). Pain perception in people with Down syndrome: a synthesis of clinical and experimental research. *Frontiers in behavioral neuroscience*, 9, 194. <https://doi.org/10.3389/fnbeh.2015.00194>. **Conclusion:** On the basis of the limited data on sensory and behavioral testing, we tentatively conclude that individuals with Down syndrome are more sensitive to pain than normal. The evidence suggests that although pain expression appears to be delayed, once pain is registered, there appears to be a magnified pain response.

Reduced Pain Responses in Individuals with Down Syndrome. Lisa Dahl, DO Family Medicine Resident at Advocate Lutheran General Hospital. Individuals with Down syndrome have reduced and delayed pain responses. They are not insensitive to pain, but their expression is delayed and less precise. It is hard to tell if there is a decreased ability to sense the pain, localize the pain, or if the reaction to the pain is delayed

Pain perception in people with Down syndrome: A synthesis of clinical and experimental research.

Mcguire, Brian & Defrin, Ruth. (2015). Pain perception in people with Down syndrome: A synthesis of clinical and experimental research. *Frontiers in behavioral neuroscience*. 9. 194. 10.3389/fnbeh.2015.00194. Conclusion: The literature suggests that people with Down syndrome experience pain, both acute and chronic, with at least the same frequency as the rest of the population. Furthermore, the evidence suggests that although acute pain expression appears to be delayed, once pain is registered, there appears to be a magnified pain response https://www.researchgate.net/publication/281141821_Pain_perception_in_people_with_Down_syndrome_A_synthesis_of_clinical_and_experimental_research

Antipsychotics

Centers for Medicare and Medicaid Services (CMS) – Use of antipsychotics in nursing homes initiative. The article below published in Health Affairs in 2017 outlines the CMS initiative. It is relevant to IDD service and health care providers as well.

CMS Strategies To Reduce Antipsychotic Drug Use In Nursing Home Patients With Dementia Show Some Progress. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2016.1439>

Use of Antipsychotics for Treatment of Behaviors in Dementia

For more information about the use of antipsychotics for treatment of behaviors, this is an excellent resource from American Family Physician. Also discussed are the risks of using these medications in the elderly.

Behavioral Disorders in Dementia: Appropriate Nondrug Interventions and Antipsychotic Use

<https://www.aafp.org/afp/2016/0815/afp20160815p276.pdf>

Memory Aids, Activities, Bathing Supplies, Wandering Prevention, Etc.

The Alzheimer's Store

The Alzheimer's Store is the #1 source for comfort and safety products designed specifically for those with Alzheimer's, Dementia, Stroke and other memory related conditions.

<https://www.alzstore.com/Default.asp>

Bathing

Bathing Without a Battle. Creating a Better Bathing Experience for Persons with Alzheimer's Disease and Related Dementias.

Person-centered, practical approaches to care, information on innovative bathing equipment and supplies, policy recommendations, and guidance for regulatory compliance.

<https://bathingwithoutabattle.unc.edu/>

Virtual Dementia Tour.

<https://www.secondwind.org/virtual-dementia-tourreg.html> A window into the world of dementia through the evidence-based dementia simulation training. If you ever get a chance to do the VDT, do it!

Understanding Difficult Behaviors: Some practical suggestions for coping with Alzheimer's disease and related illnesses.

This book was written for caregivers of persons with dementia. Caregivers may include family members as well as staff working in nursing homes, assisted living programs, adult day center programs, home care agencies, hospitals, hospice care and other settings providing care to persons with dementia. This material is intended to help caregivers understand the many possible explanations for why challenging behaviors may occur. Practical coping strategies for responding to challenging situations such as agitation, wandering, incontinence and resistance to care are also offered. <https://www.amazon.com/Understanding-Difficult-Behaviors-suggestions-Alzheimers/dp/0978902009>

Light Therapy

Light Therapy and Alzheimer's Disease and Related Dementia: Past, Present, and Future.

Hanford, N., & Figueiro, M. (2013). Light therapy and Alzheimer's disease and related dementia: past, present, and future. *Journal of Alzheimer's disease : JAD*, 33(4), 913–922. <https://doi.org/10.3233/JAD-2012-121645>. A carefully orchestrated light/dark pattern has been shown in several controlled studies of older populations, with and without ADRD, to be a powerful non-pharmacological tool to improve sleep efficiency and consolidation. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3553247/>

A Systematic Review: Light Therapy for Individuals with Dementia and Implications for Practice.

Two studies, which both utilized the Cohen-Mansfield Agitation Inventory (CMAI) as an outcome measure, found light therapy to be a clinically significant intervention.

https://jdc.jefferson.edu/cgi/viewcontent.cgi?article=1034&context=student_papers

A-B-C Model for Dementia Care

Back to the A-B-C's Understanding & Responding to Behavioral Symptoms in Dementia.

This is actually a lecturer's script but it's an excellent overview of using the A-B-C Model. PUBLISHED BY THE JOHN A. HARTFORD CENTER OF GERIATRIC NURSING EXCELLENCE (HCGNE), COLLEGE OF NURSING, UNIVERSITY OF IOWA. https://pogoe.org/sites/default/files/ABCs_lecture.pdf

Recommended by Prior Workshop Participants

HELP for behaviors that challenge in adults with intellectual and developmental disabilities.

Most adults with IDD are followed by primary care providers but they comprise a small proportion of primary care practices. Unique ways of communicating needs, diagnostic queries, and BTC are common in this population. This complexity can lead to missed diagnoses and inappropriate antipsychotic medication use with attendant risks. This article presents a systematic approach, HELP, to the assessment and treatment of factors of Health, Environment, Lived experience, and Psychiatric conditions that can lead to BTC and includes tools to support these assessments.

https://www.cfp.ca/content/64/Suppl_2/S23

Retrogenesis

Dr. Barry Reisberg, Professor of Psychiatry at New York University School of Medicine, and his colleagues have studied Alzheimer disease for many years and have developed a system to identify stages of the disease called the Global Deterioration Scale (GDS). Reisberg (1999) believes that persons with Alzheimer's proceed through the disease in a somewhat predictable manner, though there will always be unique variations. The Retrogenesis theory refers to "the process by which degenerative mechanisms in dementia reverse those of normal human development" (Reisberg, et.al, 1999). In other words, the person regresses backwards as a child's brain progresses forward, e.g., a person in the early stages of dementia will have the skill level of a 5- to 7-year-old. This leads us to alter our expectations of the cognitive and motor abilities to those of a 5- to 7-year-old child, e.g., they cannot live alone. This does not mean, however, that we can treat people as children: they have history and life-long skills still available. By determining the developmental age of the person with Alzheimer's, we can better understand their behavior and adapt their environment so we can be realistic in our expectations, and they can be successful in daily tasks and activities. This table, developed by Reisberg and his colleagues (1999), gives clarity to this Retrogenesis theory. <https://www.islandhealth.ca/sites/default/files/2019-01/dementia-video-series-behaviours.pdf>

Roll-Back Memory

From *The Simplicity of Dementia: A Guide for Family and Carers* by Huub Buijssen.

<https://www.amazon.com/Simplicity-Dementia-Guide-Family-Carers/dp/1843103214>

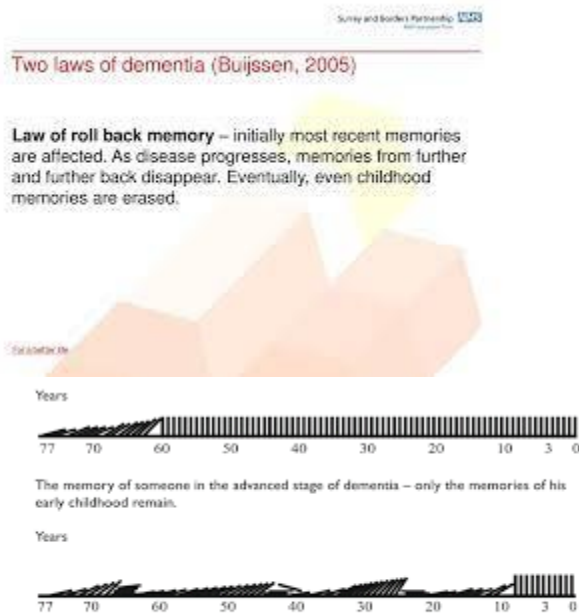
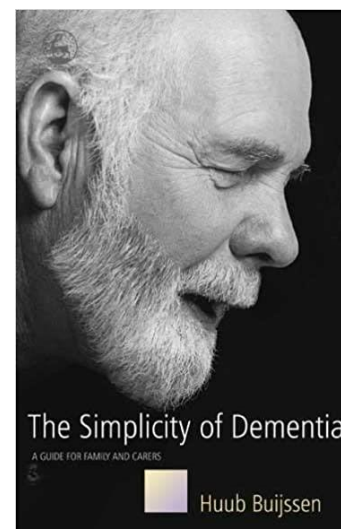


Figure 4.1 An illustration of Buijssen's 'Shelf of Diaries'. Source: Buijssen, H. (2005) *The Simplicity of Dementia*. London: Jessica Kingsley Publishers, p.37.



At first, long term memories will remain intact, however, as the dementia progresses, long term memories will also begin to deteriorate and eventually disappear altogether. Deterioration begins with the most recent memories and progresses until only memories of early childhood remain, hence memory can be said to be 'rolling back'.

Food Molds for Pureed Foods

Foods with an adapted texture EPIKURA. Epikura offers a full line of textured, reshaped therapeutic foods for mild to severe dysphagia. Chopped or pureed, Epikura foods are characterized by a texture index for safe swallowing. <https://www.epikura.com/home>

Newly Approved Alzheimer's Medications

Equitable Access to Alzheimer's Disease Therapeutics for Adults with Down Syndrome

<https://helenjournal.org/september-2023/equitable-access-to-alzheimers-disease-therapeutics-for-adults-with-down-syndrome>

Adults with Down syndrome face a heightened risk of developing Alzheimer's disease (AD) at an earlier age compared to the general population. With a cumulative risk of Down syndrome associated with Alzheimer's dementia (DS-AD) reaching 50% by their mid-50s, it is crucial for this vulnerable group to have timely access to the emerging class of anti-amyloid Alzheimer's disease immunotherapeutics, including lecanemab and donanemab. However, current prior authorization prescribing criteria for these treatments fail to consider inclusion parameters unique to adults with Down syndrome, thereby creating barriers to equitable care. To address this issue, under the leadership of the NTG and the Lumind IDSC Foundation, a multinational working group of experts convened to examine and propose necessary adaptations to prescribing criteria, ensuring that adults with Down syndrome qualify to benefit from the new class of disease-modifying drugs, anti-amyloid immunotherapies.

This article explores the key findings and recommendations put forth by the Working Group on Criteria for Access to Alzheimer's Therapeutics for Adults with Down Syndrome. Its report can be found at <https://www.the-ntg.org/lumind-drug-equivalency>.

Environmental Modifications Resources

Dementia Enabling Environments (Australia). <http://www.enablingenvironments.com.au/>. *This is a GREAT interactive resource!* The Dementia Enabling Environment Virtual Information Centre provides practical tips, guides and resources to help make the places where we live more dementia enabling. An enabling environment will encourage a person with dementia to lead as full and independent a life as possible. There are many simple modifications that anybody can make to their home or to landscaping, as well as architectural design changes. Use this site to explore different home settings and learn more

about key design principles in each area of the house and to download useful information and resources.

They have a companion resource that addresses specific behaviors in the context of the physical environment.

http://www.enablingsenvironments.com.au/uploads/5/0/4/5/50459523/dementia_enabling_environment_-_design-impact-and-symptomologies-of-dementia.pdf

They also have a great audit tool that you can use to assess your environment.

http://www.enablingsenvironments.com.au/uploads/5/0/4/5/50459523/r3_eat-assessmenttool_19.3.17.pdf

Dementia Friendly Environment Checklist

<https://www.alzheimers.org.uk/sites/default/files/2019-01/Dementia%20Friendly%20Environment%20Checklist.pdf>

How to design dementiafriendly care environments

This help sheet explains how a well-designed care environment can enable people living with dementia to make the best of everyday life. It outlines key Dementia Enabling Design Principles and suggests ways to review an existing care environment or plan a new one.

https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-Environment03_HowToDesign_english.pdf

Designing Environments for Dementia

This list is a reviewed collection of articles, books, web resources and videos prepared by the Alzheimer's Association Green-Field Library staff. <https://www.alz.org/media/Documents/design-environ-for-alzheimers-rl-2019.pdf>

NTG Issues Advisory on Settings Rule and Dementia Housing

The NTG has issued a public policy advisory on applications of the CMS 'Settings Rule; with applications to **community-based housing** for adults with intellectual disability living with dementia. The advisory covers adaptations agencies could use to provide HCBS supports in small dementia capable group homes and designing person-centered care plans. https://www.the-ntg.org/files/ugd/8c1d0a_84c6c6b5e73e4d9da968258f9af0cfed.pdf

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