

## Down Syndrome and Dementia

This list is a reviewed collection of items prepared by the Alzheimer's Association Green-Field Library staff. Contact your local chapter or local library for availability of the items.

### On this resource list:

**General & Medical Information**

**Clinical Research & Analysis**

**Drug Information**

**Diagnosis & Care Management**

### Alzheimer's Association

*Down syndrome and Alzheimer's disease*

Chicago, IL

<http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp>

### General & Medical Information

#### Articles, Journal

Hithersay, R; Hamburg, S; Knight, B. Cognitive decline and dementia in Down syndrome. *Current Opinion in Psychiatry*. Mar 2017; vol. 30(2), pp. 102-107.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/28009725>

Green-Field Library does not own

Lott, IT; Dierssen, M. Cognitive deficits and associated neurological complications in individuals with Down's syndrome. *Lancet Neurology*. Jun 2010; vol. 9(6), pp. 623-633.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/20494326>

Green-Field Library owns

Lott, IT; Doran, E; Nguyen, VQ; et al. Down syndrome and dementia: seizures and cognitive decline. *Journal of Alzheimer's Disease*. 2012; vol. 29(1), pp. 177-185.

Full-text: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3406603>

Green-Field Library owns

Nevel, KM. Down syndrome and aging: a leadership and social justice landscape. *Journal of Cultural Diversity*. Spr 2010; vol. 17(1), pp. 34-38

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/20397572>

Green-Field Library does not own

Malt, EA. Dahl, RC; Haugsand, TM; et al. Health and disease in adults with Down syndrome. *Tidsskr Nor Laegeforen*. Feb 5, 2013; vol. 133(3), pp. 290-294. [article in English and Norwegian]

Full-text: <http://tidsskriftet.no/article/2970890>

Green-Field Library does not own

Urv, TK; Zigman, WB, Silverman. Psychiatric symptoms in adults with Down syndrome and Alzheimer's disease. *American Journal on Intellectual and Developmental Disabilities*. Jul 2010; vol. 115(4), pp. 265-276.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/20597723>

Green-Field Library does not own

Zigman, WB. Atypical aging and Down syndrome. *Developmental Disabilities Research Reviews*. Aug 2013; vol. 18(1), pp. 51-67.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/23949829>

Green-Field Library does not own.

## Books

Janicki, M.; Dalton, A. (eds.). *Dementia, aging, and intellectual disabilities: a handbook*.

Philadelphia, PA: Brunner/Mazel, 1999. Twenty-one chapters on a range of topics related to dementia in persons with intellectual disabilities including biology and physiology, neurological and medical complications, assessment, the parent's perspective, the care provider's perspective, best practices, policy issues and more.

Green-Field Library Call No.: WM 220 D376 1999

Prasher, V. *Alzheimer's disease and dementia in Down syndrome and intellectual disabilities.*

Oxford: UK; Seattle, WA: Radcliffe, 2005.

Green-Field Library Call No.: WM 300 P911 2005

### Video

*Down syndrome and Alzheimer's – On Our Mind*

University of California Television (UCTV)

<https://www.youtube.com/watch?v=5sABT0R-4VA>

*Investigating Alzheimer's in people with Down syndrome*

National Institute on Health

<https://www.youtube.com/watch?v=HLyYblQqF3g>

### Web Sites

*Alzheimer's Disease international's fact sheet on dementia and intellectual disabilities.*

Risk factors, numbers of people affected, signs, diagnosis, principles of care, and resources are covered in this fact sheet. Versions are available in English, Spanish, German, Chinese, Japanese, and Hebrew.

London, UK.

<http://www.alz.co.uk/adi/publications.html>

*Learning about Down syndrome.*

National Human Genome Research Institute

<https://www.genome.gov/19517824/learning-about-down-syndrome>

*National Down Syndrome Society (NDSS).*

The society provides a Web page to help link persons with Down syndrome to information and resources in the community. Available online, search "alzheimer's")

New York, NY.

<http://www.ndss.org>

*“My thinker’s not working.”*

A national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their community and receive quality supports. The plan, developed by the National Task Group on Intellectual Disabilities and Dementia Practices presents findings and recommendations on the impact of Alzheimer’s. It includes an overview of the population, challenges facing them, community services, education and training, financing, and possible solutions. It also provides an action plan for national, state, and local agencies and recommends a specific assessment tool for recognizing dementia in this special population.

Prospect, KY; Chicago, IL.

<http://www.aadmd.org/ntg>

<http://www.rtcadd.org>

*NTG FAQ: some basic questions about adults with intellectual/developmental disabilities affected by Alzheimer’s disease or other dementias*

Prospect, KY

<http://aadmd.org/sites/default/files/FAQ-Table-v9.pdf>

*Working resources lists on dementia care management and intellectual disability. Preparing community agencies for adults affected by dementia - "PCAD" project.*

Extensive bibliography on a range of publications and media materials primarily addressing community care of people with intellectual disabilities and dementia.

Chicago, IL

[https://aadmd.org/sites/default/files/abstracts-12g-July\\_12.pdf](https://aadmd.org/sites/default/files/abstracts-12g-July_12.pdf)

## Clinical Research & Analysis

### Articles, Journal

Adams, D; Oliver, C. The relationship between acquired impairments of executive function and behavior change in adults with Down syndrome. *JIDR. Journal of Intellectual Disability Research*. May 2010; vol. 54(5), pp. 393-405.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/20367747>

Green-Field Library does not own

Esbensen, AJ; Mailick, MR; Silverman, W. Long-term impact of parental well-being on adult outcomes and dementia status in individuals with Down syndrome. *American Journal of Intellectual and Developmental Disability*. Jul 2013; vol. 118(4), pp. 294-309.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/23949829>

Green-Field Library does not own

Lautarescu, BA; Holland, AJ; Zaman, SH. Early presentation of dementia in people with Down syndrome: a systematic review of longitudinal studies. *Neuropsychology Review*. Mar 2017; vol. 27(1), pp. 31-45.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/28289920>

Green-Field Library does not own

Lott, IT. Neurological phenotypes for Down syndrome across the life span. *Progress in Brain Research*. 2012; vol. 197, pp. 101-121.

Full-text: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3417824>

Green-Field Library does not own

Moncaster, JA; Pineda, R; Moir, RD. Alzheimer's disease amyloid-beta links lens and brain pathology in Down syndrome. *PLoS One*. May 20, 2010, vol. 5(5), pp. e10659.

Full-text: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2873949>

Green-Field Library does not own

Strengthening connections between Down syndrome and AD. *Lancet Neurology*. Oct 2013; vol. 12(10), p. 931.

Green-Field Library owns.

Strydom, A.; Hassiotis, A.; King, M. et al. The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity. *Psychological Medicine*. Jan 2009; vol. 39(1), pp. 12-21.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/18410700>

Green-Field Library does not own.

Wikcock, DM; Griffin, WS. Down's syndrome neuroinflammation and Alzheimer neuropathogenesis. *Journal of Neuroinflammation*. Jul 2013; vol. 16(10), p. 84.

Full-text: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3750399>

Green-Field Library does not own

### Books

Dierssen, M; de la Torea Fornell, R. *Down Syndrome: From Understanding the Neurobiology to Therapy, Volume 197* (Progress in Brain Research).

New York, NY: Elsevier, 2012.

Green-Field Library does not own.

Prasher, V. (ed.). *Down Syndrome and Alzheimer's Disease: biological correlates*.

Abingdon, UK: Radcliffe, 2006.

Green-Field Library Call No.: WM 300 D748 2006

Prasher, V. *Neuropsychological Assessments of Dementia in Down Syndrome and Intellectual Disabilities*.

New York, NY: Springer, 2017.

On order

## Drug Information

### Articles, Journal

Goodman, MJ; Brixner, DI. New therapies for treating Down syndrome require quality of life measurements. *American Journal of Medical Genetics, Part A*. Apr 2013; vol. 161A(4), pp. 639-641.

Abstract: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3750399>

Green-Field Library does not own

Kondoh, T; Kanno, A; Itoh, H. et al. Donepezil significantly improves abilities in daily lives of female Down syndrome patients with severe cognitive impairment: a 24-week randomized, double-blind, placebo-controlled trial. *International Journal of Psychiatry in Medicine*. 2011; vol. 41(1), pp. 71-89.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/21495523>

Green-Field Library does not own

Livingston, G; Strydom, A. Improving Alzheimer's disease outcomes in Down's syndrome. *Lancet*. Feb 11, 2012; vol. 379(9815), pp. 498-500.

Abstract:

<http://www.sciencedirect.com/science/article/pii/S0140673611619296>

Green-Field Library does not own

Mohan, M.; Bennett C.; Carpenter PK. Galantamine for dementia in people with Down syndrome. *Cochrane Database of Systematic Reviews*. Jan 2009 vol. 21(1), CD007656.

To read the abstract search "PMID: 19160342" without quotation marks at <http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed&itool=toolbar>

Green-Field Library does not own.

Mohan, M.; Bennett C.; Carpenter PK. Memantine for dementia in people with Down syndrome. *Cochrane Database of Systematic Reviews*. Jan 2009 vol. 21(1), CD007657.

To read the abstract search "PMID: 19160343" without quotation marks at <http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed&itool=toolbar>

Green-Field Library does not own.

Mohan, M.; Bennett C.; Carpenter PK. Rivastigmine for dementia in people with Down syndrome. *Cochrane Database of Systematic Reviews*. Jan 2009 vol. 21(1), CD007658.

To read the abstract search “PMID: 19160344” without quotation marks at <http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed&itool=toolbar>

Green-Field Library does not own.

Mohan, M.; Carpenter, PK.; Bennett C. Donepezil for dementia in people with Down syndrome. *Cochrane Database of Systematic Reviews*. Jan 2009 vol. 21(1), CD007178.

To read the abstract search “PMID: 19160328” without quotation marks at <http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed&itool=toolbar>

Green-Field Library does not own.

Prasher, V; Hague, MS. Rivastigmine transdermal patches in the treatment of dementia in Alzheimer’s disease in adults with Down syndrome- pilot study. *International Journal of Geriatric Psychiatry*. Feb 2013; vol. 28(2), pp. 219-220.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/23296840>

Green-Field Library owns

Goodman, MJ; Brixner, DI. New therapies for treating Down syndrome require quality of life measurements. *American Journal of Medical Genetics, Part A*. Apr 2013; vol. 161A(4), pp. 639-641.

Abstract: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3750399>

Green-Field Library does not own

## **Diagnosis & Care Management**

### **Articles, Journal**

Adams, D.; Oliver, C.; Kalsy, S.; et al. Behavioural characteristics associated with dementia assessment referrals in adults with Down syndrome. *Journal of Intellectual Disability Research*. Apr 2008; vol. 52(Pt 4), pp. 358-368.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/18221333>

Green-Field Library does not own.



Carling-Jenkins, R; Torr, J; Iacono, T; et al. Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments. *Journal of Intellectual and Developmental Disability*. Mar 2012; vol. 37(1), pp. 54-60.

Abstract: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3406603>

Green-Field Library does not own

Costa, AC. Alzheimer disease: treatment of Alzheimer disease in Down syndrome. *Nature Reviews. Neurology*. Mar 13, 2012; vol. 8(4), pp. 182-184.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/22410580>

Green-Field Library does not own

Deb, S.; Hare, M.; Prior, L. Symptoms of dementia among adults with Down's syndrome: a qualitative study. *Journal of Intellectual Disability Research*. Sep 2007; vol. 51(Pt 9), pp. 726-739.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/17845241>

Green-Field Library does not own.

Carson, VB. Alzheimer's in those with Down's syndrome. *Caring*. Sep. 2013; vol. 32(7), pp. 52-23.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24308164>

Green-Field Library owns.

Janicki, MP. Coping with dementia and older families of adults with Down syndrome. *Dementia*. Aug 2010; vol. 9(3), pp. 391-407.

Abstract: <http://dem.sagepub.com/content/9/3/391>

Green-Field Library owns

Janicki, M.; Heller, T.; Seltzer, G.; et al. Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disabilities. *Journal of Intellectual Disability Research*. Aug 1996; vol. 40(Pt. 4), pp. 374-382.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/8884593>

Green-Field Library does not own

Janicki, MP; Dalton, A.J.; McCallion, P.; et al. Group home care for adults with intellectual disabilities and Alzheimer's disease. *Dementia: The International Journal of Social Research and Practice*. 2005, vol. 4(3), pp. 361-385.

Abstract: <http://dem.sagepub.com/content/4/3/361>

Green-Field Library does not own.

Malt, EA; Dahl, RC, Haugsand, TM; et al. Health and disease in adults with Down syndrome. *Tidsskrift for den Norske Laegeforening*. Feb. 2013; vol. 133(3), pp. 290-294.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/23381164>

Green-Field Library does not own.

MaCarron, M; Dunn-Lane, J. Supporting persons with Down syndrome and advanced dementia. *Dementia*. May 2010; vol. 9(2), pp. 285-298.

Abstract: <http://dem.sagepub.com/content/9/2/285>

Green-Field Library owns

McCarron, M.; Gill, M.; McCallion, P.; et al. Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia. *Journal of Intellectual Disability Research*. Jul 2005; vol. 49(Pt. 7), pp. 560-566.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/15966964>

Green-Field Library does not own

Numminen, H.; Service, E.; Ahonen, T.; et al. Working memory and everyday cognition in adults with Down's syndrome. *Journal of Intellectual Disability Research*. Apr 2001; vol. 45(Pt. 2), pp. 157-168.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/11298256>

Green-Field Library does not own.

Prasher, V. End-stage dementia in adults with Down syndrome. *International Journal of Geriatric Psychiatry*. Dec 1995; vol. 10(12), pp. 1067-1069.

Abstract:

<http://onlinelibrary.wiley.com/doi/10.1002/gps.930101213/abstract>

Green-Field Library owns

Schultz, J.; Aman, M.; Kelbley, T.; et al. Evaluation of screening tools for dementia in older adults with mental retardation. *American Journal on Mental Retardation*. Mar 2004; vol. 109(2), pp. 126-141.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/15000667>

Green-Field Library does not own

Smith, D. Health care management of adults with Down syndrome. *American Family Physician*. Sep 2001; vol. 64(6), pp. 1031-1038.

Abstract: <http://www.aafp.org/afp/20010915/1031.html>

Green-Field Library does not own.

Stanton, LR; Coetzee, RH. Down's syndrome and dementia. *Advances in Psychiatric Treatment*. 2004; vol. 10, pp. 50-58.

Full-text: <http://apt.rcpsych.org/content/10/1/50.full>

Green-Field Library does not own.

Strydom, A; Al-Janabi, ; Houston, M; et.al. Best practice in caring for adults with dementia and learning disabilities. *Nursing Standard*. Oct 5, 2016; vol. 31(6), pp. 42-51

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/27823134>

Green-Field Library does not own.

Waldman, HB.; Perlman, SP.; Roesch, RE. Down syndrome and Alzheimer's disease: children grow older. *General Dentistry*. Jul-Aug 2008; vol. 56(5), pp. 420-422.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/18683397>

Green-Field Library does not own.

### **Book Chapters**

Davis, D. Parent's perspective. IN: Janicki, M.; Dalton, A. (eds.). *Dementia, Aging, and Intellectual Disabilities*.

Philadelphia, PA: Brunner/Mazel, 1999, pp. 42-50.

Green-Field Library Call No.: WM 300 D376 1999

Hammond, B.; Beneditti, P. Perspectives of a care provider. IN: Janicki, M.; Dalton, A. (eds.). *Dementia, Aging, and Intellectual Disabilities*.

Philadelphia, PA: Brunner/Mazel, 1999, pp. 32-41.

Green-Field Library Call No.: WM 300 D376 1999

Holland, A. Down syndrome and dementia. IN: O'Brien, J.; Ames, D; Burns, A. (eds.). *Dementia*.

London, UK; New York, NY: Edward Arnold; Oxford University Press, 2000, pp. 813-819.

Green-Field Library Call No.: WM 200 D3761 2000

Janicki, M.; McCallion, P.; Dalton, A. Supporting people with dementia in community settings. IN: Janicki, M.; Ansello, A. (eds.). *Community Supports for Aging Adults with Lifelong Disabilities*.

Baltimore, MD: Paul H. Brookes Publishing, 2000, pp. 387-413.

Green-Field Library does not own.

### CD-ROMs & Videos

*Adults with Down syndrome and Alzheimer's disease: a practical guide for caregivers.*

Chicago, IL; Terra Nova Films, 2006

1 DVD (48 min.)

Green-Field Library Call No.: WM 300 DVD no. 1 2006

*Hi Buddy: the developmentally delayed individual with Alzheimer's disease.*

Baltimore, MD: Video Press, 1998.

1 videocassette (18 min.)

A 53-year old man with a diagnosis of Down syndrome and Alzheimer's disease is the subject of this video, which covers the symptoms, disease progression, seizures, and employment issues. Includes interviews with professional caregivers.

Green-Field Library Call No.: WM 300 DVD no.174 1998

## Web Sites

*Alzheimer disease in individuals with Down syndrome.*

eMedicine.com.

eMedicine.com provides a comprehensive article for healthcare professionals on the background, pathophysiology, prevalence, differential diagnosis, medical workup, and treatment, including an extensive medications chart.

[http://www.emedicinehealth.com/alzheimers\\_disease\\_in\\_down\\_syndrome/article\\_em.htm](http://www.emedicinehealth.com/alzheimers_disease_in_down_syndrome/article_em.htm)

*Dementia and people with intellectual disabilities: what can we do?*

Albany, NY: New York State Developmental Disabilities Planning Council, 2001.

A multimedia training tool for healthcare professionals covering aspects of diagnosis and care for persons with dementia and intellectual disabilities.

<http://youtu.be/wrKLURsAy6Y>

*Edinburgh principles.*

Rehabilitation Research and Training Center on Aging with Developmental Disabilities.

Stirling, Scotland: The Edinburgh Working Group on Dementia Care Practices (EWGDCP) developed these practice guidelines and recommendations to support persons with intellectual disabilities and Down syndrome in the community.

[http://www.rrtcadd.org/TA/Dementia\\_Care/Resources/Edinburgh\\_Principles/Info.html](http://www.rrtcadd.org/TA/Dementia_Care/Resources/Edinburgh_Principles/Info.html)

*Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia., 2013*

N Jolkinen, M.P. Janicki; S.M. Keller; et al.

[https://aadmd.org/sites/default/files/NTG\\_Guidelines-posting-version.pdf](https://aadmd.org/sites/default/files/NTG_Guidelines-posting-version.pdf)

*When people with developmental disabilities age.*

Albany, NY: New York State Developmental Disabilities Planning Council

<http://youtu.be/MEtkmI2xEG8>

## **Down Syndrome and Dementia**

A selected list of references compiled by  
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