

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

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Clinical Research & Analysis

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Diagnosis & Care Management

- Articles, Journal
- Book, Chapters
- CD-ROMs & Videos
- Web Sites

Onset & Prevalence

- Articles, Journal

General Medical Information

Articles, Journal

Lott, I.; Head, E. Alzheimer disease and Down syndrome: factors in pathogenesis. *Neurobiology of Aging*. Mar 2005; vol. 26(3), pp. 383-389.

Green-Field Library owns

Nelson, L.; Orme, D.; Osann, K.; et al. Neurological changes and emotional functioning in adults with Down syndrome. *Journal of Intellectual Disability Research*. Oct 2001; vol. 45(Pt. 5), pp. 450-456.
Green-Field Library does not own

Rasmussen, S.A.; Whitehead, N.; Collier, S.A.; et al. Setting a public health research agenda for Down syndrome: summary of a meeting sponsored by the Centers for Disease Control and Prevention and the National Down Syndrome Society. *American Journal of Medical Genetics*. Part A. Dec 1, 2008; vol. 146A(23), pp. 2998-3010.
Green-Field Library does now own.

Silverman, W.; Zigman, W.; Kim, H.; et al. Aging and dementia among adults with mental retardation and Down syndrome. *Topics in Geriatric Rehabilitation*. Mar 1998; vol. 13(3), pp. 49-64.
Green-Field Library does not own

Books & Book Chapters

Dalton, A. Alzheimer's disease: a health risk of growing older with Down syndrome. IN: Nadel, L; Rosenthal, D. (eds.). *Down syndrome: living and learning in the community*.
New York, NY: Wiley-Liss, Inc., 1995, pp. 58-64. ISBN: 0471022012.
<http://www.riverbendds.org/index.htm>. Search left-hand navigation bar: Medical Series/Alzheimer's
Green-Field Library does not own

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. ISBN: 034075916X.
Green-Field Library Call No.: WM 200 D3761 2000

Janicki, M.; Dalton, A. (eds.). *Dementia, aging, and intellectual disabilities: a handbook*.
Philadelphia, PA: Brunner/Mazel, 1999. ISBN: 0876309163.
This book contains twenty-one chapters on a range of topics related to dementia in persons with intellectual disabilities. The areas examined are 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. ISBN: 1857756088.
Green-Field Library Call No.: WM 300 P911 2005

Web Sites

Alzheimer's disease and Down syndrome: dual diagnosis.
Cincinnati, OH, Alzheimer's Association Greater Cincinnati Chapter, 2007.

Explains the genetic link, diagnosis, assessment, and treatment.

<http://www.alz.org/cincinnati/documents/DownAD.pdf>

Alzheimer's disease and people with mental retardation.

The ARC.

This Web page Q&A answers questions about Alzheimer's disease in people with developmental disabilities, with a particular focus on Alzheimer's and Down syndrome.

<http://www.thearc.org/NetCommunity/Document.Doc?&id=95>

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.

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

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")

<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.

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

<http://www.rtcadd.org>

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.

http://www.rtcadd.org/TA/Dementia_Care/Resources/assets/Dementia_Resources_v10d5.pdf

Clinical Research & Analysis

Articles, Journal

Ball, S.L.; Holland, A.J.; Hon, J.; et al. Personality and behaviour changes mark the early stages of Alzheimer's disease in adults with Down's syndrome: findings from a prospective population-based study. *International Journal of Geriatric Psychiatry*. Jul 2006; vol. 21(7), pp. 661-673.

Green-Field Library owns.

Coppus, A.M.; Evenhuis, H.M.; Verberne, G.J.; et al. Survival in elderly persons with Down syndrome. *Journal of the American Geriatric Society*. Dec 2008, vol. 56(12), pp. 2311-2316.

Green-Field Library owns.

Deb, S.; Braganza, J.; Norton, N.; et al. APOE epsilon 4 influences the manifestation of Alzheimer's disease in adults with Down's syndrome. *British Journal of Psychiatry*. May 2000; vol. 176(5), pp. 468-472.

<http://bjp.rcpsych.org/cgi/content/full/176/5/468>

Green-Field Library does not own

Head, E.; Lott, I. Down syndrome and beta-amyloid deposition. *Current Opinion in Neurology*. Apr 2004; vol. 17(2), pp. 95-100.

Green-Field Library does not own

Isacson, O.; Seo, H.; Lin, L.; et al. Alzheimer's disease and Down's syndrome: roles of APP, trophic factors and ACh. *Trends in Neuroscience*. Feb 2002; vol. 25(2), pp. 79-84.

Green-Field Library does not own

Rubinsztein, D.C.; Hon, J.; Stevens, F.; et al. Apo E genotypes and risk of dementia in Down syndrome. *American Journal of Medical Genetics*. Aug 1999; vol. 88(4), pp. 344-347.

Green-Field Library does not own

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. Green-Field Library does not own.

Book

Prasher, V. (ed.). *Down syndrome and Alzheimer's disease: biological correlates*. Abingdon, UK: Radcliffe, 2006. ISBN: 1857756371. Green-Field Library Call No.: WM 300 D748 2006

Drug Information

Articles, Journal

Mohan, M.; Carpenter, P.K.; 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.

Mohan, M.; Bennett C.; Carpenter P.K. 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 P.K. 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 P.K. 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.

Prasher, V. Review of donepezil, rivastigmine, galantamine, and memantine for the treatment of dementia in Alzheimer's disease in adults with Down syndrome: implications for the intellectual disability population. *International Journal of Geriatric Psychiatry*. Jun 2004; vol. 19(6), pp. 509-515.

Green-Field Library owns

Prasher, V.; Adams, C.; Holder, R.; et al. Long term safety and efficacy of donepezil in the treatment of dementia in Alzheimer's disease in adults with Down syndrome: open label study. *International Journal of Geriatric Psychiatry*. Jun 2003; vol. 18(6), pp. 549-551.

Green-Field Library owns

Prasher, V.; Fung, N.; Adams, C. Rivastigmine in the treatment of dementia in Alzheimer's disease in adults with Down syndrome. *International Journal of Geriatric Psychiatry*. May 2005; vol. 20(5), pp. 496-497.

Green-Field Library owns

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.

Green-Field Library does not own.

Antonangeli, J.M. Alzheimer project: formulating a model of care for persons with Alzheimer's disease and mental retardation. *American Journal of Alzheimer's Disease*. Jul-Aug 1995; vol. 10(4), pp. 13-16.

Green-Field Library owns

Aylward, E.; Burt, D.; Thorpe, L.; et al. Diagnosis of dementia in individuals with intellectual disability: report of the Task Force for Development of Criteria for Diagnosis in Individuals with Mental Retardation. *Journal of Intellectual Disability*. Apr 1997; vol. 41(Pt. 2), pp. 152-164.

Green-Field Library does not own

Ball, S.L.; Holland, A.J.; Huppert, F.A.; et al. The modified CAMDEX informant interview is a valid and reliable tool for use in the diagnosis of dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research*. Sep 2004; vol. 48(Pt. 6), pp. 611-620.

Green-Field Library does not own

Burt, D.; Primeauz-Hart, S.; Loveland, K.A.; et al. Aging in adults with intellectual disabilities. *American Journal of Mental Retardation*. Jul 2005; vol. 110(4), pp. 268-284.
Green-Field Library does not own

Bush A.; Beail, N. Risk factors for dementia in people with Down syndrome: issues in assessment and diagnosis. *American Journal of Mental Retardation*. Mar 2004; vol. 109(2), pp. 83-97.
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.
Green-Field Library does not own.

Chaput, J.L. Adults with Down syndrome and Alzheimer's disease: comparison of services received in group homes and in special care units. *Journal of Gerontological Social Work*. 2002; vol. 38(1-2), pp. 197-211.
Green-Field Library owns

Deb, S.; Braganza, J. Comparison of rating scales for the diagnosis of dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research*. Oct 1999; vol. 43(Pt. 5), pp. 400-407.
Green-Field Library does not own

Deb, S.; Hare, M.A.; Prior, L.; et al. Dementia screening questionnaire for individuals with intellectual disabilities. *British Journal of Psychiatry*. May 2007; vol. 190, pp. 440-444.

Devenny D.A.; Wegiel, J.; Schupf, N.; et al. Dementia of the Alzheimer's type and accelerated aging in Down syndrome. *Science of Aging Knowledge Environment*. Apr 6, 2005; vol. 2005(14), dn1 [electronic resource].
A case study following the decline of a person with Down's syndrome for eleven years. This electronic article is available through Sage KE at <http://sageke.sciencemag.org/cgi/content/full/2005/14/dn1>. Registration is required.
Green-Field Library does not own

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.
Green-Field Library does not own

Janicki, M.P.; 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.

Maatta, T.; Tervo-Maatta, T.; Taanila, A.; et al. Mental health, behaviour and intellectual abilities of people with Down syndrome. *Down's Syndrome Research and Practice*. Aug 2006; vol. 11(1), pp. 37-43.

Green-Field Library does not own

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.

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.

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.

Green-Field Library owns

Prasher, V.; Farooq, A.; Holder, R. The Adaptive Behaviour Dementia Questionnaire (ABDQ): screening questionnaire for dementia in Alzheimer's disease in adults with Down syndrome. *Research and Developmental Disabilities*. Jul-Aug 2004; vol. 25(4), pp. 385-397.

Green-Field Library does not own

Prasher, V.; Metseagharun, T.; Haque, S. Weight loss in adults with Down syndrome and with dementia in Alzheimer's disease. *Research and Developmental Disabilities*. Jan-Feb 2004; vol. 25(1), pp. 1-7.

Green-Field Library does not own

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.

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.

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

Green-Field Library does not own

Strydom, A.; Hassiotis, A. Diagnostic instruments for dementia in older people with intellectual disability in clinical practice. *Aging and Mental Health*. Nov 2003; vol. 7(6), pp. 431-437.
Green-Field Library does not own

Temple, V.; Konstantareas, M.M. A comparison of the behavioural and emotional characteristics of Alzheimer's dementia in individuals with and without Down syndrome. *Canadian Journal on Aging*. Sum 2005; vol. 24(2), pp. 179-189.
Green-Field Library does not own

Urv, T.K.; Zigman, W.B.; Silverman, W. Maladaptive behaviors related to adaptive decline in aging adults with mental retardation. *American Journal of Mental Retardation*. Sep 2003; vol. 108(5), pp. 327-229.
Green-Field Library does not own

Waldman, H.B.; Perlman, S.P.; Roesch, R.E. Down syndrome and Alzheimer's disease: children grew older. *General Dentistry*. Jul-Aug 2008; vol. 56(5), pp. 420-422. "This article presents a review of the natural history of Down syndrome and Alzheimer's disease, along with the particular signs and symptoms of individuals with these co-morbidities and the implications for dental practice."
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. ISBN: 0876309163.
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. ISBN: 0876309163.
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. ISBN: 034075916X.
Green-Field Library Call No.: WM 200 D3761 2000

Holroyd, S. Similarities in visual deficits in Alzheimer's disease and Down syndrome. IN: Cronin-Golomb, A. (ed.). *Vision in Alzheimer's Disease*. New York, NY: Karger, 2004. ISBN: 3805577575.
Green-Field Library Call No.: WW 140 V831 2004

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. ISBN: 1557664625.

Green-Field Library does not own

CD-ROMs & Videos

Alzheimer's disease and intellectual disabilities (Down syndrome): tool kit.

Albany, NY; Chicago, IL: Center for Excellence in Aging Services at the University of Albany; RRTC in Aging and Developmental Disabilities at the University of Illinois at Chicago, 2003.

1 videocassette (24 min.) and CD-ROM

A computer-based course with supplemental resources for working with persons with developmental disabilities and Alzheimer's disease.

Green-Field Library Call No.: WM 300 VC no.802 2003

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

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

1 CD-ROM (23 min.)

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

Green-Field Library Call No.: WM 300 CD no.12 2001

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 VC no.541 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.emedicine.com/neuro/topic552.htm>

Dementia: understanding and supporting people with dementia.
An American Association on Intellectual and Developmental Disabilities sponsored presentation on adaptations for community living for persons with intellectual disabilities affected by dementia. Speaker materials are included with references to assessment scales.

http://www.aamr.org/content_1006.cfm

Edinburgh principles.

Rehabilitation Research and Training Center on Aging with Developmental Disabilities.

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.albany.edu/aging/IDD/edinburgh.htm>

Onset & Prevalence

Articles, Journal

Devenny, D.; Krinsky-McHale, S.; Sersen, G. Sequence of cognitive decline in dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research*. Dec 2000; vol. 44(Pt. 6), pp. 654-665.
Green-Field Library does not own

Haier, R.J.; Alkire, M.T.; White, N.S.; et al. Temporal cortex hypermetabolism in Down syndrome prior to the onset of dementia. *Neurology*. Dec 23, 2003; vol. 61(12), pp. 1673-1679.
Green-Field Library owns

Holland, A.; Hon, J.; Huppert, F.; et al. Incidence and course of dementia in people with Down's syndrome: findings from a population-based study. *Journal of Intellectual Disability Research*. Apr 2000; vol. 44(Pt. 2), pp. 138-146.
Green-Field Library does not own

Janicki, M.; Dalton, A. Prevalence of dementia and impact on intellectual disability services. *Mental Retardation*. Jun 2000; vol. 38(3), pp. 276-288.
Green-Field Library does not own

Schupf, N.; Pang D.; Patel, B.N.; et al. Onset of dementia is associated with age at menopause in women with Down's syndrome. *Annals of Neurology*. Oct 2003; vol. 54(4), pp. 433-438.
Green-Field Library owns

Tyrrell, J.; Cosgrave, M.; McCarron, M.; et al. Dementia in people with Down's syndrome. *International Journal of Geriatric Psychiatry*. Dec 2001; vol. 16(12), pp. 1168-1174.
Green-Field Library owns

Down Syndrome and Dementia

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