

Younger Onset Dementia

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

On this resource list:

Association Publications

Care Management

Clinical / Genetic Studies

For the Person with Early Onset Alzheimer's Disease

Association Publications

Early onset dementia: a national challenge, a future crisis.

Chicago, IL, Alzheimer's Association National Office, 2006.

Single copy free.

(800) 272-3900

http://www.alz.org/national/documents/report_earlyonset_summary.pdf

Genetics (heredity) and Alzheimer's.

Chicago, IL, Alzheimer's Association National Office.

http://www.alz.org/research/science/alzheimers_disease_causes.asp#genetics

Younger-onset Alzheimer's: I'm too young to have Alzheimer's disease.

Chicago, IL, Alzheimer's Association National Office, 2010.

Single copy free.

(800) 272-3900

http://www.alz.org/national/documents/brochure_earlyonset.pdf

Younger onset issues.

Chicago, IL, Alzheimer's Association National Office.

Free to download.

http://www.alz.org/professionals_and_researchers_early_onset.asp

Care Management

Articles, Journal

Beattie, A.M.; Daker-Whitie, G.; Gilliard, J.; et al. Younger people in dementia care: a review of service needs, service provision and models of good practice. *Aging & Mental Health*. Aug 2002; vol. 6(3), pp. 205-112.

Green-Field Library does not own.

Chaston, D.; Pollard, N.; Jubb, D. Young onset dementia: a case for real empowerment. *Journal of Dementia Care*. Nov-Dec 2000; vol. 12(6), pp 24-26.

Green-Field Library owns

Gelman, C.R.; Greer, C. Young children in early-onset Alzheimer's disease families: research gaps and emerging service needs. *American Journal of Alzheimer's Disease and Other Dementias*. Feb 2011; vol. 26(1), pp. 29-35.

Green-Field Library owns

Harris, P.B. The perspective of younger people with dementia: still an overlooked population. *Social Work in Mental Health*. 2002; vol. 2(4), pp. 17-36.

Green-Field Library does not own.

Harris, P.B.; Keady, J. Living with early onset dementia: exploring the experience and developing evidence-based guidelines for practice. *Alzheimer's Care Quarterly*. 2004; vol. 5(2), pp. 111-122. Green-Field Library owns.

Heiser, S. Working with people with young- onset dementia. *Dementia: The International Journal of Social Research and Practice*. Jun 2002; vol. 1(2), pp. 259-261. Green-Field Library owns.

Hunt, D.C. Young-onset dementia: a review of the literature and what it means for clinicians. *Journal of Psychosocial Nursing and Mental Health Services*. Apr 2011; vol. 49(4), pp. 28-33. Green-Field Library does not own.

Leibson, E.; Rauch, P.; Graff, S.; et al. Early-onset dementia: diagnostic considerations and implications for families. *Harvard Review of Psychiatry*. Mar-Apr 2005; vol. 13(2), pp. 102-111. Green-Field Library does not own.

Roach, P.; Keady, J.; Bee, P. et al. Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice. *Reviews in Clinical Gerontology* May 2008; 8(2), pp. 165-172. Green-Field Library does not own.

Robles, A.; Sobrido, M.J.; Garcia-Murias, M.; et al. Clinical picture of a patient with a novel psen1 mutation. *American Journal of Alzheimer's Disease & Other Dementias*. Feb-Mar 2009; vol. 24(1), pp. 40-45 . Describes patient with younger onset. Green-Field Library owns

Rose, K.; Yu, F.; Palmer, J.L.; et al. Care considerations for persons with early-onset dementia: a case studies analysis. *Alzheimer's Care Today*. Jul-Sep 2010; vol. 11(3), pp. 151-61. Green-Field Library owns.

Rossor, M.N.; Fox, N.C.; Mummery, C.J.; et al. The diagnosis of young-onset dementia. *Lancet Neurology*. Aug 2010, vol. 9(8), pp. 793-806. Green-Field Library owns.

Saad, K. Integrated care pathways for young onset dementia. *Journal of Dementia Care*. Mar-Apr 2004; vol. 12(2), pp. 29-31.

Green-Field Library owns

Sampson, E.L.; Warren, J.D.; Rossor, M.N. Young onset dementia. *Postgraduate Medical Journal*. Mar 2004; vol. 80(941), pp. 125-139.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1742955/?tool=pubmed>

Green-Field Library does not own.

Sharp, S.; Cosgrove, C. Network. Young onset survey: UK services update. *Journal of Dementia Care*. Jul-Aug 2006; vol. 14(4), pp. 14-15.

Green-Field Library owns.

Shlosberg, E. ; Browne, C.J.; Knight, A.; et al. What users and carers think of a service for younger people. *Journal of Dementia Care*. 2004; vol. 12(1), pp. 36-37.

Green-Field Library owns.

Svanberg, E.; Stott, J.; Spector, A. 'Just Helping': children living with a parent with young onset dementia. *Aging & Mental Health*. Aug 2010; 14(6), pp. 740-751.

Green-Field Library owns.

Webster, J.L.; Duncan, M.A. E-mail connections: an innovative communication network for families and persons with early-onset Alzheimer's (best practice). *Alzheimer's Care Quarterly*. Jul-Sep 2005; vol. 6(3), pp. 197-200.

Green-Field Library owns.

Books and Book Chapters

Alzheimer's Society Dementia Care and Research. *Alzheimer's. Younger people with dementia: an approach to the future*.

London, UK: Alzheimer's Society, 2005.

Green-Field Library Call No.: WM 220 A478y 2005

Baldwin, R.C.; Murray, M. *Younger people with dementia: a multidisciplinary approach*.
London, UK: Martin Dunitz, 2003.
Green-Field Library Call No.: WM 220 Y56 2003

Cox, S.; Keady, J.; (eds.). *Younger people with dementia: planning, practice, and development*.
London, UK: Jessica Kingsley Publishers, 1999.
Green-Field Library Call No.: WM 220 Y78 1999

Hodges, J.R. *Early-onset dementia: a multidisciplinary approach*.
New York, NY: Oxford University Press, 2001.
Green-Field Library Call No.: WM 220 E128 2001

Peterson, B. *Jan's story*.
Lake Forest, CA: Behler Publications, 2010
CBS News reporter Barry Petersen writes about his wife, Jan Chorlton, also a television reporter,
and her diagnosis with young onset Alzheimer's Disease at age 55.
Green-Field Library Call No.: WM 75.5 P484 2011

Yale, R. *Developing support groups for individuals with early-stage Alzheimer's disease: planning
implementation, and evaluation*.
Baltimore, MD: Health Professions Press, 1995, 2001 [third printing].
Green-Field Library Call No.: WM 220 Y18d 1995

Videos

Early onset memory loss: a conversation with Letty Tennis.
Chicago, IL: Terra Nova Films, 1992.
1 videocassette (20 min.)

This video presents an interview with Letty Tennis, a woman who has been diagnosed with early
onset Alzheimer disease. The program provides insight into the unique issues and concerns
related to early onset Alzheimer's disease.

Green-Field Library Call No.: WM 220.8 VC no. 82 1992

Malcolm and Barbara: a love story.

London, UK: Granada Media International, 2000.

At age 51, Malcolm Pointon, a professor of music at Cambridge University, was diagnosed with Alzheimer disease. This documentary, which aired on the BBC, chronicles four years in the lives of Malcolm and Barbara, showing the progression of the disease, and the effects it has on them. Green-Field Library does not own.

Web Resources

National Consumer Summit younger onset dementia.

Alzheimer's Australia, 2009

<http://203.89.197.244/common/files/NAT/20101027-Nat-YODCommunique2009.pdf>

Quality dementia care. Younger onset dementia: a practical guide.

Alzheimer's Australia, 2009

<http://www.ftdrg.org/wp-content/uploads/yod-practical.pdf>

Understanding younger onset dementia.

Alzheimer's Australia, 2008

http://www.alzheimers.org.au/common/files/NAT/20080400_Nat_QDC_QDC4UnderstandYOD.pdf

Younger onset dementia: help sheets.

Alzheimer's Australia

<http://www.alzheimers.org.au/understanding-dementia/section-7-younger-onset-dementia.aspx>

Young onset Alzheimer's disease: one family's story.

Maria Shriver: ideas, inspiration and information for architects of change. [blog]

<http://www.mariashriver.com/blog/2011/06/young-onset-alzheimer-s-disease-one-familys-story>

Clinical Research / Genetics

Articles, Journal

Allen, J.; Oyebode, J.R.; Allen, J. Having a father with young onset Alzheimer's. *Dementia*. Nov 2009; vol. 8(4), pp. 455-480.

Green-Field Library owns.

Arai, H. Women suffer from early-onset Alzheimer's disease more seriously than men (editorial). *Psychogeriatrics*. Dec 2004; vol. 4(4), pp. 107.

<http://onlinelibrary.wiley.com/doi/10.1111/j.1479-8301.2004.00049.x/pdf>

Green-Field Library does not own.

Arai, A.; Matsumoto, T.; Ikeda, M.; et al. Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia?

International Journal of Geriatric Psychiatry. Dec 2007; vol. 22(12), pp. 1255-1261.

Green-Field Library owns.

Arends, D.; Frick, S. Without warning: lessons learned in the development and implementation of an early-onset Alzheimer's disease program. *Alzheimer's Care Today*. Jan-Mar 2009; vol. 10(1), pp. 31-41.

Green-Field Library owns.

Bertram, L.; Tanzi, R. The current status of Alzheimer's disease genetics: what do we tell the patients? *Pharmacological Research*. Oct 2004; vol. 50(4), pp. 385-396.

Green-Field Library does not own.

Bekris, L.M.; Chang-En, Y.; Bird, T.D. et al. Genetics of Alzheimer's disease. *Journal of Geriatric Psychology and Neurology*. Dec 2010; vol. 23(4), pp. 213-227.

Provides overview of deterministic genes (*APP*, *PSEN1*, and *PSEN2*) and 1 genetic risk factor (*APOEε4* allele).

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3044597/?tool=pubmed>

Green-Field Library owns.

Harris, P.B.; Keady, J. Selfhood in younger onset dementia: transitions and testimonies. *Aging & Mental Health*. May 2009; vol. 13(3), pp. 437-444.
Green-Field Library owns.

Janssen, J.C.; Beck, J.A.; Campbell, T.A.; et al. Early onset familial Alzheimer's disease: mutation frequency in 31 families. *Neurology*. Jan 28, 2003; vol. 60(2), pp. 235-239.
Green-Field Library owns.

Kaiser, S.; Panegyres, P.K. The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease & Other Dementias*. Dec 2006-Jan 2007; Vol. 21(6), pp. 398-402.
Green-Field Library owns.

Kelley, B.J.; Boeve, B.F.; Josephs, K.A. Cognitive and noncognitive neurological features of young-onset dementia. *Dementia & Geriatric Cognitive Disorders*. 2009; 27(6), pp. 564-571.
Green-Field Library owns.

Kelley, B.J.; Boeve, B.F.; Josephs, K.A. Young-onset dementia: demographic and etiologic characteristics of 235 patients. *Archives of Neurology*. Nov 2008; vol. 65(11), pp. 1502-1509.
<http://archneur.ama-assn.org/cgi/reprint/65/11/1502.pdf>
Green-Field Library owns.

Koedam, E.L.; Lauffer, V.; van der Vlies, A.E.; et al. Early-versus late-onset Alzheimer's disease: more than age alone. *Journal of Alzheimer's Disease*. Jan 2010; vol. 19(4), pp. 1401-1408.
Green-Field Library owns.

Leibson, E.; Rauch, P.; Gradd, S.; et al. Early-onset dementia: diagnostic considerations and implications for families. *Harvard Review of Psychiatry*. Mar-Apr 2005; vol. 13(2), pp. 102-111.
Green-Field Library does not own.

Licht, E.A.; McMurtray, A.M.; Saul, R.E.; et al. Cognitive differences between early- and late-onset Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias*. Jun-Jul 2007; vol. 22(3), pp. 218-222.
Green-Field Library owns.

Marshall, G.A.; Fairbanks, L.A.; Tekin, S.; et al. Early-onset Alzheimer's disease is associated with greater pathologic burden. *Journal of Geriatric Psychiatry and Neurology*. Mar 2007; vol. 20(1), pp. 29-33.

Green-Field Library owns.

McMurtray, A.; Clark, D.G.; Christine, D.; et al. Early-onset dementia: frequency and causes compared to late-onset dementia. *Dementia & Geriatric Cognitive Disorders*. 2006; vol. 21(2), pp. 59-64.

Green-Field Library owns.

McMurtray, A.M.; Mendez, M.F. Family history of dementia in early-onset versus very late-onset Alzheimer's disease. *International Journal of Geriatric Psychiatry*. Jun 2006; vol. 21 (6), pp. 597-598.

Green-Field Library owns.

Rosness, T.A.; Engedal, K. Occurrence of depression and its correlates in early onset dementia patients. *International Journal of Geriatric Psychiatry*. Jul 2010; vol. 25 (7), pp. 704-711.

Green-Field Library owns.

Shinagawa, S.; Ikeda, M.; Toyota, Y.; et al. Frequency and clinical characteristics of early-onset dementia in consecutive patients in a memory clinic. *Dementia & Geriatric Cognitive Disorders*. 2007; vol. 24(1), pp. 42-47.

Green-Field Library owns.

Suribhatla, S.; Baillon, S.; Dennis, M.; et al. Neuropsychological performance in early and late onset Alzheimer's disease: comparisons in a memory clinic population. *International Journal of Geriatric Psychiatry*. Dec 2004; vol. 19(12), pp. 1140-1147.

Green-Field Library owns.

Swearer, J.M.; O'Donnell, B.F.; Parker, M.; et al. Psychological features in persons at risk for familial Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*. May-Jun 2001; vol. 16(3), pp. 157-162.

Green-Field Library owns.

Toyota, Y.; Ikeda, M.; Shinagawa, S.; et al. Comparison of behavioral and psychological symptoms in early-onset and late-onset Alzheimer's disease. *International Journal of Geriatric Psychiatry*. Sep 2007; vol. 22(9), pp. 896-901.

Green-Field Library owns.

van der Vlies, A.E.; van der Flier, W.M. Most rapid cognitive decline in APOE ϵ 4 negative Alzheimer's disease with early onset. *Psychological Medicine*. Nov 2009; vol. 39 (11), pp. 1907-1911.

Green-Field Library does not own.

Werner, P.; Korczyn, A.D. Early onset dementia: clinical and social aspects. *International Psychogeriatrics*. Aug 2009; vol. 21 (4), pp. 631-636.

Green-Field Library owns.

Williamson, J.; Goldman, J.; Marder, K.S. Genetic aspects of Alzheimer's disease. *The Neurologist*. Mar 2009; vol. 15(2), pp. 80-86.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3052768/?tool=pubmed>

Green-Field Library does not own.

Books

Jeong, S.H. (ed). *Alzheimer's disease in the middle-aged*.

New York, NY: Nova Science Publishers, 2008.

Contains several chapters on scientific aspects related to early onset Alzheimer's disease.

Green-Field Library Call No.: WM 220 A47882 2008

Pollen, D.A. *Hannah's heirs: the quest for the genetic origins of Alzheimer's disease*.

New York, NY: Oxford University Press, 1996.

Green-Field Library Call No.: WM 220 P65 1996

Tanzi, R.; Parson, A. *Decoding darkness: the search for the genetic causes of Alzheimer's disease*.

New York, NY: Perseus Press, 2000.

Green-Field Library Call No.: WM 220 T171d 2000

Video

Amanda's choice.

New York, NY: Filmmakers Library, 2001.

1 videocassette (48 min.)

Early onset Alzheimer's is explored through the story of Amanda who watches her mother's decline at age thirty-nine. Amanda may be predisposed to Alzheimer's and undergoes a genetic test.

Green-Field Library Call No.: WM 220.75 VC no. 809 2001

Web Resources

Alzheimer's disease genetics fact sheet.

Silver Springs, MD: ADEAR (Alzheimer's Disease Education and Referral Center).

<http://www.nia.nih.gov/Alzheimers/Publications/geneticsfs.htm>

Early onset familial Alzheimer's disease.

Bird, T.D.

Bethesda, MD: National Library of Medicine, 2010.

<http://www.ncbi.nlm.nih.gov/books/NBK1236>

Early onset familial Alzheimer's disease.

Cambridge, MA: Alzheimer Research Forum.

<http://www.alzforum.org/eFAD/default.asp>

Early onset familial Alzheimer's disease. What is eFAD?

Strobel, G.

Cambridge, MA: Alzheimer Research Forum.

<http://www.alzforum.org/eFAD/overview/essay2/default.asp>

Genetics home reference: Alzheimer's disease.

Genetics home reference.

Bethesda, MD: National Library of Medicine.

Covers the genetic changes related to Alzheimer's disease types 1 – 4. Includes information on how it is inherited, the related genes, and prevalence.

<http://ghr.nlm.nih.gov/condition=alzheimerdisease>

Genetics of Alzheimer's disease.

Washington, DC: Alliance for Aging Research.

A 3-minute consumer teaching module on the genetics of Alzheimer's containing a chart of genes and chromosomes for early-onset Alzheimer's disease including presenilin 1, presenilin 2, and beta amyloid precursor with prevalence statistics.

<http://www.agingresearch.org/content/article/detail/3079>

Noonan family story.

Barbato, Patti Noonan

Alzheimer's Association, Massachusetts Chapter.

<http://www.alzmass.org/memoryride/aboutnoonans.asp>

Noonan family saga [blog].

Alzheimer's Solution.

<http://alzheimersolution.com/the-noonan-family-saga>

For Persons with Young Onset Alzheimer's Disease

Article, Journal

Taylor, R. What's it like to have Alzheimer's? One year later. *Alzheimer's Care Quarterly*. Jul-Sep 2005; vol. 6(3), pp. 179-193.

Green-Field Library owns.

Books

DeBaggio, T. *Losing my mind: an intimate look at life with Alzheimer's.*

New York: The Free Press, 2002.

Green-Field Library Call No.: WM 220.5 D286 2002

DeBaggio, T. *When it gets dark: an enlightened reflection on life with Alzheimer's.*

New York, NY: The Free Press, 2003.

Green-Field Library Call No: WM 220.5 D286w 2003

Genova, L. *Still Alice.* [novel]

New York , NY: Pocket Books, 2009.

Green-field Library Call No.: PS 3569 G335 2009

Mobley, T. *Young hope.*

Hazelwood, MO: Emerald Falcon Press, [2004].

Green-Field Library Call No.: WM 220.5 M687

Raushi, T.M. *A view from within: living with early onset Alzheimer's.*

Albany, NY: Northeastern New York Chapter, Alzheimer's Association, 2001.

Green-Field Library Call No: WM 220.5 R248 2001

Rose, L. *Show me the way to go home.*

Forest Knolls, CA: Elder Books, 1996.

Green-Field Library Call No: WM 220.5 R796 1996

Newsletter

Perspectives: a newsletter for individuals diagnosed with Alzheimer's disease.

Snyder, L.

La Jolla, CA: Alzheimer's Disease Research Center.

Address: Lisa Snyder, LCSW. Alzheimer's Disease Research Center

9500 Gilman Drive 0948, La Jolla, CA, 92093

Phone number: (858) 622-5800 Fax (858) 622-1012; email: lsnyder@ucsd.edu.

Green-Field Library owns.

Videos

Forget me never.

Los Angeles, CA: CBS Television, 1999.

1 videocassette (1 hr. 29 min.)

Dramatization of the story of Diana McGowin who was diagnosed with early onset Alzheimer's disease.

Green-Field Library Call No.: WM 220.5 VC no. 800 1999

Forgetting (the): a portrait of Alzheimer's: stories of love, courage, and hope

Twin Cities Public Television, Inc., 2003.

A PBS documentary with experts Steven DeKosky and Rudolph Tanzi that follows several research studies and the lives of families, including the Noonan family affected by familial Alzheimer's disease (FAD). Includes a panel discussion of nationally recognized experts led by David Hyde Pierce. This discussion covers symptoms, treatment options, research, coping, community resources, and more.

Green-Field Library Call No.: WM 220 DVD no.1 2003

My challenge with Alzheimer's.

Chicago, IL: Terra Nova Films, 1996.

1 videocassette (16 min.)

This video features an interview with Beverly Wheeler, an elementary school teacher in her mid-fifties who has been diagnosed with Alzheimer's disease.

Green-Field Library Call No.: WM 220.5 VC no. 374 1995

Stolen memories: Alzheimer's disease.

New York, NY: Filmmakers Library, 2002.

1 videocassette (49 min.)

Follows three people in their 50s, who have been recently diagnosed with Alzheimer's disease (AD), over a period of 10 months.

Green-Field Library Call No.: WM 220 VC no. 820 2002

Web Resources

Alzheimer's spoken here.

Although not specifically for early onset dementia, this site was started by Jenny Knauss, a person diagnosed with Alzheimer's and her husband Don Moyer, to promote a forum for educational material and advocacy opportunities for and by persons with Alzheimer's disease and their families.

<http://alzsh.net/jqa.html>

By Us For Us© guides.

<http://marep.uwaterloo.ca/products/bufu.html>

PDF guides created through the Kenneth G. Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo by persons with dementia for persons with dementia. The guides are practical tools to help enhance well being and manage daily challenges.

DASN International: Dementia Advocacy and Support Network.

"A worldwide organization by and for those diagnosed with dementia working together to improve our quality of life." Includes sections on: Principles, Beliefs and Values; DASN's History; Connecting with People; Finding Information; and News Headlines About Dementia.

<http://www.dasninternational.org>

Definition of Alzheimer disease, early-onset familial.

San Clemente, CA: MedicineNet, Inc.

<http://www.medterms.com/script/main/art.asp?articlekey=22931>

Early-onset Alzheimer's: an interview with a Mayo Clinic specialist.

Rochester, MN: Mayo Clinic.

<http://www.mayoclinic.com/health/alzheimers/AZ00009>

In our own words.

Alzheimer's Australia, 2009

<http://www.alzheimers.org.au/common/files/NAT/20101027-Nat-YOD-InOurOwnWords.pdf>

Long & lonely road: insights into living with younger onset dementia.

Alzheimer's Australia

<http://www.alzheimers.org.au/common/files/NAT/20101027-Nat-YOD-LongLonelyRoad-resource.pdf>

Subjective experience of early onset dementia: voices of the persons.

Harris, P.B. Boston, MA: Gerontological Society of America, 2002.

http://www.dasninternational.org/research/subj_exp_eoad.pdf

Younger people with dementia.

London, UK: Alzheimer Society.

Contains information to consider following a diagnosis, working with younger people with dementia, news, publications, and more.

http://www.alzheimers.org.uk/Younger_People_with_Dementia/index.htm

Younger Onset Dementia

A selected list of references compiled by

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