

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

General

Clinical Care

Clinical Research

Association Publications

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

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

(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/Early Onset Alzheimer's & Dementia

Chicago, IL, Alzheimer's Association National Office.

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

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

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

(800) 272-3900

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

General

Draper, B.; Withall, A. Young onset dementia. *Internal Medicine Journal*. Jul 2016; vol. 46(7), pp. 779-786.

Full-text: <https://onlinelibrary.wiley.com/doi/epdf/10.1111/imj.13099>

Green-Field Library does not own.

Greenwood, N.; Smith, R. The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. *Maturitas*. Oct 2016; vol. 92, pp. 102-109.

Full-text: [Download here](#):

Green-Field Library does not own.

Kuruppu, DK; Matthews, BR. Young-onset dementia. *Seminars in Neurology*. Sep 2013; vol. 33(4), pp. 365-385.

Full-text:

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4033406/pdf/nihms574381.pdf>

Green-Field Library does not own.

Onyike, CU. The practice and science of young-onset dementias. *The Psychiatric Clinics of North America*. Jun 2015; vol. 38(2), pp. 13-14

Full-text: [http://www.psych.theclinics.com/article/S0193-953X\(15\)00030-1/pdf](http://www.psych.theclinics.com/article/S0193-953X(15)00030-1/pdf)

Green-Field Library does not own.

Sansoni, J.; Duncan, C.; Grootemaat, P.; et al. Younger onset dementia. *American Journal of Alzheimer's Disease and Other Dementias*. Dec 2016; vol. 31(8), pp. 693-705.

Full-text: <https://journals.sagepub.com/doi/pdf/10.1177/1533317515619481>

Green-Field Library does not own.

Stanley, K.; Walker Z. Do patients with young onset Alzheimer's disease deteriorate faster than those with late onset Alzheimer's disease? A review of the literature.

International Psychogeriatrics. Dec 2014; vol. 26(12), pp. 1945-1953

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24989902>

Green-Field Library owns.

Book

Kapsambelis, N. *The inheritance: A Family on the front lines of the battle against Alzheimer's disease*.

New York, NY: Simon & Schuster, 2017

Green-Field Library Call No.: WM 220.5 K17 2017

Web resources

Younger onset dementia

Perth, WA, Australia: Healthdirect Australia

Twenty-six consumer related resource about young onset dementia

<http://www.healthdirect.gov.au/younger-onset-dementia>

Young onset dementia.

Psychiatric Clinics of North America

[https://www.psych.theclinics.com/issue/S0193-953X\(14\)X0003-1](https://www.psych.theclinics.com/issue/S0193-953X(14)X0003-1)

Young onset dementia: a guide for employers.

Hospital Employee Health, Mar 2012; vol. 31(3): p. 34. Full-text:

<http://www.ahcmedia.com/articles/76953-young-onset-dementia-a-guide-for-employers>

Issue

Onyike, CU. Young-onset dementia. *Psychiatric Clinics of North America*; June 2015 issue Abstract and purchase available [here](#) or on [Amazon](#)

Green-Field Library does not own.

Clinical Care

Articles, Journal

Arntzen, C.; Holthe, T.; Jentoft, R. Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers. *Dementia (London)*. Apr 29 2014.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24784941>

Green-Field Library owns.

Bakker, C.; de Vugt, ME; van Vliet, D; et al. Predictors of the time to institutionalization in young-versus late-onset dementia: results from the Needs in Young Onset Dementia (NeedYD) study. *Journal of the American Medical Directors Association*. Apr 2013; vol. 14(4), pp. 248-253.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/23123009>

Green-Field Library owns.

Bakker, C.; de Vugt, ME; van Vliet, D.; et al. The relationship between unmet care needs in young-onset dementia and the course of neuropsychiatric symptoms: a two-year follow-up study. *International Psychogeriatrics*. Dec 2014; vol. 26(12), pp. 1991-2000.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24001688>

Green-Field Library owns.

Bakker, C.; de Vugt, ME; van Vliet, D.; et al. Unmet needs and health-related quality of life in young onset-dementia. *American Journal Geriatric Psychiatry*. Nov 2014; vol. 22(11), pp. 1121-1130.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/23871115>

Green-Field Library owns.

Baptista, M.; Santos, R.; Kimura, N.; et al. Quality of life in young onset dementia: an updated systematic review. *Trends Psychiatry Psychotherapy*. Jan-Mar 2016; vol. 38(1), pp. 6-13.

Full-text:

http://www.scielo.br/scielo.php?script=sci_arttext&pid=S2237-60892016000100006&lng=en&nrm=iso&tlng=en

Green-Field Library does not own.

Barca, ML; Thorsen, K; Engedal, K.; et al. Nobody asked me how I felt: experiences of adult children of persons with young-onset dementia. *International Psychogeriatrics*. Dec 2014; vol. 26(12), pp. 1935-1944.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24423756>

Green-Field Library owns.

Cabote, C.; Bramble, M.; McCann, D. Family caregivers' experiences of caring for a relative with younger onset dementia: a qualitative systematic review. *Journal of Family Nursing*. Aug 2015; vol. 21(3), pp. 443-468.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/25724671>

Green-Field Library does not own.

Holdsworth, K.; McCabe, M. The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: a systematic review. *International Psychogeriatrics*. Jan 2018; vol. 30(1), pp. 15-29.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/28927483>

Green-Field Library owns.

Lockeridge, S.; Simpson, J. The experience of caring for a partner with young onset dementia: how younger carers cope. *Dementia (London)*. Sep 2013; 12(5), pp. 635-651.

Abstract: <http://dem.sagepub.com/content/12/5/635.abstract>

Green-Field Library owns.

Millenaar, J.; Bakker, C.; Koopmans, R.; et al. The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review. *International Journal of Geriatric Psychiatry*. Dec 2016; vol. 31(12), pp. 1261-1276.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/27271788>

Green-Field Library owns.

Millenaar, JK; van Vliet, D.; Bakker, C.; et al. The experiences and needs of children living with a parent with young onset dementia: results from the NeedYD study.

International Psychogeriatrics. Dec 2014; vol. 26(12), pp. 2001-2010.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24230480>

Green-Field Library owns.

Richardson, A.; Pedley, G.; Pelone, F.; et al. Psychosocial interventions for people with young onset dementia and their carers: a systematic review. *International*

Psychogeriatrics. Sept 2016; vol. 28(9), pp. 1441-1454.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/27072752>

Green-Field Library owns.

Shnall, A. Public advocacy and community engagement: interventions for individuals with young-onset dementia and their families. *The Psychiatric Clinics of North America*.

Jun 2015; vol. 38(2), pp. 353-362.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/25998121>

Green-Field Library does not own.

Tan, B.; Fox, S.; Kruger, C.; et al. Investigating the healthcare utilization and other support needs of people with young-onset dementia. *Maturitas*. Apr 2019; vol. 122, pp. 31-34.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/30797527>

Green-Field Library does not own.

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

Videos

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

<https://www.dementia.org.au/sites/default/files/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_QDC4Unders tandYOD.pdf

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>

Younger onset dementia: help sheets.

Alzheimer's Australia

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

Clinical Research

Articles, Journal

Atwood, C.; Bowen, R. A unified hypothesis of early- and late-onset Alzheimer's disease pathogenesis. *Journal of Alzheimer's Disease*. 2015; vol. 47(1), pp. 33-47.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4807856/pdf/nihms753067.pdf>

Green-Field Library does not own.

Bakker, C.; de Vugt, ME; van Vliet, D.; et al. Predictors of the time to institutionalization in young- versus late-onset dementia: results from the Needs in Young Onset Dementia (NeedYD) study. *Journal of the American Medical Directors Association*. Apr 2013; vol. 14(4), pp. 248-253.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/23123009>

Green-Field Library owns.

Cations, M.; Withall, A.; Draper, B. Modifiable factors for young onset dementia. *Current Opinion in Psychiatry*. Mar 2019; vol. 32(2), pp. 138-143.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/30520739>

Green-Field Library does not own

Cations, M.; Withall, A.; Low, L.; et al. What is the role of modifiable environmental and lifestyle risk factors in young onset dementia? *European Journal of Epidemiology*. Feb 2016; vol. 31(2), pp.107-124.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/26620808>

Green-Field Library does not own.

Dai, M.; Zheng, H.; Zeng, L.; et al. The genes associated with early-onset Alzheimer's disease. *Oncotarget*. Dec 2017; vol. 9(19), pp. 15132-15143.

Full-text:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5871104/pdf/oncotarget-09-15132.pdf>

Green-Field Library does not own.

Devineni, B.; Onyike, C. Young-onset dementia epidemiology applied to neuropsychiatry practice. *The Psychiatric Clinics of North America*. Jun 2015; vol. 38(2), pp. 233-248.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4441762/pdf/nihms-675718.pdf>

Green-Field Library does not own.

Draper, B.; Cations, M.; White, F.; et al. Time to diagnosis in young-onset dementia and its determinants: the INSPIRED study. *International Journal of Geriatric Psychiatry*. Nov 2016; vol. 31(11), pp. 1217-1224.

Full-text: <https://onlinelibrary.wiley.com/doi/epdf/10.1002/gps.4430>

Green-Field Library does not own.

Mendez, M. Early-onset Alzheimer disease and its variants. *Continuum*. Feb 2019; vol. 25(1), pp. 34-51.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/30707186>

Green-Field Library does not own.

Nordström, P.; Michaëlsson, K.; Gustafson, Y.; et al. Traumatic brain injury and young onset dementia: a nationwide cohort study. *Annals of Neurology*. Mar 2014; vol. 75(3), pp. 374-381.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24812697>

Green-Field Library does not own.

Spreadbury, J.; Kipps, C. Measuring younger onset dementia: a comprehensive literature search of the quantitative psychosocial research. *Dementia (London)*. Jan 2019; vol. 18(1), pp. 135-156.

Full-text: <https://onlinelibrary.wiley.com/doi/epdf/10.1002/gps.4430>

Green-Field Library owns.

Tellechea, P.; Pujol, N.; Esteve-Belloch, P.; et al. Early- and late-onset Alzheimer disease: are they the same entity? *Neurologia*. May 2018; vol. 33(4), pp. 244-253.

Full-text:

<https://www.elsevier.es/en-revista-neurologia-english-edition--495-pdf-S217358081630133X>

Green-Field Library does not own.

Tolhurst, E.; Bhattacharyya, S.; Kingston, P. Young onset dementia: the impact of emergent age-based factors upon personhood. *Dementia (London)*. Mar 1 2014; vol. 13(2), pp. 193-206.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24599813>

Green-Field Library owns.

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

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.

<https://www.alzforum.org/early-onset-familial-ad/overview/what-early-onset-familial-alzheimer-disease-efad>

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>

Videos

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.

<http://www.pbs.org/program/forgetting>

Web Resources

By Us For Us® guides.

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.

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

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>

Early onset dementia

National Health Services (NHS – UK.gov)

<http://www.nhs.uk/video/pages/Earlyonsetdementia.aspx>

In our own words.

Alzheimer's Australia, 2009

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

Support pathways for people with younger onset dementia.

Alzheimer's Australia

<https://www.dementia.org.au/resources/support-pathways-for-people-with-younger-onset-dementia>

Young-onset dementia.

London, UK: Alzheimer Society.

The pages explain what young-onset dementia is, including the causes and symptoms, and how it is diagnosed and treated.

<https://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia>

Younger Onset Dementia

A selected list of references compiled by

Alzheimer's Association Green-Field Library and Resource Center

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