Support Groups and Dementia

This list is a reviewed 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:

Alzheimer's Association Publications

General Resources

Clinical Research

Function, Implementation, and Caregiver Program Models

Supporting Persons with Dementia

Support Group Manuals

Alzheimer's Association Publications

Brochure

Staying strong: stress relief for caregivers.
Chicago, IL: Alzheimer's Association.
http://www.alz.org/national/documents/aa_brochure_stressrelief.pdf

Web Resources

Alzheimer's Association support groups.
Chicago, IL: Alzheimer's Association.
Contact your nearest Alzheimer's Association chapter to find support groups in your area.
https://www.alz.org/events/event_search?etid=2&cid=0

Alzheimer's Association message boards and chat rooms.
Chicago, IL: Alzheimer's Association National Office.
The Alzheimer's Association message boards and chat rooms are an online communication forum for sharing thoughts and experiences and querying colleagues.
Message Boards.

General Resources

Books

Capossela, C.; Warnock, S. *Share the care: how to organize a group for someone who is seriously ill.*
New York, NY: Simon & Schuster, 2004.
Green-Field Library Call No.: WY 200 C246 2004

Steinberg, D.M. *The mutual-aid approach to working with groups: helping people help one another.*
New York, NY: Hawthorn Press, 2004.
Green-Field Library Call No.: HV 1461 S819 2004

Web Resources

Lotsa Helping Hands.
Friends, family members and neighbors can offer to lend a hand with caregiving for a person with dementia using Lotsa Helping Hands to keep track of care volunteers.
https://lotsahelpinghands.com

Relieving stress & anxiety: resources for Alzheimer's caregivers
National Institute on Aging
This resource list offers a selection of articles, books, and other materials that may help caregivers cope with their own stress, anxiety, and emotions.
https://www.nia.nih.gov/health/relieving-stress-anxiety-resources-alzheimers-caregivers

Clinical Research

Articles, Journal

Austrom, MG; Geros, KN; Hemmerlein, K; et al. Use of a multiparty web based videoconference support group for family caregivers: innovative practice. *Dementia (London).* Sep 2015; vol. 14(5), pp. 682-690.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/25062788
Green-Field Library owns

Laakkonen, ML; Kautiainen, H; Holtta, E; et al. Effects of self-management groups for people with dementia and their spouses – randomized controlled trial. Journal of the American Geriatrics Society. Apr 2016; vol. 64(4), pp. 752-760
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/27060101
Green-Field Library owns.

Lauritzen, J; Pedersen, PU; Sorensen, EE; et al. The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review. *JBI Database of Systematic Reviews and Implementation Reports.* Jul 2017; vol. 13(6); pp. 373-433
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/26455756
Green-Field Library does not own.

Martindale-Adams, J; Nichols, LO; Zuber, J; et al. Dementia caregivers' use of services for themselves. *Gerontologist.* Dec 2016; vol. 56(6), PP. 1053-1061.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/26350152
Green-Field Library owns

McKechnie, V.; Barker, C.; Stott, J.; et al. The effectiveness of an Internet support forum for carers of people with dementia: a pre-post cohort study. *Journal of Medical Internet Research.* Feb 28, 2014; vol. 16(2), e68.
Abstract: http://www.ncbi.nlm.nih.gov/pubmed/24583789
Green-Field Library does not own.

O'Connor, MF; Arizmendi, BJ; Kaszniak, AW; et al. Virtually supportive: a feasibility pilot study of an online support group for dementia caregivers in a 3D virtual environment. *Journal of Aging Studies.* Aug 2014; vol. 30, pp. 87-93. Ahead of print
Abstract: http://www.ncbi.nlm.nih.gov/pubmed/24984911
Green-Field Library does not own.

Quinn, Catherine, Clare, Linda. A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia (The SMART Study). *International Psychogeriatrics..* May 2016; vol. 28(5), pp. 787-800.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/26674087
Green-Field Library owns

Robinson, KM; Buckwalter, K., Reed, D.; et al. Differences between dementia caregivers who are users and nonusers of community services. *Public Health Nursing.* Nov-Dec 2013; vol. 30(6), pp. 501-510.
Abstract: http://onlinelibrary.wiley.com/doi/10.1111/phn.12041/abstract
Green-Field Library does not own.

Function, Implementation, and Caregiver Program Models

Articles, Journal

Austrom, MG; Geros, KN; Hemmerlein, K; et al. Use of a multiparty web based videoconference support group for family caregivers: innovative practice. *Dementia (London).* Sep 2015; vol. 14(5), pp. 682-690.
Full-text: https://www.ncbi.nlm.nih.gov/pubmed/25062788
Green-Field Library owns.

Bateman, DR; Brady, E; Wilkerson, D; et al. Comparing crowdsourcing and friendsourcing: a social media-based feasibility study to support Alzheimer's disease caregivers. *JMIR Research Protocols.* Apr 2017; vol. 6(4) e56.
Full-text: https://www.ncbi.nlm.nih.gov/pubmed/28396304
Green-Field Library does not own.

Berwig, M; Dichter, MN; Albers, B; et al. Feasibility and effectiveness of a telephone-based social support intervention for informal caregivers of people with dementia: study protocol of the TALKING TIME project. *BMC Health Services Research.* Apr 17, 2017; vol. 17(1q), pp. 280.
Full-text: https://www.ncbi.nlm.nih.gov/pubmed/28415999
Green-Field Library does not own.

Chien, LY; Chu, H.; Guo, JL; et al. Caregiver support groups in patients with dementia: a meta-analysis. *International Journal Geriatric Psychiatry.* Oct 2011; vol. 26(10), pp. 1089-1098.
Abstract: http://www.ncbi.nlm.nih.gov/pubmed/21308785
Green-Field Library owns.

Cristancho-Lacroix, V; Wrobel, J; Cantegreil-Kallen, I; et al. A web-based psycheducational program for informal caregivers of patients with Alzheimer's disease: a pilot randomized controlled trial. *Journal of Medical Internet Research.* May 2015; vol. 17(5), e117
Full-text: https://www.ncbi.nlm.nih.gov/pubmed/25967983
Green-Field Library does not own

Dam, AE; deVugt, ME; Klinkenberg, et al. Systematic review of social support interventions for caregivers of people with dementia: are they doing what they promised? *Maturitas.* Mar 2016; vol. 85, 117-130.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/26857890
Green-Field Library does not own.

Damianakis, T; Wilson, K; Marziali, E. Family caregiver support groups: spiritual reflections' impact on stress management. *Aging & Mental Health.* Jan 2018; vol. 22(1), pp. 70-76.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/27647207
Green-Field Library does not own.

Dickinson, C; Dow J; Gibson, G; et al. Psychological intervention for carers of people with dementia: what components are most effective and when? A systematic review of systematic reviews. *International Psychogeriatrics.* Jan 2019; vol. 29(1), pp. 31-43.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/27666669
Green-Field Library owns.

Donnelian, WJ; Bennett, KM; Soulsby, LK; et al. Family close but friends closers: exploring social support and resilience in older spousal dementia carers. *Aging & Mental Health.* 2017; vol. 21(11), pp. 1222-1228.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/27438380
Green-Field Library does not own.

Egan, KJ; Pinto-Bruno, AC; Bighelli, I; et al. Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: a systematic review. *Journal of the American Medical Directors Association.* Mar 2018; vol. 19(3), pp. 200-206.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/29306605
Green-Field Library owns.

Greif, GL. Ten steps in training volunteer support group facilitators. *American Journal of Alzheimer's disease and other dementias.* Nov 2010; vol. 25(7), pp. 562-565.
Abstract: http://www.ncbi.nlm.nih.gov/pubmed/20930185
Green-Field Library owns.

Han, A; Brown, D. Perspectives of caregivers and volunteers on Stepping Stones for people with dementia. Hong Kong Journal of Occupational Therapy. Dec 2018; vol. 31(2), pp. 86-96.
Full-text: https://www.ncbi.nlm.nih.gov/pubmed/30643496
Green-Field Library does not own.

Jao, YL; Epps, F; McDermott C. et al. Effects of support groups for individuals with early-stage dementia and mild cognitive impairment: an integrative review. *Research in Gerontological Nursing*. Jan 1, 2017; vol. 10(1), pp. 35-51.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/27665754
Green-Field Library does not own.

Javadpour, A.; Ahmadzadeh, L.; Bahredar, MJ. An educative support group for female family caregivers: impact on caregivers psychological distress and patient's neuropsychiatry symptoms. *International Journal of Geriatric Psychiatry.* May 2009; vol. 24(5), pp. 467-471.
Abstract: http://www.ncbi.nlm.nih.gov/pubmed/18937279
Green-Field Library owns.

Kucukgucxlu, O; Akpinr, S; Yenedr, G. et al. The effects of support groups on dementia caregivers: a mixed method study. *Geriatric Nursing*. Mar-Apr 2018; vol. 39(2), pp. 151-156.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/28826975
Green-Field Library owns.

Lee, E. Do technology-based support groups reduce care burden among dementia caregivers? A review. *Journal of Evidence-Informed Social Work.* Mar 2015; vol. 20, pp. 1-14. Ahead of print.
Abstract: http://www.ncbi.nlm.nih.gov/pubmed/25794367
Green-Field Library does not own.

Mavandadi, S. Wray, LO; Toseland, RW. Measuring self-appraised changes following participation in an intervention for caregivers of individuals with dementia. *Journal of Gerontological Social Work*. Apr 2019; vol. 62(3), pp. 324-337.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/30545282
Green-Field Library owns.

Mazurke, J; Szczesniak, D; Lion, KM; et al. Does the Meeting Centres Support Programme reduce unmet care needs of community-dwelling older people with dementia? A controlled, 6 month follow-up Polish study. *Clinical Interventions in Aging*. Jan 11, 2019; fol. 14, pp. 113-122.
Full-text: https://www.ncbi.nlm.nih.gov/pubmed/30666097
Green-Field Library does not own.

Phinney. A; Kelson. E; Baumbusch, J; et al. Walking in the neigbourhood: performing social citizenship in dementia. *Dementia (London)*. May 2016; vol. 15(3), pp. 381-394.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/27170588
Green-Field Library owns.

Piersol, CV; Canton, K; Connor, SE, et al. Effectiveness of interventions for caregivers of people with Alzheimer's disease and related major neurocognitive disorders: a systematic review. *American Journal of Occupational Therapy*. Sep-Oct 2017; 71(15); 7105180020p1-7105180020p10
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/28809652
Green-Field Library does not own.

Pihet, S; Kipfer, S. Coping with dementia caregiving: a mixed-method study on feasibility and benefits of ta psycho-educative group program. *BMC Geriatrics*. Sep 10, 2018; vol. 18(1), pp. 209.
Full-text: https://www.ncbi.nlm.nih.gov/pubmed/30200899
Green-Field Library does not own.

Potter, AJ. Factors associated with caregivers' use of support services and caregivers' nonuse of services sought. *Journal of Aging and Social Policy*. Mar-Apr 2018; vol. 30(2), pp. 155-172.
Abstract: https://www.tandfonline.com/doi/full/10.1080/08959420.2017.1414539
Green-Field Library does not own,

Reynoso-Vallejo, H. Support group for Latino caregivers of dementia elders: cultural humility and cultural competence. *Ageing International.* Jun 2009; vol. 34(1/2), pp.67-78.
Abstract: http://link.springer.com/article/10.1007%2Fs12126-009-9031-x
Green-Field Library does not own.

Rio, R. A community based music therapy support group for people with Alzheimer's disease and their caregivers: a sustainable partnership model. *Frontiers in Medicine*. Nov 6, 2018; vol. 5, 293.
Full-text: https://www.ncbi.nlm.nih.gov/pubmed/30460236
Green-Field Library does not own.

Scharet, E; Madathil, KC; Lopes, S; et al. An investigation of the information sought by caregivers of Alzheimer's patients on online peer support groups. *CyberPsychology, Behavior & Social Networking*. Oct 2017; vol. 20(10), pp. 640-657.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/29039697
Green-Field Library owns.

Steffen, AM; Jackson, CS. Predicting facilitators' behaviors during Alzheimer's family support group meeting. *American Journal of Alzheimer's Disease and Other Dementias.* Mar 2012; vol. 27(2), pp. 114-120.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/22495339
Green-Field Library owns.

Toms, GR; Clare, L.; Nixon, J; et al. A systematic narrative of review of support groups for people with dementia. *International Psychogeriatrics*. Sep 2015; vol. 27(9); pp. 1439-1465.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/25990373
Green-Field Library owns.

Wiersma, ED; O'Connor, DL; Loisells, L; et al. Creating space for citizenship: the impact of group structure on validating the voices of people with dementia. *Dementia (London).* May 2016; vol. 15(3), pp. 414-433.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/27170590
Green-Field Library owns

Willis, E; Semple, AC; de Waal, H. Quantifying the benefits of peer support for people with dementia: a Social Return on Investment (SROI) study. *Dementia (London).* Apr 2018; vol. 17(3), pp. 266-278.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/27013520
Green-Field Library owns

Book

Mittelman, MS; Epstein, C.; Pierzchala, A. Support groups for the caregiver. IN: *Counseling the Alzheimer's caregiver: a resource for health care professionals.* Chicago, IL: AMA Press, 2003, pp. 115-128.
Green-Field Library Call No.: WM 220 M685c 2003

Video

Alzheimer's and dementia: caring for the caregiver.
Princeton, NJ: Films for the Humanities, 2002.
1 videocassette (57 min.)
The program gives examples of persons who have learned to cope effectively with the stresses of caregiving. Support groups and other outlets of self-care are examined.
Green-Field Library does not own.

Web resources

Caregiver & Alzheimer's Support Groups
Clarksburg, MD: BrightFocus Foundation
https://www.brightfocus.org/alzheimers/article/caregiver-alzheimers-support-groups

The 5 best emotional support groups for Alzheimer's caregivers.
Alzheimers.net
https://www.alzheimers.net/best-alzheimers-support-groups/

Supporting Persons with Dementia

Articles

Argyle, E; Lewlly T; Gladman, J; et al. The effective ingredients of social support at home with dementia: a literature review. *Journal of Integrated Care.*
Abstract: https://www.emeraldinsight.com/doi/abs/10.1108/JICA-09-2016-0032
Green-Field Library does not own.

Bailey, J; Kingston, P; Alford, S; et al. An evaluation of cognitive stimulation therapy sessions for people with dementia and concomitant support group for their carers. *Dementia (London).* Nov 2017; vol. 16(8), pp. 985-1003.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/26787748
Green-Field Library owns.

Hedman, R; Norberg, A. Expressed sense of self by people with Alzheimer's disease in a support group interpreted in terms of agency and communion. *Journal of Applied Gerontology.* Apr 2016; vol. 35(4), pp. 421-443.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/24776791
Green-Field Library does not own.

Kelly F; Innes, A. Facilitating independence: the benefits of post-diagnostic support project for people with dementia. *Dementia (London).* Mar 2016; vol. 15(2), pp. 162-180.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/24535818
Green-Field Library owns.

Ledung, P; Orgeta, V. Social support group interventions in people with dementia and mild cognitive impairment: a systematic review of the literature*. International Journal of Geriatric Psychiatry.* Jan 2015; vol. 30(1), pp. 1-9.
Abstract: https://www.ncbi.nlm.nih.gov/pubmed/24990344
Green-Field Library owns.

Books and Book Chapters

Synder, L. *Living your best with early stage Alzheimer's: an essential guide*.
North Branch, MN: Sunrise River Press, 2010.
Green-Field Library Call no.: WM 220 S992 2010

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

Yale, R.; Snyder, L. The experience of support groups for persons with early stage Alzheimer's disease and their families. IN Harris, P. *The person with Alzheimer's disease: pathways to understanding the experience*. Baltimore, MD: Johns Hopkins University Press, 2002, pp. 228–245.
Green-Field Library Call No.: WM 220 P47 2002

Video

Alzheimer's disease : inside looking out
Cleveland, OH: Alzheimer's Association Cleveland Area Chapter, 1994.
Personal interviews with people in the early stages of Alzheimer's disease offer insights into how the illness alters their everyday life. Discussion include dependence on others, driving, becoming a burden, attitudes toward them, airing emotions and support groups as a valuable resource for those in the early stages of the disease.
Green-Field Library Call No.: WM 220 DVD no.79 1994

Web Resources

Support groups: make connections, get help.
Mayo Foundation for Medical Education and Research (MFMER), Rochester, MN.
http://www.mayoclinic.com/health/support-groups/MH00002/METHOD=print

Books

Ballard E.L. Support groups: meeting the needs of families caring for persons with Alzheimer's disease. IN: Cox, C.B. *Dementia and Social Work Practice Research and Interventions.*
New York, NY: Springer Publishing Company, 2007.
Green-Field Library Call No.: REF HV 687 D3755 2007

Doka, K.J. *Caregiving and loss: family needs, professional responses.*
Washington, DC: Hospice Foundation of America, 2001.
Green-Field Library Call No.: BF 575 C271 2001

Esme, M-C.; Manthorpe, J. *Early psychosocial interventions in dementia: evidence-based practice.*
Philadelphia, PA: Jessica Kingsley Publishers, 2009.
Green-Field Library Call No.: WM 220 M744 2009

Haight, B.K.; Gibson, F. *Burnside's working with older adults: group process and technique.*
This textbook is exclusively about support group work including dementia.
Sudbury, MA: Jones and Bartlett, 2005.
Green-Field Library Call No.: HQ 1061 H149 2005

Hartley, P.; Kennard, D. (eds.). *Staff support groups in the helping professions: principles, practice and pitfall.*
New York, NY: Routledge, 2009.
Green-Field Library does not own.

Support Group Manuals

Book

Grief and loss support group facilitator's manual.
Susan Hansen
Available on Amazon.com

Web Resources

A family caregivers support group guide.
Nancy Carson.
This brief article covers the benefits acquired from supports groups, what makes them effective, the types, online groups, questions to ask, and the administrative aspects of running them.
http://www.agis.com/Document/4521/a-family-caregivers-support-group-guide.aspx

Starting a self-help group.
London, UK: Alzheimer Disease International.
An online booklet on the purpose of self-help groups, how to get started, planning the first meeting, and keeping the meetings going.
http://www.alz.co.uk/adi/startgroupfull.html

Support group facilitation guide.
Alexandria, VA: Center for Peer Support, 2016
https://www.mentalhealthamerica.net/conditions/resources-and-support-peers

Support group toolkit
Greater Wisconsin Agency on Aging Resources, Inc.
http://www.gwaar.org/for-professionals/family-caregiver-support-for-professionals/10-articles/aging-programs-and-services/209-support-group-toolkit.html

Training manual for facilitators of family/friend caregiver support groups.
Aging Successfully and Saint Louis University
https://www.slu.edu/medicine/internal-medicine/geriatric-medicine/aging-successfully/pdfs/caregiver-support-training-manual.pdf

Support Groups and Dementia

A selected list of references compiled by

Alzheimer's Association Green-Field Library and Resource Center
Alzheimer's Association National Office
Chicago, IL 60601

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