

End-of-life care, planning & decision making

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:

Association Publications

General

Advance Directives

Artificial Nutrition (Hydration and Tube Feeding)

Guardianships and Conservatorships

Staff Issues Regarding End-of-Life Care

Association Publications

Dementia care practice recommendations for assisted living residences and nursing homes. Phase 3 end-of-life care.

Chicago, IL: Alzheimer's Association National Office, 2007.

Contains recommendations for care practices related to decision making and hospice services.

http://www.alz.org/national/documents/brochure_DCPRphase3.pdf.

End-of-life decisions: honoring the wishes of the person with Alzheimer's disease.
(brochure).

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

Available online.

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

Planning ahead for long-term care expenses (topic sheet).
Chicago, IL: Alzheimer's Association National Office, 2007.
Available online.

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

Quality end-of-life care for individuals with dementia in assisted living and nursing homes and public policy barriers to delivering care.

Chicago, IL: Alzheimer's Association National Office, 2007.
Available online.

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

General

Articles

Find current studies on end-of-life issues in this search.

Bartley, MM; Suarez, L; Shafi, RMA; et al. Dementia care at end-of-life: current approaches. *Current Psychiatry Reports*. Jun 23, 2018; 20(7), p 50.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/29936639>

Green-Field Library does not own.

Bunn, F; Lynch, J; Goodman C; et al. Improving living and dying with advanced dementia living in care homes. A realist review of Namaste Care and other multisensory interventions. *BMC Geriatrics*. Dec 6, 2018; vol. 18(1), p. 303

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/30522450>

Green-Field Library does not own.

Volicer, L. Review of programs for persons facing death with dementia. *Healthcare (Basel)*. Apr 17, 2019; vol. 7(2) e62.

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/30991668>

Green-Field Library does not own.

Book

Kenny, A. *Making tough decisions about end-of-life care in dementia*.
Baltimore, MS: Johns Hopkins University Press, 2018
Green-Field Library Call No.: WM 220 K34 2018

Kind, V. *Caregiver's path to compassionate decision making: making choices for those who can't*.
Austin, TX: Greenleaf Book Group Press, 2010.
Green-Field Library Call No.: HV 1461 K51 2010

Videos

Caring for patients with late stage dementia.

Peter V. Rabins.

Baltimore, MD: Video Press, 2005.

1 DVD (20 min.)

Contains information on nursing and terminal care for persons with dementia.

Green-Field Library Call No.: WY 152 DVD no.34 2005

Saying goodbye: a personal documentary of attachment and loss at end of life.

Geri Fox.

Chicago, IL: Terra Nova Films, 2013.

1 DVD (38 min.)

Award winning documentary; follows a father who is facing emotional, health and lifestyle adjustments that lead him to understand his life is ending. Reveals the power of family connections and their reactions, including his wife who has memory loss and in need of increased caregiving.

Green-Field Library does not own.

Web Resource

Encouraging comfort care.

Kuhn, D.; J. Forrest.

Chicago, IL: Alzheimer's Association Greater Illinois Chapter.

http://www.alzheimers-illinois.org/pti/comfort_care_guide.asp

Ethnicity online.

Cambridge, UK: NHS Workforce Development Confederation (WDC) for Norfolk, Suffolk and Cambridgeshire.

Contains information on death, dying, issues for healthcare staff, and the dead by ethnic groups.

http://www.ethnicityonline.net/ethnic_groups.htm

Family involvement in care for persons with dementia (FIC).

Iowa City, IA: University of Iowa, College of Nursing, 2001.

<https://igec.uiowa.edu/fic>

Knowledge and skills needed for dementia care: a guide for direct care workers.

Okemos, MI: Michigan Dementia Coalition, Michigan Public Health Institute, 2008.

<http://phinational.org/sites/phinational.org/files/clearinghouse/DemCompGuide-EverydayLang.pdf>

Making end of life decisions. What are your important papers.

San Francisco, CA: Family Caregiver Alliance.

<https://www.caregiver.org/making-end-of-life-decisions-what-are-your-important-papers>

My life until the end: dying well with dementia

Alzheimer's Society: London, UK

https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/my_life_until_the_end_dying_well_with_dementia.pdf

Spiritual assessment.

Oakbrook Terrace, IL: The Joint Commission, 2008.

http://www.jointcommission.org/mobile/standards_information/jcfaqdetails.aspx?StandardsFAQId=290&StandardsFAQChapterId=29

Try this: assessing pain in older adult with dementia.

Horgas, A.L.

New York, NY.

http://consultgerirn.org/uploads/File/trythis/try_this_d2.pdf

Advance Directives & Decision Making

Articles, Journal.

Arcand, M. End-of-life issues in advanced dementia: part 1: goals of care, decision-making process, and family education. *Canadian Family Physician*. Apr 2015; vol. 61(4), pp. 330-334.

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/25873700>

Green-Field Library does not own.

Ashton, SE; Roe, B; Jack, B; et al. End of life care: the experiences of advance care planning amongst family caregivers of people with advanced dementia – a qualitative study. *Dementia*. Sep 2016; vol. 15(5), pp. 958-974.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/25187482>

Green-Field Library owns.

Harrison Denning, K; King, M; Jones, L; et al. Advance care planning in dementia: do family carers know the treatment preferences of people with early dementia? *PLoS*; Jul 13, 2016; vol. 11(7), pp. e0159056

Erratum in: [PLoS One. 2016;11\(8\):e0161142.](https://doi.org/10.1371/journal.pone.0161142)

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4943594/>

Green-Field Library does not own.

Jones, K; Birchley, G; Huxtable, R; et al. End of life care: a scoping review of experiences of advance care planning for people with dementia. *Dementia (London)*. Apr 2019; vol. 18(3), 825-845.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/27821714>

Green-Field Library owns.

Lee, EE; Chang, B; Huege, S; et al. Complex clinical intersection: palliative care in patients with dementia. *American Journal of Geriatric Psychiatry*. Feb 2018; vol. 26(32), 224-234.

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/28822692>

Green-Field Library owns.

Nicholas, LH; Bynum, JP; Iwashyna, TJ; et al. Advance directive and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs*. Apr 2014; vol. 33(4), pp. 667-674.

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/24711329>

Green-Field Library owns.

Piers, R; Albers, G; Gilissen, J; et al. Advance care planning in dementia: recommendations for healthcare professionals. *BMC Palliative Care*. Jun 2018; vol. 17(1), p 8 (17).

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/29933758>

Green-Field Library does not own.

Sani, G; Sampson, EL; Davis, S; et al. An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes. *BMC Palliative Care*. Jul 7, 2016;

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/27388766>

Green-Field Library does not own.

Sellers, M; Chung, O; Nolte, L; et al. Perspectives of people with dementia and carers on advance care planning and end-of-life care: a systematic review and thematic synthesis of qualitative studies. *Palliative Medicine*. Mar 2019; vol. 33(3), pp. 274-290.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/30404576>

Green-Field Library does not own.

Steinbock, B; Menzel PT. Advance directives for refusing life-sustaining treatment in dementia. *Hastings Center Report*. Sep 2018; Suppl 3, S75-S79

Full-text: <https://onlinelibrary.wiley.com/doi/epdf/10.1002/hast.919>

Green-Field Library does not own.

Xie, B; Berkley, AS; Kwak, J; et al. End-of-life decision making by family caregivers of persons with advanced dementia: a literature review of decision aids. *SAGE Open Medicine*. May 2018; vol. 21.

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/29844911>

Green-Field Library does not own.

Tools

Caring connections, state advance directives.

Alexandria, VA: National Hospice and Palliative Care Organization.

Provides free advance directives and instructions for each state.

<http://www.caringinfo.org/stateaddownload>.

*End of life choices for families: who has the final say about end-of-life choices?
(Information from your family doctor).*

Leawood, KS: American Academy of Family Physicians, 2004.

<http://www.aafp.org/afp/20040815/725ph.html>

Five wishes.

Tallahassee, FL: Aging with Dignity, 2007.

<http://www.agingwithdignity.org/5wishes.html>.

Lawyer's tool kit for health care advance planning.

Washington, DC: Commission on Legal Problems of the Elderly, American Bar Association, 2000.

Cost: \$29.00

<https://shop.americanbar.org/eBus/Store/ProductDetails.aspx?productId=217475>

Green-Field Library Call No.: KF 3827 L38 2000

Project GRACE advance care plan documents.

Clearwater, FL: Project GRACE, 2000.

https://www.alpha1.org/Portals/0/Documents/Project_Grace.pdf

Ten tips for talking to your aging parents.

Westport, CT: MetLife Mature Market Institute, 2005.

[Download here](#)

Tool kit for health care advance planning.

Chicago, IL: American Bar Association.

[Download here](#)

Your life your choices: planning for future medical decisions. How to prepare a personalized will.

Pearlman, R; Starks, H; Cain, K; et al.

Seattle, WA: Veterans Administration Medical Center, [?].

[Download here](#)

Video

Hospice and Alzheimer's disease.

Peter V Rabins.

Baltimore, MD: Video Press, 2015.

1 DVD (17 min.)

Green-Field does not own.

Artificial Nutrition (Hydration & Tube Feeding)

Articles, Journal

Arcand, M. End-of-life issues in advanced dementia: part 1: goals of care, decision-making process, and family education. *Canadian Family Physician Medecin de famille canadien*. Apr 2015; vol. 61(4), pp. 330-334.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4396757/pdf/0610330.pdf>

Green-Field Library does not own.

Arcand, M. End-of-life issues in advanced dementia: part 2: management of poor nutritional intake, dehydration, and pneumonia. *Canadian Family Physician Medecin de famille canadien*. Apr 2015; vol. 61(4), pp. 337-341.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4396758/pdf/0610337.pdf>

Green-Field Library does not own.

Bravo, G; Sene, M; Arcand, M. Surrogate inaccuracy in predicting older adults' desire for life-sustaining interventions in the event of decisional incapacity: is it due in part to erroneous quality-of-life assessments? *International Psychogeriatrics*. Jul 2017; vol. 29(7), pp. 1061-1068.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/?term=28260547>

Green-Field Library owns.

Brooke, J; Ojo, O. Enteral nutrition in dementia: a systematic review. *Nutrients*. Apr 3, 2015; vol. 7(4), pp. 2456-2468.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4425154/>

Green-Field Library does not own.

Chung, AM. Percutaneous gastrostomy feeding tubes in end stage dementia: don't "just do it". *Canadian Association of Radiologists Journal*. Aug 2012; vol. 63(3 suppl), pp. S5-6.

Full-text:

<http://www.sciencedirect.com/science/article/pii/S0846537112000526?via%3Dihub>

Green-Field Library does not own.

Douglas, JW; Lawrence, JC; Turner, LW. Social ecological perspectives of tube-feeding older adults with advanced dementia: a systematic literature review. *Journal of Nutrition in Gerontology and Geriatrics*. Jan-Mar 2017; vol. 36(1), pp. 1-17.

Abstract: <http://www.tandfonline.com/doi/abs/10.1080/21551197.2016.1277174>

Green-Field Library does not own.

Flaschner, E; Katz, D. American geriatrics society position statement on feeding tubes in advanced dementia. *Journal of the American Geriatrics Society*. Jul 2015; vol. 63(7), pp. 1490-1491.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/26189864>

Green-Field Library owns.

Goldberg, LS; Altman, KW. The role of gastrostomy tube placement in advanced dementia with dysphagia: a critical review. *Clinical Interventions in Aging*. Oct 2014; vol. 14(9), pp. 1733-1799.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4205113>

Green-Field Library owns.

Pengo, V.; Zurlo, A.; Voci, A.; et al. Advanced dementia: opinions of physicians and nurses about antibiotic therapy, artificial hydration and nutrition in patients with different life expectancies. *Geriatrics & Gerontology International*. Mar 2017; vol. 17(3), pp. 487-493.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/27004847>

Green-Field Library does not own.

Reinhardt, J.; Boerner, K.; Downes, D. The positive association of end-of-life treatment discussions and care satisfaction in the nursing home. *Journal of Social Work in End-of-Life & Palliative Care*. 2015; vol. 11(3-4), pp. 307-322.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/26654063>

Green-Field Library does not own.

Ribeiro Salomon, AL; Carvalho Garbi Novaes, MR. Outcomes of enteral nutrition for patients with advanced dementia: a systematic review. *The Journal of Nutrition, Health & Aging*. Feb 2015; vol. 19(2), pp. 169-177.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/?term=25651442>

Green-Field Library owns.

Smith, L.; Ferguson, R. Artificial nutrition and hydration in people with late-stage dementia. *Home Healthcare Now*. Jun 2017; vol. 35(6), pp. 321-325.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/28562402>

Green-Field Library does not own.

Ying, I. Artificial nutrition and hydration in advanced dementia. *Canadian Family Physician*. Mar 2015; vol. 61(3), pp. 245-248,e125-8.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4369630/>

Green-Field Library does not own.

Guardianship, Conservatorship, Surrogate Decision Making

Articles, Journal

Badrakalimuthu, V. Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age and Ageing*. Jan 2014; vol. 43(1), pp. 13-19.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/24128594>

Green-Field Library does not own.

DaDalt, O.; Burstein, A.; Kramer, B.; et al. Dementia and financial incapacity: a caregiver study. *Working with Older People: Community Care Policy & Practice*. 2016; vol. 20(2), pp. 66-75.

Full-text: http://agelab.mit.edu/sites/default/files/private-files/publications/DaDalt_etal_WWOP_2016.pdf

Green-Field Library does not own.

Fetherstonhaugh, D; McAuliffe, L; Bauer, M; et al. Decision-making on behalf of people living with dementia: how do surrogate decision-makers decide? *Journal of Medical Ethics*. Jan 2014; vol. 43(1), pp. 35-40.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/27780889>

Green-Field Library does not own.

Givens, JL; Spinella, S; Ankuda, CK; et al. Healthcare proxy awareness of suspected infections in nursing home residents with advanced dementia. *Journal of the American Geriatrics Society*. Jun 2015; vol. 63(6), pp. 1084-1090.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4478162/>

Green-Field Library owns.

Jox, RJ. Surrogate decision making for patients with end-stage dementia.

International Journal of Geriatric Psychiatry. Oct 2012; vol. 27(10), pp. 1045-1052.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/22139621>

Green-Field Library owns.

Kim, H; Ersek, M; Bradway, C; et al. Physician orders for life-sustaining treatment for nursing home residents with dementia. *Journal of the American Association of Nurse Practitioners*. Nov 2015; vol. 27(11), pp. 606-614.

Full-text: <http://onlinelibrary.wiley.com/doi/10.1002/2327-6924.12258/epdf>

Green-Field Library does not own.

Lord, K; Livingston, G; Cooper, C. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *International Psychogeriatrics*. Aug 2015; vol. 27(8), pp. 1301 – 1312.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/25870004>

Green-Field Library owns.

McSwiggan, S; Meares, S; Porter, M. Decision-making capacity evaluation in adult guardianship: a systematic review. *International Psychogeriatrics*. Mar 2016; vol. 28(3), pp. 373-384.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/26412394>

Green-Field Library owns.

Mills, M. Dementia and guardianship: challenges in social work practice. *Australian Social Work*. Jan 2017; vol. 70(1), pp. 30-41.

Full-text: <http://www.tandfonline.com/doi/full/10.1080/0312407X.2016.1168463>

Green-Field Library does not own.

Page, KS; Hinrichs, KLM. Swimming against the tide: a case study on the removal of conservatorship and guardianship. *Clinical Gerontologist*. Jan-Feb 2017; vol. 40(1), pp. 35-42.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5412591/>

Green-Field Library owns.

Petriwskyj, A; Gibson, A; Parker, D; et al. Family involvement in decision making for people with dementia in residential aged care: a systematic review of quantitative literature. *International Journal of Evidence-Based Healthcare*. Jun 2014; vol. 12(2), pp. 64-86.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/24945958>

Green-Field Library does not own.

Pope, TM; Sellers, T. Legal briefing: the unbefriended: making healthcare decisions for patients without surrogates (part 1). *The Journal of Clinical Ethics*. Spring 2012; vol. 23(1), pp. 84-96.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/22462389>

Green-Field Library owns.

Pope, TM; Sellers, T. Legal briefing: the unbefriended: making healthcare decisions for patients without surrogates (part 2). *Journal of Clinical Ethics*. Summer 2012; vol. 23(2), pp. 177-192.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/22822709>

Green-Field Library owns.

Raymond, M. Palliative care services for people with dementia: a synthesis of the literature reporting the views and experiences of professionals and family carers. *Dementia (London)*. Jan 2014; vol. 13(1), pp. 96-110.

Abstract:

<http://dem.sagepub.com/content/early/2012/08/08/1471301212450538.abstract>

Green-Field Library owns.

Snyder, S; Amjad, H. Surrogate prediction of quality-of-life and desire for treatment: a guess of a guess. *International Psychogeriatrics*. Jul 2017; vol. 29(7), pp. 1059-1060.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/28473002>

Green-Field library owns.

Walton, BG. The powers that be: understanding powers of attorney, conservators, guardianships and more: a primer. *ISNA Bulletin (ISNA BULL)*. May-Jul 2017; vol. 43(3), pp. 10-15.

Full-text:

https://d3ms3kxrsap50t.cloudfront.net/uploads/publication/pdf/1504/Indiana_Bulletin_5_17.pdf

Green-Field Library does not own.

Werner, P.; Doron, I. The legal system and Alzheimer's disease: social workers and lawyers' perceptions and experiences. *Journal of Gerontological Social Work*. Aug-Sep 2016; vol. 59(6), pp. 478-491.

Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/?term=27661790>

Green-Field Library owns.

Web Resource

Guardianship and supported decision-making

Chicago, IL: American Bar Association

[Download here](#)

Guardianship and the right to visitation: an overview of recent state legislation

Dari Pogach

Chicago, IL: American Bar Association

[Download here](#)

National Guardianship Association.

Bellefonte, PA.

Contains best practices and business tools for guardians, and such publications as *Standards of Practice for Guardians* and *Models Code of Ethics for Guardians*.

[Download here](#)

Staff Issues Regarding End-of-Life Care

Articles, Journal

Adams, JA; Bailey, DE; Anderson, RA; et al. Nursing roles and strategies in end-of-life decision making in acute care: a systematic review of the literature. *Nursing Research and Practice*. 2011; article ID 527834, (15).

Full-text: <https://www.hindawi.com/journals/nrp/2011/527834>

Green-Field Library does not own.

Husebo, B.; Achterberg, W.; Flo, E. Identifying and managing pain in people with Alzheimer's disease and other types of dementia: a systematic review. *CNS Drugs*. Jun 2016; vol. 30(6), pp. 481-497.

Full-text:

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4920848/pdf/40263_2016_Article_342.pdf

Green-Field Library does not own.

Martinsson, L; Lundstrom, S; Sundelof, J. Quality of end-of-life care in patients with dementia compared to patients with cancer: a population-based register study. *PLoS One*. 2018; vol. 13(7) e0201051.

Full-text: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6066197>

Green-Field Library does not own.

Parsons, C. Assessment of factors that influence physician decision making regarding medication use in patients with dementia at the end of life. *International Journal of Geriatric Psychiatry*. Mar 2014; vol. 29(3), pp. 281-290.

Abstract: <http://www.ncbi.nlm.nih.gov/pubmed/23836439>

Green-Field Library owns.

Tilburgs, B; Vernooij-Dassen, M; Koopmans, R. Barriers and facilitators for GPs in dementia advance care planning: a systematic integrative review. *PLoS One*. 2018; vol. 13(6) e0198535.

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/29924837>

Green-Field Library does not own.

Van Leeuwen, E; Petrovic, M; van Driel, ML; et al. Withdrawal versus continuation of long-term antipsychotic drug use for behavioural and psychological symptoms in older people with dementia. *Cochrane Database Systematic Review*. Mar 30, 2018; vol.3, CD00726

Full-text: <https://www.ncbi.nlm.nih.gov/pubmed/29605970>

Green-Field Library does not own.

Book

Assessment of older adults with diminished capacity: a handbook for lawyers.

Washington, DC; Washington, DC: American Bar Association Commission on Law and Aging, American Psychological Association, 2005.

<http://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf>

Web Resources

Caring for persons with Alzheimer's and other dementias: guidelines for hospice providers.

Alexandria, VA.

National Hospice and Palliative Care Organization.

Includes key clinical issues in dementia care including decision making and more.

<http://www.nhpco.org/sites/default/files/public/Dementia-Caring-Guide-final.pdf>

Decision making in older adults and dementia. Try this: best practices in nursing care for hospitalized older adults.

Mitty, EL.

New York, NY: John, A. Hartford Institute for Geriatric Nursing; Division of Nursing; New York University, 2007.

http://consultgerirn.org/uploads/File/trythis/try_this_d9.pdf

When advanced directives are ignored [blog]

New York, NY: New York Times, June 24, 2014

<https://newoldage.blogs.nytimes.com/2014/06/24/when-advance-directives-are-ignored>

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Compiled by

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*Alzheimer's Association Green-Field Library and Resource Center Alzheimer's Association
National Headquarters, Chicago, IL*

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