

Caregiver Well-Being Teaching Module

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Introduction

Competencies Addressed

Values, Ethics, and Theoretical Perspectives

* Respect and promote older adult clients’ right to dignity and self-determination.
* Address the cultural, spiritual, and ethnic values and beliefs of older adults and families.
* Support persons and families dealing with end-of-life issues related to dying, death, and bereavement.

Assessment

* Assess caregivers’ needs and level of stress.

Intervention

* Establish rapport and maintain an effective working relationship with older adults and family members.
* Assist caregivers to reduce their stress levels and maintain their own mental and physical health.

Aging Services, Programs, and Policies

* Provide outreach to older adults and their families to ensure appropriate use of the service continuum.
* Identify the availability of resources and resource systems for older adults and their families.

Objectives

* Gain understanding of the definitions and types of care-recipient and caregiver populations.
* Understand the positive and negative impacts of the caregiving experience for the care-recipient and the caregiver.
* Conceptualize the caregiver experience from a strengths-based perspective.
* Identify evidence-based tools to assess caregivers’ needs and well-being.
* Develop skills in conducting strengths-based assessments of caregiver well-being.
* Develop knowledge of evidence-based interventions to promote and enhance family-centered caregiver well-being.
* Develop understanding of the importance of conducting culturally competent assessments and interventions.
* Understand current policy implications related to family caregiving.

Overview of Topic and Module Content

Providing care for an older member of one’s family is not a role for which most of us are prepared, but a role that nonetheless becomes part of our futures. In fact, approximately 34.2 million adults in the United States have provided care to a family member age 50 or older in the last 12 months (AARP/National Alliance for Caregiving, 2015). Family and friend caregivers fulfill a range of caring roles from occasional transportation and shopping to round-the-clock skilled care in the home. Social workers routinely interact with members of the older adult’s care network but may only have learned about the caregiving experience “on-the-job” from talking with their older patients/clients and the persons who care for them. Relatively few social workers receive formalized training to prepare them for understanding the types, roles, and challenges of caregiving or for effective interventions that can support the caregiver and enhance the quality of life for the caregiver and the care-recipient.

Given that nearly 20% of the U.S. population serves as a caregiver at any one point in time and that this proportion will increase along with the aging of our population, social workers and other social service and health care practitioners may find themselves assuming more responsibilities related to caregiving. Social workers may serve as surrogate caregivers, supplementing the care that has historically been provided almost exclusively by family members. In addition to working with the older adult to assess and plan for transitions, access resources, and strive for an optimal quality of life, social workers are engaging in assessment and interventions with caregivers of spouses, parents, parents-in-law, extended family, partners, and friends and neighbors. Such interventions can require the need to have skills in crisis management, mediation, information and referral, brokering services, clinical interventions related to relationships, health events, and end-of-life issues. As all racial and ethnic groups in our society are living longer, having cultural competency skills for working with multigenerational families is more critical than ever.

This module is developed for instructors to utilize when teaching about caregiving for older adults in classes focused on gerontological social work practice as well as in classes on working with individuals and families, health and mental health care, and end-of-life care. Instructors may select topics within the module specific to the competencies being addressed for the class; these include readings, presentation, exercises, and resources targeted for both professionals and caregivers.

The module includes materials that may be incorporated into lectures or presentations to help students understand how to assess and intervene with older adults and their care partners. The following components are included:

1. Two PowerPoint Presentations (with notes added to each slide)

[*Caregiver Well-Being: What We Know and Can Do*](http://www.cswe.org/File.aspx?id=84140)

* What are definitions and types of caregiving? (Slides 6-10)
* Who are the care-recipients (Slides 11-15) and caregivers (Slides 16-25)?
* What are the impacts of caregiving on the care-recipient and caregiver? (Slides 26-41)
* Types of negative and positive impact
* Emotional and Physical
* Financial
* Quality of life
* What are the phases of the caregiving experience? (Slides 42-46)
* Continuum of Caregiving
* Early phase
* Middle phase
* Ending phase
* How can the caregiving experience be assessed? (Slides 47-50)
* Caregiver well-being (Slides 51-54)
* Caregiver Well-Being Scale (Slides 55-62)
* Post-caregiving well-being (Slides 63-66)
* How can we support caregivers/interventions (Slides 67-79)
* Resources for caregivers (Slides 80-83)

[*Caregiver Self-Care: Body Movement*](http://www.cswe.org/File.aspx?id=84142)

* Caregiver Needs (Slide 4)
* Interventions (Slides 5-7)
* Psycho/pharmacological interventions
* Complementary and Alternative Medicine (CAM)/Body-Mind-Spirit Interventions
* Caregiver-centered Approach (Slides 8-9)
* Yoga (Slides 10-13)
* Practice (Slide 14)
* Take Home Messages (Slides 15-16)
* Resources (Slides 17-21)

Complete references cited in the overview and PowerPoint presentation

American Association of Retired Persons/National Alliance for Caregiving. (2015). *Caregiving in the U.S.* Retrieved from <http://www.caregiving.org/caregiving2015/>

Behrman, G., & Tebb, S. (2009). The use of complementary & alternative interventions as a holistic approach with older adults. *Journal of Religion & Spirituality in Social Work: Social Thought, 28*(1-2), 127-140.

Berg-Weger, M., & Rubio, D. M. (1996). Role induction and caregiver strain: A structural equation approach. *Journal of Social Service Research, 21*(2), 33-53.

Brotman, S. B., Ryan, S., Collins, L., Chamberland, R., Cormier, D., Julien, E.,…Richard, B. (2007). Coming out to Care: Caregivers of gay and lesbian seniors in Canada. *Gerontologist*, *47*(4), 490-503.

Burns, R., Nichols, L. O., Martindale-Adams, J., Graney, M. J., & Lummus, A. (2003). Primary care interventions for dementia caregivers: 2-year outcomes from the REACH study. *Gerontologist, 43*(4), 547-555.

Coon, D. W. (2003). *Lesbian, gay, bisexual and transgender (LGBT) issues and family caregiving*. San Francisco, CA: Family Caregiver Alliance, National Center on Caregiving.

Croghan, C. (2014, August 28). What's different about LGBT informal caregiving? American Society on Aging. Retrieved from <http://www.asaging.org/blog/whats-different-about-lgbt-informal-caregiving>

Goldstein, H. (1990). Strength of pathology: Ethical and rhetorical contrasts in approaches to practice. *Families in Society, 71*(5), 267-275.

Grossman, A., D’Augelli, A., & Dragowski, E. (2007). Caregiving and care receiving among older lesbian, gay, and bisexual adults. *Journal of Gay and Lesbian Social Services, 18*(3/4), 15-38.

Kuhn, D. R. (1990). The normative crises of families confronting dementia. *Families in Society, 71*(8), 451-459.

MetLife Mature Market Institute and American Society on Aging. (2010). *Still out, still aging: The MetLife study of lesbian, gay, bisexual and transgender baby boomers*. Westport, CT: MetLife.

Orzech, D. (2007). Complementary & alternative medicine for older adults. *Social Work Today*, *7*(5) 39-43.

Saleebey, D. (2006). *The strengths perspective in social work practice* (4th ed.). Boston, MA: Allyn & Bacon.

Shippy, R. A. (2007). We cannot do it alone: The impact of informal support and stressors in older gay, lesbian, and bisexual caregivers. *Journal of Gay and Lesbian Social Services*, *18*(3/4), 39-51.

2. Bibliography of the following topics with brief introductions:

* General Caregiving
* Impact of Caregiving
* Assessment of Caregivers’ and Care-recipients’ Needs
* Caregiver Well-Being Scale
* Care-recipient Assessment
* Social Work Practice and Interventions for Caregivers
* Caregiver-related Policy Issues

3. Web-based resource list for caregiving

* Resources for LGBT caregiving

4. Caregiving-focused videos and films

5. Two Classroom Activities:

* Assessment of Caregiver Well-Being
The goal of this exercise is to familiarize students with a strengths-based caregiver assessment tool, the Caregiver Well-Being Scale, and to provide an opportunity to practice administering the scale and reflecting on the experience.
* Yoga Break
The goal of this exercise to provide an opportunity for students to gain insight into a caregiver self-care exercise using body movement, breathing, and meditation.

Existing Related CSWE Gero-Ed Teaching Resources

* [Caregiving Bibliography](http://www.cswe.org/File.aspx?id=45337) For Infusion in Foundation Practice, HBSE, or Policy Curriculum
* [Hospice Social Work and Caregiver Stress: Case Study](http://www.cswe.org/File.aspx?id=26851)
* [Multigenerational Issues and Caregiving Case Study](http://www.cswe.org/File.aspx?id=26787)

Bibliography of Caregiving Resources

This organized bibliography is meant to serve as a resource to instructors who wish to add readings to their syllabi. The topics are not exhaustive.

General Caregiving

These articles and books provide general information regarding the informal caregiving experience for older adults and their care partners.

Berg-Weger, M., & Tebb, S. S. (2015). Caregiver well-being: Is it on your radar? *Journal of the American Medical Directors Association, 15*(16), 908-910.

Gaugler, J. E., & Kane, R. L. (2015). *Family caregiving in the new normal*. London: Academic Press.

Gibson, M. J., Kelly, K. A., & Kaplan, A. K. (2012). *Family Caregiving and Transitional Care: A Critical Review.* San Francisco, CA: Family Caregiver Alliance. Retrieved from <https://www.caregiver.org/sites/caregiver.org/files/pdfs/FamCGing_TransCare_CritRvw_FINAL10.31.2012.pdf>

Greene, R. R., & Kropf, N. P. (2014). *Caregiving and care sharing: A life course perspective*. Washington, DC: NASW Press.

Tally, R. C., & Montgomery, R. J. V. (2013). *Caregiving across the lifespan. Research, practice, & policy.* New York: Springer Publishing.

Redfoot, D., Feinberg, L., & Houser, A. (2013). The aging of the baby boom and the growing care gap: A look at future declines in the availability of family caregivers. Retrieved from <http://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html>

Impact of Caregiving

These articles and books provide research findings related to the multi-faceted and complex physical, mental health, and social impact that caring for an older adult can have on the caregiver.

Bleijlevens, M. H. C., Stolt, M., Stephan, A., Zabalegui, A., Saks, K., Sutcliffe, C.,… Zwakhalen, S. M. G. (2015). Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. *Journal of Advanced Nursing, 71*(6), 1378–1391.

Dauphinot, V., Ravier, A., Teddy, N., Delphin-Combe, F., Moutet, C., Xie, J.,… Krolak-Salmon, P. (2015). Relationship between comorbidities in patients with cognitive complaint and caregiver burden: A cross-sectional study. *Journal of the American Medical Directors Association.* Published Online first, November 24, 2015.

George, N. R., & Steffen, A. (2014). Physical and mental health correlates of self-efficacy in dementia family caregivers. *Journal of Women & Aging, 26*(4), 319-331.

Luhmann, M., Hofmann, W., Eid, M., & Lucas, R. E. (2012). Subjective well-being and adaptation to life events: A meta-analysis. *Journal of Personality & Social Psychology, 102*(3), 592-615.

Nogales-González, C., Romero-Moreno, R., Losada, A., Márquez-González, M., & Zarit, S.H. (2015). Moderating effect of self-efficacy on the relation between behavior problems in persons with dementia and the distress they cause in caregivers. *Aging & Mental Health, 19*(11), 1022-1030.

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging, 26*(1), 1-14.

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: Health of caregivers of Alzheimer’s disease and other dementias. *Current Psychiatric Report, 15*(7)*,* 367. doi: 10.1007/s11920-013-0367-2

Roth, D. L., Dilworth-Anderson, P., Huang, J., Gross, A. L., & Gitlin, L. N. (2015). Positive aspects of family caregiving for dementia: Differential item functioning by race. *Journal of Gerontology, 70B*, 813-819.

Roth, D. L., Perkins, M., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle-aged and older adults. *Quality of Life Research,* *18*, 679-688.

Smith, G. R., Williamson, G. M., Miller, L. S., & Schulz R. (2011). Depression and quality of informal care: A longitudinal investigation of caregiving stressors. *Psychology & Aging, 26*(3), 584-591.

Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist, 42*(3), 356-372.

Tebb, S. S., & Steiger, F. R. (2008). Time taken as a caring family. *Reflections, 14*(3), 37-46.

Thai, J. N., Barnhart, C. E., Cagle, J., & Smith, A. K. (2015). ‘‘It just consumes your life’’: Quality of life for informal caregivers of diverse older adults with late-life disability. *American Journal of Hospice & Palliative Medicine*. (Epub ahead of print)

Vroomen, J. M., Bosmans, J. E., van de Ve, P. M., Jolin, K. J., van Mierlo, L. D., Meiland, F. J. M.,… de Rooji, S.E. (2015). Community-dwelling patients with dementia and their informal caregivers with and without case management: 2-year outcomes of a pragmatic trial. *Journal of the American Medical Directors Association, 16*(9), 800.e1-800.e8.

Assessment of Caregivers’ and Care-Recipients’ Needs

These articles and books provide a sampling of available information regarding assessment tools and strategies to utilize with informal caregivers along with information on one specific caregiver well-being assessment tool. Resources for determining care-recipient needs is also provided.

Cameron, M., Kremer, L., Sherman, C., & Sumner, H. (2009). *Caregiver assessments 2009*. Michigan Dementia Coalition, Michigan Department of Health and Human Services. Retrieved from <http://www.rosalynncarter.org/UserFiles/Michigan%20Assessment%20Grid.pdf>

Family Caregiver Alliance & Benjamin Rose Institute on Aging. (2012). *Selected caregiver assessment measures: A resource inventory for practitioners (2nd ed.).* San Francisco, CA: Family Caregiver Alliance. Retrieved from <https://caregiver.org/selected-caregiver-assessment-measures-resource-inventory-practitioners-2012>

Feinberg, L. F. (2002). *The state of the art: Caregiver assessment in practice settings.* San Francisco, CA: Family Caregiver Alliance.

Montgomery, R., & Kwak, J. (2008). TCARE: Tailored caregiver assessment and referral. *Journal of Social Work Education, 44*(3), 59-64; Supplement. Reprinted with permission from the *American Journal of Nursing, 108*(9), 54–57 (2008).

Steffen, A. M., Tebb, S., & McGillick, J. (1999). How to cope: Documenting the changing information needs of Alzheimer’s caregivers. *American Journal of Alzheimer’s Disease and Other Dementias, 14*(5), 262-269. doi: 1177/153331759901400508

Caregiver Well-Being Scale

Berg-Weger, M., Rubio, D. M., & Tebb, S. (2000). The caregiver well-being scale revisited. *Health and Social Work, 25*(4), 255-263.

Tebb, S. (1995). An aid to empowering: A caregiving well-being scale. *Health and Social Work, 20*(2), 87-92.

Tebb, S. C., Berg-Weger, M., & Rubio, D. M. (2013). The caregiver well-being scale: Developing a short-form rapid assessment instrument. *Health and Social Work, 38*(4), 222-230.

Care-Recipient Assessment

Activities of Daily Living:

Katz, S. (1983). Assessing self-maintenance: Activities of daily living, mobility, and instrumental activities of daily living. *Journal of the American Geriatrics Society, 31*(12), 721-727.

Instrumental Activities of Daily Living:

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist, 9*, 179-186.

Social Work Practice and Interventions with Caregivers

These articles and books provide information on an array of practice interventions that can be incorporated into working with informal caregivers.

Alliance for Aging Research, Administration on Aging, MetLife Foundation. (2012). Translating innovation to impact: Evidence-based interventions to support people with Alzheimer’s disease and their caregivers at home and in the community. Washington, DC: Alliance for Aging Research. Retrieved from <http://www.agingresearch.org/publications/view/18#.Vh1NT_m6fcs>

Bonner, G. J., Wang, E., Wilkie, D. J., Ferrans, C. E., Dancy, B., Yashika, J., & Watkins, P. (2014). Advance Care Treatment Plan (ACT-Plan) for African American family caregivers: A pilot study. *Dementia, 13*(1), 1-17.

Cameron, M., Massuch, L., & Wishart, D. (2008). *Research-based recommendation for effective caregiver interventions*. Michigan Dementia Coalition, Michigan Department of Health and Human Services. Retrieved from http://www.rosalynncarter.org/UserFiles/Recomm\_Eff\_CG\_Interventions\_3\_6\_08.pdf

Connolly, A., Sampson, E. L., & Purandare, N. (2012). End-of-Life care for people with dementia from ethnic minority groups: A systematic review. *Journal of the American Geriatrics Society, 60*, 351–360.

Elliott, A. F., Burgio, L. D., & DeCoster, J. (2010). Enhancing caregiver health: Findings from the resources for enhancing Alzheimer’s caregiver health II Intervention. *Journal of the American Geriatrics Society, 58,* 30–37.

Elvish, R., Lever, S., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. Counselling and Psychotherapy Research: Linking Research with Practice, *13*(2), 106-125, doi:10.1080/14733145.2012.739632

Glueckauf, R. L., Davis, W. S., Willis, F., Sharma, D., Gustafson, D. J., Hayes, J.,… Springer, J. (2012). Telephone-based, cognitive-behavioral therapy for African American dementia caregivers with depression: Initial findings. *Rehabilitation Psychology, 57*(2), 124-39. doi: 10.1037/a0028688

Hayden, L. J., Glynn, S. M., Hahn, T. J., Randall, F., & Randolph, E. (2012). The use of Internet technology for psychoeducation and support with dementia caregivers. *Psychological Services, 9*(2), 215-218. doi: 10.1037/a0027056

Jones, C. B., Drake, R., Leurent, B., & King, M. (2011). Interventions for supporting informal caregivers of patients in the terminal phase of a disease (review). *The Cochrane Library (6).* John Wiley & Sons, Inc.: The Cochrane Collaboration.

Lavretsky, H., Epel, E. S., Siddarth, P. Nazarian, N., Cyr, N. S.,… Irwin, M. R. (2013). A pilot study of yogic meditation for family dementia caregivers with depressive symptoms: Effects on mental health, cognition, and telomerase activity. *International Journal of Geriatric Psychiatry, 28*(1), 57-65.

Masters, J. L. (2006). The benefits of consumer-directed services for caregivers of persons with Alzheimer’s disease. *Families in Society, 87*(4), 583-589.

Nápoles, A. M., Chadiha, L., Eversley, R., & Moreno-John, G. (2010). Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer’s Disease & Other Dementias, 25*(5) 389-406. doi: 10.1177/1533317510370957

National Association of Chronic Disease Directors. (n.d.). *Implementing a community-based program for dementia caregivers: An action guide using REACH OUT*. Ann Arbor, MI: University of Michigan Health System. Retrieved from <http://www.rosalynncarter.org/UserFiles/ReachOutActionGuide.pdf>

National Association of Social Workers. (2010) *NASW standards for social work practice with family caregivers of older adults*. Washington, DC: National Association of Social Workers. Available at: <http://www.socialworkers.org/practice/standards/Family_Caregivers_Older_Adults.asp>

Vinson, L. D., Crowther, M. R., Austin, A. D., & Guin, S. M. (2014). African Americans, mental health, and aging. *Clinical Gerontologist*, 37, 4-17.

Waelde, L. C., Thompson, L., & Gallagher-Thompson, D. (2004). A pilot study of a yoga and meditation intervention for dementia caregiver stress. *Journal of Clinical Psychology, 60*, 677-687.

Whitebird, R. R., Kreitzer, M., Crain, A. L., Lewis, B. A., Hanson, L. R., & Enstad, C. J. (2013). Mindfulness-based stress reduction for family caregivers: A randomized controlled trial. *Gerontologist 53*(4), 676-686. doi:10.1093/geront/gns126

Caregiver-related Policy Issues

These articles and reports highlight current and future policy-related issues and actions related to informal caregiving.

Butrica, B., & Karamcheva, N. (2014). The impact of informal caregiving on older adults’labor supply and economic resources. Washington, DC: The Urban Institute. Retrieved from <http://www.urban.org/research/publication/impact-informal-caregiving-older-adults-labor-supply-and-economic-resources>

Reinhard, S. C., Feinberg, L., & Choula, R. (2012). A call to action: What experts say needs to be done to meet the challenges of family caregiving. *Spotlight, 1*. AARP Public Policy Institute.

Reinhard S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). *Valuing the invaluable: 2015 Update. Undeniable Progress, but Big Gaps Remain*. Washington, DC: AARP Public Policy Institute. Retrieved from <http://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from Population-based studies. *The Gerontologist*, *55*(2), 309-319.

Rowe, J. W., & Fried, L. P. (2013). Beyond Medicare reform: Strategies to enhance health and well-being in older persons. *Public Policy and Aging Report, 23*(4), 23-25.

(The) Center for Aging and Work at Boston College. (2012). Aging today: Family caregiving & the older worker. Retrieved from <http://www.bc.edu/content/dam/files/research_sites/agingandwork/pdf/publications/FS29_FamilyCaregiving.pdf>

U.S. Department of Health and Human Services ASPE Issue Brief. (2015). The Affordable Care Act and caregivers. Retrieved from <https://aspe.hhs.gov/basic-report/affordable-care-act-and-caregivers-research-brief>

Caregiver Web-based Resources

There are an array of informational, educational, support, and advocacy and policy organizations that provide resources for gerontological professionals and formal and informal caregivers. While a number of organizational websites are included here, the list is not exhaustive.

**AgeLine:** This database focuses exclusively on issues of aging and the population of people aged 50 years and older. (Updated on a weekly basis.)https://www.ebscohost.com/academic/ageline

**AgingCare.com:** This on-line community for caregivers and persons who support caregivers provides resources, education, and linkages to services.
<https://www.agingcare.com/>

Administration on Aging (AoA), Alzheimer’s Disease Supportive Services Program (ADSSP) Resource Compendium: This website offers caregiving-related resources in the areas of: case studies, evidence-based practice, project planning tools, and toolkits.
<http://www.aoa.gov/AoA_Programs/HPW/Alz_Grants/compendium.aspx>

American Association of Retired Persons (AARP)

* **Caregiving Glossary:** This comprehensive listing of caregiving-related terms is available at:<http://www.aarp.org/home-family/caregiving/info-05-2012/caregiving-resource-center-glossary.html>
* **Caregiving Resource Center:** The national organization’s web site provides a range of resources for the elderly and for caregivers.
* [http://www.aarp.org/home-family/caregiving/caregiving-tools/](http://www.aarp.org/home-family/caregiving/caregiving-tools/%20%20)
* **Caregiving App:** An app for organizing and privately sharing crucial information for with family and caregivers.[https://www.oplytic.com/desktop-to-mobile/?g={5163B0C7-20F2-40BC-BB75-0B22CD43388D}&tr=195173492&campaignid=CG-INT-DSK&vehicle=promo-desktop](https://www.oplytic.com/desktop-to-mobile/?g=%7b5163B0C7-20F2-40BC-BB75-0B22CD43388D%7d&tr=195173492&campaignid=CG-INT-DSK&vehicle=promo-desktop)

**Alzheimer’s Association:** This national organization provides leadership in promoting and advocating for funding for research, legislation to support, and services for persons experiencing dementia and their care partners. There are chapters in each state to provide education and services.
[www.alz.org](http://www.alz.org/); <http://www.alz.org/apps/findus.asp> (To locate a specific chapter, enter a zip code into the chapter locator box)

**Association of Jewish Family and Children Agencies (AJFCA) Senior Resource Connect:** Offers resources and information for older adults, caregivers, and family members.
<http://www.ajfca.org/senior-resource-connect/resources-and-information/>

**The Brookdale Foundation Group Relatives as Parents Program (RAPP):** RAPP provides extensive services, primarily to relative caregivers caring for children outside the foster care system, in 44 States, the District of Columbia, and Puerto Rico. They conduct a National Orientation and Training Conference and provide technical assistance through site bulletins, a listserv, an annual newsletter, conference calls, and webchats to facilitate opportunities for networking and information exchange.<http://www.brookdalefoundation.org/RAPP/rapp.html>

**Caregiver Support Services:** This Nebraska-based organization provides information and support for caregivers and has listings for professional caregiving training programs. The group’s website features an interactive stress test.
<http://www.caregiversupportservices.org/>

**Caregiver Action Network (formerly National Family Caregivers Association):** Grassroots organization dedicated to supporting and improving the lives of America's family caregivers. Created to educate, support, empower, and advocate for the millions of Americans who care for their ill, aged, or disabled loved ones.
<http://caregiveraction.org/>

**Caregiver Wellness Solution Center: Information to help caregivers with self-care.**<https://www.caring.com/caregiver-wellness>

**Center for Aging and Work at Boston College:** This research center provides an array of publications and fact sheets related to older workers, including family caregivers.
<http://www.bc.edu/research/agingandwork/>

**Children of Aging Parents (CAPS):** This national organization provides information, referrals, and support to caregivers of the elderly or chronically ill. CAPS sponsors caregiver support groups nationwide.

[http://www.caps4caregivers.org/](http://www.caps4caregivers.org/%20)

**eXtension Service, Family Caregiving:** Hosted by the U.S. Department of Agriculture, eXtension is an interactive learning environment delivering research-based information emerging from America's land-grant university system.

[http://www.extension.org/family\_caregiving](http://www.extension.org/family_caregiving%20)

**Family Caregiver Alliance (FCA):** FCA is a not-for-profit organization that offers programs at national, state, and local levels to support and sustain caregivers. The group’s website provides hundreds of articles with advice for caregivers. It also includes good disease-specific information.
[https://caregiver.org/about-fca](https://caregiver.org/about-fca%20)

See FCA's national policy statement here:
<https://www.caregiver.org/national-policy-statement>

**The Family Caregiver Program:** Run by the Department of Pain Medicine and Palliative Care of Beth Israel Medical Center, the program provides counseling and support for caregivers, offers referrals to community resources, and conducts research and education initiatives. The program’s website offers online support, education, and information on daily aspects of caregiving.
http://netofcare.org/

**Medicare Interactive:** Created by the Medicare Rights Center, this website provides information and resources for older adults and their caregivers regarding Medicare rights, options, and benefits.
[http://www.medicareinteractive.org/page2.php?topic=counselor&page=script&script\_id=1404](http://www.medicareinteractive.org/page2.php?topic=counselor&page=script&script_id=1404%20)

**The National Alliance for Caregiving (NAC):** The Alliance is a not-for-profit coalition of national organizations focused on family caregiving. The web site has searchable databases of articles and guides for caregivers.
[http://www.caregiving.org/](http://www.caregiving.org/%20%20)

**National Caregivers Library:** Hosted by Family Care America, this online resource has hundreds of articles for caregivers.

<http://www.caregiverslibrary.org/home.aspx>

**National Family Caregiver Support Program (NFCSP):** NFCSP is a government program that funds local agencies to provide information and assistance to caregivers caring for people aged 60 and over.

<http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/>

Most of the local programs are overseen by **Area Agencies on Aging (AAA)**. To find your local AAA, click on the Eldercare Locator link at:

<http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>

**Next Step in Care:** Provides information and advice to help family caregivers and health care providers plan safe and smooth transitions for patients. All materials for family caregivers are available in English, Spanish, Russian, and traditional Chinese.

[http://www.nextstepincare.org/](http://www.nextstepincare.org/%20)

**Rosalyn Carter Institute for Caregiving (RCI):** RCI offers a wide array of caregiver-related education and resources in the following areas: dementia capability webinars, dementia training for Area Agency on Aging case managers, implementation tools, and guides.
<http://www.rosalynncarter.org/>

**Well Spouse Association:** This national, not-for-profit membership organization gives support to wives, husbands, and partners of people with chronic illnesses and/or disabilities. Its website hosts online caregiver chat forums and lists face-to-face support groups around the country.
[http://www.wellspouse.org/](http://www.wellspouse.org/%20)

**Alzheimer’s Association
LGBT Caregiver Concerns: Important Considerations for LGBT Caregivers**<https://www.alz.org/national/documents/brochure_lgbt_caregiver.pdf>

**American Society on Aging
What’s Different About LGBT Informal Caregiving?**<http://www.asaging.org/blog/whats-different-about-lgbt-informal-caregiving>

**Family Caregiver Alliance LGBT Caregiving:**

* **Frequently Asked Questions**<https://caregiver.org/lgbt-caregiving-frequently-asked-questions>
* **Special Concerns of LGBT Caregivers**<https://caregiver.org/special-concerns-lgbt-caregivers>

**National Resource Center on LGBT Aging
LGBT Caregiving Facts**<http://www.lgbtagingcenter.org/resources/resource.cfm?r=2>

**Next Step in Care**

<http://www.nextstepincare.org/>

**For Family Caregivers: LGBT Caregiving**<http://www.nextstepincare.org/Caregiver_Home/LGBT_Guide/>

**SAGE (Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders)
Caregiving in the LGBT Community**<https://www.sageusa.org/newsevents/news.cfm?ID=57>

Caregiving-focused Films and Videos

Incorporating documentary and feature films and videos into a course can be an impactful strategy for promoting discussion and learning. The following list includes a sampling of available films and videos that can be helpful in stimulating students toward gaining insight into the caregiving experience.

Documentaries and Training

*Caring for Mom and Dad* (2015): This one-hour PBS documentary provides insights into the health, emotional, and financial challenges of caring for aging parents.
<http://www.pbs.org/wgbh/caringformomanddad/>

*Caring for Your Parents* (2008): Two-hour PBS documentary that examines the experiences of five families who are each caring for older parents. The website includes information and materials for organizing a caregiver fair and creating a caregiver handbook. Available in English and Spanish. <http://www.pbs.org/wgbh/caringforyourparents/>

*Caregivers Like Me:*A video-based curriculum in English and Spanish for caregivers caring for a family member at the end of her or his life.

[http://aging.slu.edu/index.php?page=caregivers-like-me](http://aging.slu.edu/index.php?page=caregivers-like-me )

*Genius of Marian:* Made by Marian’s son, this film documents the journey of their family through Alzheimer’s disease.
<http://geniusofmarian.com/>

Feature Films

*Age Old Friends* (1989)—This comedy, starring Hume Cronyn, depicts the relationship between two friends living in a nursing home—one with physical impairment and the other with cognitive decline—and how they support each other.

*Aurora Borealis* (2006)—This drama portrays a 20-something who lacks a life plan and becomes his grandparents’ handyman.

*Away From Her* (2007)—A poignant story about a married couple struggling with the wife’s (Julie Christie) dementia, placement in a nursing home, and her relationship with a male resident.

*Driving Miss Daisy* (1989)—This Oscar-winning film shows aging, dementia, and caregiving through the experiences of Daisy (Jessica Tandy), her son, Boolie (Dan Akroyd), and the driver (Morgan Freeman) that Boolie hires to care for his mother.

*Five Flights Up* (2015)—Morgan Freeman and Diane Keaton play a husband and wife who are selling the home they have lived in for four decades.

*Iris* (2001)—Dame Judi Dench portrays the journey through Alzheimer’s disease of novelist Iris Murdoch and her husband and caregiver, Joyn Bayley.

*Mimi and Donna* (2015)—this PBS documentary on family caregiving focuses on 92-year-old Mimi and her 64-year-old daughter, Dona, who has an intellectual disability, and their lives as Mimi contemplates that she has little time left with her daughter. For more information, visit: <http://www.pbs.org/independentlens/films/mimi-and-dona/>

*Nebraska* (2014)—Bruce Dern is curmudgeonly Woody Grant who insists on travelling from Montana to Nebraska to collect a sweepstakes prize. His son, David, is forced to accompany him to see that he is safe.

*On Golden Pond* (1981)—Aging, caregiving, and relationships are the themes present in this movie starring Henry Fonda, Katharine Hepburn, and Jane Fonda.

*The Savages* (2007)—Siblings Wendy (Laura Linney) and Jon (Philip Seymour Hoffman) have a strained relationship with each other and their father which boils to crisis level when the father develops dementia and requires nursing home care.

*A Song for Martin* (2001)—This Swedish (English sub-titles) drama/romance follows a professional musician couple from first meeting through to their struggle with dementia.

*Still Alice* (2014)—Columbia University professor, Dr. Alice Howland, develops early-onset Alzheimer’s disease. The movie provides a glimpse into the onset of symptoms, diagnosis, and family caregiving decisions that accompany Alzheimer’s disease.

Resources for Caregivers

While the previous resource lists are relevant and appropriate for caregivers to utilize, the following list includes publications and web-based resources specifically created for use by caregivers and families.

Publications:

Hurme, S. B. (2015). Checklist for Family caregivers. A guide to making it manageable. Chicago, IL: American Bar Association.

Keefe, D. M. (2012). Blueprint for care: A practical guide to managing care for your loved one. St. Louis, MO: Caring for Parents Together Publishing Company.

Powerful Tools for Caregivers. (2013). The caregiver helpbook (3rd ed.). Portland, OR: Powerful Tools for Caregivers. Available at: <https://www.powerfultoolsforcaregivers.org/>

Web-based Resources:

*Caring Bridge:* This web-based organization provides the opportunity for individuals and families to create their own website to share news with others about a loved one.
<http://www.caringbridge.org/>

*Caring from a Distance:* Aimed at supporting caregivers who do not live near the person for whom they are caring, this organization provides service directories, links to locating assistance, tools for coordinating service, educational resources, and free conference calling options.
<http://www.cfad.org/>

*ElderCare at Home:* This website offers connections to services for older adults and their caregivers and has a section directed specifically at caregiver health that includes tips and tools, self-assessment, resources, and information on research.
[http://www.healthinaging.org/aging-and-health-a-to-z/topic:caregiver-health/](http://www.healthinaging.org/aging-and-health-a-to-z/topic%3Acaregiver-health/)

*National Respite Locator:* This website provides assistance for caregivers who are in need of respite care throughout the United States.
<http://archrespite.org/respitelocator>

*Today’s Caregiver:* This website offers a comprehensive array of resources “for, about and by” caregivers, including a monthly on-line magazine, a newsletter, tips and local resources for caregiver, and more.
[www.caregiver.com](http://www.caregiver.com)

*When You Need Help Caring for Mom or Dad. Advice for People Having What This Writer Calls the "Caregiving Dilemma:"* A resource provided by the Public Broadcasting System (PBS) Next Avenue, this website offers insights and support for family and informal caregivers.
<http://www.nextavenue.org/when-you-need-help-caring-for-mom-or-dad/?utm_source=bestofnewsletter&utm_medium=email&utm_content=Best_of_October-15_Control&utm_campaign>

Class Exercises and Assignments

The following two exercises can be incorporated into a web-based or classroom course. The focus is on providing students with opportunities to engage in assessing caregiver well-being and it offers guidance for a caregiver self-care activity.

1. Assessment of Caregiver Well-Being

Through the completion of this activity, students will develop skills in conducting a strengths-based assessment to gain insight into the self-perceived emotional, physical, and financial well-being of a caregiver who is providing care for an older family member. The care-recipient may be a spouse, parent, parent-in-law, partner, or other family member. There are a number of psychometrically validated and well-established tools for assessing caregiver burdens that may be utilized for this assignment (see resources listed in the reference list); one particular strengths-based assessment tool is being highlighted here.

The Caregiver Well-Being Scale (CWBS) (Tebb, 1995) was developed as a tool for use in the clinical setting that would enable the social worker to conversationally engage the caregiver in a discussion about her or his current well-being. While the tool is intended to capture the caregiver’s perceptions of her or his functioning, the CWBS can also serve as an intervention tool to empower the caregiver to initiate change in the caregiving experience that will enhance her or his emotional, physical, and/or financial coping as it relates to the caregiving responsibilities. The tool can also serve as a strategy for monitoring progress toward the goals established in collaboration with the caregiver. Three versions of the CWBS are available; all three include the same two sub-scales, basic needs and activities of living: 1) the original 45-item version includes 22 items to assess basic needs and 23 items address activities of living; 2) the shortened CWBS is a 16-item measure with 8 items in each sub-group; and 3) the Rapid CWBS (R-CWBS) is a 6-item scale with 3 items in each sub-group. Copies of the 45- and 16-item scales are provided here.

WELL BEING SCALE

BASIC NEEDS

Below are listed a number of basic needs. For each need listed, think about your life over the past 3 months. During this period of time, indicate to what extent you think each need has been met. Circle the appropriate number on the scale provided below.

1. Never or almost never 3. Sometimes 5. Almost always
2. Seldom, occasionally 4. Often, frequently

1. Having enough money 1 2 3 4 5

2. Eating a well-balanced diet 1 2 3 4 5

3. Getting enough sleep 1 2 3 4 5

4. Attending to your medical and dental needs 1 2 3 4 5

5. Having time for recreation 1 2 3 4 5

6. Feeling loved 1 2 3 4 5

7. Expressing love 1 2 3 4 5

8. Expressing anger 1 2 3 4 5

9. Expressing laughter and joy 1 2 3 4 5

10. Expressing sadness 1 2 3 4 5

11. Enjoying sexual intimacy 1 2 3 4 5

12. Learning new skills 1 2 3 4 5

13. Feeling worthwhile 1 2 3 4 5

14. Feeling appreciated by others 1 2 3 4 5

15. Feeling good about family 1 2 3 4 5

16. Feeling good about yourself 1 2 3 4 5

17. Feeling secure about the future 1 2 3 4 5

18. Having close friendships 1 2 3 4 5

19. Having a home 1 2 3 4 5

20. Making plans about the future 1 2 3 4 5

21. Having people who think highly of you 1 2 3 4 5

22. Having meaning in your life 1 2 3 4 5

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ACTIVITIES OF LIVING

Below are listed a number of activities of living that each of us do or someone does for us. For each activity listed, think over the past 3 months. During this period of time, to what extent do you think each activity of living has been met. Circle the appropriate number on the scale provided below. You are being asked to rate the extent to which each activity of living has been taken care of by or for you in a timely way.

1. Never or almost never 3. Sometimes 5. Almost always
2. Seldom, occasionally 4. Often, frequently

1. Buying food 1 2 3 4 5

2. Preparing meals 1 2 3 4 5

3. Getting the house clean 1 2 3 4 5

4. Getting the yard work done 1 2 3 4 5

5. Getting home maintenance done 1 2 3 4 5

6. Having adequate transportation 1 2 3 4 5

7. Purchasing clothing 1 2 3 4 5

8. Washing and caring for clothing 1 2 3 4 5

9. Relaxing 1 2 3 4 5

10. Exercising 1 2 3 4 5

11. Enjoying a hobby 1 2 3 4 5

12. Starting a new interest or hobby 1 2 3 4 5

13. Attending social events 1 2 3 4 5

14. Taking time for reflective thinking 1 2 3 4 5

15. Having time for inspirational or spiritual interests 1 2 3 4 5

16. Noticing the wonderment of things around you 1 2 3 4 5

17. Asking for support from your friends or family 1 2 3 4 5

18. Getting support from your friends or family 1 2 3 4 5

19. Laughing 1 2 3 4 5

20. Treating or rewarding yourself 1 2 3 4 5

21. Maintaining employment or career 1 2 3 4 5

22. Taking time for personal hygiene and appearance 1 2 3 4 5

23. Taking time to have fun with family or friends 1 2 3 4 5

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CAREGIVER WELL-BEING SCALE (shortened)

I. ACTIVITIES

Below are listed a number of activities that each of us do or someone does for us. Thinking over the past 3 months, indicate to what extent you think each activity has been met by circling the appropriate number on the scale provided below. You do not have to be the one doing the activity. You are being asked to rate the extent to which each activity has been taken care of in a timely way.

1. Rarely 2. Occasionally 3. Sometimes 4. Frequently 5. Usually

1. Buying food 1 2 3 4 5

2. Taking care of personal daily activities
(meals, hygiene, laundry) 1 2 3 4 5

3. Attending to medical needs 1 2 3 4 5

4. Keeping up with home maintenance activities (lawn,
cleaning, house repairs, etc.) 1 2 3 4 5

5. Participating in events at church and/or in the community 1 2 3 4 5

6. Taking time to have fun with friends and/or family 1 2 3 4 5

7. Treating or rewarding yourself 1 2 3 4 5

8. Making plans for your financial future 1 2 3 4 5

II. NEEDS

Below are listed a number of needs we all have. For each need listed, think about your life over the past 3 months. During this period of time, indicate to what extent you think each need has been met by circling the appropriate number on the scale provided below.

1. Rarely 2. Occasionally 3. Sometimes 4. Frequently 5. Usually

1. Eating a well-balanced diet 1 2 3 4 5

2. Getting enough sleep 1 2 3 4 5

3. Receiving appropriate health care 1 2 3 4 5

4. Having adequate shelter 1 2 3 4 5

5. Feeling good about yourself 1 2 3 4 5

6. Feeling secure about your financial future 1 2 3 4 5

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© 1999 Susan Tebb, Marla Berg-Weger, and Doris M. Rubio (original scale © 1993), revised 2012.

This exercise may be completed as an in-class role play, or students can be assigned to complete an interview with an actual self-identified family caregiver of an older adult. The instructor may opt to pre-select sites or organizations in which family caregivers may be willing to meet with students.

*Prior to class, the instructor might wish to assign the following readings:*

Berg-Weger, M., Rubio, D. M. & Tebb, S. (2000). The caregiver well-being scale revisited.
*Health and Social Work, 25*(4), 255-263*.*

Tebb, S. (1995). An aid to empowering: A caregiving well-being scale. *Health and Social Work, 20*(2), 87-92.

To promote discussion with the caregiver without hampering the development of possibilities, there is no defined scoring mechanism or scale. The CWBS is designed to aid social worker and caregiver in discussing each item and strategizing about potential strategies for enhancement.

The student is assigned to develop a written plan of action, to include:

1. Engagement of the caregiver;
2. Assessment of caregiver well-being including strengths of the caregiver, care- recipient, and environment;
3. Strengths-based intervention to enhance caregiver well-being; and
4. Termination and evaluation of the intervention.

Optional Reflection Paper: Upon completion of the assignment, the student may be asked to provide a written reflection on the experience in one of more of the following areas:

1. Personal and professional strengths and areas for growth in conducting an intervention with a caregiver;
2. Challenges related to conducting a clinically-based open-ended assessment; and
3. Knowledge and skills needed and learned.

2. Yoga Break

This exercise will assist you in teaching the caregiver to learn to take a short but important “break” just for themselves. It will help them begin to feel centered and energized any time of day when they need to just “take a break.”. Most of us have patterns of behaving and thinking that are ingrained, and these habitual patterns become our reality. By learning to use breath, movement, and meditative time for oneself, changes to thoughts and actions begin to happen and the reality of offering care to a loved one changes. Encourage the caregiver to find a dedicated space where they can go and take this “break,” so it becomes their place where they can “escape” for a little while to rest and relax their minds and find that quiet peacefulness inside each of us.

Go through this exercise with the caregiver several times so she or he will be comfortable with completing it.

Instructions for Yoga Break:

*Exercise #1:*

  Stand with feet a bit wider apart than hip distance.

  Breathe in and out, allowing your eyes to close if you like.

  Notice your breath and let it deepen, taking it into the lower part of your lungs so your belly rises on an inhale and deflates on an exhale.

  Now bend your knees slightly and think of every joint from your neck and jaw to your ankles and toes as having springs in the joints. Just let these joints move and bounce to the extent you are comfortable.

  After bouncing for a while, allow yourself to shake all over. Using your breath, move with your breath, allowing the whole body to shake for a minute.

  When you are ready, let yourself slow down, come to a standing position, and be still.

  Let your breath come to its natural rhythm and again, notice how you feel, just notice.

*Exercise #2:*

  Sit in a chair with your feet firmly planted on the ground.

  Allow your jaw and belly to relax.

  Inhale, feeling your belly rise.

  Then exhale, allowing the belly to go in towards the belly button.

  With each inhale, take in energy and with each exhale, allow troubling or concerning thoughts to just flow out of your body.

  Begin to breathe so there is no break between the inhale and the exhale; the breath is like a wave coming in and going out from the shore.

  Continue this breathing for two minutes.

  Sit while shifting to breathing in your natural rhythm.

  Allow yourself to sit for five minutes.  As thoughts come to the mind allow them, but then let them go; keep coming back to your natural breath.

Adapted from Townsend, M. (August, 2015). Breathe. *Real Simple*, p. 58.