Training Manual for Facilitators of Family/Friend Caregiver Support Groups

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U1QHP28716 Geriatrics Workforce Enhancement Program for $843,079. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.

Training Manual for Facilitators of Family/Friend Caregiver Support Groups

Table of Contents **Page(s)**

Introduction. 3-4

Pre-group Planning and Preparation for Support Groups. 5-8

Seven Support Group Sessions:

.

1. Basic knowledge on dementia. 9-11
   - Medication management
   - Managing personal health record

2. Supports for the Caregiver and Care-recipient. 12-13
   - Formal
   - Informal

3. Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). 14-15
   - Bathing
   - Eating
   - Sleeping
   - Driving

4. Behavior Management and Communication. 16-17
   - Agitation
   - Wandering
   - Paranoia

5. Making End-of-Life Decisions with Care-Recipient. 18-19

6. Physical and Psychological Self-care of Caregiver. 20-23

7. Last Session—Group Members' Choice. 24

8. Caregiver Well-Being Scales. 25-30

Introduction

The purpose of caregiver support groups is to identify prevent caregiver-related stress and prevent psychological, physical, behavioral, and social problems among caregivers and care receivers. The seven sessions described in this manual are created to be approximately one hour in length and each session offers suggested session topics and materials.

This support group training is designed to be offered in seven sessions. Included in the descriptions of each of the seven sessions are the following:

- Learning objectives
- Session Introduction
- Key messages
- Agenda (this can be used as a master copy for your group). Always give time for discussion.
- Supplies needed for the session
- Handouts if included in a session may be reproduced as needed and they have been designed for customization for your group.
- Resources and/or References-this is where you will find the resources mentioned earlier is each module, such as in “Handouts”, “Agenda” and/or “Supplies”.

The 7th session is left open so that the group might plan a closing celebration, address topics not covered in this manual, continue with topics that might need more attention, and/or n invited speaker on a topic the group chooses. As you work with your group, assess the needs and interests for the final session. The facilitator-organized session seven can follow the same format

As a leader of a caregiver support group you may want to invite local “experts” on the various topics to some or each of the seven sessions, including physician working with persons with dementia, local Alzheimer’s Association professionals, home care providers, local Area Agency on Aging staff, physical therapists, occupational therapists, social workers, and dietitians. Take into consideration the group you are working with and the topic as you think about what local “experts” you might invite.

This manual project is funded by Health Resources and Services Administration (HRSA) and Saint Louis University (http://aging.slu.edu/). We reference several modules designed for caregivers by HRSA in some of the individual session’s resource sections.

The selection of session topics is guided by the following references:

McCabe, M., You, E. & Tatangelo, G. (2016). Hearing their voice: Systematic review of dementia family caregivers need. *The Gerontologist, 56*(5), e70-e88. DOI:10.1093/geront/gnw078

Zubatsky, M., Aragon-Prada, M., Muse, F., Rainey, P. & Martin, R. (2016). Navigating without a roadmap: Challenges of early Alzheimer's caregivers with their health care team. *Global Qualitative Nursing Research, 3,* 1-9 DOI:10.1177/2333393616673456

Outline and session content is adapted from the following:

Cancer Survival Toolbox®Basic Skills found at https://www.canceradvocacy.org/wp-content/uploads/2013/02/Cancer-Survival-Toolbox-Resource-Booklet.pdf

Frenzel, M.G., Toseland, R. & Goebel, S.T. (1990). Caregiver's support group facilitator's manual: A product of the caregiver's support research project. Caregiver support group: "we give priority to caring for the veteran's caregiver". Washington, DC: Social Work Service, Veterans Health Service & Research Administration, Department of Veterans Affairs.

Pre-group Planning and Preparation for Support Groups

Group Recruitment

A natural place to identify members for a caregiver support group is from the persons your agency might be serving. In all walks of life, there are family members and friends who are now caring for a person and the caregiver may be in need of support to carry out this responsibility. Caregivers with a family member or friend who is attending a Cognitive Stimulation Therapy (CST) group or other group where the person with a dementia has a regular session may have time and interest in attending a support group.

Group Size

Once potential group members have been selected, and agree to participate, the first meeting can be scheduled. The size of the group is important. Groups of six, although intimate, are problematic when one or two members is not in attendance. Ideally, 8-10 members comprise a groupsmall enough to be intimate, but large enough to stay interesting if one or two members are unable to attend a given group.

Challenges and Considerations

There are a number of potential obstacles which may occur as you begin to organize a support group for caregivers. It is helpful to have an idea of the solutions before they arise. Potential challenges and resources include:

- **Respite care for care-recipient** while family/friend attends group. Resources may include:
    1) having a family member, friend, or formal caregiver spend time with the care-recipient or
    2) participation in in Cognitive Stimulation Therapy (CST) while the caregiver in is group at the same facility.
- **Transportation** for both caregiver and care receiver. If transportation is needed, resources may be identified in the Seniors Resource Guide.

In working with groups, the following 7 points from **Seven Lessons Toward Cross-Cultural Understanding** (adapted by Dr. Darla Deardorff on Craig Storti's work *Cross-Cultural Dialogues: 74 Brief Encounters with Cultural Difference.* Intercultural Press, 1994) can be helpful for group facilitators:

1. Don't assume everyone is the same.
2. Familiar behaviors may have different meanings

3. What you think of as a normal behavior may only be cultural
4. Don't assume that what you meant is what was understood
5. Don't assume that what you understood is what was meant
6. You don't have to like "different" behavior, but understanding where it comes from may help you respond with more sensitivity.
7. Most people do behave rationally; you just have to discover the rationale!

Materials Needed

1. **Chalk/Dry Erase Board or Easel/Paper** can enable the group to return to a particular topic at various points in time and compare them to the present.
2. **Name Tags** are helpful in the first several sessions, until members and facilitators are familiar with one another.
3. **Refreshments** can be an ice-breaker and socializer but not always needed.
4. **Personal Notebooks** can be useful and, if possible provided at the first meeting/session. Notebooks could include a list of meeting times and dates, notepaper and session outlines. Members can add handouts if they are distributed.

General References and Resources for Caregivers and Caregiver Support Group Facilitators

1. CAREGIVING. See the recent publication Families Caring for an Aging America, from National Academies Press, available at: http://www.jhartfound.org/images/uploads/main/files/Family_Caregiving_Report_National_Academy_of_Medicine_IOM.pdf
   -
   Video: ***Symptoms of Caregiver Burnout*** (5:45 min) https://www.YouTube.com/watch?v=da-4GEaWK4I

2. Video: ***Caregiver Stress and Tips to Avoid Burnout*** (4:00 min) https://www.YouTube.com/watch?v=NicLfniMJwU

3. **Visuals and/or Stories on Caregiving**

4. Caregiver or Failure; Learning Caregiving the Hard Way; and Caring for My Mother Who has Huntington's Disease. (these are short stories) https://www.caregiver.org/caregiver-stories

5. *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/

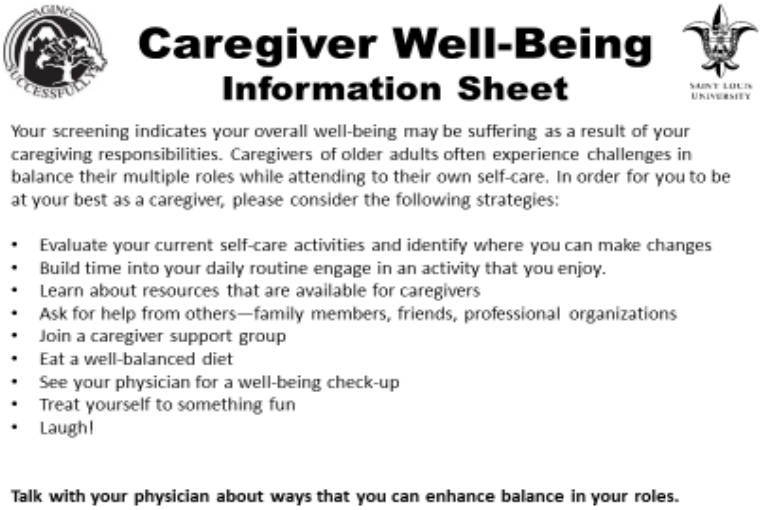
6. *Caring for Your Parents* (2008): Two-hour PBS documentary that examines the experiences of five families who are each caring for older parents. The website includes information and materials for organizing a caregiver fair and creating a caregiver handbook. Available in English and Spanish. http://www.pbs.org/wgbh/caringforyourparents/

Possible Assessment Tools for Caregiving

1. Caregiver Readiness Test ------Kane, R. L., & Ouellette, J. (2011). *The good caregiver.* New York, NY: Penguin Press. (**This is attached for your review not for use unless it is decided that IP wants to use and then I will obtain permission**)

2. Caregiver Self-Assessment Questionnaire
    a. http://www.healthinaging.org/resources/resource:caregiver-self-assessment/

3. Caregiver Well-Being Scale (CWBS)—there are three versions of the CWBS: 1) the original 42-item scale; 2) the shortened 16-item scale; and 3) the Rapid 6-item CWBS. The original and shortened versions are included in the last section of this manual. The Rapid CWBS can be found at http:/aging.slu.edu/ and the following information sheet should be given to each upon completion of the Rapid CWBS.



Caregiver Well-Being
Information Sheet

Your screening indicates your overall well-being may be suffering as a result of your caregiving responsibilities. Caregivers of older adults often experience challenges in balance their multiple roles while attending to their own self-care. In order for you to be at your best as a caregiver, please consider the following strategies:

- Evaluate your current self-care activities and identify where you can make changes
- Build time into your daily routine engage in an activity that you enjoy.
- Learn about resources that are available for caregivers
- Ask for help from others—family members, friends, professional organizations
- Join a caregiver support group
- Eat a well-balanced diet
- See your physician for a well-being check-up
- Treat yourself to something fun
- Laugh!

Talk with your physician about ways that you can enhance balance in your roles.

Resources and References for Facilitating Caregiver Support Groups

1. Tebb, S.S. & Steiger, F.R. (2008). Time taken as a caring family. *Reflections, 14*(3).
2. Toseland, R. W. (2004). *Caregiver education and support programs: Best practice models*. San Francisco, CA: Family Caregiver Alliance: National Center on Caregiving.
3. The Alzheimer's Society of PEI () *Support group facilitation training manual*. Charlottetown, PE Canada http://www.alzheimer.ca/pei/~/media/Files/pei/Training%20Manual.pdf

4. National Coalition for Cancer Survivorship. () *The Cancer Survival Toolbox®: The First Step to Cancer SurvivalTM: Training manual for group facilitators*. http://www.canceradvocacy.org/resources/cancer-survival-toolbox/

5. MacGregor, L. & McElhaney, M. (2014). *Alzheimer's Caregiver Support Group: Facilitator's Guide*. Belize City, Belize: National Council on Ageing & Mercy Care Centre . http://www.ncabz.org/wp-content/uploads/2015/05/Alzheimers-caregiver_support_group_handbook.pdf

6. Volunteer Service, Department of Veterans Affairs *Caregiver Support Group: Volunteer Training Manual.* Washington, DC: Department of Veterans Affairs. https://www.kofc.org/un/en/resources/military/serve/vavs_caregivers.pdf

7. Administration on Aging "Promising Practices in the Field of Caregiving". http://www.cmcoa.org/downloads/caregiverpromisingpractices.pdf

8. Alzheimer's and Dementia Caregiver Center. https://www.alz.org/care/alzheimers-dementia-care-training-certification.asp

9. AARP I love Caregivers. https://act.aarp.org/iheartcaregivers?utm_source=google&utm_medium=cpc&utm_term=caregiversupportgroups&utm_content=CaregiverSupport&utm_campaign=AARPCaregivers2016

Seven Sessions for Caregiver Support

SESSION 1: BASIC KNOWLEDGE ON THE CARING PROCESS

LEARNING OBJECTIVES:

- Demonstrate an initial understanding of dementia
- Acknowledge caregiving responsibilities and readiness to be a caregiver
- Demonstrate an understanding to basic home health care management of self and care-recipient.
- Demonstrate an understanding to Cognitive Simulation Therapy (CST).

SESSION INTRODUCTION:

As you prepare for this session on obtaining **knowledge** in the basic **process of caring,** the items listed below may be helpful to view together as a group during the session. All references to these videos and websites can be found in Resource and References section of this session.

1. Watch podcast, **Dementia - The Facts- Dr. Milta Little Podcast** at http:aging.slu.edu followed by a discussion.
2. Watch video on "Building Caregiver Partnerships".
3. Watch "Are You Ready to be a Caregiver" and Complete Caregiving Readiness Questions- https://youtu.be/QMYSlLYbOhk
4. Discussion of home health care needs. Possible topics include: home arrangement-bathroom, bed, walkways, kitchen safety; health care planning for care partner and YOU: medical history, medication record, diet, names and phone numbers, health insurance plan and policy numbers and how to work with your health care team (there is a video noted in resources but is 25 minutes long but has very good information and resources. Some of the resources are listed under "resources" below.
5. Watch video CST-preface watching this video that it is a CST group in Perryville, MO, a small very rural hospital.
6. Watch "Are You Ready to be a Caregiver" and Complete Caregiving Readiness Questions- https://youtu.be/QMYSlLYbOhk

KEY MESSAGES

- Know caring changes each and every day as do your feelings towards it. Be OK with your feelings.

AGENDA

1. Introductions, including care-recipient identity, relationship to caregiver, and length of caregiving experience, etc. Ask caregiver to note one area of care that they believe they are doing well in and one area in which they could use help.
2. Review purpose and goals of groups, including "ground rules", for example not talking when someone else is.
3. Check in time-use this time to learn about concerns people might have and how they are feeling that day.
4. Watch and discuss any videos selected from the list below for the session topic on **basic knowledge on the caring process,** to include, basic caregiving issues, and Cognitive Stimulation Therapy (CST).

    - Watch podcast **Dementia - The Facts- Dr Milta Little Podcast** at http:aging.slu.edu.
    - Look at website on "Building Caregiving Partnerships" http://www.neomed.edu/academics/medicine/departments/palliative-care/building-caregiver-partnerships
    - Watch "Are You Ready to be a Caregiver" and Complete Caregiving Readiness Questions- https://youtu.be/QMYSlLYbOhk
    - Discuss needs for home health care-possible topics: home arrangement-bathroom, bed, walkways, kitchen safety; health care planning for care partner and YOU: medical history, medication record, diet, names and phone numbers, health insurance plan and policy numbers and how to work with your health care team (there is a video noted in resources but is 25 minutes long but has very good information and resources. Some of the resources are listed under "resources" below.
    - Watch video on CST-preface watching this video that it is a CST group in Perryville, MO, a small very rural hospital.

SUPPLIES NEEDED FOR THE SESSION

- Internet access and a projector and screen for viewing videos as a group
- All supplies needed for this session are found in the Resource Section.

HANDOUTS

- As support group leader, you may have handouts and/or copy some of the resources noted in the Resources and/or Reference section below, such as, the Doctor's Checklist, the Medication Log, the Care Log or the websites to these so they have references to take home.

RESOURCES AND/OR REFERENCE

1. http:aging.slu.edu **Dementia - The Facts- Dr Milta Little Podcast**

2. The film and companion discussion guides, as well as resources for case-based learning and structured clinical encounters, are freely accessible on the website (20 min): http://www.neomed.edu/academics/medicine/departments/palliative-care/building-caregiver-partnerships.
3. "Are You Ready to be a Caregiver" and Complete Caregiving Readiness Questions- https://youtu.be/QMYSlLYbOhk
4. Perryville "What is CST" 11 min.
    a. https://www.YouTube.com/watch?v=kh3XqDEqVN4
    b. Short version: 2 1/2 min
    c. https://www.YouTube.com/watch?v=ohM8WGo2gO4
5. HRSA "Working with the health care team" https://youtu.be/98AYINhDbTw and resources suggested in this video prepared by HRSA for Caregivers.
6. Worksheets to fill out when preparing to talk with health care providers at https://www.nia.nih.gov/health/publication/talking-your-doctor/your-convenience-worksheets
7. Care Log: Use it to keep track of what happens between visits
    a. http://www.alz.org/national/documents/samplecarelog.pdf (Accessed November 30, 2016.)
8. Medication Log: Helps to keep track of medications taken, dosage, side effects, etc.
    a. http://www.alz.org/national/documents/samplemedicationslog.pdf , (Accessed November 30, 2016.)
9. Appointment Log: Can help you before, during, and after a visit
    a. http://www.alz.org/national/documents/sampleappointmentlog.pdf (Accessed November 30, 2016.)
10. HIPAA and Health Information Privacy: A government site about privacy of health information and how it applies to you
    a. http://www.hhs.gov/ocr/hipaa/ (Accessed November 30, 2016.)
11. Doctor's Visit Checklist
    a. http://www.alz.org/alzheimers_disease_doctors_visit_checklist.asp (Accessed November 30, 2016.)
12. You can watch a quick video about how CareTree can help you at: https://youtu.be/XcR5REn-IO4. The assessment is available at: https://web.caretree.me/assessment. CareTree.me

SESSION 2: FORMAL AND INFORMAL SUPPORTS

LEARNING OBJECTIVES

- Discuss possible supports both formal and informally.
- Explain the importance of having a wide variety of supports.
- Describe how and why one might transition care.

SESSION INTRODUCTION

In preparing for session 2 on formal and informal supports, review chapter 15 in *The Caregiver Helpbook* as well as pages 37-52 in *Checklists for Family Caregivers* and chapter 4 in *Blueprint for Care*, should you have this reference. See Resources below for access to this material.

KEY MESSAGE

- Know that you are not alone in this challenge.

AGENDA

1. Welcome participants and have each check in sharing about time since last met.
2. Discuss informal supports and how to utilize them.
3. Discuss formal supports and how to utilize them.
4. Create list of formal and informal supports-suggested use of lists on pages 37-52 of *Checklist for Family Caregivers*. Please look in resources for this reference.
5. Introduction to Community Resource Finder.
6. Questions and answers.

SUPPLIES NEEDED FOR THE SESSION

- Alzheimer's Association website-Community Resource Finder
- *The Caregiver Helpbook*
- Checklist for Family Caregivers
- Internet access, projector, and a screen large enough for group to view

RESOURCES

- Community Resource Finder
  - http://www.alz.org/sandiego/in_my_community_60350.asp
- http:aging.slu.edu

- Hurme, S. B. (2015). *The ABA/AARP checklist for family caregivers: a guide to making it manageable*. Chicago, IL: American Bar Association, Senior Lawyers Division.
    - Checklist for Family Caregivers http://www.aarp.org/content/dam/aarp/entertainment/books/2015-04/Caregivers_Excerpt.pdf

- Keefe, D. M. (2012). *Blueprint for care: a practical guide to managing care for your loved one.* St. Louis, MO. Caring for Parents Together Pub.

SESSION 3: ACTIVIES OF DAILY LIVING (ADLs) AND INSTRUMENTAL ACTIVITES OF DAILY LIVING (IADLs) ISSUES

LEARNING OBJECTIVES

- Demonstrate possible effective ways of making meal time and planning easier on all.
- Discuss effective ways of bathing and possible solutions to bathing-related issues.
- Explain proper sleep hygiene for person with dementia and possible sundowning effects.
- Discuss the possible driving-related challenges.

SESSION INTRODUCTION

In preparing for session 3 on ADLs and IADLs, review chapter 18 in *The Caregiver Helpbook* and look at the resources noted in this session, then consider goals for yourself and the caregivers.

KEY MESSAGES

- The more knowledgeable you are about these activities, the easier it will be to complete them!

AGENDA

1. Welcome participants and have each check in sharing about time since last met.
2. Invite discussion regarding issues they are currently having with bathing, eating, and sleeping pertaining to their older adult.
3. Discuss bathing and proper ways to handle bathing of person with dementia.
4. Discuss eating and effective ways to handle eating for person with dementia.
5. Discuss proper sleep hygiene for older adult. Discuss sundowning with caregiver and possible behaviors.
6. Discuss driving issues and watch video: Driving and Dementia
7. Questions and answers.

SUPPLIES NEEDED

- *The Caregiver Helpbook*
- Handout on Coping Strategies for sleep issues and
- Caregiver Tips and Tools: The Battle of Bathing
- Internet access and a screen large enough for group to view

HANDOUTS

- Caregiver Tips and Tools: The Battle of Bathing
- Coping Strategies for sleep issues and sundowning

RESOURCES

- Driving and Dementia:
  - http://aging.slu.edu/index.php?page=Dr_Milta_Video
- Coping Strategies for sleep issues and sundowning
  - https://www.alz.org/care/alzheimers-dementia-sleep-issues-sundowning.asp#coping
- Caregiver Tips and Tools: The Battle of Bathing
  - https://www.alz.org/cacentral/documents/Dementia_Care_32-_The_Battle_of_the_Bathing.pdf

SESSION 4: BEHAVIOR MANAGEMENT AND COMMUNICATION

LEARNING OBJECTIVES

- Explain need to identify, manage, and prevent challenging behaviors.
- Describe effective ways to communicate with older adult
- Describe effective ways to reduce agitation
- Discuss paranoia-what one might expect and how to respond

SESSION INTRODUCTION

In preparing for session 4 on behavior management and communication, review the following:

1. The Alzheimer's Society Factsheet on communication, section on dementia and the section regarding agitation and anxiety in
2. *The Caregiver Helpbook*, sections on dementia, agitation and anxiety
3. HRSA YouTube on *Addressing Behaviors in Dementia* (20:03 minutes) decide if this will be shown to caregivers in group meeting or if it is for your information in leading discussion on behaviors.
4. Review the Alzheimer's Association: What to Expect and How to Respond.

KEY MESSAGES

- Using effective ways to communicate with your loved one will reduce frustration and help the relationship.
- Using effective ways to reduce agitation and paranoia will help reduce anxiety for yourself.

AGENDA

1. Welcome participants and have each check in sharing about time since last met.
2. Select items for the session from the following list:
    a. Watch HRSA video: Addressing Behaviors
    b. Ways to communicate with older adult-Handout communication fact sheet
    c. Watch video: How Do I Talk to Someone With Dementia?
3. Discuss ways to reduce agitation
4. Discuss paranoia and delusion-Alzheimer's Association *What to Expect and How to Respond*
5. Questions & Answers

SUPPLIES NEEDED FOR THE SESSION

- Alzheimer's Society Factsheet: Communication-section on Dementia

- *The Caregiver Helpbook*
- Alzheimer's Association: What to Expect and How to Respond
- Internet access and a screen large enough for group to view HRSA video

Handouts

- Factsheet-Communication-see resources for obtaining factsheet.

RESOURCES

- Video on communication:
  - https://www.YouTube.com/watch?v=jfWfJy3s0B4
- Alzheimer's Society Factsheet: Communication-section on Dementia
  - https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1128
- Alzheimer's Association: What to Expect and How to Respond
  - https://www.alz.org/care/alzheimers-dementia-suspicion-delusions.asp#respond
- HRSA video-Addressing Behaviors:
  - http://www.hollowaymedia.com/caregiver-modules/

SESSION 5: MAKING END-OF-LIFE DECISIONS WITH CARE-RECIPIENT

LEARNING OBJECTIVES

- Describe the importance of having conversation about one's wishes about death before it is needed and while all people are able to have the conversation and possibly role-play this conversation
- Demonstrate awareness about Advance Directives and importance for both the caregiver and one receiving care to have completed advance directives

SESSION INTRODUCTION

As you prepare for this session, consider reviewing *The Caregiver Helpbook* Chapter 21 "Loss, Grief, and End-of-Life Issuers". Consider a structure for role playing enable the group members to practice having these difficult discussions with family and friends.

KEY MESSAGE

- Have that conversation while you both still can!

AGENDA

1. Welcome participants and have each check in sharing about time since last met.
2. Share this website as you begin: https://ago.mo.gov/docs/default-source/publications/lifechoices.pdf?sfvrsn=6
3. Discuss importance of talking about one's wishes regarding one's death while the care-recipient is still able to have this conversation. Offer the "5 Wishes" if using this resource.
4. Discuss advance directivees and the need for them-see resources for obtaining forms and information. If wishes are not known or advance directives not completed before the care-receiver is unable to make these decisions, discuss legal options available to the caregiver.
5. Talk about ways to have the conversation with family.

SUPPLIES NEEDED FOR THE SESSION

- Internet access and a screen large enough for group to view
- If you will be having group members fill out "5 Wishes" you will need to order ahead of time-cost is between $2-$3/document.
- Advance Directive forms

HANDOUTS

- See supplies

RESOURCES AND/OR REFERENCES

- Suggestions for how to have the conversation:
  - http://www.nextavenue.org/talking-about-death-wont-kill-you/?utm_source=bestofnewsletter&utm_medium=email&utm_content=Best_of_September-15_Control&utm_campaign=
  - Dementia Guide Expert for families by University of Illinois at Chicago GWEP-mobile app-has end of life section https://appsto.re/us/h28L_.i
  - Forms and Aids to fill out and/or help with the conversation, including Advance Directives
    - https://ago.mo.gov/docs/default-source/publications/lifechoices.pdf?sfvrsn=6

- Other Resources and Aids:
  - https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/planning-end-life-care-decisions
  - http://www.aarp.org/home-family/caregiving/end-of-life/
  - https://www.everplans.com/articles/end-of-life-checklists
  - Five Wishes Information:
    - http://www.agingwithdignity.org/five-wishes.php
  - Suggested Readings:
    - A guide to end of life. (December, 2014). A beautiful death. *Consumer Reports*, 48-52
    - Powerful Tools for Caregivers. (2013). *The caregiver helpbook,* (3rd Ed.). Portland, OR: Powerful Tools for Caregivers.

SESSION 6: PHYSICAL AND PSYCHOLOGICAL SELF-CARE OF CAREGIVER

LEARNING OBJECTIVES

- Describe possible effects of caregiving on one's own health and well-being.
- Demonstrate and practice ways to protect one's health such as self-care plan.
- Demonstrate need for one's self-care and select a method to implement this next week.

SESSION INTRODUCTION

In preparing for Session 6 on self-care, consider watching the HRSA's "Caregiver Self-Care" (25:12 minutes) and review the references included at the end of this session in reference section.

KEY MESSAGES

- Discuss your self-care with primary care provider, including a discussion of any contra-indications to self-care plan
- Keep things SIMPLE, such as, simple foods
- Do what Works for YOU
- Mix it Up
- Have Fun

AGENDA

1. Welcome participants and have each check in sharing about time since last met.
2. Take short daily stress test
3. Practice a calm breathing technique
4. Watch the HRSA module on Caregiver Self-care if you decide it will be of help to your group. You might decide instead to use the PowerPoint with your own words.
5. Introduce Wellness/Health Menu and importance of self-care as a caregiver
6. Have each work on Wellness/Health Menu
7. Share Wellness/Health plan and where they might need help in staying with their plan. Name one area that they believe they could do for the next week that they are not already doing. Have group offer ideas.
8. Questions & Answers: Especially ask what participants would like to cover in the 7th session. The last session could be a celebration, an invited speaker on a particular topic or more discussion on what they are realizing they might need help with to be healthy caregivers.

SUPPLIES NEEDED FOR THE SESSION

- HRSA's YouTube on *Caregiver Self-Care* https://youtu.be/4jc0h0JhxWQ
- Wellness/Health Menu-form that can be used to help plan self-care.
- Internet access and a screen large enough for group to view

Wellness/Health Menu

What	How	When	Accountability
Nutrition			
Somatic Exercise			
Skill Building			
Personal Growth			
Social Support			
Relaxation or Meditation			
Spiritual			

HANDOUTS

- Wellness/Health Menu

RESOURCES AND REFERENCES FOR SELF-CARE

1. HRSA's YouTube on *Caregiver Self-Care* https://youtu.be/4jc0h0JhxWQ

2. Calm **Breathing** - AnxietyBC
   https://www.anxietybc.com/sites/default/files/CalmBreathing.pdf

3. Daily **Stress Test** - Self Quiz - anxietycentre.com
   . *http://www.anxietycentre.com/anxiety-tests/stress-daily-test.shtml*

4. Areas to Address for Stress Management and Self-care

- Strengthen yourself
  - Pay attention to nutrition & weight control
  - Don't smoke
  - Get proper exercise-being present
  - Set time aside for structured relaxation-meditation

- Change your mind
  - Labeling and relabeling a situation-the way you perceived can help or hurt-avoid guilt-you use CBT-use it on yourself
  - Use positive self-talk-what do you say about yourself??
  - Humor & laughter-energizing, freeing
  - Set boundaries and balance-taking personal breaks

- Organize yourself
  - Values clarification-take a big picture look at what is important to you, what gets you excited-set priorities
  - Assertiveness-be clear about what you want, be respectful in communicating it
  - Listen, empathy
  - Time management

- Build your support system
  - Lean on your philosophical/spiritual beliefs
  - Find people from different areas of your life who support you
  - Identify strengths and gaps in your support system

- Recommended to eat to stay calm
  - Low carbs, protein, avoid, caffeine, high sugar, soda and alcohol

- 9 Stress Busters to Possibly Try:
  - Soothe with food
  - Ask 3 questions-is it important? Is my reaction appropriate? Is this situation changeable?
  - Run from your problem-literally-exercise
  - Check your perspective
  - Take a "mini"-belly breath
  - Look to the light side-humor
  - Use less caffeine
  - Take a timeout
  - Do a daily ritual (e.g., a prayer, stand on your head or legs up the wall)

- Stress Symptoms-Body Response
  - Increased breathing,
  - Increased heart rate
  - Tense muscles
  - Release of energy producing hormones, e.g., adrenaline & cortisol (immediate fuel fight or flight, overtime physical/emotional issues)'
  - Fatigue
  - Lack of energy
  - Physical symptoms-headaches, upset stomach, heart palpitations, colds

SESSION 7: GROUP MEMBERS' CHOICE

(The following can be used as a master copy as you plan the agenda for this final meeting)

- Learning objectives
- Session Introduction
- Key messages
- Agenda: Welcome participants and have each check in sharing about time since last met. In planning this session always give time for discussion. This session could be a celebration after 6 weeks of meeting together; a speaker; or group members learning or sharing.
- Supplies needed for the session
- Handouts
- Resources and/or References

WELL BEING SCALE

BASIC NEEDS

Below are listed a number of basic needs. For each need listed, think about your life over the past three 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
2. Seldom, occasionally
3. Sometimes
4. Often, frequently
5. Almost always

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

Use only with permission by author Susan Tebb, Saint Louis University (314)977-2730

c 1993 Susan Tebb

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 three 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
2. Seldom, occasionally
3. Sometimes
4. Often, frequently
5. Almost always

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

Use only with permission by author Susan Tebb, Saint Louis University (314)977-2730

c 1993 Susan Tebb

CAREGIVER WELL-BEING SCALE

I. ACTIVITIES

Below are listed a number of activities that each of us do or someone does for us. Thinking over the past three 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 three 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

Use only with permission by authors Susan Tebb, Marla Berg-Weger and Doris M. Rubio, Saint Louis University (314)977-2730

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