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Caregiving for Persons with Dementia: Evidence-based resources for SLPs

Michelle S. Bourgeois

University of South Florida, msbourgeois@usf.edu

Caregiving has been defined as the provision of help with personal care needs and household chores to another person by unpaid relatives or friends, or trained professionals (National Alliance for Caregiving and the American Association of Retired Persons [NAC/AARP], 2015). Caregivers range in age, relationship, ethnicity, knowledge and skills, and response to their caregiving responsibilities (Bourgeois, 2018). Current reports estimate that there are more than 16.1 million family caregivers providing 18.4 billion hours of unpaid care to an adult in the United States (Alzheimer's Association, 2018), 67% of whom are non-Hispanic White families, 9% are Hispanic, 10% are African-American, and 5% are Asian (Alzheimer's Association, 2018). In addition, once caregiving demands exceed the family's abilities and the person is moved to residential care, professional and paraprofessional caregivers (i.e., nurses, nursing assistants, personal care, home health, and hospice aides) are responsible for providing quality care to residents with some form of cognitive impairment (Alzheimer's Association, 2018; Gilster, Boltz, & Dalessandro, 2018). It is estimated that by 2050, 20 million persons with dementia will need paid professional caregivers (Gao, Tilse, Wilson, Tuckett, & Newcombe, 2015; www.longtermcarelink.net). In the past three decades, there has been an increasing recognition that, as the population of persons with dementia grows, there is a critical need to educate and support their caregivers in order to prevent negative caregiver outcomes, and subsequently, negative patient outcomes. It has been observed that there are more similarities than differences among family and professional caregivers who are all "providing care for a vulnerable person they have come to know and care about" (Bursack, 2018, p. 2). Pearlin's conceptualization of the process of caregiving (the Stress Process model) linked the stressors of caregiving (i.e., the objective problems with the patient and their own subjective responses to these problems) with negative outcomes (e.g., depression, poor health, family conflict, financial strain, and institutionalization of the patient) (Pearlin, Mullan, Semple, & Skaff, 1990; Spillman & Long, 2009). This model continues to be used to explain the relationships between objective patient behaviors and subjective caregiver responses (Gitlin & Hodgson, 2015). As providers

Correspondence Address Dept. of Communication Sciences and Disorders, University of South Florida, 4202 E. Fowler Ave. Tampa, FL. 33620.

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gain experience with a variety of support options, it has become evident that the consequences of caregiving and caregiver needs vary as a function of the physical and cognitive changes in the person with dementia over time (Figure 1).

Many of the early dementia caregiving interventions addressed the reality that high levels of health issues and mortality were a consequence of caregiving. Caregivers of disabled spouses were reported to be at 63% increased risk of mortality when they had increased levels of caregiving strain (Schulz & Beach, 1999; Schulz et al., 2002; Schulz & Sherwood, 2008). Persons with dementia who exhibited challenging behaviors were at high risk of institutionalization (Gitlin, Kales, & Lyketsos, 2012; Spillman & Long, 2009). Thus, a plethora of caregiver interventions were developed and evaluated to address these concerns.

The rich literature base on interventions for dementia caregivers includes those that address the educational and psychosocial needs of caregivers through behavioral and environmental supports, skills training approaches, and multicomponent interventions that provide a menu of options for handling caregiving challenges (Gaugler & Burgio, 2016; Gitlin & Hodgson, 2015). In their review of 24 meta-analyses and systematic reviews representing over 200 interventions, Gitlin and Hodgson found promising, but modest improvements in caregiver knowledge, self-efficacy, depression, burden, reductions in anxiety, anger and hostility, and delayed institutionalization of the person with dementia. Multicomponent interventions (e.g., Mittelman et al., 2006; and REACH II, that included 5 components (reducing depression, decreasing burden, improving self-care, enhancing social support, and managing problem behaviors)), had the strongest effects on reducing caregiver burden and delaying time to institutionalization of the person with dementia (Belle et al., 2006; Czaja et al., 2009). Education interventions had the largest effects for improving caregiver knowledge; relaxation training had the largest effects on reducing caregiver anxiety. More recently, interventions designed to address the needs of families across the full continuum of the disease from early onset to end of life by reducing caregiver stress using yogic meditation (Lavretsky et al., 2013), transcendental meditation (Leach, Francis, & Ziaian, 2014), mindfulness meditation (Whitebird et al., 2013), and multicomponent interventions designed to impact burden, strain, and psychological morbidity using telephone delivery (Martindale-Adams, Nichols, Burns, Graney, & Zuber, 2013; Tremont et al., 2014), videophone (Czaja et al., 2013) or web-based platforms (Kajiyama et al., 2013) have reported reductions in burden, strain, psychological morbidity, as well as positive aspects of caregiving (e.g., preparedness, competency, and mastery). Interestingly, there is evidence that some people report positive effects from their caregiving chores and that positive experiences of caregiving can potentially buffer against some of the possible stress-related health consequences (Cohen et al., 2002; Roth, Fredman, & Haley, 2015). For example, caregivers have reported personal satisfaction in developing new skills in cooking, cleaning, paying the bills, and feeling that they are giving back to the spouse who did those chores in previous years. It has been reported that the most important factors for positive caregiving outcomes included (a) care recipients were involved in the intervention (i.e., when caregivers learned how to modify patient behaviors rather than just receiving a didactic approach), (b) programs were tailored to caregivers' multiple needs, (c) programs lasted over the duration of caregiving and were not time-limited, and (d) the dose, intensity, and focus of intervention was adjusted based on caregiver's risk or need profile (Gaugler & Burgio, 2016).

Professional and paraprofessional caregivers in nursing homes, assisted living, memory care, and other residential settings also have needs for education, support, training and resources related to the stressful conditions of their job. This workforce is predominantly female, provides 90% of resident care, and receives low wages for working in a stressful environment (e.g., demanding physical labor and disruptive behaviors; shortage of staff and high turnover) (Gilster et al., 2018). They also need recognition for a job well done (Hickey & Bourgeois, 2018). As with any other clinical population, speech-language pathologists (SLPs) have to be creative at finding ways to align caregiver training needs with the client's goals, and to provide education, communication training, skills training, and referral to resources within the limitations of their setting. The SLP whose client is a person with dementia must recognize that the caregiver(s) of this person also has(have) needs, and differing needs, depending on the stage of dementia of the person to whom they are providing care. It is within the SLP's scope of practice to provide education, support, and counseling to the families of their clients using many of the above-mentioned interventions; therefore, it is important for the SLP to know that these interventions exist and to seek out appropriate services to which to refer the caregivers of their clients (ASHA, 2018). Other interventions specifically developed for SLPs to implement with their clients with dementia and their caregivers, interventions to address the cognitive-communication challenges of dementia, will be described in this article.

The diversity of caregivers and caregiving needs demand that there is a menu of caregiver intervention options, tailored to the needs of the individual and the time course of their experience with the disease, as well as the setting of care. In the early stages some family caregivers only need or want education; later they may want more support from others, or even relief from caregiving in the form of respite care. Professional and paraprofessional caregivers often receive some basic information about dementia when hired to work in the nursing home or assisted living residence. However, skills training in person-centered care, communication, and interprofessional teamwork are continuing needs in order to meet the demands of a quality dementia care workforce (Douglas & Hickey, 2015; Gilster et al., 2018).

The purpose of this article is to provide an overview of evidence-based interventions focusing on caregivers of people with dementia living at home and in residential settings. The types of intervention approaches that are most common include: (a) educational (via face-to-face, telephone, online, multi-media, written materials), (b) skills training (problem solving, communication and behavior skills), c) psychosocial/emotional support (coping and self-care strategies), and (d) counseling.

Supporting Caregivers with Education

Many caregiver support programs begin with an educational component that details the signs and symptoms of specific types of dementia, the progressive decline and course of changes in communication and behavior, the relationship between communication and responsive behaviors, and strategies that facilitate communication (i.e., ways to reduce the demands on the impaired cognitive systems and ways to capitalize the relatively spared ones) (Mahendra, Hickey, & Bourgeois, 2018; Zeintz et al., 2007). As shown in Table 1, education comes in

many formats, including websites (e.g., alz.org), print materials (e.g., Health Professions Press), interactive multimedia training program for communication skills (Irvine, Ary, & Bourgeois, 2003), and internet- and telephone-delivered positive caregiving classes (Glueckauf et al., 2005).

Educational approaches have targeted many different outcomes including, improved caregiver knowledge of dementia (e.g., Brodaty, Roberts, & Peters, 1994), improved problem solving skills (Labrecque, Peak, & Toseland, 1992), reduced dysfunctional thoughts (Gallagher-Thompson & Steffen, 1994), improved coping (Gallagher-Thompson & DeVries, 1994), improved perception of the care recipient's quality of life (Fletcher & Eckberg, 2014), improved understanding of communication challenges in dementia (Purves & Phinney, 2012), and improved positive affect (Teri & Uomoto, 1991). Strong evidence of change was documented for reducing psychological morbidity, burden, depression, and improving well-being with a psychoeducational intervention (Thompson et al., 2007), and when education was delivered individually rather than in groups (Selwood et al., 2007). Nevertheless, caregivers desire continued education and support even when the educational program documents reduced stress and burden (Samia, Hepburn, & Nichols, 2012).

Supporting Caregivers with Training to Use the Effective Strategies Identified for Persons with Dementia

Memory-related communication deficits were among the first recognized symptoms of dementia (Bayles, Tomoeda, & Trosset, 1992). Memory books were found to be effective for improving the conversational interactions between persons with dementia and their caregiver and conversational partners (Bourgeois, 1990, 1992, 1993; Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001; Bourgeois & Mason, 1996). In the initial 1990 study, caregivers were taught to review the memory book with the person on a daily basis. In subsequent studies, this caregiver training was omitted without compromising the positive effects of increased factual statements and reduced ambiguous statements. With repeated replications of the 1990 study, it was discovered that written statements in the memory book (e.g., "My money is safe in the bank.") reduced the repetitive questions of the person with dementia. Bourgeois and colleagues (1997) taught spousal caregivers to use a variety of written cues to reduce repetitive questions. In 2001 Bourgeois and colleagues taught nursing aides to use memory wallets and reminder cards with residents with dementia during care routines and Dijkstra and colleagues (2002) documented positive changes in nursing aides' verbalizations when using memory aids. Instructions for caregivers to make and use written cues and memory aids with persons with dementia were published in Bourgeois (2014).

The first published communication-specific program for caregivers of persons with dementia in the Speech Language Pathology field was the *FOCUSED* program (Ripich, 1994; Ripich, Wykle, & Niles, 1995). Designed to provide caregiver training for communication facilitation, this interactive discourse model of conversational exchange consisted of six 2-hour modules designed for family and professional caregivers including discussion questions, videos, role play activities, a caregiver's guide, and a reminder card with strategies. Topics of discussion included: Alzheimer's disease (AD) and associated

communication and language decline; differences among normal forgetting, depression, and AD; interpersonal skills and value of such skills in care of persons with AD; cultural and ethical considerations; stages of AD and communication characteristics, including how to assess and recognize patients at each stage and maximize their communication; and use and evaluation of FOCUSED strategies for promoting effective communication between caregivers and persons with AD (Ripich, 1994). This educational and skills training program first delineates the course of the disease and its impact on communication and then it teaches a specific communication strategy using the FOCUSED mnemonic, as shown in Table 2. Both family and professional caregivers demonstrated increased knowledge across all areas with significant gains in communication strategies. They also reported improved communication satisfaction and a greater sense of “feeling in control” during communication as compared to prior feelings of frustration. Fewer communication problems and increased AD knowledge maintained at the one-year follow-up (Ripich, 1994; Ripich, Wykle, & Niles, 1995; Ripich, Zioli, & Lee, 1998).

Another approach for improving communication skills has been reported by Small and Gutman (2002) who suggested a list of useful strategies to teach staff (Table 3). Mason-Baughman and Lander (2012) evaluated a caregiver intervention that exposed caregivers to 11 communication strategies, including Small and Gutman’s 10 strategies and an additional strategy of using books, pictures, and games to enhance communicative interactions. Comparing pre- and post-training questionnaires, caregivers were found to increase the use of 9 of the 11 communication strategies from pre- to post-training, but significant differences in use were noted for only two strategies, eliminating distractions during interactions and using materials (books, pictures, and games).

In the early years of dementia caregiving interventions, it was not clear whether it was more effective to teach caregivers specific skills to modify their own caregiving behaviors or to modify the behaviors of the person with dementia. With funding from National Institute on Aging, Bourgeois and colleagues (2002) developed a randomized control trial evaluating two different approaches to caregiver skills training of spouses living at home with a spouse with dementia. One group of caregivers received patient-change training that involved having the caregivers identify the three most concerning problems of their person, keeping daily frequency data about those behaviors, and then teaching them specific strategies to reduce the frequency of those behaviors. For example, they were taught a variety of personalized strategies such as the use of a written card to decrease repetitive questions, a message board to decrease phone calls, activity stations to decrease wandering, and the use of memory books and activities to increase engagement (Bourgeois et al., 2002). The second group received self-change training which were strategies to improve their own responses to caregiving, and their mood. These included (a) increasing positive events in their life (Table 4), (b) a problem-solving strategy (Table 5), and (c) a progressive relaxation strategy. An attention-control group only received social phone calls and educational materials. Caregivers in all 3 groups took daily data on the three most stressful behaviors of their spouse with dementia.

Both training groups learned skills that resulted in improved targeted behaviors (reduced patient problem behaviors and improved caregiver mood, respectively) in comparison to the

control group. Other outcomes, such as depression, perceived stress, caregiver strain, and self-efficacy, showed modest effects (Bourgeois et al., 2002). Caregivers in the patient skills training group demonstrated success in changing the most commonly reported challenging behavior, repeated verbalizations, using individually designed written cues (Bourgeois et al., 1997). All caregivers in this study completed daily data sheets on the frequency of problem behaviors; interestingly, caregivers in the control group reported modifying their behavior or the environment because of the objective nature of the data collected. For example, one wife, who was tallying the frequency of her husband's negative outbursts at the grandchildren, decided to limit the number of grandchildren per visit and thereby reduced outbursts to zero. Changes in responses to behavior due to data collection underscore the importance of taking baseline data before implementing an intervention program, and empowering caregivers to do so.

The increasing number of communication-based dementia caregiver interventions has supported systematic reviews in order to identify the most effective ones for specific caregiving populations. Egan and colleagues (2010) reviewed 13 studies; eight examined the effects of memory books, three evaluated training programs, and two reported on the outcomes of activity programs. The use of memory aids with caregiver training was recommended for use by clinicians; intensive caregiver training was not supported; and only a daily group intervention that focused on communication stimulated by the preparation and sharing of breakfast was recommended (Pietro & Boczeko, 1998).

Eggenberger and colleagues (2013) in their systematic review of 12 communication skills training interventions involving 831 persons with dementia, 519 professional caregivers, and 162 family caregivers found improvements in the quality of life and wellbeing of people with dementia cared for in both nursing homes and home-care settings. Significant increases in professional and family caregivers' communication skills, competencies, and knowledge compared to those in non-intervention conditions led to increased positive behavior and satisfying interactions of the person with dementia. In addition, professional caregivers reported a greater feeling of control and enjoyed the opportunity to learn more about their patients. In one of the studies reviewed, Bourgeois and colleagues (2001) designed a study to demonstrate that nursing assistants (NAs) ($n = 64$) could improve both the quantity and the quality of communicative interactions with their residents with dementia using external memory aids (Allen-Burge et al., 2001; Bourgeois et al., 2001). Two hallways of five nursing homes were randomly assigned to the communication-enhancing intervention that included a staff management component, or to the usual care control condition. NAs in the intervention group easily learned to use strategies during care interactions and they increased and maintained the use of effective strategies over time (Burgio et al., 2001). Residents in the intervention group produced more positive statements during observation periods and engaged in more verbal interactions with other residents. Lessons learned from this study provide suggestions for success for SLPs interested in staff training: (a) Establish rapport with staff, (b) Offer to help with challenging behaviors and challenging residents, (c) Partner with NAs by soliciting their advice and ideas for specific residents, (d) Provide workshops on communication skills and strategies (as well as other topics such as swallowing, end of life communication) to staff and families, and (e) Involve caregivers in treatment goals to facilitate generalization and maintenance of trained skills.

Overall, it is important for SLPs to be the point-person for in-servicing the staff about communication and dementia. This interaction will make a positive difference in how staff interact with the SLP, and for getting them to see the value of skilled services. In long-term care settings SLPs will have opportunities to conduct staff in-services in order to teach specific person-centered communication, cognition, and swallowing techniques to professional and paraprofessional caregivers (Douglas, Bourgeois, & Hickey, 2018). For example, teaching nursing aides to use spaced retrieval prompts with persons with dementia for whom spaced retrieval is effective can improve task performance at both the impairment and activity/participation levels of functioning (Hopper et al., 2013). Benigas and Bourgeois (2016) documented the effects of teaching persons with severe dementia to use external memory aids to follow safe swallowing techniques during mealtimes. Nursing aides were subsequently taught to use the spaced retrieval prompts to maintain the behaviors. Therefore, SLPs have an ethical responsibility to train caregivers in long-term care to provide the highest quality of care to persons with dementia through evidence-based approaches like spaced retrieval. The success of staff training, however, depends on a good understanding of adult learning principles (Douglas, Bourgeois, & Hickey, 2018), and institutional culture and climate (Douglas & Hickey, 2015). Without these, individual buy-in and carryover of training will be lacking. Key factors for success in staff training include having a staff management component comprised of providing one-to-one training and direct observation of trained skills, setting clear goals and task activities, training staff behaviors to a criterion level, monitoring staff performance frequently with supportive feedback, and providing consistent consequences for staff performance (Burgio & Burgio, 1990; Burgio & Scilley, 1994). When face-to-face training is not possible, online internet training programs for professional caregivers have been evaluated and shown to be effective for increasing knowledge of dementia and communication skills; however, without the opportunity to observe the enactment of skills in person, it is not certain that this intervention modality will achieve the desired effects (Bourgeois & Irvine, 1999; Irvine, Ary, & Bourgeois, 2003; Irvine, Bourgeois, Billow, & Seeley, 2007).

Supporting Caregivers with Psychosocial/Emotional Support

Caregivers of persons with dementia, or any type of chronic illness, may benefit from interacting with others who are, or have been, experiencing similar symptoms in their care recipients. Not only can caregivers share solutions to commonly occurring problems, but they also provide emotional support in the knowledge that they are not alone in coping with this disease. Positive effects for a variety of psychological outcomes have been reported for support groups (both in-person and online), family and individual psychotherapy, and other counseling models. In their meta-analysis of 78 caregiver interventions, Sörensen, Pinquart, and Duberstein (2002) found that psychoeducational and psychotherapeutic interventions showed the most consistent short-term effects on all outcome measures including caregiver burden, depression, subjective well-being, perceived caregiver satisfaction, ability/knowledge, and care receiver symptoms, compared to support group and respite interventions. Many variables, however, moderated these effects, including number of sessions, setting, care receiver age, caregiver age, gender, type of caregiver-care receiver relationship (spouse vs adult child), initial burden, and study characteristics. Similarly,

Chien and colleagues (2011) in their meta-analysis of 30 support group studies (1998–2009) showed a significant positive effect on caregivers' psychological well-being, depression, burden, and social outcomes as a result of group participation. Also, the type of approach, and length and intensity of group sessions had a significant impact on outcomes. Positive effects on psychological well-being and depression are more frequent in women than men, and older caregivers have fewer positive social outcomes than younger caregivers (Burgio, Gaugler, & Hilgeman, 2016; Rose-Rego, Strauss, & Smyth, 1998).

The importance of this research is that SLPs are able to directly, or indirectly through referrals, provide a menu of supportive options for caregivers of their patients with dementia, or other diseases, that is backed with evidence. Understanding the potential emotional and psychosocial barriers that might prevent acceptance and implementation of caregiving recommendations, as well as the educational and cultural factors, is necessary for appropriate matching of caregivers with potentially effective interventions. For more information about the range of psychosocial interventions available for family caregivers, see Bourgeois (2018), and for professional and paraprofessional caregivers, see Douglas, Bourgeois, and Hickey (2018). Table 7 provides examples of online support group resources.

Supporting Caregivers with Counseling

In contrast to providing emotional support and resources, counseling is a more direct intervention approach. While a review of the many different counseling approaches is beyond the scope of this article, the positive psychology approach described in Holland and Nelson (2014) may resonate with many SLPs working with caregivers to achieve the goal of a quality life in spite of dementia. They advocate for coaching caregivers to use explicit ways to increase resilience and optimism for coping with catastrophes in life. They recommend that SLPs help translate supportive information into satisfying and successful actions by coaching that is grounded in “wellness,” emphasizing normalcy and health, such as using humor as a coping mechanism and creating moments of success and joy. The process involves correctly identifying problems, teaching problem-solving skills, developing and implementing action plans, and differentiating problems within a person’s control from those that are beyond control (Holland & Nelson, 2014).

It is important also for the SLP to look for “counseling opportunities” in situations where communication has become difficult for the client and caregiver (Holland & Nelson, 2014). For example, at the end of life, when the caregiver may want to have meaningful communication with his/her spouse, Holland and Nelson advise SLPs to provide facilitative activities or communication tools and support. Hickey and Bourgeois (2018) discuss the role of SLPs in providing person-centered care to maintain and enhance quality of life when communication, cognitive, and social functioning are limited at the end of life. Alternative communication strategies, including visual and environmental supports, will be needed to understand the person with dementia’s needs, desires, and preferences for topics ranging from conversation partners to comfort measures to advance care directives. Thus, an integral part of SLPs’ clinical responsibility with persons with dementia (ASHA Roles and Responsibilities, 2016) is to provide the basic tools to help clients achieve their goals, which can be done by coaching caregivers through the process of gaining skills in caregiving.

Implications for SLPs

In conclusion, SLPs have a critical role in educating and counseling caregivers of individuals with dementia to enhance the overall cognitive communication care of our clients. Due to the diversity of caregiver types and situations, caregiver services must be person-centered and integrate a wide range of evidence-based approaches (Samia, Hepburn, & Nichols, 2012). The described research emphasizes the need for SLPs to educate caregivers specifically on understanding the relationship between responsive behaviors and communication and providing training to criterion and feedback on strategies to enhance communication (e.g., visual cues and using short sentences) (Egan et al., 2010; Eggenberger et al., 2012). SLPs should involve the caregiver in the client's goals to promote generalization. For example, the caregiver can be taught to use spaced retrieval, memory books, or written cues to improve communication with the client and reduce responsive behaviors. In addition, caregivers must also be taught self-change strategies to improve their own health, mood, and attitudes toward caregiving. SLPs have an important role in supporting the psychosocial needs of caregivers by offering caregiver counseling sessions in group-format that provide individuals with an opportunity to share and learn from one another who have similar experiences (Chien et al., 2011). Counseling methods, such as the positive psychology approach (Holland & Nelson, 2014), are necessary for SLPs to help caregivers gain skills to enhance their overall wellness and the goals of individuals with dementia. Thus, by SLPs delivering caregiver education, skills training, and counseling interventions, the potential for improving the quality of life of individuals with dementia and their caregivers is increased.

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Figure 1.

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Table 1.**Educational Resources for Caregivers**

Internet Resources: Useful information about symptoms, behaviors, and treatments for different dementia subtypes.

- Alzheimer's Association: www.alz.org
- Alzheimer's Foundation of America: www.alzfnd.org
- Online Caregiver Magazine: www.caregiver.com
- National Institute on Aging: www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet
- Mayo Clinic: www.mayoclinic.org/diseases-conditions/alzheimers-disease/home/ovc-20167098
- Medline: www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html

Books and Materials: Sources of Alzheimer related materials, activities, and workshops.

Books by Jennifer Brush, MA, CCC-SLP available at www.brushdevelopment.com

- Getting Started with Montessori Volume 2: It Takes a Team | Empowering Care Partners to Implement Montessori for Aging and Dementia
- Getting Started with Montessori Volume 1: Practical Life Activities for Older Adults
- A Day on the Wind Seeker
- I Care: A Handbook for Care Partners of People with Dementia
- Spaced Retrieval Step by Step | An Evidence-Based Memory Intervention
- Creative Connections in Dementia Care™
- Environment and Communication Assessment Toolkit for Dementia Care (ECAT)

Books by Cameron Camp, PhD available at www.cen4ard.com

- A Therapy Technique for Improving Memory: Spaced Retrieval
- Montessori Based Activities for Persons with Dementia, Vol 1
- Montessori Based Activities for Persons with Dementia, Vol 2
- Hiding the Stranger in the Mirror
- Teaching Empathy and Conflict Resolution to Persons with Dementia
- Reading Roundtable: reading materials for persons with dementia

Books by Gail Eliot, MA available at www.DementiAbility.com

- DementiAbility Methods: The Montessori way
- Memory Aids for Dementia
- Checklist for Change
- DVDs and reading materials for persons with dementia

Other sources of books and materials for dementia caregiving: www.healthpropress.com

Courses and Training

CD-Rom and Videotape Inservice training programs (Irvine, Ary, & Bourgeois, 2003) available from ORCAS, Oregon Center for Applied Science, Inc., Eugene, OR.

Montessori-based Dementia Training: www.BrushDevelopment.com, www.cen4ard.com, www.DementiAbility.com

Table 2.

The FOCUSED mnemonic (Ripich, 1994)

•F = Face person directly, call by name, gain and maintain eye contact   •O = Orientation to topic of conversation   –Repeat topic/key words   –Repeat sentence exactly   •C = Continuity (maintenance of topic)   –Continue same topic for as long as possible   –Prepare person if new topic must be introduced   •U = Unsticking for overcoming communication blocks   –Ask questions to clarify (e.g., “Do you mean...?”)   –Repeat person’s sentence using correct word   •S = Structure of questions   –Use choice rather than open-ended, with no more than two options   –Provide options that person would like   •E = Exchange ideas, needs, and feelings   –Keep up normal exchange of ideas   –Begin conversations with pleasant, normal topics   –Ask easy questions that person can answer, and give clues to answer   •D = Direct types of verbal messages   –Use simple, short sentences in active voice   –Use specific, concrete nouns   –Communicate in as many modalities as possible

Table 3.

Useful dementia communication strategies (Small & Gutman, 2002)

- Use short, simple sentences
- Speak slowly
- Ask one question or give one instruction at a time
- Approach slowly from front; establish eye contact
- Eliminate distractions (e.g., TV and radio)
- Avoid interrupting; allow plenty of time for responding
- Use yes-no rather than open-ended questions
- Encourage circumlocution during word-finding problems
- Repeat messages with the same wording
- Paraphrase repeated messages

Table 4.

Increasing Pleasant Activities Strategy (Bourgeois et al., 2002)

1. Decide what activities and events are pleasant.
2. Decide how often and when you might like to do these PLEASANT ACTIVITIES.
3. Identify obstacles that might prevent you from doing what you planned.
4. Find ways to overcome the obstacles through PROBLEM SOLVING.
5. Start engaging in your planned PLEASANT ACTIVITIES.
6. CONGRATULATE YOURSELF. For doing something good for yourself!!

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Table 5.

Problem-Solving Strategy (Bourgeois et al., 2002).

PROBLEM-SOLVING STEPS
1. Achieve a CALM STATE OF MIND
2. DEFINE THE PROBLEM as specifically as possible.
3. LIST as many SOLUTIONS as you can think of.
4. Consider. PRO's and CON's, PICK THE SOLUTION that seems to have the best chance of working.
5. Make a plan and CARRY OUT THE SOLUTION.
6. SEE HOW WELL THE SOLUTION WORKS. If necessary, repeat steps 1–6 until a satisfactory solution is found.

Table 6.

Communication Skills and Staff Management Skills (Burgio et al., 2001).

Communication Skills	Staff Management Skills
<ul style="list-style-type: none"> •1-hour staff in-service <ul style="list-style-type: none"> –Behaviors related to dementia –Ways to prevent/respond to challenging behaviors <p>Approach techniques</p> <p>Announce every activity</p> <p>Use one-step, specific instructions</p> <p>Use positive statements</p> <p>Use communication cards to explain care activities</p>	<ul style="list-style-type: none"> •Set clear goals and task activities •1:1 staff training of positive communication techniques to 80% performance criterion using Checklist <p>•CNA self-monitoring system</p> <p>•Licensed practical nurse (LPN) monitoring and feedback to NAs</p> <p>•Apply support, feedback, and consequences for staff performance</p>

Table 7.**Online Support Groups****Online Support Groups**

- Alzheimer's Association Online Community: www.alzconnectAd.org/
- AlzOnline: <http://alzonline.php.ufl.edu/>
- Empowering Caregivers: www.care-givers.com/
- Elder Care Online: www.ec-online.net/