

# A Guide To Community Resources For Dementia Care

Francine C. Parfitt, MSH CCRC

While a formal diagnosis of Alzheimer's disease or a related form of dementia is rarely unexpected, family caregivers are seldom adequately prepared for the voyage that lies ahead. As progressive disorders, the dementias require a care plan that is flexible, adaptable, nurturing and above all multi-disciplinary. While most care is provided by family caregivers, with current estimates at more than 15 million adults providing care to relatives,<sup>1</sup> seldom does one caregiver have the ability or fortitude to provide the level of care necessary as the dementia progresses. The best options for assistance are provided through community resources that aim to support the caregiver while allowing the patient to remain an integral part of the family unit.

Once an assessment has been conducted and a diagnosis of probable Alzheimer's disease or a related form of dementia has been made, a few important issues should be addressed. First and foremost is there a primary, family caregiver available? If so, does this individual understand the diagnosis and prognosis? Is this caregiver physically able to care for their loved one? If the responses to these questions are negative, then the best solution may be to have a social worker or a geriatric care manager intervene to establish a care plan to assure safety and stability for the patient. If the responses are positive, then having the ability to suggest appropriate community resources is a major advantage in initiating a support system for the patient and caregiver alike.

Community resources represent any of the services available within a community setting that enhance an individual's quality of life, understanding of a pertinent health issue and ability to cope with the issues at hand. As dementia is a progressive disorder, accessing appropriate community resources is most commonly viewed along a continuum based on the severity of the dementia. Community resources run the gamut from information and referral services, to adult day care, to residential care options.

During the phase of dementia that one may classify as pre-diagnosis the resources most commonly sought are information. During pre-diagnosis a family may be struggling with the decision to see a physician and may also be experiencing a sense of denial by trying to overlook, and possibly cover-up for their loved ones failings. At this time a caregiver may contact the primary physician to inquire as

**Francine C. Parfitt, MSH CCRC is an Associate in Neurology Research and Program Director of the Memory Disorder Clinic at Mayo Clinic Jacksonville.**

**This paper is supported in part by the State of Florida Alzheimer's Disease Initiative Program.**

**Table 1. Triggers To Indicate Need For Dementia Evaluation**

<b>SYMPTOM</b>	<b>DESCRIPTION</b>
<b>MEMORY</b>	Consistent lapses in short term memory that appear to be increasing and are noticeable to those familiar with the individual's prior abilities.
<b>LEARNING</b>	Difficulty in learning and storing new information. Tendency to repeat the same stories or asks the same question.
<b>ORIENTATION</b>	Becoming lost in one's neighborhood. Forgetting appointments and trying to cover-up for the actions with humor or placing blame on another.
<b>BEHAVIOR</b>	Changes in grooming, hygiene and personality. Difficulty in handling tasks that had been commonplace.
<b>JUDGEMENT</b>	Inappropriate or uncharacteristic decision making. Inability to reason or understand the potential danger of a situation.
<b>LANGUAGE</b>	Difficulty with word finding or word usage.

to the appropriate steps to take or may also contact a memory disorder clinic or a geriatric medical center. Either of these resources would be able to describe the key points that would trigger an evaluation and recommend the components of a full dementia evaluation.

Triggers indicating that an evaluation for memory may be appropriate are indicated in Table 1. Overall the pattern suggestive of dementia is a gradual loss of cognitive abilities, which is progressive in nature and noticeable to those familiar with the individual while the affected individual may not be aware of their shortcomings.

Once the diagnostic evaluation commences, both the patient and caregiver will need support and guidance. At this point one may offer general information on dementia and initiate a discussion on the availability of assistance, a support system and the need for a long-range plan. This is also an appropriate time to encourage the involvement of close family members especially the adult children. If after the evaluation, a diagnosis of probable Alzheimer's disease or a related form of dementia can be made, then the time is right to direct the patient and caregiver to the resources that are most appropriate.

Starting with the mildest form of memory loss which may be classified as Mild Cognitive Impairment, the primary issue would be the need to provide encouragement and support and suggest that the patient attempt to maintain as much of his/her regular routine as possible as long as the activity remains enjoyable. Withdrawal should be avoided as it can lead to depression. With a diagnosis of Mild Cognitive Impairment it is appropriate to suggest consideration of a consultation with an attorney to be certain that legal and financial documents are in order. Key documents to consider are a durable family

power of attorney, a living will, a living trust, and a designation of health care surrogate. Planning ahead may help a family avoid the emotional distress of either a guardianship hearing or making decisions at less than optimal times.

If a diagnosis of Mild Dementia can be made, then it is imperative that the patient and caregiver consult with an elder care attorney if this has not been previously accomplished. An elder care attorney will be able to address advance directives, trusts, spousal impoverishment issues, Medicaid qualifications and other financial and legal matters that will influence life care plans. Planning ahead allows the patient to participate in the decision making process. Creating a legal and financial plan early on also avoids the possibility of obtaining a guardianship at a later date. At this time, a caregiver also needs to have the opportunity to attend an educational program or possibly a support group if it is geared towards early onset patients. Some communities offer support groups for early onset patients as well, and this could be a consideration depending on the personality of the patient. Also at the Mild Dementia stage, it is often a good idea to contact organizations such as Meals on Wheels, alternate transportation services and volunteer respite providers as a means of providing initial support and assistance on the homefront. Many individuals with mild dementia may continue to fare well at senior community nutrition centers. If attending a senior center alone, consideration should be given to obtaining an identification bracelet through the Alzheimer's Association or the Medic Alert project. There are community centers funded in part through the Older Americans Act where seniors can obtain a hot noon meal and participate in independent activities. Transportation is usually available to the community center closest to one's residence.

As dementia progresses from mild to moderate, the caregiver may often require as much care and attention as the patient. Caregivers at this point can feel overwhelmed and their own health may be in jeopardy due to personal neglect. According to a survey of 500 caregivers conducted for the national Alzheimer's Association, caregivers were shown to be at high risk of developing symptoms such as nervousness, exhaustion, decreased appetite, and difficulty sleeping.<sup>2</sup> In addition, caregivers may also become depressed. Self-reported rates of caregiver depression range between 30% and 55%, which is two to three times the rate in comparable demographic groups.<sup>3</sup> Other caregivers may develop negative coping skills such as poor nutritional habits, increased use of alcohol, prescription and over the counter medications. According to reports by the National Alzheimer's Association, caregivers make 46% more visits to their physicians, use 71% more prescriptions drugs, and are more likely to be hospitalized when compared with controls.<sup>4</sup> A form of respite care is indicated at this time.

Respite care simply means relief for the primary caregiver. Respite care is available either in the patient's home or at a facility such as an adult day center or senior center. In-home respite care is usually provided in blocks of time that are convenient for the caregiver. Either a companion or a certified nursing assistant provides respite care in the home depending on the needs of the patient. The advantage of in-home respite is that the patient remains in the familiar environment of his or her own home and the caregiver does not need to transport the patient to another location. The disadvantage of in-home respite care is that often, if the caregiver elects to remain at home, the patient tends not to bond with the respite provider, as he/she would prefer to shadow the caregiver. Another disadvantage is the lack of socialization and formal activities. Facility based respite care is usually provided by adult day care centers. These centers may follow either a social or therapeutic model. A social model typically provides activities that promote social interaction among the participants; while a therapeutic model tends to incorporate recreational therapy, occupational therapy and a variety of modalities to enhance a participant's capabilities.

Adult day care programs may be dementia specific or they may serve a varied population. Programs usually operate weekdays from early morning to late afternoon or early evening. Fees include meals and snacks. If transportation is provided an additional fee is usually charged. Reimbursement and financial assistance may be available through several funding sources.

As the dementia continues to progress, the next step along the continuum of care could possibly be an assisted living facility or extended care center. Assisted living facilities are a form of congregate living enhancing independence and autonomy, while providing assistance with the activities of daily living. Recognizing the special needs of the dementia population has prompted the assisted living industry to focus on dementia care, and this has resulted in dementia specific assisted living facilities. In addition, many assisted living facilities now have either extended care components or limited nursing home licenses that allow care to be provided into the severe phase of the disease process. Many of these assisted living facilities will initiate hospice care when, and if, appropriate. One advantage of the extended level of care is that the chance of the patient relocating is minimized.

Perhaps the most difficult challenge in caring for a loved one with Alzheimer's disease or a related dementia is the prospect of nursing home placement. For many elderly caregivers long time promises were made never to place one another in a nursing home and compromising this produces much dread and guilt on the caregivers part. Nursing home placement is often viewed as giving up on the patient and not doing enough when actually most primary caregivers jeopardize their own health long before considering nursing home placement. Selecting a nursing home may focus on the following criteria:<sup>5</sup>

- **Availability:** Is a bed available at the care level required when placement is anticipated?
- **Special Care Needs:** Nursing homes may have a dementia specific unit or residents with dementia may be blended into the frail and skilled care population. One must consider if the environment and activity schedule is created to meet the needs of residents with dementia. Is there adequate space for wandering? Is it a secure unit? Are there specific criteria for admission to and discharge from this unit?
- **Philosophy of Care/Mission:** Does the long-term care facility support the family's wishes for advance directives? Religious and cultural preferences must also be considered.

- **Geographic location:** Although the primary caregiver's role will change with the nursing home placement, the caregiver remains active in the care plan. Therefore, consideration should be given to how convenient the nursing home is for the caregiver.
- **Method of Payment:** Long term care is extremely expensive with the average cost near \$4,000 per month. An intake counselor at the nursing home will discuss payment options such as Medicaid; long term insurance and if appropriate the role of Medicare. Most care for residents with dementia is considered custodial care and thus most likely would not be covered by Medicare.

Timing for nursing home placement varies from family to family. Perhaps the most important consideration is the health of the primary caregiver. When the caregiver is no longer able to receive proper rest and is neglecting their own health and well-being, then the status of both care recipient and caregiver are in jeopardy and support should be provided to ease the transition to nursing home care. Another important consideration is safety. If the care recipient is constantly wandering away or demonstrating aggressive behavior towards the caregiver then once again nursing home placement should be considered.

Selecting the right nursing home is a very difficult decision and is best done with advance planning before a crisis strikes. It is suggested that families visit facilities prior to the time of placement. Speaking with other families also is helpful in learning about a particular facility. Once a placement has been made the family and facility staff must

Table 2. Resources		
<i>Northeast Florida Resources</i>		
Northeast Florida Alzheimer's Association	Information and referral, literature and support groups. Wanderer's identification program.	(904) 398-5193
Mayo Clinic Jacksonville Memory Disorder Clinic	Training and education, information and referral, clinical evaluation and research opportunities.	(904) 953-7103
Northeast Florida Area Agency on Aging	Umbrella agency for senior services in northeast Florida	(904) 786-5111
Urban Jacksonville/Community Care for the Elderly	Personal care services, homemaking services and respite care.	(904) 798-9500
<i>National Resources</i>		
National Alzheimer's Association	Literature, clearinghouse for information, SAFE-RETURN program.	(800) 272-2900
Alzheimer's Disease Education & Referral Center (ADEAR)	Source of information, literature and research updates.	(800) 438-4380
Eldercare Locator	Refers to local groups familiar with home care, transportation and nutrition programs for the elderly.	(800) 677-1116

work together as a team for the benefit of the resident. Becoming involved with the family council at the nursing home is another possibility. For problems in long-term care, one may contact the Long Term Care Ombudsman or consult with the resident council at the facility.

For the final stages of dementia care, hospice care may be appropriate, but this is at the recommendation of a physician and subsequent approval by hospice. Criteria for hospice usually requires a six-month prognosis and features of severe, late-stage dementia such as non-ambulatory, non-communicative and difficulty accepting nutrition and hydration.

In summary, providing care for a patient with dementia requires a team approach with a primary care physician as the team leader with the primary caregiver alongside. However, community based providers such as adult day care, respite providers, companions and friendly visitors are a vital part of the team. Support is the greatest element.

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