“Caregiving Issues for those with dementia and other cognitive challenges.”

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Goals & Objectives

• Understand how the caregiver is effected by the diagnosis of dementia.
• Develop a care plan that has meaning for the caregiver.
• Create ways for the caregiver to develop routines with loved one.
• Understand the most recent journal articles to assist caregivers in their daily lives.
Words from the caregivers

• “I’ve cared for Dad, 88, for five years without any help from our family. Last year, I started taking off every Tuesday afternoon to have a good time for myself—I go to the hairdresser, run errands, shop. It doesn’t do any good; I am still stressed and exhausted. Is it always going to be like this???”
More words from caregivers

• “We can’t agree on what to do. I want to keep Mother at home. My sister wanted her in a nursing home. We don’t even agree on what is wrong.”

• “My father has always been the head of household. How can I tell him he can’t drive anymore?”
• “My brother doesn’t call and he refuses even to talk about it. I have to take care of Mother alone.”
• “I get so depressed. I cry. Then I lie awake at night and worry. I feel so helpless.”
• “I feel like a fool washing lady’s underwear in the laundromat.”
Some problems seem …

- Insurmountable because they involve change in roles and the need to learn new tasks.
- Learning that new task when the person is upset and tired can be difficult.
Caregiver observation . . .

• “I know my husband can’t manage his money anymore, but it seems like it is taking away the last of his manhood to take away that checkbook. I know I have to, but I just can’t seem to do it.”
Dealing with the Diagnosis

• Caring for a person with AD or other related dementia in the home is a difficult task and can be overwhelming at times. Each day brings new challenges as the caregiver copes with changing levels of ability and new patterns of behavior.
Dealing with Diagnosis

• When the diagnosis is given to the family, the news is always stressful, frightening and overwhelming.
• Roles, responsibilities, and expectations within the family change when a person becomes ill with dementia.
Roles vs. responsibilities

• IMPORTANT to know the differences between these two words: Responsibilities are the jobs each person has in the family while roles include who you are, how you are seen in the family and what is expected of you. (role means a person’s place in his/her family i.e. head of household, Mom or the person everyone turns too)
Roles vs. responsibilities

• Learning new responsibilities, such as keeping a checkbook/washing clothes, can be difficult when also faced with the many day-to-day needs of a confused person.

• However, changes in roles are more difficult to adjust to or accept.
Role changes

• Relationship between a husband and wife change when one of them becomes ill. Some changes can be sad and painful; others can be enriching experiences.
Learning new skills & responsibilities

• Learning new things require energy and effort and means added work to what you already have to do.

• But most of all is the realization that you must take a job away from your spouse may symbolize all of the sad changes that have taken place
Adult child’s words . . .

• “I can’t tell my mother she shouldn’t live alone anymore. I know I have to, but every time I try to talk to her she manages to make me feel like a small child who has been bad.”
Parent and child relationships

• Change happens when the parents is diagnosed with dementia and now the child is in charge.
• This is role reversal and this can be one of the most difficult to adjust for both parties because we still feel that our parents are parents.
Parent/child roles

• Sometimes there are not good relationship between the parent and child.
• Sons and daughters have different roles as seen in the caregiving household.
• Adult children may feel embarrassed by the physical tasks for caring for a parent
Person with dementia has changes too.

- The person with dementia must adjust to his/her changing roles in the family.
- The parent must give up some independence, responsibility or leadership in the family—
- Depression or anger realizing that some abilities are waning and he/she may not want to change or recognize the decline.
Emotions that caregivers feel . . .

- Anger
- Embarrassment
- Guilt
- Grief
- Depression
- Worry
- Physical issues i.e. fatigue & illness
Case Manager’s Role

• Understanding Family Conflicts
• Division of Responsibility
• Effects on the Families
• Coping with Role Changes
• Loss of dreams
• Providing Care Plan for the Caregiver
The Caregiver Plan

• As the number of older adults continues to grow, the number of AD cases will also continue—AD is now the third cause of death. So it is important to develop an appropriate and timely care plan, not only for the patient, but more importantly for the caregiver—1 in 10 people over 65 and ½ of persons over 85 will be diagnosed with dementia.
The importance of care plans

• Care plans can improve the health and well-being of older adults. Over the last three decades, there has been evolution in the role, responsibilities and knowledge base of care managers, thereby providing a broader knowledge enabling them to provide more effective care.
Care Managers

• Health care workers have benefited from the development of best practices, think tanks, graduate programs and increasing number of current Web sites that focus on geriatric care management—so care plans should be added to the top of the list of enriching developments and resources.
The goal of a care plan

- Major goal of treating the older adult is to maintain and improve the social, cognitive, and physical function despite advanced age and chronic health conditions. Disease management is important for AD and other related dementia, but due to nature of the disease—individualized care plans are a “must” for both patient and caregiver.
The Assessment

• Careful assessment is the foundation—to ID the problem and needs of the older adult.

• When assessing elderly patients—especially those with AD—you’ll find that these patients/caregivers differ from others who have chronic conditions.
The Assessment continued . . .

- Age-related changes affect individuals at different times and rates, and to different degrees. To assess older people with AD, you should adapt your assessment to take into account the role of the caregiver, role transitions, and psychological adjustments that may affect these kinds of caregivers.
The Assessment

• Performing the assessment
• Obtaining the health history—variables are your attitude, the patient’s and caregiver’s attitude
• Preparing for the assessment—Zarit Caregiver Burden Assessment
• Current Health Status and Medical HX
Assessment continued . . .

- Review of systems
- Psychosocial assessment
- ADLs assessment
- Balance and gait check
Caregiver Centered Approach

• We have personal trainers, personal shoppers, personal stylist—everyone wants to feel special so individualized attention for personal needs are important—then why not for health care needs!!
Personalized Care Plans

- Health care for patients and caregivers should be personal—same care manager works with family to help coordinate an individualize care plan, rather than to divide into disease conditions—patient/caregiver centered approach with a step-by-step intervention and outcomes of each activity—care manager is now the care coach with family participation in care plan meetings.
Special help for the caregiver

• Establish a stable daily routine
• Reduce patient’s stress
• Minimize noise
• Establish a bedtime and a low bed
• Plan frequent rest periods
• Keep house well lit, safety rails in the bathtub, and medical alert ID
Six Step Plan

1. ID the problems from the caregiver’s point of view—use core listening skills
2. Provide a secure place for the caregiver to speak freely
3. Emphasize communications—assure caregiver that you are the one to assist
Steps for care plans

4. Help patient to recognize many different ways to solve problems.
5. Make plans—be sure that the caregiver owns the plan
6. Obtain a commitment
Special information for caregivers

• Communication
• Bathing
• Dressing and Eating
• Activities and Exercise
• Incontinence
• Wandering
• Home Safety and Driving
Caregiver guide to daily activities

• The Alzheimer’s Activities Guide
• Journal Writing
Latest Research on Caregiving and AD

• Caregiver Burden
• Multisensory Environment for Dementia
• Music for Alzheimer’s dementia
• Bathing Individuals with AD
• Reducing AD patient’s Repetitive Questions
• Spousal Caregivers' health promotional behaviors
• Promoting Exercise Behavior Using a Cognitive Behavioral Intervention