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After the Alzheimer's Diagnosis: Practical Information for Family Caregivers



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 - Medical and Scientific Advisory Board of Alzheimer's San Diego
 - Medical Advisory Board of the San Diego Chapter of the National Alliance for the Mentally Ill



Lecture Outline

- Six key points
- Strategies for creating successful caregiver teams
- Effective communication
- Tips for caregivers to avoid isolation and depression
- Patient-centered care
- Common family dynamics and possible remedies
- Summary



Key Points

- 1) Make an inventory of who is willing and able to help and what special skills and talents they possess.
- 2) As much as possible, share the burden of caregiving.
- 3) Encourage all care giving family members and friends to learn and use effective communication techniques when interacting with the person member who is living with Alzheimer's
- 4) Knowledge is power. Although sometimes painful or uncomfortable to talk about, knowing as much as possible about Alzheimer's and about the affected family member's prognosis is essential.



Key Points

- 5) Watch out for isolation and depression.
- 6) Become familiar with some of the common problematic family dynamics and their respective potential remedies:
 - ✓ the out-of-town family member
 - ✓ the parent who refuses help from their adult child
 - ✓ the adult child with unrealistic expectations.



Creating Successful Caregiver Teams



Creating Caregiving Teams

- How to create a successful caregiving team
 - Make a list of family members (and friends and neighbors) who are willing and able to help and what special skills and talents they possess
 - Give family members/friends specific tasks or assignments that, when possible, exploit their strengths and talents
 - Keep in mind that caring for a family member with Alzheimer's can be extremely stressful and that stress has a tendency to cause psychological regression
 - Anticipate that long-standing patterns of behavior and communication between family members may be intensified by the stress of the situation



Creating Caregiving Teams

- How to create a successful family caregiving team
 - Periodically solicit feedback and offer praise and thanks
 - Strive for open honest communication
 - Encourage all involved family members and friends to become as educated as possible about Alzheimer's, in general, and the strengths, weaknesses, preferences, needs and priorities of the afflicted family member in particular
 - Encourage (require?) caregivers to attend a course on how best to communicate with someone who has Alzheimer's
 - Encourage caregivers to attend support groups



Creating Caregiving Teams

- How to create a successful caregiving team
 - As much as possible, share the burden of caregiving with as many people as possible. This strategy helps protect any one caregiver from stress related illness or burn out.
 - Assign out-of-town individuals tasks that do not require them to be geographically close to the patient (e.g. using email to keep all those interested in the family member with Alzheimer's informed or designing and maintaining a phone tree for efficient communication)



Creating Caregiving Teams

- How to create a successful caregiving team
 - Do not hesitate to set limits if a caregiver is saying or doing things that hurt more than help.
 - Monitor each caregiver for signs of physical or psychiatric illness or burn out
 - Depending on the caregivers role, insist that each person has vacations from their caregiving duties
 - Establish clear lines of authority and communication



Effective Communication

- **Helpful hints**

- Make one request at a time
- Speak clearly and slowly
- Allow time for the patient to respond
- Maintain eye contact
- Assume a comfortable posture with arms and hands relaxed
- Identify the person's affect and verbalize this for him or her
- Time communications optimally based on circumstances (e.g. hunger, fatigue, background noise, etc.)
- Remember that even when words may no longer convey meaning volume, rate and melody of speech may still convey information



Tips Family Caregivers to Avoid Isolation and Depression



Tips to Avoid Isolation and Depression

- Seek help from professionals
- Use community resources such as support groups and “Meals on Wheels”
- Schedule time for yourself
- Schedule time with people who love you and care for you
- Watch out for the “martyr complex”
- Avoid arguments with your loved one



Tips to Avoid Isolation and Depression

- Challenge yourself to find the good in difficult situations
- Balance optimism with realistic expectations
- Don't be afraid to ask difficult questions
- Be flexible and willing to adjust
- Laugh long and often



Learn About Your Loved One's Prognosis

- Although Alzheimer's is now recognized as a terminal illness, individual's with Alzheimer's may live for years.
- It is important for caregiving family members to have the best information possible about life expectancy.
- Family caregivers need to plan ahead in order to ensure that their resources (personal, psychological, social and financial) will last until the individual with Alzheimer's passes away.
- Having adequate resources makes things better for both the person who is living with Alzheimer's and their care giving family members.



Important Factors to Consider: Life Expectancy

- The average life expectancy of someone with Alzheimer's is 8-10 years after the onset of symptoms.
- Some individuals with Alzheimer's have lived up to 20 years after the first signs of the illness emerge.
- As a general rule of thumb, a person diagnosed with Alzheimer's can expect to live half as long as someone of the same age who doesn't have the disease.
- The average 75-year-old can expect to live another 12 years. A 75-year-old with Alzheimer's would be expected to live for six more years.



Important Factors to Consider: Life Expectancy

- An NIA-funded study done at the University of Washington (2004) identified several factors that influence life expectancy of individuals living with Alzheimer's dementia
 - **Gender:** women in this study tended to live longer than men (6 years after diagnosis versus 4 years after diagnosis)
 - **Age at diagnosis:** individuals diagnosed with Alzheimer's in their 70s had longer survival times than those older than 85 at the time of diagnosis
 - **Severity of symptoms:** the amount of impairment at the time of diagnosis was inversely correlated with life expectancy
 - **Degree of cognitive impairment:** an MMSE score of 0 is correlated with a life expectancy of 6 months or less
 - **Rate of progression:** a 5 point drop on the MMSE over 1 year was associated with a decreased survival rate
 - **Other health problems:** survival was poorest among those aged 85 or older who had diabetes, congestive heart failure or a history of heart attack



Important Factors to Consider: Life Expectancy

- Individuals over 85 who wander or have trouble walking are among those with the shortest life expectancies



Patient-centered Care



Patient-centered Care

- Keep the focus on the patient
- If a family care giver is stirring up trouble, invite that individual to consider how his or her behavior is impacting the person with Alzheimer's



Common Family Dynamics and Possible Remedies



The Martyrdom Syndrome

- Many factors may trigger or perpetuate the martyrdom syndrome. These factors include:
 - A desire to express love and devotion
 - Guilt regarding past actions, inactions or situations
 - Survivor guilt
 - Fear of being judged by others (this may be more likely in blended families)
 - Sublimation of painful feelings
 - Avoidance
- The major risk of the martyrdom syndrome is that the caregiver who has slipped into this pattern is actually jeopardizing the safety and well-being of the patient AND him- or herself.



The Martyrdom Syndrome: A Potential Remedy

- Perhaps the most consistently helpful remedy for this pattern of behavior in a caregiver is to explain to the caregiver how essential he or she is to the well-being of the individual who is living with dementia.
- In essence, the caregiver needs to be reminded that, although their devotion may arise from the most noble of motives, it is, ultimately a strategy that is likely to backfire and to cause more harm than good.
- Specifically, the caregiver, especially caregiving spouses, need to be reminded that no one knows the patient better and no one is more qualified to provide care or supervise care. If martyrdom causes the spousal caregiver to become ill or to die, then the spouse with dementia will be placed in a potentially very precarious situation.



The Out-of-Town Family Member

- One fairly common challenge is keeping out-of-town family members accurately informed of the patient's status
- Out-of-town family members are often unaware of the level of impairment of the person living with Alzheimer's disease
- Often this lack of understanding is the result of
 - The family member with Alzheimer's having preserved social skills
 - The style and content of communication between the out-of-town family members and the family member living with Alzheimer's
 - No recent, or only very minimal recent, contact between the person living with dementia and the out-of-town family member
 - The common tendency for individuals and family members to experience denial in the face of tragic life threatening illnesses like the various forms of irreversible dementia
 - Pre-existing trust or communication issues between family members



The Out-of-Town Family Member: Remedies

- Invite out-of-town family members to visit as often as possible
- When out-of-town family members do visit, engage them actively in caregiving
- Consider letting the out-of-town family member provide respite care when the primary caregiver is on vacation
- Request that a neutral third-person explain to the out-of-town family member the nature and extent of the cognitive losses that the person with dementia is experiencing
- Look for opportunities to explore with the out-of-town family member what it means to him or her that his or her family member is living with dementia
- Encourage the out-of-town family member to attend a Alzheimer's caregiver support group



The Parent who Refuses Help from Adult Children

- Once a parent, always a parent
- For most parents, regardless of their age and the age of their children, it feels wrong to “lean on” or “burden” their children
- Many individuals living with dementia and many spousal caregivers of patient’s with dementia
 - Minimize the symptoms of the patient
 - Minimize the challenges of care for the patient
 - Refuse offers of help from adult children



The Parent who Refuses Help from Adult Children: A Potential Remedy

- Every stage of life has important psychological developmental tasks.
- An important developmental task for individuals who are middle aged is to adequately thank their parents for all that their parents did to help the child grow up and become a reasonably healthy, successful adult.
- Although this gratitude can be expressed verbally and this is helpful, it is generally not as helpful as actually having opportunities to express gratitude through helpful actions or behaviors.
- If a parent is able to allow for their adult child or adult children to provide help then this parent is doing the adult child or children a favor and helping the child or children accomplish an age appropriate developmental task.



The Adult Child with Unrealistic Expectations

- Watch out for the adult child who, perhaps due to denial, has unrealistic expectations of what the person with dementia can accomplish (e.g. resolve an issue from childhood, travel, etc.).
- Another important developmental task of mid-life is to resolve residual conflicts with one's parents.
- If the parent who was party to these unresolved or enduring conflicts has dementia then it may no longer be possible for the parent and child to achieve resolution of the conflict and repeatedly attempting to do this will only make matters worse.
- Each time the adult child attempts to resolve the conflict the adult child may end up feeling re-injured or re-traumatized.



The Adult Child with Unrealistic Expectations: Potential Remedies

- Work to help the adult child understand that their goal may be healthy and reasonable but their method is no longer realistic
- Encourage the adult child to find some other pathway to achieve resolution of the conflict:
 - Individual psychotherapy
 - Group psychotherapy
 - An Alzheimer's support group



Summary: Key Points

- 1) Make an inventory of who is willing and able to help and what special skills and talents they possess. Assign tasks accordingly.
- 2) As much as possible, share the burden of caregiving.
- 3) Encourage all caregivers to learn and use effective communication techniques when interacting with the family member who is living with dementia.



Summary: Key Points

- 4) Knowledge is power. Although sometimes painful to talk about, knowing as much as possible about dementia and about the affected family member's prognosis is essential.
- 5) Watch out for isolation and depression.
- 6) Become familiar with some of the common problematic family dynamics and their respective potential remedies: the out-of-town family member, the parent who refuses help from their adult child; the adult child with unrealistic expectations.



References

- 1) What's Happening to Grandpa? by Maria Shriver. New York: Little, Brown and Company and Warner Books, 2004
- 2) The 36-Hour Day by Nancy L. Mace and Peter V. Rabins. New York: Warner Books, Inc. 1981, 1991



Resources

1) Alzheimer's Association

www.alz.org/sandiego

24/7 Helpline 1-800-272-3900

2) Alzheimer's San Diego

Help & Info: 858-492-4400

Information: info@alzsd.org

Alzheimer's San Diego Shiley Center for Education and Support

6632 Convoy Court

San Diego, CA 92111

3) The George G. Glenner Alzheimer's Family Centers, Inc.

www.glenner.org

619-543-4704

3686 Fourth Avenue

San Diego, CA 92103

4) Southern Caregiver Resource Center

www.caregivercenter.org