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Making the Most of Life Following a Dementia Diagnosis

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Disclosures

- **American Association for Geriatric Psychiatry**
  - Chair of the 2013 AAGP Annual Meeting
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- **Uncompensated Board Memberships**
  - The George G. Glenner Alzheimer’s Family Centers, Inc.
  - Medical and Scientific Advisory Board of the San Diego/Imperial Chapter of the Alzheimer’s Association
  - Medical Advisory Board of the San Diego Chapter of the National Alliance for the Mentally Ill

Lecture Outline

- Overarching theme and key points
- Prognosis and life expectancy of individuals with dementia
- Peak frequencies of behavioral expressions in individuals with AD
- An overview of potentially helpful resources
- Strategies for creating successful care partner teams
- Effective communication techniques and common causes of behavior change related to the environment
- Tips to avoid isolation, depression and the martyrdom syndrome
- Summary

The Overarching Theme of this Talk

The most important objective for an individual living with dementia and his or her care partners is to go on living as rich, full and meaningful a life as possible in spite of the diagnosis of dementia. This objective includes remembering to laugh.

Key Points

1) Expect the unexpected.
2) Knowledge is power. Plan ahead and prepare by learning as much as possible about dementia. Although painful or uncomfortable to talk about, knowing as much as possible about dementia and about the affected individual’s prognosis is essential.
3) Plan ahead and prepare by knowing when specific changes in behavior are most likely to occur over the course of the individual’s dementia illness.
4) Plan ahead and prepare by learning as much as possible about available supportive resources and by building a successful care partner team.

Key Points

5) Plan ahead and prepare by learning effective communication techniques and common causes of behavior change related to the environment.
6) The signs of care partner overload include: feeling as if you have no life; drinking, eating, sleeping, or taking more pills than before; feeling like a martyr.
7) Tips for care partners to avoid Isolation, depression and the “Martyrdom Syndrome” include: expecting the unexpected, using available resources, scheduling time for yourself, and remembering to laugh.

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Knowledge is Power

Plan ahead and prepare by learning as much as possible about dementia including prognosis and life expectancy

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Prognosis and Planning

- Although Alzheimer’s is now recognized as a terminal illness, individual’s with Alzheimer’s may live for years.
- It is important for care giving family members to have the best information possible about life expectancy.
- Family caregivers need to plan ahead to ensure that their resources (personal, psychological, social, financial and legal) will last until the individual with dementia passes away and so they will have enough to go on living afterwards.
- Having adequate resources makes things better for both the patient 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 emerged.
- 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 studied 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 years old who wander or have trouble walking are among those with the shortest life expectancies

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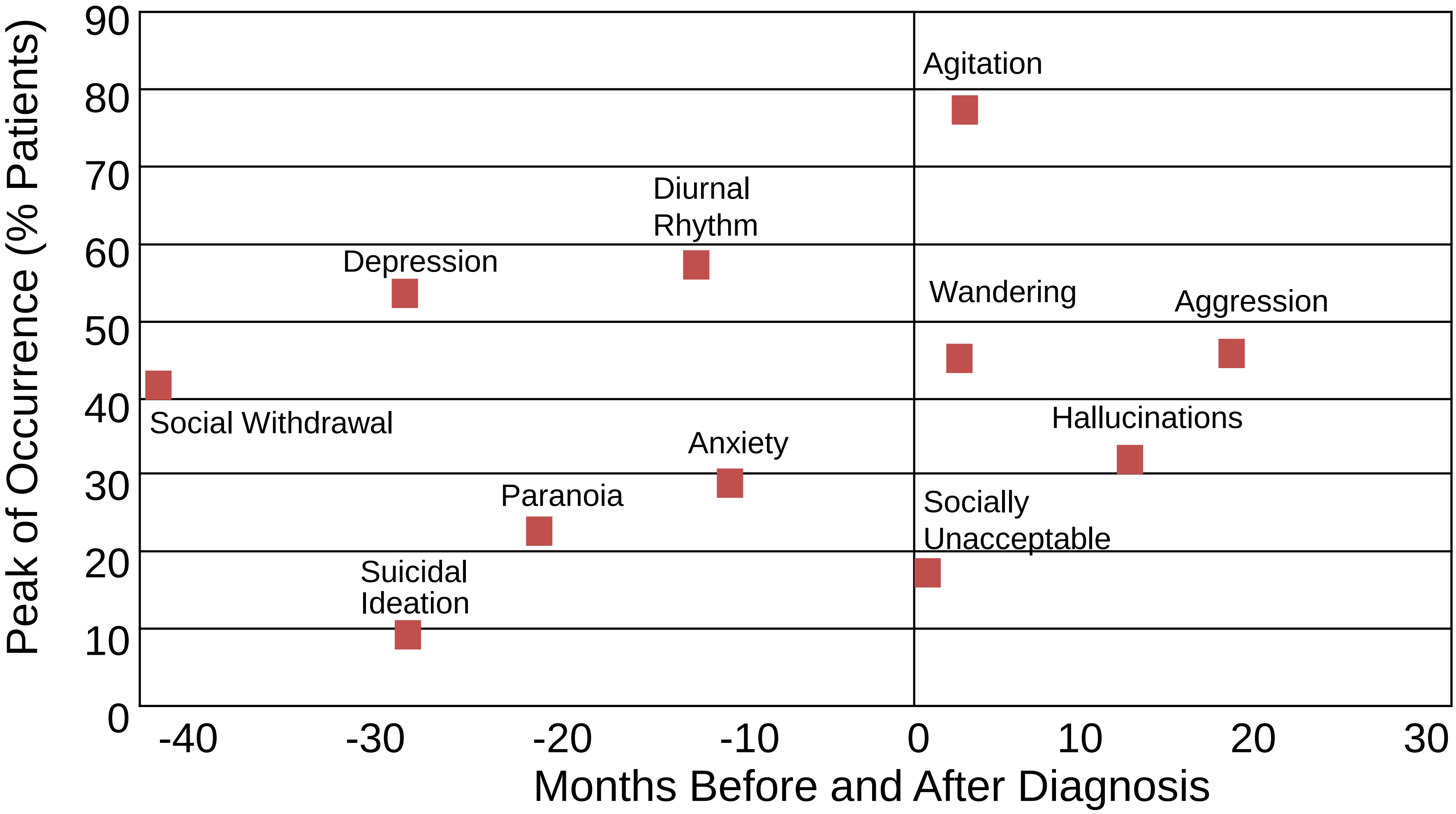
Knowledge is Power

Understand when specific changes in behavior are most likely to occur over the course of the individual’s dementia illness

Peak Frequencies of Behavioral Expressions in Individuals with AD



Jost BC, et al. *J Am Geriatr Soc*. 1996;44:1078-1081.

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Plan Ahead and Prepare

By learning as much as possible about supportive resources

Some Potentially Helpful Resources

- The 36-Hour Day by Nancy L. Mace and Peter V. Rabins. New York: Warner Books, Inc, 1981, 1991
- What’s Happening to Grandpa? by Maria Shriver. New York: Little, Brown and Company and Warner Books, 2004
- Southern Caregiver Resource Center
- The Glenner Memory Care Centers
- The Meals on Wheels Program

Some Potentially Helpful Resources

- The Alzheimer’s Association www.alz.org/sandiego; 24/7 Helpline 1-800-272-3900
- The UC San Diego Shiley-Marcos Alzheimer’s Disease Research Center and the “Memories at the Museums” Program
- The In Home Supportive Services (IHSS) worker program, a part of the California Department on Aging

Some Potentially Helpful Resources: IHSS Program

- Provides home & personal care assistance to those receiving Supplemental Security Income or who have low income & need aid to remain independent at home
- IHSS employees provide domestic and personal help such as grooming and bathing, house keeping, laundry, shopping and meal preparation and clean up
- The IHSS recipient is the employer of his/her homemaker and is responsible for hiring & supervision
- Aging and Independence Services phone: 800-510-2020 and home page http://www.sdcounty.ca.gov/hhsa/ programs/ais/inhome supportive services/

Some Potentially Helpful Resources

- The UC San Diego Senior Behavioral Health Program (Phone: 619-543-3772)
- Care management agencies
- Residential care facilities for long-term and respite care
- The Safe Return Program
- Senior Community Centers
- Technology

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Plan Ahead and Prepare

By creating successful care partner teams

Special Challenges for Family Member Care Partners

- Witnessing the constant deterioration of their loved one
- Adapting the quality of the relationship as the disease progresses
- Avoiding increased personal health risks
  - Medical morbidity: e.g. Deterioration in immune function, premature death
  - Psychosocial morbidity: decreased time for social activities

Creating A Successful Care Partner Team

- How to create a successful care partner 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 specific tasks or assignments that, when possible, exploit their strengths and talents
  - Keep in mind that caring for a family member with dementia 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 A Successful Care Partner Team

- How to create a successful care partner team
  - Periodically solicit feedback and offer praise and thanks
  - Strive for open honest communication
  - Encourage all involved family members to become as educated as possible about dementia, in general, and the strengths, weaknesses, preferences, needs and priorities of the afflicted family member in particular
  - Encourage (require?) care giving family members to attend a course on how best to communicate with someone who has Alzheimer’s or other forms of dementia
  - Encourage care partners, especially family members whether in town or out-of-town, to attend support groups

Creating A Successful Care Partner Team

- How to create a successful care partner team
  - As much as possible, share the burden of care giving with as many family members and other care partners as possible. This strategy helps protect any given care partner from stress related illness or burn out
  - Assign out-of-town family members 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 A Successful Care Partner Team

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

Creating A Successful Care Partner Team

- Patient-centered care
  - Keep the focus on the patient
  - If a care partner is stirring up trouble, invite that individual to consider how his or her behavior is impacting the patient with dementia

Plan Ahead and Prepare

By learning effective communication techniques and common causes of behavior change related to the environment

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 patient’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, prosody and melody of speech may still convey information

Effective Communication: Redirection

- **Redirection**
  - Represents a thwarting of a goal-directed behavior
  - May trigger frustration and agitation
  - **Simple Redirection**
    - A compliment, a request for help or the use of humor
    - E.g. “My that’s a beautiful sweater!”
  - **Complex Redirection**: 4 steps
    - Validate: “You look worried”
    - Join: “You’re looking for…I’m trying to find…Let’s look together…”
    - Distract: “Let’s look over there…”
    - Redirect: “That coffee smells good. Do you want a cup?”

Common Causes of Behavior Change Due to the Environment

- The lack of purpose
- The absence of routine and structure
- Boredom
- Overstimulation
- Unrealistic expectations
- Frequent changes in environment
- No place to exercise safely such as a secure area in which to roam safely without cul-de-sacs and dead-ends which create agitation

Signs of Care Partner Overload and Tips for Care Partners to Avoid Isolation, Depression and the “Martyrdom Syndrome”

Potential Signs of Care Partner Overload

- You feel that you cannot turn your back for a minute
- You are taking your frustration out on yourself or your loved one
- You see nothing beyond care giving tasks
- You feel as if you have no life
- You resent everything
- Your best efforts are not making you loved one “behave”

Potential Signs of Care Partner Overload

- Your family seems to be unfairly critical of you
- You feel as if you have no time to think
- You are drinking, eating, sleeping, or taking more pills than before
- You have fantasies about disappearing or running away
- You have fantasies about letting the older adult go if he or she wants to

Potential Signs of Care Partner Overload

- You feel you do everything but it is never enough
- You feel like a failure
- You see no end in sight
- You cannot remember loving or pleasant times
- You feel like a martyr

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 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 care partner who has slipped into this pattern is actually jeopardizing the safety and well-being of the patient AND themselves.

The Martyrdom Syndrome: A Potential Remedy

- Perhaps the most consistently helpful remedy for this pattern of behavior in a care partner is to explain to the care partner how essential he or she is to the well-being of the individual who is living with dementia.
- In essence, the care partner 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 care partner, especially care giving 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 care partner to become ill or to die, then the spouse with dementia will be placed in a potentially very precarious situation.

Tips to Avoid Care Partner Overload, Isolation, Depression and the Martyrdom Syndrome

- Remember you are not alone and don’t be afraid to call in reinforcements.
- Seek help from professionals.
- Use community resources.
- Schedule time for yourself.
- Schedule time with people who love you and care for you.
- Watch out for the “martyrdom syndrome.”
- Avoid arguments with your loved one.

Tips to Avoid Care Partner Overload, Isolation, Depression and the Martyrdom Syndrome

- Join and regularly attend a support group.
- Think twice before giving up that job, club, or church group.
- Avoid making promises that include the words: always, never, or forever.
- Find ways for your loved one to give to or help you.
- Take time to celebrate small victories when things go well.
- Challenge yourself to find the good in difficult situations.
- Don’t be afraid to ask difficult questions.

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Tips to Avoid Care Partner Overload, Isolation, Depression and the Martyrdom Syndrome

- Expect the unexpected
- You can only do what seems best at the time
- Identify what you can and will tolerate and then set limits
- Remember that doubts are inevitable
- Find someone with whom you can be brutally honest, express your feelings and then move on
- Remember your faith and spiritual needs

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Tips to Avoid Care Partner Overload, Isolation, Depression and the Martyrdom Syndrome

- Be wiling to listen but remember that you can not fix or do everything
- Know that it will not necessarily get easier but things will change
- You are living with a situation that you did not create
- Your choices are limited by circumstances beyond your control
- Seek options that are good enough for now

Tips to Avoid Care Partner Overload, Isolation, Depression and the Martyrdom Syndrome

- Balance realistic expectations with optimism. In other words, hope for the best but plan for the worst.
- Be flexible and willing to adjust. Considering what is best for your family usually involves compromise.
- Solving problems is much easier than living with the solutions.
- Beware of (avoid?) distant relatives second-guessing or criticizing.
- Remember that sick people often take out their frustration on close family members.
- Laugh long and often.

Summary: 7 Key Points

1) Expect the unexpected.
2) Knowledge is power. Plan ahead and prepare by learning as much as possible about dementia. Although painful or uncomfortable to talk about, knowing as much as possible about dementia and about the affected individual's prognosis is essential.
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Questions and Answers

Thank You!