



April: "Does Anybody Really Know What Time It Is?"

One of the most troubling symptoms reported by people with dementia is their loss of the sense of time. Time is a very abstract concept because you can not see it or feel it. Even early in the disease, people may lose track of time by missing appointments or showing up early worried about missing an activity. Repetitive questions are common, particularly about when an activity will occur or the time of day. Advised by dementia books, well-meaning families purchase calendars, watches and clocks only to find the person still worries about time – sometimes even more than before.

In moderate disease, people begin to sleep more during the day. Families report that announcing events in advance causes anxiety and even refusal to participate as the person struggles to figure out what "next Tuesday" means. Often people with dementia become obsessed trying to remember what is supposed to happen and when.

Many people with moderate dementia will go to bed so early (7 p.m. –8 p.m.) they awaken in the pre-dawn hours looking for something to do. When families try to reason with them, having them look outside and guess whether it is 3 a.m. or 3 p.m., they find the person still doesn't understand what time it is or what they should be doing at 3 a.m. versus 3 p.m. In advanced dementia, there is generally a reversal of day and night.

One person with dementia, Carole M., describes her problems with time: "The sleeping and time sense thing is huge for me. I have a number of middle stage signs now and I think I struggle most with my loss of the sense of time. I'm not aware of the passage of time, I rarely am able to sleep at night and often feel compelled to sleep in the late afternoon. I think it might be related to the sun downing thing as well. Before dusk, I get this restless, anxious feeling that seems to come from a very primal place. It reminds me of many nights at the farm, watching the birds flit about and twitter around the trees as they settle in for the night. I feel the way I think they must feel. Draw the drapes, pull up the covers, nestle in -- it's time for bed. If it doesn't come upon me when I'm sitting down, I know I'm supposed to get up, turn on all the lights and get busy doing something.

If you think about it, for centuries, human beings probably did get ready for bed along about time for dark. Relatively speaking this behavior has been comparatively recently that the use of lights (candles, fires, electricity) allowed us to extend our functional days beyond dusk. This "prepare for bed now" feeling seems to me to be a very natural thing, and not something unique to people with dementia." (published with permission)

Carole's description is both troubling and comforting. We must take Carole's insight at face value. She acknowledges the problem in a humble straightforward manner that encourages us to change the expectations of our loved ones. It gives us guidance on accepting this symptom, without feeling it is something we must change. It encourages us to stop focusing on issues related to time, such as becoming frustrated when they don't understand or remember an appointment even though you have repeatedly reminded them of it days in advance or even the day of the appointment. It encourages us to stop insisting the person remember appointments or know when visitors are coming. It allows us to relax.

Coping with the lost sense of time

Understanding time and schedules

- Don't bother with trying to get the person to remember the day, month and year.
- Recognize that using a calendar does not have the same meaning as it once did for the person. Most people with mild-to-moderate dementia rely on others to cue them when they need to do something.
- Use the person's schedule as a predictable sequence of activities verses the exact timing of the activity.
- Try not to announce things too far in advance.
- Recognize that the lost sense of time is a source of anxiety. Focusing on it can produce depression, fear, or feelings of inadequacy.

Normalizing the sleep schedule

- Encourage at least two rest periods during the day. In later disease these may be "snoozes."
- Avoid rest periods in bed so the cues won't mislead the person to think it is morning when they waken.
- Avoid caffeine — particularly after noon.
- Try to follow a routine with a predictable series of tasks and activities.
- Exercise at least 20 minutes, 4-5 times each week.
- Minimize time spent at the TV.
- Recognize that for most people with dementia, "reading" is really a "time out" or "quiet activity."
- If the person is going to bed before 9 p.m., encourage another rest period before supper and develop a bedtime ritual such as ice cream at 8:30 p.m.
- If the person is still awake at night consult with the physician about either using mild medication for pain prior to bedtime (arthritis is a common culprit) and/or if pain medication does not work, trying a prescribed sleep medication.



“Ask the Expert”
By Geri Hall, PhD, ARNP
Family & Community Services

Dear Geri:

I am caring for my 50-year-old husband who was diagnosed two years ago with very early Alzheimer’s disease. Since then I’ve read everything I can find on the subject and I hate to say it, but he just doesn’t fit! He has become very rude, often saying hurtful things to me, the children and even strangers. One minute he is obsessed, shopping for hundreds of toy cars online, but later sits staring into space for hours. He insists there is nothing wrong with him and refuses to go back to the doctor. We tried giving him the Alzheimer’s medications but they made him much worse. The doctor says that he tests well and nothing more can be done for him. He still works but I think he may be fired soon. And, I am afraid he will spend us into debt. Is this Alzheimer’s disease?

Signed “Am I Crazy?”

Dear “Not Crazy,”

First, you are not crazy. Almost every caregiver feels this way at some point. Remember that dementing illnesses are progressive diseases so unfortunately, in time everyone else will know you are correct. Second, you **do** need to see a specialist for several reasons:

1. Your husband is quite young and often younger people have less common

- presentations of dementia.
2. Due to your husband’s age you will need to have help with qualifying for disability insurance.
 3. With the symptoms you describe it might be expected that he might have a different dementing illness than Alzheimer’s disease.

Although many types of dementia share at least some symptoms in common with Alzheimer’s disease, they differ by:

- presentation and patterns of symptoms;
- the course of the illness;
- age of onset;
- response and sensitivity to medications.

Many non-Alzheimer dementias including frontotemporal dementia, ALS, vascular dementia, and Lewy body disease may look like Alzheimer’s for a year or two and then develop different symptoms as the diseases progress. I suggest you contact his primary doctor and ask to see a “dementia specialist,” such as a behavioral neurologist or geriatric psychiatrist who has special expertise in differentiating between types of dementia. Once the diagnosis is re-established, interdisciplinary teams of social workers, nurses, neuropsychologists and occupational therapists can help to guide you through his illness.

What’s New in the Library

Coach Broyles’ Playbook for Alzheimer’s Caregivers (2006) was written by Frank Broyles, athletic director, University of Arkansas. When his wife was diagnosed with Alzheimer’s disease (AD), he created his own “playbook” that allowed him to build his caregiving team and have a solid game plan. The book provides practical information and solutions to common situations encountered by caregivers. To obtain your free copy, call (800) 272-3900 or www.alzheimersplaybook.com.

What if it’s not Alzheimer’s? A caregiver’s guide to dementia (2003) was written by Linda and Gary Radin who cared for a family member with frontotemporal dementia. This book begins with a discussion on medical facts, followed by strategies to enhance everyday living. Ideas to access community and legal resources are covered along with an emphasis for caregivers to take care of themselves.

Beacon Bits

A free new resource is available from the NIH:

"Hospitalization Happens: A Guide to Hospital Visits for Individuals with Memory Loss," (February 2009) To order: <http://www.nia.nih.gov/Alzheimers/Publications/happens.htm>.

April’s COMPASS Caregivers of Memory Impaired People Acquiring Successful Strategies Class will be held on April 16, 2009 (Thursday) at the BAI 901 E. Willetta St. , third floor conference room from 10 a.m. - 11:30 a.m., free of charge. Registration is required.

BAI Explorer May Event will be held Wednesday, May 27, 2009 at the Hall of Flames from 10 a.m. - noon for the price of \$3 per person and will include a privately guided tour of the museum. Learn about the basics of firefighting and the history of firefighting. Registration is required.

Contact Veronica Ellis at (602) 239-6850 or veronica.ellis@bannerhealth.com, to register for any of the above events.

BAI Beacon is going green!



Beginning in May, the Beacon will be posted to the BAI website or will be sent via email in order to save the trees. If you would like to be added to the e-distribution list, please contact Rose Ann Barton at 602-239-6918 or via e-mail at roseann.barton@bannerhealth.com.

Our Mission

To end Alzheimer’s disease without losing a generation, to set a new standard of care for patients and their families and to forge a model of collaboration in biomedical research.

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