

February 2010

"Piecing the Puzzle Together"



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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Piecing the Puzzle Together: Analyzing Problem Behaviors

What is a problem behavior? Simply, it is one that makes you crazy, makes the person with dementia (PWD) uncomfortable, or poses a potential danger to you or the PWD. Behaviors such as repetitive questions, pacing, and late day anxiety or aggression are indicators of emotional distress in the PWD. Therefore, it is important to discuss these problems with the dementia care team. While the physician looks at medical factors and potential medications, a dementia capable nurse or social worker can help the family to understand, minimize and/ or prevent problem behavior(s). This month's Beacon will address how to identify and keep track of problem behaviors. In the March edition, we will focus on how to prevent and manage them.

Since behaviors can be vague and perceived differently by family members, it is important to define the exact nature of the problem. In many dementing illnesses, especially Alzheimer's disease, Lewy body disease, and frontotemporal dementia, the disease symptoms are either new behaviors or the behaviors with increased intensity that were present before the disease. Teasing this apart requires attention to detail when the behavior occurs. It is the single most important thing the health care provider needs to successfully treat a problem behavior.

First, get a notebook or calendar and write the name of the behavior and when it occurs. Use descriptive terms such as "angry," "belligerent," "wandered from home," "agitated," "more confused," "is sexually aggressive," "threatens me," or "asks the same question over and over." Don't use words that describe a cause such as "manipulative," or

"trying to annoy me." Note the approximate time the behavior occurred and each time afterward. Keep this record for several weeks. Then you can report to the provider good descriptive information, e.g., "She is saying this is not her home at about 4:00 till 6:00 pm four times a week." Remember that behaviors that drive you crazy are as important as those that are dangerous because your sanity and ability to cope with them is important.

It is also essential to think about what happened in the 24 hours before the behavior occurred. A visit from grandchildren, dinner out, shopping, holidays, fatigue, and company are common triggers for behaviors. If you do recognize something, write it down to see if a pattern emerges. For example a person who has lost their driving privileges will often act out for a while. In addition to the health team, share the calendar with your family and others who provide care. This is a very good way to let family members know the extent of the illness and some of the current challenges that you are facing as the caregiver.

Most important is, the calendar will help you to identify if you are in danger. If you feel threatened or in danger you must , 1) realize that it is not your fault; 2) that this behavior is a medical emergency; and 3) if left untreated it will worsen. Problem behaviors can be managed successfully. The first step to successful treatment begins with a good description of the behavior provided by the caregiver!

Piecing the Puzzle Together: What to do

Sometimes the role of the caregiver is that of detective, particularly when changes in behavior appear and are disturbing to you or the person with dementia. It has been suggested that 80% of all behaviors could be managed without medications. This may be particularly true when caregivers closely observe, record, and report what they are seeing to the health care provider. All of these “pieces” can fit together to provide a clear picture of what the behavior is, what it means, and options to minimize or alleviate the specific behavior.

Begin to take note of changes in mood. For example, the person may be cheerful and cooperative early in the day and by late afternoon become more irritable and argumentative. Perhaps the person becomes more anxious anticipating an upcoming appointment or event. Note if the person is withdrawn or won't participate in a favorite activity. Watch how your mood and voice tone affect your person.

Look at specific times during the day (or night) when behaviors occur; and take note of how long the behavior lasts. Late afternoon and early evening are common times for behaviors as fatigue sets in. Also take note if there are certain tasks or situations that lead to behaviors. Balancing a checkbook or cooking a meal may lead to frustration and agitation as examples of tasks causing behavior changes. Large groups/social gatherings may cause the person to withdraw or abruptly leave.

If the person is seeing things that aren't present (hallucinations), take note of what the person is telling you. If they have fixed thoughts and beliefs that are untrue (delusions) or think that someone is trying to steal from them/harm them (paranoia), make note of those specific issues.

Bring your notes and observations when you meet with your healthcare provider to discuss the specific behaviors. These important observations will assist the clinicians to provide any necessary medications and behavioral strategies to employ to solve the puzzle.

“Ask the Expert”

Dear Geri

My wife has been diagnosed with Alzheimer's disease. Last night she became confused and called me a “monster.” She tried to strike me with a fireplace poker. I locked myself in the bathroom to avoid being hurt. Later she said she couldn't imagine doing something like that and promised it will never happen again. We've always such a close marriage. I want to believe her but my daughter wants me to tell her doctor.

I probably caused this and am ashamed to tell anyone about it! People might think I've abused her. I'm frightened; she could have killed me. I believe it won't happen again but I'm not sure because she doesn't remember doing it and she doesn't seem quite normal today. If it happens again I might hurt her trying to protect myself. What to do?

Signed,
“Not a Monster”

Dear “Not”

First, you are not a monster; you are her husband and caregiver. Second, you probably did nothing to cause this so don't blame yourself. Third, without prompt medical intervention it will happen again. You have to call the doctor and reveal everything that happened. She needs to be seen within 24 hours.

Your wife was having a behavioral episode

caused by her disease or possibly a secondary condition such as an infection (urinary tract infections are a common cause), acute and/or painful medical problem, or a medication reaction. Your wife's problem needs to be examined and any underlying issues such as infection must be treated. In addition, because she was so agitated that she tried to injure you, she may need medication for her mood until any underlying problem subsides. This probably means use of an antipsychotic-type medication.

If the episodes continue, your wife may need a brief inpatient psychiatric admission and to be followed by a geriatric psychiatrist. Violent behaviors may be an indication that what looked like Alzheimer's disease early on is actually a different type of illness called Lewy body disease. If this is the case, she will need ongoing care by a dementia specialist.

One thing you do not want to do is move her to a new residential setting before she receives medical treatment, as she could pose significant danger to other residents and staff. The first step is to stop blaming yourself or your wife. This is a disease-related problem that you should not manage alone. You need to seek medical attention now.

Stay safe.



Geri Hall, PhD, ARNP
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Beacon Bits & Tips

February 19, 2010 – MAPS (Memory Assistance and Planning Session) is a full-day workshop to assist family caregivers to understand the treatment and progression of dementia; implement strategies to enhance successful daily living and find practical sources of community help and assistance. Church of the Beatitudes, 555 W. Glendale Ave. \$25 includes cost of instruction, materials and lunch.

March 11, 2010 - “**Unlocking Your Memory Vault**” is a 4-hour workshop designed to help people with early memory loss and caregivers to learn how to capture, record, and share favorite memories for years to come. Class will be held at the Flinn Foundation, 1802 N. Central Avenue, Phoenix. \$25 per person includes instruction, materials and lunch. Limited seating is available.

March 26, 2010 – “**Memory Fitness Event**” at Sun Lakes Unite Methodist Church in Sun Lakes from 9am – 1pm. Free memory screening is provided along with education and strategies on improving brain health. Reservations are required for memory screening.

Tip on Brain Health

Did you know that eating dark chocolate may actually be good for your brain? Dark chocolate contains a large number of antioxidants, which has benefits for your brain, heart and blood pressure. In addition to its good tastes, dark chocolate stimulates endorphin production which gives a sense of pleasure and it contains serotonin that acts as an antidepressant. So, treat yourself and someone you love to a nice piece of dark chocolate!

