

Challenging Behavioral Responses and Dementia Care

Many people with dementia develop challenging behavioral responses as their disease progresses. As speech and other abilities are lost, behavior becomes a way to express needs. Behavioral responses present great challenges to family caregivers. Family may believe that the person chooses to behave in a difficult way. But it is important to remember that it is the disease, not the person, creating the difficulty.

Consider bodily needs as the cause:

Even if the person is verbal, they may not be able to recognize or express bodily needs. These bodily needs are then expressed through behavioral responses.

Needs may include:

- Fatigue
- Hunger
- Constipation
- Need to urinate
- Pain
- Processing the senses – need to make sense of world around you
- Need to move, be active

Behavior signals of pain and other bodily needs:

- Facial expressions: frown, grimace, tightened eyes, wrinkled forehead, sad, frightened
- Verbal expressions: crying, chanting, calling out, grunting, asking for help, abusive language
- Body movements: tense posture, fidgeting, pacing, rocking, gait changes, moving less
- Actions toward others: aggressive, resistive, withdrawn, disruptive, rude, easily annoyed
- Sudden changes in: normal routine, appetite, sleep pattern and frequency, wandering, level of confusion

Pain research and dementia

Research suggests that about 50 % of people with dementia have routine pain. The World Health Organization suggests Tylenol as the first drug of choice. Studies recommend regular scheduled use of Tylenol for people with moderate to severe dementia. Maximum Dosage is 3000 mg per day. Research shows behavioral responses decrease with routine Tylenol use. Be sure to check with the physician first.

Be a behavior detective:

It takes a bit of detective work to figure out the cause of a behavioral response. Identifying a cause helps identify ways to manage the behavior. Try these steps:

1. Pay attention to when, where and with whom the behavioral response happens
2. Identify possible causes of behavior
3. Observe the person's body language as a clue to possible bodily needs
4. Use trial and error process to remove possible causes
5. Take care of any suspected bodily need
6. Observe any changes in behavior

Helpful tips:

- Use specific communication strategies (See *Communication and Dementia*.)
- Try therapeutic fibbing – small lies that can redirect the person without challenging their reality
- Be aware of underlying emotions; provide support and reassurance. Emotions may include:
 - Anxiety
 - Fear
 - Anger
 - Frustration
 - Irritation
 - Apathy
- Know when you need help and seek it:
 - Call 911 if a danger to self or others
 - Call Alzheimer's Association 24/7 Helpline (800-272-3900)
 - Call the ADRC to speak with the Dementia Care Specialist
 - View the online caregiver training at the site listed below

Sources of Information:

- Wisconsin Department of Health Services, Dementia Capable Wisconsin, Online Training for Caregivers; dhs.wisconsin.gov/dementia/family-caregiver-training.htm
- *Pain and Suffering in Dementia*, Dr. Jane Mahoney, MD, Dementia Care Training Day, September 27, 2017