

Alzheimer's Aid Society
OF NORTHERN CALIFORNIA

“THE BLUE BOOK”

2013 Edition



**A PRACTICAL GUIDE FOR
ALZHEIMER'S CAREGIVERS**

Part 2 - Behavior Management

Our Mission:

We exist to provide support, education and compassion to patients and caregivers throughout the journey of Alzheimer's Disease, to support medical research, and to promote public awareness.

*The Alzheimer's Aid Society of Northern California is a
Non-Profit, Tax-Deductible 501(c)(3) corporation*

Federal ID Number: 94-2721961

BEHAVIOR MANAGEMENT: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

INTRODUCTION

- ♦ Problem behaviors need understanding and managing.
- ♦ All problem behaviors have an underlying cause—anger, frustration, pain—physical or psychological, effects of medication, or lack of understanding.
- ♦ Determine if this is a lifelong pattern of behavior or behavior developed to cope with late-life changes. Some lifelong patterns are depression, negativity, suspiciousness, bullying, manipulation, bipolar disorder, personality disorders.

NOTE: medication for lifelong problems needs to be continued but closely monitored for changes in metabolism and interactions with other drugs.

- ♦ Those with dementia don't perceive the world in the same way you do. Nevertheless, their perceptions are very real to them.
- ♦ If they see and understand the world differently, it follows that your line of logic and explanation probably won't be accepted.
- ♦ In trying to cope with their perception of the world and their diminishing control over it, Their behavior may become strange, disturbing, and/or irritating.
- ♦ You need to understand the behavior, why it's occurring, and how you can change the environment and/or your own behavior in order to minimize the problem.

WHAT IS PROBLEM BEHAVIOR?

- ♦ Does it interfere with daily functioning? Does it have the potential to harm the person or someone else? Does it bother the person exhibiting the behavior?
- ♦ Sometimes it is difficult to differentiate the person's behavior from your reaction to it.
EXAMPLE: Is eating with fingers really a problem, or is the problem that it really bothers you?
- ♦ There is a need to evaluate the circumstances in which the behavior occurs.
- ♦ What was happening before the problem occurred?
 1. This helps you define the context of the problem and yields clues to finding a solution.
 2. What makes something abnormal is often defined by the context in which it occurs.

Continued on page 31...

"The Blue Book" A Practical Guide for Alzheimer's Caregivers

A publication of The Alzheimer's Aid Society of Northern California, Edition 2013
916-483-2002

BEHAVIOR MANAGEMENT: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

Continued from page 30...

PROBLEM SOLVING

- ♦ Identify the problem behavior being sure that it is not just your problem. You can work on only one behavior at a time.
- ♦ Try to identify the trigger for the behavior—where does it occur? What happens just before it occurs? What time of day does it occur? With whom does it occur?
- ♦ What purpose or need does the behavior fulfill? Need for attention, need to be left alone, need to feel a sense of power, need to be heard, need for reassurance, need to communicate?
- ♦ Define what you want to happen. Remember goals have to be considered in terms of both what is optimal and what is possible.
- ♦ The best approach to a problem is prevention--anticipating reactions, planning ahead, being aware.
 1. Preventing incontinence may involve a program of being taken to the toilet every two hours.
 2. Be aware of potential explosive situations and defuse them before they happen.
- ♦ Replace problem behavior with a suitable activity.
 1. People with dementia cannot perform as well as they once did; however, they often still have a desire to participate in activities.
 2. Suitable activities can make the person with dementia more satisfied, less apt to be anxious, and easier to look after.
 3. A suitable activity must keep the person involved and not cause frustration and anger.
- ♦ Change the environment
 1. Remove items - obstacles, clutter, confusion, distractions.
 2. Add items - signs pointing to the bathroom, a chair with armrests, warm colors.
 3. Modify the environment - Velcro instead of buttons, large spoon instead of fork, fencing for safety.
 4. Maintain a calm environment.
- ♦ Reassure the person continually that he/she is safe.

Continued on page 32...

“The Blue Book” A Practical Guide for Alzheimer’s Caregivers

A publication of The Alzheimer’s Aid Society of Northern California, Edition 2013
916-483-2002

BEHAVIOR MANAGEMENT: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

Continued from page 31...

CHANGE YOURSELF

- ♦ Nothing is a “problem” until it is perceived and defined that way.
 - ♦ Some behaviors are problems only because they are defined that way. Is hallucinating *really* a problem? Only if it interferes with the participant’s functioning, produces fear or threatens someone.
 - ♦ Otherwise, they’re quirks, interesting behaviors, or differences in opinion about how things should be done.
 - ♦ Problems that arise because of the way behavior is perceived and judged rather than because the behavior is truly harmful are usually due to one of two things:
 1. Limited knowledge or misinterpretation about the behavior or
 2. Extreme standards and expectations regarding how people should act.
- NOTE:** If either or both of these are changed, behavior that was once a problem may suddenly become a non-problem.



Continued on page 33...

“The Blue Book” A Practical Guide for Alzheimer’s Caregivers

A publication of The Alzheimer’s Aid Society of Northern California, Edition 2013
916-483-2002

BEHAVIOR MANAGEMENT: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

Continued from page 32...

GENERAL PRINCIPLES

- ♦ Approach the person slowly from the front and stand within the person's field of vision—don't startle.
- ♦ Remain calm—speak in a calm and reassuring voice.
- ♦ Smile.
- ♦ Avoid confrontations and power struggles—don't argue or challenge.
- ♦ Never yell, scold or strike back at the person.
- ♦ Never make fun of or laugh at a confused person's behavior.
- ♦ Remember the confused person is frightened and needs to feel safe. Reassure the person that you will take care of the situation.
- ♦ Improve your communication:
 1. Stand where you can be seen and maintain eye contact.
 2. Gentle touch helps focus attention on the conversation.
 3. Don't expect a quick response.
 4. Look for visual clues of misunderstanding.
 5. Use simple, short sentences and avoid abstractions.
 6. Most sentences are too complex for the impaired person to understand:

NOT: "Come here, Bill, it's time for you to eat your lunch."

INSTEAD: "Bill, come here" "Here's lunch."

Avoid sentences phrased in the negative:

NOT: "Don't go outside."

INSTEAD: "Stay inside"

Continued on page 34...

"The Blue Book" A Practical Guide for Alzheimer's Caregivers

A publication of The Alzheimer's Aid Society of Northern California, Edition 2013
916-483-2002

BEHAVIOR MANAGEMENT: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

Continued from page 33...

GENERAL PRINCIPLES (continued from page 33)

7. Avoid offering difficult choices or decisions.

EXAMPLE: “Bill, do you want to go to exercise group with Mary and Joe like you did yesterday, or would you rather try the new craft project with yarn and pictures that I bought yesterday at the store?”

NOTE: This sentence is ten times too long to be understood.

8. Monitor your own tone of voice and body language – nonverbal cues speak louder than words.
9. Try using gestures, pantomime or pictures.
10. Don’t speak “down” to the person with dementia. The person may act “childlike”, but is still an adult and deserves respect.
11. Avoid topics that cause anxiety – don’t say “don’t you remember?” Talk about pleasant, easily accessed topics and memory.

♦ **Distraction** - one advantage of dementia is that the person is more easily distracted.

1. You can often turn the person’s attention to something else and the problem will be forgotten.
2. This has to be done slowly and calmly so as not to add more frustration to the situation.



“The Blue Book” A Practical Guide for Alzheimer’s Caregivers

A publication of The Alzheimer’s Aid Society of Northern California, Edition 2013
916-483-2002

SUNDOWNING

Barbara Gillogly, Ph.D., LMFT, CPG

WHAT IS IT?

Approximately one quarter of patients with Alzheimer's-type dementia exhibit disruptive, restless, and/or confused behavior that tends to be more apparent in late afternoon or early evening.

The person may pace more, display increased anxiety, repeatedly ask questions, become more confused as to person and place.

WHY IT OCCURS

No one knows for sure why sundowning occurs, but there are several hypotheses:

- ⌚ Being tired toward the end of the day.
- ⌚ Disturbance in the circadian rhythms of a patient.
- ⌚ In a darker setting, people and objects may become less distinct which can lead to anxiety, fear, and/or paranoia.
- ⌚ Late afternoon is also a period of a natural drop in blood sugar that could lead to agitated behavior.

WHAT CAN YOU DO ABOUT IT?

- ⌚ Exposure to bright light during the day.
- ⌚ Playing quiet, soothing music during the sundowning period—music previously enjoyed by the individual.
- ⌚ Increasing the light in the environment.
- ⌚ Offering a late afternoon snack containing some protein.
- ⌚ Minimizing sensory input—creating a calm, soothing environment.
- ⌚ Minimizing expectations of the person with dementia.
- ⌚ Low doses of anti-anxiety medication may be helpful.

“The Blue Book” A Practical Guide for Alzheimer’s Caregivers

A publication of The Alzheimer’s Aid Society of Northern California, Edition 2013
916-483-2002

SPECIFIC BEHAVIOR PROBLEMS: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

WANDERING

Memory impaired individuals tend to stray away when they are agitated or angry. Wandering is more likely to occur when the patient is in an unfamiliar situation or the caregiver is distracted.

- Wandering is often a response to a need to move or to find something or someplace. The impaired person may have excess energy, or a need for stimulation.
- Walk along with the person and then gently guide them back to safe area.
- Do not reprimand.
- Provide them freedom to walk within safe areas.
 - Use fences or hedges to secure areas.
 - Place latches and locks on gates either higher or lower than normal – but, insure ease of exit in emergencies –a sliding bolt at floor level.
 - Block or lock exits to balconies.
 - Ponds, pools, creeks need to be fenced off.
 - Place secure gates at the top and bottom of stairs.
 - Camouflage exits to areas that are unsafe, use child-proof door knobs.
 - Securely lock outside exits. Install an alarm that sounds when a door is opened.
 - Place large “STOP” signs on doors you do not want opened. Also, try a barrier such as a curtain or colored streamers to mask the door.
 - A black mat in front of the door may appear to be an impassable hole the dementia patient will not try to cross.
 - Put away items that the person will not leave without such as coat, purse, keys, glasses.
- Use nightlights in the person’s bedroom, bathroom, and hallways to decrease nighttime confusion.
- Have the person wear ID bracelet. Keep current photos in case you need it for the police.
- Alert neighbors and police/sheriff to the possibility of the person wandering – make sure they have your phone number.
- Provide regular exercise to dissipate excess energy.
- Never restrain - this just escalates the situation.

“The Blue Book” A Practical Guide for Alzheimer’s Caregivers

A publication of The Alzheimer’s Aid Society of Northern California, Edition 2013
916-483-2002

SPECIFIC BEHAVIOR PROBLEMS: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

AGITATION

- Maintain your own calm.
- Take the person to a quiet area.
- Assess for any physical discomfort: thirst, hunger, pain, need for toileting, overstimulation.
- Use validation: respond to the person's emotions, ask non-threatening questions about whatever is upsetting the person, help him/her to talk about it.
- Listen without rationalizing, explaining or denying.
- Listen to quiet music.
- Talk soothingly about familiar things.

DENIAL OF THE NEED FOR HELP

- ◆ Explanations are useless and only increase resistance.
- ◆ Normalize the situation and emphasize how we all need help.
- ◆ Have their doctor "prescribe" the help or level of care.
- ◆ Speak of the help in terms of your help being temporary—until the person "gets better".

"The Blue Book" A Practical Guide for Alzheimer's Caregivers

A publication of The Alzheimer's Aid Society of Northern California, Edition 2013
916-483-2002

SPECIFIC BEHAVIOR PROBLEMS: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

VIOLENCE

- Combativeness is a response to either external or internal stimuli - it is a response to fear and/or frustration.
- Stop whatever activity that is going on.
- Take five steps back.
- Stay calm and then offer your hands, palms up.
- Apologize—even if you think you did nothing wrong—this is about the impaired individual, not about you.
- Never strike back or use force unless the person is in immediate danger.
- Reaffirm your caring for the person—let him/her know you will keep him/her safe.
- Move to a quiet place, if possible.
- Encourage the person to talk about what is happening and listen without judging.
- Evaluate the underlying cause of the combativeness:
 - ◇ Is the person overtired?
 - ◇ Is it due to medication side effects?
 - ◇ Is the person in pain?
 - ◇ Was the person over stimulated?
 - ◇ Was the person in an unfamiliar environment?
- Try not to take it personally.
- Try not to act afraid—the person will sense your fear.
- Sometimes pets or stuffed animals can soothe the person.
- Request that the doctor re-evaluate medications.

“The Blue Book” A Practical Guide for Alzheimer’s Caregivers

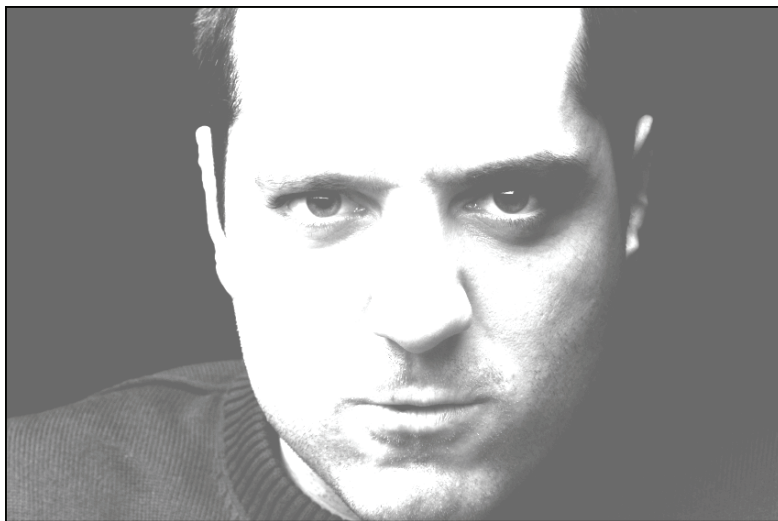
A publication of The Alzheimer’s Aid Society of Northern California, Edition 2013
916-483-2002

SPECIFIC BEHAVIOR PROBLEMS: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

SUSPICIOUSNESS

- ◆ May be due to loss of control, insecurity, being threatened or a need to preserve self-esteem.
- ◆ Don't argue, but ask factual questions regarding the problem.
 - ◇ "What color was your purse?" "How big is it?" "Do you always carry it?"
 - ◇ "I'll help you look for it."
- ◆ Reassure the person of your love and caring.
- ◆ Check the trash routinely.
- ◆ Don't argue or rationalize – respond to the emotion and provide reassurance.
- ◆ Don't take accusations personally—remember it is the disease talking, not the person.



"The Blue Book" A Practical Guide for Alzheimer's Caregivers

A publication of The Alzheimer's Aid Society of Northern California, Edition 2013
916-483-2002

SPECIFIC BEHAVIOR PROBLEMS: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

INAPPROPRIATE SEXUAL BEHAVIOR

- All individuals, regardless of age, have a need for love, touch, companionship and intimacy.
- Due to a lack of understanding of the sexual needs of older adults, the impaired person's sexual interests are often viewed as behavior problems rather than a need for love and intimacy.
- Distinguish between inappropriate sexual behavior and just normal sexual desire.
- With dementia there is a loss of inhibitions, but not a loss of normal sexual urges. Care givers need to understand that this loss of judgment and inability to control impulses or judge what is socially appropriate are due to the dementia.
- Confronting the impaired person or trying to reason with him/her is useless.
- Gently guide the person to a private place where the behavior may be more appropriate.
- Distract rather than confront.
- Don't shame or demean.
- Adjust clothing for comfort and to make inappropriate undressing more difficult. Put their trousers or dress on backwards or use pull-on pants with a drawstring at the waist.
- Give the person plenty of physical contact in the form of stroking, patting, hugging to satisfy the need for physical contact and reassurance.

"The Blue Book" A Practical Guide for Alzheimer's Caregivers

A publication of The Alzheimer's Aid Society of Northern California, Edition 2013

916-483-2002

BEHAVIOR MANAGEMENT: CONCLUSION

Barbara Gillogly, Ph.D., LMFT, CPG

CONCLUSION

- ◆ Similar to young children, people with dementia have difficulty differentiating between what is factual and what they are thinking about.
- ◆ The person is not willfully forgetful, rude, or combative, but cannot control his/her behavior.
- ◆ Don't waste time and energy fretting over what cannot be changed.
- ◆ Praise and support the abilities that are left; find tasks the person can do reasonably well, and try to avoid frustrating situations.
- ◆ Remember, all behavior has a reason, even though you don't understand it.
- ◆ Remember what works today may not work tomorrow. What works for someone else may not work for you. Tomorrow it may all be different.
- ◆ "Tips for Responding to Challenging Behaviors" *
 - ◇ Stay calm and be understanding.
 - ◇ Be patient and flexible.
 - ◇ Look for reasons for each particular behavior.
 - ◇ Respond to the emotion, not the behavior.
 - ◇ Don't argue or try to convince.
 - ◇ Acknowledge requests and respond to them.
 - ◇ Accept the behavior as a reality of the disease and try to work through it.
 - ◇ Explore various solutions.
 - ◇ Find other outlets for the behaviors.
 - ◇ Use memory aids.
 - ◇ Try not to take behaviors personally.
 - ◇ Talk to others about your situation.
 - ◇ Find time for yourself.

* *Alzheimer's Association*

"The Blue Book" A Practical Guide for Alzheimer's Caregivers

A publication of The Alzheimer's Aid Society of Northern California, Edition 2013
916-483-2002