

Alzheimer's Aid Society

OF NORTHERN CALIFORNIA

“THE BLUE BOOK”

2013 Edition



A PRACTICAL GUIDE FOR ALZHEIMER'S CAREGIVERS

Part 1 - Caregiving

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*

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CAREGIVING

Barbara Gillogly, Ph.D., LMFT, CPG

Care of the Caregiver

In the partnership between caregiver and care receiver, the more important partner is the care-giver—***the caregiver is the foundation of this partnership.***

Caring for yourself is legitimate and of first priority. It is not being selfish. Remember, one-third of caregivers die before the person they are caring for because they have not taken care of themselves first.



Boundaries

We all have limits, both physical and emotional, and we all must function within the confines of reality.

Consider carefully each task and where your physical and emotional boundaries lie.

Then accept that you have the right and obligation to set realistic boundaries and the right and obligation to maintain them.

If you do not do this, you will eventually resent the person you care for, become angry with yourself, and then feel guilty. This destroys your effectiveness. ***In the interest of yourself and others, boundaries must be set and maintained.***

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CAREGIVING

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Steps in Establishing/Maintaining Boundaries

Set realistic goals for yourself and your loved one. Much stress is self-induced—especially when you feel you “should” be able to do this or you “ought” to do it. You feel guilty when you can’t be perfect and expectations are not met. “Should” and “ought” have no basis in reality—allow yourself to be human. This is what your loved one needs most of all.

Learn to say “no” to others and to yourself. “No” is a life-saving word—it literally can preserve you and your loved one. It is OK to say, “No, I can’t do that”—good people say “no”, too.

Accept the fact that you cannot and should not do, or solve, everything. It is often difficult to accept that we can’t fix everything or do everything. Many things have no solutions or explanations. The world is full of unexplainable things. You’re not expected to have all the answers.

Talk to yourself using positive statements. Remind yourself of all the things you are doing—if you can’t do anything about a situation, remind yourself that it’s a waste of energy to get upset about it. Tell yourself it’s OK not to be able to do everything. Let go of things you really cannot do and refer them to someone who can. Let go of those that really don’t matter—decide what’s really important, do that, and let the rest go.

Have someone to talk to. It helps to talk with someone who will listen and not judge you. Be each other’s support system—the benefit is in talking about it.

Accept the fact that all emotions are OK. Emotions are part of being human and are meant to be felt and expressed. Saying how you feel is satisfying and reduces stress. Talking about your feelings is OK—how you act on them can be OK or not OK.

Take care of yourself. Many people depend on you and need you. If you give everything you have without replenishing yourself, soon you’ll have nothing left to give. By taking care of yourself, you’re taking care of those who depend on you. Taking care of yourself is not selfish, it is essential.

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THE CAREGIVER

Margie Eisenhower

There is a wonderful saying that goes like this (anonymous):

“Today I bent the truth to be kind, and I have no regrets, for I am more sure of what is kind, than I am of what is true.”

As caregivers of a patient with Alzheimer’s Disease or other dementia, there will be times when the patient imagines things that aren’t real. Because of their confused and jangled minds, they become frightened or stressed by these things. You can try to relieve them of the worry from these things if they can’t let it go. For instance, one woman in a care home ‘imagined’ there were two children coming in and out of her room, and she was afraid they’d be hurt. She called her husband, very agitated; she didn’t know what to do. He told her, “not to worry,” -- the police department knew about them and was sending someone right out to take them to their parents. She was so relieved.

My own mother told me the neighbor boys were coming into her home and stealing money. She lived a great distance from me but I knew the neighbors well, and knew this couldn’t be so. Contradicting her and trying to reason with her about the impossibility of this would have been futile. Instead, I said, “Yes, I know about that, Mom, it’s terrible! However, I’ve talked with the parents and they will make sure it doesn’t happen again.” That truly appeased her. When it came up again another time, I said the same thing, and again she was relieved. Eventually, I moved my mom closer to me, and when I packed up her home,

I found several rolls of twenty-dollar bills – one roll inside a cereal box, one inside a roll of paper towels, one hidden in a secret drawer in an old trunk, and rolls in a couple of other places. It was a “Catch-22.” She’d go to the bank and draw out money. She’d worry about the neighbor boys stealing it, so she’d “hide it,” from them. When she needed money she couldn’t remember hiding it; hence, the neighbor boys took it!

One daughter told me her mother was very frightened, as she thought a burglar had entered her home and she feared he’d be returning. The daughter told her mom she had called the police and they’d already caught and arrested the burglar, so she needn’t worry any more. That’s all it took.

As a Peer Counselor for Alzheimer’s Aid Society, I’ve had both men and women tell me that they can’t imagine lying to their own mothers. But, that’s where the quote above comes in. This ‘white lie’ you’re telling is a way to bring comfort to that mom (dad, sibling or friend) whom you love, respect and want to protect.

I had someone explain to me once, that having Alzheimer’s or dementia, is like having someone fly you to a foreign country, set you down on a bench in the city and just leave you! You can’t speak the language, you don’t know where you are, you don’t know where to go, you don’t know anyone around you. Can you imagine the fear and anxiety this would bring? Many patients deal with confusion and stress on

a regular basis. They forget they have Alzheimer’s but they know *something* is very wrong with them and it is always frightening.

A simple rule when dealing with loved ones: Be Kind. Don’t argue with them. Don’t tell them they are wrong. Don’t tell them they don’t make sense. Don’t say, “You already asked me that!” Don’t say, “You’ve told me that five times!” They can’t help it that their brain is off balance and mixed up. Ask yourself, “How would I want to be treated if that were *me*?”

When your loved one is gone, you will be happy that you treated them with kindness, love and respect. But don’t be hard on yourself either. Joe Frazier, the great boxer once said, “If I lose [a fight], I’ll walk away and never feel bad, because I did the best I could, and that’s all I can do.”

This job isn’t easy! Caregiving is probably the toughest occupation out there right now. Call our office for help. P-l-e-a-s-e take yourself to a Support Group. Not only can you visit with people who are going through the same thing you are, but you will pick up ideas and suggestions that will make your job much easier. No one knows how difficult this job is unless they’ve done it themselves. And sometimes other family members make it tougher instead of easier because they simply ‘don’t get it.’ What they don’t know is that unless they spend two full days with the patient, they have no idea how bad the disease is or how hard it is for you, the caregiver.

I salute you! I admire you! I wish you well!

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COMMUNICATION AND DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

Understanding Communication Problems

Communication problems with dementia are caused by damaged nerve cells and the decrease in neurotransmitter activity.

Symptoms

- ◇ Trouble with naming, word-finding, fluency, comprehension and repetition. In some cases, difficulties with reading and writing.
- ◇ Body language may be impaired.
- ◇ Don't assume the person's communication tools have the same meaning as before.
- ◇ May only be able to use a limited number of words.
- ◇ The person with dementia may be dealing with one or more of the following:

Confusion
Fear
Depression
Inability to learn new things
Loss of self-esteem

Anxiety
Irritability
Short attention span
Loss of inhibition

Your Response

The caregiver's response needs to be:

Calm
Accepting
Kind, patient and respectful
Listening more than talking

Reassuring
Connecting, not correcting
Flexible

General Techniques

- ◇ Approach from the front.
- ◇ Proceed slowly.
- ◇ Maintain a routine and structure.
- ◇ Have realistic expectations.
- ◇ Be involved in their daily tasks.
- ◇ Break down tasks into simple steps.



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Remember:

- ◇ Disorientation may be greater at specific times of the day.
- ◇ The patient needs a quiet, non-distracting environment.
- ◇ When you think you understand what's being communicated, try to help finish the sentence or complete the task.
- ◇ Be alert to signs that you have misunderstood the message and try again.
- ◇ Try to find a word you recognize and then repeat that word with inflection while mirroring the person's facial expression.
- ◇ If you cannot understand their verbal input, respond to their feelings or emotions.
- ◇ Patients may revert to original language in the later stages. Try to learn some simple adaptive words and phrases to help during this time.
- ◇ Every behavior has a reason.
- ◇ The patient is doing the best they can at the moment.
- ◇ Don't overreact.
- ◇ Don't embarrass, scold, shame, moralize or punish.
- ◇ Correct, if possible, any hearing or vision deficit.



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Verbal Communication

- ◇ Speak slowly.
- ◇ Construct communication to match the person's ability.
- ◇ Use simple words and short sentences.
- ◇ Use words frequently used by the person in the past.
- ◇ Use nouns rather than pronouns.
- ◇ Don't use two-part questions.
- ◇ Address the person by name .
- ◇ Make one request or ask one question at a time.
- ◇ Give the impaired person time to respond.
- ◇ If you need to repeat, use the same words.
- ◇ Change topics slowly.
- ◇ Use humor.
- ◇ When questions are repeated, answer once and then use reassurance.
- ◇ If necessary, speak louder or lower your tone of voice.

Nonverbal Communication

Nonverbal Cues

- ◇ Nonverbal communication ultimately becomes more important than verbal.
- ◇ More is communicated through nonverbal means.
- ◇ Your body language expressed while talking with someone other than the person with dementia will be interpreted by him/her as pertaining to him/her.

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Remember:

- ◇ The tone of our voices can be colored by the history of a relationship.
- ◇ The person needs to feel that his/her dignity and self-esteem remain intact, even if their mental condition is declining.

Techniques:

- ◇ Maintain eye contact.
- ◇ Your verbal message should match your body language.
- ◇ Listen and pay attention.
- ◇ Use gestures.
- ◇ Show love and affection.
- ◇ Touching can enhance attention and listening.
- ◇ Be alert to the feelings being communicated.

Non-verbal Messages from Person with Dementia

Be alert to physical signals -

- ◇ Pale or flushed face, perspiration, etc. may mean the person is receiving too much sensory stimuli.
- ◇ Averting the eyes, looking down and increasing use of hand gestures may mean the person does not understand.
- ◇ Feelings of hostility may be expressed by an increase in motor activity (pacing), frowning, speaking loudly, pursed lips, and tight facial muscles and jaw.
- ◇ Non-listening behavior may be exhibited by a lack of direct eye contact, failing to nod or affirm.
- ◇ Being receptive is often indicated by decreased or absent body motion, relaxed facial muscles, smiling, extending hands.
- ◇ Anxiety may be exhibited by hand wringing, crossing and uncrossing legs, stepping toward you, increased body movement.

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ALZHEIMER'S AND DEPRESSION

MaryLee Moritz, RN

Alzheimer's disease and depression are among the most common disorders of the elderly and both can have a major impact on quality of life for patients and caregivers alike. In fact, experts believe that two out of every five people with Alzheimer's will eventually suffer from depression.

We all feel low or down from time to time but this isn't the same as being depressed. Depression is a more persistent condition in which a number of feelings, such as sadness and hopelessness, dominate a person's life and make it difficult for the person to cope.

However, many people with moderate to severe Alzheimer's don't have the insight or the words to express how they feel and they may have trouble realizing where their sadness comes from. Older people with depression may also experience physical symptoms, such as loss of energy and appetite changes.

People with both Alzheimer's and depression will be struggling with two sets of difficulties, and they may find it even harder to remember things and may be more confused or withdrawn. Depression may also worsen behavioral symptoms in people with Alzheimer's, causing aggression, problems sleeping or refusal to eat. These upsetting behaviors can lead to earlier placement in care facilities if not properly treated.

SIMILAR SYMPTOMS

Some of the symptoms common to both Alzheimer's and depression include:

- Depressed mood (sad, hopeless, discouraged, feelings of guilt)
- Social withdrawal and isolation.
- Memory problems and impaired thinking, inability to concentrate.
- Loss of interest and pleasure in hobbies or activities once enjoyed.
- Sleeping too little or too much, tiredness or loss of energy.
- Irritability, mood changes

DIAGNOSIS AND TREATMENT

The most common treatment for depression in Alzheimer's involves a combination of medicine, counseling, support at home and gradual reconnection to activities and people that bring happiness. Simply telling the person to "cheer up" is seldom helpful. Depressed persons with or without Alzheimer's are rarely able to make themselves feel better just because they want to, or without professional help, lots of support and reassurance. Proper treatment relies on the education and patience of caregivers and physicians and can greatly improve a person's quality of life.

Many of the depressive symptoms shared by Alzheimer's and depressed persons are so similar that even doctors may have trouble deciding which one it is. Because these symptoms often overlap when depression and Alzheimer's occur together, thorough physical, mental and psychological exams are helpful in diagnosing the two disorders.

Much of the diagnoses may rely on the observations of caregivers since they have daily contact with their loved ones. Fortunately, symptoms and behaviors are often treatable with medications and change. Successful treatment requires easing anxiety through a combination of treatments, including medications and improving situations at home. Support groups and counseling may help persons with depression in the early stages of Alzheimer's, before their ability to communicate deteriorates.

Caregivers can help ease anxiety by:

- Creating a calm environment. Try to get rid of the triggers that could set off anxiety, such as machines that make loud or unusual noises, bright lights and other distractions.
- Simplifying frustrating tasks and routines. Take over some chores that the person may have trouble with, such as bathing and dressing.
- Making sure the person is comfortable. Is your loved one feeling any

pain, hunger or thirst? Is the home at a comfortable temperature and is the bathroom easy to find and use when needed.

- Giving the person chances to burn off excess energy, especially in the morning. Take daily walks with your loved one and encourage them in other forms of exercises, such as gardening or taking care of pets.

Anti-anxiety medications are also available. SSRIs (Selective Serotonin Reuptake Inhibitors) such as citalopran (Celexa) and Sertraline (Zoloft) are antidepressants used for people who have depression and Alzheimer's because of the low risk of side effects and drug interactions. Making the right diagnosis and getting treatment can help make life easier and more enjoyable for the person with Alzheimer's and depression as well as his or her caregivers.

If you are caring for a person who is suffering from depression or anxiety related to Alzheimer's, don't let them endure the pain any longer than necessary. Remember that everyone is unique and depression symptoms can vary greatly among people. Always contact your loved one's doctor to answer your questions about any unusual symptoms or concerns. Try the tips mentioned here and take steps to handle situations in positive ways. Proper treatment of both diseases can greatly improve quality of life for patients as well as those who care for them.

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APPOINTMENTS AND COMMUNICATION WITH THE DOCTOR

Clara Jackson, RN

Medical appointments can be very stressful for caregivers and patients alike. Here are some tips to help ensure a successful visit to the doctor.

Try to get an appointment for the time of day the confused person is at his or her best to gain better cooperation. This is a good rule to follow whenever any medical problems arise in the future.

Allow enough time for getting the impaired person ready, the trip and getting into the office. If bathing before the appointment is likely to create another battle, skip that step. You should not feel rushed or exhibit stressfulness as this can agitate the impaired person.

When arriving for the appointment let the receptionist know that the person is memory impaired and confused. If the waiting room is crowded and noisy, ask for a quiet room in which to wait. Take items from home to keep the person occupied while waiting, such as you would do for a small child. At the same time remember to respect the person as an adult. If the patient is restless, ask the receptionist if you can be paged or called on your cell phone when it is nearly time for the patient to be seen by the doctor. Take a walk with the person. Most medical centers have art displayed on walls and a nice landscaped area outdoors. Stay with the impaired person at all times to minimize fright in a strange place. It is helpful to take a friend with you.

Provide written information and questions for the doctor. Make a copy for yourself. In this way important information and questions are not forgotten and efficient use of time is made. State the person's name and reason for the appointment. List all medications such as prescription drugs, over the counter medications and any herbal products. List the reason for taking these medications and products. If you have questions or concerns you feel uncomfortable saying in front of the patient, list these in "bullet fashion" so they are easy and efficient for the doctor to review.

If the person does not have a medical power-of-attorney, learn more about this. Contact the Alzheimer's Aid Society for more information. Without power-of-attorney or conservatorship, the doctor may decline sharing information with you. Remember though, even if the doctor will not give you information, YOU can give information to the doctor.

Learn more tips by attending a support group or talk with a peer counselor at the Alzheimer's Aid Society.



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BATHING

Barbara Gillogly, Ph.D., LMFT, CPG

- Persons with dementia often exhibit a fear of undressing and of water.
- A handheld showerhead can be less threatening.
- A shower chair with arms can be reassuring.
- Give the person his/her own washcloth while you are helping with the washing.
- Consider showering with the person.
- Allow the person to enter the tub or shower wearing underwear or a robe and then when wet, suggest the person take it off.
- Older people do not have to shower daily - 2-3 times per week is sufficient. Alternate with sponge baths.



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DEMENTIA AND INTIMACY

Barbara Gillogly, Ph.D., LMFT, CPG

Introduction:

- ◆ Sexual behavior is seldom discussed as it is considered very personal.
- ◆ We tend to accept the myths we are raised with.
- ◆ Little is written on the topic of sexuality and dementia.
- ◆ Due to a lack of understanding of the sexual needs of older adults, the sexual interests of the individual with dementia are often viewed as behavior problems rather than a need for love and intimacy.

Sexual Behavior:

- ◆ It is a human to need to be touched and held and to express sexual feelings.
- ◆ All of us are sexual beings from birth throughout our life span. Even impaired, dependent people with dementia retain adult feelings.
- ◆ We may not always be sexually active, but we are still sexual beings.
- ◆ Most people with dementia respond to the opportunity to give and receive affection.
- ◆ People with dementia may express inappropriate sexual behaviors because they cannot remember or understand the consequences or meaning of such behaviors.
- ◆ Persons with dementia lose impulse control. They lose the ability to make appropriate judgments about when, how, and with whom sexual activity is appropriate.
- ◆ Older men who feel their physical strength and abilities waning, may feel the need to reassure themselves they are still men by flirting and making inappropriate sexual comments and behavior. Today's elderly men grew up in a society that expected men to make sexual advances to prove their manhood.

Affection and Sexual Intimacy:

- ◆ Sexuality involves expressions of affection as well as sexual intimacy.
- ◆ Affection: kissing, touching lovingly, caressing, holding hands, placing arm around, sleeping in the same bed.
- ◆ Sexual intimacy: sexual intercourse.

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Problems and Coping:

The issues are as different as the couples involved.

- ◆ Both can be very affectionate with sexual activity.
- ◆ Both can be very affectionate without sexual activity.
- ◆ For some, sexual activity becomes more physical and less emotional.
- ◆ There may be little affection, but one or both partners may still be interested in sexual activity. If it is the caregiver, he/she may seek it elsewhere.
- ◆ Hypersexuality may be exhibited on the part of the person with dementia. The caregiver may be reluctant to show affection as he/she fears it may lead to unwanted sexual activity.
- ◆ Confronting the impaired person or trying to reason with him/her is useless.
- ◆ Gently guiding the person to a private place where the behavior (masturbation) may be more appropriate.
- ◆ Distraction works better than confrontation. Asking the individual to hold something for you will keep his/her hands busy.
- ◆ Shaming or demeaning is counterproductive. The individual is expressing normal adult feelings, but he/she has lost the ability to judge appropriateness.

Effect on Relationship:

Many factors influence the relationship between the spouse who is the caregiver and the spouse with dementia.

- ◆ Belief in what is perceived as “normal” or “abnormal.” Belief that diminished sexual desire is expected with age.
- ◆ Quality of the past relationship is a factor in present feelings.
- ◆ Pattern of life over time.
- ◆ How important sex was in the past.
- ◆ Conflict in roles: caregiver/lover.
- ◆ Increase in responsibility leaves less energy, physical and emotional, for sexual intimacy.
- ◆ Afflicted spouse may believe he/she is still sexually active when that is not the case—the mind’s eye is in the past.

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DEMENTIA AND INTIMACY

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Summary:

- ◆ **There is no one right way to feel or deal with the issue of intimacy in the presence of dementia.**
- ◆ **You have a right to feel whatever you feel and the right to say “no” when you want .**
- ◆ **The one constant is that the individual with dementia needs to be treated as an adult with respect and caring. He/she is suffering with a disease that changes how the person reacts.**
- ◆ **It is important to talk with someone about this issue, so that you know you are not alone and that all your feelings are valid.**



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HOPE: Art Therapy For Those With Dementia

Cynthia Wilson MA, MFTI, AT

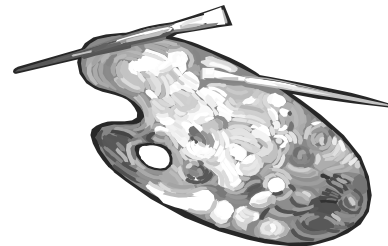
Hilda Goldblatt Gorenstein was a painter in the Chicago area in the mid 1900's. During her later years she developed dementia. Yet she was able to live a long and fulfilling life in a nursing home, thanks to her daughter's persistence. Her daughter, Berna Huebner, hired the art students from the School of the Art Institute of Chicago to come and work with her mother in painting again. "Her mother had said to Berna when asked if she wanted to paint again, 'I remember better when I paint.'" (Whitcomb 2010) Hilda had not painted in several years. She had a history of being withdrawn and sometimes agitated to the point where staff would give her mild tranquilizers to help calm her in her dementia. (Whitcomb 2010)

Jenny Shepard, the first art student to work with Hilda, received little results and equally poor support from facility staff. "One told Shepard, 'You're wasting your time. The lights are either on or they are off, and with Hilda, they are definitely off.'" (Whitcomb 2010) I have many years of managing and observing caregivers of those with dementia and this statement can be very discouraging. This staff member was most likely uneducated about the disease or closed-minded due to being overworked. Whatever the motive for her statement, don't be discouraged by statements like this one. There's always something for which to be hopeful. For instance, it took some time, but the art students got Hilda painting again. They got her back to doing something she had always loved.

There used to be the idea that if you are artistic you are "right brained". However, it has since been discovered that the creative aspects of the human mind are located all over the brain. (Lusebrink 2004) There is no one special place for creativity, allowing the mind to always have creative capacity. Even those with dementia, whose brains are being taken over by a devastating disease that gradually inhibits their ability to remember and physically function, still have the potential to be creative. There is no prior artistic skill or desire needed in order to do this in an Art Therapy setting.

"As Samuel Gandy, associate director of the Mount Sinai Medical Center Alzheimer's Research Center in New York, puts it: 'Alzheimer's typically hits memory areas of the brain early, while sparing areas responsible for creativity. Art and music are perfect modalities for stimulating these creativity areas.'" (Whitcomb 2010)

As an Art Therapist who has worked with several groups and individuals with various forms of dementia, I have witnessed amazing things coming from them. The act of creating allows them to still have self-expression when they can no longer make sense of their world. The creation of the artwork gives vision to their voice when they can no longer speak. It can also give a voice to those who are capable, but normally wouldn't talk anymore. The process of making art in a therapeutic environment helps them to be themselves again by expressing their emotions in a non-judgmental environment.



I have also discovered that art is a great way to spark creativity, individuality and self-confidence in those with dementia. I have seen group Art Therapy sessions help people reconnect and find their place in the world as well as find their voice again.

Sometimes I have to put a brush in their hand to get them going. At other times, once I have set up the paints and brushes, they start by themselves. One gentleman I'll call Ebert (pseudonym), when using water colors, would not wait for me to pour the water. He would spit in his paints and just get to painting. As soon as he was finished with his painting he would ask, "So teacher, did I get an A?" I would always reply, "You get two thumbs up," as I held my thumbs up for him. He would laugh and the group would laugh with him.

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HOPE: Art Therapy For Those With Dementia

Cynthia Wilson MA, MFTI, AT

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As an Art Therapist I know that if I told Ebert he got an 'A' like he wanted, then the others in the group could feel that they were being judged on quality of work and not process. Giving the "Two thumbs up" was a fun and playful response that pulled on his personality allowing him to feel as though he did well and yet not give a direct judgment. No judgment is a key component to an Art Therapy session. The artwork created in an Art Therapy session is a form of self-expression however the artists need to express themselves in that moment.

The goal of every group I do with those with dementia is to get them feeling comfortable, relaxed and confident in what they are doing and who they are. There are so many things going on around them that they no longer understand or remember. Feelings of anxiety, fear, disorientation, sadness or anger can be very overwhelming for one with dementia. Giving them at least 1 hour a week to regain that confidence, control and self-confidence can carry on throughout the rest of the week.

With some of the clients I have worked with, staff has reported to me that it has helped prevent the need for tranquilizing medications for at least a few hours if not days. The clients socialize and laugh and know that whatever they create is the right thing for them to create that day. They talk about old memories and bond over this art process. I find that some of them actually remember me when I come back again. They even tell me how great the art makes them feel and that they were just waiting for me to come back.

I had one client say that her mind was feeling all fuzzy that day and she just couldn't get things figured out, but that after she completed a painting in my group she finally felt relaxed, her headache was gone and she wasn't worried anymore. "I don't know what I painted for sure, but it doesn't matter because I feel happy now," she said with a smile.

Another time this same woman entered the group complaining of her loss of eye-sight and that it seemed worse this day than others. I brought in another group member who had never been there before, but also had the same eye condition, and sat them next to each other. The new member stated she could not do the art because she couldn't see well as she had this special eye condition. The regular attending client said she couldn't see either, but painted anyway because it was fun to let go and just do whatever. She further explained, "At first the loss of my eyesight was horrible, but now I realize that it allows me to relax and do whatever I want. I can't see what I'm doing so it doesn't matter anymore. I'm free. I'm free to imagine whatever I want to and just paint." She used to be very meticulous and precise in everything she did as a seamstress. She says coming to the art class has taught her to be otherwise and she very much enjoys it.

During the art process, I get to see the most wonderful thing ever. These individuals--who spend day in and day out, often feeling isolated, scared, frustrated, confused and disoriented--relax their shoulders, giggle to themselves and visually lighten up. It's as if the shell of the disease breaks open and the person who is hidden inside is freed. Their eyes, face and whole being, change as they create art. People who haven't talked in months hold conversations with others in the group. People who haven't done anything for themselves and have a 24hour caregiver taking care of all their needs, pick up a brush and paint a picture on their own.

So, I say to that staff member at Hilda's nursing home who said, "Hilda's lights were definitely off": **No one should ever be discounted in their abilities to create beauty. Those with dementia have their light on at all times.** It's breaking through the shell of Alzheimer's that allows us to see them in their light once more.

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INCORPORATING MUSIC IN CAREGIVING

Clara Jackson, RN

Dr. Oliver Sacks, Professor of Clinical Neurology and Psychiatry at Columbia University, in his current best-selling book, *Musophilia*, writes about the amazing therapeutic effects of music on people with Alzheimer's disease and other dementias. Dr. Sacks describes how familiar music is the key to eliciting emotions and unlocking words that have been silent.

The parts of the brain where we make memories, the medial temporal lobes like the hippocampus, are the first areas to be attacked by Alzheimer's. The cortical and sub-



cortical areas of the brain are the "music areas" and have less damage. Studies have been done on the effects of music therapy on the five brain chemicals of melatonin, serotonin, norephedrine, ephedrine, and prolactin in Alzheimer's patients. Melatonin is associated with mood regulation. With music therapy, aggression and depression were reduced and sleep was enhanced. The brain chemicals of epinephrine and norepinephrine rose immediately but did not last long after the music was stopped. Serotonin and prolactin were not affected by music therapy.

Listening to music that is person-

ally enjoyable to the patient has positive effects on cognition as well as decreasing problem behavior. Researchers from Boston School of Medicine have shown that patients with Alzheimer's are better able to remember new verbal information when it is provided in the context of music (can remember new information if it is sung to them.)

For both the patient and the caregiver, music can bring relaxation, feelings of peacefulness and a sense of calm. Music can also bring energy and feelings of happiness. Music floods our brains with memories and emotions. Music brings joy!

Activities to consider:

Look for music on CD's, DVD's and sing along videos containing music from the 1930's through the 1950's familiar to your loved one. Selections from their teen years through young adult years are most likely to have the best responses. Also try music of Mozart, Chopin, Gershwin and show tunes.

Live music such as acoustical guitar, piano, etc.

Soothing music on the radio.

Singing and humming while doing your daily activities. Encouraging your loved one to sing along.

Encouraging clapping hands, swaying or dancing to music.

Keep musical activities to no more than 30-40 minutes.

Use stimulating music with quick tempos to rouse those who tend to fall asleep at meals or other activities of daily living.

Ballads and lullabies with slow tempos are best at bed time or for any change that might cause agitation.

In late stage dementia, music from their childhood works well such as lullabies, folk songs and favorite hymns. If your loved one spoke another language in childhood, be sure to sing in that language.

Avoid:

Music that is loud or inharmonious. This may confuse, agitate, or increase disorientation.

Videos of ocean waves and roar of surf as this can be disturbing.

Song books showing notes. Musical notes are often seen as confusing figures.

CAREGIVING TIP:

Some patients enjoy music more when they are doing something else at the same time. Folding towels, sorting silverware or nuts and bolts. During a bath, grooming rituals or meals music can provide a bridge to feeling more "at home."

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DEMENTIA AND HOME SAFETY

Barbara Gillogly, Ph.D., LMFT, CPG

INTRODUCTION

Dementia affects the brain and its ability to process information. Each person goes through the stages of dementia in his/her own way, so what works today may not work tomorrow. The caregiver's job is to watch, listen and constantly adjust to any changes. The goal of home modification is to provide safety and comfort to all family members.

SAFETY

- The person with dementia loses the ability to think rationally, so it helps to think of this as “child-proofing” your home. For example, an electrical plug may appear to be a curious hole to explore.
- Cleaning supplies and other potentially dangerous products if consumed in excess, including alcoholic beverages, need to be kept in locked containers or cupboards. Lock up matches, lighters, and cigarettes. Childproof latches on cupboard doors are often effective.
- The garbage disposal is a potential danger. You can have it rewired to a hidden switch (inside a cabinet) that the person with dementia cannot find or access.
- Electric stoves can also be rewired to a hidden switch that controls the on/off function. Gas can be turned off at the valve for gas stoves. Control knobs can be removed so the stove cannot be turned on.
- Doorways leading to stairwells, balconies, garage, and pool areas need to be blocked to prevent access.
- The person with dementia can often be diverted from a door by placing small scenic posters on the door, placing removable gates, a curtain, or brightly colored streamers across the door. The door can also be wallpapered to match the adjoining walls. Place *STOP*, *DO NOT ENTER*, or *CLOSED* signs in strategic areas on doors.
- Stairways should have at least one handrail that extends beyond the first and last steps. If possible, stairways should be carpeted or have safety grip strips. Check the carpet to see that it is not frayed or torn which could pose a tripping hazard.
- Yards need to be enclosed by a fence that is not easily climbed, and gates need to be locked to prevent the person with dementia from getting outside the yard. Slide locks can be installed on gates at the very bottom where the person would not think to look.

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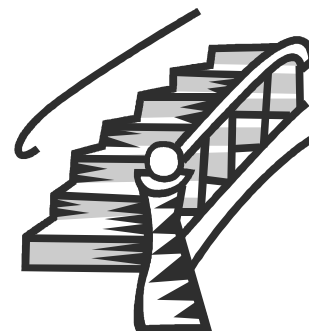
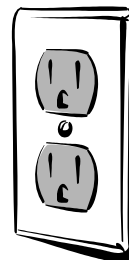
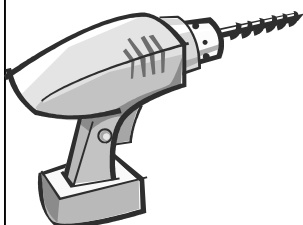
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SAFETY continued...

- Exit doors can be alarmed to alert the caregiver when they are opened, or additional locks can be installed either higher or lower than the normal lock position.
- For doors that lock from the inside, such as a bathroom, either remove the lock or keep an emergency key nearby.
- Lower the thermostat on your hot water heater to its lowest setting or no higher than 120 degrees to prevent accidental burns.
- Grab bars beside the toilet and at the bathtub can provide safe access. A non-slip mat in the tub or shower can prevent falls.
- Hide a spare key outside in case the person with dementia locks you out of the house.
- Avoid the use of extension cords where possible. If extension cords have to be used, tack them to the baseboards to avoid tripping.
- Cover unused outlets with childproof plugs.
- Make sure smoke alarms are functioning
- Get rid of clutter which can create confusion and danger. Keep all walk areas free of furniture. Get rid of throw rugs which can pose a tripping hazard.
- Keep plastic bags out of reach as these can be a choking hazard.
- Lock up or store elsewhere all firearms and power tools.



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SAFETY continued...

- Remove all poisonous plants from the home and yard. Check with local nurseries or poison control centers for a list of poisonous plants.
- Keep fish tanks out of reach. The combination of glass, water, electrical pumps, and potentially poisonous aquatic life could be harmful to a curious person with dementia.
- Provide adequate lighting that does not produce glare or shadows by using soft light or frosted bulbs. Use nightlights in bedroom, bathroom, and hallways to orient person at night.
- Remove artificial fruits and vegetables or food-shaped kitchen magnets—all of which might appear to be edible.
- Avoid the use of electric mattress pads, blankets, sheets, or heating pads as they can cause burns.
- Move the bed against the wall for increased security, or place the mattress on the floor if falling is an issue.
- Remove small electrical appliances from the bathroom.
- Remove or cover mirrors if they cause the person with dementia to become confused or frightened.

COMFORT AND EASE OF FUNCTION

- Vary the home environment as little as possible to minimize the potential for visual confusion. Keep furniture in the same place.
- Use dishes and placemats in contrasting colors for easier identification.
- Place brightly colored signs or simple pictures on important rooms (the bathroom) for easier identification.
- Remove all unnecessary clothing from the closets and drawers to avoid confusion.

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SUMMARY

Changing and adapting the home environment can promote better functioning while increasing safety. If the person with dementia is doing better, the caregiver will do better. There are many items available to help you provide safety and function for someone with dementia. One source is “The Alzheimer’s Store” which can be accessed online at www.alzstore.com or by phone at 800-752-3238.



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END STAGE OF ALZHEIMER'S AND HOSPICE

Clara Jackson, RN

As abilities fade it becomes more difficult to figure out how to stay in touch with the person with Alzheimer's disease. The person may no longer recognize you or understand speech. However the sound of your voice and holding your hand can be comforting. Massaging hands and feet with scented lotion helps to stimulate the senses. Music is stimulating and comforting, especially if it is music your loved one grew up with. Visitors and laughter may provide comfort and stimulation even if the visitors may not be recognized. Flowers, plants and the outdoors are stimulating if the person can be in a wheel chair. This is enjoyment for the care giver as well.



End stages are stressful for family members including children. Explain events in a kindly way to children in terms they can understand. There may be family conflicts and differences concerning care, treatment and placement. A professional advisor can help the family in coming to agreement and preparing for the inevitable loss. Hospice services, bereavement experts and spiritual advisors can help you work through your feelings.

In spite of the best of care the disease wins and your loved one approaches the end of life. Health declines as body systems begin to shut down. Swallowing is impaired, speech is lost and walking is no longer possible. Communication, if at all, is through moans or cries. The brain is no longer able to interpret sensory input. Sleeping is increased. There is no bowel or bladder control. The person is bedridden and requires total care around the clock for all functions of living. The person may develop an intermittent fever. Average length of life in this stage is a matter of days to a few weeks. Although all physical and cognitive functions are depleted the capacity to feel frightened, lonely, sad, secure, or loved is still there. The emotions remain.

Hospice care is considered when someone with a terminal illness no longer responds to medical intervention and has a life expectancy of six months or less. Hospice care is usually available around the clock every day of the week. It is provided in the home, hospital, private care facility or nursing home. Nurses, doctors, social workers, home health

aides, volunteers and clergy are just a few who make up the hospice team. Hospice does not provide direct caregivers but does assist by training caregivers and offering support to them, whether family members or professionals. Hospice workers focus on the family as well as the patient. Hospice always provides palliative (comfort) and compassionate care specialized for the dying patient. Palliative care does not hasten or delay death. It means taking care of the whole person in body, mind and soul, helping the patient to live out his/her life in a comfortable way by relieving symptoms and pain. A reputable hospice supports their client's faith by encouraging contact with their own clergy, offer chaplain assistance if needed, provide volunteers to read spiritual resources as requested. They do not take the place of the family's spiritual mentor.

Hospices can be funded in many ways but usually Medicare covers the cost of care. Most hospices belong to the National Hospice and Palliative Care Organization (www.nho.org) but each hospice is its own entity and runs itself accordingly.

Professor Mark Braun in the journal **Clearly Caring**, Second Quarter 2010, Vol. 30 / Number 2 writes about a movie he saw 40 years ago based on a 1930's novel, "They Shoot Horses...". In the movie Robert shoots his girl friend, Gloria, who wishes to die. Questioned by the police, he responds, "They shoot horses, don't they?" He implied that he was acting from an ethic of compassion. Isn't it more merciful to end a hopeless or pain filled life than to force people in such straits to go on living? But Brian Pollard, retired anesthetist and palliative care physician, has called such termination of life a "form of abandonment." *Compassion*, he notes, derives from Latin and means "to suffer with." In reference to dying patients, it translates as walking the rest of life's journey beside them, offering comfort and support at every stage. To end their lives is an act of abandonment, not compassion. It does not address the best interests of the patient but is often done because the journey is too difficult on the others. (Used by permission from **Clearly Caring**.)

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