UofL Geriatrics

SUMMER NEWSLETTER

A Lifetime of Letting Go: Dealing with Grief and Dementia

by Kim Toebbe

There is a relaxation exercise during which the participant consciously relaxes each body part one at a time. Tense your whole body and then let your head relax, your neck, your shoulders and arms, your torso, limbs and feet. Try letting go little by little until your whole body is limp.

Having a loved one with Alzheimer's Disease or other dementing illness reminds me of that exercise in that we let go of parts, bits and pieces of the person a little at a time. Because of the slow progression of the disease, we are often forced to let go little by little until our loved one "goes limp".

Chronic grief experienced by families and caregivers of those afflicted with dementing illness often manifests in many physical and emotional symptoms. We may be walking around with our whole bodies "tensed" due to the stress of dealing with the illness.

We may think we are preparing gradually to let the person go when we may actually be delaying a catastrophic reaction to grief by as many as ten years if we wait to grieve until the person is actually gone. Grief is a process of letting go and dealing with the emotions which trouble us.

If we choose to look at "letting go" as a natural way of life which we will experience again and again throughout our lifetime, there is a certain grace which comes from letting go instead of grasping and attempting to control that which you cannot.

More families are choosing Palliative Care for their loved ones. "Allow a natural death" is how one Hospice professional put it. Aggressive treatment of every ailment may be appropriate for some patients and inappropriate for others for whom there is no chance of recovery.

Unresponsive patients who have not made their wishes known prior to becoming so, may find themselves hooked up to feeding tubes, respirators, IVs and in and out of hospitals., which may cause suffering for all involved.

Can you let go? Of course you can and you will all in good time. Practice patience, grace and be as good to yourself as you are to your loved one. You may experience joy and beauty where you never thought possible.

Alzheimer’s Disease Behaviors | Suspicion of Others

Memory loss and confusion may cause the person with Alzheimer’s to perceive things in new, unusual ways. Individuals may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. Sometimes the person may also misinterpret what he or she sees and hears.

How to respond

•Don’t take offense. Listen to what is troubling the person, and try to understand that reality. Then be reassuring, and let the person know you care.

•Don’t argue or try to convince. Allow the individual to express ideas. Acknowledge his or her opinions.

•Offer a simple answer. Share your thoughts with the individual, but keep it simple. Don’t overwhelm the person with lengthy explanations or reasons.

•Attempt to redirect the focus to another activity. Engage the individual in an activity, or ask for help with a chore.

•If possible, duplicate any lost item. If the person is often searching for a specific item, have several available. For example, if the individual is always looking for his or her wallet, purchase two of the same kind.

*Provide the person with a purse, bag or knapsack so they may keep “important” items inside.

Aggression:

Aggressive behaviors may be verbal, (shouting, name-calling) or physical, (hitting or pushing). These behaviors can occur suddenly, with no apparent reason, or may result from a frustrating situation.

Possible causes

Physical discomfort: fatigue, pain, medication side effects?
Environmental factors: overstimulation, loud noises, physical clutter, feeling lost or frightened.
Poor communication: asking too many questions of the person? Giving complicated instructions? Conveying your own stress, negativism or critical thoughts.

How to Respond

Try to identify the immediate cause, while focusing on feelings, not facts. Don’t get angry or upset or take the behavior personally. The person isn’t necessarily angry with you. Be positive and reassuring in a slow, soft voice. Limit distractions and try a relaxing activity.
Decrease you level of danger. You can often avoid harm by simply stepping back and standing away from the person.
Avoid using restraint or force unless the situation warrants it, such as when the person is attempting to harm herself or others.

Attend Support Group Meetings

You will find that many care-partners are having some of the same issues you are.

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Social Security Disability for Early-Onset Alzheimer's Disease Patients

What is the Compassionate Allowance Initiative?
Under this initiative, the Social Security Administration (SSA) finds individuals with certain diseases/conditions eligible for Social Security disability (SSDI) and Supplemental Security Income (SSI) benefits by the nature of the disease. While applicants still have to meet other SSDI criteria and/or SSI criteria, when it comes to the disability criterion, they are considered eligible by virtue of the disease and fast-tracked for a favorable decision about their eligibility for SSDI and SSI benefits.

Why is this important to individuals with early-onset Alzheimer's disease and related dementias?
Social Security disability benefits are very important to those with early-onset (younger-onset) Alzheimer's and related dementias because these individuals are often initially denied benefits – but usually win on appeal. Those affected by early-onset Alzheimer's are often simultaneously faced with the enormous challenges that the disease presents, while also undergoing a long disability decision process that is financially and emotionally draining. By adding Alzheimer's disease to the list of "Compassionate Allowance" conditions, it will simplify and streamline the SSDI/SSI application process and should result in receiving SSDI/SSI benefits in an expedited manner.

Aggression in the Dementia Suffers

Some persons suffering from dementia may become aggressive, as evidenced by: shouting, cursing, hitting, pushing, name-calling or the like. These behaviors are distressing to caregivers who may feel hurt or even frightened by their persons actions and or words.
It is hard for caregivers to understand why the person is acting out and the following are some possible causes and their interventions:

Physical discomfort: does the person have pain or a need to relieve himself? Is the person too hot or too cold? Is clothing uncomfortable or positioning a problem? Is the person tired or has he started a new medication?
The way to alleviate symptoms of discomfort is to identify and eliminate the cause of the discomfort, whenever possible. A caregiver may have to try many different interventions before finding one which works, especially in the non-verbal person.

If physical discomfort is not found or has been addressed and the person still behaves aggressively look at environmental factors such as noise, lighting, overstimulation or clutter. Create a calm, peaceful and soothing environment free of noise and distraction to try to calm the person.

Communication can be an issue if caregivers ask the person too many questions such as "Do you know who I am?", ""What is that?", etc. Keep communication simple and clear to set the person up to succeed. Ex: "Would you like chocolate or vanilla ice cream?" Say "It is such a beautiful Monday and the sun is shining brightly" instead of "Do you know what day it is?"

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Safety is of the utmost importance for the person and others around him. Make sure the person is safe from injury by removing any possible weapons and leaving plenty of space between yourself and the person, when possible. Do not crowd the person or badger them about their actions or words-this may actually make the situation worse.
Try to redirect the person to another activity, if possible and avoid restraining the person unless absolutely necessary to keep the person or yourself safe. Restraints have been shown to increase frustration and do more harm than good.

If you have questions or concerns about your loved ones behavior, call the Alzheimer's Association at 1 (800) 272-3900.

Tips for Caregivers!

by Kim Toebbe

Many people with memory deficits continually "lose" everyday items and sometimes become convinced that others have "stolen" them. A caregiver reported that her mother would no longer speak to a once beloved niece because she thinks the niece "stole" her well-used eyebrow pencil!

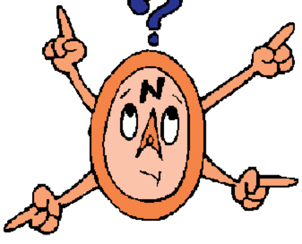
Those not in this situation may think it laughable that people are accused of stealing half-used lipstick, 20 year old moth-eaten sweaters and the like, but to those facing this situation this issue can be very distressing.
One helpful tip is to label everything! A label-maker can be used to clearly label drawers, cabinets, shelves, containers and more which may help cue the person and the caregiver to put things back where they belong each time to avoid losing items.

Some caregivers go so far as to label appliances, doors, microwave instructions and more in order to allow the person to keep her independence as long as possible.
Consideration for the persons dignity must be kept in mind when labeling and one should avoid offending the person by putting labels in places seen by others. Embarrassment can upset the person and backfire on the helpful caregiver but most people are grateful for simplification and organization to avoid confusion.

Other great options for keeping track of things are: purses for women and tool boxes for men. These items represent the "normal" way many people kept personal items organized so are dignified options for some people.

If items are still misplaced or even hidden by the person, try not to argue with their perceptions of what happened to the items. It does no good to argue and may escalate the agitated behaviors the person displays. Instead ask the person to describe the item and relate where the item was last seen. Search for the item, if possible, and if not found help the person "write a report" on the missing item. Keep a file of the reports for the person so they feel like their complaints are being heard.

Try to keep a sense of humor but do not laugh at the person which may make them feel less than important. Do not blame or get angry at the person who cannot help their behaviors and would never hurt feelings on purpose.
Go to www.alz.org/kyin for more tips and information.



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Hospitalization Happens:

A Guide to Hospital Visits for Individuals with Memory Loss

Planning ahead is key to making an unexpected or planned trip to the hospital easier for you and your care partner. Here is what you should do now:

- Think about and discuss hospitalization before it happens and as the disease and associated memory loss progresses. Hospitalization is a choice. Talk about when Hospice may be a better and more appropriate alternative.

- Register your loved one for a MedicAlert + Alzheimer's Association Safe return bracelet through your local Alzheimer's Association chaper. People who are lost may be taken to an emergency room. This bracelet will speed up the process of reconnecting you with your care partner.

- Know whom you can depend on. You need a family member or trusted friend to stay with your care partner when he or she is admitted to the emergency room or hospital. Arrange to have at least two dependable persons you can call on to go with you to meet you at the hospital at a moment's notice so that one person can take care of paperwork and the other can stay with the person with memory loss.

- Pack and "Emergency Bag" containing the following: Personal information sheet including preferred name and language, Contact information, illness or medical conditions, current medications and dosages, a list of any allergies or medications which have caused bad reactions, glasses, dentures, hearing aid. Family information, insurance cards, change of clothing, toiletries, briefs, personal items. Durable Power of Attorney, Health Care Power of Attorney, Living Will and or original DNAR order.
    - Put a note on the outside of your "Emergency Bag" to take your cell phone with you.
    - Prepare to be patient if the illness for which your loved one is being seen is not life threatening.
    - Realize that the Emergency Room personnel often have limited training in dementia.
    - Do not assume your care partner will be admitted to the hospital.
    - Do not leave the ER without a follow- up plan. If you are sent home, make sure you have all instructions for follow-up care.
    - Have someone trustworthy with the care partner at all times if possible-even during medical tests. This may be hard to do, but it will help keep your care partner calm and less frightened.
    - •f anesthesia is necessary, ask if local anesthesia and outpatient services are an option to minimize your loved ones' stress.
    - Realize that hospital staff persons are providing care for many people. Practice the art of patience.
    - What is possible and what is reasonable are two different things…which would your loved one want?

Helpful Services

Smooth Transitions
Assistance with downsizing your home.
Barbara Morris
(502) 897-9332
info@movingforseniors.com

Alzheimer's Association
Greater Kentucky and Southern Indiana Chapter
Kaden Tower
6100 Dutchman's Lane, Suite 401
Louisville, KY 40205
www.alz.org/kyin
(800) 272-3900 Helpline

Alzheimer's Caregivers Support Group
3rd Friday of each month in 2010 at 2 PM
U of L Geriatrics
215 Central Avenue
Suite 102
Louisville, KY 40208
(502) 852-7449
khtoeb01@louisville.edu

Driver's Test for Seniors
Frazier Rehab
(502) 451-6886

AAA
www.seniordrivers.org

DearWatch, Inc.
A Quality of Care Evaluation Company
When YOU cannot be there, WE will be.
Mary Romelfanger, RN, President/CEO
4965 U. S. Highway 42
Suite 1000
Louisville, KY 40222
mar@dearwatch.net

Legal Aid Society
Rita J. Ward, Attorney
416 Muhammad Ali Blvd., Suite 300
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Questions? Requests for Information on a Certain Topic? Let us know!

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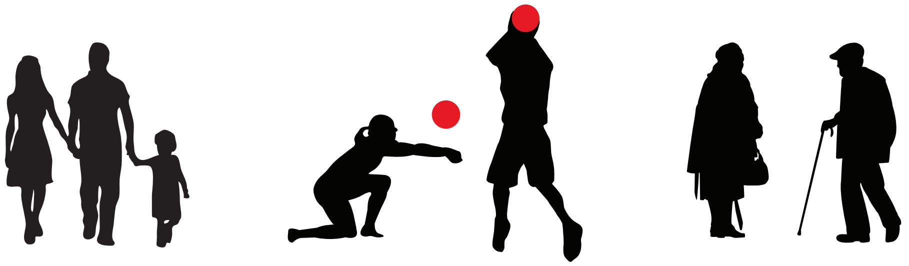

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