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# The Alzheimer's Support Network News

Fall 2010

## As I See It . . .

### From Chuck's Desk

Dear Friends,

No, we didn't take you off the mailing list! For those who only receive this publication from us, we do apologize if you thought we removed you.

It is great to be writing to you all again! Suky has taken a bit of a "respite" from putting the Support Network News together. But here we are.

We use that word "Respite" a lot at the Network. It can be a confusing word. Wikipedia defines it as "A brief interval of rest or relief, In law it is a reprieve, especially from a sentence of death. When we use the term, we are usually talking about sending a care-receiver to a facility for a relatively short time to give the caregiver a break. In the broader sense, everyone needs respite from time to time — *especially* caregivers!

A respite of a different kind can be achieved on a very short term basis by using help in the home so that you, the caregiver, can go out and do whatever it is that you want, or need, to do. Or, it can be achieved by using an adult day care center. We are blessed to have four of those now in the area.

Respite is sometimes called "vacation." In our working lives, we made sure to have vacations from work on a regular basis.

You, dear caregiver, need vacations from the often thankless job that you do sometimes 36 hours a day! Because it becomes harder and harder to travel with someone with dementia, it is often a good idea to make arrangements for the person you care for to be looked after by someone else while you are gone. Many keep trying to take their care receiver along until that awful trip when they say, "I'm never doing THAT again!"

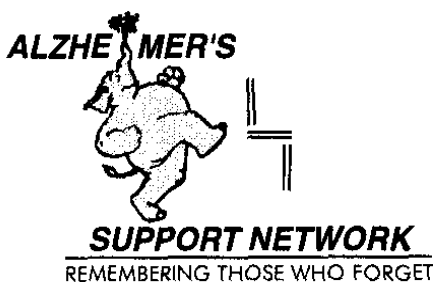
The important thing is that you find a way to have some relief before the constant caregiving affects your mental and/or physical health! You are no good to your loved one if you are in the hospital!

Many Assisted Living Facilities (or ALF's) will provide care for someone for a week or two, if the person is appropriate for that facility and if they have a bed for him or her. This is a great way to see how your loved one might fit in to an ALF when the time comes to place him or her. We can help you make a choice and also to make arrangements with the facility. We will also check on your loved one while you are away. There is some limited funding for this kind of stay. Ask us about that.

Unfortunately, space does not permit me to go into other forms of respite — adult day care and help in the home. Both are important and useful in giving you the break you need to keep going.

I say it all the time and I mean it. ***You have to take care of yourself and respite is a great way to do that! Ask us!***

*Chuck Pollard*





## Living Their Truth

by Jolene Brackley

When a person has Alzheimer's disease (AD), they lose their short-term memory. They repeat stories over and over again and often can not remember what they just did. One of the positive aspects of AD is that people retain their long-term memory in detail — *if we learn how to trigger it*. So, when you are having a conversation with the person, **focus on their long-term memory**. Instead of asking what they had for breakfast, ask what they like to eat for breakfast. You may have to take it further and ask the question so that the person only has to answer yes or no. They can answer yes or no far into the disease.

It is also important to know that, **as AD progresses, the person's age regresses**. In other words, they get younger and younger in their mind. They are looking for people who were important to them in the past and they do not recognize their family as they are now — older — but as they were years ago. They may lose the last 20 years, the last 40 years, or even the last 60 years of their memory. If they are looking for someone of the past, like their babies or a parent, you need to give an answer that reassures them that the person is okay.

Many people think that this is lying, but if you think about it, you are actually **living their truth**. They have lost their short-term memory and are living in their long-term memories. They would not ask about their babies or parent if they knew that they were all grown up or deceased.

A positive aspect about working with people with AD is that you can correct your mistakes because they have short-term memory loss. If you give an answer that they do not believe or are upset by, you get many chances to find the answer that works. Keep trying different responses until you find the one that helps the person feel safe and secure. Once you find the answer that calms the AD person down, you have found a treasure you can use and reuse.

You need to be genuine and sure of yourself when you "live their truth". Your gift to a person with AD is to help them find joy and comfort in the place where they live.

Courtesy of Creating Moments of Joy, in *Activities Directors Quarterly for Alzheimer's and Other Dementia Patients*, Volume 2, Number 1, Winter 2001

## An Interesting Analogy

A psychologist at the Santa Barbara Veterans Affairs Medical Center recently provided insight into Alzheimer's disease with the analogy of a brain being "like an onion."

You can peel an onion down to its core, leaf by leaf. A brain with AD sheds memory much the same way. The outside leaf has the recent memory while the center of the brain (the core of the onion) contains the earliest memory. An example is speech — one of the earliest memories. Words become harder to find, until in the final stage the person with Alzheimer's has forgotten how to talk.



## When Love Means Letting Go

by Wayne Lavengood, LCSW, MFCC

**For Your Reference File**

Life is often a series of contradictions. Trying too hard may produce less desirable results. We may gain control at times when letting go of someone we care about can be an expression of love, and not abandonment.

Alzheimer's disease leaves a person with a strong desire to hold to whomever and whatever feels secure. It is almost like a magnet pulls the patient to the caregiver. Questions may seek reassurance for the feeling of being disconnected from the world. Distance from the caregiver may create, at least temporarily, fear or panic. Ironically, the tighter someone with memory loss holds on to a caregiver, the more the patient risks losing that security, much like a lifeguard rescuing a swimmer.

The caregiver is left with the following dilemma: "Am I really the only one my relative can be safe with?" and "Is giving over responsibility to someone else (respite worker, day care, facility) an act of abandonment or an act of love?" The patients often prefer the safest solution, yet will not be able to understand fully the toll that their needs take on their caregivers.

Perhaps this is reminiscent of the same dilemma felt the first time we leave our infants home with a baby sitter, the first day of sending a child off to school, or the day a son or daughter leaves home for college.

Should we stay home and not risk our infant in someone else's care because the child fears separation? Should we teach our children at home to protect them from the first step in leaving the nest? The answer is clear. Caring parents must learn the fine art of letting go because it is, in the long run, in the best interest of their child. It is, in fact, an expression of their love because they are not just giving in to their own fears and needs or their children's perception of needs. Abandonment, on the other hand, either pays no respect to what the patient needs or meets only the needs of the person doing the "abandoning."

This struggle has been called "tough love" because it means doing sometimes what is hardest. Whether it be taking a loved one to a day care program for the first time, introducing a home care worker or perhaps the toughest of all decisions, placement, letting go can be a loving, although painful act. It does not mean letting go of responsibility, only sharing it.

Letting go is a fine art, because, to be effective, it must be practiced and looked at for the long run, not just for today. Just as you think back about what you did for your children in letting go, try to consider your caregiving in the same manner.

Courtesy Alzheimer's Association  
Charlottesville - Piedmont Chapter



## **“Give Yourself Permission”**

### **Moving on without your spouse**

By Jennifer Dixon

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"Give yourself permission," is what Elizabeth Graham, LCSW, says is an essential factor in continuing your own life after your spouse has been diagnosed with Alzheimer's disease. It is important for you to allow yourself to feel the feelings you may be experiencing, even if they seem wrong to you. It is equally important for you to allow yourself to carry on with your plans and learn to enjoy your life even without your partner.

Since Alzheimer's disease is a terminal illness, the grieving process often begins before your spouse has actually died. According to Graham, beginning to live your own life again and grieving should be a parallel process. Although going on with your life without your partner may be difficult, or even frightening, it is necessary. Many people feel that it is unfair to live their life to the fullest while their partner can no longer do the same. This is a normal thought, but not always true. You must accept that you cannot change your spouse's condition.

Having a loved one with Alzheimer's disease places a big void in your life even if your spouse is still living with you. There is an empty space every morning when you wake up and the same routines that you practiced together for many years are not repeated, instead, he/she does something completely out of the ordinary. You feel alone when you go off to work and rather than discussing dinner plans with your wife on your way out the door, you discuss dinner with the nurse or a companion. It does not feel normal when you want so badly just to have an intimate evening alone with your partner. Since the person with Alzheimer's disease still seems physically healthy, it is hard to accept that they are not the same person with whom you once shared a special relationship. In all senses, a death has already taken place.

The lonely feeling that comes from having a spouse with Alzheimer's is painful but typical. What is also typical is the feeling of not wanting

to feel alone forever. At some point, you are likely to want to reestablish some type of social activity. This presents the difficult problem of mixed emotions; part of you wants to do things to occupy your time so that you do not feel so alone, and the other part of you feels selfish or guilty for not including your spouse or not dedicating your time to their care even though they may not even be aware of your presence. When faced with these type of conflicts, it is important to remember to "give yourself permission." Giving yourself permission will be difficult, especially if your spouse is still alive, but it is necessary for you to do so in order to be a better caregiver or continue your own life.

Retirement is another aspect that might present a problem when progressing into your new life. Many couples have retirement plans that were made prior to receiving a diagnosis of Alzheimer's disease. Some plans might include relocating, buying a summer home, traveling, or joining country clubs and participating in senior activities. Graham strongly suggests that, "It is very important to carry on with whatever retirement plans you might have had before, although it will be much more difficult if your plans were made together before your spouse was diagnosed." A common battle that is dealt with when attempting to go on with plans is the question, "Am I allowed to live when my spouse cannot?" If you find yourself feeling guilty or questioning your decisions, it is important to realize that avoiding retirement plans will not change your partner's condition.

An even tougher issue to tackle is that of dating. Dating is much more common than you might suspect. The concern of most people when beginning to date is whether or not they are being unfaithful, particularly if their spouse is in a nursing home and not yet deceased. It is difficult to be socially active while your spouse is still "medically alive" because our culture has traditionally viewed this as unacceptable. It is hard not to feel guilty or as if you are not respecting your mar-

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## Moving on without your spouse, Continued

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riage vows, "For better or for worse" and now that the worst is here, you find comfort and recreation elsewhere. Although it is difficult, it is necessary to understand that your spouse is unable to fully participate in your relationship. There is no reason that you cannot provide support for your husband/wife, and at the same time continue your own life.

Once you have conquered your own feelings of guilt and decide that dating, socializing, or participating in other activities is right for you and you feel comfortable with it, then your worry shifts to the acceptance of others. Many people choose not to date simply because they are afraid of being judged by other people. This is unfortunate because you may close yourself off to a supportive new friend. In many of Graham's cases in which she has dealt with a couple being affected by the early stages of Alzheimer's disease, she affirms that the spouse with Alzheimer's disease has made it very clear that they want their mate to go on living — even if that includes dating. Graham also tells us that family and friends generally feel the same way. This offers some support or comfort to those who have seen a counselor with their mate or have the opportunity to discuss such issues with their spouse before they become unable to communicate. Where does that leave those who do not?

People who have not had the opportunity to get the approval of their mate while communication is still possible can take comfort in knowing that more people are accepting of socializing and dating than are not. According to Graham, there are a few factors that may make a difference on the opinions of others. The level of denial that others have about the diagnosis of Alzheimer's disease and the inevitability of death makes a big difference. If the person has accepted that your spouse has Alzheimer's disease, and your mate is going to die, then they are very likely to accept that you want to begin a social life while your spouse is in a nursing home. If your relationship with the family and friends of the person with Alzheimer's disease was solid before diagnosis, then they will probably be supportive

of you and whatever decisions you make concerning your new life.

A lot of people feel as if they should be secretive about dating because they fear being judged or confronted, but this usually perpetuates the possible problems in your situation. Family members of the person with Alzheimer's disease might be very understanding if you are open and honest about your feelings and your desire to become socially active. However, if you choose to be secretive about your social life, they may be quite suspicious or become judgmental. Graham states, "Most of the time, family members of the person with Alzheimer's disease are very supportive, but if for some reason they are not, you need to be very firm and confident with them." She suggests that you should say, with confidence, if confronted by someone who disagrees with your decision to date, "I am sorry you feel that way, but this was a very hard decision for me to make and it was my decision to make, and I feel comfortable with it." If the person continues to try to make you feel uncomfortable about meeting new people, then you may have to distance yourself from that person for awhile, until they are ready to accept you and your feelings.

When making these types of decisions regarding your new life, you may feel the need for some type of emotional support. In a lot of cases, support groups may be helpful when attempting to restart your life after grieving for a loved one. There are plenty of support groups available for the spouses of people with Alzheimer's disease. These groups can be very comforting; hearing about people who have had similar experiences with Alzheimer's disease helps you to realize that you are not alone. Sometimes people are not comfortable sharing their feelings with a group or listening to other people's problems. In this case, individual counseling can offer support as you begin your new life. The most important thing to remember each time you are faced with a challenging decision, feeling or desire is to, "give yourself permission."



## When A Caregiver Feels Guilty

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Every person who provides care to a loved one asks, "Am I doing enough? Am I doing it right?"

For caregivers of adults with a degenerative brain impairment, these questions often lead to a feeling of guilt. When faced with a deteriorating illness in a loved one, it is difficult to see the extraordinary value of the care that respite provides. It is even more difficult to allow ourselves to be less than perfect.

Guilt, therefore, is one of the many feelings that all caregivers experience at one time or another, and guilt can sometimes be an obstacle to getting the help you need.

There is so much work that goes into a routine day of caregiving — constant vigilance, shopping, running errands, planning and preparing meals, bathing, dressing, managing the household finances. The list, already exhausting, may go on to include dealing with night walking, behavior management, or nursing duties. It is usually more than a 24-hour-a-day job. A caregiver manages so much, yet he or she may feel that more could be done.

Caregiving can also be very frustrating when we cannot control another person's behavior, or when there are no thanks for our devotion, or when we are just plain tired and cannot rest because of another's immediate needs.

Frustration and anger are part of every caregiver's life. When these negative feelings come up, guilt often follows, and

copied with guilt is hard.

Your feelings are normal and acceptable. You can actually use these feelings as a reminder to take a break and to make a point of seeking some pleasure to become renewed and continue devoted caregiving.

Recognize that you are doing the best you can. Let yourself be human and give yourself strokes for what you are contributing to your relative's quality of life. The brain-impaired person's needs increase over time and, as they do, the caregiver needs more help. It may be difficult to ask for help, but once we begin to reach out, many people are willing to provide it.

It is important to ask family and friends for help in specific ways. Once they understand the tasks, people usually feel relieved that there is something concrete and helpful to do. Help that gives the family time to renew is called **respite**.

When we go without help or a break, we are attempting the impossible. The earlier we take time for ourselves, the better. Respite is especially effective when it is schedule and dependable. The brain-impaired family member may also benefit from the support and stimulation of someone or some place different.

Another respite option is for the impaired individual to attend a program outside the home, which may provide a welcome change of environment as well as some social stimulation.

Courtesy Duke Family Support Program





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# Dementia

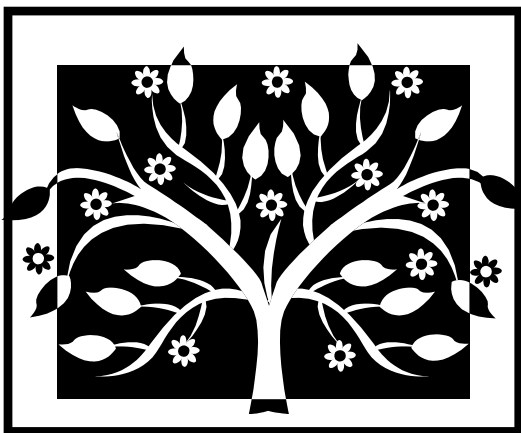
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You leave me  
bit by bit  
pieces chip off  
blow away.

In the morning as you sleep  
I watch your face  
never knowing how much of you  
will remain  
when you open your eyes.

I am always on the edge  
of fear, of anger  
walking a precipice of tears  
while you live  
in constant confusion  
not knowing how or when or where  
all time meaningless  
but now.

Courtesy *The Caregiver*, Newsletter of  
the Duke Family Support Program



**Musings**