

CONFESSIONS OF A CAREGIVER

"What should I do about these dark, scary and intrusive thoughts?"

by ROBERT B. SCHAEFER

*Published in the Greater Richmond Chapter - ALZHEIMER'S ASSOCIATION -
QUARTERLY NEWSLETTER
May - July 2003*

It is difficult to think of a more devastating diagnosis than that of the “probable early onset of Alzheimer’s disease” or for that matter any diagnosis of “dementia”. From the moment that you hear those words spoken, you visualize your life and the life of your loved one literally shattered. Nothing for either of you will ever be the same again.

Fortunately, your defense mechanisms kick into action in an effort to protect you both from this horrible disease. Your lives first become filled with denial, which lasts from weeks to sometimes even years depending upon your individual makeup. Almost simultaneously, you begin to feel a terrible embarrassment at the diagnosis on both a conscious and subconscious level while making every effort to hide or mask the outward symptoms for as long as you both possibly can. Eventually, and this too may take months or even years, you both come to the realization that you can no longer hide this disease from your family and friends. Exhaustion and frustration begin to surface and take over as you both attempt to adapt to this new way of life that you begin to hate. You make every attempt to rationalize the devastation caused by this disease but nothing seems to work any longer.

It goes without saying that it is a difficult path that the victim of Alzheimer’s must follow, especially in the early stages of the disease, but as the disease progresses and the long and short-term memories disappear, I believe that the loss of awareness brings about a certain serenity and peace. The second victim of this disease, the caregiver, is not as fortunate and that is what we need to identify and discuss further.

The time will come that you as a caregiver will think that you are losing your mind, as strange, bizarre and evil thoughts seem to take control of your days and nights. At the

same time, you might feel constantly fatigued and agitated; suffer from a loss of/or too much appetite, too little or too much sleep and even difficulty staying asleep. You will notice increased feelings of isolation and loneliness, as friends and family seem to avoid you in your role as the caregiver. It might become more and more difficult to rid yourself of these “dark thoughts” and you feel so alone because you have no one to share them with. Some nights you’ll find yourself lying awake in bed while these “dark thoughts” seem to start to make sense to you as your world crumbles before you. Let me give you some examples of these “dark thoughts”:

- I need to divorce my wife/husband as soon as I can to avoid financial ruin in the future. We can still live together, but she/he must be on their own financially.
- I need to liquidate what I can and take flight as I change my identity.
- I need to kill her/him and then myself and we will both be at peace.
- Will she/he die before me so that I can start having fun again and enjoy my retirement?
- Sometimes as a spouse, I get so tired of caregiving, I want to forget the wedding vows and find a part-time partner or lover.
- I do it all the cooking, cleaning, laundry, grocery shopping and anything else that needs to be done. How long can I go on? I’m about to go off the deep end – I want something to happen and end this all.
- How can anyone be so stupid? She/he cannot do a thing. I hate her/him and the fact that I’ve been placed in this horrible situation.
- I am so tired of giving, giving, and giving. Why me? I know what the wedding vows say, but why isn’t this happening to everyone else? It is not fair and I don’t think that I can go on any longer! I want out!
- I can’t stand the repetition, pacing, rocking back and forth, following and hovering over me. Every time I turn around she/he is behind me. I want to shake her/him silly till they stop.

- Sometimes I feel like I just want to die – I don't have the strength to continue.
- Why do I have to take care of my parent(s). Where is the rest of my family? Damn my parent(s) for not being prepared for this. Why are they making me suffer like this?
- I need to get her/his attention - "Hello, is anyone in there?" I get so frustrated and angry that I can barely stop myself from slapping, hitting, pushing, or shoving her/him. Who would know if I did? She/he would never remember it.
- Everyone thinks that I am a loving and wonderful caregiver. How would they react if they knew about these thoughts that I have been having?

The above list could continue for pages and pages, but I'm sure that I have hit home with the majority of you having experienced at least some of these thoughts. When we do, something is missing. The disease has robbed us of the ability to share these "dark thoughts" with our loved one, especially if the affected person is your spouse. That is the point at which your isolation, loneliness and paranoia is exacerbated. We have shared our deepest and most sensitive thoughts and feelings with our spouses and in some case our parents over the years and now that outlet is no longer available to us. How can we rid ourselves of these evil thoughts without carrying them out?

This is an important moment for caregivers. These "dark thoughts" represent a normal reaction to an abnormal situation. It is ok and perfectly normal to experience such thoughts so long as you avoid acting them out. Recognize that your mind needs to process these thoughts and you need to talk to someone about them. This can often be best accomplished in a support group setting or perhaps with a close friend who has been exposed to a similar situation. Some might choose to consult with a member of the clergy or even a mental health professional. The important thing is that you verbalize your thoughts to someone and validate your emotions within a non-threatening

environment regardless of the source and remove your mind of this emotional baggage. If you do not take the time to debrief yourself then you will likely continually fight or repress these thoughts, which could lead to health or psychological breakdowns making you unable or unfit to continue your important responsibilities as a caregiver.

I have painted a very negative picture of your role as a caregiver. WELL, CAREGIVERS LISTEN CLOSELY. You are probably feeling very negative about your situation at this very moment. You are letting the negativism take over because that is the easier route. Yes, the role of a full-time caregiver is not a glamorous, exciting and rewarding experience, but you and only you can remove some of the stress from your daily activities in order to at least make life a slight more bearable again. It is your decision, “Do you want to get better or become bitter?” When there seems to be no light at the end of the tunnel, and this might occur daily for you, sit back, take a deep, deep breath and exhale as you repeat to yourself the ten most important two letter words that you will ever learn in your life: “IF IT IS TO BE IT IS UP TO ME”. The ball is in your court. You can survive as a caregiver with a minimal amount of scar tissue, but it will take a great deal of work on your part. You have to want to be positive in order to achieve that milestone. Concentrate always on the two most power-filled words, “I can”.

There is no doubt that the stress of caregiving will at times become unbearable. Caregivers must constantly be on guard and attuned to protecting themselves against burnout. It is so so important that you as a caregiver continually monitor your stress level, but the reality is that we as caregivers are often the last to know when we are stressed out. Prior to her diagnosis of Alzheimer’s, my wife acted as my “stress

barometer”. I, as many of you, need to shift gears and to make sure that a new “stress barometer” is in place to monitor us daily. Be it a family member or a close friend, someone needs to monitor your behavior for the telltale signs of overload, such as sleep disturbances, changes in personality, continued somatic or physical symptoms, excess use of self-medication in the form of alcohol and/or drugs and a general feeling that nothing is pleasurable any longer.

Review the following list of ways to keep your stress within tolerable limits and prevent an overload. Debrief yourself daily, monitor your “stress barometer” and utilize some or all of the following suggestions to live a more meaningful and satisfying life. Hopefully you won’t have the time to dwell on “the dark, scary or any other negative thoughts.” All of your available energy should be channeled into controlling your emotions while striving to make something positive out of a very negative passage of your life. Stay clear of the most worthless emotion, which is self-pity.

- Realize your limitations as a caregiver. Acknowledge early on that in order to survive in the role of caregiver you will constantly need to ask for help.
- Attend and get involved in the church of your choice
- Remember that you still have your own life to live.
- Seek some type of daily respite in the form of an Adult Day Center or a friend or hiring someone privately or through an agency.
- Eat a well-balanced diet, get adequate sleep and monitor your health with annual physical examinations.
- Exercise regularly.
- Utilize relaxation exercises daily.
- Keep a sense of humor.

- Volunteer your time at organizations such as the Alzheimer's Association.
- Work part-time to keep yourself actively involved outside of your caregiver role.
- Socialize with friends and family.
- Find time for a hobby that is pleasurable.
- Educate yourself about Alzheimer's disease.
- Prepare yourself in advance to develop the mindset over time that assisted living or a nursing home setting will be appropriate and even necessary in future years.
- And last but not least, if you feel that you are losing control in spite of your efforts, for heaven's sake, seek professional help. There is no stigma attached to helping yourself when your role as full-time caregiver begins to destroy your very being.