

ATTITUDE, ATTITUDE, ATTITUDE – THE SECRET TO SUCCESSFUL VISITING

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Bob Schaefer was a full-time care partner for his wife Sarah who was diagnosed with the probable early onset of Alzheimer's while she was still in her forties. After caring for Sarah at home for fifteen years, Bob was forced to place her in a nursing facility where she currently resides.

Family and friends often have a difficult time visiting a resident with a dementia in a facility, especially if some time has elapsed since their last visit. It is so easy for us to forget that dementia affects the entire person and not just his or her memory alone. That is what makes Alzheimer's such a dreaded disease for everyone. It is oh so difficult to see and accept what has happened to the person that we have loved and respected for so many years.

It is overwhelming for us to acknowledge that we might no longer be recognized or that our family member/friend may not be able to speak in sentences like we do, or remember past events, family and friends, or be able to walk, or feed themselves or they keep repeating, and repeating their questions and thoughts. The list can go on and on. They may even have a tendency to become agitated while we are visiting. Sadness can easily take over our emotions and lessen our ability to think clearly and make the best of the situation that we are exposed to at that very moment. In other words, it can cloud our thought process and make it difficult for us to respond appropriately. We become uncomfortable and the result is that we no longer want to visit our family member or friend that is cognitively impaired.

Your attitude prior to and during your visit will determine your success or failure while visiting a person that has been diagnosed with memory impairment. The first thing that comes to mind when I prepare to visit my wife Sarah is that I am going to support her and to pray with her during her time of need. I am not there necessarily to entertain her or tell her funny stories or jokes or even to make her laugh. If I can accomplish that then I am way ahead of myself and I will believe that I have done more than I had planned. I was able to accomplish some of that earlier on in her journey, but Sarah has now progressed beyond that point. Actually, your visiting behavior will be dictated by the degree of impairment and the stage of the disease of your family member/friend. It is important to realize that there will be good days and there will be bad days no matter what you do or try to do.

Recognize your limitations. Be careful not to set your expectations too high. You must be realistic. You are not capable of changing this situation no matter how hard you try. You have done a great job up to this point. Give yourself a "big pat on the back." Do not let guilt take over your emotions and lead you down the wrong path. You are merely a visitor not a miracle worker. Keep these thoughts in mind as you prepare yourself mentally for your visit.

Sarah best expressed her mental state in the early stages of her Alzheimer's when she said on March 23, 1997, "I'm in a different world and I don't think I'll ever find the other." She followed that by telling me on May 31, 2003, "Someone did something to me and I don't know what." Both of these comments reinforced the fact for me that Sarah has

always had some awareness that something was happening to her brain, although she did not know exactly what it was. That awareness can cause varying degrees of depression for many dementia victims, which adds another dimension to their behavior. At times, they may even appear to be riding on a roller coaster of emotions, which can make visits uncomfortable at best.

How scary for her and every other victim of dementia. Sarah's profound statements made me finally recognize that she is no longer in my world. She is not able to negotiate with me on my terms and in my comfort zone. Once again, dementia has put the onus on me. That doesn't seem fair, but I must press on and deal with it, if I am to remain a survivor rather than a second victim of this "mind thief." I must relate to Sarah in her world, wherever that might be or my efforts will be in vain. It is certainly much easier for me to ignore that and just proceed as if she was in my world, but my visits would not serve any purpose. Short cuts certainly do not work during visits. We must avoid rushing our family member/friends. We must be blessed with unbelievable patience that will permit us to do everything at a slower pace in our fast moving society. Once we master the art of entering into the world of the dementia resident, much of the stress of our visit will begin to lessen or almost disappear.

Most of us tend to forget that a mere seven percent of our communication with each other is verbal. The other ninety-three percent involves non-verbal communication to include body space, eye contact, touch, facial expression, tone and volume of voice, and gestures. It is not necessary that we say an awful lot. In fact, again depending upon the stage of your resident, little conversation may be necessary. Conversation should be kept very simple without asking our loved one to remember things, which are likely to cause frustration and embarrassment. The question I hear asked most often when visiting Sarah is, "Do you know who I am?" Chances are if they could answer that question they would not be there. Be considerate of your family member's/friend's feelings and emotions. Learn exactly where they are in the progression and ask appropriate questions.

Here are some observations that I have collected as a man "who has been there" or "walked the walk" during my years of visiting. I offer these, as suggestions to consider if your visits are not what you think they should be. Hopefully, you will be able to avoid some of the mistakes and pitfalls that bothered me during my earlier visits to Sarah.

- Attitude, Attitude, and Attitude
- Continually educate yourself about Alzheimer's/dementia.
- Don't visit with a chip on your shoulder such as guilt or anger at the facility.
- Leave your negative emotions at home, e.g. – anger, loneliness, fear of the future, etc. Negativism is very contagious and you don't want your family member/friend to become negative by association.
- Don't expect too much in return for your visit and you'll never be disappointed.
- Acknowledge your new role as care manager rather than that of care partner. This is often MOST DIFFICULT for us to do, but with a little extra effort we will master it.
- Focus upon the skills and abilities that your loved one has left and not what he/she was capable of in the past.
- Learn to have confidence in your loved one's professional caregivers. They are professionals with the comfort, safety and quality of life of your loved one foremost in their minds. Their job will be even tougher without your support.

- Stop being a perfectionist – it is ok for a hair to be out of place, a shirt on inside out, trousers and blouse that don't match perfectly, etc. This is not a perfect world!
- If you feed your loved one do so at their pace and don't worry about spilling a drop of food here and there – it is important to get them to eat –Do not worry if you soil their bib or cover.
- Avoid taking short cuts – a little extra time and effort will pay off.
- Do not stand over or talk down to your loved one.
- Maintain eye contact.
- Talk in short simple sentences –using simple words. You would be amazed how effective words or phrases such as – “It's okay, I'm at your side, I love you, or really” - can be.
- “Silence is golden.”
- Reduce distractions and excessive noise.
- Try not to ask questions that you know will embarrass your loved one – again, depending upon where they are at that moment. Examples I've heard are - “Who am I?” “What did you have for breakfast this morning?” “Did you sleep last night?” “What did you do today?” - Learn to read your loved one's BODY LANGUAGE. If they become anxious or seem embarrassed with your questions, try another approach.
- Never argue
- Reminisce
- DO NOT TALK ABOUT YOUR LOVED ONE IN FRONT OF THEM – They understand more than you think they do – conversations about them can often be a source of anxiety since they may not be able to respond in any other way.
- If your loved one becomes anxious during your visit attempt to determine cause(s)
- Bring a favorite food or dessert in limited portions
- Don't make your visits too long – All day visits are inappropriate. Remember, like it or not, you and your loved one have entered into a new passage of your lives. Each of you needs to take the time and space to adapt successfully to your new role. Your loved one needs to become dependent upon the facility rather than you for their activities of daily living.
- It is not necessary to visit every day – give yourself a stress break so that you can live your new life to its fullest. BE CONSIDERATE OF OTHERS - DO NOT VISIT IF YOU ARE SICK
- Attitude, Attitude, and Attitude

I hope that you noticed that I intentionally began and ended my observations with Attitude, Attitude, and Attitude. I did that because I believe that with the proper attitude all visits to your family members/friends with dementia can be tolerable, if not pleasurable.

I believe after several years of trial and error the quality of my visits with Sarah has improved tremendously by my concentrating on the above suggestions. I would like to share a typical visit to Sarah in Clover Hill with you. I immediately greet and introduce myself to Sarah and take her by the hand. I give her a warm and sincere hug – to make her feel as comfortable as is possible under the circumstances. Additionally, I attempt – to rub her back and neck, to whisper sweet nothings in her ear and tell her that I love her, to quietly sing one of her favorite songs to her, to talk to her about us and our

children even if she doesn't seem to understand all of what I am saying, to tell her that I know that she understands what I am saying even though she is not able to respond to me. I try to feel and share her frustrations and comfort her, to walk with her, to help reduce her anxiety when it appears, to share meals with her and even help her to eat if that is necessary, to help her to participate in activities if she is still able, but most of all to let her know and feel my presence and love so that she will know that she is not alone on her journey through this long, difficult, and scary passage of her life.

I put a great deal of effort into reading her body language, which helps tremendously in deciding what I should do during any particular visit. I prefer to visit at a time that might be beneficial for Sarah and at the same time afford me some quality time with her (such as at lunch or dinner) and perhaps even give her nursing team a few minutes of well needed respite, which is so hard for them to come by in their daily routines. I think before I ask Sarah any questions. I make sure that all questions are directed toward Sarah in her own world. If you have any doubts, ask yourself if you were in your family member/friend's position, would you like being asked those questions or more importantly would you be able to answer them? The one question that I normally ask Sarah is – "Are you happy?" This is something that I have done from the beginning. Believe it or not, she will normally respond by saying, "Happy" on a "good day." Occasionally, she will say, "Happy, Happy" which I interpret to be a "great day." We are there to visit, create and maintain a positive attitude, new memories and not to induce any additional stress into our loved one's lives.

I have learned to savor and cherish those unique and special moments that occur when you least expect them. For example, on a recent visit, Sarah looked very serious and tuned into "her own world." I didn't seem to be able to get her attention until I said, "Sarah, who are you talking to?" She said loud and as clear as could be, "God." I didn't know how to react to that since I had just returned from a funeral service for a friend that had passed away from complications due to Alzheimer's disease. During the homily at that service, the priest talked about people suffering from Alzheimer's disease and where they go when they seem to drift away from family and friends and into their own world. He speculated that they were talking to God. Wow, how powerful and beautiful was that one word response from Sarah.

It is a personal thing with me, but I never say "good bye" to Sarah when I leave her. I tell her that I love her and I usually say, "have fun or behave yourself," as I quietly slip away. I believe it is better not to draw attention to the fact that I am leaving because she had previously been so paranoid that I was going to abandon her due to her diagnosis of Alzheimer's disease.

Hopefully by now you have picked up on my central theme, which has been based upon my eighteen years of experience with Alzheimer's disease. I have been emphasizing that the victims of this brain disorder are still people. They are indeed human beings deserving of our respect and love. Their diminished cognitive functioning does not make them any less a person than they were prior to their confrontation with this "mind thief." We must constantly remind ourselves of that, especially when the going gets rough. They are not a number, a thing or an object – they are "very special human being" with strong feelings and emotions.