

Caring for a loved one with Alzheimer's Disease

Hello and welcome to alzcast.org. Today we have the privilege to hear from Meryl Comer. Meryl has published articles and has spoken on behalf of caregivers as well as assisting with philanthropic activities to help advance Alzheimer's research. She has been caring for her husband, an acclaimed researcher and clinician who developed early onset Alzheimer's disease at the age of fifty eight. Meryl is sharing her thoughts and entries in her journal to equip caregivers with the information and insights that can better prepare them for the challenges of caring for a loved one with Alzheimer's disease. This podcast is one of two that has been sponsored by a grant from Elan pharmaceuticals.



Meryl Comer
Presenter
Caregiver

My name is Meryl Comer I was a journalist for thirty years and forced to leave my work because of my husband's illness. My husband was a physician researcher who got early onset Alzheimer's at age of fifty eight. A very complicated case and I left to take care of him personally. So from my journal each morning for more years than I wish to remember I reintroduce myself to my husband Harvey with "Good morning love my name is Meryl. I'm your wife we've been married for twenty-five years don't worry this is your home and you are safe. His eyes are blank and mine filled with tears. The truth is my husband maintained his brain, over two hundred published research papers fluent in three languages and crossword puzzles in ink. A long distance runner he was physically fit and it just didn't matter his life was faded by a genetic predisposition. In our case my physician husband was fifty eight, young, strong in denial about being sick, fighting to hold on and in the early stages, the first warning from the doctors was call 911 if he gets too dangerous. So I put away all sharp objects, hid the car keys locked the garage so he couldn't endanger others. The second warning after a two month hospital stay was your husband is too dangerous to come home.

My husband is still young. The average life span from diagnosis to death is eight years. The range is three to twenty years. We're into year twelve, the first five years I managed alone until the doctors became concerned about my health and physical safety. And what you need to remember is that when a family member with Alzheimer's is placed in an institution it is not because the spouse or family hasn't tried to take care of them. It's because it's become too physically or emotionally difficult. The caregiver gets sick or children are at risk, and trust me no one who has ever done it sits in judgment of someone who's said I just can't do it anymore. Today

my husband requires more care than my seven month old grandson. At age seventy he has late stage dementia twenty-four/seven care.

What you are hearing is my story. Things that have happened to me may never happen in your situation. Years ago my husband stopped calling my name but I do know that he knows my touch. I can calm him with my voice, kisses, a gentle pat that he sometimes returns with a morose code of recognition and when my husband calls out for his mother I'm the one who answers "Here I am".

The caregiver is also the keeper of the secret "reality becomes irrelevant" and it is the ultimate in couples self collusion and delusion but most importantly for the caregiver it's a survival technique.

I would like to make one comment about denial. Denial in the beginning that delays diagnosis of a cruel illness for which there is no cure is actually very dangerous to everyone's well being. The best pharmacology is available to you attached to the earlier stages of the disease, so the sooner you get medicines the more helpful they are, and what does it buy you? Perhaps six months, a year of quality of life, of a spouse who might know your name, might know your grandchildren. In my mind it's worth it and that's why I encourage everyone to pay attention to the signs. Typically in families, diagnosis is delayed for about two years. That's a lot of living and quality of life that you missed with a loved one because by the time they are diagnosed they are well into a disease for which there is no cure and I always recommend to caregivers type up your observations. It's your word against their word and it's your husband and spouse which makes it even more complicated. I mean you're creating a challenge to someone you love that something is wrong with them. Now you tell me man or woman whether you want to listen to that. Very hard, rarely do you have people buying into the idea that something is wrong with them like that. It's much, much easier to have anything else but that disease because there is no way to respond to the disease, except to say ok you have the disease now live with it. And it's not just forgetting, it's forgetting things that you've done for years. For example he got lost coming home. My husband was a scientist who had a messy desk but he could always access the exact paper he wanted. A great frustration to me but very impressive when that pile became chaos and his frustration level grew because he couldn't find it. Things if you couldn't know where to sign a credit card receipt.

In the early stages you are trying to respect a loved one's independence, keep them as independent because they are going to fight for it whether you respect it or not they're going to fight for their independence and my ground rule was that I would respect his independence, support his independence as long as he didn't endanger himself and others. And others were very important to me. I was the one who that snuck out in the middle of the night and pulled the plug on the battery of his sports car because he was not in a position to say I can't drive anymore and I refused to have him jeopardize someone else while I was trying to keep my husband independent. More accidents occur from people who are in a process of dementia because someone hasn't said

sorry you can't drive anymore. Have the doctor do it, don't have that fight with your loved one but otherwise you have to act and I acted proactively locked the garage door and told him his car was in the shop. And he asked about his car for four years and I said "Sorry you know it's in the shop, remember we put it in the shop."

You're living their reality, alright its my husband it was never my desire over my husbands desire. I would always couch it "Darling you told me that you wanted me to take care of this and I just did it for you". It was never my idea over his idea you don't win those fights and wear yourself out. It's always a negotiation when you are dealing with someone with a dementing mind. The danger with this disease is you're protecting a loved one's dignity and when I said the caregiver is the keeper of the secret, you don't want a loved one embarrassed. I have a husband who was a world renowned expert in disease, a fine doctor. I don't want him to embarrass himself. Behavior has become totally inappropriate so you hide the victim away. There is no poster child for a disease like that and unless you are close to the disease you don't see the horror. People think of it as a little old lady or man or somebody who has forgotten their address. Well it affects their ability to be independent. None of us want to be totally dependent on another person for every function of our life. That's not the way we see ourselves. The challenge is that the victim is not seen and people don't understand the disease. It's one of the cruelest of diseases to watch the mind unravel and slowly diminish one's dignity. Every situation is different and that's why you have to be flexible, that's why it's very hard. There is no handbook that gives you the way into this disease. It will give you a clue and the best book that I know is "The Thirty-six Hour Day" by Dr. Peter Rabin at John's Hopkins. The advantage of that book is on the need to know basis you go and check the chapter.

Because I do hands on care and trust me there is nothing that I ask caregivers to do that they haven't seen me do for my husband and we work in twenty-four/seven shifts I do the night shift, I lead the team.

So I've watched the brain slowly unravel and I do believe in regenerative theories about the brain but the tangles that clog the pathways like brambles have overrun my husband's mind and his spirit and I do believe and I think it's important for caregivers to think this way that there is always something left of the person to reach because that the mind is a treasure chest of memories but can be terribly distorted by the disease. Let me give you an example, because I do the nightshift at night when my husband screams and flails his arms which he does I use to be very frightened and then I started to listen, and in time I came to recognize a young boy that was catching a ball that won the game. So what do I do now? Now I cheer him on the louder he screams the louder I cheer and it always feels that we connect in one brief moment in laughter, just for a moment and then it dissolves again into silence, he becomes peaceful. As a caregiver I am trapped with my husband in a long goodbye that may last for years because my husband is very young and healthy and I've applied to have

my husband participate in clinical trials that are so vital to advance research on the disease.

My husband who is totally out of it hasn't known who I am for more than five or six years is still in charge. This man is in charge of our life, what goes on at home we apply to every function that is still intact. We give him special meals because olfactory senses are the last to go and they stimulate multiple sites in the brain. Remember that. Don't mush the food together keep it separated, let them taste things. It's going to take a long time anyway. Make a plateful; always telegraph what you are feeding them so you can prepare them for it.

We play Beethoven and Brahms in the morning and new age music at night to calm him always in lieu of medications. Music therapy -- if you watch again how they respond to the music take them back in time. If they were from the rock and roll era let them hear rock and roll. You'll see a foot tap and that means in some way you've connected with your loved one.

My husband was a physician and researcher so we read his research papers aloud to him hoping for a connection and I also keep elaborate records on our daily care and behavior. I do that because if you have nurses in shifts that work with you it respects the nurse who is handing off to the next nurse. We get to watch behaviors. We know if he was having a difficult day. We're alerting each other and I found it to be very successful.

The trick is how long you can manage a loved one at home with out wearing out yourself and you're always looking to preserve function. Alzheimer's care is the ultimate in what they call palliative care. Palliative care is playing to what ever function you still have in a patient and testing new medication so in desperation to preserve function so that I can keep my husband at home I've even gone on the internet to purchase a drug that was used successfully in Europe for late stage dementia over the last decade I did that prior to FDA approval its since been approved by the FDA and it was called Namenda. Here in the states in Europe it was called Memantine. Very low side effects but it became the booster to a drug called Aricept which is used extensively with Alzheimer's patients and together it gave me a bit more function now. What does that mean a bit more function? Number one my husband was less combative when we tried to change his clothing or toilet him. What's the big deal? It's a huge deal when you are attached to personal care of a loved one. The other observation about this disease is that this is a disease that over time tears families apart. As a caregiver be prepared to be always seconded guessed. But remember that nobody wants the work that you're doing. My husband is more care than my seven month old grandson. I think I said that to you earlier so what do I do? I will pay a nurse so I can spend time with my grandchildren. We play, we laugh I'm a free spirit and the patience and love I put in comes back in their eyes and out of their mouth and they help me take the emptiness out of my life. When you oversee deterioration twenty-four/seven for years on end it's very demoralizing so I call my

grandchildren my anti-depressant of choice. My best friends and I would recommend it to anyone. That's the best respite than you can ever have.

One other thing for caregivers which is important just when you think that you have things under control, the bottom falls out from under you. Just when you are getting into a routine and it happens because the disease changes. Right now my husband who as I told you earlier is late stage dementia has begun to drool.

Well that is a sign the swallowing will soon be an issue and that the pleasure of eating will be lost and as I said olfactory senses are the last to go because what is interesting is that olfactory senses trigger emotional sensors in the brain. So we work very hard to tease these senses with those favorite meals that for some reason keeps the synapses sparking. So I'll have run out of ways to reach my husband and that's very upsetting to me but I have to pay attention to the signs because it means that I have to reconfigure how I'm going to help him each day. I can't get locked in to what I've just done. The food that he can now chew will have to be put through a blender. Everything is about to change for me one more time. So just be prepared to be either anticipate these changes or get yourself resolved to them and if it's not working change with it. Don't try and fight and maintain the routine that you had, it won't work, you'll hurt yourself emotionally and wear yourself out and burnout unfortunately is not an option

My husband fell several weeks ago and that is always an issue. You're trying to keep them mobile and that helps the circulation and he basically stopped walking and I have a very sinking feeling that we are entering the twilight phase of an illness where he will linger indefinitely. What I've done and with the help of the nurses is that instead of letting him sit in the chair we still get him up. Every hour on the hour even if it's just to physically stand up and reclaim the balance if its there to be reclaimed. We are not giving up because he fell on the idea that he can be mobile.

Now people will say to me now Meryl why do you persist in this way? Well I persist because it's easy for the nurses and for anyone around a loved one to fall into the easier way out. And that's why you see so many people sitting in facilities and in institutions. In an institutional environment they don't have enough nurses to have that kind of one-on-one personal care or go back they're concerned that someone might fall and be injured. I'm trying to see if there is anything left attached to that function that I can play to.

This is a disease where there is you say good bye over and over and over again. All the care, all the love, all the time spent to make each day count I refuse to dwell on the end of the disease because there is no cure and the disease always wins. So the key is how do you get through each day and you learn to live a day at a time? This is a disease of our baby boom generation. They will live long enough they will out live the

cancers and the other diseases. This is a disease of the future it's not a disease of the past.

The information about maintaining your brain it makes good sense but what happens in our baby boom generation is we all want easy fixes and I think that's the missed message of the campaign that in fact you control whether or not you get this disease. And if there is a genetic predisposition and there was no sign in my husband's family with any aunts, uncles, senile grandparents no warning. If you have that predisposition none of these crossword puzzles or games will help you. This is an equal opportunity destroyer which is said over and over again. Again my concern is if the public buys a message if they can control whether or not they can get this very cruel disease with simple adjustments in their behavior it undermines the impetus for research and right now the budgets are being cut on a disease that will be of epidemic proportion because we'll live that long. If you're a baby boomer, if you're born between nineteen forty-six and nineteen sixty you're expected to live to eighty-five plus. Well at eight-five one in two gets this disease. This is a disease of aging but you're going to live that long and then your going have another nine years being mindless. I think this has the potential to be the biggest woman's issue since breast cancer. We outlive the men statistically and if we don't outlive them we end up being their caregiver. So this is our disease and women make the majority of health decisions and I think it's an opportunity for women to again take control of the future and their own lives this will be a huge, huge problem it is of epidemic proportion. They can't build facilities fast enough and think of communities with people that need this kind of care. The other point is this is not custodial care this is specialized care it requires people trained to patients and we need better trained nursing aids to manage it. These are individuals they have to be treated with dignity and respect all the way into this disease so there is a constant training program going on.

We wish to thank Meryl Comer for sharing her personal insights in caring for her husband and it is our sincere hope that these words of strength, compassion and experience will provide the tools to better enhance our ability to care for a loved one with Alzheimer's disease. We also want to thank the sponsor of this program, Elan Pharmaceuticals, Inc.