

Caregiving From a Son's Perspective

Welcome to alzcast.org providing key insights and perspectives on Alzheimer's disease for nurses, doctors and caregivers. In this broadcast we are featuring Archie a caregiver whose father had Alzheimer's disease. Archie will share his experiences and insights regarding the care of his father who suffered with Alzheimer's disease. It is our hope that Archie's insights will help our audience of caregivers.

Jon Merrill: Archie thank you so much for agreeing to share your insights and perspectives about your father who had Alzheimer's disease.

Archie: Well Jon it's so nice to be with you, thank you so much for including me in the segment on Alzheimer's. As you know I have first hand experience in dealing with this disease. I had a Dad who passed away about two and a half years ago at the age of eighty-two at Copper Ridge which was the most fortunate place I ever found but more importantly a place that helped me to understand the dynamics of this disease and how to cope and also assisted my Mother who was an at home caregiver with the pressures and stresses which come with dealing with a Alzheimer's companion. Now my father had the disease I think I first noticed it he had slowed down and he was retired playing golf and stopped playing golf and began to forget certain things certain things he enjoyed. Not me or my name and became part of what many people my age and I am in my late fifties who

believe that maybe it was just part of the normal aging process but some people are hard to adjust to the fact that he was ill and he had not had a good physical and didn't understand the merits that was going on so by the time I got involved I found we were behind the eight ball in both our knowledge of the disease and how to cope with it and quite frankly what the way ahead was. So it was a five year six year process for me personally almost weekly in dealing with Alzheimer's.



Archie
Presenter
Caregiver



Jon Merrill, MD
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Jon Merril: Archie can you share with us how your Father was initially diagnosed with Alzheimer's disease and how you became a caregiver.

Archie: Well at the time that I got involved we actually had a family Christmas a number of years ago. My brother and family were in and we actually had a conversation about it. I remember distinctly my Mother not wanting to talk about Alzheimer's or say the word out loud even as if it would bring some sort of reaction from my Father. My Father other than, he was depressed occasionally, had sort some medication and I was the oldest am the oldest son and living in the area. So I became someone who had the ability to weigh in with the family and begin the process of deliberation on the way ahead and believe me I was stumped and also like others in my family I was in denial for a bit. I was not at all happy with the family physician that was treating my Father. Some of the things that occurred to me were

Treatments that I thought were outside of norm of how you treat this particular disease. Quite by accident my wife's hairdresser had a mother who had gone through this experience and she recommended a book called "The Thirty-six Hour Day" and that got me once I read it and saw the way ahead and all the things that one should start doing I then must of read six or seven different books on the subject an I understood then the disease, the way ahead I'm a ex military so I began the process of rank ordering what I thought we should do starting with a physical a good diagnosis getting the best help going down the list and that's what I did and while that went on my Father began to exhibit a few problem symptoms. We did some daycare work and then I began after several years looking for a resident facility that could help us and help the family.

Jon Merril: Archie what things went wrong in the diagnosis and treatment of your father?

Archie: I found the diagnosis, the early diagnosis or prognosis to be marginal. Certainly the physician did his assessments and perhaps he had blood workups and some other things but the other sorts of mental tests or acuties that need to be done you know there was no psychological profile done or anything like that was done that would help you go through it. Nor necessary any particular reading that would put you in the direction of how you would pursue this. If you and I had a severe disease chances are that our provider would send us on to a specialist why in this particular case did this go on for say eighteen months without being sent on to a specials in the field. If I known

what I know now I would have jumped on it immediately and maybe I could have gotten into an Alzheimer's treatment which have resulted over the last seven or eight years that would have helped stabilize the disease earlier rather than later because once it gets to a certain point no matter what you do you know your on a slippery slope and I think that I lost probably twelve to eighteen months because I just didn't either know how to ask for advise or advice wasn't provided when it should have been. I blame myself and no one else for that.

Jon Merril: Archie you obviously experience both some not so good healthcare as well as some very, very good healthcare for your father. Can you describe a little bit about what you consider best practices for the diagnosis and treatment of Alzheimer's disease.

Archie: I suppose that each family who has a general practitioner they see routinely and who has watched or monitored family members for a while may know, he knows a lot about a lot of different diseases but as they bore into the specific aspects of something like Alzheimer's that require I think some both geriatric work maybe even psychology added to it and I found that in Constantine Lyketsos there at John Hopkins at Copper Ridge a guy who could explain to me the merits of what we were facing, how we're facing it and then watched him help my family through this transition as well as helping my parent with stress. I did not get that sort of support or I don't think my parents got that sort of support from their family physician. I think that the treatment load was different I think that they treated one thing and then they might have treated something else and the dosages changed I don't think there was a good safety net for my parents by the family physician and I think it required me to go out and find somebody who could do this and thank god we live in the Maryland area and John Hopkins is renown as it is for this treatment but I was very discouraged by some of the things that were pushed on the family and I would rather not even elaborate but such things as herbal treatments to me are outside the norm of how you should attack this particular disease.

Jon Merril: Archie what do you see the role of the internet as being for a caregiver and what is the value of the research that's contained on the internet?

Archie: If we assume that a parent say age seventy-five has the disease chances are if its early on and if they're computer literate the chances are that they can do some research. If there is someone who has a son or daughter

living in the area or wherever they are who is use to resourcing the internet and finds this particular website they're going to latch onto it. I personally went into the Alzheimer's association, then I went into the state of Maryland. I did some research into Quality Care who was checking on facilities, what was the criteria. I visited facilities I picked up literature there and so if I were to tackle this problem from the very beginning right now aside from reading it a book such as "The Thirty-six Hour Day" that would automatically point me back to Hopkins and from Hopkins I would then borrow down and take a look at the better Alzheimer's programs in the state of Maryland and now once I'm there then like every other website its got to be hugely easy to navigate. You know some people are more adroit at working internet sites and others aren't. An older parent is going to have a huge difficulty so maybe there is a simple set of criteria for an older person who comes to the site and maybe some advance things for some one who is a little bit more schooled in it and maybe even something on the professional side that's more schooled than that. Perhaps ultimately Copper Ridge will have the ability to do something like Google's doing with its You Tube were its actually going to have an interactive site where Lyketsos actually gives an interactive video and talks to the patient or Kathleen does that who's so marvelous. Or any of the other staff no matter who they were, they all had capabilities' that I relied on throughout the time that I visited Copper Ridge and while my Father was in care there.

Jon Merril: Archie knowing what you know now having gone through the trials and tribulations and caring for your father what insights and inspirations can you share with the audience to help them become better caregivers and also understand their role in caregiving in the broad context of what's going on with Alzheimer's disease.

Archie: Well I think that part of the caregiver process and part of what Copper Ridge does is reaching out and working with the caregiver and one of the things that I learned was that the professional staff the providers at Copper Ridge and other places like Dr. Lyketsos see things when they are talking to families that help families adapt and adjust to the disease. Specifically I mean this in our case when we did some counseling we saw evidence to the fact that there was a level of stress in my other parent that needed to be dealt with and that resulted in our ability to adjust and take some periods for respite care it became vitally important, we did that a couple of times over a period of time in order to make sure that we mitigated the stress on the healthy parent. The parent who has Alzheimer's doesn't see it, he or she; they just go through their day to day. So one of the things the family has to do is make sure that your kinda doing a self

examination of how's everybody doing, you know sometimes you need to take a time out and that is part of the healthy process of maintaining good mental health as well as good physical health for all caregivers involved in this process. A friend of mine in another area was telling me that he was overdoing everything. He was bathing, and he was feeding and what not and I said you know you've got to step back from this a little bit and make sure you take care of your self because your no good to either of your parents, your certainly no good to the person who has Alzheimer's if you yourself becomes ill and you've got to maintain balance but you do need some professional guidance periodically to make sure that you do maintain equilibrium it seems to me. I think there's got to be some sort of a discussion by a professional such as Dr Lyketsos that tells a caregiver not to be ashamed that this is a disease like any other. That together we can educate ourselves to take care of the person who suffers from this disease.

One in three of us at the age of seventy five in the future will have this disease. I don't think America is ready for the onslaught of what potentially might lie ahead. Don't assume and I think another piece of instruction ought to be that don't assume that a caregiver in the home has the skill set beyond loving the person their married to has the skill set to see this thing through. It's hugely demanding and the worst the condition, the more demand, the more the stress and after all they have to take care of themselves to. They have to cook for themselves and clean and bath and do those things.

And so the website I think has got to have a kind of don't be discouraged there's lots of help out here and here is the kind of toolsets that are available to you, depending on what your need is and allow that person to select from the toolset and then maybe there is some sort of instantaneous e-mail where they can get responses from not only caregivers at Copper Ridge or else where around the state but from professionals if in fact somebody like Lyketsos could ever have five minutes where he could actually do a little bit more than that. Maybe there even set answers that roll up in the computer if in fact I type in a pro word that causes the computer to kind of come back.

I have some very strong beliefs after having gone through this which I've found this to be a very expensive proposition because I also enlisted a lawyer to help us through which was both expensive and proved to be very beneficial. But one has to understand a wide range of things you know it's not only about the person who has Alzheimer's and therefore understanding the disease. But where they are as a snap shot in time and where there going to be a year from now, two years from now, five years from now because things will change. The

personality will change that's number one. Number two if you have a provider such as a Dr. Lyketsos what is he advising? Well he's going to start a one point then he may have to adjust the medication and what should you be looking for to help your provider better treat and care for your loved one that's number two the medications. Number three what are the places that you can go to for resource assistance because eventually you know you're going to need respite care, you may need to know adult day care. Well Howard county was great about that and we had a place close by that I did some adult day care and then what's the place beyond it and how does one think though both the cost and the proximity so you can get to your loved one. I mean all of us want the Ritz Carlton to take care of our loved one we really do but not all of us can afford that. Number four is what lies ahead financially, how are you going to get from point a to point b. I've tried to tell other people in my peer group how to think through that particular problem on financial care because it requires a plan of its own and that's where you need legal assistance.

Number five you need some legal documents. A will, a power of attorney and the thing that saved me and my family I executed my Fathers wishes in a health care directive. That is an absolute mandatory document that you have to have in your possession.

Number six you know enjoy the time that you have you know appreciate get over your own, gosh how should I say it get over your own problem with denial. This in nothing to be ashamed of its just a disease, your loved one doesn't know the difference so why should you care and I think once your at peace about that you can better support your family as we go through the years of this disease until it is no more.

And so maybe the website could have these kinds of thoughts in there too. I mean "The Thirty-six Hour Day" was written by Hopkins Alzheimer's guys, so when I saw that I looked for a guy like Lyketsos so that's how he popped out of the woodwork and low and behold he turned out to be thirty minutes up the road from my house. I mean gee what kind of luck is that?

You know my dad was probably like your dad was a virile guy. You know you remember all the times that you did all the things that guys did together you know l ball, hunting, fishing what ever it is and you know to cut to the chase it breaks your heart; it just breaks your heart.

But with all the things we've just been talking about Jon, with respect to educating yourself you can make up the difference and you can smooth over the pain by working the problem and helping your family have a quality of life

by bringing all these resources to bear it makes a difference and that's what you have to focus on, don't get discouraged.

Jon Merril: Archie we very much appreciate the insights and perspectives that you shared with us with regard to caregiving and Alzheimer's disease.

Archie: Jon I thank you so much for allowing me to participate in this new venture. I think the more that we get out on the net and the more that we educate particularly folks younger than I am will use the resource and they will be better prepared than I was and the whole intent of this thing is to make people that come behind us better capable of dealing with their loved ones than say we were.

Maybe we did some of the things the hard way but make it a little easier for everyone concerned.

Jon Merril: Please continue to tune in to other broadcast and resources on alzcast.org to gain additional viewpoints and information about Alzheimer's disease.