

Wayne S.



Objective 1: Identify factors that motivate individuals to seek diagnosis

“I think probably the biggest thing is memory, because I used have a...I remembered everything. I used to meet someone, see them 6 months later and remember them. Now it’s like “oh we met?” I think it was that and sideline of that is short-term forgetfulness. in a regular check up they pointed that there were some concerns that it is very possible it might be alz.

How long ago was this?

I wanna say like 3 years, I’m not sure...my brain. Its not hat recent but it wasn’t ages ago

Did you bring it up to your PCP that you had a concern?

I’m trying to remember, umm. I think almost we talked about it both at the same time. I sort of felt this was happening and they were testing and saying look...when one of us brought it up, the other wasn’t surprised...let’s put it that way. I know that it was like yeah, it might be something.

So you weren’t like blindsided?

No, no I wasn’t. I knew something was going on. Like I said, I thought I had a very good memory and I kept catching myself having problems.

Were you aware of any immediate changes at home once you received the diagnosis?

I’m trying to remember...when I got the diagnosis...after I got divorced or before? I think it was after...definitely after...actually there wasn’t any specific change that occurred after. I

remember going back and looking one of the question was “do you think this had an impact before the ALZ. And actually people...and number one: I had no problem talking about it. And it’s like, it’s sorta like you’re scared to tell someone you have a cold. Well it’s not as though I did something bad to get this. It’s nothing to be ashamed of, it’s just...hey...I have it and I much rather have people be aware of it. I have not (told a lot of people) because I thought of this a couple weeks ago: I was going to say something to this organization about it and then I thought well, that’s ok, but why are you doing this? Are you looking for sympathy? Are you trying to hide something or will it make these people uncomfortable, so I haven’t done it. If I’m talking to someone one on one sure. But to stand up and make a statement I’m not sure, I have no problem what so ever with it but don’t want to make an issue out of something that’s not an issue and right now if work exclusively with someone on a project, I will say something, I’ll say ”look...if I forget something, just kick me and let me know and Ill work on it” but to announce to the group, I don’t know if anyone benefits. Now if someone asks a question does anyone have alz? (raises hand) I have no problem at all so in that sense I won’t hide it, I’m not in the least bit ashamed of it. To me those who have it...I think they’re great people...you know...you do what you can to keep going.

Objective 2: Describe the emotional experience of a person who has recently received a diagnosis of Alzheimer’s

How did you wife and your children react to your diagnosis?

They were, my wife’s reaction to it was...she wasn’t surprised. She said I think that’s good, at least you have a name now.” Which I agree, and the children said “you know... glad you found out. They do what they can do and at least you know what the problem is.” And the same way...nobody said “ohhh that’s terrible!” and like I said, I use it to joke around with my sister when she calls, when she calls and says “this is Jackie” I say “who” (Laughs) she’ll say cut it out.

So when you found out was it kind of a relief b/c you had something to call it?

Yeah, exactly and it’s like you worry about why you forget about something, what’s going on here well, now you kind of know...well that doesn’t make it better but at least it explains it. And that has benefits b/c you think “what’s going on? am I losing my mind? Is there something growing in my head? Or am I eating wrong? What’s the problem? Ok, no am not happy I have it, but I’m happy I know what it is b/c it’s well known, it’s well supported, people understand it, a lot of people have it and you’ll be one of the many that benefit if something comes along that can change the outlook.

Day to day, what do you notice about your diagnosis?

I try to judge if things are getting worse and I have noticed recently I seem to be a little more forgetful. I also try to form habits and patterns so you don’t have to think about everything, where did I put that pen, where did I put this, I try to keep things in a certain place. I pretty carefully watch, when I’m working on things, how I file it. You know it’s once you get aware of the fact that you have forgotten, it’s like what steps can be taken to prevent it. Some things

I do still forget, but I'm not as worried about it. Worrying about it makes it worse. It may or may not make it worse, but it prevents you from doing some things, you may hesitate when you don't have to.

Do you keep lists of what you need to do for the day?

Oh yea, I did that before the diagnosis. The reason is (it's really kind of selfish) b/c if I write it done, it's done, I don't have to think about it...I'll get around to it.

Objective 3: Recognize social stigmas and provider assumptions related to AD.

Have you noticed that when you do tell someone...do they react differently? Do they know what it is? Do they have questions? Do they treat you differently b/c of it?

Actually no, they haven't the general...more frequently they say, "oh that's too bad" and then they talk about someone they know with the diagnosis. And its like "gee I have a bad cold today" or they ask "are you seeing anybody or are you taking anything?" Generally it's been very positive, but it may be my awareness that I see more then I did in the past. But generally, the population is much more aware than 15 years ago. It's not as unique and rare and *horrible* as it was. And I guess you think back at least 2 generations and I don't think they had a name for it...it was dementia. Okay, alz is a form of dementia but not all dementia is alz, there is benefit to that b/c at least you know what you're addressing, and that helps.

After your diagnosis, did you begin to tell your friends pretty quickly?

If someone is interested I definitely tell them, or has noted something, but to tell them...in some cases is under the guise of looking for sympathy, I hate that. I don't have to wear it as a badge but I have no problems of people knowing, or telling them about it. More times then not, its like "I know so-and-so with that"

My wife lives with it more than most. She says "don't give me that excuse, you didn't do it b/c you didn't want to do it." It's true to! She tells it like it is!

Benefits of an early diagnosis?

One I think is earlier the diagnosis there are limited medications that at least you have access to right away, how much it affects you depends on the individual. That's probably the biggest thing. Secondly, I think it allows you to begin to pattern what you do, modify how you do things in such a way that it doesn't have an impact. You know like, when I'm parking a car I pay attention to where I park, I pick a landmark so when I come out of the store I know where my car is based on those landmarks. So that's sort of small patterns. Just things to do but I do it every time I park my car, otherwise I'd be wandering around for days!

Anything similar to that at home, such as routines?

Oh yeah, I put things, mainly in the bathroom, where I put toiletries I make sure I put in the same place and make sure there is a rhyme or reason to it. If I'm running out of something, I keep a pen and sticky pad on the sink and while I'm there I'll write it down and see it. It takes a lot of pressure off, b/c otherwise I'll be thinking all day "don't forget that...don't forget that" I don't have to remember it...I've written it down!

Do you think it was helpful to learn about your diagnosis early? – do you think it WAS early for you? Would you have liked to know about your diagnosis sooner?

I do believe the earlier the better and I think the key is: it's not just early or late it's acceptance, that's the hard part and the earlier you can do that, the better. Therefore, the earlier the diagnosis the better. 2 things: the more you accept it and realize there are patterns of behavior you can adopt that will limit the impact...that's huge. And the other thing is that it's not a social stigma that's gonna follow you around like a little cloud over your head. That's up to you how you deal with it. Would you like to go back in time and get your memory and not have to worry about it...sure! But...has it really made that much difference in your day to day life? And the answer is no. Will it in the future...yes probably worse but you deal with it as it happens.

Does the possibility of it getting worse scare you?

Yea, sure, I've seen it really advanced...my mother didn't know who I was. It's kind of a wake up call b/c it kind of all happened after we had left...moved away...so we would come back and see her and I was, in my mind, seeing a more rapid progression b/c I saw spots over a period of time. One of the things we laughed about is..only b/c it's the only way to deal with it, when we were home one time and we were leaving she said "thank you for coming by, it's always nice to meet new people." It's enough to make you cry, but it just becomes funny b/c it's the only way you can deal with it. Now will I be at the same point? There's no guarantee that that will or will not happen I mean with some medication, it may not ever get there, but you can't guarantee that. And that's okay, if you do what you can to try to help it...that's it...you do what you can.

Advice: What to do if someone around you gets diagnosed?

"Have compassion, but don't treat them like a baby...and don't expect miracles" you don't, and I don't think I know how much you internalize all this. It's tough, I sympathize with all caregivers that feel trapped in some respect. It's got to feel like a trapped environment. My wife does a tremendous amount for me, at times I wish I could in some way say: from the 1st to the 15th of this month, I don't have this disease...put it in a box and bring it out when we get home. We'll have nothing to worry about!

What is some advice to someone newly diagnosed?

A series of things. One: make sure they understand the diagnosis, make sure they take the

medication that is advised and 2 is to consciously find ways to work around a problem you have, don't let it stop your life and what you're doing. There is always a way get something done that's a little different pattern, look for that. Last, it's nothing to be ashamed of; conversely you don't have to brag about it. You have to find that balance.