

**Singapore, Alzheimer's Disease International Annual Conference**

**Final, Final**

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## What's it Like to Live with Alzheimer's Disease?

1 - What's It Like to Live with Alzheimer's Disease Richard Taylor, Ph.D.  
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Hello, my name is Richard 2. Picture and I have Alzheimer's disease. 3. Fade to next picture Six years ago, after undergoing more than a year of testing everything from my urine to my memory, a neurologist in the United States of America, Houston, Texas to be exact, walked into his office, sat down at his desk, stared directly at the desktop, and said to me. Richard 4. Fade to next picture you have dementia, probably of the Alzheimer's type. What he said after those words my brother 5. Fade to next picture nor my wife 6. Fade to next picture nor I can recall. We drove home in silence. As I entered my house. I was overwhelmed with emotion and began to cry hysterically, I ran out into the backyard crying. Only to have my wife 7. Fade to next picture suggest I should come back into the house, because the neighbors would think she was hitting me. Everyone in my family cried for three weeks. 8 fade to next picture We cried until we no longer had tears to shed, and we were all emotionally exhausted. The irony was - here I was a PhD, a psychologist, with little to no knowledge of dementia, much less dementia probably of the Alzheimer's type. We were crying for ourselves and we were crying for each other. We were crying for our future, a future turned upside down 9. Fade to next picture and inside out by the unexpected visit of Dr. Alzheimer, and his sticky footed army who now apparently were and still are tramping down brain cells between my ears.

After I ran out of tears. I turned to Mr. Google 10. fade to picture of Google page and opened many of the 16,700,000 WebPages containing the word Alzheimer's. It was quite filling, but not very satisfying. Like many folks with too much education, I had hoped to calm my fears with vast amounts of information. I thought I could control my out of control fears of tomorrow by understanding what was happening today. It did not work. One fact I discovered in my internet wanderings burned into my consciousness 11. The Average Age lifespan of someone diagnosed with dementia is 8 years from the day of diagnosis - "the average lifespan of someone diagnosed with dementia is eight years from the date of the diagnosis." Naturally, I began to prepare for my own death. I dragged my family down with me, a fact that to this day sometimes upsets them and still troubles me for doing it in the first place. I went to my local Alzheimer's Association, and they told me I must get my affairs in order. I checked out black-and-white videos from their library and saw people in the latter stages of the disease.

I was being pro-active. I was practicing what professionals preach. Three years later, another fact jumped off a webpage I was reading. 12 fade in - The average age of someone who is diagnosed with dementia is 72 years old. "The average age of someone who is diagnosed with dementia is 72 years old." Wow," I thought. I was only 62 at the time.

Therefore,  $72+8$  equals 80 my hand held calculator told me. And, I must confess I have always thought I was slightly above average. I had 18 years left. "Hooray!" thought I.

Fast-forward to today. **13. Fade into picture** Here I stand, 66 years of age, probably in the latter stages of early stage dementia, probably of the Alzheimer's type. **14 fade into picture** I am speaking to angels from all parts of the globe who watch out and support millions and millions of folks like me, living with declining cognitive skills. What to say? **15 fade to blank** So much, in so little time. So complicated, and so simple, both at the same time.

Difficulties are compounded by a "Cassandra" effect. As I am sure the members of the Greek Alzheimer's Society already know, the name Cassandra is associated with the richness of myth from Greek mythology. **16 picture of Cassandra and Ajax** Cassandra was a daughter of the King of Troy. Struck by her beauty, Apollo provided her with the gift of prophecy, but when Cassandra refused Apollo's romantic advances; he placed a curse ensuring that none would believe her warnings. Cassandra was left with the knowledge of future events, but could neither alter these events nor convince others of the validity of her predictions. **17 fade in - You have knowledge of the future events, but you can neither alter these events nor convince others of the validity of your predictions** And isn't this where many of you find yourselves when talking to your media, your funding sources, your governments, and the world? You, and I, show the hard data, show the projections, show what Alzheimer's will do to the world's population, and yet, if we are lucky, our words end up on the back page of the newspaper, at the end of newscasts, or on the cutting room floor. **18 fade to blank**

So as a preface to my remarks, I urge you to stand up and speak out. Though we are often ignored, we have a duty to stand up, speak out, and come out of our closets. In the USA, AIDS research gets twice the amount of funding as does Alzheimer's disease, yet less than half as many citizens are diagnosed with AIDS as are diagnosed with dementia. Mind you, I'm not opposed to funding AIDS research, but when there are a limited number of dollars available for research, the bulk goes to those who stand up on tables and speak out, not to those of us who retreat to closets or pretend there is nothing wrong with us. At this point, I this point I used to jump up on a table and speak out. But ever since I fell off a table in Little Rock Arkansas, I just speak of this rather than do it.

The Cassandra paradox we find ourselves in is based on a simple truth: I cannot claim to speak for anyone other than myself. **19 fade to If you have met one person with dementia: you know only one person with dementia.** If you have met one person with dementia: you know only one person with dementia. Each person's life has evolved differently. Each person's brain creates a unique reality for him or her. Each is cursed and blessed with the ability to think about their own thinking. Thus, any cognitive disorder is by definition difficult to catalog, understand, much less predict or alter through eating more blueberries, playing more games on the computer, or psychopharmacology. Because there is no one certain description of Alzheimer's, Cassandra's curse makes it difficult to explain to the world what we know.

In response, we must focus our vision. **20 fade to blank**

So, exactly what is it that I want to get off my chest? What do I want you difference makers, you leaders, to know that only I can know because I have dementia? What do the Cassandra's of dementia need to hear from people who live with the disease? This I see as the primary reason I have been invited here to speak.

I want you to take away with you one fact about me, and several ideas about how to treat me and others who face the challenges of dementia. I want and need you to help me as my

cognitive skills decline . I want you to enable me to hold on to the world for as long as humanly possible.

First, I want you to know, appreciate, and act as if I am a whole person. That is the fact I hope no one ever forgets. **21 I want you to know, appreciate, and act as if I am a whole person.** For indeed I am, and will be up to the moment of my death. I am not half-full, nor half empty. I never, ever want to hear you say as I sit mute in a wheel chair, lay in bed, or wander around my village "there is Richard Taylor, only it's really not Richard, it's just Richard's shell. He unfortunately is gone." I am not now, nor will I ever be reduced to existing as a turtle. **22 I am a Person I am a whole human being** Just because when you knock on my door I don't answer, or I answer and I don't know who you are, or you don't recognize me: That does not mean I am anything less than a whole and complete human being. It is everyone's birthright to live a full, complete, joy filled, loving, satisfying, and purposeful, and purpose-filled life. **23 fade to blank** In other tragedies, for example, when someone loses a leg, their family, the community, the government, and the world rallies around them and seeks to provide a prosthetic leg. When a human being is losing the ability to control some of her or his cognitive functions, the family cries, the community draws away, the governments are too busy saving their banking systems. For better or worse the world depends on the people seated in this room to make it right for people living with the symptoms of dementia.

"This is not fair." say you."Certainly", say I! "We are so underfunded." you complain? "Most certainly," respond millions of human beings living with declining cognitive abilities." My staff and I arefeeling overwhelmed." you tell your Board of Directors. "And therefore..." say I. But you are the people who can most directly impact how I and other human beings living with and in a dementia, probably of this or that type, can continue being ourselves, to continue having a complete and whole human identity.

Now I want to speak briefly about your governments, for they are, in my mind, the organizations whose sole purpose is to do for its citizens what each individual citizen cannot do alone. **24 Governments are the organizations whose sole purpose is to do for its citizens what each individual citizen cannot do alone.** Governments should keep me safe from invaders. Keep the air I breathe and the water I drink pure and safe. Do something now about global warming. And oh by the way, assume the leadership in organizing your resources to affirmatively prepare for the tsunami of persons living with dementia such as myself. **25 Governments should Lead Governments should mobilize resources. Governments should plan for what will inevitably impact most of the citizens who elect and support it.**

For even now, the waves of baby boomers are nipping at the ankles of their governments to do something about the dementia tsunami. A wave that will sweep away memory, competence, and eventually millions upon millions of lives. The flood the wave leaves behind will drown me and many, many others, and bankrupt social services. While at the same time shredding the safety nets for people who cannot help, much less cure themselves of their failing cognitive skills. This year in my country alone, 67,000 citizens will die of dementia-related causes. That is the equivalent of 170 Boeing 747 aircrafts crashing, all within a year's time.

And now to speak directly to you, **26 You are the difference makers in my life. You are leaders more than doers.** the difference makers, the leaders, the "go to" folks when it comes to dealing with the issues of Dementia and its interrelated forms. My family and I do not have the resources, both financially and emotionally, to successfully cope with this affliction by ourselves. We look for leadership from our leaders, from our Alzheimer's Societies to do more than raise money for research. We look to you to do more than provide

information, group experiences, places to store us for a day, and pamphlets and forms addressed to meet the present and future needs of our carers.

But research is an easy bucket to throw money into. There are clear markers of success—were symptoms lessened or slowed? Was empirical evidence found as to causation? There can be clear answers if research worked. We have thrown as much money as fast as we can for twenty-five years in search of the cure pill. And how much closer are we today than Alois Alzheimer was?

Similarly, money given for caregivers is money well spent, but it is also money easily spent. I assume heaven loves and supports caregivers. I know I am here primarily because my wife, Linda, **27 insert picture** has given more than I can imagine to enable me to give speeches like this. I would like to acknowledge her as the one who made it possible for me to be here, the person whom I love and who loves me every day. **28 insert picture** She loves me as I am, not who I was. My wife Linda is here and I thank her in front of the world for being my partner down a road neither of us wanted nor expected to take. **29 insert picture** Thank you Linda. I love you. I love her and try to appreciate the difficulties she faces with a, pardon the expression, pain in the butt like me. She is a saint and such people need to be supported. **30 fade to blank**

And now to speak of my personal concerns as a person living with the disease, and to share with you the questions I have heard from the voices of hundreds of others in my same shoes. **31 fade to picture** **32 fade to picture** I ask some, perhaps most of you: Why isn't your first priority - a priority made clear in your budgets, your staffing, your fund raising - why isn't the number one priority seeking to understand the psychosocial needs of those in whose name you raise your budgets? Why don't you do first things first - directly support your citizens living with Alzheimer's disease? Why must some of you spend a significant portion of your budget on research for a cure? **33 fade to picture** Why do you so over promote your quest for a cure, when the roadsides are littered with individuals who already have the disease and are not being served by you? Why does it seem and feel to me and too many as if you are the Alzheimer's carers society? Or the Alzheimer raising funds for a cure association? Please, first things first! Be THE Alzheimer's Association or Society.

I want everyone one in the world living with dementia to stand up **34 scroll this then hold on screen**

**Richard's call to action**

**Stand up! Speak Up! Do not become a victim of your own silence.  
Speak for yourself and those who will follow.**

**Ask Carers and Friends to do the same.  
Today will never be here again.**

**Time is of the Essence! Use it wisely!  
Tell as many people as possible your perceptions of your interactions with  
professionals, with carers, with friends, with strangers, with your government.  
They will not change unless they know, and they cannot know unless and until you  
SPEAK UP!  
Seek to create a Palpable Sense of Change and of Urgency!**

and speak out. To tell others what it is like to live in and with dementia. And, appeal to everyone in this room to welcome and encourage their input. How many societies in this room have individuals living with dementia on their boards of directors? What percentage of

your board is made up of people with dementia? How many of you form advisory committees composed of people with dementia for every one of your programs designed to support people with dementia and their caregivers? How many have yearly in-services for their staffs during which they meet and work with people with dementia? How many of you will return home to an office filled with volunteers living with some form of dementia? **34 fade to blank** We do not bite. We may sometimes need an explanation; we may need to be told several times, we may get confused in ways you are not. But does that mean we should not be full partners with you in our crusade? It means you may sometimes have to do your business in less efficient ways. It means there may be mistakes and misunderstandings in your office that do not crop up in the offices of the Cancer Society. You are for God's sake The Alzheimer's Society! Let us in! Affirm our worth by partnering with us.

Professionals, the medical community, even carers know what they know, but they don't know, they can't know us unless and until they make and take lots of opportunities to talk to us, and most importantly, to listen to us.

Next I 'd like to discuss what I see as a troubling trend in dementia treatment. There seems a worldwide epidemic sweeping through dementia households to encourage people with dementia to live in the past. "Let's reminisce about the good old days" **35 fade in "Let's Reminisce about the Good Old Days"** say the children to the parents. "Remember when?" ...and if we do remember smiles appear on everyone's faces because this is evidence to all that I, their father, mother, sister, loved one is still here.

It has been established that the symptoms of dementia eat away our older memories after they have consumed most of our more recent and short-term memories. Everyone around us lovingly wants us to be who we were. They understood us then. They knew us then. They could connect with us then.

But what about today? Who enables me to stay in today? **36 fade in What about today? Who enables me to stay in today?** This day, my day, your day, is all the day we have to live in together right now. Living in today is easier to you. It comes naturally. Living in today is difficult for me. I do not always understand what is going on around me, or in me. I forget and get confused about parts of today, even before the sun goes down. Today is always a partial mystery to me. Is it any wonder I pull into myself, withdraw, and become paranoid and defensive?

And you offer me as an alternative my yesterdays. But they do not meet my needs today! Why is it for instance that that nice young man comes into my room every night, including weekends, and wakes me up at 4 AM so I can go pee? In addition, if I have a bowel movement he writes it down and there is rejoicing that there was a BM in room 104. Why do you now ask me what I want for breakfast (you have adopted a person-centered approach) when I do not fully understand what breakfast is? Why it is? And what I should know about it. Help me understand today, **37 fade in Help me, enable me to understand and appreciate today!** every day, maybe even twice a day, or thirty times a day. Always introduce yourself. Ask me if I know, or want to know, why you are here, what you are going to do, where I am being taken, why I am going there, how long I'll be, what happens after that. Tell me the day, the date, the season, something about the weather. Engage me. When you assume I do not need to know, when you act as if my knowing is not your most important priority. When you act this way it send an unintended disabling message to me. It tells me my needs come second to yours.

Another example of disabling me, when you honestly believe you are enabling me, occurs when you lovingly take some forms out of my own hands because I am not filling them out accurately. You fill them out for me, and you never let me fill out a form in your presences

again. When you pick out "the right clothes." When you speak for me without asking. When you talk about me as if I am not in the room, when I am. While intending these to be loving acts, the unintended consequence is to disable me from my own sense of wholeness, my own sense of self-confidence and self-competency. I must always try to deal with the consequences of a failing and faulty set of cognitive skills. You can choose to engage me, to support me, to offer to provide the skills I am missing to complete my task. Or, you can attempt to be me. To act like me, or rather as the me you want me to be. **38 fade in Please don't disable me. Please enable me**

Often you can do it yourself. It's quicker that way. You can be sure it was done the right way - your way. I need you to honor my way. How do you know what I want to figure out for myself unless you ask me?

The best way to want to stay in today, is to have something you really want to do today. The best way to be a human being is to have a purpose. **39 Everyone needs a purpose. Everyone needs to live a purposeful and purpose filled life.** When you lose your job, when you can't drive, when people begin to stay away from you, even friends and family, when you can't go out by yourself and you find yourself having to adjust your comings and goings to the comings and goings of others - when all this happens almost at once - is it any wonder people with dementia lose their sense of purpose? They cannot access the support they needed to achieve it - driving somewhere, walking somewhere, doing something on your own and by yourself. In developed countries, we sleep more and watch more TV. I confess I do not know for sure how the majority of people living with Alzheimer's in our world spend their time. My world is probably not the world of, dare I say, most folks living with dementia in this world. But I do know everyone, in every shack, hut, home, community, village, city, state and nation of the world who is living with dementia is losing or has lost his or her purpose for living. I do know their purpose is at best eroding, and more likely being destroyed.

So what is left for us? Why do we open our eyes in the morning - to shuffle through another empty, confusing, and ultimately meaningless day? A day that is forgotten as it happens? For me, and dare I speak for us, we need your support to redefine our sense of purpose. We need your support to provide opportunities for us to experience what it feels like to be living a purposeful and purpose-filled life every day of our lives.

Some of us need to be reabled. **40 fade in 40 fade in - Reable some Enable all** Many who have withdrawn into themselves will and/or can no longer make choices for themselves. They need to relearn that they have the right and the ability, albeit sometimes with your support, to be in charge, as best they can be, of themselves. To be responsible for their own actions. Ask many folks who are deep into cognitive decline to make even the simplest of decisions and they will say, "You decide, it doesn't matter to me." Now, how you help us discover and live a renewed sense of purpose is the topic for another time and another speech. But, please, please when you look into the dulled and silent eyes of someone with dementia, ask yourself, ask them, how you can help them find meaningful activities. Meaningful in the sense that they feel good about themselves when they participate in them. Playing Bingo seems to be a great stretch for me when I consider the best use of my time to meet my universal need to feel good about myself. **41 Fade to Blank** Ask yourselves, "Are my activities entertaining or meaningful and meaning- filled? Do I provide one activity for everyone, or a meaningful activity for each individual under my care? Finally, will any of you die unhappily if you do not get to play more **42 flashing pop up Bingo! Bingo?** **43 fade-to blank**

I believe professionals and to a lesser degree, carers have an obligation to do more than love us, or like us, or be kind to us. Of course, we want and need this - but everyone wants

and needs love in their lives. It is the way everyone wants to be treated, to be respected, to be loved, to be honored for being themselves.

The reality is the progressive form of dementia of this or that type creates new and unique needs in human beings, in us who live with the declining ability to remember and understand and appreciate ourselves, others, our lives, and today. We need your support in a way that is different from how you naturally support others. We need an ever-changing balance between helping and doing, between asking and telling, between assuming we think like you and assuming we don't think at all or it doesn't make much difference what we are thinking. This is a very difficult task, but that is why we pay professionals - people who have studied us, people who are trained to listen to us, people who appreciate us as whole human beings, people who know how to help us understand and fully participate in everything, every time, every moment of our lives as a functioning, purposeful, loved and loving human being.

When I was first diagnosed folks asked me, "What's It Like to Have Alzheimer's disease?" I saw and felt the disease as if I was sitting in my grandmother's house on Irving Park Street in Chicago, Illinois staring out the window, and viewing the world through her lace curtains. [44 fade in picture here](#) I thought I could see everything that was going on, but obviously my brain had to compensate because I could not actually see through the threads in the lace curtains. Occasionally the wind would gently blow and move the curtains and my view of reality would quickly change. There were knots in the curtain, and I could not see around them so I just sort of ignored the parts I couldn't see and filled in the missing darkness with my own unique interpretation. It didn't hurt. I really didn't know I had it, whatever "it" turns out to be, until I stumbled upon a symptom for which my brain could not compensate. I had to admit to myself, and sometimes show to others I forgot, or I was confused, or I misunderstood, or I wasn't in their moment - I was in my own moment.

Six years later and I see my state of mind as having slowly changed, slowly evolved into what it is, who I am today. [44 fade in picture here](#) As I hope by now you all realize, I am still Richard. I am still me, but me has changed (haven't we all?). I am more verbally assertive, some would say verbally aggressive, than I was six years ago. I have rediscovered my temper from when I was two or three years old and I really believed everyone on earth was here to meet my every need and want. And meet them NOW! [45 fade in picture here](#) I blurt out observations and opinions that sometimes shock even me for their directness and sometimes inappropriateness. I forget, lots and often. Sometimes I know I have forgotten as when I am speaking with my [46 Fade in picture here](#) granddaughter and I cannot for the life of me remember her name. I do not confuse her name with the name of my other granddaughter, I just do not know her name. [47 fade to blank](#)

Sometimes I am unaware that I have forgotten, I am confused, I have lost the train of thought; and I ramble on until the quizzical looks of my listener catches my attention. Then I try to cover up, as best I can. I do not consciously try to cover up, it just happens. I forget as if I am dead, there is no recollection, no hint of a recollection, no sounds like, no the first letter is, - I just can't get to what I am looking for. I don't have a clue.

[48 fade in picture](#) Six years ago, honestly, I could have sat at my computer for two hours and written this speech. Maybe it would need a second draft and maybe it wouldn't.

[49 fade in picture](#) Six years later, today, I have been working on this speech for three weeks. I have probably invested more than 30 hours creating it. Sometimes I feel as if I am hanging on by my fingertips. Sometimes I feel contented where I am. And sometimes I try

not to feel, because I know my fears will exaggerate my feelings and cast a dark pall over them. 50 fade to blank

And, while I have your attention, please include in your support services all people who have all forms of dementia.52 scroll -- There are over 100 different diseases associated with the clinical symptoms of dementia among them are:.....

All too often the words Alzheimer's disease takes up all the air in the room leaving thoseers with other forms of dementia wondering who speaks for them, who are their leaders, who wants to understand that they too are, and always will be, complete human beings. 53 fade to black

I do not think I am Cassandra now, this audience is proof that people listen in this world. And it is not that I am still Richard. It is that I am Richard. 54 fade in and slowly grow it - I am Still Richard

Please give thoughtful consideration to my appeals for enabling and supporting me to stay in today, every day of my life. Speaking like this has brought new and deep purpose to my life. I know my time is limited to act on and in this newfound purpose.

You are, to an extent greater than all the other citizens of our world, - you are a large part of my future. My future in large part is in your hands and the hands of your organizations.

I have for a long, long time hoped that I would leave this world with a bang and not a whimper. Perhaps this is as close to a bang as I am going to get.

I am still, and always will be, Richard. And I have and always will have-to the moment of my death-dementia, probably of the Alzheimer's type. 55 fade in

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