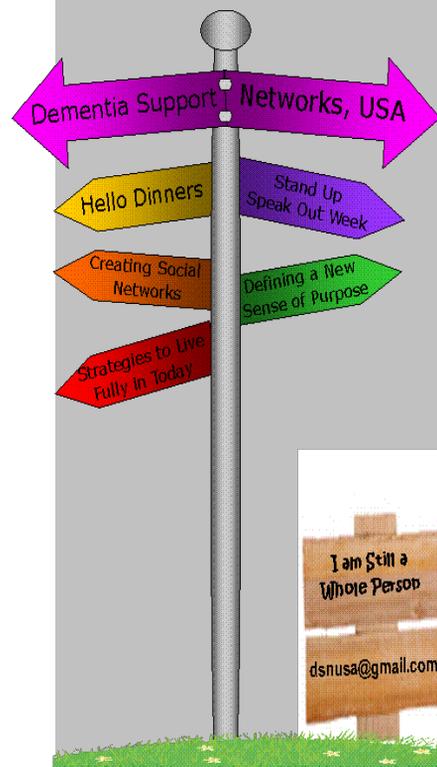
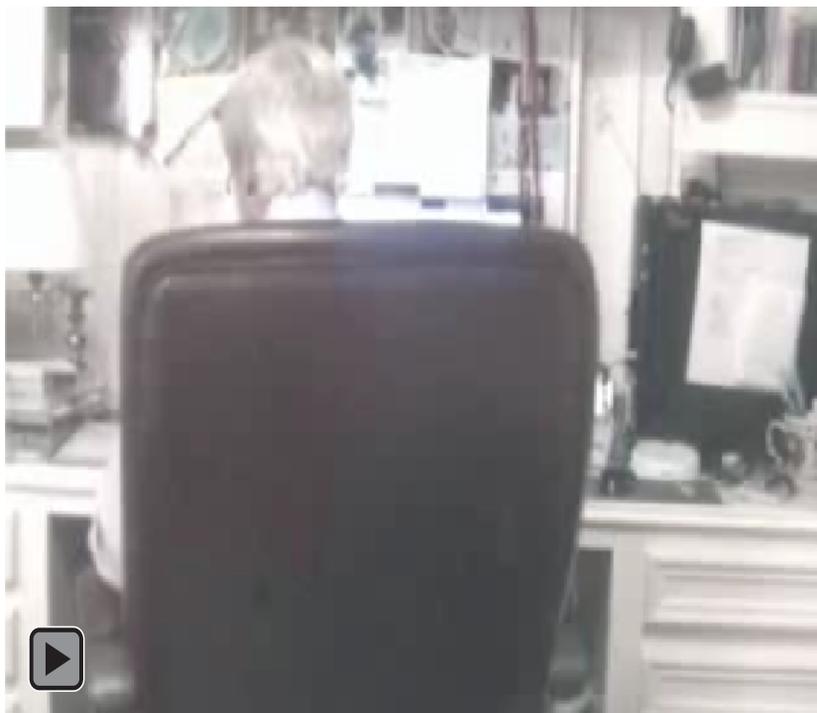


The Voices of Dementia

A Journal of and by Individuals Living with the Symptoms of Dementia

July 2011
Vol. 1
Issue 1



Hello,

And welcome to the inaugural issues of the Journal of the Voices of Dementia. Since this is the first issue, since I am impatiently waiting for others living with the symptoms of dementia to submit their first articles, since I have reached the limits of my patience, since I'm the one who is at least for now publishing this – I decided to publish the first issue by myself, right now!

My name is Richard Taylor, and I live in Cypress, Texas together with my spouse, and my symptoms of dementia.



I have long wanted to collect the thoughts, feelings, and experiences of individuals living with the symptoms of dementia from various communities around the earth. My limited experience with creating chat rooms around the world convinced me that while culture plays a strong role at the edges, the core life experience/myths/fears/stigmas attached to those living with the symptoms of dementia is amazingly consistent across oceans, continents, classes, languages, and generations. My wish is that over time some of these universal "truths" will begin to take shape and gain traction around the world through efforts like this to connect people living with dementia with each other, and then more honestly/directly connecting them with the professionals and care partners who seek to support them.

My hope is that quite quickly this journal will be translated and published in many, many languages and published on country specific web sites. I am looking for volunteers/organizations that might be willing to take on this task for the people they serve, in the language they speak.



As for myself, I find all the traveling and speaking about my own experiences is wearing on my own personal quest to engage my symptoms as fully as I can, increasingly I find myself depending on others



around me to enable me where I can no longer do it by myself. I will still stand up and speak out; I will still travel – just not so much. I hope to write more, publish more, engage more people to think for themselves about this massive public health crisis/pandemic caused by dementia.

I've decided to refer to myself as the acting editor because I will for a while at least will act like an editor. The position I am sure will be temporary until the rotating editors assumes these duties. I envision two or three co-editors, each of whom will rise up and identify themselves to me and take the responsibility for continuing this necessary attempt to give voice to folks whose voice has weakened because of their disability caused by their symptoms of dementia. Each editor comes from a different country. Each of them serves for no more than two years.

I don't expect that I will get this completely right in the first six months, so there will I am sure be changes – suggested by others and/or not yet, but soon to be

obvious to me. This is an idea I know whose time has come. The only question to be answered is can I do this, and will I do it fairly and well?



Currently this journal is available only on-line. You may subscribe to the Journal at www.richardtaylorphd.com. Change of email addresses are processed through DSNUSA@gmail.com. Cancellation of your subscription may be done through the link at the bottom of each issue of the journal or notification of DSNUSA@GMAIL.COM.

Honestly, I could have filled this entire issue with my own writings. I actually write that much in a month that doesn't make it into my monthly newsletter and/or occasional mass mailings to friends, etc. over issues that come to my immediate attention and require in my mind an immediate response. However, I decided just to send the skeleton this month so all could see where they might want to put meat on this new way for people living with dementia



to speak to each other and care partners and professionals from around the world.



Please write something, now and send it to me. We can work it out, print it as it is, write something together, and hook up with other people with dementia. I need copy; I need the collective thoughts and experiences of people living with dementia who are willing to share these thoughts on paper with others.

I have a vision of turning this into an electronic journal where we could if we chose read or speak our article – but that is in the future. I am experimenting with embedding videos into the body of the journal so you can read either it, or just click on it and the author will read it to you, but that is in the future – soon I hope. I also have a vision of this being published in many languages. We have set this up as a series of word documents, making it as easy as possible for bilingual folks to retype the articles into our templates, email them to us, and we will put them back in our PDF form and begin to build a mailing list in your native language. Any takers? Please write richardtaylorhd@gmail.com.



I am mulling over in my sometimes out of control mind if I should fold my newsletter into this Journal or keep it a separate document. I will just mess around with this for a couple of months before I make up my mind. I hope I receive so much copy from others there will only be room but for one or



two items from me in the Journal, but as I told my children when they were much younger when they asked me a question I did not want to answer right then "we'll see."

Please send me a piece of your mind, your experience, your feelings, your fears, your joys, your purpose, and your successes. Please pass this along to friends. Please let me know what you think of the new format and how I might improve it.

As always, you decide. Thank you.

Richard



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Departments

Letters to the Editor

Dear Editor

My husband William has been diagnosed with Alzheimer's disease and frequently when he asks me question or I must tell him something I don't know the right thing to say, the right words to use, the right way to go about it. I don't want to sound defensive or offensive. I just want to be me, just like he wants to be him – but lately we seem to be, or at least I seem to feel as if when I speak to him I am “walking on eggs.” I hope you understand what I'm trying to say.

Is there a right way? Are there right and wrong answers? Help! Please.

Anna H.
Berkeley, VA

Hello!

Frequently folks ask or write me for advice. They want to know what is "the right thing I (they) should say?" I really don't know what to say. I'm not them. I don't live with or in them. I'm still a work in progress deciding what I should say! And, in addition to that excuse for not answering them directly with a "dear Abby" type of advice response - What I am finding is there is no one "right" thing to do or say. Some are better than others, especially better in certain circumstances, but life is easier if we just would trust, love, be open, and accept each other for who we are today. And if we don't know sure for

sure, we should ask, we should listen, and we should just be.

Maybe sometimes we just shouldn't say anything if we are in the midst of an emotionally charged and defined moment. Maybe we should say, "time out." "I'll be back in five or ten minutes"



Being is difficult enough without dementia, being and sharing that process of being with one of the sets of symptoms of dementia is made even more difficult by other's attempts to hang on to, shape, reinforce parts of our being which are either not accessible or aren't there any more. We are being in the moment regardless of the best or worst behaviors of those around us. It's just it would be easier for all concerned if we stopped this "long good bye" nonsense" and started to say "hello" to each other more often.

Medically accurate and socially acceptable labels for diseases are issues for physicians to lose sleep over. The fact for us is it really doesn't need to make a difference to us what words others use to label our syndrome, our collection of atypical behaviors. It's how we decided to react emotionally to the words we ourselves utter, think about, and tell each other.

We all need to keep constantly reminding ourselves and each other of this. We need to enable everyone to be themselves, to understand themselves, to love and to feel loved. The medical community, society, culture, history are all trying to convince us who we are, and we aren't - who they say that is. We are ourselves. That, to me is what getting "it" means. At the same time we are, we must be all of ourselves, we are also a person with dementia who loves, needs, lives with his/her caregivers. They too need a "right" answer. We are to a large extend what we say and think we are.

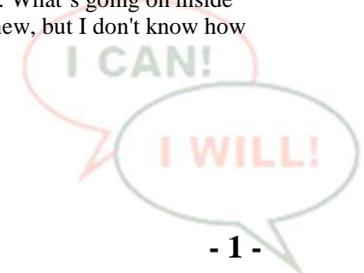
Perhaps the right answer for me is the wrong way to frame it. I need, we need to find a right answer, the right thing to say for us. We need to stop looking for right and start talking to each other about what meets my needs, your needs, our needs. Best wishes to both of you on this journey. Stay in touch and I will do likewise.

Richard

My dear Richard:

I just can't understand the way my husband acts. He sometimes seems to be five different people in the course of a single day. What's going on inside his head? I know he is no longer the Zachary I knew, but I don't know how to know the Zachery he is today.

Margaret
Montebello, VA



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Hello!

I too am meandering to a different drummer. I no longer can say I am marching, following a defined beat as I previously did. The map we both drew for us to walk together on the last 1/3 of our lives is of no use any more. But, understand I still need a map, I still need a sense of purpose. I still need to know where I am today.

Too often you want to remind me of my past, my old memories, and who I was. That is not all that helpful. Instead I need to pay attention to today.

It's true that sometimes I do things "right" in the morning and "wrong" in the afternoon. I often recall details no one else does. I sometimes forget major points everyone else knows. My thinking varies day to day and hour to hour. Sometimes I improve several steps, and then find myself stepping backwards, or more likely, sideways.

If you unnecessarily take over my decisions, lay out my clothes, dress me, choose my groceries, order my food for me, then there is less and less for me to decide. Instead of making all my decisions for me, simply prompt me to make as many decisions as possible. Give me cues or memory aids that encourage me to live fully in today.

In the eyes of many I am seen as less someone. I am still grandpa, and dad, a friend, and a whole human being. I have always been a complete person and I still am. I am not becoming any less a person simply because I cannot remember exactly like you do, talk like you do, or think like you do.

It is true that I am fundamentally different from you. I am different in ways I can't express and you can't fully perceive or understand. Our brains are different. But I am still a complete human being. I am marching to a different drummer and down a different path than you. But I am still Richard, a human being with all the same needs as any other human being. Thanks for taking the time to write. I wish you both best wishes on this journey. Stay in touch, and I will do likewise.

Richard

Heart to Heart

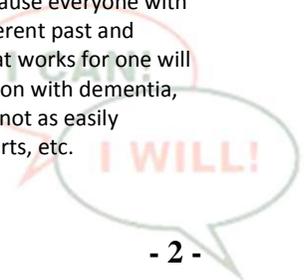
Hello,

I'm Richard Taylor and I live in Houston, Texas. I wrote a book by accident and from that accident came a new purpose to my life. I now go around as speak about what it is like to live with the symptoms of dementia. You know there aren't many of this doing this, considering there are millions of us living with this disability. I wouldn't recommend it is a way to earn a living, but it sure gives you a reason to get up each morning. I have something to do today that I want to do, that I can do, that I will do. I tell folks that I am running away from my future as fast as I can, and I believe the reason I am who I am today, after living for years with the symptoms of dementia is because of this purpose, my passion, and the family, assistants, and hundreds of friends I have made that allows/encourages/motivates/enables me so every day I can make a most times successful effort to accomplish my purpose. My blowtorch burns at both ends, and "oh the glow." Will you share with us through these pages something you would like others to know about you – heart to heart? Thanks,

Richard

Best Practices

Hello, it is very trendy now, could it be because the Federal Government and Insurance companies are requiring it, that treatments for most anything be based on evidence-based research/best practices. When it comes to treating folks living with the symptoms of dementia this will never be a good standard to decide if it should be used/reimbursed to support that person dealing with their symptoms and the social/psychological fallout from them. This is true because everyone with dementia is a different brain, a different person, a different past and present, a different set of symptoms and severity. What works for one will not necessarily work for another. If you know one person with dementia, you know one person with dementia. Aging brains are not as easily classified and boxed as are aging prostrates, livers, hearts, etc.



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Then just how are we to decide what to do? Guess? Go with our heart? Our Guts? What I read on the internet? What someone told me in a book? How about someone in a white coat? It is not as easy as we would like it to be, as the TV commercials make it out to be - "Mom's forgetting more but since she started taking m and m's placebos, expensive pills, drinking more avocado juice, _____ she is almost her "old" self again."

The answer is not based on statistics, years of experience in dealing with dementia, or how many letters someone has after their last name. The answer is based on the individual and how well we know them. The answer is based on first appreciating the underlying needs of every human being. The answer is based on open communication between service deliverer and service recipient.

A very wise person, whose name I can't connect to this wide advice one told me can't "give" care, it must be accepted. Best practices occur when our well intended intent that is expressed by our behavior is openly received and accepted by the recipient. This is a best practice.

Now having said that are more than a few practices here that have a very low probability of ever making the best practices list of anyone. What has worked for you as a caregiver? As a person living with the disability of dementia? As a professional working with folks dealing with dementia in one way or another? Please share them with us, and let each of us

decide for ourselves if this might be "best" for us. Many of us need ideas. We feel like we have exhausted all possible ways of dealing with some issue. Tell us your way, and as always, we will decide. Thanks,

Richard

O.M.G.



Founder and Chairman USAgainstAlzheimer's

"There is no treatment or therapy available today to Prevent, modify, stop, or reverse Alzheimer's disease; and because of this dynamic, no one survives Alzheimer's disease. There is no remission. There is no cure. There is no "living with Alzheimer's," there is only "dying with Alzheimer's." In the end, Alzheimer's is 100 percent effective in killing its victims." -- George Vradenburg, Co-

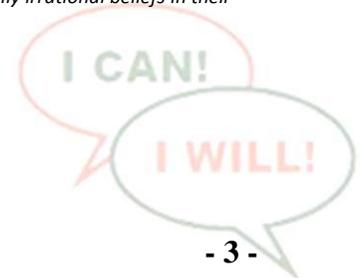


A friend of mine, Bob Demarco sent me this quote. This is stigma building at its best/worst. There is lots of living to be had living with Alzheimer's. In fact every moment after you have been diagnosed is living. Of course every moment after the doctor slapped you on your naked butt was also dying, but did he place you in your Mom's arm and say "Mrs. Taylor, Richard is dying with life? Life is 100 percent effective in killing its victims. We just don't yet know the exact label to place on your Richard's death certificate as the cause of death, but we are sure we will be able to think of one after seventy or eighty years of living."

The editor (Richard Taylor) has an interest in "outing" those who openly preach to all who will listen the message of emptiness, suffering, lack of any human emotions and needs other than safety and a full belly that lies ahead for any and all folks living with the symptoms of dementia. If you come across quotes by folks who are telling you how awful it is to live with dementia, especially folks who themselves don't have dementia, please send them to this department and I will publish them together with a picture if I can find one on Google of the person who made these awfulizing* remarks concerning lives lived with the symptoms of dementia. Then you can decide for yourself if what they say is true or false, is it inevitable or a self-fulfilling prophesy. As always, you decide. Thanks,

Richard

**Albert Ellis would be proud of me, I think. These beliefs about the absolute emptiness of folks living with dementia are most certainly irrational beliefs in their purest forms.*



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Link of the Month Club

[Alzheimer's Club](#)

A forum for non-censored ideas, news, research, clinics, therapy, technology, amyloid, tau, Alzheimer disease and related disorders. In memory of Mark A. Smith.

Hello, AlzClub and AlzheimerCode are not-for-profit web sites for non-censored ideas, news, research, technology and clinics on Alzheimer's disease and related disorders. Both are run personally by me, Alexei Koudinov, MD, PhD, DrSci, well known for his Alzheimer's and basic science research, and for battling against the corruption of Alzheimer's field, to protect public interest. Few examples are under must read links above, most notable of which are correspondence with the Wall Street Journal that yielded [three WSJ articles on Alzheimers, Security and Exchange Commission \(SEC\)](#) and [Written Evidence to UK Parliamentary committee](#). My contribution to Alzheimer's research is summarized in [cholesterol failure hypothesis of Alzheimer's](#) and in [the series of publications here](#).—Alexei Koudinov, M.D., PhD. DrSc

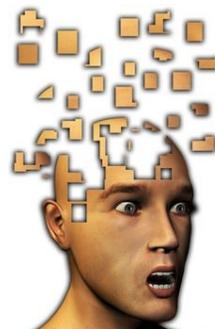
<http://www.alzclub.org/2010/12/why-there-is-no-cure-for-alzheimers.html>



My friend Anne Bastings, the creator of “Time Slips” offered the following links of being of interests to me and others.

What's interesting to Anne is interesting by definition to me, I thought they might be of interest to others.

1) [John Michael Kohler Art Center](#) in Sheboygan just opened Hiding Places: Memory in the Art and the show (is amazing!) and will be up until Dec. 31st .Tell your friends!



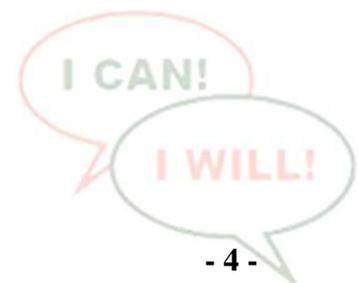
2) [The TimeSlips Creative storytelling project](#) is launching a new website that enables folks to read, write, and share creative stories. The official launch is Sept. 24th, but it will be soft launched this summer. In the mean time, just check out the [current site](#), which is also very cool!

3) The UWM Center on Age & Community (which I direct) is hosting a Summer Institute NEXT June 24-28th (2012).

Spots will be limited so you can contact the Center today to get more info. [Visit their website for more info.](#)

4) [The Penelope Project](#) has its own blog that is full of fascinating stories from the entire project.

5) Gary Glazner does the [Alzheimer's Poetry Project](#)



Writers Block, and How to Overcome It!

By **Richard Taylor**

When it doubt, when confused, when blocked look it up in Wikipedia or Google it. They will help you to understand – e.g. writers block

From Wikipedia, the free encyclopedia:

“For other uses, see [Writer's block \(disambiguation\)](#).”

“**Writer's block** is a condition, primarily associated with writing as a profession, in which an author loses the ability to produce new work. The condition varies widely in intensity. It can be trivial, a temporary difficulty in dealing with the task at hand. At the other extreme, some "blocked" writers have been unable to work for years on end, and some have even abandoned their careers. It can manifest as the affected writer viewing their work as inferior or unsuitable, when in fact it could be the opposite.

Causes of writer's block



Writer's block may have many or several causes. Some are essentially creative problems that originate within an author's work itself. A writer may run out of inspiration. The writer may be greatly distracted and feel he or she may have something that needs

to be done beforehand. A project may be fundamentally misconceived, or beyond the author's experience or ability. A fictional example can be found in George Orwell's novel Keep The Aspidistra Flying, in which the protagonist Gordon Comstock struggles in vain to complete an epic poem describing a day in London: "It was too big for him, that was the truth. It had never really progressed; it had simply fallen apart into a series of fragments."

Other blocks, especially the more serious kind, may be produced by adverse circumstances in a writer's life or career: physical illness, depression, the end of a relationship, financial pressures, a sense of failure. The pressure to produce work may in itself contribute to a writer's block, especially if they are compelled to work in ways that are against their natural inclination, i.e. too fast or in some unsuitable style or genre. In some cases, writer's block may also come from feeling intimidated by a previous big success, the creator putting on him or herself

a paralyzing pressure to find something to equate that same success again. The writer Elizabeth Gilbert, reflecting on her post-bestseller prospects, proposes that such a pressure might be released by interpreting creative writers as "having" genius rather than "being" a genius.¹ In George Gissing's New Grub Street, one of the first novels to take writer's block as a main theme, the novelist Edwin Reardon becomes unable to write and is shown as suffering from all those problems.

In her 2004 book The Midnight Disease: The Drive to Write, Writer's Block, and the Creative Brain (ISBN 9780618230655), the writer and neurologist Alice W. Flaherty has argued that literary creativity is a function of specific areas of the brain, and that block may be the result of brain activity being disrupted in those areas.

Popular mentions of writer's block



In the 2004 psychological thriller Secret Window, which is based on the novella "Secret Window, Secret Garden" by Stephen King, the main character is a writer by the name of Mort Rainey played by Johnny Depp, who portrays a man who is going through a divorce and as a result is suffering from writer's block.

Rapper Eminem suffered from writer's block for some time as the artist mentioned in "Talking to Myself", a track on his top selling album Recovery. It was one of the causes for his musical hiatus.

English rapper Just Jack's song "Writer's Block" refers to writer's block and how he suffered from writer's block whilst writing the song as he had too much else on his mind.

Author Julia Cameron advocates the practice of morning pages as a remedy to writer's block. Morning pages are 3 handwritten pages of free writing where the purpose is to write without the intention of using the writing for anything. It is a practice that can bring your thoughts to the surface and allow you enter a more creative zone."



Hello,

Okay, that is enough reading the excuses of other's not to write. I **have found it to be therapeutic for me to write**. I try to write each day at the same time for about an hour what has happened to me that day. What I was thinking about. What

pissed me off? What pleased me? Then I sort of go with the flow of my brain which these days is more like rafting down the Snake River in early Spring. It is fun and become a necessary part of my morning to read what I wrote the night before – just to see if it still makes sense to me. Just

I WILL!

to see if I can do it. Of late, I find many grammatical errors, repeated words, misspellings, and wrong words popping up here and there. Thank heavens for spell check, Google, and dragon naturally speaking voice recognition software.

Try writing something down. Do not tell anyone you are doing. Do not show it to any one, at least not just yet. When you get comfortable with doing it, reading it, saying it aloud, show it to the most non-judgmental person in your family. I showed my 9-year-old Grand Daughter. She said "so what am I supposed to say now?" I said, "Nothing, you have said enough." I can still write so others will understand and so can I!

Here are some ideas to help you unblock yourself.

Ideas for themes for future issues: How my country is planning/dealing with dementia. What should they do more/less of? What role should people with dementia play in the planning and implementing process?

How I feel when I tell someone about my diagnosis. How that has changed over time? How others react to it. How that has changed over time. What I have learned about talking about my diagnosis with family, friends, professionals.

What went through your mind/heart the first four weeks after you were told: "You have dementia, probably of this or that type" How has what and how you feel and think about changed since the shock of the announcement started to fade? Or has it faded? What would you tell others about to hear to the news to lessen the negative impact of the words on them and their family?

How did you and your employer handle your symptoms of dementia and/or your telling him/her you were diagnosed with dementia? What were the short and long-term consequences? What/How should others handle it to move toward a better outcome? If you could do it over, what would you do?



After the after-shock of hearing the news, after the loss of your job and your access to driving – what did you do? What happened? How did your life change? What are you doing now to

make your life better for you, given you haven on job and can't drive?

Why do you continue to drive after you have received the diagnosis of dementia? How will you know when it is time to turn in your car keys and no long drive?

How do you respond to people who tell you they don't believe you have dementia? That you are just like them. That they too forget, get confused, and do and live as you do? How does it make you feel? What do you say back to them?

How do you believe you have changed since the diagnosis? How do others tell you that you have changed? Why is there a difference in perceptions? What can you do about it?



If you deny there is anything wrong with your mind, and claim it is others who misunderstand you, not you that misunderstand others – how does this make you feel? What are you doing to

convince them they are wrong? Have you ever thought they might be right? How do you know you are right and they are wrong?

What do you think and feel about the emphasis on raising more funds for research for a cure for Alzheimer's disease, and less emphasis on raising more funds for research to better understand the dynamics of families living with Alzheimer's disease? Is this the right thing to do? The right way to do it?

If you ran your local Alzheimer's Association, what would you do more of? What would you do less of? Why? Why do you think this isn't happening right now?



If you had a \$1,000,000 and were told to donate to the dementia cause how and who would you give it to? Why?

Is it important/meaningful to know the difference between Alzheimer's disease and dementia? Dementia and any and all of its other forms? Why?

Why hasn't your family, your community, your state, your country, out world responded more forcefully to the public health crisis dementia is creating? How should they respond? What can you do to make this happen?



What are three things you wish people would do different when they are around you? How can they enable you when the feel must disable you? Give a couple of



examples. Why do you think they haven't figured this out for themselves? How can you help them?

What are three fears of the future you have about yourself? Your family? Others living with the

symptoms of dementia? The rest of the folks who aren't living with the symptoms of dementia?

What should you have done better, what should you have said, during the first year after you were diagnosed? Why didn't you say it? How could you better say it now?

What did you say/do the first during the first year after you were diagnosed that worked and continues to work very well for you and your family? Why do you think others don't say/do this?

Who in your life has been the most/best help for you dealing with the symptoms of dementia? Why? How? Have you told them this? Every day?

Do you believe people lie (more) to you since you were diagnosed? Give a couple of examples? Why do you believe people have more trouble telling you all the truth now than prior to your diagnosis?

How have you changed? How do you know? Is this good or bad? If bad what are you doing about changing it?

What is the most difficult thing to say/do to/with your care partner now, that prior to the diagnosis was easier? Why do you think this is? How can you make it easier?

What new stuff have you learned about yourself since you have been diagnosed? Why didn't you know it earlier?

In dark moments, have you considered divorce, living alone, or even suicide? Why did you consider the action, and what make you change your mind? How common do you believe this in amongst people living with the symptoms of dementia.



Who causes, who promotes, who perpetuates myths and stigmas such as "the long good bye, suffering, loss of

soul, dying twice, fading away, becoming half full/half empty? Where did you first hear these myths? Why are they so powerful? How do we flush them from our system? What are the consequences if we don't?

Why do you think you have the symptoms of dementia? What are the physical causes? The spiritual causes? The environmental causes? Is it important for you to know what caused/causes your symptoms?

How long do you believe you have left to live? Prior to the diagnosis how long did you believe you have left to live? How has/will the symptoms of dementia effect your living?

Defining Your Purpose



Do you have a purpose? Something you love to do, something that is one of the reasons you open your eyes in the morning so you can accomplish some of this

today. After you were diagnosed, how did your purpose change? How did you ability to create and live in it change? What did you do about it? What are the consequences of living a purposeless life? A purposeful life? Your life?

Do you enjoy living in yesterday with friends and family (reminiscing they call it)? What purpose for you does it serve? What purpose does it serve for them?

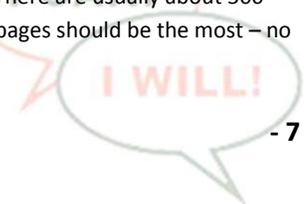
Do believe you live fully in today? The same today others around you live in? Is this a good or a bad thing to happen to you? What can you do about it?

How do you stay in the moment, in today? What aids do you use to make sure you understand as best you can what is happening around you right now?

What is the best idea yet you have come up with to aid you to overcome one or some of your symptoms of dementia? What are two others? Why do you think they are great aids?

What is something humorous/funny/strange that happens to you when one of your symptoms sneaks up on you? How do you respond? How do others respond?

Please pick one or two of these ideas, or ideas of your own and send me 1,000-1,500 of your best thoughts and words in the form of an answer. There are usually about 500 words to a page, so three pages should be the most – no



longer than five pages please. I want folks to read an article in one sitting and depending on where they are sitting that can be about 3-5 minutes. Don't preach, don't digress, do be yourself, let you shine through the words. Be direct, honest, and concise. You should probably write it once, come back to it a day later and rewrite, and then give it one more day and one more editing. They send it off.

Of course you are also welcome to sit right now and write it all in one sitting. Just write, please. Look in your pockets and drawers for things you have already written and don't know who to show them to, or what to do with them. We can't have our own journal if we don't contribute our own words.

Thanks, **Richard**

+++++

We are the World

Part II A Call to Action

By **Richard Taylor**



Hello, the dementia archangels at the World's Alzheimer's Association (an organization ((Alzheimer's Disease International or ADI for short – check out their web site at www.ADI.org)) composed of the National Alzheimer's Associations representing most of the countries of our world) have declared September as World Dementia Awareness Month. One of the goals of this worldwide event is to encourage people living with the symptoms of dementia to stand up and speak out to others about what it like to live with their symptoms. The citizens of our world need to hear from us, our

families need to listen to us, professionals need to learn from us, and most importantly we need to feel more comfortable discussing and living with the disability of dementia than many of us currently do. The emphasis is on convincing and demonstrating to the world that folks living with the dementia can and will speak up about their disability. "I can" and "I will" are the watchwords for the activities.

The Whole World is Watching and Waiting for us/you/me to Stand Up - Speak Out

It's time for us to accept our moral responsibility to support our kindred spirits living around our world. It's



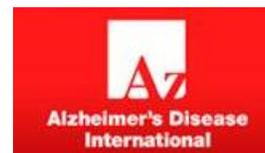
Immanuel Kant
1724-1804

time for us to accept this personal responsibility. I can and I will. We can and we will. You can and you will. Show the world we are whole people. We are not fading away as human beings. We still have souls! We still have needs for human contact.

The time has come for folks all over the world who are not living with the symptoms of dementia, but who are at risk of someday living with the symptoms to listen to and appreciate the wholeness of others living with the symptoms of dementia. It's time for them to accept their moral obligation to enable the disabled to live whole purpose full lives. It is time for us all to play a proactive role, to become a difference maker and respond to the Dementia Public Health Crisis.

Sometime(s) during the month of September, World Dementia Awareness month, I hope those of us living with the symptoms of dementia and those of you who are not presently living with the symptoms will talk to each other about how the Dementia Public Health Crisis affects our respective lives, and how each of us needs/wants the others to support them and respond to this cognitive disability.

If you have suggestions based upon your own life experiences of how you have successfully and unsuccessfully stood up and spoken out, and you want to share it with others around the world please drop me a note at: . A friend of mine, Laura Bramley and I are working A.D.I. to set as a page web site there yet, it



closely with up a web site within their (don't rush won't be up



for a few more weeks. I'll let you all know the address when it is available) that will contain (we hope) hundreds and hundreds of ideas of how everyone can take part in this worldwide stand up and speak out activity. On the site we will publish cyber books. Each book will be filled with your suggestions. One book for people living with the symptoms, one for their care partners, one for professionals, and as many other volumes as your input/suggestions create. This site can develop into a source of ideas for individuals, groups, countries to consult when they are looking for ideas of how to stand up and speak out.

Several months ago we formed a steering committee, and we met during the world conference of A.D.I. in Toronto.

Here are some ideas from folks from around the world:

Hello, I am Tina Hackel, and I live now in my home country Switzerland.



Living with my late husband Alex in Florida for ten years, we have together and at home experienced his journey with Mr. Alzheimer increasingly intruding into our partnership and marriage.

One problem Alex did NOT have was the kind doctors prescribe a blue pill for. He was still, in his seventies, a healthy man, full of energy, and he loved to make love. And I, nineteen years younger than him, loved to make love, too.

Mr. Alzheimer didn't change that. What changed - as one of the first symptoms showing up - was Alex becoming more and more careless about the condition of his bathroom and especially the cleanliness of his body. This turned me off. Asking Alex to read a "How to..." book didn't help; to argue didn't help either.

Finally we found a nice solution: I moved out of our master bedroom and king size bed to a spare twin bed. And I asked Alex: "Please, feel free to visit me here anytime - but, please, take a shower first!"

Alex did not only take a shower. He put on some fragrance and a beautiful silk Kimono, he looked great and the expression of excitement in his eyes surely turned me on, too!

Best wishes to you and your family,

Tina Hackel, Switzerland; tinahackel@yahoo.de

Hello:

My name is Beatriz Valles. (sorry I don't have a picture of her at this time) I live in Venezuela and work as a volunteer at the Alzheimer's Foundation of Venezuela, Chapter Nueva Esparta.

I am a Language Therapist and for five years I have been investigating the characteristics of conversation between people with dementia and their primary caregivers.

In the initial results of this research, I have been able to demonstrate that conversation is an activity that is influenced by the healthy conversational care partners who actively participate and help the person with dementia to compensate for their limitations. The care partners thus support the person with dementia to remain active and present in the conversation, despite the negative characteristics that many researchers have described such as: anomia, paraphasias, circumlocutions and repetitions. Thus, when evaluating how the person with dementia participates in conversation, it is necessary to also evaluate "how" and "how much" people talk around the patient.

E-mail: brvallesg@gmail.com



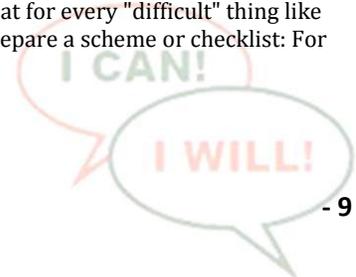
Hallo:

My name is Nina Baláčková and I live in Prague, Czech Republic. I am 52 years old. I have a very good husband and two adult children. I have Alzheimer's disease from 2007.

I would like to share with other people fighting with Mr. Alzheimer about some things that help me.

Every evening I prepare my schedule for the next day. I write on paper all the activities and then I enter a reminder in my phone to inform me of a meeting or appointment. Usually I have two times reminders, just to be sure :-)

My second idea is that for every "difficult" thing like washing clothes I prepare a scheme or checklist: For example:



- choose the clothes
- put in the washing machine
- add washing powder
- switch on washing machine
- put a reminder in my phone to remind me when the washing machine will finish

Then I do all these points and check them off as I do them.

I try when I can to speak up. Two months ago, I organized a meeting in our library about Alzheimer's and other dementias. I ask my doctor-psychiatrist to talk about this disease and I was there like her patient. People could to ask me and her questions about this disease. The director of library told me later that it was very successful.

I am grateful that I am still able to do this. This is because I have some special form of Alzheimer's disease, not typical as I am "young." Secondly, I know about my problems and I can speak about it. For me being able to speak about my disease and my problems was not good at the start of my problems because the doctors thought that I did not speak true and that I fabricate the problems with my memory and reasoning and thinking. It took 9 months to find out that I have really AD! I was at many doctors and I was in hospital for observation -- in Psychiatry hospital -- for 3 weeks.

With best regards Nina Baláčková

E-mail: bariz@centrum.cz



Hello, I'm Mona Johnson and I live in the state of Wisconsin, in the United States of America. My father developed dementia when he was in his 60s. After reading about scientific breakthroughs and improved diagnosis, I encouraged Dad to seek testing right away, and to get the best treatment possible.

Years after his death, I wish we had moved more slowly. We might have avoided stressful tests and the medicines that seemed to make him worse. I might have spent more time just being with Dad, and less time trying to "fix" him.

If you're a caregiver or family member, I would encourage you to recognize that the science behind

dementia diagnosis and treatment is still evolving, and that each person's dementia may be different.

I think it's best to be skeptical when you hear generalizations about symptoms, diagnosis, treatment and care. Be cautious when experts talk about what "they" [people with dementia] need -- consider the individual instead.

This does not mean you should ignore the needs, safety or comfort of the person with dementia. Some issues must be addressed immediately. But when you can, take the time to educate yourself about the state of the science, and try to separate hype from reality. Don't be influenced by advertisements or headlines about the latest study. Think carefully about the risks and benefits of each treatment.

Above all, spend some time listening to the person with dementia. If communication is difficult, try to think about what he might want based on his life history and current situation. Take into account his age, overall health and specific preferences. Relate to him as a person, not as a patient.

Sometimes "slow care" is best.

Best wishes on your journey, Mona

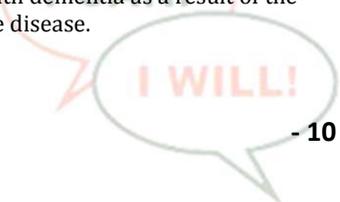
Email: mona@tangledneuron.com
Website: www.tangledneuron.info



Hello:

My name is Laura Bramly, I am a Canadian citizen, living in the State of Arizona, in the United States of America, and I was a family caregiver for my mother, who had vascular dementia and passed away in 2008.

My idea is to arrange for youth groups to visit people in the later stages of dementia and who live in memory care and/or long-term care facilities. Besides the value for the residents in having the opportunity to socialize with the younger generation, it was a chance for the kids to meet with and come to understand people with dementia—especially elderly people with dementia—and to overcome any negative thoughts the teens might have in association with dementia as a result of the stigma attached to the disease.



A few years ago, I was involved in organizing and leading a youth group in our faith-based community. Before the holidays (in this case it was the winter holidays, but it could be any holiday, including the Fourth of July!), I contacted the activity director of a long term care facility near us, and asked if our group of 15 or so teens could come and visit and put on a holiday program for their residents with dementia. The answer was a resounding YES! Activity directors are always eager for someone to come in and put on a program, so don't be concerned that you will be turned away!

Before our visit, I spent a little time with the group of teens to talk about Alzheimer's disease and related disorders and how the people with dementia might be feeling or thinking, and how the youth should approach them and talk with them (approach at eye-level, look into their eyes, what kind of questions to ask, etc.).

Any hesitation the kids might have had initially seemed to be overcome quickly, because when our group visited the home, they had no hesitation at mixing in with the residents and making conversation. In fact, it was hard to gather the kids together to do their "show!" After their songs and music, the kids once again mixed with the residents and played some holiday-related games. We spent a delightful hour or so with the residents. If you are planning a program, you don't need to worry too much about the quality of your performance; you need to be concerned about the quality of your interaction with the residents.

The proof that the teens had reached a new understanding of dementia and had realized that people with this disease are "just people with a disease," much as any other person might have an illness or challenge to deal with, came in the following weeks, when several kids asked to go back to visit their new friends in the home, and to do so independently and on their own time. Some of them maintained lengthy and regular friendships with residents. Please don't hesitate to contact me if you want to talk about taking your youth group to visit people in long-term care and who are in the later stages of dementia.

Best wishes, Laura
laura@mindsetmemory.com
www.mindsetmemory.com



Hello,

I thank those of you who used your second language to express your thoughts. I wish that I and most other Americans were as fluent in one, two or three other languages as are many of the other citizens of the world.

The web site is within weeks of completion. I'll send out a special issue of the Journal when we are on line so you all can join us. But in the mean time please feel free to send us your suggestions.

Here are some goals/objectives/end points we hope to accomplish through this project.



Speak Up

Goal: 100,000 folks living with the symptoms of dementia will stand up and tell others what it is like to live with the symptoms of dementia.

Goal: Exponentially expand the number of folks living with the symptoms of dementia who:

1. Accept this condition/disability as a fact of their life
2. Understand, accept their feel comfortable talking about their symptoms
3. Embrace their obligation to act as "change agents" for their own lives and the lives of others living with the symptoms of dementia

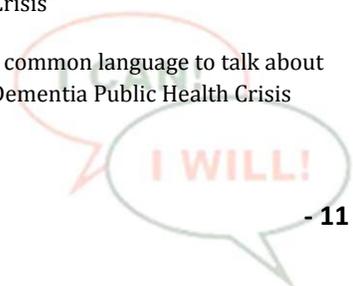
Exponentially expand the number of folks not living with the symptoms of dementia who:

1. Understand and appreciate the wholeness of people living with the symptoms of dementia.
2. are willing to take a public stance concerning what they will do to enable people living with the symptoms of dementia to live whole, purpose filled lives.

3. Exponentially expand the number of folks (living with and living without the symptoms of dementia) working together to respond to the dementia public health crisis

Broad Goals

1. Make the words world public health crisis and dementia synonymous - "We are in the early stage of The Dementia World Public Health Crisis"
2. Create a common language to talk about and respond to the Dementia Public Health Crisis



3. Create a common set of assumptions about the effects of the symptoms of dementia on any one

Narrow "Not" goals

1. This is not another World Alzheimer's day, week or month.
2. This is not about reminding people of the awfulness of the myths and stigmas associated with dementia.
3. This is not about finding a cure for any of the probable, maybe, perhaps forms of dementia.
4. This is not about raising money to spend on research to cure or slow down the progress of any of the probably, maybe, perhaps forms of dementia.
5. This is not the first stage of establishing a new organization. There are plenty of them around who are already committed to "addressing" the Dementia Public Health Crisis.

Broad "Is" goals

1. This is about understanding and appreciating folks living with the symptoms of dementia.
2. This is about re-educating existing organizations: what it is really like to live with the symptoms of dementia, what folks at all stages of living with dementia really need and want, what is the best (better) use of their resources to research/serve people living with dementia.



3. This is about encouraging everyone to support research into the everyday problems faced by those living with the symptoms of dementia and those who care about and for them. (Socialceutical research vs. pharmacological research)
4. This is about supporting and improving nonpharmacological practices to enable folks living with the symptoms of dementia to live full lives.

5. This is about creating new, informed social support networks composed of people with living with the symptoms of dementia.
6. This is about creating a balance between meeting the needs of folks who are living with the symptoms of dementia and the needs of folks who are not living with the symptoms of dementia.
7. This is about calling public attention to the impact the Dementia Public Health Crisis will have on their lives and the lives of folks living with them who are or will live the symptoms of dementia.
8. This is about organizing local, state and country based groups of people living with dementia to confront the myths, fears, and misinformation in the minds and hearts of their fellow citizens, and dare I say in their own hearts too.



I'm not Elton John. He is shorter than I am, and he plays the piano and I play the banjo. Other than my youngest grand daughter who is going to start to learn to play the violin this fall I don't know anyone who plays a musical instrument, he obviously knows a lot of musicians.

Other than these few differences my hope is that the "We are the world" movement (children) that he started will morph this year into a "We are the world" movement (folks living with the symptoms of dementia). I probably won't host a worldwide musical event, but my hope is this web site creates the same enthusiasm/impact on the thinking and awareness of the citizens of the world as did the first "We are the world."

What do you think about this idea? How do you feel about it? Will you support it? How? Make September World Awareness month in your household, your community, you country, your world!



You decide. You act! Stand Up! Speak Out. You Can! You will! I can! I will!

Richard

Post Script: We should each participate in this in our own ways. We should limit organizing efforts, and emphasize recruiting efforts. Let everyone decide how best these events can serve their own needs, and how they can serve the needs of others. Some organizations may adopt these ideas. Some countries may adopt them. What is most important is the adoption of the principles behind these events first be adopted by everyone who participates in the events. The rest can/will organize itself however it organizes itself. There are many, many folks out there who are better at creating/organizing public events on various scales than am I. This just seems like a good idea to me.

As for me, I can and I will!

Richard

After the Diagnosis of Early Onset, What to Do?

By Norman McNamara

“Use it or Lose It”



Just after my diagnosis of Alzheimer’s had been given to me three years ago the Dr concerned give me what I consider to be one of the best pieces of advice I have ever had. He quite simply looked me in the eye and said Don’t

Forget “USE IT OR LOSE IE “whilst tapping the side of his head.

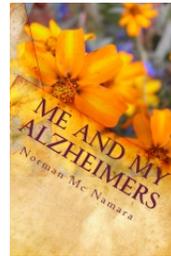
This is something I have carried with me ever since and I am totally convinced it helps stave off the awful inevitable ending of this terrible disease.

This is an example of what I mean whilst moving I had to be offline for nearly three weeks, so it was three weeks of not using the computer, not having any hand to eye coordination and three weeks of not having that much to think about apart from the move itself. After only ten days, I visited the library to try to catch up on a few e-mails only to find out that I could not remember my password, e-mail and many more things computer related. I was horrified. My “Angel” Elaine had also noticed a downturn in my speech ability and general orientation.

Now I know the move was very unsettling for me but I never expected my computer abilities to take such a

downturn, but worse was to come. When I went to write a story on “Word” which as you know, doesn’t need internet connection, my 12yr old granddaughter was with me and stopped me more than once to say what I had written did not make any sense whatsoever.

Since having my computer back I have become once again quite fluent on the computer (But spell check is still my best friend LOL) and things are getting back to normal, well as normal as they can be. This has been such a revelation to me and now makes me think of others who are not as fortunate as me.



This is why daily; if not hourly, activities MUST be put in place in care homes and Dementia Units. This is why we must rid these places of practices that sit people in the same chair, at the same time, watching the same television program day in day out!!! People with this awful disease just don’t want to sit there and waste away!! We want to carry on our lives

as best and as normal as possible. We want to go out in the fresh air on a daily basis (Weather permitting) and look at what is going on in the world. We want to be taken to Garden centers to smell the fresh flowers and feel the textures. We want to be taken out into the countryside to “Wonder “at everything this glorious world has to offer. As you can probably guess, I am back, and I am still on my soapbox, but I make NO apologies about this. All I will say is I will not rest until we see a general change in practices and attitudes towards Dementia and those people it affects.

I Have Alzheimer’s, if people won’t listen to people like me who ACTUALLY HAVE this awful illness who will they listen too??

Best wishes, Norrms

Across the Pond, Norman McNamara lives with the symptoms of dementia. He is a father, grandfather, and advocate for himself and others. He is a noted advocate, a poet, a writer and a friend. He has a perspective and understanding of living with dementia that is sometimes identical, sometimes different from mine. It is worth a read as his poetry is moving in a most profound way. He is the primary organizer of an All-England Dementia Awareness month, in conjunction with the worldwide Dementia Awareness Month. You may contact Norman at:

www.norrms.web.officelive.com



Do You Live with Alzheimer's or Die With It or Do You Do Both?

Hello,

It is becoming increasingly fashionable (see OMG in the departments of this issue) to bash the quality or lack thereof of the lives of millions and millions of people living with the symptoms of dementia, some of whom probably have the Alzheimer's Type. Telling folks they are going to die not live with Alzheimer's, telling folks they are going to lose their souls - these "dire" warnings and statements do more than throw the baby out with the bathwater. They poison the water for unborn babies. They ignore the fact that these statements "write off," dismiss, directly or indirectly claim there is no chance of a meaningful life, no chance that even near death people living with the symptoms of dementia have the same basic needs as those just born.



These "scare" warnings, these "stigma" producing and reinforcing warnings are morally wrong, and the fact others call them "dire" suggests to me they believe these are dire times

requiring dire methods to achieve reasonably possible goals.

A world without dementia is simply not a reasonably possible goal.

A world without the form of dementia called Alzheimer's disease is at best high suspicious and at worst considered reasonably possible mostly amongst those who have a vested interest in believe it, not a science based interest, not a growing consensus based interest (at least outside of the relatively small club of Alzheimer's myth and stigma makers and promoters).



This strategy of dire warnings could also reasonably be called a strategy of half truths (you (together with everyone else on the planet) are in the midst of the long good bye), deliberately twisted truths (everyone with Alzheimer's disease is gonna die), lies (you lose your soul when you have Alzheimer's), reversals of long held beliefs (amyloid is good/bad/good and bad/we don't know), and conveniently ignoring the questions because

there are no answers - so let's proceed even faster into the fog.



The fact that a National disease organization is publically given up on building/funding research and treatments (I call them socialceuticals, others call them nonpharmacological interventions, some refer to them as psychosocial issues) for lives of those who may have the very disease in whose name they raise money, in favor of preventing - or at best slowing down the progress (and if it so bad living with this disease why bother to spend research to slow it down) is just not an unfortunate occurrence (especially for those living with the disability and turn towards "their" organization for support).

This just isn't a matter of which strategy is best - the present one is wrong, wrong, wrong. Moreover, no amount of rationalization, yes-but arguments changes that. It's time this strategy was met head on, instead of dismissing it as an unpleasant but necessary sacrifice of millions living with dementia in favor or maybe a world without one form of dementia (assuming it is only one form, and even this is doubted by even the strongest of believers in the world without Alzheimer's fantasy. This is not a close call. This is not the right thing to do, period. Otherwise we need to put a "dire" black box warning on

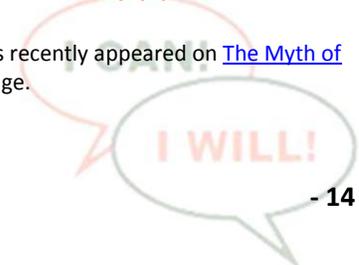


every myth producing stigma producing statement the National Alzheimer's Association makes that says (we know this isn't all/necessarily true but our focus groups told us this was the best way to raise money for the "world without Alzheimer's" we all want).

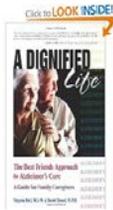
We know this might inadvertently make your life, spirit, and family unnecessarily more fearful, more dysfunctional, more depressed, sadder - but the "higher good" we seek makes it okay for us to know we are creating this ill in the world in the name of saving the world from an exact form of dementia about which there is no consensus as to its cause, singularity, progression, or even given recent autopsy reports if it even exists as we say it exists. **You decide, then write harry.johns@alz.org and tell him what you have decided about this turn of events.**

~Richard

Note, portions of this recently appeared on [The Myth of Alzheimer's](#) home page.



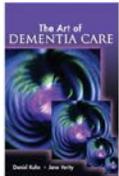
Classifieds



A Dignified Life: The Best Friends Approach to Alzheimer's Care
Virginia Bell and David Troxel



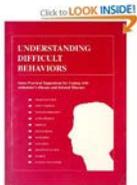
Be with me Today (A challenge to the Alzheimer's Outsider)
Richard Taylor



The Art of Dementia Care
Jane Verity and Daniel Kuhn



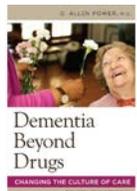
Living with Dementia
G. Allen Power, M.D. & Richard Taylor



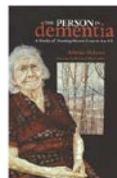
Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses
Anne Robinson, Beth Spencer & Laurie White



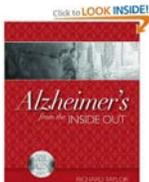
Listen to the Talk of Us: People with Dementia Speak Out
Trisha Kotai-Ewers
Mail order to: Alzheimer's Australia WA Ltd
PO Box 1509, SUBIACO WA
6904



Dementia Beyond Drugs: Changing the Culture of Care
G. Allen Powers MD



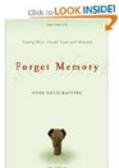
The Person in Dementia: A Study of Nursing Home Care in the US
Athena McLean



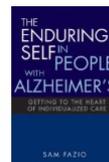
Alzheimer's from the Inside Out
Richard Taylor



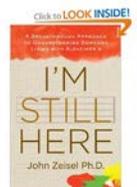
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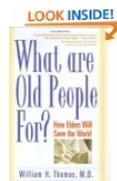
Forget Memory: Creating Better Lives for People with Dementia
Anne Bastings



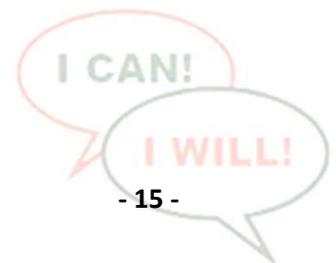
The Enduring Self in People with Alzheimer's
Sam Fazio



I'm Still Here: A Breakthrough Approach to Understanding Someone Living with Alzheimer's
John Zeisel



What are Old People For? How Elders will Save the World
William H. Thomas, M.D.



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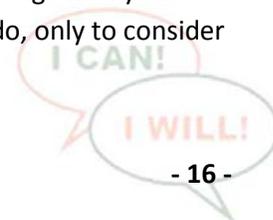
Disclaimers: No one, on one article, no group of articles in this Journal claim to be “the” voice of dementia. The authors whose words you read in this journal do not represent nor express claim to anything more than their own opinions. We speak/write as individuals living with some of the symptoms of dementia. We do not speak as who we were, where we went to school, what degrees we earned, or from the initials that were tacked on to the end of our names by institutions of higher learning. **We speak as who we believe ourselves to be today.**

Most of these opinions are based upon the authors’ own life experience, reading, feelings, fears, and personal conclusions. Everyone who writes on these electronic pages is living with some of the symptoms of dementia. Most of us have been diagnosed a number of times, by a number of physicians, using a variety of tests. Most of us have embraced a pro-active approach to engaging our symptoms through purposeful activities, one of which is standing up and speaking out from time to time, one of which is writing what is in our hearts and minds from time to time. We do not claim to represent anything, anyone other than ourselves. We may in your eyes be right or wrong, some of both, more of one than the other, on balance more right or wrong. It is not our intent to tell you what to think, how to think - what to feel or how to feel about our symptoms and us. In fact we collectively urge you read what we write, read what others write, and draw your own opinions. Do not let someone with more initials after their name than you tell you what to think.

Other than the symptoms themselves: absolute truths, scientific certainty, even growing consensus is very difficult to find in the entire field of dementia. Every time we know something new, we discover something more we do not know. Anyone who tells you they know for sure the progression of someone’s dementia, anyone who tells you they have a “gold standard” by which they diagnosis this or that form of dementia; in fact most any generalization about dementia that is applied to one specific human being as being “for sure” a fact is in our opinion “whistling in the dark.”

We all believe the voices of professionals and care partners have multiple means at their exposure to be heard, far more than are available to us. We all believe our feelings, thoughts, experiences, and words are unrepresented in almost all discussions concerning our symptoms and ourselves. We all believe the moral imperative to enable those human beings who are living with life altering disabilities to live full lives up to the moment of their death is frequently ignored when it comes to enabling and re-abling individuals living with the disabilities that come with slipping cognitive abilities and an increasingly dependable memory.

As always all the staff and authors encourage/require readers to think for themselves, to draw their own conclusions – not based on what we wrote but on if you believe it or not, how true it rings with your own life experience. We are not in the business of convincing anyone to think as we do, only to consider our points of view. **You decide.**



Information for Authors

Please submit your articles ASAP. I did not want to make a first issue all my own writings, so I didn't write much, just explained what I hope will happen through the writings of others. I will of course also include some of my own. Start writing; send writings to DNSUSA@gmail.com. The deadline for the next month's issue is usually the 20th of the month, but send it whenever you get it ready. We reserve the right to edit for brevity/clarity your submission but we will always send it back to you for your approval prior to publishing it.

Send us a photo of yourself. We will include it with your article. If you have a couple of other photos that relate to your article include them too, just make sure you have permission from those whose faces and identifiable body parts in the photo give you permission to give us permission to distribute their likeness on the internet.

Remember that by sending it to us you are granting us permission to publish it. Please include this signed permission stating this at the end of your submission.

If you are including material that someone else holds the copyright too, you must get their signed permission to reproduce their material in your own submission, and of course, you must give them credit somewhere in your submission for their own words/ideas. Please send your articles as a word file (word doc). Keep a copy of the file for yourself. We cannot return any of the files we receive. Watch for the next couple of issues to see if your submission appears, if not send it again and we will look at again. We will print most everything everyone submits. However, we reserve the right to edit it for length, clarity, and anything else that might in our own minds make us feel uncomfortable in sending it out. We will of course always ask your permission to change what we want, you are always free to refuse our suggestions and publish your writings yourself or in some other arena. We do not anticipate this will be an issue, but thought in interests of openness we had to bring the subject up.

Want to be on **the editorial board** of this journal? Let me know, there are lots of places open. You must be living with the symptoms of dementia to be directly involved in this undertaking, although we do welcome the support and comments of others who are not living with the symptoms of dementia.

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