

## Welcome

Thank you for coming today. I was trying to think of something funny to start us off but I'm afraid that I failed miserably. I guess that is because there isn't anything funny about the statistics that – at minimum - one out of three of us at 80 years old could be dealing with dementia. At 85, it could be 50% of us. But, hopefully - together we will find a way to lower those statistics. I want to point out that much of what we will discuss may benefit many diseases – whether it be heart, arthritis, autoimmune or dementia. My research has lead me to believe that “the standard American” diet and lifestyle can lead us to many unpleasant diseases...

Another point that I want to make is that I am not a medical doctor and I am not advising you as to what you should do for your own personal situation. My goal is that this group and the information that we discuss together along with your doctor will help guide you to the best solution for you. One important note is that you will know the questions to ask your doctor.

So again – thank you for joining us. I look forward to working together toward a meaningful, productive journey of hope.

You might question how can I aspire to provide light on this subject?

A. The main reason for my aspiration is to get the word out.

1. Even standard medicine is starting to recognize that dementia is, for the most part – a preventable disease. In our meetings we will talk about this and how important it is not to ignore symptoms. As Dr. Perlmutter, a leading neurologist would say, “Why wait until the whole house is on fire when you could have doused it at the stove – where it began?”
2. What has become known as “functional, holistic or integrative medicine” – medicine that runs on the belief that avoiding a disease in the first place is the best medicine – has found not only ways to prevent illness, but to slow, stop and/or reverse many illnesses. Who are these functional medicine doctors? They are regular MD's, neurologists, etc. that almost without exception has had someone in their life that has had a devastating disease that standard medicine couldn't cure – so they did their research, found help and adopted functional medicine.
3. To offer an opportunity to fight dementia and disease together. There is strength in numbers! There is strength in shared ideas! There is strength in people caring about each other and working toward a common goal. We don't have to agree on the methods, just to respect

one another's ideas and share our results - good and bad for a common goal.

B. To share our personal story to help others understand why I believe functional medicine has made a difference.

Here is part of the story that I haven't previously shared:

During those first 7 years I truly believed that Neil's problem was brain damage from his surgery. That was my greatest mistake and one I hope to encourage others to avoid.

In the summer of 2008 we bought a home in Cape Coral and became part-time residents. I noticed immediately that Neil couldn't find places that we had recently visited. That was totally unlike him. But he did learn after a time.... So, I let it pass. He mostly drove around the Cape & had no problem, even learning the way to places in Fort Myers that we visited frequently... OK, he was getting better – wasn't he?

After the first year as part time residents of Florida, Neil announced that if he was going to live in Florida, he wanted a view he could enjoy! (Not a guy in a rocking chair across the canal – staring into our lanai day in and day out.) Long story – short, we found and moved into our dream home.

There were little incidents after that – an acquaintance from our old neighborhood asking him for his new address and Neil not able to provide it. It wasn't until a little over 4 years ago that I began to admit this was a problem that wasn't getting better. We started our journey with a wellness program from Dr. Danial Amen. (You may be familiar with him from his many books and public TV) After about 6 months and still no improvement - just more incidents like after a trip to the bait store, putting away his wallet in the tool box in the garage, and going to the bank to get vacation cash, and before going into the hardware store, hiding the cash under the seat – forgetting where he put it and sending us on another hide and seek expedition. We finally spoke to the doctor and she arranged an appointment at the memory care center.

The day they gave us the diagnosis of Alzheimer's was the worst day of our lives.... They gave no hope and very little direction. They were cold and uncaring... it was just a nightmare!

We went home and cried, called the kids and cried some more. We updated our estate documents – especially our end of life documents and I could feel myself becoming more depressed.

After about a week or so, I kicked myself in the kiester and had a long talk with myself about the problems of allowing myself to wallow in self-pity. From that point I began the journey to see if there was something out there that could be of help.

The next few months were a blur. Neil was diagnosed – needing a pacemaker and in addition to the pacemaker - we tried supplements, coconut oil, increased our exercise... the list goes on. He improved from his first MMSE of 17 out of 30 in early June to a 24 in August at the research center. But we were told that he couldn't be a part of the Research because of the pacemaker.

The problem for me was – we threw so much at it at once, I had no way of knowing what made the difference? There was no way to know.

Time rolled on. My research continued. So many doctors – so many differing opinions. The question always was – “How much of this is real and how much is BS.” Finally, some things began to come together. There was a common thread running throughout. Things like the importance of sleep, the fact that memory loss can come from medications, Lyme disease, etc. I began to read what the Mind, Mood & Memory newsletter from Massachusetts General Hospital wrote about prevention of dementia with positive studies backing it up. (They included diet, exercise, supplements, and brain training). Then there was the focus on supplements to help boost memory, and in further publications they found that exercise, social activity, diet, intellectual engagement & meditation created “super agers” that avoided dementia. The big correlation was in May of 2015 when they reported about a study that improved cognition in Alzheimer's (AD) & Mild Cognitive impaired (MCI) patients & that those improvements were sustained over the initial 3 years. That study followed much of what I had been reading in the functional medicine realm. Even with that, I still wasn't sure. It took another year and a half to finish putting the dots together.

We had been on a low carb, gluten free diet since November of 2013. From that point until December of 2016, I had lost over 25 pounds while Neil gained weight. (the difference between us is that he is pre-diabetic/insulin resistant.) I tried everything imaginable but could not get rid of his tummy. (Which was my major concern because I had learned that visceral fat causes the most damage to the heart and the brain.) In December of 2016 I saw a commercial for the “Fast Metabolism Diet”. Out of desperation, I tried it. Four of the seven days of the diet rotation allowed no oil what so ever. By the end of the first 4 days, Neil was getting lost... could not find his way out of a paper bag! I was amazed.

Finally, I knew that a Ketogenic Diet – one that is high fat, low carb with limited protein was what we needed to do. In July, I found a psychiatrist - specializing in functional medicine to help us with the testing including testing for foods that he might be sensitive to and we are embarking on a new journey. Neil lost the 30 pounds that eluded us for over 3 years and we are now on our way. To be honest, I'm not pleased with the time it has taken to get to some of the blood & body fluid tests. That process is still ongoing. I'll talk more about that as time goes on.

The main thing I caution myself to remember is that this disease has been causing damage for more than 20 years, most likely 30 years. If we can stop or reverse it at all, it will take time. (They say that the damage begins 20 years before the symptoms become apparent.)

One of our greatest accomplishments is when Neil took his driving test last May: –The test is especially formatted for dementia patients. The instructor told us that Neil is the only patient that he has had that passed the driver's test more than once. He was very impressed that Neil passed it 3 times.

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As an aside, following a gluten free, low carb diet has not only allowed me to lose weight and keep it off, my legs no longer swell – unless I get MSG or some other preservative at a restaurant. In addition, a friend of ours that we've known for over 30 years pointed out that I no longer have the Parkinson's type head tremor that I had for many years.

I would like to stress that my goal is to learn with you, to share information, to create a group of friends to enjoy and have some good laughs with, to create an atmosphere of hope but to be there for one another when things get tough.

The following are some points I would like to make:

1. I don't cry myself to sleep at night worrying about what is to be because I HAVE HOPE. And I know that if all else fails, I've done my very best to beat this damn disease. Yes, I've made some mistakes, mistakes I hope to help others avoid.
2. Let's get the word out. Help others to be on top of this problem. Don't wait until it is next to impossible to do something about it.
3. Start asking for healthier food in our restaurants:
  - a. Organic salads and vegetables – at minimum, cover the dirty dozen
  - b. Grass fed, pastured meat, chickens, dairy and eggs
  - c. Wild Alaskan salmon and other wild caught fish. Favor smaller fish – less likely to be full of mercury
4. Look for exercise that fits your physical ability and work up to an aerobic pace. Build up that BDNF! That is Brain Derived Neurotropic factor – meaning brain plasticity or the ability for the brain to grow new cells. Get your exercise everyday! It is one of the most important things you can do for yourself.
5. In future meetings you will hear from doctors that will explain how important mouth and gut health are to your brain health. Just making sure that you do a really good job of brushing your teeth and flossing can make a difference. In addition, avoiding toothpaste and mouth wash that kill good bacteria. You'll learn about leaky gut and how detrimental that is to your health. You'll learn why organic vegetables, pastured meats, dairy and eggs are best. This is not a quick, in and out program. It is a journey. One I hope you will take with us.

I want to mention how much I have appreciated talking to many of you. From these conversations, I know we all have much to learn from you as we share our stories and experiences. And that is what will make this group special. I didn't start this group because I thought I knew it all. Some of you have authors that you have been following and had good success with. Some just have some good, common sense ideas and some, because of family history of dementia have found your own way of dealing with it. I have asked some of you to share a little with the group today. (One gal commented that she was so happy that we are forming this group. She said that she & many of her friends were just waiting for the "grim reaper" to come steal their brain. She felt that even though she had good friends, she couldn't count on them to tell her if she was "losing it". She hoped that this group would be a support in that way.)

\*\*\*\* We showed 25 minutes of Dr. Perlmutter's presentation.

(After break) Welcome back!

**Before I begin, I must reiterate that this group is my idea and is not supported by Shell Point. I do want to thank them for allowing us to use this venue. ~~Our next meeting date is April 19<sup>th</sup>, at 1 PM in this room (TBD – As soon as I have a firm date, I'll email.). If you plan to attend please make a note on your questionnaire before you hand it in today.~~ For those of you that didn't give me an email, if you have a friend that wouldn't mind your notifications through their email – it would be a great help in letting you know about future meetings. I will be sending my initial plan for this group and the results of this meeting to all with an email. In addition, if there are any volunteers to be on a steering committee – please make a note on your questionnaire before you hand it in. I will be in touch to set up a meeting to begin the planning.**

**(small group activity and reporting back)**

Some of the responses from the groups and individual questionnaires:

**They Joined Us Because:** – getting older and looking for ways to deter dementia - To create a partnership with others – an opportunity to come together – to learn together – to have laughter and be positive together – to be a support for one another – for information and resources, coming with an open mind – to learn to advocate for their own health – to meet people with similar problems – to meet others interested in promoting newer and better ideas on all health care – to learn how drugs can promote earlier Alzheimer's - dementia in family and want to avoid it if possible -

They liked the “grass roots” approach

They want Shell Point to be aware of functional, integrative, or holistic medicine.

**They Hope to Get Out of This Group:** More awareness of new research and access to new techniques – finding what other people are doing to help themselves – fellowship and joint learning – Transfer of knowledge from those who have traveled this path before me – Support – Suggestions to manage diet and some practical recipes – Information on probiotics to improve autoimmune system - To Share experiences, what has worked and what hasn't -

**The Main Purpose of the Group:** Support for those wishing to take control of their health. – Sharing ideas with one another – Develop grass root initiative – Guide Shell

Point in terms of our needs – To combine accumulated knowledge in order to help each other. -To learn how the drugs I take might affect my body. – To provide information and emotional support to those that are in the early stages of cognitive decline – To provide same kind of support to those who are caregivers and those that are cognitively impaired. – To learn and share information – Friendship as we all share experiences – To let Shell Point know residents are deeply concerned as patients and caregivers and we want them to stay active learning new treatments. – Present a unified voice for presenting recommendations and request to Shell Point leadership – A positive group accomplishing positive goals – To raise awareness, make people healthier –

**(To close the meeting):**

First, I want to thank Riv Swartz, Joy Ellyn Ryan and Kathy & Pete Fischbach for all they have done to help make this happen. A big Thank you to our grandkids, Jason & Kim for making the trip from Chicagoland to be a support.

I hope that you feel, as I do that this group is essential and you will want to be part of its success. I am only one person and I need the help of many to make this a reality. If there are many, it will make it much easier to put the programming together and communicate with the group. I understand that many are not able to help, but if you can do anything at all – it would be appreciated – even just handing out things at meetings... To start with, as many of you now realize, I need a secretary/editor!!! I could also use someone to help with contact lists, etc. Most important, we need a steering group to decide on programming.

We noticed that this month's Shell Point Life has a number of things that would benefit brain health. We hope you will sign up for those things that you feel would be of benefit.

Joy Ellyn Ryan shared her copy of *The Healing Self* by Dr. Rudolf Tanzi. Although I haven't had time to do an in depth read, my initial take away was how timely the book is to our group. How important is it to reiterate how stress causes disease! How important is it to reiterate how love, community, optimism, and hope can help us heal and be healthy. In my mind, that is what this group should focus on. We'll work on all the methods that may help, but we should keep the love, community, optimism and hope in the forefront.

Many thanks to all of you for coming!