

Dear Shell Point Neighbors,

With my husband Neil's Permission, I am writing this letter to share his story and invite you to join us in our endeavor to stop or at least slow dementias. (I'm NOT asking for money!) Alzheimer's/dementia may affect anyone of us indiscriminately. Through extensive research, course work, consultations and our own experiences, I believe that I have found methods to help. It is my hope and dream to share this information and with your help, to test its validity. In addition, I hope to learn from you and any experiences you have to offer!

Background:

Neil & I started this journey in February 2007 when he had surgery for prostate cancer. He was 59 years old. Immediately after surgery he had dementia symptoms, but we thought it would improve in time. Unfortunately, that didn't happen. These symptoms worsened and became more obvious until he was finally diagnosed with Alzheimer's in June 2014. Unfortunately, (or fortunately – whichever way we wish to look at it) that same month he needed a pacemaker which eliminated him from any research trials. This set us on a search for other methods to slow, stop and/or reverse this disease. I have spent the better part of the past 4 years researching Alzheimer's and other related diseases.

Through books, research studies, university publications and yes, the internet, I have no doubt that we have slowed the progression and still have hope we can at least stop it from progressing further. Our dream is to find individuals that are just embarking on this journey to find out if our research will make the difference for them. I believe that we have found what is needed and, depending on the progression of the disease, it is possible to reverse Alzheimer's disease and other dementias.

Are we personally going to lose this battle? Probably, but that doesn't mean that others have to follow in that direction. If we would have had this information four years ago, this could be a different story. We are just now finishing all the tests that should have been done long ago. For instance, I was sure that the surgery caused the dementia, but 6 months ago we both did a "23andMe" test. The test showed that Neil inherited the Alzheimer's gene from both of his parents – 2 copies of this gene! The surgery most likely caused an earlier arrival of the disease. Another test showed that certain foods cause inflammation, contributing to the disease.

What things help to fight Alzheimer's and other dementias? The list is long, but to give you an idea: gut health, diet, exercise, meditation, good sleep, the right food and supplements that are different for each individual.

The following are the reasons I have written this letter:

1. To ask you to be aware of those with dementia. Please do your best to engage these individuals in conversation. They may not initiate a conversation, but generally will have something to add. It is important that they don't feel left out.
2. To start a group with individuals who are concerned that they or their loved ones may be beginning to lose their memory and those that are already diagnosed. If you are just interested in the conversation, you are welcome. This group will be for the caregiver, for the patient or any individual. For the most part, we will do everything as a group.

- a. An initial meeting would just be fact finding for each of us to determine if this would be of interest and might help them personally. The meeting will include a video of either Dr. Perlmutter or Dr. Bredesen.
 - b. If it goes to a second meeting, as a group we would put together a structure and include another video.
3. Please understand that there is no group that I have been able to find that meets this need. Shell Point has groups, but they do not meet this need. My vision is a group of people that “work for the best outcome” while they plan for the worst -which is why many of us are at Shell Point. We may not agree on the methods that we will use to work for the best, but by sharing our information we will have a better idea of what seems to be the best course of action. For instance, some may be in drug trials while others are interested in what diet, etc. can do for them. We can each take on an area of research or just an item like homocysteine to understand how that can affect our health. These research projects can be meeting topics. **One main thing I have come to understand is that we must be our own advocates and knowledge is power.**
4. To suggest that this group might be a spin off on the “Carefree” group, with a bit of a different twist. The name for our group could be “New Hope”.

If you are interested in this group or you just want to talk, please call, text or email. If I'm not available, I'll get back to you as quickly as I can.

The first meeting will be on Friday, April 6th, 2:30 PM.

Location: Social Center on the Island. Please RSVP by March 28th. The Social Center has limited space.

Thank you for your time. We sincerely appreciate it.

Joan Koebernick

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This project is a personal endeavor of Neil & Joan Koebernick. If you're wondering who Joan Koebernick is and why you might care about what she has to say...

I am just a woman who has lived this and has decided not to take standard medicines word that there is no way to slow or stop this disease. There are many well regarded doctors and researchers that are proving that there is hope.