

Introducing....The Memory Loss Compass Rose

Towards a New Identity, Hope, and Strength Post-Diagnosis

Chapter 2 of My Journey from Disease into Advocacy

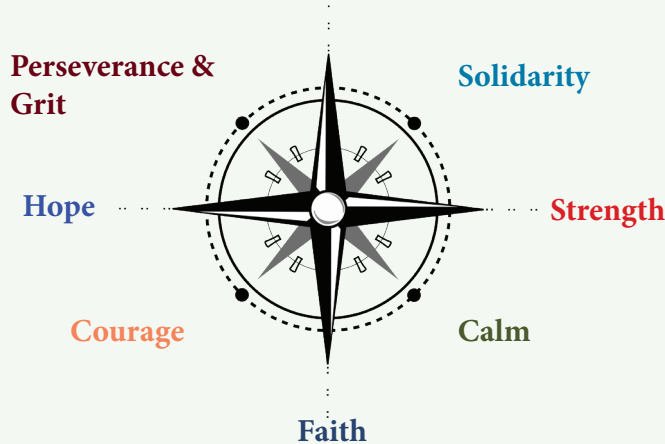


Hello Friends! My name is Kevin Kvarda and you can call me “K-Squared.” I have Younger Onset Alzheimer’s Dementia, and PPA (Primary Progressive Aphasia). In the months before I got my diagnosis in 2019, I was in agony. I had to pick: 1) FIGHT or 2) FLIGHT with these diseases. I CHOSE to FIGHT and became a Strong Advocate for the CURE for these diseases, and being an Alzheimer’s Association board member helps me with my mission. Overall, I am doing very well currently, and because of that, I want to help others and give back in any way I can. I know that someday I might not be able to do this anymore, but until that day, I will keep going STRONG. One day at a time! I want to share about what has helped me in my journey to stay strong and grow after my diagnosis and give encouragement to others.

In last year’s Spring 2020 issue of Dimensions and the MBWC website, I [introduced my creation called PRISM](#). This sculpture communicates my wishes to increase strength and hope of patients and all people in the dementia community. But, PRISM was just the beginning. I’m still here! I want to expand the potential of the PRISM.

When the pandemic stopped in-person activities and support groups, I began to think about encouraging messages for people living with a diagnosis like mine. This developed into the idea of a compass and kept growing... into a gift that can help guide you to your True North— your source of well-being, meaning, and identity building. Introducing the Memory Loss Compass Rose!

"What is Your True North?"



Journey Key

SOLIDARITY People that have Memory Loss NEED others on their side! (Family, Friends, Caregivers, Doctors). When we are connected to others, it is easier to see a path forward. Being connected with others gives you an opportunity to give yourself to others as well as receive friendship.

HOPE What would the world be without Hope? Sometimes, I don't see hope, and later something ALWAYS comes to me or my family. When I feel like there's no hope, I PAUSE what I was doing, and then go to do something else and after that come back to complete.

COURAGE is a blend of solidarity and hope. I believe that everyone has courage in them, BUT without other's support life can be challenging. As we go every day with our Memory Loss, we need USE our tools, such as Solidarity, Hope, family, friends, etc. I believe it is CRUCIAL. Tip: Try to find new friends who know about your Memory Loss and maybe others that don't. Finding new friends will make you more courageous. You WANT to have others on your side who can help with being Courageous.

FAITH I believe that Faith is done by work with Courage, Hope, and Solidarity. I believe that Faith is something that YOU should “Opt IN”. No one can dictate your Faith...it's personal and wonderful.

STRENGTH What was a moment when you had STRENGTH in your life? For me, it was back when I was a pilot, when I was flying solo or with a student. What was a moment when you didn't have STRENGTH in your life? For me, my wife Norma is strong, so most of the time, I deferred things that I should have been doing to her. What will you do in the future to make you STRONG?

PERSEVERANCE & GRIT Persistence in doing something despite difficulty or delay in achieving success.

CALM "A calm mind brings inner strength and self-confidence, so that's very important for good health." - Dalai Lama

The Memory Loss Compass Rose Comes To Life

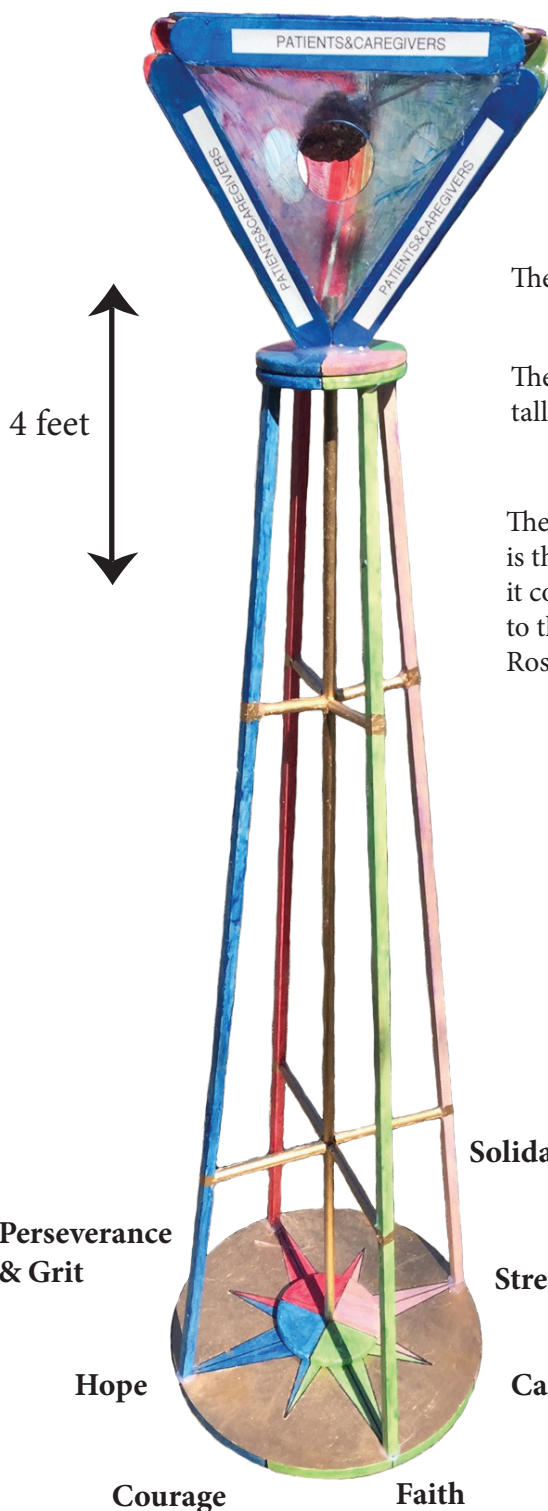


The Memory Loss Compass Rose

The Memory Loss Compass Rose is a GIFT that can guide you toward your new 'True North'. It can help you navigate your journey after a diagnosis, and to embrace change.

Here's how it works:

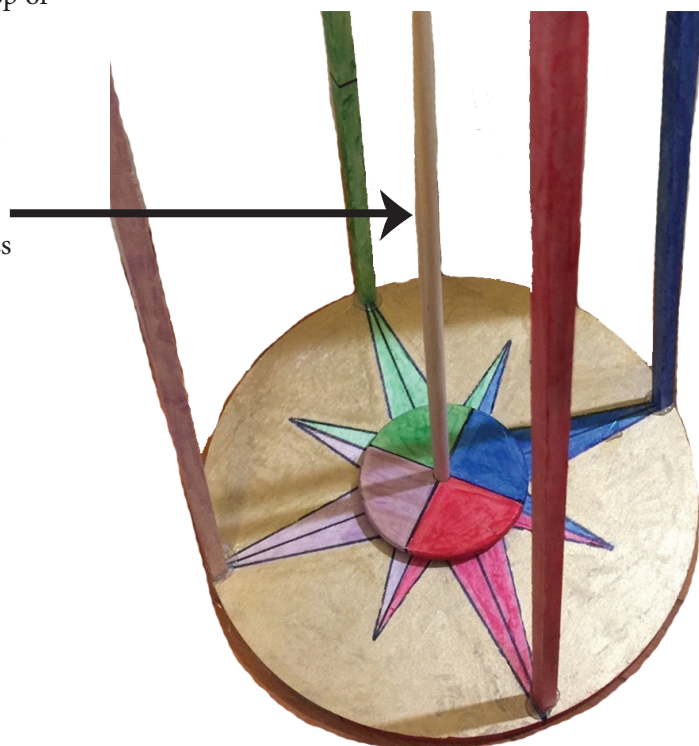
A person can turn the PRISM because it sits on a rotating platform, or a "flange." Learn about the story behind PRISM from my 2020 article: www.depts.washington.edu/mbwc/news/article/journey-from-disease-into-advocacy. Anyone who needs encouragement can use this Memory Loss Compass Rose, including patients, caregivers, researchers, doctors, and staff of support associations.



The gold ball inside the PRISM represents humanity.

The PRISM rests on top of tall wooden legs.

The pole in the middle is the "gold fueler" and it connects humanity to the 8-point Compass Rose.

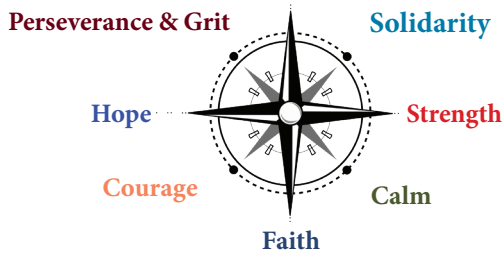


When a user rotates the PRISM above, they will land on different points on the Compass Rose. It is like a matrix of options. The person can explore how these concepts may apply to their journey with memory loss or a challenge. Is there a special recipe (e.g. Courage + Solidarity) that helps define your true North?

Read on for examples of the knowledge you can discover for yourself.

Lessons from The Memory Loss Compass Rose + Worksheet →

What is Your True North?



HOW CAN THE MEMORY LOSS COMPASS ROSE GUIDE YOU? A WORKSHEET

BY KEVIN KVARDA



Leverage your helpers! (Solidarity, Courage, Strength) Take advantage of help that family and friends can offer. For me, word finding, writing, math, lack of comprehension with NEW concepts, etc, take a long time.

Do you like to do things by yourself? Why? _____

Do you like to have others help you? Why? _____

Find and use your higher power to gain strength and knowledge and guide your Mission Statement

(Solidarity, Hope, Courage, Faith, Strength) For example, my higher power is God. My mission statement is “As a STRONG advocate for the cure for Alzheimer’s Dementia, Primary Progressive Aphasia, etc. I co-create a world where all these diseases are gone by 2025. How: By working with Doctors, SLP’s, others who have these diseases, local agencies (UW MBWC, Alzheimer’s Association, etc.), Washington State Capitol, Washington D.C.”

What is your higher power? _____

Do you have a Mission Statement? _____

Embrace change (Solidarity, Hope, Faith, Strength, Calm, Perseverance & Grit) We are “different” now. This is a good thing! This is a “new me”. Many things are still intact, and I have gained many new friends through my disability and diagnosis. Embracing change IS difficult sometimes. For example, I am not adept with multi-tasking anymore. Conversations with multiple people and loud animals are very challenging most of the time. But I find that I have great stamina with projects, chores, and some days are more normal. Embracing change relies on trust of your self, family, friends, caregivers.

What is your Vision for your self? _____

What Actions can you take to achieve your Vision? _____

Support groups are GOLD (Solidarity, Hope, Courage, Faith, Strength, Calm, Perseverance & Grit) After I got my diagnosis, I wanted to find as many support groups as I could find. It was so EASY to find them, especially here in the Seattle/Eastside/Snohomish areas. My Memory Loss support groups are also my new “rock”. We talk about almost anything, and through each meeting we all get ‘lifted up’ in different ways. It’s like a wonderful ‘surrogate family’.

What do you need or want to get out of a support group? _____

Compassion (Solidarity, Hope, Courage, Strength, Calm) To recognize the suffering of others and then take action to help. Since my disability, my family (Norma, Riley, Andrew, Quinlan, and Jordan) gives me compassion every day in different ways. Marigrace Becker, Program Manager at UW MBWC gives compassion to EVERYONE, EVERY time she leads meetings!

Have you ever received compassion? How did it feel after? _____

Have you ever given compassion to others? How did it feel after? _____

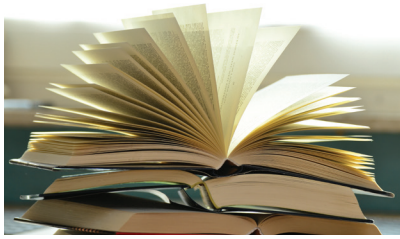
Giving back (Solidarity, Hope, Faith, Calm) I want to help...one day in the future, I believe that the cure will be found, and I hope I made a dent in the cure in my lifetime. Educate yourself and your caregivers, go to events or Zoom meetings, ask “Hi, can I help?”

What can I do to help, now with my disability? _____

More Resources >>>

Further Reading & Resources

Kevin's Library



Books in progress:

[Mindfulness](#) by Ellen J. Langer

[Memory Boosting Puzzles](#) by Charles Timmerman

[Us Against Alzheimer's: Stories of Family, Love, and Faith](#) by Marita Golden

[A Daybook of Grace: A Year of Devotions to Draw You Near to the Heart of God](#) by Mark Gilroy and Paul Shepherd

[A Promised Land](#) by Barack Obama

[The Moment of Lift: How Empowering Women Changes the World](#) by Melinda French Gates

[Keep Sharp: Build a Better Brain at Any Age](#) by Sanjay Gupta

Kindle books in progress:

[Identity Theft: Rediscovering Ourselves After Stroke](#) by Debra Meyerson and Danny Zuckerman

[Beating the Dementia Monster: How I stopped the advance of cognitive impairment from Alzheimer's disease](#) by David H. Brown with Vaishali Phatak

[Grit: The Power of Passion and Perseverance](#) by Angela Duckworth

Examples of Advocacy in 2020-2021!

- I engaged with our local memory loss community through [virtual Zoom meetings hosted by the UW MBWC](#). The “Virtual Coffee Chats” provide a chance to connect with others in an informal, supportive environment. I led group discussions about the themes included in the Memory Loss Compass Rose.
- I attended a Dementia Action Collaborative meeting. The group meets twice a year, to drive the State Alzheimer's Plan in Washington, as organized by state legislative directive in 2014. I was invited to the meeting by the Alzheimer's Association to represent the perspective of a person living with Alzheimer's disease, as a community stakeholder.
- I participated in the 2021 Alzheimer's Association's virtual [Advocacy Day](#), to represent District 44 (Snohomish). I asked Rep. John Lovick to support \$1.9 million for Dementia Resource Catalyst programs in WA State. These would will improve access to home-based services for people affected by dementia. I also advocated for congress to protect \$1.3 million to continue the work of the [Dementia Action Collaborative \(DAC\)](#). The day brought in 71 participants with a total of 50 meetings. We were the first chapter in the nation to host our advocacy day and have been able to offer tips and advice for other chapters.

The House and Senate released their proposed budgets near the end of March. Here is how our top priorities fared:

- > Dementia Action Collaborative staff and programs: FUNDED in both budgets
- > Specialty dementia care Medicaid rate increase: FUNDED in both budgets; funded at a higher rate in the Senate than the House.
- > Dementia Resource Catalysts: FULLY FUNDED in the Senate at the \$1.914M requested level; PARTIALLY FUNDED in the House.

ACKNOWLEDGMENTS - 2021

- My family of 5, my mother, father, brother, and many relatives in different states.
- Marigrace Becker, Dr. Kimiko Domoto-Reilly, Genevieve Wanucha, Brad Rolf, and James DeLappe (UW Medicine)
- Leslie Kot (UW Speech & Hearing Sciences) and Graduate Student Clinicians: Nicole Campbell, Sarah Harrison, Clarke E. Smith, Ping Lau, Savannah Bailey, Ivy Hoekman, Samantha Bartolo
- Hazel Borden, Katya Strohl, and Peter Newbould (Alzheimer's Association WA State Chapter).
- My 3 spiritual men's groups.

LEARN MORE

- Contact Kevin Kvarda: kevin.kvarda@gmail.com
- Read 5-part article, [Wicked Diseases, Advocacy, and Gifts, Oh My!](#) from Dimensions Spring 2020 by Kevin Kvarda
- Linked In Profile: <https://www.linkedin.com/in/kevinkvarda/>
- Facebook: <https://www.facebook.com/kevin.kvarda>
- Watch Kevin Kvarda's presentation at the MBWC Primary Progressive Aphasia Education Day, on the MBWC video channel here: <https://youtu.be/P-uTsrrx-i0>.
- ['Where is My Identity?'](#) Powerpoint by Kevin Kvarda