

How does our central nervous system (CNS) do it?

Well, to be honest, this article took on a whole new face in light of the pandemic that has swept across the globe. My initial plan was to talk about the parts of the brain that are responsible for the autonomic and automatic functions of the human body. The article was written to highlight the role of later states of dementia, dementia plus an acute episode of illness, and dementia plus an acute episode of illness on top of a chronic health condition, and how each related to the person's ability to live well or even survive as more and more brain wiring and functions are compromised.

Little did I realize when I started the article at the beginning of the month, how very real and overwhelming it would be to consider how we will support our frail **Pearl** and **Ruby** state friends, family members, and clients through this enormous firestorm of challenges, until they can complete their journey and finally be at rest. Or how we would need to be immensely and intensely creative to support and serve our **Amber** and **Emerald** state loved ones by changing almost everything in their world and ours. Nor did I begin to imagine the extreme difficulties of trying to provide virtually or remotely what had been given on a daily basis in person and intimately for our **Diamond** and **Sapphire** colleagues, partners, friends, and family.

Suddenly the term **social distancing** became a term for survival. Public space, beyond six feet between us with no shared surfaces or shared airspace, has been deemed the only way we should consider interacting in order to try to keep this virus from spreading among us. The *biggest* and *most underreported* high-risk populations for severe symptoms and mortality are:

- People living with mid to later state dementias
- Their committed and 24-7 care providers in homes, communities, centers, and residential care facilities
- The environmental maintenance providers in the setting where care and living occurs
- The food provision preparers and providers in these situations
- The laundry service providers for all of these situations

Now, I am going to be what I have always been, honest and truthful. I will say what both my scientific knowledge and awareness tells me, as well as, what my heart and spirit demands be shared.

- The **people living in the *Ruby or Pearl* states** of abilities and changes are at such a high risk due in large part to their internal brain and body changes related to advancing dementia. The probability of compromised immune systems and other chronic health issues is also really high. Their frequent inability to produce a high fever, along with limits in taking in nourishment and hydration, combined with limited oxygenation abilities, decreasing skills in organizing and using suck-swallow-breathe coordination, and effective coughing to clear airways, are all problematic. Their chances of surviving the interventions that are being used to try to combat this virus are mostly slim to none. I truly believe one of the most important tasks we have in front of us is reviewing their preferences and desires about extreme measures to prolong their lives and creating safeguards to ensure that they will receive *comfort and palliative care* at the onset of symptoms of COVID-19, rather than heroic measures that are in all probability doomed to fail miserably and painfully, until their time on this earth is completed. It seems to me that to re-house a person into a traumatic care situation, who is at this point in the journey would serve no positive purpose. In this case, sheltering in place will involve the voluntary isolation of all who are part of this care team, for the duration of the care and for at least 14 days afterward. It will also involve rigorous attention to risk reduction strategies with a clear appreciation, that there is no safe distance in this world of care. Interactions and space will be both personal and intimate. What people at my talks and programs often refer to as the ***splash zone***. Personal protective gear, being in short supply or absent at a professional industry-produced mode, will force care providers to create options with the best alternatives we can find. We will be sharing what we are finding out about from those on the front lines and those with experience in reducing the spread of viral conditions.
- The **people living in the *Amber and Emerald* states** will have abilities, interests, and changes in ability that place them in a higher risk category than their peers without dementia. This will create many challenges and difficulties for them, their house or lodging mates, and those providing support and care. Due to the common symptoms that involve movement patterns, activity preferences, space and engagement habits and routines, and an inability to practice social distancing or perform intimate or personal tasks and actions without guidance or support from within the ***splash zone***. As a matter of fact, this is the population at higher risk for expanding the typical ***splash zone*** to greater distances and in more unexpected or surprising ways. It will take innovative and creative partners and care providers to manage both the person's risk, their own risk, and the risk for others in the immediate and surrounding spaces and places. For people in these states, who are strong connectors or controllers, restrictions on movement, activity, or interactions could well trigger an intense need for exactly what is

being denied them as part of their primitive brain's belief that they can only survive if they can do what they believe needs to be done, when it needs to be done. There is not a logic model that will solve this challenge. It will take truly **Sapphire** team members who are getting enough rest, restoration, moments of joy, social connections that they need, and belief that what they are doing has intense value and purpose. One added element is that these providers must have an assurance that while they provide this vital service, those in other parts of their life and world are safe, well cared for, and comforted in their absence. Despite all of this hard work, it is truly probable that a large number of these individuals will also develop significant symptoms and will have a higher mortality rate. So, preparing for the possibility of making hard decisions and choices regarding comfort and supportive care versus attempts at curing COVID-19 for this group will also be a major concern to begin to address, before rather than in a time of personal crisis.

- The **people living in the *Diamond* state** will be at a slightly higher risk than their peers with the same health and risk factors. The reason being challenges with habit change and the ability to consistently use new safety patterns and protocols. Also consider some of the specific heightened risk elements of; lack of sleep, heightened anxiety, distress, inactivity, changing environmental and social expectations and experiences. Combined with loss of the familiar and the routine the risk climbs even more. This is where our responses, new habits, and supportive communication skills can help to level the playing field and diminish the impact of dementia on these individuals. We will want to brush up on how to connect. We will need to determine current awareness and wants or needs, before we introduce any agenda items. How we start or respond to questions makes a tremendous difference. Knowing how to determine state of mind regarding discomfort, alertness, distress, focus, and beliefs will provide the foundation for a more effective interaction, even at a distance. The art of using reflection, validation, and empathy will be critical for success. The ability to identify and provide possible options when the preferred ones are not allowed for now, will make all the difference in the day and the person's risk state. There is of course, no guarantee that these people will come through unscathed.
- The **people living in the *Sapphire* state** on a regular basis may well find themselves moving rapidly from one GEMS state to another as emergencies, surprises, losses, and challenges continue to emerge. The greatest risk is becoming emotionally isolated, spiritually despairing, socially disconnected, and overwhelmed. If any of us are experiencing these symptoms or conditions, please connect with us on line, on our social platforms, or through our free sessions in our chat space. We are a community filled with people who will help, not hide, from what you are feeling or not feeling, thinking or not thinking, but rather will do our utmost to use whatever abilities we have in that moment to offer support, comfort, and care.

Just as with dementia, we know that until there is a cure, there is care. We will continue to care in all the possible ways we can.

From here to eternity – we will try our best.