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Changing a Culture of Care

It Takes Movement!

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When it comes to dementia, there is a long-standing culture of mis-information, misunderstanding, fear, and stigma.

There is a developing counter-culture led by people living with dementia in early states of changed ability and their friends and families. These are people who are standing up and asking that the existing culture become more aware, that their continued abilities, their still present capacities, and their rights to be self-determining be recognized, unless or until it is proved otherwise.

Then there is my vision of dementia care culture. It is essentially why I started Positive Approach® to Care (PAC). I believe that any boundary between people not having dementia and people who are living with dementia is artificial. Therefore, I advocate for an inclusive culture, where the ability to provide support and care are universal and expected. Rather than isolating and labeling those who have observable symptoms, culling them from the group and labeling them as less, I would like us to develop our own abilities to provide the support we are able and help the person and others find support in other ways when we are not able.

The fact is, we are not actually aware of dementia in ourselves or others until the symptoms manifest, become apparent. A genetic code or laboratory test is not an accurate predictor of ability to function in that moment, or even that year. Even after the symptoms are apparent to some people, they are still hidden from others. For some individuals living with dementia, an ability to notice internal shifts in ability is not possible due to damage in areas of the pre-frontal cortex that guide that skill. They have a condition called anosognosia. For other people, the changes are not apparent because of frequency, duration, or intensity of contacts with the involved individual. Social encounters can be brief and shallow, allowing the more subtle shifts to be missed, or perhaps the person is actually still skilled in those areas of interaction compared to more in-depth intimate friend or family relationships. Daily contact can also blunt the impact of changes as the brain of the partner can habituate to the degree of change, if it occurs slowly over time. Episodic exposure, however, can highlight the changes over time, as your abilities are very different than the last time I was with you.

In PAC, we seek not to label or categorize people for their losses, but rather attempt to understand what the person is trying to share, do, or communicate. We use our appreciation of [GEMS States](#) to guide us in interpretation. We believe the person is using the abilities that they are able to use in that moment. Abilities may be visual, verbal, or sensorimotor in nature. If we are challenged by what is being communicated or how communication or interaction is happening, we work to pause for a moment. At that point our first task is to look at ourselves. Is it the state of our own brains and abilities that is creating some of the mis-communication or challenging situation? Could it be our own

abilities, perspectives, and weakness that are different than usual? After the pause for assessment and self-reflection we attempt to objectively assess the situation and the person's present state of function and distress, to collaboratively determine the next steps forward.

The purpose of the GEMS State model is not to stick a label on someone, but rather to highlight for ourselves and others what abilities are prominent at this moment, what support is helpful, what cues, environmental modifications, and task revisions might make an interaction or activity more beneficial or less harmful.

How do we change a culture? It starts with noticing something. Once you notice that something, developing a willingness to see things differently, to become curious about what you think you know, and why you believe or think what you do, is critical. Then, developing a theory about what might help and testing it out. Finally comes that hardest part for some, and yet the most rewarding for many, make the change – do something different, change. Get the change firmly embedded into daily routines and practices.

At PAC we are on the move, we are changing perspectives, attitudes, skills, and routines around the world. As those who are a part of the current culture shift to something new, early adopters lead. Through the active use of PAC related language, skills, and practices others start to notice. Over time, shifts occur. Large blocks to progress begin to crumble under mounting pressure combined with the flow around them. Being part of the change begins to be more appealing than standing in the way of the change.

Transitions are never easy or smooth. Going from stillness to action is a process. Likewise going from action to stillness is similar but different. Culture change involves a combination of movement to something better or different while sustaining what is currently being done, until there is enough support to move the system forward with control.

I personally believe dementia care will become one of the most important human rights stories of the 21st century. I believe our medical systems, legal systems, legislative systems, and even our social systems have not yet recognized the impact dementia and other brain changing conditions are having, and will continue to have on our lives, our economies, and our way of living.

Until those systems are ready for change and movement, I as an individual and PAC as an organization, will keep up the movement to help those who are able to face the challenges and opportunities that happen when someone is living with brain changes by helping them:

- become more aware
- gain more knowledge
- develop more skills
- demonstrate more confidence and competence

Our purpose and goal is to foster interaction that promotes a better appreciation and understanding of:

- What each person is experiencing, their perspective
- What is really happening for each person involved, from an observer's point of view

- Why these things might be happening for each individual, as well as for the combination of people in that environment, at that time, in that situation
- How that relates to a bigger picture, the past, other areas of life and situations
- What can be done to promote a more optimal interaction, situation, or outcome for all involved

With PAC, it is vital to work with individuals living with dementia and without dementia throughout the spectrum of abilities. If you are ready for change, come and join us in the work we are doing. Start by [reaching out and connecting](#), online or in person, both work.