Dementia, Wholeness and The Power of Patients

Dementia incidence increases with age. Can you imagine what it would be like to forget not only your passwords but how to turn the key in a lock or how to turn your computer on. You repeat things and not just old jokes but the same questions and they never feel answered. Would this make you sad and afraid? The society we live in is harsh for those with dementia, medicines are temporary and although some interventions can help nothing stops the onslaught of neurodegeneration. Much of communication is non verbal and instinctively those with dementia sense they no longer fit. What if we could change this by changing not those with dementia but instead the society around them. Dr. Jadad shares in this thought provoking video how we could make the world work and make life a kinder place. Let us stop taking away patients person-hood by making illness their identity and let us value them so they can celebrate life. All people have value. Dignity, respect and inclusion are gifts we can offer regardless of where life takes us. The first Alzheimer’s group I worked with along with colleagues at Sparks of Genius opened my eyes to how much can be done to restore identity, quality of life and initiate healing. Our group was classified as high functioning and indeed they were in the past, we had former heads of multi-national corporations, advisors to past president, diplomats, and former CIA. They were all later stage alzheimer patients looking at us hopefully quite aware of their limitations but still with the undeniable need to be loved and belong. When an individual is brain challenged there is a part of the brain (hippocampus/amygdala) that is extremely vulnerable when they are hurt or marginalized. They don’t fight back for a long time if at all because they are paralysed with self doubt and shame. The brain plays negative
events over and over while the brain tries to connect the dots. This stress leads to an inflammation spiral that produces greater cognitive losses. I couldn’t do that to them so I moved forward to accept them and they me. I wanted to run or hide behind a lack of qualifications or diagnostic fatalism but their eyes and vulnerability drew me in. They knew about stem cells, gene therapy and international policy but could not spell their names, draw a clock or find their way back from the bathroom alone. Together we found ways to communicate, conquer fear or anger and learn. I gave them my mind and they gave me their trust and experience. Together we grew and I understood the strength of the human spirit and how brain potential can be tapped. They learned to work as a group to protect each other with collective memory and without blame. Their ability to communicate and function improved. We used art, computers, music, books, dance and diaries to help them learn to re-love themselves and connect with their families. We gave family workshops. I did power point presentations on the illness until they understood it for themselves and could walk away with hope. When faced with dementia in others remember they are still the same person on the inside and love acceptance and caring brings healing and quality of life. You may not be able to change their life but it might be within your grasp to make their day good