

Lessons Learned from a Pearl Expert

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In 2012, I began postgraduate studies in gerontology at Medical University and was introduced to a term, Geriatric Giants. One of those was Alzheimers disease. It is hard to admit, but looking from time perspective, I have to say that I gained no valuable knowledge about it at classes at all. After graduation, I signed up as a volunteer in a nursing home to get to know more about this phenomenon. I was assigned to a group of people diagnosed with Alzheimers. That was a quite new initiative in that facility; its main background was to handle issues occurring at meal times more effectively.

The management decided to separate residents with Alzheimers diagnosis and create a dedicated space for them. “Are you going to the kindergarten?” I was asked the first day by one of the staff members, on my way up to the day room. “Oops” I thought. I entered the room, said “Good morning” and the residents replied “Good morning”. “Can I join you”? “Yes, you can, have a seat” answered a nice old lady sitting on the right. She and the other five people were busy doing some stuff, painting I guess. They were not engaged, they did stuff. Soon, lunch began and the symptoms were more visible – they got pierogis with meat (kind of tortellini, but bigger, to make you more familiar with some Polish food). One lady ate with her hands, taking the filling out and eating the dough only. Another lady ate quickly and looked like a hamster. But the lady on the right was fine. “Not so bad” I thought. And she got up and nicely said: “Thank you all for your company and lunch, but I must go home, before my husband returns from work. And dinner has to be ready when my sons are back from school”. She headed towards the exit. “Don’t let her out” the therapist said to me, but it was too late. She left. This is how I learned that this very nice elderly lady’s husband died years ago and her sons were 50+. I had no idea that I had a pleasure to meet and great an Emerald. I should’ve been somehow prepared for what I saw – I had a diploma in gerontology after all. But I wasn’t.

Whenever they teach you about dementia, they say: be patient and be empathetic. And remember that they don’t remember and often are aggressive. That knowledge is far too little and does not prepare you for the real life experience at all. I am lucky to have the Pearl expert (70) living with Lewy Body Dementia. We met 18 months ago, now it is his sixth year with diagnosis (four years with Alzheimers, and two with LBD – the Alzheimers diagnosis was changed to LBD). He is unable to move and his arms are heavy as iron. But once you approach him with Hand-under-Hand, it is magic! We can open boxes, cut things, put something in or take it out, we can screw and drill, and we can plug in headphones when we listen to music. His arms do work, slowly, but they do, his face tells me “not too high” or “not too fast”. The only moment of the week when he can stay aware for sixty minutes is during our sessions, his wife says. I hope you had a chance to see a Pearl smiling – a tiny little motion around his mouth and a sparkle in his eyes. It is a true breathtaking award. I am the only person who receives a spontaneous

goodbye gesture from him. This is not because of me having a diploma in gerontology nor me being patient and empathetic, this is because I've been trained in dementia care and I have the skills. That is PAC bridging the gap in my theoretical and practical dementia education.

Engagement is more than filling people's lives with meaningful activities. Three weeks ago, as always, on Monday 11:00 am, I came to my Pearl expert. We started out our workout and twenty minutes later his eyes went upside down, he went pale and his body went soft, he stopped breathing. Next fifteen mins were like a film. I remember a sentence his wife said when we were fighting to save his life "I can't stand this anymore". By the time the ambulance arrived, he was fine. "Is he always like that?" the ER team asked (meaning him being so rigid). My Pearl expert was taken to the hospital. In the ER, waiting for the doctor to tell us how things are, his wife said: "I am not ready for death yet, I'll never be." They safely got home in the evening. We met again on Wednesday and she said "You know, I still have this fear inside. It is new to me." We've assessed what happened and it could be, that even though he doesn't have problems with swallowing food and drink, he doesn't swallow saliva when he speaks. And he often speaks when we work. During that process there is an excessive saliva production, I can see it leaking out of his mouth. He had spoken before it happened. But we think there was also another factor. During our workouts when we listen to the music, we never do anything else, his hands are not active. When his hands work - the music and TV is off - and it is only me telling him what we do and what we touch. This time however, we turned the music on – a top song of the 70s, very meaningful to Polish history. We've figured out, that he probably choked with his own saliva as his brain was over stimulated.

I learned a lot from this experience. I realized, that although I am prepared to work with people living with dementia (PLWD) and train other professionals, I am not trained in physically saving people's lives in an emergency. The question is "Should I be?" Let's leave it open for discussion.

There is one more thing I'd like to share. Once I was told a story about a staff member trying to use Positive Physical Approach™ (PPA). She wanted to approach a resident with Alzheimers diagnosis, when he asked her "Why are you doing this thing with your hand?" And she instantly gave up. What in fact happened, was not a failure in using the technique, it was an unexpected information, that this man was not as impaired as much as he was labelled with. Thinking differently is a proficient skill. And that is why we need PAC. Our residents are ready for it. We – the professionals – need to learn more.

How to bridge this gap in dementia education? Life became a cycle: in 2012 I was a student at the Medical University in northern Poland poorly taught about dementia. In 2013 I learned about "Positive Approach to Care" which completely changed my perspective, and in 2015 – became a PAC Independent Trainer. In October 2017, I will be teaching speech language pathologists about PPA, HuH and GEMS (and hopefully, as PAC Engagement Leader - how to connect Six Pieces of the Puzzle) at the Medical University in southern Poland. I am convinced that this time students will leave classes with a totally different set of skills to those which were my – not extensive at all - experience after graduation. PAC not only gave me tools to equip people with new knowledge and skills, it gave me tools to change the way people think about dementia.

Believe it or not, sometimes I think that not having PAC in Poland on a global scale yet, is actually a good thing. It gives the advantage to do it in the proper way right from the very beginning!