

Caregiving in a Changing World

Even in this vastly changing world, some things remain the same. I was reminded of this as I was speaking to a woman recently who is caring for her spouse. Her husband has been diagnosed with dementia and her frustration in trying to find the right thing to say and do was wearing on her. That's not unusual for anyone who has been in that circumstance. As our conversation progressed she shared she's been caregiving for some time, and the outlets that used to serve her as an occasional break from her caregiver role were no longer available, causing her frustration level to grow. Again, all makes sense.

As our conversation progressed I had an aha moment. This conversation brought me into my own reality of this new covid world...working remotely from home, can't hug my grandkids, can't worship in-person with my faith congregation but rather having to stream my Sunday worship. All of those things are very real, and VERY frustrating. And because those thoughts are top of mind for me, regardless of who I'm speaking with and where I happen to be, I was prepared to hear a caregiver tell me how this virus has negatively impacted her already difficult world. And yes, there was some of that.

But my aha moment came when I realized that similar to hundreds of caregivers that I've spoken with and counseled over the years, at the core of her frustration was the fact that she didn't fundamentally understand dementia. She certainly acknowledged all the symptoms her husband showed, and she understood that it was clearly impacting his memory and his ability to function as he once had.

What she didn't understand was how the memory loss limited his ability to take in new information. Even something as simple as "why don't you put that back

in the cupboard and close the door." No matter his intent, he simply could not execute that two-step request. Her reactions and interactions with him were not resulting in the help she was intending to provide. Her intentions were loving, but the path she was on was only exacerbating the situation for both of them.

I shared with her a brief story that I experienced while collaborating with a local physician who specializes in the science of dementia. In the process of presenting his power point on understanding dementia he displayed a slide that contained an object. It was one of those pictures that consists of many shades of gray, where some individuals can see the object, others simply see a lot of gray. He asked his audience what the object in that picture was. Typically half the audience will see the object instantly and shout out "it's a cow" while the other half are wondering where in the world is that cow. He proceeded to take his pointer and outline the ears, the snout, the back leg and so on until the audience came alive with "oh, now I see it!"

The doctor proceeded through a few more slides and then that darn cow in all it's gray glory popped up again. He asked audience members who previously couldn't see it if they now see it. A unanimous YES! He proceeded to explain that when he took his pointer and outlined the picture for them he was literally creating a new connection in their brain. Once they could see that picture, no matter how long it was since they last time they saw that picture, they would always see the cow going forward because that new connection gave them the ability to see it instantly. He went so far as to say that they can't help but see it now because that information is now stored in their brain.

He then compared that to a person with dementia, and explained that they can no longer create new

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connections in their brain, which means that no matter how many times you repeat something, no matter how much you want to help them to remember, it's simply not possible. Through no fault of their own, new information can be shared, but moments later it's gone...because a new connection wasn't hardwired.

With that new understanding my client had the awakening that she wasn't failing or doing anything wrong...it wasn't her fault. It's the disease and it's impact on her husband. With that new understanding, it allowed her to assess how she might change her conversation and approach in communicating with her beloved.

Knowledge is power in any circumstance. But in this case, it's more than that. It's the peace of mind that comes with understanding it's not your fault. It's recognizing what someone is capable of and

not expecting more than they're able to deliver. And it's the weight of guilt being lifted from unrealistic expectations.

At the end of our conversation you would have thought my client had won the lottery. Her relief was palpable through the phone. Her enthusiasm for gaining a new start and anticipation of more meaningful and positive exchanges between them was powerful.

Is this time more difficult for caregivers? Absolutely. But let's recognize the power of knowledge and the reality of any single story. Let's also make sure we're coming into these conversations with an open mind, focused on the real and not perceived challenge.

This article is a reprint of a blog posted by Adele Lund, Laureate Group's Director of Community and Business Relations