Living with Alzheimer's: Caregiving

“Are you feeling good today? Oh that's good. It’s nice to see you. Yeah, are you happy to see me? I hope so.”

“One of the first things I come out and do every morning, um, when I see him is I'll come over to him and I'll grab his hands and I'll say, Fred, how are you doing?”

“One, two, three. Oh very good.”

“And as much as it looks like, I'm a caring son – I am - but I'm also assessing how he is for the day. Is he awake? Is he alert? And it's just that basic little walking over to him and saying, hi, how are you... that really, you know, like, you know, what kind of a day he's gonna have based on his response.”

“Bup, Bup, Bup, Bup.”

“This stupid happy dance that I invented, um, you know, you just grab his hands and he always responds to melody. Dementia patients tend to do very well with music.”

“Bup, Bup… BUP!”

“But it ends with da, da, da, BUP BUP. And at the end of the BUP BUP, even then, if he's laughing, I know he's in a good mood. This is gonna be a good day. If he's not, nine times out of 10, he's also giving the aid trouble that day. With like OK he doesn’t want to get up and go to the bathroom.”

“The goal here with him is to keep him as happy as possible for as long as possible.”

“Bup, Bup, Bup, Bup. Oh good, are you ready to start walking?”

“One night he woke up and wandered to the front door. He was confused. He thought the front door was the bathroom. The real problem is that it was in the middle of January, and it was absolutely freezing outside. So, had he wandered out the door, had gotten lost, he would have been dead in a matter of minutes. And it really is one of those basic safety issues that relates to wandering that you really don't think like – ‘Oh wow, that could happen. And literally someone walking out their own front door at one o'clock in the morning could become fatal.”

“Safety and oversight. What does that mean? That means that you literally need someone to babysit that person around the clock to make sure they're not getting themselves in trouble.”

“Fortunately we have aids in the house who help me deal with that. For me personally, it has been better not to have this be a patient-caregiver relationship, and as much as possible to keep it a father-son relationship.”

“That's why, whenever I talk about my role, I say I'm a care coordinator: I make sure all the pieces are in place, and it helps keep our relationship father-son and not client- caregiver.”

“Here we go.”

“I always heard these stories, growing up, about ‘Daddy used to be a professional soccer player,’ It became apparent to me later on in life, after he already had dementia. One day, I just decided to Google and do some research. All of a sudden everything that they told me when I was a kid, it all made sense. And it was all crystal clear.”

“He was a very high level professional soccer player. He began playing in Malta, which was his home country. But then the majority of his career was spent playing in Australia. Uh, and while he was playing in the league in Australia, he actually won MVP in that league two years in a row.”

“The takeaway from that is that at the end of the day, dementia is the ultimate humbling disease. Here is a person who is a high level international athlete, who now needs help getting off the couch and walking to the bathroom. And when you stop and think about that and that perspective it affects you.”

“It’s still so familiar to him. He can watch a soccer game and life is good. And that's where you do have to look at the positive aspects of this disease.”

“And for me, the positive aspect of the disease now is that for us, we already went through our bumpy patch at the beginning when he was delusional, when he was aggressive.”

“Fred, is it a good game? Who is winning?”

“He and I can sit and watch a New York Ranger game, as father and son; and we can't have a conversation about the game - but we can still enjoy it together. And that means more to me than anything at the moment.”

“Are you feeling good today? Good, are you hungry? You feel good? Good.”

"The most important thing to keep in mind with dementia patients and safety is that as a caregiver you have to do your best to stay 6 months ahead of the disease because you don't know when the next symptom is going to pop up."

"That's where your clinical folks, your nurse practitioners, your doctors, your social workers, can be of great help because as a caregiver you're going down the road for the first time."

"Even in the presence of this disease, he's still enjoying his life relative to his ability. And he is still connected with us in some way, which is a blessing."

"I know, soccer and rice pudding, it doesn't get much better than this, right?"