

From the Desk of Claude Thau

Care Coordination Experiences

People tell me that I don't need care coordination help because I am so expert in LTCi. But I respond that I am not expert in:

1. Assessing people's needs
2. The strengths and weaknesses of local providers.

Twice I have sought care coordinators for family situations regarding people who were uninsured for LTC. Hiring those care coordinators have been among the best investments of my life. It is hard for me to avoid choking up when I describe these situations.

My mother-in-law (MIL) had alcohol-induced dementia. She felt inferior because she never went to college. Prior to family events, she would drink. When she got drunk, she would get ornery and there was no way to have a conversation with her. When I realized that she was having cognitive problems, my wife and I flew to her house to deal with the problem. I contacted a friend who was ran a care coordination company and told her I'd like to hire her top person. The engagement would involve:

A pre-meeting with my wife, my sister-in-law (who lived with my MIL) and me. I wanted my wife and sister-in-law to understand what was going to happen. More so, I wanted to help the care coordinator (Holly Pazda) by letting her know the situation she would be walking into. (I learned that Holly had absolutely no need for such insight from me.)

A meeting between Holly and my MIL.

I had grown up in the area where my MIL lived. So sometimes when we stayed with her for a week or two, high school friends might stop by. In this case, I told her that an associate was going to visit and when she did, I would introduce them.

When Holly arrived, we went into the kitchen and sat at the dining room table. I sat across from my mother-in-law, with Holly at the end of the table to my left and my wife sitting next to me on my right.

As soon as we sat down, my MIL turned to Holly and said "I know about people like you! People like you put people like me away." (Note: people with dementia are NOT stupid. Furthermore, they sharpen other skills to offset the cognitive deficiencies they experience.)

I knew from years of experience that when my MIL was ornery like that, the conversation was over. There was NO way to have a meaningful conversation with her.

But to my amazement, Holly did not bat an eyelash. She calmly and soothingly spoke with my MIL and succeeded in engaging her in conversation. I cannot convey how impressed I was. I felt that I was watching a miracle.

As Holly asked my MIL about the season, the current president, etc., my MIL's answers exposed serious issues.

Four other times in the conversation, my MIL flew off the handle. When she did that it was as though somebody swatted a checkerboard halfway across the room with pieces flying everywhere. How do you reconstruct where all the pieces were?

Each time that happened, I “knew” the conversation was over and thought in my mind how thankful I was that Holly had succeeded to that degree. I proved to be a very slow learner that day because each time that happened, Holly succeeded in resuming the conversation. The conversation did not end until Holly wanted it to end.

In my entire experience with my MIL (covering about 45 years), I only saw that happen 5 times and each of those 5 times was that day with Holly. I NEVER saw such a conversation with my MIL on any other day during those 45 years.

As Paul Harvey would have said “And now the rest of the story...” For the next half-hour, my wife and I were with my MIL. When my MIL went upstairs, my wife turned to me and said “My Mom did pretty well, didn’t she?”. I’m usually a quick responder, but I was biting my tongue and my wheels were spinning frantically trying to figure out how to answer that question. My wife is a very bright person, but she was blind to the problems clearly exposed during Holly’s interview of her mother because my wife was fooled by Holly’s calm, professional, non-judgmental demeanor. I thought Holly deserved a gold medal for her performance before I understood my wife’s perception. Upon hearing my wife’s question, my admiration grew by bounds to a level which I could never adequately describe .

My sister is, in my opinion, a serious schizophrenic. My mother left her an estate that seemed likely to be capable of taking care of my sister for the rest of her life. However, my sister would check herself into the hospital and then would check herself out. The hospital had no legal way to keep her so that it could help her. So she yo-yo’d in and out of the hospital, racking up huge bills that threatened the adequacy of the estate. There was a guardian and a guardian pro litem, but neither of them addressed the situation. My sister lived in Las Vegas, so I called an attorney I knew to seek a referral to a care coordinator who might help. He referred me to Mary Shapiro.

When I called Mary, I quickly became convinced that she was just who we needed. However, when she asked me how old my sister was and I responded that she was in her fifties, Mary told me that she was not an appropriate choice because she worked only with people over 65. In a flash of good judgment, I responded that it was **my** job, not hers, to determine whether she was a good fit for our need. When she agreed to accept the assignment, I imposed a requirement. – she had to get a separate cell phone solely for my sister. Mary objected to the expense but I explained that my sister would get upset and call again and again all night. Mary needed to have a separate phone that she could put in a drawer in a room other than her bedroom during the night. Mary agreed.

Mary quickly got the situation settled down. She got Home Instead involved with my sister. Home Instead took her on outings in the city which delighted my sister. I no longer worried about my sister going out on the town. (Previously, she’d go out and accuse people of being part of the conspiracy against her, yelling at them. I feared someone was going to get upset and clobber her, perhaps killing her.)

Unfortunately, the other people involved in the situation strongly disliked Mary. The guardian and guardian ad litem reacted very negatively because she stepped on their toes and exposed their failures. My sister disliked her (not understanding the good that she did); I don't remember why my sister disliked her. However, later my sister reviewed her accounts and observed that Mary had been allowed to charge her cell phone to the trust. Fortunately, she complained to me and I was able to tell her that I had authorized that charge. I'm not sure my admission helped at all. I was always part of "the conspiracy" in my sister's eyes, so I think both Mary and I remained "problems" in her eyes. I saw no reason to ask her about Mary thereafter, so I can't be sure.

As Paul Harvey would have said "And now the rest of the story..." For many years thereafter, I wondered how Mary was able to get Home Instead into my sister's house. My sister is very distrustful, thinking everyone is part of the conspiracy against her. It was hard for people to help her with maintenance problems in her house because she would find a reason to distrust them.

So when I had a conference in Las Vegas years later, I contacted Mary and invited her to join me for breakfast. At breakfast, I asked her "How were you able to get my sister to open the door for Home Instead?"

Mary's response started with a knee-jerk "That was easy!" I laughed internally but managed to keep a straight face. In one respect, it seemed like a slap in the face. If it was so easy, why had I never been able to figure it out in so many years? Of course, I knew Mary was not intending to insult me. She continued with a tremendous explanation. "I sent Home Instead to your sister's house on a Sunday morning with a basketful of a variety of warm pastries." What a great idea which demonstrates how important it is to call upon experts to help you. I would never have thought about that great solution. Yes, indeed, it was easy! I have mentioned this explanation frequently to spread the knowledge of such an exquisite approach.

I'd like to have an opportunity to see Holly or Mary in a crowded mall so I could kiss the ground they walked on, in order to draw attention to their wonderful service.