

Near You

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*You always learn something
by finishing the dance.*



“A story is created by both teller and listener.”
—Daniel J. Siegel, *The Developing Mind*

FOR MY SIXTIETH BIRTHDAY, MY husband gave me ballroom dancing lessons. I had always admired the graceful couples waltzing around the floor arm in arm, seemingly focused completely on each other. Of course, I was to find out how much patience and hard work it takes to make the dancing appear effortless. Dancing also requires trust. You must trust your partner—to lead or to follow your lead.

Trust is just as important in dance as it is in something like caring for an elderly parent. It is also intimate, physically close as your dance partner holds you in their arms. That intimacy may be less physical and more psychological in the case of a parent, but not always. There are things you must know about them and do for them that are uncomfortable. But this I know for certain: while you could break away from either embrace, you always learn something by finishing the dance.

Connecting

Our dance instructor was a young man named John who started our lessons with American-style box step. But even before the music started, before he told us what to do with our feet, he described the dance frame, explaining that the dance frame is critical in knowing how you should stand, hold your arms, and physically connect with your partner. John said the correct frame begins with the four points of connection—the lead’s left hand to the partner’s right hand, the lead’s right hand to the partner’s left (the muscles in the upper

back), the partner’s left forearm to the lead’s right elbow, and the partner’s left hand to the lead’s right bicep.

Another key to connecting in dance is resistance—balancing what your partner does. The first time John tried to guide me into dance, I stumbled. “You’re too stiff,” he said. “Relax; feel that pressure,” he said as he pressed his fist into my hand. “I want you to match it, but move to the pressure.” When I did as he asked, the lesson went much easier. Then he showed my husband how to set the tone by applying slight pressure in the connected palm. And of course, don’t forget posture. Appearance counts, as my mother would say. Like being in grammar school, someone always seems to be saying “stand up straight.”

Sometimes my husband’s lead wasn’t as strong as it should have been. You could always tell when we were connected and when we weren’t. When we weren’t connected, my body leaned in one direction for balance, or we would stumble. Experts say the partner has to be very precise in giving back the same amount of resistance as the lead. It has to be a perfect connection, a balance of energy and electricity traveling from one person into the other.

For the lead, the first step is the “invitation to dance”—opening their arms to their chosen partner as an invitation to dance.

Though my mother did not open her arms, it was much the same type of invitation, and I was the

only one on the dance floor. Since my father had died years earlier and my brother who lived in another state was ill, I was the only family member left. When my mother was first diagnosed with dementia with Lewy bodies, I was both baffled and relieved that her hallucinations had a name. My mother had thought, among other things, that there were people in the ceiling with guns trying to kill her. The difficulty was that to her they were real, and I didn't know what I should be doing to move forward.

Matching Steps

My husband is 6'2" and I am 5'4", so his stride is much longer than mine. In the beginning he took long steps that made it really difficult for me and threw me off balance. It wasn't until he began to take smaller steps that I got comfortable and could concentrate on the tempo and matching his steps.

When it came to caring for Mom, the suggestions were varied and some far reaching. One medical professional suggested memory care immediately, but her memory was fine and she could carry on a conversation without any problem. She did lack good judgement, and I had already glimpsed some of that when she would make financial decisions based on her emotions at the time. Another professional suggested I immediately seek guardianship, but as the days passed, she seemed to understand that her beliefs weren't real and unless she voluntarily gave it to me, my attorney said the courts were unlikely to grant it. So, I was uncertain about what to do next and when, how to protect her physically and financially. Fighting a parent in court is not something that comes naturally. It's not like stepping

on someone's toes when you're dancing or even bumping into another couple. It's more like knocking them to the dance floor and possibly breaking their leg. You can put it off, but only for a while. Eventually, unless death comes quickly, you will have to face their anger and bewilderment.

Whatever my legal designation — power of attorney or guardian — I realized that at the early stage of her disease, I needed to guide, not dictate. Despite several embarrassing incidents of paranoia (one where I was under investigation by the department of social services), I kept reminding myself that my mother wasn't a toddler, but an adult that did not understand her judgement was faulty. In this case, I was the lead. I needed to move with my mother in a way that would allow her to follow, initially making suggestions and reminding her what she had decided in the past and that many people had agreed with whatever decision was being made. It shouldn't have surprised me, but as the years wore on, I had days in which I almost felt our relationship was symbiotic, as if we were one or that she was the lead and I her partner.

Dealing with Frustration

During our lessons, I would dance with John first and then he would dance with my husband. Finally, my husband and I would dance together. It took about two minutes that first night for John to say, "Don't look at your feet. You dance through memory — muscle memory," John explained. "This is about contact with your partner. You can't do that looking down. You won't be able to follow." I finally had to admit that it wasn't just about touch for me, but being in control. I wanted to look perfect, immediately, but that wasn't going to happen until I could

become one with the dance, moving without thinking, like riding a bike.

Some dances are more difficult to learn than others. Some dances have complicated steps and require a lot of concentration. One of the most difficult for me was the international foxtrot, which is done at angles with inside and outside steps. I had to learn it was okay to get upset, not to be perfect, and to ask for help. Yes, I did not always have to be in control (yes, really).

When my mother was first diagnosed, I spent a great deal of time thinking about her symptoms and analyzing what stage she might be at. Yet it quickly became clear that almost everything was beyond my control. My mother's symptoms might rapidly decline one day, then suddenly improve. In fact, the more I read about and witnessed dementia, the more I became fearful for her and then fearful with every small change in my own health. Watching her felt like a predictor of my own fate, like watching my future self. Even though Lewy body dementia is not hereditary, because of my mother and my grandmother (my mother's mother had Parkinson's disease) I have a much greater chance of getting LBD or Parkinson's disease.

While everyone seems to like a certain amount of control, it's a competitive sport in our family, both a learned and a genetic trait. I definitely inherited the genes for this quirk of human nature, but I also had the best teacher in the world — my mother. Even from a young age I learned she had ways to know and control what was happening around her. And like the detective in a mystery novel, she often set traps.

One of my earliest memories is watching my mother get ready to go out on a Saturday

night. She sits at a mahogany dressing table and lifts the round lid of a metal musical powder box that begins to play the familiar tune. Without knowing for certain, I sense that the music box was a gift from my father. From the bowl below the lid she takes a powder puff and begins dabbing powder on her face. I know there are rules about the music box — I am not to touch. She says she is afraid I will spill the powder. But one day shortly after that Saturday evening, I cannot help myself. I see the round blue box sitting on the dark polished surface. I remove the lid slowly so I won't upset the contents, but instantly she is in the room. She knows I have disobeyed, not because I have spilled powder, but because when I lifted the lid, she heard music. She left the music box wound to detect any disturbance.

Even decades later I remember. Now the music box sits on my mother's dresser in the assisted living facility, but is rarely opened. One day as I enter her room, I find her sleeping in her hospital bed, legs swollen and propped up because of edema. Her mouth is open and she is gently snoring. I see the music box that has followed her to every house and apartment, every bedroom. I imagine that it reminds her of happier times with my father, perhaps even when there were no children.

When I turn quickly to leave the room, I suddenly see a second identical music box. It is positioned just across from the first one though at an angle. It takes a second before I realize it's just a reflection in the mirror — not two music boxes. I stare at it, and as if on cue, "Near Me" begins to play in my head. I can almost hear George Jones singing, "There's just one place for me, near you." ❖