

A monthly newsletter for people caring for those affected by Alzheimer's disease or another form of dementia.

Jordana Lawrence on her Support Group Experience

This week, we spoke with Jordana Lawrence about her many experiences with our Caregiver Support Groups. Jordana has been involved with our Support Groups for 25 years, first as a participant while caring for her mother, then as a volunteer facilitator after her mother passed away. Today, she is celebrating over 4 years of service as a member of our staff. Jordana's full circle story highlights the power behind one of the Alzheimer's Association's best offerings: Caregiver Support Groups.



The Caregiver

In the mid to late-1990s, I knew something was wrong with my mom. My family didn't want to talk about it but I knew she was changing, and I knew these changes were not normal.

I had read a story about Rita Hayworth's daughter advocating for her mom following an Alzheimer's diagnosis and the challenges she faced as a caregiver. She spoke about the Alzheimer's Association as a group of compassionate individuals who guided and supported her through her caregiving journey.

I immediately wanted to know more about this organization and reached out to the Alzheimer's Association's Santa Barbara office. The Chapter's team met me with kindness and understanding of what I was going through with my mom. They guided me to a caregiver support group and I made it a priority to attend.

In my first session, I listened to each of the caregivers share what they were observing in their loved one and how it made them feel. Every time a caregiver would share, their story would resonate not only with

what I was going through with my mom but also with the wave of emotional and functional challenges that emerged as a result of her dementia. The support group confirmed my feelings and confirmed what I was observing were not signs of aging, but something abnormal.

I started attending a group regularly, while still working full time and caregiving for my mom, until my mom's final chapter in 2008. I relied heavily on the support and community that I found there. I remember that the groups took a hiatus at one point and not having that close network of people going through what I was experiencing was incredibly stressful. Once the groups started back up, I never missed another meeting.

In support groups, you will hear things that scare you, but I think confronting the uncertainty allows you to prepare for the future. For example, in my support group, I

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heard other caregivers talk about their loved ones' aphasia and it terrified me, but it also allowed me to prepare mentally for the possibility of this happening to my mom. When it did happen, I knew I had support in navigating the next steps in both of our journeys.

The Volunteer

In 2009, a year after my mom had passed, I got an email from the Alzheimer's Association saying they needed support group facilitators. I felt called to this role because of the impact these groups had on my caregiving journey and I wanted to help others navigate through their journeys. I signed up and attended several training sessions.

I started my first support group at Heritage House in Santa Barbara. When I was caring for my mom, I needed consistency in my personal life so that's what I tried to be for the caregivers in my group. Every other week at 5:30pm, they could count on me being there, even if only one person showed up. They could also count on me to provide information about the disease and its progression, which was something that I had craved as a caregiver.

Being a new support group facilitator had a learning curve. There were times I received tough feedback on talking too much or not enough, but eventually, I found my groove by just being myself. I wanted the participants to feel comfortable and have a sense of camaraderie, and I think I achieved that.

The Employee

In 2017, I was contacted about joining the organization as a staff member. I accepted the role and was delighted to find that one of my main duties was to oversee and reinvigorate support groups throughout Ventura County. I immediately got to work on strengthening communication between support group facilitators and the Association. Keeping facilitators informed and supported throughout their tenure with us continues to be one of my highest priorities. As much as we value consistency in our work, we know life

can take a turn at any moment. I will always support facilitators to do what is best for them; if that means taking a temporary or permanent step away from their volunteer role, we will continue to value those relationships and serve as an indefinite resource of support for volunteers.

For me, I am right where I am supposed to be. It took me 40 years to find my place, but I am now where I truly want and need to be for caregivers in their moments of crisis, helping them through feelings of despair and to see the unexpected beauty in caring for a person with dementia.

Final Wisdoms

Every caregiver has to draw their own unique roadmap, but it can't be done all at once. Support Groups offer a place for caregivers to pick up the information, skills and techniques they need and are ready to take in that moment. These tips given by other caregivers and the facilitator can be used to draw your own roadmap so that after each meeting, the journey ahead becomes a little clearer.

I recommend that every caregiver go to a support group. It is amazing how meaningful a simple "How are you?" can be for caregivers deep in the trenches of this disease. Dementia can be extremely isolating for persons living with the condition and their caregivers. Support Groups are the one place that brings together people who can truly empathize with you. Family members often have their own issues and grief to deal with, or they might be in denial about what's going on, but coming to a support group consistently reminds you that you are not alone in your pain or joy as a caregiver.

Jordana Lawrence is an Educator & Care Specialist for the Alzheimer's Association, California Central Coast Chapter. She works out of the Ventura County office and can be reached at 805.261.2189 or jolawrence@alz.org.

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