

## Maybe It's the Season

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Maybe it's from the season or maybe it's from the darker and colder days, but the conversation in the last few caregiver sessions of the Without Warning program has taken a turn. Without Warning is a support program for those living with younger onset Alzheimer's disease. This group will soon turn 20 years old. Through the years, the caregivers in Without Warning have always discussed the mechanics of their role. They have talked and given tips around helping their person dress, eat, sleep, and get around through the day. They have shared the learning curve they have all been on and give encouragement to each other.

Recently though, the conversation has turned to the emotional side of caregiving. They have talked about what it means to love and care for someone who seems like a different person. They talk about how stressful it can be to live with a person who now doesn't respond in familiar ways.

Over the last few weeks, the conversation has centered around the loneliness of Alzheimer's and the loneliness of being a caregiver. They say that the mechanics of caregiving is doable. It's something they can learn over time. A skill they can develop. But the loneliness is different. It's hard to express and is with them throughout the day. They have shared trying to remember when they had their last kiss with their spouse. They miss those everyday moments and the give and take that comes with a long relationship. One shared that caring for a person with dementia was like living alone but with a person who had constant and unpredictable needs. Another shared that watching their person change was like taking on countless paper cuts.

But within this conversation on loneliness, the caregivers also share the moments of humor they see throughout the day. They share moments of joy in small interactions with their person. They share the satisfaction of a laugh or smile from their person.

And maybe that's really the season. It might not be the happiest time of the year. It's being able to hold and acknowledge those moments of sadness, loneliness, and those moments of joy, connection. It is both. It's never either, or.

As support group leaders, we need to recognize this. We need to give space for people to talk about both their pain and their joys. We are not there to minimize or erase anyone's experience. When these moments are expressed, we shouldn't feel the need to make it better. We are there to listen and create space for people to share and support each other.

It's always the season to lift-up the full experience of being a caregiver for someone with Alzheimer's disease.