

The long-distance dilemma

By Ellen Waldman

January 25, 2015

Some years ago, I worked with a family whose mother had lived in Ashland for a long time. The three adult children were scattered from Minnesota to two different locales in California. This made it very challenging to monitor her needs from so far away.

Although Louise lived in Ashland at an independent facility for aging adults, as her dementia progressed, she was less able to manage her own needs. One of the sad parts of dementia is that people really think that they are doing fine — when, in fact, there are gaps in big areas of their daily care needs. On her own, she choose to move to another facility outside of Ashland, and it was then that I heard from the family asking for some assistance in evaluating her situation.

It was shocking to see how far she had declined, and I felt it imperative to suggest that Louise move to a different type of facility, where she could really be cared for. This adult foster care home turned out to be the perfect spot for her. She actually thrived for some time, until she passed away in this final home.

Last summer, the family gathered at the Ashland Community Center to hold a memorial for Louise. Friends and family came from all over to honor and celebrate her life. At the memorial, they had a table set up with brand new children's books, for all different ages. Everyone was asked to please take one in Louise's honor and give to a child who would enjoy reading this book. Honestly, isn't this a terrific idea?

Recently, the adult children did something amazing. They sent me a long and eloquent testimonial letter, stating in detail what it was that I was able to do for them and their mother. Before you think I'm just patting myself on the back, there is a reason for this true story. Here are a few lines from their letter:

"Ellen also visited Mom for us when we could not. She observed things relating to Mom's care that we might not have even noticed as non-professionals. She also helped strengthen the fabric of Mom's safety net, because Mom liked her and trusted her. That was very important to us."

Here's the point of selecting these lines to share in this column. If you are a long-distance caregiver (and this is the term used for family members living at a distance), then you will want to know how best to attend to the needs of your loved one. Having a relationship established with a care team of professionals early on in the process means that as things continue to change, someone will notice the difference and be able to report on this. Just as important, the level of trust that this requires for client and professional takes time to develop. We (meaning care providers and care managers) just can't waltz into someone's life and expect immediate rapport and acceptance, no matter what their age. This is why sooner is not too soon, when it comes to getting help.

For those who might need more information on how to care from a distance, especially when the person has Alzheimer's disease, there are many online resources. One that is particularly helpful is a booklet by the National Institute on Aging (www.nia.nih.gov; 800-222-2225) called "So Far Away:

Twenty Questions and Answers about Long-Distance Caregiving.” They also have a wealth of other booklets and articles that might apply to your needs.

AARP.org has many wonderful resources for this topic. Just put “long-distance caregiving” in the search box.

Some of this next information I’ve mentioned before, but it bears repeating. Here in Ashland, it helps to find out what organizations like Ashland at Home (<http://ashlandathome.org>; 541-613-6985) might be able to provide.

The Adult and Disability Resource Connection (ADRCofOregon.org; 855-673-2372) is very helpful, especially for those with lower incomes.

The Alzheimer’s Association has an office in Medford (711 E. Main St; 541-772-2230) and Lori Stanton, regional coordinator, is very willing to take the time to help you solve these problems.

As I often mention, the National Association of Professional Geriatric Care Managers (caremanager.org) has hundreds of members like me in just about any region in the US. They can provide just this sort of overseeing that is so needed by families living at a distance.

And please consult with the Ashland Library, as they are sure to have a book that addresses this topic as well. With families often living far away, peace of mind comes from planning in advance.