

Recommended resources for Caregivers supporting loved ones with Alzheimer's Disease or other Dementia (updated 12/25 Allyson Schrier)

Caregiver Support

Caring for someone with a dementia diagnosis, whether they live with you or hundreds of miles away, is hard work. We cannot overstate the importance of finding a support group. Nobody understands what you're going through like others who are going through the same thing. Many caregivers identify finding a support group as the #1 most important thing they did upon receiving a diagnosis. The Alzheimer's Association hosts virtual and in-person support groups all over the United States. The Alzheimer's Foundation has a much smaller offering, but some are via telephone if that is more comfortable/available for you. You can also check with your healthcare provider about support available through their office, or in your area. Libraries and Faith Communities sometimes host community-based support, too. There are many Facebook and Reddit groups where caregivers share in a less structured environment what is and is not working for them. But best of all is to join a group led by a person well-versed in dementia care.

Diagnosis Support

While the <u>Alzheimer's Association</u> provides education and support for a cross section of dementia types, it can be helpful to find **support groups** and **education** that is specific to your diagnosis.

Frontotemporal dementia: The Association for Frontotemporal Degeneration

Lewy body dementia: The Lewy Body Dementia Association

Traumatic Brain Injury: Brain Injury Alliance of WA

Parkinson's Disease: Parkinson's Foundation (Pacific Northwest Chapter)

Younger Onset of any type: Lorenzo's House

Support for the Person with Dementia

For the newly-diagnosed person who would like to become an advocate for themselves and others doing their best to live well with dementia, check out the <u>National Council of Dementia Minds</u> and the <u>Dementia Action Alliance</u>.

Support for Kids

If there are children involved who would benefit from being part of a supportive community, reach out to <u>Lorenzo's House</u>. They do an excellent job of providing programming to help kids struggling with a parent or

grandparent who is experiencing brain changes. This group is very much focused on supporting families living with Young Onset (younger than 65 at diagnosis) dementia.

Caregiver Education (and more support options)

<u>Dementia Careblazers</u> is a **FANTASTIC** resource for free educational videos on YouTube and a paid option for more personalized **support**.

<u>Teepa Snow's Positive Approach to Care</u> organization is filled with options for education and support for both those giving care and those who are living with a diagnosis.

<u>Zinnia TV</u> hosts monthly online education and support group, with <u>recordings of previous sessions</u> posted on YouTube. Go to the <u>Zinnia contact page</u> to sign up to receive information about upcoming support group sessions. <u>This is a great video to start with!</u>

<u>UCLA has a long list of videos to help caregivers understand how to support a loved one with dementia.</u>

The Alzheimer's Association is one-stop shopping when it comes to both support and education.

Books, Films, Podcasts, Social Media

Favorite books include <u>Dementia Beyond Disease</u> by Dr. G. Allen Power, <u>The Emotional Survival Guide for Caregivers</u> and The <u>AARP Caregiver Answer Book</u> by Barry Jacobs, and <u>Responsive Dementia Care</u> by Helen and James Whitworth.

There are new films being released all the time. I worked with Kitty Norton on her film <u>Wine</u>, <u>Women and Dementia</u>, and acknowledge that I am biased. But the response from audiences of dementia caregivers is powerfully validating.

A favorite podcasts is <u>The Caregiver's Journey</u>. Not only are the episodes educational and inspirational, they have an extremely <u>well organized blog</u> that makes it super easy to locate a topic and explore solutions.

Social Media is a NOISY place and it can be hard to sift through the myriad of influencers vying for your attention. I highly recommend following Adria Thompson (**belightcare**) on Instagram, Teepa Snow (**@teepasnow**) on TikTok and Dr. Reza Ghomi (https://www.linkedin.com/in/rezahg/) on LinkedIn.

Help is a FREE phone call away!

<u>Alzheimer's Foundation of America</u> has licensed social workers available to take calls 7 days/week from 9am-9pm ET – **866-232-8484**

<u>The Alzheimer's Association Hotline</u> is available 7-days/week, 24 hours. The call is answered by a Helpline Agent who is well versed in Alzheimer's disease and other dementias. They can instantly upgrade your call to a Care Consultant to answer more in depth questions. **800-272-3900**