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FORREFRONT LIVING

Dementia Live® Empowerment Tool for Long Distance Caregiving

When a loved one is diagnosed with Alzheimer's disease or another type of dementia, it is painful and upsetting. Being a caregiver who lives far away makes things even more difficult. There are ways to be involved in your loved one's care from a distance.

IF YOU ARE THE PRIMARY CAREGIVER:

1. **Set up communication channels with your loved one's care providers.** Arrange for video calls. Include other family members or caregivers if possible.

2. **Document the information you receive.** When/If you participate in doctor visits by phone or meetings with other care providers, take notes. Doing so will help you keep track of progress. Write down questions before you conduct the meetings.

3. **Find out if all the legal paperwork is in order.** If documents such as power of attorney for health care is not in place, it is important to get it completed sooner than later. Do so while your loved one can participate in the decision-making process.

4. **Make a list of what you need help with.** There will likely come a time when people will offer to provide help. By having some ideas in mind, it will be easier to request help.

5. **Share information with your loved one.** Decide if/when you will share a diagnosis. In some cases, caregivers do not tell their loved one, who undoubtedly knows something is wrong. Having a diagnosis may help relieve your loved one's stress by putting a name to their condition. In some cases, caregivers feel the diagnosis will create more stress and uncertainty. Determine what will be best for your loved one.

6. **Share information with family members and other caregivers.** Keep them up to date in order to keep them involved. They will be better equipped to support you.

7. **You will get questions and opinions about your loved one's care.** Be open and to communicating with family members. Take what you can from the advice and opinions you receive and disregard the rest.

IF YOU ARE THE NOT PRIMARY CAREGIVER:

8. **Set up communication channels with your loved one's primary caregiver.** If possible, conduct video calls. Keep in touch in a way that works for them.

9. **Ask the primary caregiver how you can help.** Consider ways to help that do not require you to be onsite. Be open to providing support where you can, even if it is not what you had in mind.

10. **Offer to document information in doctor or care provider visits.** Doing so will help you keep track of progress. It will also be helpful for the primary caregiver to focus on asking questions knowing that you are keeping notes.

11. **You will have questions and opinions about your loved one's care.** Remember that your loved one's primary caregiver is doing the best they can. Ask yourself if your opinion, advice, or question would be helpful if you were the primary caregiver before sharing your thoughts.

IF YOU ARE OR ARE NOT THE PRIMARY CAREGIVER, KEEP IN MIND:

12. **Do not feel guilty about your level of involvement.** You are doing all you can do, whether you are the primary onsite caregiver or not.

13. **Remember that you will see changes in your loved one that may be unsettling.** When you are not able to see your loved one frequently, the changes can be stark from visit to visit. Be prepared and accept where your loved one is at that moment.

14. **Seek additional information and support as needed**Area Agencies on Aging and the Alzheimer's Association are two sources for additional support and information.