Early-Onset Alzheimer’s Disease Study (LEADS) is a multi-site study that will begin enrollment in 2019. The study, funded by a $44.7M National Institute on Aging grant, aims to recruit participants ages 40-64 who have EOAD and age-matched cognitively normal volunteers. The study will track changes in cognition, imaging, and fluid biomarker measures over five years, with the first visit expected to begin in mid-2019.

In the past two years, the Indiana University School of Medicine launched a study that will begin enrollment in 2019. The study, funded by a $44.7M National Institute on Aging grant, aims to recruit participants ages 40-64 who have EOAD and age-matched cognitively normal volunteers. The study will track changes in cognition, imaging, and fluid biomarker measures over five years, with the first visit expected to begin in mid-2019.

For more information, call the Alzheimer’s Association at 800-272-3900.
Tips for Enrolling in AD Studies

1. Know your values. Knowing yourself is the first step to understanding the time around the holidays should you choose to participate in a research study.

2. If you are feeling overwhelmed, it is time to simplify. As your holiday plans start to pile up, it is important to cut back on other activities or delegate certain tasks to others. For example, “Can you help me watch your dad for 4 hours on Christmas?”

3. If you are not sure what do for your holiday plans, make a Plan A, a Plan B, and a Plan C. Then decide which one works best for you. “Plan A: Fly 6 hours to visit our children for 4 days on Thanksgiving. Plan B: Celebrate Thanksgiving with our neighbors. Plan C: Buy dinner, sleep in, and watch TV at home.” Even if you still end up going with Plan A, going through this process will give you perspective.

4. Changes in routine can sometimes cause stress and confusion for your loved one. Pace accordingly. If possible, take your loved one to visit a familiar place. Stick to familiar routines and bring familiar items and foods.

5. If you decide to fly, sign up for TSA pre-check for shorter lines and to minimize removal of shoes, laptops, liquids, belts, and light jackets.

6. If you decide to travel, consider bringing family, friends, or hired helpers assist you.

7. If you are feeling overwhelmed, it is time to simplify. As your holiday plans start to pile up, it is important to cut back on other activities or delegate certain tasks to others. For example, “Can you help me watch your dad for 4 hours on Christmas?”

8. If you are staying at a hotel or you are a guest at someone’s home, consider childproofing the door knob or bringing a portable door alarm to prevent wandering.

9. If you are hosting, ask the family to help with preparations ahead of time. If you agree to host, you should not feel obligated to do it all by yourself. Ask family and friends to help bring food and clean up. Clear what about time the people need to get home.

10. If you are staying in a hotel or you are a guest at someone’s home, consider childproofing the door knob or bringing a portable door alarm to prevent wandering.

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13. Provide education to all generations of family about Alzheimer’s disease.

14. Spend time enjoying the holiday and simply watching the snowflakes fall.

15. Listen to others’ advice, but trust yourself. At the end of the day, you know what you and your loved one can handle. Prioritize your safety and do not worry about pleasing others. "Plan A: Go to the movies with your family or friends. Plan B: Go for a walk in the park. Plan C: Stay home and watch TV."

16. Check out more travel tips from these websites:

   - https://www.alz.org/help-support/resources/kids-teens
   - https://www.alz.org/help-support/resources/other-caregiving-support
   - https://www.alz.org/help-support/resources/other-caregiving-support
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Tips for Enjoying Your Holidays

1. Know your values. Know that you will spend time during the holidays around the people who are important to you and your values as a caregiver. You should not feel pressured by other family members or friends into making holiday plans that do not reflect your personal values and your values as a caregiver. You should not feel pressured by other family members or friends into making holiday plans that do not reflect your personal values and your values as a caregiver.

2. If you are feeling overwhelmed, it is time to simplify. As your holiday plans start to pile up, it is important to cut back on other activities or delegate certain tasks to others. For example, “Can you help me watch your dad for 4 hours so I can go for a walk?” or “Can you help me with the cooking so I can go for a walk?”

3. If you are not sure what do for your holiday plans, make a Plan A, a Plan B, and a Plan C. Then decide which one works best for you. Plan B: Fly 6 hours to visit one children for 3 days on Thanksgiving. Plan B: Celebrate Thanksgiving with our neighbors. Plan C: Stay, sleep, and watch TV at home. Even if you still end up staying home, you have planned ahead.

4. Changes in routine can cause stress and confusion for your loved one. Pace yourself. If possible, take your loved one to visit a familiar place. Stick to familiar routines and bring familiar items and favorite foods.

5. If you decide to fly, sign up for TSA pre-check for shorter lines and to minimize removal of shoes, laptops, liquids, belts, and light jackets.

6. If you are flying long distance, consider stopping for one day at the halfway point to help with the jet lag.

7. If your flight is delayed, stay well-hydrated with plain water to minimize the effects of jet lag.

8. If your loved one has incontinence, place chux pads on the mattress (and the seat of the airplane or car).

9. If you are flying, stay well-hydrated with plain water to minimize the effects of jet lag.

10. If you are staying in a hotel or you are a guest at someone’s home, consider childproofing the door knob or bringing a portable door alarm to prevent wandering.

11. If you are hosting, ask all family members to have their preparations ahead of time. While you host, you should not feel pressured to do all it yourself. Ask friends and family to help bring food and clean up. Clear up slowly what your loved one will need to get home.

12. If your loved one is coming in from out of town, please let your host or hostess know about accommodations beforehand. See if there can be a quiet room so your loved one can get a break. Bring photos of familiar people and activities to keep your loved one occupied and calm. Consider lunch or dinner instead of a dance to avoid confusion.

13. Provide education to all generations of family about Alzheimer’s disease. It will help your family members understand the disease and will set the stage for clinical trials in this unique patient population.

14. Encourage parents to read the kids-teens section of the Alzheimer’s Association website with their children so they can learn more about and reduce fear of Alzheimer’s disease.

15. Listen to others’ advice, but trust yourself. At the end of the day, you know your loved one to best. Prioritize your safety and well-being during the holiday season.

When you need help:

- NCRAD: Call our 1-800-526-2839 or use our online chat service at www.ncrad.org.
- Alzheimer’s Association: Call 1-800-272-3900 or visit www.alz.org.
- ClinicalTrials.gov: Visit the website to learn about clinical trials testing treatment for Alzheimer’s disease and other dementias.
- 4RTNI: Contact 1-855-247-6797 or visit www.4rtni.org.
- DIAN: Contact 1-800-978-8676 or visit www.diant.org.
- LEADS: Contact 1-855-247-6797 or visit www.leads-study.org.
- NCRAD on Twitter: https://twitter.com/ncrad/.

Check out more travel tips at these websites:

- www.alz.org/support/caring-for-people/safety/traveling
- https://alz.org/caregiver-tools/free-tools-and-resources
- https://alz.org/online-support
- Call 1-800-526-2839 for more help. 

Don’t forget to check out the Alzheimer’s Association’s latest news and resources in our bi-monthly newsletter, NCRAD Now on Twitter, www.twitter.com/alz_4rtni.

NCRAD Welcomes Your Ideas and Suggestions

We would love to hear from you! Please let us know what you would like to see added to our website or anything you feel should be updated. We welcome suggestions from patients, caregivers, and the general public. We would also welcome suggestions as future topics for articles, questions you would like us to ask the NCRAD doctors, or anything you would like shared with our readers about your family’s experience with Alzheimer’s Disease. Please send us your ideas by email or phone: 1-800-526-2839.

Check out more travel tips at these websites:

- www.alz.org/support/caring-for-people/safety/traveling
- https://alz.org/caregiver-tools/free-tools-and-resources
- https://alz.org/online-support
- Call 1-800-526-2839 for more help.

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- 4RTNI: Contact 1-855-247-6797 or visit www.4rtni.org.
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NCRAD Welcomes Your Ideas and Suggestions

We would love to hear from you! Please let us know what you would like to see added to our website or anything you feel should be updated. We welcome suggestions from patients, caregivers, and the general public. We would also welcome suggestions as future topics for articles, questions you would like us to ask the NCRAD doctors, or anything you would like shared with our readers about your family’s experience with Alzheimer’s Disease. Please send us your ideas by email or phone: 1-800-526-2839.
Holiday Season Tips for Family Members and Caregivers for Loved Ones with Alzheimer's Disease

With the holiday season in full swing, family members and caregivers of loved ones who suffer from Alzheimer's disease and other dementias wonder what are the right decisions when making holiday plans. Prioritizing your needs versus your wants can help you figure out how you should spend your holiday season. Consider making the "BrainSearch Square" to help you with this process, and then decide how to take action.

### Urgent

- **Needs to finish within 2 weeks**
- **More than 2 days**

### Important

- **Tasks you will do immediately**
- **More than 2 weeks**

### Defer

- **Tasks you will delegate or cut back on (whenever possible)**
- **Defer all**

### What to Do with Each Square

#### Part-time job
- Urgent: Finding a new job (No more than 2 jobs)
- Important: Shopping, cleaning, cooking
- Defer: Watching TV, painting pictures

#### Grocery shopping
- Urgent: Buying groceries for a week
- Important: Longer-term planning
- Defer: Shopping online

#### Movie night (Netflix, Amazon)
- Urgent: Doing laundry (No more than 3 times)
- Important: Washing and folding clothes
- Defer: Watching TV, painting pictures

#### DELEGATE

- **Tasks you will delegate or cut back on (whenever possible)**
- **Defer all**

### URGENT

- **Need to finish within 2 weeks**
- **More than 2 days**

### IMPORTANT

- **Tasks you will do immediately**
- **More than 2 weeks**

### DELEGATE

- **Tasks you will delegate or cut back on (whenever possible)**
- **Defer all**

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Tips for Enjoying Your Holidays

1. Know your values. You know your values. Decide how long you should spend the time around holidays should the loved ones around you and your values as a caregiver. You should not feel pressured by other family members or friends to do what they think is best for you.

2. If you are feeling overwhelmed, it is time to simplify. As your holiday plans start to pile up, it is important to cut back on other activities or delegate certain chores or tasks to others. For example, "Can you help me watch your dad for 4 hours while I go shopping to prepare for the holidays?"

3. If you are not sure what to do, make plans, A Plan A, B Plan and a C Plan. Then decide which one works best for you. "Plan A Fly 6 hours to see our children for 2 days on Thanksgiving. Plan B: Celebrate Thanksgiving with our neighbors. Plan C: Stay home, sleep, and watch TV at home."

4. Changes in routine can cause stress and confusion for your loved one. Pace yourself. "If possible, make your loved one visit a familiar place. Stick to familiar routines and bring familiar items and foods to your loved one.

5. If you decide to fly, sign up for TSA pre-check for shorter lines and to minimize removal of shoes, laptops, liquids, belts, and light jackets.

6. If you are going long distances, consider stopping for one day at the halfway point to help with the jet lag.

7. If your loved one is tired, make sure they get plenty of rest (the seat of the airplane or car)

8. If you are leaving a hotel and a loved one is staying in the area, check that they are okay. Consider a child-like day by bringing a portable doorbell to prevent wandering.

9. If you are hosting, ask the family to help with preparations ahead of time. If you agree to host, you should not feel pressured to do it all by yourself. Ask family and friends to help bring food and clean up. Clear about what time people need to get home.

10. If you are planning to host a family event, talk to your host or hostess about accommodations beforehand. See if there can be a quiet room so your loved one can get a breather. Bring photos of familiar people and activities to keep your loved one occupied and calm. Consider brunch or lunch instead of dinner to avoid sundowning.

11. If you are hosting or planning an event, make sure you and your loved one can handle. Prioritize your safety and comfort of your loved one. Consider your ability to stay focused and avoid collapsing.

12. Provide education to all generations of family about Alzheimer's disease. Encourage parents to read the kids-teens section of the Alzheimer's Association website with their children so they can learn more about the disease and how to handle.

13. If you are feeling overwhelmed, it is time to simplify. As your holiday plans start to pile up, it is important to cut back on other activities or delegate certain chores or tasks to others. For example, "Can you help me watch your dad for 4 hours while I go shopping to prepare for the holidays?"

14. Spend time enjoying the holiday and simply watching the snowflakes fall.

Check out more travel tips at these websites:

- [https://www.alz.org/help-support/resources/kids-teens](https://www.alz.org/help-support/resources/kids-teens)
- [https://purpletables.us/](https://purpletables.us/) (list of dementia friendly restaurants)
- [https://dailycaring.com/6-simple-auto-aids-for-seniors-make-car-travel-easier/](https://dailycaring.com/6-simple-auto-aids-for-seniors-make-car-travel-easier/)
- [https://www.alz.org/help-support/caregiving/safety/traveling](https://www.alz.org/help-support/caregiving/safety/traveling)
- [https://www.alz.org/help-support/resources/kids-teens](https://www.alz.org/help-support/resources/kids-teens)
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Research Opportunities:

4 Repeat Tauopathy Neuropathologic Initiative (RTNI-2)

- **Purpose:** To identify the best methods of analysis for tracking P301L and PABP1 over time. This results from this study may be used to help clinicians to track clinical change in the same study and to identify the best repeatable outcome measures.

- **Eligibility:** Male and women ages 65 to 95, diagnosis of Progressive Superficial Frontal Cortical Degeneration (SFD)

- **Mechanisms:** Mechanisms: Cortical tau, SFD, TDP-43, component in Alzheimer's disease.

- **Contact:** 415-476-7264 or 4RTNI2 webpage: [https://leads-study.medicine.iu.edu/](https://leads-study.medicine.iu.edu/)

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Dominantly Inherited Alzheimer Network (DIAN)

- **Purpose:** To study the associations of longitudinal clinical and cognitive assessments with multitudinal imaging and Bartter's panel data that capture different elements of AD pathophysiological cascade.

- **Eligibility:** Male and women ages 20 to 55 years, diagnosis of mild Alzheimer's disease, good general health and medically able and socially active.

- **Locations:** USA - CA, IN, MA, MO, NY, RI; United Kingdom; Australia

- **Contact:** 314-286-2683 or DIAN webpage: [http://www.dian-info.org](http://www.dian-info.org)

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Longitudinal Early-Onset Alzheimer’s Disease Study (LEADS)

- **Purpose:** To study the associations of longitudinal clinical and cognitive assessments with multitudinal imaging and Bartter’s panel data that capture different elements of AD pathophysiological cascade.

- **Eligibility:** Male and women ages 45 to 70 years, diagnosis of mild Alzheimer's disease, good general health and medically able and socially active.

- **Locations:** USA - CA, FL, PA, IL, IN, MD, MA, MN, HI, NY, TX

- **Contact:** 510-284-2863 or LEADS webpage: [https://leads-study.medicine.iu.edu/](https://leads-study.medicine.iu.edu/)

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NCRAD Welcomes Your Ideas and Suggestions

We encourage everyone who has been impacted by Alzheimer's disease to share your own personal stories and insights. We would welcome suggestions as future topics for articles, questions you would like to ask the NCRAD doctors, or anything you would like to share with our readers about your family's experience with Alzheimer's disease. Please send us your ideas by email or by phone.

**Contact:** 800-533-3839
**Email:** info@ncrad.org
**Website:** [www.ncrad.org](http://www.ncrad.org)

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Dr. Liana Apostolova
When Alzheimer’s Disease Strikes Young: Spotlight on Early-Onset Alzheimer’s Disease and LEADS (Longitudinal Early-Onset Alzheimer’s Disease Study)

Early-onset Alzheimer’s Disease (EOAD) accounts for approximately 5% of all Alzheimer’s disease (AD) cases, which represents around 250,000 individuals in the United States. Early-onset is defined as disease onset prior to age 65. While the majority of EOAD cases have a memory-predominant presentation, a significant number of them might present with unusual difficulty with language, conceptual processing or executive functioning (decision making, problem solving) rather than memory, or have an atypical presentation. Because of their young age and the higher frequency of atypical presentations, an accurate diagnosis is often delayed or missed in EOAD individuals. This causes significant delays to treatment and services. Moreover, available services are often not tailored to this younger population.

The consequences of living with Alzheimer’s are unique for someone who is under 65. For instance, many still have younger children who actively need them. The financial strains (e.g., loss of income and health benefits) are very different under 65. For instance, many still have younger children who actively need them. The financial strains (e.g., loss of income and health benefits) are very different when Alzheimer’s strikes early and specific planning needs to occur. Getting older in order is important because EOAD individuals often decline at a faster rate than people diagnosed later in life. This also underscores the importance of an accurate, timely diagnosis.

Mild to late-onset AD (LOAD), many factors can contribute to the development of the disease. From a biological standpoint, most people diagnosed with early-onset AD have the non-familial type, which means the disease is not caused by a known inherited mutation in certain genes known to cause Alzheimer's. Alzheimer’s in this early and specific planning needs to occur. Getting older in order is important because EOAD individuals often decline at a faster rate than people diagnosed later in life. This also underscores the importance of an accurate, timely diagnosis.

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