

## Adult Children of Individuals with Younger-Onset Dementia (COYOD)

### What is Younger-Onset dementia?

Younger-onset dementia affects people who are under age 65. Many people with younger-onset are in their 40s and 50s.

Younger-onset dementia may be caused by Alzheimer's disease or other diseases including Lewy Body, Frontotemporal, and Parkinson's disease. People who have younger-onset dementia may be in any stage of dementia – early, middle, or late.

Up to 10 percent of people with Alzheimer's disease have younger-onset. In the United States, that's about 200,000 people. There are even more cases of younger-onset dementia caused by other diseases and conditions.

### What does COYOD\* mean?

COYOD (Children of Those with Younger-Onset Dementia) are young adults who are coping with a parent's younger-onset dementia. COYOD are often balancing college, new careers, and young families with concerns for their parent's health and their own futures.

COYOD may face a wide range of challenges and issues, depending on one's situation. Some COYOD may serve as their parent's primary caregiver. Others may be managing caregiving support from long distance. Some are actively parenting young children while also managing the needs of the family member with younger-onset dementia.

\*The acronym COYOD, pronounced kai-ode, was created by [spokeyourmind.org](http://spokeyourmind.org)

### Life as COYOD

We are still striving to learn more about the COYOD experience. Here are some of the common experiences you may share with other adult children of chronically ill parents:

- Adjusting to changes in roles and responsibilities in the family
- Finding the positive in a challenging situation
- Serving as a caregiver
- Thinking about the future health of one's family and self
- Adapting as symptoms of the disease progress
- Developing methods to balance caregiving, work and family
- Managing the impact of the disease within the context of one's unique situation

(Blanchard, A., Hodgson, J., Lamson, A., & Dosser, D. (2009). Lived experiences of adult children who have a parent diagnosed with Parkinson's disease. *The Qualitative Report*, 14(1), 61-80.)

### 10 quick tips for COYODs

1. Expect good days and bad days
2. Share your story—educate others and express yourself
3. Discuss the challenges and changes you are facing with a trusted counselor
4. Support your parent with younger-onset dementia and your well parent
5. Reach out to your friends
6. Discuss the possibility of adapting job hours or duties with your parent
7. Get professional legal and financial help
8. Maintain your health and reduce stress
9. Take steps to address safety concerns
10. Help your parent to record his/her thoughts, memories and family history

## Resources at the Alzheimer's Association

Join our **COYOD mailing list** by contacting Nicole McGurin at [nicole.mcgurin@alz.org](mailto:nicole.mcgurin@alz.org) or 617.868.6718. By joining, you will be notified of relevant events and resources.

Our **Helpline** provides support, information, and referral. For 24-hour support, please call us at 800.272.3900.

**Care Consultation** is an in-depth service that may cater to your unique needs as a COYOD. This service may help you develop an understanding of the disease, make a plan to secure needed care, develop strategies for symptom management, and more. Consultations are provided in person and by phone. [http://www.alz.org/manh/in\\_my\\_community\\_8974.asp](http://www.alz.org/manh/in_my_community_8974.asp)

**Educational workshops** led by trained professionals provide practical information and include topics such as caregiving, brain health, Alzheimer basics and living with dementia. [http://www.alz.org/manh/in\\_my\\_community\\_education.asp](http://www.alz.org/manh/in_my_community_education.asp)

**Support groups** provide a forum for family members and caregivers of people with dementia to share feelings, concerns and information, and to support each other in coping with the effects of this disease. In early-stage support groups, there are two concurrent groups—one for care-partners and one for people with Alzheimer's disease. Some early-stage support groups are offered specifically for those affected by younger-onset dementia. COYODs are welcome to attend the early-stage, younger-onset support groups with their parent. While there are currently no support groups specifically for COYODs, there are several groups for adult children of individuals with dementia. [http://www.alz.org/manh/in\\_my\\_community\\_support.asp](http://www.alz.org/manh/in_my_community_support.asp)

## Additional Resources

**Spoke Your Mind** provides an online forum for COYOD to share resources and stories. Additionally, Spoke Your Mind is in the process of producing a full length documentary about the COYOD experience. [www.spokeyourmind.org](http://www.spokeyourmind.org)

**Alzheimer's Australia** provides support and advocacy for Australians living with dementia and their families. Their website provides extensive information regarding younger-onset dementia. <http://www.alzheimers.org.au/>

**DIAN** stands for the Dominantly Inherited Alzheimer's Network. DIAN is a research partnership of scientists determined to understand a rare form of Alzheimer's disease that is caused by a gene mutation. COYOD who are biological adult children of a parent with a mutated gene known to cause dominantly inherited Alzheimer's disease may be eligible to serve as study participants. [www.dian-info.org](http://www.dian-info.org)

**The Alzheimer Research Forum** provides access to current developments in dementia research. Their website includes a special section dedicated to Early-Onset Familial Alzheimer's Disease. <http://www.alzforum.org/>

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## Alzheimer's Association Contact Info

Massachusetts/New Hampshire Chapter  
24/7 Helpline **1.800.272.3900**  
Website **www.alz.org/MANH**  
E-mail **info@alz.org**

Connect with us online via

**Facebook, Twitter, and our blog!**

<http://www.facebook.com/AlzheimersMANH>

<http://twitter.com/AlzheimersMANH>

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