



California Central Coast Chapter

Santa Barbara County
1528 Chapala St., #204
Santa Barbara, CA 93101
Tel: 805.892.4259

120 E. Jones St, #113
Santa Maria, CA 93454
Tel: 805.636.6432

San Luis Obispo County
71 Zaca Ln Suite 110
San Luis Obispo, CA 93401
Tel: 805.547.3830

Ventura County
2580 E. Main St Suite 201
Ventura, CA 93003
Tel: 805.494.5200

24-Hour Helpline:
800.272.3900

alz.org/CaCentral

Still You, Still Me, Still Us

Reflecting on the past *Tips & Tools* I realized that my voice has never spoken to those who are living with dementia. I would like to direct this issue to those of you living with memory loss because receiving a diagnosis of progressive dementia is never easy—it is life changing.

It is normal to experience a range of emotions as you begin to notice a change in your cognition. Acknowledging your feelings can be an empowering first step in coping with the challenges ahead. You noticed symptoms, you made a doctor's appointment and, more than likely, you took a battery of tests. The process comes with a roller coaster of emotions—fear, hope, despair, denial. Then you received a diagnosis of mild cognitive impairment, MCI. You may have felt numb, unsure of how to respond, or where to turn.

Although not everyone will have the same approach to coping, you may find a combination of the following approaches helpful:

- Foremost, learn about the disease. The Alzheimer's Association offers educational programs and support groups and there are books written specifically for people with mild cognitive impairment (*Ahead of Memory Loss* is an excellent resource for you).
- Express your thoughts and feelings about your diagnosis in a journal.
- Share your feelings with close family and friends. Speak openly and honestly about your fears and wishes for the future.
- Surround yourself with a good support



system, including others who are also beginning to suffer from memory loss. Join an early-stage support group; it can provide you with a safe and supportive environment with peers who share your same concerns.

- Stay engaged. Continue your normal routine and activities.
- Be flexible and realistic if you need to modify your activities. Only undertake tasks you are comfortable with.
- Take the time you need to feel sad, mourn, and grieve.

As memory loss increases, there will be changes in your roles and relationships with family and friends. As a result, you may feel:

- Excluded from conversations about long-term planning and other important decisions when family members may have conversations or make plans for the future without your presence or feedback.
- Confusion in completing tasks you normally performed.
- Angry when it's time to stop driving or making financial decisions. You may experience a loss of employment or a loss of your role as a bread-winner.
- Frustration in thinking you will burden others with a caregiving role or management of your affairs.

Continued on next page

Looking for something new to try?

Tips & Tools

- Have an afternoon tea
- Remember early great inventions
- Play Pictionary
- Paint a sheet
- Cut out paper dolls
- Identify states and their capitols
- Put together a family tree
- Color a picture of our flag
- Grill hot dogs outside
- Grow magic rocks
- Water house plants
- Reminisce about the first kiss
- Play horseshoes
- Dance
- Sing favorite hymns
- Make homemade ice cream
- Force bulbs for winter blooming
- Make Christmas cards
- Sort a deck of cards by their color
- Write a letter to a family member
- Dress in red on a football Saturday

- Fearful that you are becoming more dependent on your spouse, family, or friends.

Sharing your diagnosis with others is an important step toward accepting and integrating memory loss into your life. You may be hesitant to share your diagnosis with some people, given the stigma that may be associated with the disease. Keep this mantra in mind: *It is not your fault.*

It is normal to experience fear or discomfort in sharing your diagnosis. Bear in mind, however, the best way to combat the stigma is to educate those around you. The stereotypes, myths, and misconceptions that are held about the disease often represent a significant obstacle to the well-being and quality of life for both those with dementia and their families.

Here are some examples of the stigma you may experience:

- A diagnosis may test friendships. Friends may refuse to believe your diagnosis or choose to withdraw from your life, leaving you with a feeling of abandonment or isolation.
- Relationships with family may change. Family members may be reluctant to talk about the disease, they may perceive you as having little or no quality of life, or may avoid interacting with you.
- Others may approach your care partner to ask about you rather than asking you directly how you are doing.
- The reactions of others may cause you to withdrawn or may discourage you from interacting with others.

Let your loved ones know how you feel; let them know you are disappointed and

expect more from your relationship. Share your educational experiences with them, knowing that having information on the topic will produce greater understanding, respect, and empathy.



To help raise awareness about the disease, the following recommendations are based on the advice and experience of current and former members of

the [Alzheimer's Association National Early-Stage Advisory Group](#) (comprised by individuals in the early stage of the disease):

Be open and direct. Engage others in discussions about the disease and the need for prevention, better treatment, and an eventual cure.

Communicate the facts. Sharing accurate information is key to dispelling misconceptions about the disease. Whether a pamphlet or link to online content, offer information to help people better understand. Don't be discouraged. Denial of the disease by others is not a reflection of you. If people think that this disease is normal aging, see it as an opportunity to educate them.

Seek support and stay connected. It is important to stay engaged in meaningful relationships and activities. Whether family, friends, or a support group, a network is critical. Find an early-stage support group near you.

Be a part of the solution. As an individual living with the disease, yours is the most powerful voice to help raise awareness, end stigma, and advocate for more support and research.

You have a unique opportunity to contribute to the larger good by turning your experience into inspiration for others living with this disease. Your voice and the actions you take, big or small, are powerful tools that can help to raise concern and awareness and empower others.

It is important to let everyone know that **you are still you!** Moreover, it is crucial to remember that you are still the same person you were before the diagnosis.

Marcy