WHEN THE DIAGNOSIS IS MCI OR EARLY-STAGE ALZHEIMER'S: NEXT STEPS IN LIVING YOUR BEST

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Objectives:
- Describe up to eight common themes in early-stage dementia.
- Identify up to three reasons for denial in early-stage dementia.
- Define the distinction between “caregiver” and “care Partner”.

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When the Diagnosis is MCI or Early-Stage Alzheimer’s

Helping Families to Live Their Best

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Common Themes

• Coming to terms with the diagnosis
• Disclosing the diagnosis to others
• Acknowledging losses
• Adjusting expectations of self and others
• Reconciling role changes
• Finding meaning and purposeful activity
• Building community

Coming to Terms with the Diagnosis

“In retrospect, I experienced a common problem that occurs with dementia and Alzheimer’s patients and their doctors when first diagnosed with the condition. Should the doctor give the diagnosis to the patient and his family or not? Should the condition be given a name to the patient? Being an early stage dementia patient, I was surprised to see a New York Times ad for Aricept, stating it’s a treatment for Alzheimer’s. This is not the way I should have gotten the news of my condition.”

— Harold Seidan
Coming to Terms with the Diagnosis

Using pre/post surveys of patients coming to clinic for diagnostic workups, Carpenter et al examined short-term changes in depression and anxiety before and after receiving a diagnosis of MCI or a dementia.

RESULTS:
• No significant changes in depression were noted in pts or their companions, regardless of diagnosis or symptom severity. Anxiety decreased substantially after diagnostic feedback in most groups.

CONCLUSION:
• Disclosure of diagnosis does not prompt a catastrophic emotional reaction in most people and may provide some relief once an explanation for symptoms is known and a treatment plan is developed.


Coming to Terms with the Diagnosis

Learning to see beyond the diagnosis

“At age 54, it seemed like I was labeled incompetent after a lifetime of proficiency I was devastated. I felt like a very helpless and broken man...I wondered if there was anything for me to live for.”

-- Bill

Coming to Terms with the Diagnosis

• Denial may serve as an adaptive defense

“A degree of denial is essential. Like somebody sipping hot coffee, we sip the truth of our condition carefully and gently.”

----James Anthony
“Alzheimer’s is not a “six months to live” disease, although when we first got the diagnosis, there were many around us, including our doctors, who imparted a sense of urgency. ‘You need to take that big trip now. You have to get your finances in order. You’ll be facing nursing home decisions soon’ etc. We found that you do not need to make hasty decisions right away; you need to take time to grieve, to plan, to experience, and ultimately, to enjoy.”

--- Care partners of an early-stage support group

**Helping Families to Live Their Best**

**Key Points:**

- Review the history of the diagnostic process with families to determine their responses and any positive or negative consequences.

- Provide *stage-appropriate* educational resources and referrals.

**Disclosing the Diagnosis**

**The Reality of Stigma**
Disclosing the Diagnosis

Responses from Others

“When it comes to Alzheimer’s, you’re not sure how people will respond to you. None of us like unexpected responses. People may brush you away because they are afraid of the disease.”

———Betty

The Reality of Stigma

• ADI conducted an anonymous online survey in June 2012 of people with dementia and carers about their experiences of stigma. Over 2,500 individuals from 54 countries responded.

• Download at: http://www.alz.co.uk/


The Reality of Stigma

Themes include:

• Concealing the diagnosis
• Social exclusion:
  – Being treated differently
  – Avoiding friendships and close relationships / marginalization
  – Limited or biased understanding of dementia among others
Talking About the Diagnosis

• “It’s very interesting to see how people close to me act. Being a cancer survivor, I know that I was constantly asked how I was doing while I was going through treatment. With Alzheimer’s, no one asks.”

Talking About the Diagnosis

Speaking out and being acknowledged contributes to a feeling of purpose, value, and selfhood and reduces stigma.

Helping Families to Live Their Best

Key Points:
• Review any associations or stigma with “dementia” and related terms. Broaden the spectrum as needed to include more encouraging associations.

• “Teach me how to live with this, not just how I’m going to die from it.”
Acknowledging Losses

Memory Loss

“I remember the good days when I could list for you all of my childrens’ and grandchildrens’ names in order. And now…”

—— Maclovia

Acknowledging Losses

Barriers to Effective Communication:

• Distractions of multiple stimuli
• Pace of communication
• Stigma and marginalization
• Withdrawal due to self-consciousness

Acknowledging Losses

Autonomy

“Certainly one of the very real fears felt by anyone with early Alzheimer’s is the fear of failure. I live with the imminent dread that one mistake in my daily life will mean another freedom will be taken from me.”

—— Robert Davis
Acknowledging Losses

**Freedom and Independence**

“Losing my license was like somebody cutting off my arm. I lost something that was a part of myself.”

---Bob

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Acknowledging Losses

- Understand the specific ways the person is affected by symptoms in daily living.
- Develop strategies that are symptom-specific, succinct, and achievable.
- When advising patients, write your recommendations down! (or have them do the writing).

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1 in 7 People with Alzheimer’s Live Alone

- Systems of *gradual* support
- Benefits of care management (consider different terminology)
- Exploring useful technology
- Recognizing danger signals

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**Note:**

2012 Alzheimer’s Disease Facts and Figures, Alzheimer’s Association
Helping Families to Live Their Best

Key Points:
• Afford opportunity for all involved to have losses acknowledged in order to facilitate effective problem-solving when possible.
• Assess previous coping styles when up against a wall or dealing with loss as this will influence current coping patterns (for better or for worse).

Adjusting Expectations of Self and Others

• Learning emotional and physical warning signs and limits

“I didn’t realize that I was so short tempered. That realization has taught me something and I am in the process of trying to learn patience, but also forgiving myself when I fail.”

—Lorna Drew

Adjusting Expectations

“Be gentle with yourself. This disease requires that you lower your expectations of yourself.”

—Mary Ann Becklenberg
Adjusting Expectations

**Effects on Selfhood**

“I take a step before doing something and really ask, ‘Am I the same person... Can I do this?’”

--- Chuck

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Adjusting Expectations

**Completing Routine Tasks**

“I say I can do it – I’ve done that hundreds of times. I don’t want to admit defeat in doing anything I used to do. Having others take over because they are in a hurry makes it even harder for me to complete it and says to me I am useless. My support group facilitator said ‘Sometimes good enough is good enough.’ That’s what I need to teach my wife. I like that idea.”

--- Hank
Reconciling Role Changes

The effects of language and labeling

“We used to be on equal footing with each other, a marriage of two accomplished people. Now he is the caregiver and I am the caregiven. There must be a fine line between sensible adjustment to an essential level of dependence on others and on their memories, as compared to a total surrender of all independent thought and action.”

Reconciling Role Changes

Finding The Balance

“Changing roles requires patience – It’s a gradual process. We’re doing it over time so my husband does not feel like he’s losing control….It’s important that he retain his dignity and his feelings of self worth.”

Helping Families to Live Their Best

Key Point:

Facilitate avenues for partnership and reciprocity with persons with MCI or early-stage AD whenever possible. Limit the “medicalization” of the person with memory loss.
Finding Meaning and Purpose
Cognitive, Social, and Physical Engagement

“I began to understand the concept of marginalization and its relationship to Alzheimer’s. Simply put, get up and do what you can or you will fade fairly quickly... You remain someone.”

--- Les Dennis

Finding Meaning and Purpose

Can purpose in life reduce the effects of AD pathology on cognition in the elderly?

- **Design:** Longitudinal study with 246 elderly of Rush Memory and Aging Project. Included annual clinical evaluations and brain autopsy. Purpose in life was assessed via structured interview; cognitive function evaluated annually and near death. At autopsy, AD pathologic changes evaluated.

- **Results:** Purpose in life modified the association between the measure of AD pathologic changes and cognition. Participants who reported higher levels of purpose in life had better cognitive function despite the burden of the disease.

- **Conclusion:** Higher levels of purpose in life reduced the damaging effects of AD pathologic changes on cognition in advanced age.

Cognitive Stimulation

Unregulated and Burgeoning Industry

• Software-based cognitive training and brain games may improve users' performance on trained tasks, but there is little evidence to suggest that such gains translate into improved performance in everyday life.

• Memorizing word lists is not likely to help you remember where you left your car keys or the time of an appointment.

Cognitive Stimulation

• “Every hour spent doing solo software drills is an hour not spent hiking, learning Italian, making a new recipe, or playing with your grandchildren. Other avenues for cognitive enhancement, such as participating in your community and exploring your passions may also stimulate your mind while producing socially meaningful outcomes.”

“Expert Consensus on Brain Health”: Stanford Center on Longevity

Social Stimulation

Early-Stage Support Groups

• Time limited psycho-educational models

• Weekly ongoing model has unique benefits, but is much rarer for the person with diagnosis

• Overwhelming bias on caregiver support
As a Result of the Support Group:

N-70 from 8 ongoing support groups in USA
Mean time in group – 22 months

- Have more understanding of AD 87.9%
- More able to cope with AD changes 82.6%
- More able to accept the diagnosis 69.1%
- Feel less isolated and alone 68.1%
- Feel less frightened or anxious 52.9%
- Feel less depressed 42.6%
- Have less conflict with caregiver 27.3%


Support Group Findings

☑ Persons with AD value most the socialization and learning aspects of the support group experience.
☑ Caregivers undervalue the importance of learning for their loved ones and overvalue activity or reminiscing.
☑ The majority of PWD and caregivers agree that the PWD better accepts the diagnosis as a result of group participation.

Let’s Talk

- Peer based telephone support for people with early-stage dementia
- Training and supervision of peer counselor/friend
- Excellent for rural outreach and support

Photos courtesy Deb Bryer, RN and “Let’s Talk.”

Alzheimer’s Association St. Louis Chapter at 314-432-3422 or 1-800-272-3900 and ask for Deb Bryer or email to debra.bryer@alzstl.org.
Outings Based Programs

- Persons with Alzheimer’s as members of the community
- Accomplished through programs that get people into the community for dignified engagement
- Promotes awareness of AD and can reduce stigma; promotes other increased activity

Intergenerational

- Persons with MCI or early-AD as valued elders
- Accomplished through programs that structure engagement between the generations
- Possibilities of improving QOL through increased purpose and value, reduced stress

Finding Meaning and Purpose

“...I hope the remainder of my days is in helping people in whatever situation, whatever knowledge I have to bestow it on, or if I can uplift someone, then I’ve done a good job -- to live and learn and pass it on to others.”

--- Voyser
Finding Meaning and Purpose

Yes, Exercise is Still Good For You!

- Evidence-based intervention with multiple benefits for MCI or early-AD
- Supports self-efficacy
- Readily available / low cost
- Reduces risk for co-morbidities associated with dementia

Finding Meaning and Purpose

Participating in Research

“Life is full of ironies...I was devastated by my diagnosis. You think ‘This is the end. What can I do now?’ But there are a lot of opportunities. I have so much energy and I want to be doing something useful....People need to know the magnitude of the problem. It is solvable....We can do this.”

--- Rae Lyn Burke


Acknowledging Strengths

“It isn’t sufficient to talk about statistics or interpret computer animations of our brain. Please don’t forget our own self; don’t always ask about deficiencies, see our existing abilities. Talk to us!”

--- Helga Rohra

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Helping Families to Live Their Best

Key Point:
As science focuses more and more on early detection and diagnosis, we must advocate for the development and funding of strength-based programs and opportunities for diagnosed persons that facilitate a continued sense of purpose and quality of life.

Creating Community

“It’s depressing to keep hearing about ‘the long goodbye.’ We’re here to say that there can be a lot of ‘hellos’ along the way.”

Quote from participants of the Early-Stage Support Group at the UC San Diego Shiley-Marcos Alzheimer’s Research Center

Maintaining Hope

“It’s a bend in the road, not the end of the road...unless you fail to make the turn.”

---Anonymous