



# Difficult Conversations: Giving a Diagnosis of Dementia

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# Today's Road Map

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- Importance of early diagnosis of dementia
- Translational process of a diagnosis
- SPIKES-D Model
- Discussing dementia diagnosis with patients and families
  - Dementia Road Map
  - Resources and Further Reading

# Role of Primary Care & Geriatricians

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- PCPs are the front lines of dementia care and often the first point of contact for patients with concerns about cognitive function
  - BUT less than half of all patients with dementia have diagnosis in their medical record
- Commonly Reported Barriers of Dementia Diagnosis
  - Limited appointment time
  - Unwieldy screening tools
  - Concern of causing more stress or problems for the patient/family
  - “There’s nothing that can be done about it”

# Debunking Myths with Data

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“Nothing can be done about it, so why bother?”

- In MCI...
- Empirical support for several non-pharmacological interventions that improve emotional wellbeing and quality of life and reduce caregiver burden
- Exercise – moderate exercise for at least 30-45 min, at least 3-4 days per week (Blumenthal et al., 2019; Baker et al., 2010)
- Diet – MIND or Mediterranean (Morris et al., 2015); DASH (Tangney et al 2014))
- Stress reduction, meditation and mindfulness practice

# Debunking Myths with Data

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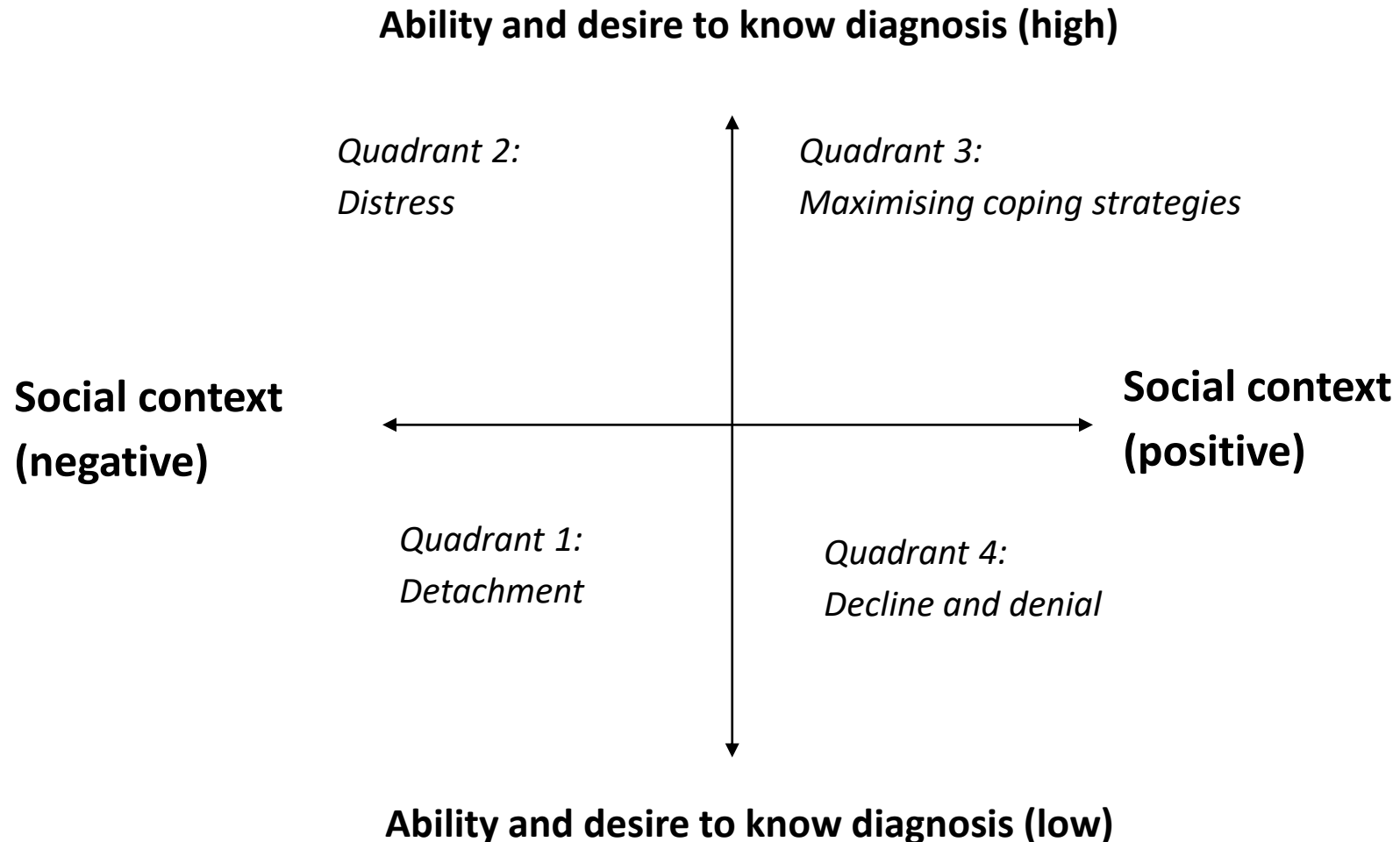
“People don’t *really* want to know that they have dementia”


- Connell et al. 2009
  - 178 adults with a family member with AD
  - >75% of family members rated the following benefits of diagnosis as being very or extremely important
    - 1) let family know what was wrong with relative
    - 2) allowed family to get information about AD
    - 3) allowed family to plan for the future
  - Only 6% of all respondents strongly agreed that “it is easier to not know what the diagnosis is”
- Ultimately, they have a right to the choice to know



Poll: You or a loved one is experiencing memory problems, but you haven't talked to a physician yet. What is one word to describe how you feel?

# Psychosocial model of receiving a diagnosis of dementia (Pratt et al., 2003)





Poll: You or a loved one was just diagnosed with early-onset Alzheimer's disease. What is one word to describe how you feel?



# Living with early-stage dementia (Steeman et al., 2006)

## Pre-Diagnostic

- Becoming aware, uncertainty, fear of what this *could* be
- Strategies of vigilance and avoidance
- Sharing Awareness (family, friends)

## Diagnostic

- Suspect a problem and seek help (or willing to receive help)
- Seeking evaluation can increase seriousness of situation (stress?)
- Diagnosis can provide validation but also threaten personal identity or mortality
- Ambivalence is common (need time to process)

## Post-Diagnostic

- Loss – cognitive, functional, independence
  - Loss of control
  - Role changes
- Feelings – irritation, frustration, fear, uncertainty, embarrassment, devaluation, shame
- Moving On – coping with challenges
  - Balance fear/despair with hope and acceptance

# SPIKES: A model for delivering bad news (Baile et al., 2000)



# From SPIKES → SPIKES-D

Dement Neuropsychol 2020 December;14(4):333-339

Views & Reviews

<https://doi.org/10.1590/1980-57642020dn14-040001>

## **SPIKES-D:** a proposal to adapt the SPIKES protocol to deliver the diagnosis of dementia

Vanessa Giffoni de Medeiros Nunes Pinheiro Peixoto<sup>1</sup>, Rosiane Viana Zuza Diniz<sup>1</sup>,  
Clécio de Oliveira Godeiro Junior<sup>2</sup>

# Step 1 – Setting Up the Interview

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- Have a care partner, family member, or other trusted person present
- Avoid social talk or long introductions
  - Maintain focus on the topic of the meeting and avoid distractions
- A multidisciplinary approach can be helpful (physician, social worker, nurse/ARNP)

# Step 2 – Assessing the Patient's Perception

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- Identify and recognize the degree of cognitive impairment and/or insight
- Address the person with dementia directly during the conversation

# Step 3 – Obtaining the Patient’s Invitation

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- Inform the patient that we have considered the cognitive concerns, lab results, neuroimaging, etc, and there is a probable hypothesis for their symptoms
  - “Mr./Mrs.\_\_\_\_, we have reviewed the tests you have undergone. It seems we have an idea of what is happening to your memory. Would you like to know?”
- If a patient declines being told the diagnosis, discuss future conversation with family member

# Step 4 – Giving Knowledge and Information

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- Provide information about a continuum of cognitive change (Dementia Road Map)
- Define “dementia”
- Briefly review any test results or findings
- Tell the patient the diagnosis. Include expectations in the short-term, and let them know that course of dementia is difficult to predict
- Avoid “drop by drop” information which can cause more confusion

# Step 5 – Addressing Patient Emotions with Empathic Responding

- Shock, disbelief, crying, denial, anger
- Allow time for silence - When emotion is high, we struggle to process new information
- Acknowledge emotions
  - “I know this isn’t what you want to hear”
  - “I wish the news were better”
  - “I can tell you were not expecting to hear this”
- Provide additional support for the care partner or family



# Step 6 – Summary and Strategy

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- Create a plan for next steps
- Offer information on treatment – pharmacological and non-pharmacological
- Available resources in the community
- Mention legal or safety issues and/or provide
  - May be addressed in a separate meeting later
- Offer educational brochures or handouts (e.g., Alz Assoc) for support
- Set a follow-up appointment for continuity

# Preparation will get you far

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- Consider specifics of your patient's situation
  - How will this diagnosis impact the patient, family, care providers?
  - What are particular barriers to treatment going forward?
  - What does their living situation or support system look like? Who are the “stakeholders”?
- Anticipate questions or concerns
  - Prognosis, Independence (driving, finances, Advanced Directives), treatment options and medications, need for a specialist referral, Support for family
- Identify appropriate resources for the patient before the appointment

# Principles for a Dignified Diagnosis

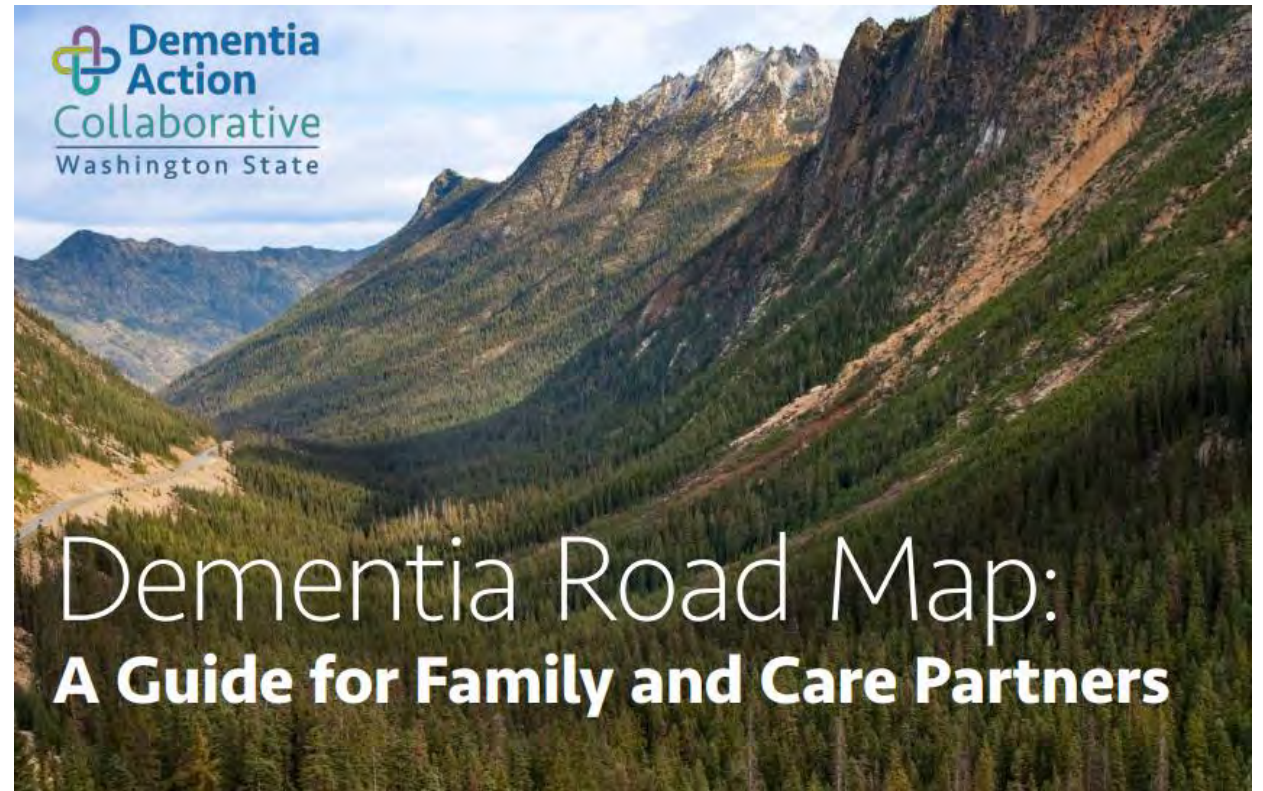
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- **Talk to me, the person living with dementia, directly.** I am the person living with the disease, and though those close to me will also be affected, I am the person who needs to know first.
- **Tell the truth.** Even if you don't have all of the answers, be honest about what you do know and why you believe it to be so.
- **Deliver the diagnosis in plain but sensitive language**
- **Test early.** Helping me get an accurate diagnosis as soon as possible gives me more time to cope, live to my fullest potential and access information and resources.
- **Take my memory concerns seriously, regardless of my age.** Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because of my age. At the same time, don't forget that the disease can also affect people in their 40s, 50s and 60s.

Source: Alzheimer's Association [www.alz.org/national/documents/brochure\\_dignified\\_diagnosis.pdf](http://www.alz.org/national/documents/brochure_dignified_diagnosis.pdf)

# DEMENTIA ROAD MAP

- Free for providers and families
- Available as PDF online
- Contact DAC for printed copies
  - Send name & mailing address to [dementiaroadmap@dshs.wa.gov](mailto:dementiaroadmap@dshs.wa.gov)
  - Also available thru WA chapter of Alzheimer's Association



Dementia Action Collaborative of Washington State

<https://www.dshs.wa.gov/altsa/dementia-action-collaborative>

# Dementia Road Map: A Guide for Family and Care Partners

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## DEMENTIA ROAD MAP OVERVIEW

### Wondering & Worried

- Is everything OK?
- Should my loved one be checked by a health care professional?
- What if my loved one won't go to a health care professional?

### Mild Cognitive Impairment (MCI)

- Where do we go to get memory loss checked out?
- How can I help my loved one with their memory and thinking?
- What can we do to promote our loved one's well-being?

### Early-Stage Dementia

- Are there any medication, treatments or lifestyle changes that could help my loved one's memory and thinking?
- How can we help our loved one stay active and connected?
- Should my loved one still be driving?
- Is our legal paperwork in order?

### Mid-Stage Dementia

- What can I do to make the home safer?
- What do we do if our loved one won't stop driving?
- Where do we get help in coping with behaviors?
- What services might help and where do I find them?

### Late-Stage Dementia

- What can we do to promote quality of life?
- What kind of care is best for my loved one?
- What do we want in terms of medical care at the end of our loved one's life?





## Communication tips

Dementia damages pathways in the brain. Brain changes make it difficult for a person with dementia to say what they want and understand what others are saying. Your loved one may have trouble coming up with the right words or a name, or may invent new words. At some point, they may repeat a question over and over. Because dementia changes communication skills gradually, a loved one's words may at times make little or no sense to you. He or she might also have trouble understanding your words. The resulting misunderstandings can fray nerves all around, making communication even more difficult.

You can expect that over time, a person living with dementia may struggle to organize their message, lose their train of thought or speak less often.

### What you can do:

- **Be present.** Let your loved one know you're listening and trying to understand. Keep your voice gentle. Hold the person's hand while you talk. Smile, nod, make appropriate eye contact.
- **Show respect.** Offer your loved one undivided attention, don't multi-task. Include your loved one in conversations, don't talk about them as if they weren't there.
- **Avoid distractions.** Background noise, like TVs or radios can compete for attention.
- **Position yourself.** Be close enough to be heard and seen clearly. Sit or stand at the same level, rather than standing over them.
- **Get hearing checked regularly.** If the person uses a hearing aid, check that it is working and inserted properly. When speaking, turn your face towards them and make sure your face is in the light so they can easily see your lip movements.

*Continued on next page...*

# Additional Resources

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- Dementia Action Collaborative of Washington State:  
<https://www.dshs.wa.gov/altsa/dementia-action-collaborative>
- Alzheimer's Association: [www.alz.org](http://www.alz.org)
  - <https://www.alz.org/professionals/healthcare-professionals/cognitive-assessment>

## Support for patients and their families

- Alzheimer's Association 24/7 Helpline: 1-800-272-3900
  - Staffed by counselors and social workers to help your patients and their caregivers with questions and local support resources
- [www.memorylossinfoWA.org](http://www.memorylossinfoWA.org)

# Further Reading

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- Baile et al. (2000). SPIKES-A six-step protocol for delivering bad news, *Oncologist*
- Bhatt et al. (2020). "Who to Tell, How and When?": Development and Preliminary Feasibility of an Empowerment Intervention for People Living with Dementia Who are Fearful of Disclosing Their Diagnosis, *Clinical Interventions in Aging*, 15, 1393-1407
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# QUESTIONS?

