Why Early Detection of Dementia Matters

MTGEC Dementia Continuum
October 15, 2019
Patricia Coon MD

Objectives

- Discuss the benefits of early detection of cognitive impairment.
- What is dementia
- Why dementia is important
- Why early detection of dementia matters
- What can healthcare organizations and communities do to help
- Diagnosing dementia

What is dementia?

Potentially Modifiable Risk Factors for Dementia

Approximately 35 percent of dementia cases are attributable to a combination of nine potentially modifiable risk factors:

- Low educational attainment
- Social isolation
- Midlife hypertension
- Midlife obesity
- Physical inactivity
- Smoking
- Diabetes
- Hearing loss
- Late-life depression

Dementia is a Public Health Crisis

- **Large disease burden**
  - 5.8 million nationally, global impact
- **Higher acute care utilization (inpatient, ED)**
  - e.g., twice as many hospital stays per year as other older people
- **High morbidity and mortality**
  - 6th leading cause of death
- **Large societal burden**
  - Most expensive disease in US - $290 billion in 2019

Alzheimer’s Association: 2019 Alzheimer’s Disease Facts and Figures

Montana Alzheimer’s Statistics

- 21,000 of our seniors have Alzheimer’s. By 2025 this number will reach 27,000
- 6th leading cause of death in Montana
- Caregiver burden in 2018
  - 50,000 caregivers provided 57 million hours of unpaid care valued at $723 million

People and Families are Unaware

- **Underdiagnosed**
  - Among individuals with Alzheimer’s disease, only about half have ever been diagnosed.
- **Not informed**
  - Less than half of seniors diagnosed with Alzheimer’s disease or their caregivers are aware of the diagnosis

We can do better!

Why we must do better

- Be safe – Story 1
- Ensure better health – Story 2
- Prevent complications – Story 3
Barriers to Diagnosing Dementia

Providers
- Question of ownership – primary care vs. specialists
- Lack knowledge about dementia
- Express discomfort in making and communicating diagnosis
- Question if early diagnosis really matters given limited treatment options
- Think patients and families don’t want to know
- Have lack of time

Primary care clinics
- Lack a standardized approach for early disease detection
- Have limited support structure for providers and caregivers

A major goal of the Montana Alzheimer’s and Dementia State Plan

Encourage all health care providers to recognize and diagnose dementia early in the process and appropriately refer individuals and families to community resources.

What Montanans Care About

<table>
<thead>
<tr>
<th>People with dementia</th>
<th>Care</th>
<th>Health care providers</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain dignity and sense of value</td>
<td>Respite care</td>
<td>Early diagnosis</td>
<td>Dementia awareness</td>
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<tr>
<td>Meaningful activities and community engagement</td>
<td>Support groups</td>
<td>Communicating diagnosis</td>
<td>Central information source for local dementia resources</td>
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<tr>
<td>Access to dementia trained professionals</td>
<td>Education and training</td>
<td>Best practices along care continuum</td>
<td>Dementia friendly</td>
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<tr>
<td>Behavioral supports</td>
<td>Financial support for care options</td>
<td>Care coordination</td>
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<tr>
<td>In-home care</td>
<td></td>
<td>Partner with families</td>
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<tr>
<td>Residential settings for mild to severe dementia</td>
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**Why early detection matters for patients**

- Help them understand the condition and its symptoms
- Time to develop a relationship with doctors and caregivers
- Better chance to benefit from treatment
- Access to services that can prolong independence and sustain quality of life
- More time to plan for the future: decisions about care, living options, transportation, financial and legal matters, and emergency situations

**Action Steps for Families**

**Plan for the Future**

- Hold a family meeting.
- Complete healthcare, financial, and legal documents.
- Discuss with person the issue of when to discontinue driving.
- Make a back-up plan for emergencies.
- Discuss end-of-life issues.
- Put safety measures in place before they are needed.
- Discuss respite options.

*A lot of people don't want to talk about the hard choices... what they don't realize though, is now is the time to plan for your future.*

Michael E., person living with Alzheimer's (www.alz.org)

**Action Steps Families**

**Can Do Now**

*Keep person with dementia active and engaged*

- Assist them to continue activities of interest.
- Encourage friends and family to visit regularly.
- Help friends & family understand how to communicate and interact
- Consider community services that can keep the person in their home.

*Keep informed*

- Go along on medical appointments if the person agrees.
- Get educated about the disease and take time for yourself.

*Stay healthy*

- Keep up with your own medical appointments.
- Carve out time for yourself.

**Why early detection matters for providers**

Once cognitive impairment is detected, the global approach to patient care is different.

By the time it's obvious, you've missed a chance to help.
Global Approach to Dementia Care

• Mitigate harm and reduce risks - a major role
  - Identify reversible causes of cognitive impairment
  - Identify and address safety concerns
  - Tailor clinical choices (including those related to other chronic conditions) to the severity of cognitive impairment and overall prognosis
  - Ensure healthcare, financial, legal, and advanced care documents are done

• Engage family or friend to help person with care needs
  - Help define medical goals and identity current and future care needs
  - Medical "partner" to provide accurate history and manage care plan

• Communicate diagnosis
  - Person, family, and caregivers
  - Other healthcare providers involved in person’s care
  - Document diagnosis in person’s medical record

Early Diagnosis Challenges

• Person does not believe he/she has a problem.
• There is no family or family pushes back when the problem is raised.
• Primary care provider (PCP)
  - not sure what to do since there’s no effective disease-modifying treatment.
  - worries that focusing on cognitive impairment may affect his/her relationship with patient and family.

What matters most!
PCP and other healthcare providers are aware of the problem.
Unless there is a safety concern, there is time for person and family to absorb it all.

Health Care Priority: Make early diagnosis and quality care the norm

Communicate diagnosis
Diagnose early
Partner with families
Coordinate care
Connect people to community resources

What patients ask of your health care providers

<table>
<thead>
<tr>
<th>Patient asks for</th>
<th>Provider action</th>
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<tbody>
<tr>
<td>Early dementia diagnosis</td>
<td>• Screen annually for cognitive impairment</td>
</tr>
<tr>
<td></td>
<td>• Provide a clear diagnosis</td>
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<tr>
<td>Help understanding what to do next</td>
<td>• Educate you about the disease and what to expect in the future</td>
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<tr>
<td></td>
<td>• Create a comprehensive care plan that fits your goals</td>
</tr>
<tr>
<td>Advice on help available in the community</td>
<td>• Share local, state, and national dementia-related resources</td>
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<tr>
<td></td>
<td>• Refer you to appropriate services when you need them</td>
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Medicare benefits that help

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<th>Patient asks for</th>
<th>Provider action</th>
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<tbody>
<tr>
<td><strong>Annual Wellness Visit (CPT code 99213)</strong></td>
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<tr>
<td>Early dementia diagnosis</td>
<td>• Detect cognitive impairment early</td>
</tr>
<tr>
<td>• Determine next steps in evaluation</td>
<td></td>
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<tr>
<td><strong>Cognitive Impairment Care Planning Visit (CPT code 99483)</strong></td>
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</tr>
<tr>
<td>Help you know what to do next</td>
<td>• Assess how dementia affects everyday life for you and your loved one</td>
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<tr>
<td>• Work with you on care plans to address each problem</td>
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<tr>
<td>Advice on community supports</td>
<td>• Share local, state, and national dementia-related resources</td>
</tr>
<tr>
<td>• Refer you to appropriate services when you need them</td>
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Diagnosing Dementia

**Starts with suspecting cognitive impairment**

• AWV - patient fails cognitive screen
• Provider visit
• Patient and/or caregiver expresses concerns memory concerns

Dementia Warning Signs

<table>
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<tr>
<th>Provider notices patient</th>
<th>Patient &amp; caregivers report</th>
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<tr>
<td>• Is inattentive to appearance, unkempt, or disheveled.</td>
<td>• Asking the same questions over and over again.</td>
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<tr>
<td>• Is a “poor historian” or forgetful.</td>
<td>• Becoming lost in familiar places.</td>
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<tr>
<td>• Fails to keep appointments</td>
<td>• Not being able to follow directions.</td>
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<tr>
<td>• Has unexplained weight loss, “failure to thrive,” or vague symptoms, e.g., dizziness, weakness.</td>
<td>• Getting very confused about time, people, and places.</td>
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<tr>
<td>• Repeatedly and apparently unintentionally fails to follow directions, e.g., not following through with medication changes.</td>
<td>• Problems with self-care, nutrition, bathing, or safety.</td>
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<td>• Defers to a caregiver or family member to answer questions.</td>
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Confirming there is a problem

**Brain Health Evaluation by PCP and care team**

- Careful medical history and physical examination
- Focusing on changes in thinking, day-to-day function, behavior, and physical abnormalities
- More detailed screening test if indicated
- Rule out reversible causes
- Laboratory tests and imaging studies as indicated
- Make provisional or definitive diagnosis if known
  - MCI
  - Dementia
- Inform the patient/family of this conclusion
Dementia
- Characterized by a decline in cognition involving one or more cognitive domains.
  - learning and memory, language, executive function, complex attention,
    perceptual-motor, social cognition.
- Decline from previous level of function.
- Severe enough to interfere with daily function and independence.

Mild Cognitive Impairment (MCI)
- An intermediate clinical state between normal cognition and dementia.
- Can also be a precursor to dementia.
- May represent a reversible condition.
  - Depression
  - Complication of certain medications
  - Recovery from an acute illness.

Determining the exact type of dementia can be harder because the symptoms and brain changes of different dementias can overlap.

Diagnosis of Dementia

Dementia Type | Prominent Clinical Features
--- | ---
Alzheimer’s disease
    Decline: Gradual | Cognitive issues: Memory loss and impaired learning early in the disease, time/space and language deficits in moderate to severe stage of disease.
    Behavior issues: Apathy, delusions, agitation, wandering
    Motor issues: Gait and swallowing problems later in disease
Frontal temporal
    Decline: Gradual | Cognitive issues: Loss of word memory and word finding, grammar and comprehension problems. Difficulty speaking, planning, and organizing
    Behavior issues: Personality change, disinhibition, compulsive behavior, lack of empathy.
    Motor issues: May have Parkinson-like motor problems
Lewy body
    Decline: Gradual | Cognitive issues: Fluctuating cognition, changes in attention, planning and organizing, judgment
    Behavior issues: visual hallucinations, delusions, REM sleep problems
    Motor issues: Parkinson-like motor problems early in disease
Vascular
    Decline: Stepwise | Cognitive and motor deficits based on extent and location of stroke(s) or vascular event. Memory loss is usually secondary to impairments in planning and organizing and judgment.
    Behavior issues: Personality and mood changes

Is it dementia or just signs of aging?

| Typical age-related changes | Signs of Alzheimer’s/dementia |
--- | ---
Making a bad decision once in a while | Poor judgment and decision making
Missing a monthly payment | Inability to manage a budget
Forgetting which day it is and remembering later | Losing track of the date or the season
Sometimes forgetting which word to use | Difficulty having a conversation
Losing things from time to time | Misplacing things and being unable to retrace steps to find them

Distinguishing Alzheimer’s from other Types of Dementia

Cognitive impairment screening tests

| Short Screening Tests | Other Primary Care Tests |
--- | ---
- **Mini-Cog**
  - 2 items, 6 points
  - Clock plus recall
  - 3 minutes
- **GPCog**
  - 6 items
  - 5-6 minutes
  - Cog test + caregiver assessment
- **AD8**
  - 8 items
  - 3 – 5 minutes
  - Caregiver assessment only
  - Can be administered by non-physician staff

- **MMSE** – cost for use
  - 10 items, 30 points
- **MoCA**
  - 12 items
  - 30 points
  - 10-15 minutes
  - Can detect MCI
- **SLUMS**
  - 30 points
  - 10 – 12 minutes
  - Validated in VA population
- **DSRS**
  - Brief informant-rated test
  - 12 item multiple choice questionnaire
  - Measures functional abilities
When to refer to specialists

Possible indications for referral:

» Inconclusive diagnosis
» Atypical presentation or rapid onset
» Behavioral/psychiatric symptoms
» Younger-onset (< 65 years)
» Second opinion
» Patient/family preference
» Family dispute
» Caregiver support

Dementia care planning

When CI suspected, develop a care plan to direct management:

- Done collaboratively by PCP, care team, patient, and family
- Identify care needs, goals, and action steps including appropriate referrals, including referrals community resources and services
- Can use Medicare Cognitive Impairment Visit benefit

Caregiver Supportive Services

<table>
<thead>
<tr>
<th>Education</th>
<th>Support services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning for future decision-making</td>
<td>Education &amp; training programs</td>
</tr>
<tr>
<td>Supporting community connections</td>
<td>Financial support</td>
</tr>
<tr>
<td>Understanding the illness and managing symptoms</td>
<td>Memory Cafes</td>
</tr>
<tr>
<td>Peer support</td>
<td>Support groups</td>
</tr>
<tr>
<td>Respite Care</td>
<td>Education &amp; training programs</td>
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Resources

- Alzheimer’s Association (www.alz.org):
  - www.alz.org/alzheimers-dementia/acts-figures
- Montana Alzheimer’s and Dementia State Plan (www.mtalzplan.org)
- Dementia Road Map: A Guide for Family and Care Partners
- KAER Toolkit: 4-Step Process to Detecting Cognitive Impairment and Earlier Diagnosis of Dementia from the Gerontology Society of America (GSA)
- National Institute on Aging (www.nia.nih.gov/)
- ACT on Alzheimer’s (www.actonalz.org/provider-practice-tools)
Montanans with dementia and families know:

**Diagnosis often missed or late**

"Getting in with the right provider is important. Our mother wasn’t diagnosed until we were directed to a behavior specialist in Billings."

Montanans with dementia and families know:

**Common and costly**

“We spend $12,000 a year—so dad can have hour of help Monday through Friday.”

**Families need help**

“A drowning man always takes someone with them—my kids said one of us was going to a facility, either my wife because of her symptoms or me because of my fatigue.”

Montanans with dementia and families know:

**Need high quality dementia care**

“When someone with Alzheimer’s goes into the hospital—with its noise, lights, and activity—it makes them more confused and they get agitated. “Can’t we do better!”

Montanans with dementia and families know:

**Need more community services**

“It isn’t going to be too long and he won’t remember some stuff. I don’t know where we are going to go looking for services.”
Alzheimer's is a Chronic Disease

**Preclinical AD** 20+ years

- Brain changes
- Brain cell injury and death

**Mild Cognitive Impairment (MCI)**

- Cognitive Impairment
- Loss in daily function

**Dementia (5 – 10 yr.)**

- Onset of Symptoms
- Brain cell injury and death
- Cognitive Impairment
- Loss in daily function

**Mild Alzheimer’s Dementia**

In the early stages of Alzheimer's:
- A person may function independently. He or she may still drive, work and be part of social activities.
- Friends, family, neighbors, and employers begin to notice difficulties
- Common difficulties include:
  - Problems coming up with the right word or name
  - Trouble remembering names when introduced to new people
  - Having greater difficulty performing tasks in social or work settings
  - Forgetting material that one has just read
  - Losing or misplacing a valuable object
  - Increasing trouble with planning or organizing

**Mild Alzheimer’s Dementia**

- Typically the longest stage and can last for many years.
- As the disease progresses, the person with Alzheimer's will require a greater level of care.
- Person with Alzheimer's is confusing words, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe.
- Difficult to express thoughts and perform routine tasks.

**Moderate Alzheimer’s Dementia**

- Symptoms will be noticeable to others and may include:
  - Forgetfulness of events or about one’s own personal history
  - Feeling moody or withdrawn, especially in socially or mentally challenging situations
  - Being unable to recall their own address or telephone number or the high school or college from which they graduated
  - Confusion about where they are or what day it is
  - The need for help choosing proper clothing for the season or the occasion
  - Trouble controlling bladder and bowels in some individuals
  - Changes in sleep patterns, such as sleeping during the day and becoming restless at night
  - An increased risk of wandering and becoming lost
  - Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding
Severe Alzheimer’s Dementia

• In the final stage of this disease, individuals
  – Lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement.
  – As memory and cognitive skills continue to worsen, personality changes may take place and individuals need extensive help with daily activities.

• At this stage, individuals may:
  – Require full-time, around-the-clock assistance with daily personal care
  – Lose awareness of recent experiences as well as of their surroundings
  – Require high levels of assistance with daily activities and personal care
  – Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow
  – Have increasing difficulty communicating
  – Become vulnerable to infections, especially pneumonia

Treating Alzheimer’s disease

Currently, there is no cure or disease modifying treatment for Alzheimer’s disease. But drug and non-drug treatments may help with both cognitive and behavioral symptoms.

General Treatment Principles

Non-drug

• Set realistic goals
• Identify and treat comorbid medical illnesses, especially vascular risk factors, e.g., diabetes and high blood pressure
• Promote brain health by exercising, eating balanced diet, reducing stress, and keeping socially engaged
• Supervised exercise slows disability and prevents fall
• Avoid medications that can affect cognition, e.g., many over-the-counter sleep medications
• For problem behaviors, identify events or changes in a person environment that trigger the behaviors. Consider non drug strategies.

Treatment Options

Treatment of cognitive symptoms (memory loss, confusion, and problems with thinking and reasoning)
  – Cholinesterase inhibitors – Aricept, Exelon, Razadyne
  – Memantine (Namenda)
  – Vitamin E 2000IU/day

Treatment of problem behaviors (depends on the behavior, use carefully)
  – Antidepressants (for mood),
  – Anxiolytics (for anxiety/restlessness),
  – Antipsychotic medications (for hallucinations)