# Next Steps After Diagnosis: Care Management Conversations for Individuals Newly Diagnosed with Mild Cognitive Impairment (MCI) or Dementia

A tool for health care professionals (underlined text links to further resources)

## The Diagnosis

A diagnosis of Mild Cognitive Impairment (MCI), Alzheimer's disease or a related dementia reflects a doctor's best judgment about the cause of a person's symptoms.

### **Questions for your Doctor**

- Why was I diagnosed with this form of dementia?
- Where am I in the course of the disease?
- What can I expect in the future?
- How to Get a Diagnosis
- What to Bring to a Memory Assessment

#### What is Dementia

Dementia describes symptoms associated with a decline in memory, reasoning or other thinking skills. Many different types of dementia exist and it is not a normal part of aging. It is caused by damage to brain cells that affect a person's ability to communicate, which can affect thinking, behavior and feelings.

#### **Glossary of Dementias**

- <u>Alzheimer's disease</u>
- Creutzfeldt-Jakob Disease
- Down Syndrome and Alzheimer's
- <u>Frontotemporal Dementia</u>
- <u>Huntington's Disease</u>
- Korsakoff Syndrome
- Lewy Body Dementia
- Mild Cognitive Impairment
- <u>Mixed Dementia</u>
- Normal Pressure Hydrocephalus
- <u>Parkinson's Disease Dementia</u>
- Posterior Cortical Atrophy
- Traumatic Brain Injury
- Vascular Dementia

#### Treatment

Treatment goals will likely change over time. It is important to work closely with the doctor and other members of the health care team to create the best treatment plan.

 Medications for Memory, Cognition, and Dementia-Related Behaviors

## Emotional Considerations After Diagnosis

### Emotional Impact

Receiving a diagnosis of MCI, Alzheimer's disease or a related dementia is life-changing for both diagnosed individuals and those close to them. It is normal to experience a range of emotions after receiving a diagnosis. Acknowledging them can be an empowering first step in coping with the challenges ahead.

Just Diagnosed - Emotions

#### **Telling Others**

Sharing the diagnosis with others is an important step toward integrating the disease into your life. It is common for someone to hesitate to share their diagnosis with others.

• <u>Sharing Your Diagnosis</u>

### Impact on Relationships

A diagnosis of MCI or irreversible dementia may affect someone's relationships with family and friends. While abilities may change over time, living well with a diagnosis depends on how one chooses to continue being a partner in the relationship.

<u>Changes in Relationships</u>

#### **Overcoming Stigma**

Facing stigma is often a primary concern of people living with dementia and their care partners. Those with the disease report being misunderstood because of the myths and misconceptions other have about the disease.

- Overcoming Stigma
- You are More than Your Diagnosis
- Leaving Your Legacy

## Next Steps: Moving Forward

Make connections and take advantage of resources. There are people who understand what it is like to receive these diagnoses. There is much that a person living in the early stages can do to cope with the changes ahead.

#### **Read More**

- I Have Alzheimer's
- Get Educated: Why it's important to learn
- <u>Take Action Workbook: For People Newly</u> <u>Diagnosed</u>
- <u>Live Healthy</u>
- <u>Stages of Alzheimer's</u>
- Taking Care of Yourself
- <u>Reducing Stress</u>
- Tips for Daily Life
- Maximize Your Independence

#### Plan for the Future

- <u>Legal Planning</u>
- Financial Planning
- Building a Care Team
- End-of Life Planning

#### Get Educated: Listen or Watch

- Healthy Living with Mild Cognitive Impairment
- <u>Addressing Systemic Racism</u>
- Dementia Matters Podcast
- <u>Understanding Alzheimer's & Dementia</u>
- <u>Living with Dementia: For People Living with</u> <u>Alzheimer's or Other Dementia</u>
- Living with Alzheimer's: For Younger-Onset Alzheimer's
- <u>Managing Money</u>

#### Get Support, Build Community, Stay Engaged

- <u>Support Groups</u>
- <u>New Friends Program</u>
- <u>ALZConnected</u>
- <u>Virtual Memory Cafes</u>
- <u>Get Movin'</u>
- <u>Minds in Motion</u>
- <u>SPARK!</u>
- Amazing Grace Chorus®
- <u>Coulee Region Giving Hearts Choir</u>
- On a Positive Note Chorus
- Precious Memories Choir
- Stand in the Light Memory Choir



## Online Resources for Individuals Newly Diagnosed

## Support

- <u>24/7 Alzheimer's Association Helpline</u> <u>800.272.3900</u>
- Alzheimer's Foundation of America Helpline
- <u>Community Resource Finder</u>
- <u>Alzheimer's Navigator</u>

## **Community Partners**

- Disability Rights Wisconsin
- Wisconsin Aging & Disability Resource Centers
- <u>Wisconsin Alzheimer's Institute: Dementia</u> <u>Diagnostic Clinic Network</u>
- <u>Wisconsin Alzheimer's Institute: Milwaukee</u> <u>Services</u>
- <u>Alzheimer's Association Wisconsin Chapter</u>

## Safety

- Medication Safety
- <u>Home Safety</u>
- Dementia and Driving
- <u>Technology 101</u>

### <u>Research</u>

- National Institute on Aging: Alzheimer's Disease Research Centers
- <u>Wisconsin Alzheimer's Disease Research Center:</u> <u>Volunteer for a Study</u>
- Wisconsin Alzheimer's Disease Research Center
  Open Studies
- <u>Wisconsin Registry for Alzheimer's Prevention</u>
- <u>Wisconsin Brain Donor Program</u>

## **Clinical Trials**

- What are clinical trials?
- How clinical trials work
- Why participate in a clinical trial?
- <u>Talk to Your Doctor</u>
- <u>TrialMatch</u>