

## Dementia in Primary Care

In this module, learn about:

- Epidemiology and under-diagnosis of dementia
- Barriers to diagnosis
- Benefits of early diagnosis
- Signs that should trigger an investigation of possible dementia

### DEMENTIA – A GROWING HEALTH CONCERN

Diagnoses of Alzheimer's disease and *other dementia causing disorders* have grown rapidly in the last twenty-five years. It is estimated that 4.5 million Americans now have Alzheimer's - more than twice the number in 1980. Those numbers are only expected to rise in the years to come, with projections of a 44% increase by 2025, and perhaps a tripling of today's number by 2050. Even in Michigan, with a rate of growth in the elderly population significantly lower than that of the Sunbelt states, a 12% increase in people living with Alzheimer's is projected for the next two decades.

The impact of dementia can also be seen in its incidence, which rises rapidly as an older adult ages. Studies have shown that from age 65, incidence doubles every five years, and that up to 50% of those over age 85 are suffering from dementia.

Today, Alzheimer's disease and other dementias account for at least 40% and, by some estimates, up to 60% of nursing home admissions. Dementia is the third most expensive disease to treat in the United States, after cancer and heart disease. However, generally diagnoses of dementia are still not made until patients are quite far into the course of the disease, even though helpful interventions could be started much earlier.

### THE ROLE OF THE PRIMARY CARE PHYSICIAN

The symptoms of Alzheimer's disease (and many other dementias) develop so slowly that they can go unnoticed for a very long time. Or, if they are observed, changes may seem so slight that their significance is not recognized. Additionally, the lack of self-awareness that is part of dementia makes it less likely that patients will report their own problems.

Despite these and other impediments to the timely assessment of cognitive impairment, current knowledge and assessment tools can lead to earlier diagnoses of dementia than is now the norm. The primary care physician who knows what signs to look for in elderly patients and what follow-up tools are available can act as an effective early warning system. In fact, the physician who routinely assesses elderly patients for early signs of dementia is often the key to determining whether patients and families will receive information, guidance, and appropriate interventions when they can help the most.

The effects of those interventions should not be underestimated. Many primary care physicians are unaware of recent changes in treatments for Alzheimer's and related disorders, and of the effective medications that are available. These medications can be successfully prescribed and managed in a primary care setting. In general, the earlier they are started, the better.

Given the prevalence of Alzheimer's in patients over age 65, dementia is a possibility that ought to be in the forefront of our thinking when seeing older patients. As primary care physicians, we can familiarize ourselves with the common triggers that should raise the suspicion of dementia. These triggers include communication problems, missed appointments, medication management issues, a history of delirium, and more, discussed in detail later in this module.

⌘ Dementia is a significant problem for elderly patients, their families and society as a whole.

⌘ Primary care physicians can improve the rate of early diagnosis and treatment.

## **COMMON BARRIERS TO DIAGNOSIS**

Early diagnosis of dementia can make a significant difference in the lives of patients and their families and caregivers, but it is relatively rare that a diagnosis is made early in the course of the disease. Most diagnoses are made much later, at a point when the patient is suffering from serious functional as well as cognitive decline.

The insidious onset of dementia is not the only reason it goes undiagnosed. There are also barriers to diagnosis that relate to patients and their families, physicians and their practices, and the attitudes of the larger culture. For example, there are individuals who may be so frightened by symptoms of mental decline that they deny them, or busy office practices for which the time commitment to diagnose and manage dementia might seem overwhelming. And to the degree that the subject of dementia is considered taboo in our society, it is easy to respond to barriers with silent acquiescence. But to a large extent, these obstacles and the concerns that lie behind them can be addressed through education of practitioners and the public.

One of the biggest concerns is that making the diagnosis of dementia will open a whole Pandora's Box of troubles – a series of problems that will only expand and never be resolved. Given the degenerative course of the disease and its incurable nature, this attitude understandably gives rise to the feeling that the topic is best avoided. But while the frightening diagnosis of dementia might suggest a state of affairs that is beyond control, there are steps that can be taken to improve a difficult situation.

Understanding the facts about barriers and misconceptions is a good place to start.

### *Barriers- Uncertainty about the Diagnosis*

Because the symptoms of the most common dementia disorders reveal themselves so slowly, over the course of months and years, it can be difficult for physicians to identify dementia in its earliest stage. It may be hard to recognize that a problem even exists especially when our encounters with a patient are isolated and relatively brief, and concerns are not raised by family members or office staff. Unless a patient comes in with a specific complaint related to memory or confusion, it's quite possible that no immediate cause for concern in those areas will present itself.

But even when the suspicion is raised by a patient, family or office staff, or through the use of screening tools, this is only a first step in diagnosis. We must then ask if dementia really is involved. Or is, perhaps, a condition whose symptoms mimic dementia, like depression or delirium, involved? Further evaluation will be required to resolve these questions.

Physicians might also ask whether a patient's dementia results from Alzheimer's disease or some other cause of dementia. Again, additional evaluation can help provide answers, and these answers will sometimes influence treatment decisions. But it is important to note that Alzheimer's is by far the leading cause of dementia in the population aged 65 and older. Alzheimer's alone or in combination with vascular dementia accounts for 70% of dementia in that age group. A consensus panel representing the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society has recommended Alzheimer's be considered a "diagnosis of inclusion." That is, unless specific, positive findings indicate another form of dementia or a disorder that mimics dementia, it is appropriate for the physician to make a clinical diagnosis of Alzheimer's. It should also be noted that Alzheimer's disease is often involved even when other causes of dementia are identified. Clinicians who see dementia in elderly patients can reasonably assume that Alzheimer's is what they should always suspect.

⌘ Alzheimer's is by far the most common cause of dementia in the elderly population, and is often present even when other causes are identified.

The primary care physician can accurately diagnose Alzheimer's and other dementias in an office setting. We simply need to be alert to common triggers and warning signs of dementia, and to employ easy-to-use cognitive screening tools (both triggers and tools are discussed in the Clinical Diagnosis section of this module). When findings are ambiguous, repeated observations and testing over time will lead to a clear answer. Given dementia's slow onset, it cannot be overemphasized that this "diagnosis over time" is central to our ability to correctly identify and treat it in the primary care setting.

### *Barriers – Mistaking Signs of Dementia for Normal Aging*

Instances of mild memory loss and cognitive slowing are common as we grow older and include: forgetting where we placed the car keys, occasionally failing to remember a name, and slowing down on some problem solving tasks. It may be hard to distinguish these common losses from the earliest stage of dementia.

However, as dementia progresses, the distinctions between disease and normal signs of aging are apparent.

### Signs of Normal Aging Compared with Signs of Dementia

NORMAL AGING	DEMENTIA
Occasional short-term memory lapses (lost details can be restored by prompts)	Increasing short-term memory problems, which interfere with daily living (unresponsive to prompts because new memories are not being formed and cannot be retrieved)
Awareness of memory lapses	No awareness of memory problems Often needs reminders about appointments, medication schedule, etc.
Forgetting where car keys were left	Forgetting what car keys are for
Occasionally misplacing items	Frequently misplacing items Leaving things in unusual places (e.g., milk in the breadbox)
Occasionally forgetting a word	Frequent inability to come up with words, communicate clearly,

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	understand what is being said
Forgetting someone's name	Difficulty identifying a close friend or relative
Taking longer to perform tasks	Inability to perform familiar tasks
Taking longer to solve problems	Problems with abstract thinking
	<i>Additional symptoms that should be recognized as possible signs of dementia:</i>
	Withdrawal, loss of interest
	Mood and behavior changes
	Decreased ability to make good judgments
	Trouble remembering the date, time or place

A person might forget the location not only of keys, but of valuable objects. Failure to recall names becomes common, and the patient may have trouble remembering the names of close family members. Even simple tasks begin to cause difficulties. As these problems increase, along with declines in organizational ability and reading comprehension, they become more noticeable to family members. Additionally, those close to the patient may see signs of behavior changes that include paranoia, withdrawal or poor hygiene. These symptoms are not signs of normal aging but of illness, and we ought to replace old assumptions about what is normal aging with increased clinical suspicion of dementia.

#### *Barriers – Lack of Appreciation for the Impact of Early Intervention*

It stands to reason that if we see no ready benefit, we will be less likely to move quickly toward a diagnosis of dementia. That's why it is important to know that addressing dementia early in its course can have a substantial positive impact on the lives of patients and families. This applies not only to drug therapies that might slow disease progression, but to the psychosocial aspects of the illness such as family stress and the patient's sense of control, and to physical safety issues. See the Benefits of Early Intervention section in this module for additional information.

#### *Barriers – Pessimism about Disease Progression and Outcome*

Without a clear understanding of the benefits that drug treatments and other interventions can bring to patients with dementia and their families, it is easy to view dementia disorders in an extremely pessimistic light. That the disease is incurable and irreversible may come to seem the only facts that count.

Thus, physicians may act or rather fail to act, on the unspoken assumption that diagnosis does not matter because “there’s nothing to be done.” This message may in turn be conveyed to patients and families even when it is not explicitly discussed. A pessimistic outlook leads physicians not to want to talk about dementia, and families not to want to ask.

### *Barriers – Inadequate Reimbursement*

The familiar issue of reimbursement that rewards procedures more than thorough doctor-patient communication can be a disincentive to evaluation and treatment of dementia. In addition, there are ICD-9 coding issues unique to dementia. Physicians generally tend to under-code for complex office visits, and are therefore under-reimbursed. If physicians do not overlook aspects of the evaluation and management of dementia patients that increase the complexity of visits, many of visits may qualify for a higher E/M code.

### *Barriers – Patient and Family Awareness*

People who begin to experience memory loss and confusion in the initial stage of dementia can find the experience frightening. Yet it may be hard for them to share their feelings and worries with family members or health professionals because they have a sense, as we all have, that naming out loud the thing we fear will make it so. This is the well-known phenomenon of denial, a defense mechanism that can certainly play a positive role in people’s lives, allowing them to digest unpleasant facts at a manageable pace. But when denial becomes fixed and allows no room at all for reality to settle in, it stands in the way of a timely diagnosis, and getting the help the patient needs

Just as individuals who suffer from the onset of dementia try to hide the facts from themselves and others, family members may also practice denial. They too fear for their loved one’s future, and so they see but refuse to acknowledge the signs of dementia. They might even compensate for the ill person’s increasing deficits, offering to “share” tasks but in fact taking them over because the individual is no longer competent. This can go on for months and years, as the problem only continues to worsen.

## **BENEFITS OF EARLY DIAGNOSIS**

A diagnosis of dementia is most likely to be made well into the course of the disease, when the patient has begun to have serious trouble carrying out the activities of daily living and is showing impaired judgment. The disease has reached a point where family members can no longer ignore or deny it.

What this means in practical terms is that by the time the illness is recognized for what it is, the family is already in crisis. There may have been an accident or hospitalization, or a scary episode in which the ill person has become lost. The patient's ability to do basic self-care may in practical terms be gone. Patient and family are understandably confused and frightened, but hardly have room to respond emotionally because there are decisions that must be made – decisions they are totally unprepared to face.

At the same time, the physician will realize that the value of medications that might have slowed the patient's decline has diminished, and that time has been irretrievably lost.

When the diagnosis is made early, at a time when symptoms are present but less severe, it is possible to:

- Reduce family stress and burden
- Empower the person with dementia
- Use medications more effectively to improve status or slow progression of the disease
- Help insure the patient's safety
- Identify potentially reversible causes of dementia
- Identify disorders whose symptoms mimic dementia but require a different treatment

**☞ Early diagnosis has many benefits for patients and their families.**

### *Reducing Family Stress and Burden*

With good reason, dementia is often called a family disease. As the patient declines, family members must face the emotional stress of witnessing that decline, and they are faced with new challenges of providing care. Early diagnosis gives individuals with dementia and their families the opportunity to plan for changes before the need becomes urgent. For families especially, the ability to anticipate upcoming changes can reduce the stress of facing an uncertain future, and help them cope with those changes when they do occur.

Education, care training and support groups help family members learn ahead of time about the best tools for communicating with their loved one, for providing a safe and comfortable environment, and for controlling difficult behaviors. Studies have shown that family members who participate in training and support groups are able to care for the patient at home longer.

Early diagnosis also prepares family members for taking over roles that the person with dementia has previously been responsible for. And it gives them time to do financial and end-of-life planning in a thoughtful and considered way, often in collaboration with the dementia patient.

### *Empowering the Person with Dementia*

When faced with an illness whose course is one of continuing losses – losses of memory, of everyday abilities, of one’s entire sense of self – anything that puts control in the hands of the ill person is usually welcome. A diagnosis of dementia made early in the disease process does exactly that, affording patients some measure of control by giving them the chance to participate meaningfully in management and planning.

Support groups can help people with dementia adjust to changes brought on by illness, and empower them to decide for themselves what some of those changes will be. Patients can take charge by setting priorities and acting on them – by choosing, to whatever extent circumstances allow, what they will do next.

At this early stage, patients can also meaningfully participate in making plans for the future related to finances, care giving, and end-of-life decisions.

### *Benefits – Effects of Medication*

Our understanding of the effectiveness of medications to treat the most common forms of dementia has changed dramatically. It is now widely accepted that cholinesterase inhibitors and memantine slow the rate of decline in cognitive function in Alzheimer’s, which has a clearly positive impact on the lives of patients and their families. Similar benefits have been shown in vascular dementia. The benefits of current medications are real and significant even when there is no measurable *improvement* in the patient’s symptoms.

The initial practice of giving a patient a trial of one of these drugs and then watching for improvement is no longer appropriate. Every patient who can tolerate these medications ought to be on them, as they have demonstrated significant value in slowing decline, including delay in nursing home placement.

Cholinesterase inhibitors, which slow the progress of disease, should be prescribed early, since lost function cannot be restored with our current knowledge. Additionally, there is evidence to suggest that earlier treatment with them yields greater benefits.

Medications can also be used to alleviate symptoms such as anxiety and depression that often accompany dementia, and to address problem behaviors.

⌘ Cholinesterase inhibitors slow the rate of decline in cognitive function and should be started as early as possible in the course of the most common dementias in elderly patients.

### *Benefits – Safety Issues*

It often takes a car accident, or a fall or other mishap at home, to bring families face to face with the problems that a loved one with dementia is experiencing. However, even these triggers might not lead to a proper diagnosis if they can be easily explained away as isolated incidents. But early diagnosis of dementia can help minimize the possibility these accidents will occur. The patient's ability to drive can be carefully assessed, and plans can be made to provide alternative transportation solutions. At the same time, families can begin to modify the home environment for safety.

### *Benefits – Identifying Potentially Reversible Causes of Dementia*

Although signs of dementia most often indicate that Alzheimer's or a related degenerative disorder is present, differential diagnosis may reveal another factor that is contributing to the syndrome or, in some cases, is the sole cause. Sometimes these other disorders can be treated and their symptoms reversed. Differentiating these separate causes sooner means earlier intervention in a potentially reversible illness, and greater possibility that the intervention will succeed.

Such reversible causes of dementia include: metabolic disturbances, vascular disease, thyroid dysfunction, vitamin B<sub>12</sub> or folate deficiency, infection, and normal pressure hydrocephalus. They are discussed in [Module 2 – Clinical Diagnosis of Dementia](#).

### *Benefits – Identifying Conditions that Mimic Dementia*

The primary care physician may see patients whose presentation raises suspicion of dementia, but who in fact are exhibiting signs of another treatable disorder. Depression and delirium in particular may be mistaken in the elderly for dementia.

It is important to be aware, however, that either delirium or depression may also coexist with dementia. These issues are discussed in greater detail [Module 2 – Clinical Diagnosis of Dementia](#).

## CLINICAL DIAGNOSIS TRIGGERS

When the early signs of Alzheimer's and other dementias go undetected, physicians miss an important opportunity to improve the lives of patients and families. Early intervention can have significant impact on the course of the disease and on the families' ability to cope with it. Therefore, it is essential that we identify the problem as soon as possible, even though the insidious onset of the most common dementias makes this more difficult.

Physicians should also be aware that recognizing the dementia syndrome in the first place is the biggest hurdle they face. The initial step of clearly recognizing dementia amid the many other details of an elderly patient's clinical presentation is not easily done. Once this step has been accomplished, the most set of barriers have been overcome. Differential diagnosis may bring to light a reversible cause of dementia or affect the precise course of treatment, yet the steps to be followed in that state of assessment are relatively easy to lay out.

⌘ Failure to recognize dementia is the single biggest problem in dementia care.

The Alzheimer's Association lists ten warning signs of Alzheimer's disease and other dementias.

**Ten Warning Signs of Alzheimer's**  
(Alzheimer's Association, used by permission)

1. **Memory loss.** Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.

**What's normal?** Forgetting names or appointments occasionally.

2. **Difficulty performing familiar tasks.** People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game.

**What's normal?** Occasionally forgetting why you came into a room or what you planned to say.

3. **Problems with language.** People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the toothbrush, for example, and instead ask for "that thing for my mouth."

**What's normal?** Sometimes having trouble finding the right word.

4. **Disorientation to time and place.** People with Alzheimer's disease can become lost in their own neighborhood, forget where they are and how they got there, and not know how to get back home.

**What's normal?** Forgetting the day of the week or where you were going.

5. **Poor or decreased judgment.** Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment, like giving away large sums of money to telemarketers.

**What's normal?** Making a questionable or debatable decision from time to time.

6. **Problems with abstract thinking.** Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are for and how they should be used.

**What's normal?** Finding it challenging to balance a checkbook.

7. **Misplacing things.** A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.

**What's normal?** Misplacing keys or a wallet temporarily.

8. **Changes in mood or behavior.** Someone with Alzheimer's disease may show rapid mood swings – from calm to tears to anger – for no apparent reason.

**What's normal?** Occasionally feeling sad or moody.

9. **Changes in personality.** The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.

**What's normal?** People's personalities do change somewhat with age.

10. **Loss of initiative.** A person with Alzheimer's disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.

**What's normal?** Sometimes feeling weary of work or social obligations.

As valuable as these signs can be for family members, they cannot always be observed in an office visit. However, the clinician is often presented with other facts about a patient that ought to *trigger* an evaluation of possible dementia.

These triggers can be grouped into five main categories. Note that the office staff may also need to be educated about these behaviors that raise the question of dementia.

### Communication

Consider dementia when an elderly patient:

- Misses office appointments
- Calls the office frequently or inappropriately
- Misses paying bills
- Has trouble handling paperwork
- Has difficulty following directions
- Is confused about medication or treatment instructions
- Has difficulty making medical decisions
- Engages in repetitive speech

### Accidents

Consider dementia in cases of:

- Motor vehicle accidents
- Fractures
- Falls
- Increased frequency of emergency room visits

### Medical Triggers

Consider dementia when an elderly patient:

- Has delirium or a history of delirium
- Has suffered a CVA – incidence of dementia increases significantly after stroke

- Has unexplained weight loss – increasing evidence shows this may be a presenting sign of dementia

### Change in Functional Status

Consider dementia when an elderly patient:

- Has decreased ability to carry out the instrumental activities of daily living

### **INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)**

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Activity	Need No Help (2 pts. each)	Need Some Help (1 pt. each)	Unable to Do At All (0 pts. each)
1. Using the Telephone	___	___	___
2. Getting to Places Beyond Walking Distance	___	___	___
3. Grocery Shopping	___	___	___
4. Preparing Meals	___	___	___
5. Doing Housework or Handyman Work	___	___	___
6. Doing Laundry	___	___	___
7. Taking Medications	___	___	___
8. Managing Money	___	___	___
Total Score: ___ =	(___ x 2 =) ___ +	(___ x 1 =) ___ +	0

- Moves to senior housing or assisted living
- Presents signs of self-neglect (e.g., hygiene, grooming)
- Becomes less compliant with medication
- Gets lost
- Requires transportation
- Is accompanied to office visits by a family member

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- Defers to a family member in answering questions

### Cognition Changes

Consider dementia when:

- An elderly patient or family member reports memory problems
- The patient is unable to list current medications
- The patient is unable to recall recommendations from a prior visit
- The patient is a poor historian
- The patient makes mistakes with medications or problems do not respond to usual medical management
- The patient experiences late life depression
- A family member calls prior to an office visit to inform the physician of concerns the patient may not mention