Tools for

Early Identification, Assessment, and Treatment

for People with

Alzheimer's Disease

and

Dementia

A publication of the Chronic Care Networks
for Alzheimer's Disease initiative

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Tools for Early Identification, Assessment, and Treatment for People with Alzheimer's Disease and Dementia

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Chronic Care Networks for Alzheimer's Disease: About the Initiative

Between 1998 and 2003 national and local partnerships of the Alzheimer's Association and National Chronic Care Consortium (NCCC) members demonstrated that networks of integrated care, support, and education can be developed to incorporate the range of services needed by people with dementia and can function under risk-based managed care financing or traditional Medicare. Furthermore, these networks result in high levels of satisfaction on the part of participating patients, family caregivers, primary healthcare providers, and Alzheimer's Association chapter staff. (See latest evaluation reports at http://www.ncconline.org.)

The national and local partners are committed to ongoing dissemination of user-friendly products, materials, tools, program descriptions, and other innovations developed through the demonstration. The materials that follow are current as of the date at the bottom of this page. Changes can and will be made to these materials as the experience of initiative implementation and evaluation suggests improvements.

Unless otherwise noted, the tools and information in this publication were developed by the Care Management Advisory Group and the Education and Support Advisory Group of the Chronic Care Networks for Alzheimer's Disease (CCN/AD) initiative. Duplication for educational and clinical purposes is authorized without prior written approval if acknowledgment is given to the National Chronic Care Consortium and the Alzheimer's Association as the source. Notification of use and suggestions for improvement are appreciated. Contact the National Chronic Care Consortium, 8100 26th Avenue South, Suite 120, Bloomington, MN 55425.

The latest version of these tools along with descriptive material about the conduct of the initiative and its research results can be found on the NCCC Web site at http://www.ncconline.org.

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Tools for Early Identification of Dementia

Dementia is very prevalent among the elderly but is often overlooked even by skilled clinicians. Clues to the presence of dementia may be subtle and nonspecific. Unrecognized dementia may lead to iatrogenic illness, unnecessary workups driven by vague symptoms, inappropriate and costly utilization of hospital and emergency room care, and poor outcomes. Improving our ability to recognize dementia is a key first step toward improving this widespread situation.

The Chronic Care Networks for Alzheimer's Disease early identification process uses two tools to identify people who may have dementia and should receive a full assessment. The flowchart on the next page illustrates the early identification process.

Tool 1: Education and Awareness Materials—Triggers

The early identification process is based on recommendations from the Agency for Health Care Policy and Research (AHCPR) Clinical Practice Guideline, *Early Identification of Alzheimer's and Related Dementias*.* This clinical practice guideline recommends the use of triggers to identify people with possible dementia.

The CCN/AD initiative uses separate but somewhat overlapping sets of triggers from three sources. These are:

- The Alzheimer's Association publication, *Ten Warning Signs of Alzheimer's Disease*

- A list of patient behavior triggers for clinical staff developed by the Care Management Advisory Group of the CCN/AD

- The triggers recommended in the AHCPR Clinical Practice Guideline, *Early Identification of Alzheimer's and Related Dementias**

The triggers should be used creatively in training sessions to increase awareness of dementia among all care system staff, health plan enrollees, and families. Useful strategies will vary in each health plan and clinic but may include training physicians and other staff, sending regular publications to enrollees, and displaying posters and pamphlets in clinic waiting areas.

Tool 2: Family Questionnaire

Family members are likely to be aware of signs and symptoms of possible dementia that are not readily apparent to clinical staff.

People who are identified as possibly having dementia by the triggers (Tool 1) and/or the Family Questionnaire should receive an Initial Dementia Assessment.

Note: Until February 2001 CCN/AD used a third tool that has been removed from the CCN/AD model based on the rational on page 11.

*Source:
  Costa, P. T., Jr., T. F. Williams, M. Somerfield, et al. 1996. "Early Identification of Alzheimer's Disease and Related Dementias." *Clinical Practice Guideline, Quick Reference Guide for Clinicians, No. 19.* Rockville, Md.: U.S. Department of Health and Human Services. AHCPR Publication No. 97-0703.

Flowchart for Tools for Early Identification of Dementia

Medical office staff and health plan enrollees and their families recognize signs and symptoms of possible dementia based on triggers from the Alzheimer's Association's "Ten Warning Signs," the list of patient behaviors for clinical staff, and the AHCPR guidelines	Family Questionnaire indicates possible dementia

Initial Dementia Assessment

Negative workup →

Uncertain results →

Monitor by reassessing triggers and administering MMSE every 6 months

Delirium or depression →

Treat and reassess

Diagnosis of dementia

Use care management tool and family support tool

Early Identification Tool 1
Alzheimer's Association Ten Warning Signs

The Alzheimer's Association developed the following checklist of common symptoms. (Some of them also may apply to other dementing illnesses.) Individuals with several of these symptoms should see a physician for a complete examination.

_____ 1. **Memory loss**. One of the most common early signs of dementia is forgetting recently learned information. While it's normal to forget appointments, names, or telephone numbers, those with dementia will forget such things more often and not remember them later.

_____ 2. **Difficulty performing familiar tasks.** People with dementia often find it hard to complete everyday tasks that are so familiar we usually do not think about how to do them. A person with Alzheimer's may not know the steps for preparing a meal, using a household appliance, or participating in a lifelong hobby.

_____ 3. **Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease often forgets simple words or substitutes unusual words, making his or her speech or writing hard to understand. If a person with Alzheimer's is unable to find his or her toothbrush, for example, the individual may ask for "that thing for my mouth."

_____ 4. **Disorientation to time and place.** It's normal to forget the day of the week or where you're going. But people with Alzheimer's disease can become lost on their own street, forget where they are and how they got there, and not know how to get back home.

_____ 5. **Poor or decreased judgment.** No one has perfect judgment all of the time. Those with Alzheimer's may dress without regard to the weather, wearing several shirts or blouses on a warm day or very little clothing in cold weather. Individuals with dementia often show poor judgment about money, giving away large amounts of money to telemarketers or paying for home repairs or products they don't need.

_____ 6. **Problems with abstract thinking.** Balancing a checkbook may be hard when the task is more complicated than usual. Someone with Alzheimer's disease could forget completely what the numbers are and what needs to be done with them.

_____ 7. **Misplacing things.** Anyone can temporarily misplace a wallet or key. A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.

_____ 8. **Changes in mood or behavior.** Everyone can become sad or moody from time to time. Someone with Alzheimer's disease can show rapid mood swings—from calm to tears to anger—for no apparent reason.

_____ 9. **Changes in personality.** People's personalities ordinarily change somewhat with age. But a person with Alzheimer's disease can change a lot, becoming extremely confused, suspicious, fearful, or dependent on a family member.

_____ 10. **Loss of initiative.** It's normal to tire of housework, business activities, or social obligations at times. The person with Alzheimer's disease may become very passive, sitting in front of the television for hours, sleeping more than usual, or not wanting to do usual activities.

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Early Identification Tool 1
Patient Behavior Triggers for Clinical Staff

Individuals with undiagnosed dementia may exhibit behaviors or symptoms that offer a clue to the presence of dementia and can be observed by physicians, nurses, and other clinical and office staff. Educational sessions and discussions with all office staff can create an awareness on everyone's part that general decline or change of the nature listed below on the part of a patient is worthy of note to a clinician for further attention.

Some examples:

The patient

✓ Is a "poor historian" or "seems odd"

✓ Is inattentive to appearance, inappropriately dressed for the weather, or dirty

✓ Fails to appear for scheduled appointments or comes at the wrong time or on the wrong day

✓ Repeatedly and apparently unintentionally fails to follow instructions (e.g., changing medications)

✓ Has unexplained weight loss, "failure to thrive," or vague symptoms (e.g., weakness or dizziness)

✓ Seems unable to adapt or experiences functional difficulties under stress (e.g., the hospitalization, death, or illness of a spouse)

✓ Defers to a caregiver—a family member answers questions directed to the patient

In addition to failure to arrive at the right time for appointments, the clinician can look for difficulty discussing current events in an area of interest and changes in behavior or dress. It also may be helpful to follow up on areas of concern by asking the patient or family members relevant questions.

All of the above needs to be modified to an office's own patient panel and can be strengthened with case examples.
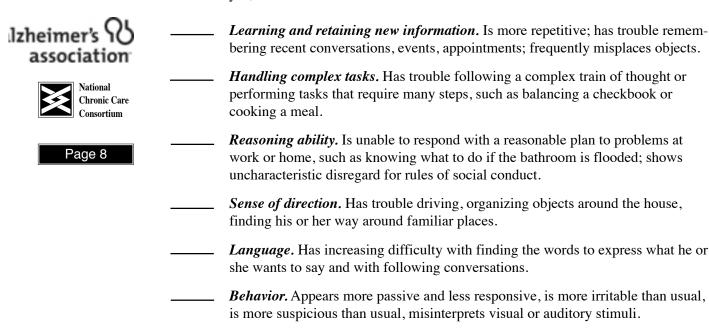
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Revised May 2003

Early Identification Tool 1
Symptoms That May Indicate Dementia

Many older adults suffer from dementia. Positive answers to the following questions can help to identify possible dementia.

Does the person have increased difficulty with any of the activities listed below? If the answer is yes, he or she should receive a dementia assessment from a doctor.

_____ *Learning and retaining new information.* Is more repetitive; has trouble remembering recent conversations, events, appointments; frequently misplaces objects.

_____ *Handling complex tasks.* Has trouble following a complex train of thought or performing tasks that require many steps, such as balancing a checkbook or cooking a meal.

_____ *Reasoning ability.* Is unable to respond with a reasonable plan to problems at work or home, such as knowing what to do if the bathroom is flooded; shows uncharacteristic disregard for rules of social conduct.

_____ *Sense of direction.* Has trouble driving, organizing objects around the house, finding his or her way around familiar places.

_____ *Language.* Has increasing difficulty with finding the words to express what he or she wants to say and with following conversations.

_____ *Behavior.* Appears more passive and less responsive, is more irritable than usual, is more suspicious than usual, misinterprets visual or auditory stimuli.

Experience from the CCN/AD Initiative Sites

Even though sites found significant overlap between this AHCPR (now AHRQ) list and the Alzheimer's Association's "Ten Warning Signs," they found both to be useful in different applications. The authority and medical source for the AHCPR symptoms list seemed especially important in physician training sessions. Other office staff, patients, and family members seemed to respond better to the "Ten Warning Signs.")

Source:
Costa, P. T., Jr., T. F. Williams, M. Somerfield, et al. 1996. "Early Identification of Alzheimer's Disease and Related Dementias." *Clinical Practice Guideline, Quick Reference Guide for Clinicians, No. 19*. Rockville, Md.: U.S. Department of Health and Human Services. AHCPR Publication No. 97-0703.

Early Identification Tool 2
Family Questionnaire

We are trying to improve the care of older adults. Some older adults develop problems with memory or the ability to think clearly. When this occurs, it may not come to the attention of the physician. Family members or friends of an older person may be aware of problems that should prompt further evaluation by the physician. Please answer the following questions. This information will help us to provide better care for your family member.

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In your opinion does _____ have problems with any of the following?
Please circle the answer.

1. Repeating or asking the same thing over and over?	*Not at all*	*Sometimes*	*Frequently*	*Does not apply*
2. Remembering appointments, family occasions, holidays?	*Not at all*	*Sometimes*	*Frequently*	*Does not apply*
3. Writing checks, paying bills, balancing the checkbook?	*Not at all*	*Sometimes*	*Frequently*	*Does not apply*
4. Shopping independently (e.g., for clothing or groceries)?	*Not at all*	*Sometimes*	*Frequently*	*Does not apply*
5. Taking medications according to instructions?	*Not at all*	*Sometimes*	*Frequently*	*Does not apply*
6. Getting lost while walking or driving in familiar places?	*Not at all*	*Sometimes*	*Frequently*	*Does not apply*

Relationship to patient _____
(spouse, son, daughter, brother, sister, grandchild, friend, etc.)

This information will be given to the patient's primary care provider. If any additional testing is appropriate, he or she will let you know. Thank you for your help.

Revised May 2003

Early Identification Tool 2
Use of the Family Questionnaire

The Family Questionnaire is designed to help us identify patients with memory problems that might otherwise go unnoticed. It consists of five simple questions. A family member or friend of the patient can complete the questionnaire in less than a minute.

When to Use the Family Questionnaire
- If the patient has no prior diagnosis of dementia
- If the patient is aged 65 or older
- If the patient comes to the clinic in the company of a family member or friend
- If the questionnaire has not been completed in the past year

We encourage the use of the Family Questionnaire for *all* patients who meet *all* of these criteria.

How to Use the Family Questionnaire
First, find out if a family member or friend has come in with the patient.

When you are checking vital signs and collecting other screening information, tell the patient you have a brief questionnaire for his or her family member or friend that will help us find out if the patient has trouble remembering or thinking clearly. Explain that these symptoms may not come to our attention unless we ask about them and that the information will help us take better care of the patient. Show the questionnaire to the patient if he or she asks to see it. Be sure the patient consents, then present the questionnaire to the family member or friend.

Use the information on the questionnaire itself when you explain it to the family member. Ask the family member to return it to you once it is complete; score the questionnaire, and attach it to the patient's chart.

Scoring: Not at all = 0   **Total Score:** _____
              Sometimes = 1
              Frequently = 2

Score Interpretation: A score of 3 or more should prompt the consideration of a more detailed evaluation.

Experience from the CCN/AD Initiative Sites
Although some staff at CCN/AD sites were concerned that patients might become upset when their family members or friends were asked to complete the Family Questionnaire, this problem did not occur at any of our sites.

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Rationale for the Removal of the High-Risk Screening Tool

When the CCN/AD model was designed, we believed that use of the triggers and the Family Questionnaire would identify many individuals with possible dementia *and* that healthcare organizations would want to reduce the total number of individuals who went on to receive a full diagnostic assessment. Therefore, we created what we believed would be a very difficult brief mental status test by taking the most difficult items from the Mini Mental State Examination (MMSE) and adding the Clock Drawing.[1] The test we created, the High-Risk Screening Tool, was intended to be used *after* individuals were identified on the basis of the triggers and/or the Family Questionnaire, and it was intended to *rule out* individuals who were very unlikely to have dementia. We set a very high score—individuals would have to score perfectly on the test to be ruled out. We reasoned that individuals with dementia would be very unlikely to score perfectly on this difficult mental status test.

After the CCN/AD sites began implementing the model, we heard about three kinds of problems with the use of the High-Risk Screening Tool:

- Staff at some sites said they were not using it due to resistance of physicians and other clinical staff.

- Staff at some sites were completing the High-Risk Screening Tool as a required activity, but they were completing it after they had already decided to proceed with the Initial Dementia Assessment. That was not the intended use of the High-Risk Screening Tool. Moreover, since the MMSE is part of the Initial Dementia Assessment and since the MMSE and the High-Risk Screening Tool include two identical items (name and remember three objects and spell "world" backwards), using both results in duplication of effort for clinicians and individuals with possible dementia.

- Staff and clinicians at some sites used or were thinking about using the High-Risk Screening Tool to screen for possible dementia in individuals who had not been previously identified on the basis of the triggers or the Family Questionnaire. That was not the intended use of the High-Risk Screening Tool, and it is probably a very poor tool for that purpose. As noted above, we created the High-Risk Screening Tool to be used *after* someone has indicated concern about the individual on the basis of the triggers or the Family Questionnaire, and we created what we thought would be a very difficult test that would identify only those individuals who are very unlikely to have dementia *even though someone had identified them on the basis of the triggers or the Family Questionnaire*.

All screening tests have the same two *potential* problems: false positives (that is, situations where the test indicates the person has the condition, but he or she really doesn't) and false negatives (that is, situations where the test indicates the person does not have the condition, but he or she really does). We believe that the High-Risk Screening Tool used as a screening test for individuals who have not been previously identified on the basis of the triggers or the Family Questionnaire will produce *many* false positives. False positives result in

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[1] Two comprehensive literature reviews show that the items we selected from the MMSE are the most difficult items on the MMSE [Tombaugh, and McIntyre, 1992. *Journal of the American Geriatrics Society* 40(9):922–35.] and that one of the items we selected from the MMSE and the clock drawing are two of the four most difficult items on any of the widely used brief mental status tests. [Siu, A. L. 1991. "Screening for Dementia and Investigating Its Causes." *Ann. of Intern. Med.* 115:122–32.]

Rationale for the Removal of the High-Risk Screening Tool (cont.)

unnecessary work for staff. More importantly, *false positives create unnecessary fear and time-consuming tests for individuals and their families*. (False negatives are probably less of a problem with the High-Risk Screening Tool because the test is so difficult, but we have no data to support that idea.)

Other brief mental status tests (for example, the MMSE and the 7-Minute Screen) are probably less likely than our High-Risk Screening Tool to produce large numbers of false positives when used for screening purposes in a general population because they include some less difficult questions, and they do not require perfect scores as our High-Risk Screening Tool did. On the other hand, research suggests that all brief mental status tests are likely to result in false positives.[2] In addition, as many of our sites found, individuals who score above the usual cutoff score on the MMSE (for example, 24–29) may nevertheless have dementia. For these reasons a committee of Alzheimer's experts formed by the Agency for Health Care Policy and Research recommended against screening for dementia in general populations of elderly people.[3] An international consensus group of Alzheimer's experts also recommended against screening for dementia in general populations of elderly people, concluding that "cognitive testing should occur for older patients when there is a reason to suspect dementia. Testing may occur in an individual considered to be at risk because of an informant history of cognitive or functional decline, clinical observation, or, sometimes, very old age."[4] In November 2000 the Medical and Scientific Advisory Council of the Alzheimer's Association reaffirmed its recommendation against screening for dementia in general populations of elderly people.

[2] In 1980–81 the federal government sponsored a large-scale survey, the Epidemiologic Catchment Areas (ECA) study in five sites in the United States. In all sites, a probability sample of adults was interviewed using the MMSE and other tests. Thus, the MMSE was used in the general population—not just people who are suspected for some reason to have dementia. In the East Baltimore site subjects whose scores on any of the tests indicated that they might have a cognitive or psychiatric disorder were then interviewed by a psychiatrist who used standardized clinical methods to make a clinical diagnosis based on DSM III criteria. Of those aged 65 and over who scored below 24 on the MMSE (the usual cutoff score for the MMSE), only 26.4 percent had dementia; 5 percent had delirium; others had other psychiatric disorders, and 33.1 percent had no diagnosable cognitive or psychiatric disorder. Thus, the use of the MMSE in this general population generated a very high rate of false positives. [Folstein, et al. 1985. *Journal of the American Geriatrics Society* 33(4):228–35.]

[3] Costa, P. T., Jr., T. F. Williams, M. Somerfield, et al. 1996. "Early Identification of Alzheimer's Disease and Related Dementias." *Clinical Practice Guideline, Quick Reference Guide for Clinicians, No. 19*. Rockville, Md.: U.S. Department of Health and Human Services of Health and Human Services. AHCPR Publication No. 97-0703.

[4] Brodaty, et al. 1998. *Alzheimer's Disease and Associated Disorders* 12(1):1–13.

Initial Dementia Assessment for Primary Care Providers: Three Levels of Investigation

Attached is the approach to dementia assessment developed by the Care Management Advisory Group of the Chronic Care Networks for Alzheimer's Disease initiative. These recommendations are based upon the Advisory Group's evaluation of currently available practice guidelines regarding dementia assessment and work by Siu. The guidelines were developed for implementation in primary care-driven, managed care settings. In such settings where there may be more opportunities for practicing population-based care and using non-physician personnel, the detection and workup of dementia is likely to be different than in fee-for-service settings. In developing the recommended assessment, the Advisory Group considered both comprehensiveness and cost effectiveness.

The approach to dementia assessment recommended by the Advisory Group assumes that people with possible dementia have been identified using case finding methods such as provider education about signs and symptoms of possible dementia, use of a family questionnaire, or other health risk assessments. It is not expected that all parts of the assessment will necessarily be implemented in one visit, rather two or three visits could be required.

The results of the Initial Dementia Assessment (IDA) support both the physician's diagnosis and the development of a care plan and management of care over time.

The Advisory Group recommends a three-step approach to assessment. The examinations and tests listed in Level 1 should be done for all clients. We estimate that 65 percent of clients will need no more than this level of assessment. Level 2 examinations and tests should be done for all clients unless there is relative certainty about the diagnosis based upon the Level 1 information, or the results of a Level 2 test would not change the care plan. We estimate that virtually all remaining clients will be in this category. Level 3 interventions are rarely needed in the routine assessment and management of dementia in primary care settings. However, if onset is early (age < 65), if course is atypical, or if diagnostic uncertainty is high, they may be helpful.

Sources:

Costa, P. T., Jr., T. F. Williams, M. Somerfield, et al. 1996. "Early Identification of Alzheimer's Disease and Related Dementias." *Clinical Practice Guideline, Quick Reference Guide for Clinicians, No. 19.* Rockville, Md.: U.S. Department of Health and Human Services. AHCPR Publication No. 97-0703.

Siu, A. L. 1991. "Screening for Dementia and Investigating Its Causes." *Ann. Intern. Med.* 115:122–32.

Veterans Health Administration. 1977. *Dementia Identification and Assessment: Guidelines for Primary Care Practitioner.* U.S. Dept. of Veterans Affairs.

Work Group on Alzheimer's Disease and Related Dementias. 1997. "Practice Guidelines for the Treatment of Patients with Alzheimer's Disease and Related Dementias of Late Life." *American Journal of Psychiatry* 154 (Supplement):1-39.

Initial Dementia Assessment
Level 1—For All Patients

Note: This workup assumes that the patient has met early identification criteria indicating the need for assessment or that the patient or caregiver has requested an in-depth assessment.

Interview (should be corroborated with family or caregiver)
- Focused history—Patterns of losses, behavioral issues, current functioning, safety concerns, onset of memory and other cognitive problems
- Past medical history—Risk factors, head trauma, neurological conditions
- Geriatric review of systems—Continence, driving, falls, constipation, vision and hearing, dental, depression, neurologic symptoms
- Social and family history
- Review of medications—Prescriptions, OTC
- Review of preventive interventions—Immunizations, appropriate cancer screening
- Advance healthcare directive status—Expressed wishes, chosen surrogate

Family Interview (without patient present)
- Caregiver strain—Reports by caregivers of negative consequences of caregiving for their: health, relationship with care receivers, non-caregiving social activities, and perceived ability to function effectively in the caregiver role. *MBRC Caregiver Strain Instrument* (Attachment 5)
- Caregiver perceptions of patient's cognitive and behavioral symptoms—Caregiver reports of common symptoms of dementia. *Cognitive Incapacity & Problem Behaviors Assessment* (Attachment 6)

Examination
- Physical exam—Hearing and vision screens, orthostatic blood pressure
- Neurologic exam—Cranial nerves, muscle strength and tone, tremor, localized findings, deep tendon and pathologic reflexes
- Functional status—*Functional Activities Questionnaire* (FAQ) and *Activities of Daily Living* (ADL) (Attachments 3 and 4)
- Mental status assessment—*Mini-Mental State Examination* (MMSE)* (Attachment 1)
- Depression assessment—*Geriatric Depression Scale* and *Single-Item Depression Indicator* (Attachment 2)

Laboratory Tests (prior laboratory studies should be sufficient if done within a relatively recent time frame)
- CBC
- Glucose
- Serum electrolytes
- BUN/creatinine
- TSH
- Drug levels (e.g., digoxin)

Therapeutic "Diagnostic" Tests
- Remove possible offending medications
- Treat depression

*Use of the MMSE is required in the Chronic Care Networks for Alzheimer's Disease sites. Other instruments mentioned in this section are highly recommended.

Initial Dementia Assessment
Attachment 1—Mini-Mental State Examination (MMSE)*

The MMSE was a required part of the Initial Dementia Assessment for the CCN/AD initiative and was previously included in the Tools for Early Identification, Assessment, and Treatment for People with Alzheimer's Disease and Dementia *document. Due to copyright restrictions that took effect after the CCN/AD tools document was developed, we can no longer reproduce the MMSE. MMSE sources are listed at the bottom of this page. Copyright and purchasing information is listed below.*

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Sources:

Crum, R. M., J. C. Anthony, S. S. Bassett, and M. F. Folstein. 1993. "Population-Based Norms for the Mini-Mental State Examination by Age and Educational Level." *J. Am. Med. Assoc.* 269:2386-91.

Folstein, M. F., S. E. Folstein, and P. R. McHugh. 1975. "Mini-Mental State: A Practical Method for Grading the Cognitive State of Patients for the Clinician." *J. Psych. Res.* 12:196–8.
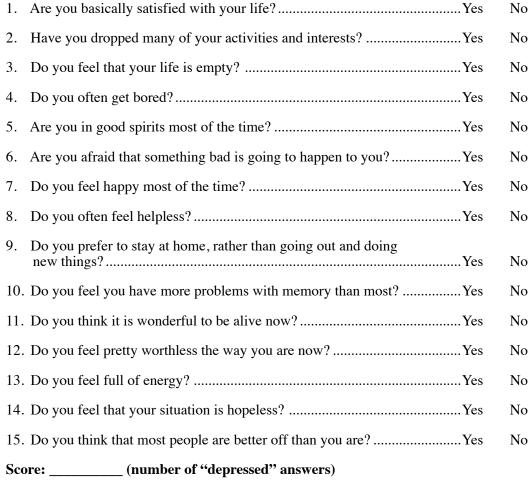
Initial Dementia Assessment
Attachment 2—Geriatric Depression Scale (GDS) and Single-Item Depression Indicator

Geriatric Depression Scale

1. Are you basically satisfied with your life?...Yes   No

2. Have you dropped many of your activities and interests? ....Yes   No

3. Do you feel that your life is empty? ....Yes   No

4. Do you often get bored?..Yes   No

5. Are you in good spirits most of the time? ....Yes   No

6. Are you afraid that something bad is going to happen to you?..................Yes   No

7. Do you feel happy most of the time? ....Yes   No

8. Do you often feel helpless? ....Yes   No

9. Do you prefer to stay at home, rather than going out and doing
   new things?..Yes   No

10. Do you feel you have more problems with memory than most? ....Yes   No

11. Do you think it is wonderful to be alive now? ....Yes   No

12. Do you feel pretty worthless the way you are now? ....Yes   No

13. Do you feel full of energy? ....Yes   No

14. Do you feel that your situation is hopeless? ....Yes   No

15. Do you think that most people are better off than you are? ....Yes   No

Score: _____   (number of "depressed" answers)

Five or more depressed responses warrants further evaluation.

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The following question could be used instead of the GDS (see Mahoney, et al., 1994) or in addition to the GDS. If using both, consider asking the Single-Item question *not* in direct sequence with the GDS.

Single-Item Depression Indicator

1. Do you often feel sad or depressed?   Yes   No

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Sources:
Lachs, M. S., et al. 1990. "A Simple Procedure for General Screening for Functional Disability in Elderly Patients." *Ann. Intern. Med.* 112(9):699–706.
Mahoney, J., et al. 1994. "Screening for Depression: Single Question versus GDS." *JAGS* 42(9):1006–8.
Sheikh, J. I., and J. A. Yesavage. 1986. "Geriatric Depression Scale (GDS): Recent Evidence and Development of a Shorter Version." In *Clinical Gerontology: A Guide to Assessment and Intervention,* edited by T. L. Brink, 165–75. New York: Haworth Press.

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Scoring:

"Depressed" answers are:

"No" on numbers 1, 5, 7, 11, 13

"Yes" on numbers 2, 3, 4, 6, 8, 9, 10, 12, 14, 15

1–4 No cause for concern

5–9 Strong probability of depression

10+ Indicative of depression

Initial Dementia Assessment
Attachment 3—Functional Activities Questionnaire (FAQ)

The FAQ is an informant-based measure of functional abilities. Informants provide performance ratings of the target person on ten complex higher-order activities.

Individual Items of the FAQ

1. ____Writing checks, paying bills, balancing checkbook

2. ____Assembling tax records, business affairs, or papers

3. ____Shopping alone for clothes, household necessities, or groceries

4. ____Playing a game of skill, working on a hobby

5. ____Heating water, making a cup of coffee, turning off stove

6. ____Preparing a balanced meal

7. ____Keeping track of current events

8. ____Paying attention to, understanding, discussing a TV show, book, magazine

9. ____Remembering appointments, family occasions, holidays, medications

10. ____Traveling out of neighborhood, driving, arranging to take buses

Total _____

The levels of performance assigned range from dependence to independence and are rated as follows.

- Dependent = 3
- Requires assistance = 2
- Has difficulty, but does by self = 1
- Normal = 0

Two other response options can also be scored.

- Never did (the activity), but could do now = 0
- Never did, and would have difficulty now = 1

A total score for the FAQ is computed by simply summing the scores across the 10 items. Scores range from 0 to 30. A cutpoint of 9 (dependent in 3 or more activities) is recommended.

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Initial Dementia Assessment
Attachment 4—Activities of Daily Living (ADL)

Please circle the response that you feel best represents the person's ability to do each of the following activities of daily living.

Activity:	Needs no assistance or supervision	Needs some assistance or supervision	Totally dependent/ cannot do at all
Eating	0	1	2
Toileting	0	1	2
Bathing (sponge, shower, or tub)	0	1	2
Dressing	0	1	2
Grooming (combing, shampooing hair; shaving; trimming nails)	0	1	2
Transferring	0	1	2

Total Score _____

Source:
Katz, S., A. B. Ford, R. W. Moskowitz, B. A. Jackson, and M. W. Jaffe. 1963. "Studies of Illness in the Aged. The Index of ADL: A Standardized Measure of Biological and Psychosocial Function." *Journal of the American Medical Association* 185:914–9.

Initial Dementia Assessment
Attachment 5—MBRC Caregiver Strain Instrument

A primary caregiver is the family member or friend who gives the most help to someone with a health problem. The following items refer to how a caregiver feels and behaves as a result of providing care.

Please use the following scale to answer questions 1–14. There are no right or wrong answers.

- Strongly agree = 3
- Agree = 2
- Disagree = 1
- Strongly disagree = 0

During the past four weeks, because of helping the patient, I felt:

1. ____unsure whether he/she was getting proper care.

2. ____uncertain about how to best care for him/her.

3. ____that I should be doing more for him/her.

4. ____that I could do a better job of caring for him/her.

5. ____that he/she tried to manipulate me.

6. ____that my relationship with him/her was strained.

7. ____that he/she made requests over and above what he/she needed.

8. ____resentful toward him/her.

9. ____angry toward him/her.

10. ____my physical health was worse than before.

11. ____downhearted, blue, or sad more often.

12. ____more nervous or bothered by nerves than before.

13. ____I had less pep or energy.

14. ____bothered more by aches and pains.

Caregiver Mastery Score _____ (Sum of items 1–4)

Relationship Strain Score _____ (Sum of items 5–9)

Health Strain Score _____ (Sum of items 10–14)

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Initial Dementia Assessment
Attachment 5—MBRC Caregiver Strain Instrument (cont.)

Please use the following scale to answer questions 15–19. There are no right or wrong answers.

- Less often = 2
- The same = 1
- Strongly disagree = 0

During the past four weeks, because of helping the patient, I:

15. ____participated in church or religious activities.

16. ____visited with friends or family.

17. ____participated in group or organized activities.

18. ____engaged in volunteer activities.

19. ____went out to dinner, the theater, or a show.

Activity Restriction Score _____ (Sum of items 15–19)

No exact cutting points for heightened caregiver risk have been determined for this tool. Answers can help caregivers describe difficulties they are experiencing, and with repeated administrations, it can be used to assess change in the care situation over time. However, scores greater than 8 for mastery, greater than 10 for relationship strain or health strain, or greater than 5 for activity restriction may indicate heightened risk and may warrant further clinical investigation.

Sources:
Bass, D. M., L. S. Noelker, and L. R. Rechlin. 1996. "The Moderating Influence of Service Use on Negative Caregiving Consequences." *Journals of Gerontology* 51B:S121–31. Used by permission of the Margaret Blenkner Research Center at The Benjamin Rose Institute.
Bass, D. M., M. J. McClendon, G. T. Deimling, and S. Mukherjee. 1994. "The Influence of Diagnosed Mental Impairment on Family Caregiver Strain." *Journals of Gerontology* 49:S146–55. Used by permission of the Margaret Blenkner Research Center at The Benjamin Rose Institute.

Initial Dementia Assessment
Attachment 6—Cognitive Incapacity & Problem Behaviors Assessment

A primary caregiver is the family member or friend who gives the most help to someone with a health problem. Primary caregivers may help with personal care (e.g., bathing, dressing), instrumental daily activities (e.g., housekeeping, laundry, shopping), or health-related decisions (e.g., when to seek care, what types of treatments to select). Because of this help, caregivers can give important information about possible symptoms that may not be noticed during a visit to the doctor or other care provider.

Please indicate the best response for each behavior listed using the following scale. There are no right or wrong answers.

- Most or all of the time = 3
- Often = 2
- Sometimes = 1
- None of the time = 0

How often in the past four weeks did the patient:

1. _____ act confused?

2. _____ talk or mumble to him/herself?

3. _____ repeat the same thing over and over?

4. _____ hear or see things that were not there?

5. _____ forget the names of his/her family or close friends?

6. _____ forget the right words to use?

7. _____ yell or swear at people?

8. _____ interfere or offer unwanted advice?

9. _____ act restless or agitated?

10. _____ act fearful without good reason?

11. _____ complain about or criticize things?

12. _____ show inappropriate sexual behavior?

13. _____ wander outside the house?

14. _____ refuse to be left alone?

Cognitive Score _____ (Sum of items 1–6)

Behavior Score _____ (Sum of items 7–14)

No exact cutting points for heightened caregiver risk have been determined for this tool. However, cognitive symptom scores greater than 7 may indicate heightened risk of caregiving problems and may warrant further clinical investigation. The presence of any behavior symptoms may warrant further investigation, with values greater than 2 indicating heightened risk.

Source:

Bass, D. M., M. J. McClendon, G. T. Deimling, and S. Mukherjee. 1994. "The Influence of Diagnosed Mental Impairment on Family Caregiver Strain." *Journals of Gerontology* 49:S146–55. Used by permission of the Margaret Blenkner Research Center at The Benjamin Rose Institute.

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Initial Dementia Assessment
Level 2—For Most Patients

Note: These tests are always worth considering as part of the assessment. If one decides not to do them there should be good justification.

Laboratory Tests
- Liver function tests

- B12 and folate levels

- VDRL (some argue FTA instead)

- Calcium

Brain Imaging*

CT scanning without intravenous contrast will detect hydrocephalus and most clinically significant mass lesions, infarcts, and subcortical ischemic changes (see note below). This study is suitable for most patients who require brain imaging. For individuals over age 75 with a classic history of Alzheimer's disease and normal neurological examination, CT scanning is unlikely to produce any clinical benefit. For those patients, brain imaging is not essential for appropriate diagnosis and treatment.

Note: No controlled studies compare the diagnostic sensitivity of non-contrast CT with contrast CT or CT with MRI in the evaluation of patients with dementia.

*Sources:
Clarfield, A. M., and E. B. Larson. 1990. "Should a Major Imaging Procedure (CT or MRI) Be Required in the Workup of Dementia? An Opposing View." *J. Fam. Pract*. 31:405–10.
Corey-Bloom, J., L. J. Thal, D. Galasko, M. Folstein, D. Drachman, M. Raskind, et al. 1995. "Diagnosis and Evaluation of Dementia." *Neurology* 45:211–8.
Frank, C. 1998. "Dementia Workup: Deciding on Laboratory Testing for the Elderly." *Can. Fam. Physician* 44:1489–95.
Siu, A. L. 1991. "Screening for Dementia and Investigating its Causes." *Ann. Intern. Med*. 115:122–32.
Small, G. W., P. V. Rabins, P. P. Barry, et al. 1997. "Diagnosis and Treatment of Alzheimer's Disease and Related Disorders: Consensus Statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association and the American Geriatrics Society." *JAMA* 278(16):1363–71.
Grossman, C. B. 1990. "Clinical Computed Tomography Application." In *Magnetic Resonance Imaging and Computed Tomography of the Head and Spine*. Baltimore: Williams & Wilkins. Pg. 22–37.

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Initial Dementia Assessment
Level 3—For Some Patients

Note: These examinations and tests are rarely needed in routine assessment and manage-ment of dementia in primary care settings. However, if onset is early (age < 65), if course is atypical, or if diagnostic uncertainty is high, they may be helpful.

Consultation
Neurology or psychiatry

Neuropsychological Evaluations
Neuropsychological testing is of value in confirming the presence of dementia when the diagnosis is in doubt, in clarifying dementia type, and in differentiating dementia from mental illness, including depression.

Laboratory Tests
- Genetic testing *(e.g., CAG triple repeat for Huntington's disease)*

- Heavy-metal screen

- Copper, ceruloplasmin for Wilson's disease

Studies
- Lumbar puncture *(e.g., if there is a positive syphilis history or screening exam, meningitis history, mixed dementia/delirium, unusual presentation with varying course)*

- EEG *(if partial or generalized seizures are a consideration)*

- SPECT, diffusion MRI *(These are primarily research tools, rarely needed for clinical management.)*

A rationale should be recorded when Level 3 examinations or tests are used.

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Care Management Blueprints for Alzheimer's Disease

This tool provides information and a basic structure that healthcare organizations and partnerships should use to establish their own approach to care management, consistent with their organizational structure(s) and care practices. The attached grids show desired outcomes, assessment procedures, goals, and possible interventions for medical and non-medical care management in three phases of disease (initial identification, longitudinal monitoring and treatment, and end-of-life) and for six important domains of care:

Domain 1. Patient Function
Patient functioning at maximum level of independence consistent with physical potential and patient and caregiver wishes.

Domain 2. Caregiver Support
Caregiver(s) identified and given information and support to best balance his or her caregiver role and personal life in accordance with caregiver needs and wishes.

Domain 3. Medical Care
Patient receives optimal medical care consistent with accepted standards of care and patient and caregiver preference.

Domain 4. Psychosocial
Patient and caregiver understand monitoring parameters to assess mood and behavioral concerns and are satisfied with management strategies employed.

Domain 5. Patient Nutrition
Patient is in targeted body weight range, and patient and caregiver are satisfied with diet and nutritional status.

Domain 6. Advance Directives Planning
Patient and caregiver understand purpose of Advance Directives/Living Will/Durable Power of Attorney for Health Care (DPOAHC), enact them according to personal values and needs, and ultimately see wishes followed.

Experience from the CCN/AD Initiatives Sites
CCN/AD sites found that this comprehensive tool was useful in training and in building relationships among the partnering organizations at each site. Shorter, less complex tools for day-to-day care management were developed at some sites, and several of these tools are available at http://www.nccconline.org.

Domain 1
Patient Function

	Initial Identification Phase	Longitudinal Monitoring and Treatment Phase	End-of-Life Phase
Pathway Outcome	Patient functioning at maximum level of independence consistent with patient/caregiver wishes	Patient maintaining targeted functional levels	Patient/caregiver satisfied with approaches being used to address functional needs
Assessment	• Assess patient/caregiver concerns regarding functional abilities • Obtain baseline information regarding ADL, IADL, continence, falls, driving, safety, assistive devices	• Assess for new patient/caregiver concerns regarding functional abilities • Evaluate for new safety concerns such as falls, wandering • Evaluate for medical complications related to functional decline (skin breakdown, weakness, weight loss, side effects)	• Evaluate patient/caregiver concerns regarding functional decline • Assess degree of functional dependency • Determine if current approaches used to meet functional needs are satisfactory to caregiver • Evaluate for medical complications related to functional dependencies
Goal Formation	• Establish functional goals in conjunction with patient/caregiver, aiming for the most satisfactory level of independence in self-care, mobility, and continence • Maximize safety • Specify time frames for reaching goals	Adjust functional goals as appropriate in conjunction with patient/caregiver	Adjust functional goals in conjunction with patient/caregiver to maximize satisfaction, comfort, and dignity
Interventions	Consider: • OT, PT referrals • Exercise program • Driving evaluation • Educational materials regarding home safety • Home safety assessment • Medication adjustment • Toileting program • ID bracelet	Consider: • Previous interventions	Consider: • In-home nursing/assistance/aides • Hospice referral • Support groups
Response	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met
Supporting documents might include functional assessment tools (Barthel Index, Katz ADL Scale), safety checklist, educational materials, and medical alert information.			

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Domain 2
Caregiver Support

	Initial Identification Phase	**Longitudinal Monitoring and Treatment Phase**	**End-of-Life Phase**
Pathway Outcome	Caregiver(s) is identified and given information and support in accordance with his or her needs/wishes	Caregiver(s) is supported to enable him or her to maximize caregiving role(s) while maintaining appropriate balance in personal life	Caregiver(s) achieves maximum satisfaction with his or her role(s)
Assessment	• Identify current and potential caregivers • Record contact information in patient chart • Assess caregiver concerns, agenda, needs, availability • Assess caregiver knowledge • Assess caregiver role with ADLs/IADLs • Assess caregiver perception of patient's living environment (appropriateness and safety)	• Update caregiver information • Follow up on status of previous caregiver concerns and needs • Assess for new issues and burdens • Assess caregiver role with ADLs/IADLs • Assess caregiver perception of patient's living environment (appropriateness and safety)	• Assess caregiver comfort/concerns with end-of-life issues • Assess burden of caregiver tasks and need for respite • Evaluate caregiver perception of patient's environment regarding appropriateness for meeting end-of-life needs
Goal Formation	• Provide caregiver with information, referrals, and resource materials • Establish caregiver role(s) as appropriate in conjunction with patient/caregiver	• Review/revise caregiver roles as appropriate according to changing needs in conjunction with patient/caregiver • Provide caregiver support to maximize ability to fulfill role with appropriate balance and satisfaction	Adjust caregiver roles by providing additional support services as needed to achieve maximum caregiver satisfaction
Interventions	Refer to Alzheimer's Association and consider: • Educational materials • Counseling referral • Social work referral • Support group • Respite services/aide services • Family meeting • Other community referrals • Home nursing referrals • PT/OT/SLP referrals • Chaplaincy referral	Refer to Alzheimer's Association and consider: • Previous interventions • Chaplaincy referral	Refer to Alzheimer's Association and consider: • Previous interventions • Hospice referral
Response	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met
Supporting documents might include information from the Alzheimer's Association chapter, community services, and educational materials. (Caregiver Support Planning Tool is attached, see page 31.)			

Domain 3
Medical Care

	Initial Identification Phase	Longitudinal Monitoring and Treatment Phase	End-of-Life Phase
Pathway Outcome	Patient receives optimal medical care consistent with accepted standards of care and patient/caregiver preferences	Patient receives optimal medical management with emphasis on 2° and 3° prevention consistent with accepted standards of care and patient/caregiver wishes	Patient/caregiver satisfied with medical management of symptoms
Assessment	• Perform (review) dementia and general assessment (see second component) • Record assessment results in chart including medical problem list, medications, pertinent physical exam, MMSE, vision/hearing screen, laboratory results • Prioritize symptoms in conjunction with patient/caregiver	• Evaluate status of previous symptoms • Assess for new symptoms since last visit • Review medications for effectiveness, compliance, and potential side effects • Repeat MMSE every 6 months or sooner as appropriate until patient scores 10 or less • Perform focused physical exam based on symptoms/ concerns • Update medical problem list	• Evaluate status of all symptoms • Review medications for effectiveness, compliance, and potential side effects • Perform focused physical exam based on symptoms/concerns
Goal Formation	• Establish treatment goals to optimize health and function for the patient in conjunction with patient/caregiver • Specify time frames for reaching goals	• Review previous goals and establish new goals in conjunction with patient/caregiver • Specify time frames for reaching goals	• Establish treatment goals to achieve greatest patient/caregiver satisfaction regarding symptom management • Specify time frames for reaching goals
Interventions	Consider: • Additional diagnostic testing • Specialty referrals • Medication changes • Educational materials • Audiology referral • Home nursing referral • PT/OT/SLP referrals	Consider: • Previous interventions	Consider: • Previous interventions • Hospice referral • Chaplaincy referral • Social work referral
Response	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met
Supporting documents might include dementia assessment tool, MMSE, sample forms for medical problem/medication lists, and flow sheets.			

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Domain 4
Psychosocial

	Initial Identification Phase	Longitudinal Monitoring and Treatment Phase	End-of-Life Phase
Pathway Outcome	Patient/caregiver understand monitoring parameters to assess mood and behavioral concerns	Patient receives optimal management of depression, disruptive behaviors consistent with patient/caregiver wishes	Patient/caregiver satisfied with management strategies used to address moods/behaviors and adjustment to end of life
Assessment	• Assess patient/caregiver concerns regarding mood, depression, sleep patterns, disruptive behaviors, agitation, aggression, wandering, etc. • Administer depression scale (GDS) • Assess patient/caregiver priorities regarding quality-of-life issues • Evaluate environmental factors affecting moods/behaviors • Evaluate relationship of activities/schedule to moods/behaviors • Evaluate relationship of other symptoms to moods/behaviors	• Evaluate current status of previously identified moods and behavioral problems • Review available behavior logs/diaries/reports for response to interventions and for new problems • Reassess for signs of depression • Update relationship of environment, activity, and other symptoms to moods/behaviors • Reassess patient/caregiver priorities regarding quality-of-life issues	• Assess patient/caregiver satisfaction regarding management of moods/behaviors • Update previous assessment
Goal Formation	• Establish methods/parameters to monitor moods/behaviors • Establish treatment goals for targeted moods/behaviors	Select management strategies to improve targeted symptoms, moods/behaviors in conjunction with patient/caregiver	Select management strategies to maximize end-of-life comfort regarding moods/behaviors in conjunction with patient/caregiver
Interventions	Consider: • Diary/behavior log • Social work referral • Psychology referral • Support group • Respite care • Home aide • Medications • Family meetings • Educational materials • Chaplaincy referral	Consider: • Previous interventions • Behavior management techniques • Changes in medications • Changes in schedule/activities • Changes in environment	Consider: • Previous interventions • Hospice referral
Response	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met
Supporting documents might include educational materials, depression scales, and behavior monitoring tools.			

Domain 5
Patient Nutrition

	Initial Identification Phase	Longitudinal Monitoring and Treatment Phase	End-of-Life Phase
Pathway Outcome	Patient in ideal body weight range	Patient maintaining targeted body weight	Patient/caregiver satisfied with diet and nutritional status
Assessment	• Evaluate patient/caregiver status and wishes regarding nutritional status • Evaluate diet and nutritional status • Assess eating function • Evaluate how food is obtained and prepared • Obtain history of weight changes • Measure weight • Evaluate for edema and hydration • Evaluate dentition • Evaluate pharmaceutical/ nutrient interactions	Evaluate for change since last assessment	Adjust goals to maximize patient/caregiver satisfaction
Goal Formation	• Establish weight/nutritional goals in conjunction with patient/caregiver • Establish home monitoring parameters in conjunction with patient/caregiver • Specify time frame for reaching goals	Adjust weight and nutritional goals as appropriate, in conjunction with patient/caregiver	• Evaluate for change since last assessment • Reassess Advance Directives regarding feeding/nutritional issues with patient/caregiver
Interventions	Consider: • Swallowing evaluation • Dietician referral • Nutritional supplements • Diet changes • Home delivered or other meals program • Social work referral • Caregiver educational materials • Dental referral	Consider: • Previous interventions	Consider: • Previous interventions • Feeding tube (only if consistent with patient/ caregiver wishes and goals) • Hospice referral
Response	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met

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Domain 6
Advance Directives Planning

	Initial Identification Phase	**Longitudinal Monitoring and Treatment Phase**	**End-of-Life Phase**
Pathway Outcome	Patient/caregiver understand purpose of Advance Directives/ Living Will/Durable Power of Attorney for Health Care	Patient/caregiver enact Advance Directive as legally allowed according to cognitive status	Patient/caregiver wishes regarding end-of-life care are followed
Assessment	• Assess patient/caregiver readiness to discuss Advance Directives • Assess patient values/agenda regarding medical treatment • Assess patient ability to understand Advance Directives • Evaluate patient/caregiver knowledge regarding Advance Directives • Assess for conflict or inconsistencies in treatment wishes	• Evaluate patient/caregiver need for additional information • Review decisions regarding Advance Directives; statements regarding treatment wishes, limitations, etc. with patient/caregiver as appropriate • Repeat elements of original identification phase assessment for patient/ caregiver if previously deferred or declined	• Evaluate for changes in patient/caregiver wishes regarding treatment decisions • Assess for conflicts among patient/family members/caregivers
Goal Formation	Provide information/documents to patient/caregiver according to identified needs	Obtain copies of Advance Directive statements regarding treatment wishes, limitations for chart(s)	• Resolve any conflicts among patient/ caregiver/ family members • Maximize patient/ caregiver satisfaction with end-of-life treatment decisions
Interventions	Consider: • Educational materials • Social work referral • Chaplaincy referral • Psychology referral • Legal counsel • Support group referral	Consider: • Previous interventions	Consider: • Previous interventions • Hospice referral
Response	• Verify that information/ documents are received and reviewed • Adjust goals or strategies if goals not met	• Verify that documents are on chart • Adjust goals or strategies if goals not met	• Assess goal attainment • Adjust goals or strategies if goals not met
Supporting documents might include copies of Advance Directives, legal information regarding Advance Directives/Living Will/Durable Power of Attorney for Health Care, and educational materials.			

Living with Dementia:
Caregiver Support Planning Tool

This tool was designed to help healthcare organizations and partnerships of organizations improve their readiness to assist and support family caregivers of people with Alzheimer's disease and related dementias. The tool uses a conceptual framework that was developed by Wayne Caron, Ph.D., and his colleagues at the University of Minnesota.[1] The framework defines phases of caregiving in terms of the tasks and challenges faced by families as they experience the progressive changes in a person with these conditions. The six phases of caregiving in the Caron framework are: (1) prediagnostic, (2) diagnostic, (3) role change, (4) chronic caregiving, (5) transition to alternative care, and (6) end of life (see note below).

The CCN/AD Caregiver Support Planning Tool includes a brief description of each of the six phases of caregiving from the Caron framework and general interventions for that phase. A grid for each phase lists specific objectives CCN/AD sites hoped to achieve for family caregivers in that phase.

In developing this tool, the CCN/AD Education and Support Advisory Group considered using a conceptual framework based on stages of Alzheimer's disease or other dementias. The Advisory Group chose the Caron framework instead because it reflects an awareness that the tasks and challenges for family caregivers do not necessarily follow the same time sequence as stages of the disease. Some families face the task of getting a diagnosis when the person is in a very early stage of his or her disease, while others do not face this task until much later in the person's disease. Likewise, the tasks and challenges of transition to alternative care occur for some families at a much earlier point in the person's disease than for other families. The tool is intended to identify programs and materials that meet family caregivers' needs regardless of the person's stage of disease.

Many different kinds of interventions may be useful to family caregivers in each phase of caregiving. The CCN/AD sites have used the grids to identify information, programs, and services that are available in their communities and to decide which of the partnering organizations (for example, the Alzheimer's Association chapter or healthcare system) will be responsible for providing them or referring people to them. Most CCN/AD sites were able to fill most of the cells in each grid, but the grids have also been useful in identifying gaps for which new materials and programs are needed.

Note: Wayne Caron and his associates at the University of Minnesota use their model, including the phase framework, to guide family therapy and support services for caregivers. Their application of the model reflects its foundation in family systems theory and collaborative family healthcare models. For further information about their model and its application, please contact Wayne Caron, Ph.D., L.M.F.T, at the University of Minnesota, College of Human Ecology, Department of Family Social Science, (612) 625-1790, or e-mail wcaron@tc.umn.edu.

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[1]Caron, W. A, J. J. Pattee, and O. J. Otteson. 2000. *Alzheimer's Disease: The Family Journey.* Plymouth, Minn.: North Ridge Press.

This tool was developed by the Education and Support Advisory Group of the Chronic Care Networks for Alzheimer's Disease initiative and is the joint property of the National Chronic Care Consortium and the Alzheimer's Association. Distribution for educational and clinical purposes is authorized without prior written approval if acknowledgment is given to the National Chronic Care Consortium and the Alzheimer's Association as the source. Notification of use and suggestions for improvement are appreciated. Contact the National Chronic Care Consortium, 8100 26th Avenue South, Suite 120, Bloomington, MN 55425.

Living with Dementia:
Caregiver Support Planning Tool (cont.)

Experience from the CCN/AD Initiative Sites

In the CCN/AD initiative, the partnering healthcare organizations and Alzheimer's Association chapters at each site completed the grids by identifying available programs, materials, and services that could be used to meet each objective and noting which of the partnering organizations would be responsible for providing or referring family caregivers to these programs, materials, and services. The sites found that this exercise was very useful as an initial cross-training exercise because it increased each organization's awareness and understanding of the capabilities and resources of the other organization. By completing the grids, sites also became aware of gaps in available programs, materials, and services, and organizations at some sites were able to take steps to fill the identified gaps. Despite the usefulness of completing the grids for cross-site training and gap identification, the sites found that the completed grids were not an effective tool for day-to-day practice. For this purpose, a shorter list of programs, materials, and services is essential, and project staff at the sites developed such lists for their communities. The sites also found that the conceptual value of the Caron framework was often lost in the work of identifying specific programs, materials, and services. As a result of their experience with the Caregiver Support Planning Tool, the sites have made the following recommendations:

1. The Caron framework should be used for initial and ongoing training to emphasize the concept that the tasks and challenges faced by family caregivers of a person with dementia do not necessarily follow the same time sequence as the stages of the person's disease.

2. For cross-training purposes, partnering organizations should complete at least a few rows on each grid to increase understanding of the capabilities and resources each organization brings to the partnership.

3. Partnering organizations should develop a relatively short list of available programs, materials, and services to be used for day-to-day referrals.

In the CCN/AD initiative, some of the objectives listed in the grids were used for evaluation purposes: in telephone interviews, family caregivers were asked questions intended to determine whether the services offered through CCN/AD had achieved these objectives. The particular objectives that were used in this way were those identified as most important by site-level project staff; they are marked with a double asterisk.

Six-Phase Model for Helping Families with Alzheimer's Disease

Phase 1. Prediagnostic

During this time there is a growing awareness that something is wrong. Both the family and the person with dementia are trying to decide how seriously they should take memory lapses, functional impairments, or periods of confusion. This phase may last for years. A major task for the family is to monitor things over time to see if they get better, stay the same, or get worse. The primary issue during this time is arriving at a realistic understanding among family members about the illness.

Suggested Intervention

Provide information that is helpful in resolving the ambiguity, educational materials on Alzheimer's disease containing clear information to help families understand their situation, and concrete steps that families can take.

Phase 2. Diagnostic

Sooner or later, as symptoms of cognitive impairment accumulate or a single, critical event occurs—making it impossible to believe nothing is wrong—families will obtain a diagnosis. The family must deal with the emotional issues of fear, sadness, anger, and denial that will be present and begin to process the meaning of the diagnosis. They must decide whom to tell about the diagnosis and find a way to maintain family morale and hope in the face of lost dreams for the future.

Suggested Intervention

Offer a one-session family consultation, the purpose of which is not to give the family more information, but rather to offer family members the opportunity to process information they have already received and to facilitate family communication and processing of the diagnosis.

Phase 3. Role Change

With the progression of impairment, the person with dementia changes from a competent, independent adult into a person who requires help with all activities of daily living. Family roles also change as the caregiving system is organized and the family begins to take greater control over the elder's life. Tasks must be assigned to different family members with a means to monitor and encourage each to take a fair share. The family must understand what the person with dementia can and cannot do and adapt situations to maximize his or her participation. Both the person with Alzheimer's and the family must deal with issues of significant loss.

Suggested Intervention

Provide educational programs, parallel support groups, and individual and family counseling to help families accept the losses of roles. Services for the person with dementia are critical to help him or her maintain a sense of self and morale.

Six-Phase Model for Helping Families with Alzheimer's Disease (cont.)

Phase 4. Chronic Caregiving

With the continued loss of abilities, the person with dementia requires greater amounts of help with activities such as dressing, bathing, grooming, toileting, and feeding. The major challenge for the family is to stave off the physical and emotional exhaustion of caregiving. Support systems must be alert to signs of exhaustion, burnout, or depression among all family members, including the person with dementia, and plans must be developed to provide respite and maintain energy in daily life. Family members can be organized as case managers to help identify appropriate services in the community and develop the means for using these services with the least amount of stress on the primary caregiver and person with dementia. At this phase the disease crowds out normal family life.

Suggested Intervention

Provide psycho-educational programs for the entire family to minimize caregiver stress and connect caregivers with community services such as day care programs, support groups, and caregiver skills training programs to provide concrete guidance in caring for the person with dementia, the caregiver, and the family system.

Phase 5. Transition to Alternative Care

As caregiving resources are exhausted, it is often no longer possible to care for the person with dementia at home, necessitating placement in a nursing home or other care facility. The family must be provided assistance to help identify the point at which placement should occur, making sure to consider the needs of all family members. This traumatic event marks the end of personal caregiving and requires a shift into collaborative caregiving with appropriate role expectations.

Suggested Intervention

Offer services that address the demoralization families experience with placement, and facilitate development of collaborative care relationships between family and facility staff.

Phase 6. End of Life

Families are faced with many decisions regarding care and the treatment of potentially life-threatening illnesses. The family must not only witness but also participate in the dying of the person with dementia. Based upon the foundation of values and benefits unique to each family, the ethical dilemmas faced in making end-of-life treatment decisions must be resolved. The family must be helped to develop an image of a "good death," including important rituals and legacies, which will help bring closure and meaning at the point of death.

Suggested Intervention

Support families as they anticipate death and multiple difficult decision-making situations. Involving the primary medical provider to educate the family on treatment options is crucial.

Programs and Materials for People with Alzheimer's Disease and Related Disorders
Prediagnostic Phase

	Objective	Program(s)*	Provided By	Appropriate Materials*
1.**	Know general information about dementia versus aging.			
2.	Know how to communicate with physician.			
3.**	Know steps for getting a diagnosis.			
4.	Have a positive attitude toward getting a diagnosis.			
5.	Discuss concerns openly with healthcare providers.			
6.	Believe options are available if diagnosis is irreversible dementia.			
7.	Have confidence in provider's ability to refer for information and services.			
8.	Call community agency with questions.			
9.**	Know what educational and supportive services are available in the health plan and community.			

*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural, and economic backgrounds and different primary languages.
**These objectives were identified as most important by site-level project staff and were used for evaluation purposes (see page 32).

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Programs and Materials for People with Alzheimer's Disease and Related Disorders
Diagnostic Phase

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	Objective	Program(s)*	Provided By	Appropriate Materials*
1.**	Obtain an accurate diagnosis. Know how to get a second opinion if necessary.			
2.	Understand how the diagnosis was made.			
3.	Know how to approach the patient with news.			
4.**	Know what possible treatments exist.			
5.	Begin to accept the diagnosis and patient's limitations.			
6.**	Understand the need for proactive planning, including financial, legal, and care plans.			
7.	Seek out supportive services as needed (early-stage support groups, education sessions, etc.).			
*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural, and economic backgrounds and different primary languages. **These objectives were identified as most important by site-level project staff and were used for evaluation purposes (see page 32).				

Programs and Materials for People with Alzheimer's Disease and Related Disorders
Role-Change Phase

	Objective	Program(s)*	Provided By	Appropriate Materials*
1.**	Understand the disease process. Know what changes to expect.			
2.	Know where to turn for information and support.			
3.	Anticipate the need for greater family involvement and support.			
4.**	Know how to talk with family about expected changes and necessary decisions (e.g., driving).			
5.	Know that all family members are experiencing grief.			
6.	Feel confident about potential family support and accept family limitations.			
7.	Feel confident about ability to provide care—caregiver self-efficacy.			
8.**	Use available services as needed.			
9.	Attend support groups.			
10.	Participate in research and clinical trials as desired.			

*All programs and materials should be adapted to meet the needs of families with different ethnic, cultural, and economic backgrounds and different primary languages.
**These objectives were identified as most important by site-level project staff and were used for evaluation purposes (see page 32).

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Programs and Materials for People with Alzheimer's Disease and Related Disorders
Chronic Caregiving Phase

	Objective	Program(s)*	Provided By	Appropriate Materials*
1.**	Use techniques for caregiving, including ways of managing difficult and dangerous behaviors.			
2.	Know ways of communicating with the patient.			
3.	Use appropriate medications for cognitive and behavioral symptoms.			
4.	Experience a caregiving partnership with physician and community agencies.			
5.**	Know how to enlist family members and others to help with caregiving.			
6.	Continue proactive planning for the future, including financial, legal, and care plans.			
7.**	Accept paid help with caregiving as needed, (e.g., aides, adult day care, respite services).			
8.	Use needed services, including skill training.			
9.	Begin grieving task without losing hope.			

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Programs and Materials for People with Alzheimer's Disease and Related Disorders

Transition to Alternative Care Phase

	Objective	Program(s)*	Provided By	Appropriate Materials*
1.**	Know what alternative care options are available in the community.			
2.	Explore care options before a crisis occurs.			
3.	Know how to evaluate dementia-specific care.			
4.**	Discuss options with family.			
5.**	Know what kinds of financial assistance the patient may quality for.			
6.**	Accept the need for alternative care, and feel positive about the process of selecting a provider.			
7.	Navigate the admission process, including knowing how to make the move easier for all.			
8.	Know how to create a new role for the family in collaboration with the care provider.			
9.	Acknowledge as a family that placement is a loss that will be associated with grief.			

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Programs and Materials for People with Alzheimer's Disease and Related Disorders
End-of-Life Phase

	Objective	Program(s)*	Provided By	Appropriate Materials*
1.**	Understand the end-stage process and physical care issues.			
2.**	Understand the key decisions that will have to be made by the family before an emergency.			
3.	Understand how to use any existing Advance Directives.			
4.	Understand methods of communication that may work well with the patient.			
5.**	Know how to access hospice care, if desired. Visit hospice programs if desired.			
6.	Feel a sense of peace about decisions that are made in this phase.			
7.	Know how to arrange an autopsy, if desired.			
8.	Be aware of bereavement services available to the family after the patient's death.			

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