

**Chapter 2**

**Characteristics of Persons  
With Dementia**

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# Characteristics of Persons With Dementia\*

What happens to the mind when a dementing illness strikes? Families and professionals alike struggle to understand why persons with dementing illnesses act as they do, and what, if anything, can be done to modify the person's strange behaviors or support lost skills.

The burden of caring for individuals with dementia arises as much out of the need to protect them from their own lack of judgment and to restrain them from dangerous behaviors as it does from providing personal or medical care (22). The difficult behaviors, poor judgment, profound memory loss, and changes in cognition as the diseases progress significantly affect both family caregivers and those working in formal support systems (see box A and chs. 4 and 7).

\* This chapter is a contract report by Nancy Mace, Consultant in Gerontology, Towson, MD.

This chapter will describe persons with dementia: the abilities they are losing, those that remain, and the ways in which these changing impairments affect the care these individuals need. The chapter:

- outlines the stages of decline of chronic dementing illnesses and discusses the usefulness of documenting stages in the illness;
- describes the symptoms of dementia and the impairments individuals experience;
- identifies the symptoms that are most readily alleviated; and
- considers the care needs of victims of dementia that arise from these symptoms.

while some causes of dementia are treatable (see Ch. 3), only chronic and irreversible illnesses are discussed here.

## Box A.—The Experiences of the Victim

Dementing illnesses do not abruptly or uniformly disrupt a person's thinking; they gradually and selectively impair intellectual functions. In addition, other illnesses, a nonsupportive environment, fatigue, or stress can make persons with dementia even more impaired in function and intellect than they need be. The seemingly strange contradictions of impaired and spared areas of intellect are probably as frightening to persons with a dementia as they are to those who care for them.

At first, individuals may be aware of their failures and become angry, depressed, and frightened. They may feel that they are going insane. As the disease progresses, however, they will forget their forgetfulness and be unaware that they are ill. They will try to continue to do what they have always done—go to the office, prepare meals, or drive—unaware that they are getting lost or making dangerous mistakes.

People with dementia may be frustrated to the point of rage when they can no longer do simple tasks, such as button a dress or jacket or tie their shoes. Their environment becomes filled with insurmountable obstacles—once familiar tasks now lead to failure and embarrassment. Unable to understand why they fail, they may struggle to cover up their failures or they may not understand what is wrong. Their clumsiness can be humiliating. As the disease progresses, they may not know who they are and may experience extreme and ongoing terror. They may cling tenaciously to the one person who seems familiar. When individuals with dementia are no longer able to control their fear, no one may respond to their distress; they will be unaware that no one can understand them. Yet their ability to enjoy human companionship—and to give and receive love—appears to continue some time after they have lost the ability to talk clearly or to care for themselves.

Although most physicians and researchers agree on the definition of dementia, there is disagreement over the stages of an individual's decline, on the causes of behaviors, and on the treatability of symptoms. The course and symptoms vary

among dementing diseases, and with patients thought to have the same disease. These variations, both in medical opinion and in knowledge of the diseases, have a significant impact on policy.

## DEFINITION OF DEMENTIA

Several different methods are used to determine whether an individual has dementia. Clinicians increasingly use the criteria specified by the American Psychiatric Association in the third edition of its *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) (1). Many of the epidemiologic and clinical studies done since 1980 have also used these criteria. The DSM-III diagnostic classification provides a method for systematically grouping symptoms that affect mental function.

A similar set of criteria was developed in 1983 in a joint effort between the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (ADRDA) (17,27).

Based on these two sets of criteria, dementia is defined as:

- a decline in intellectual function;
- global cognitive impairment, that is, memory impairment and at least one of the following:
  - impairment of abstract thinking;
  - impairment of judgment;
  - impairment of other complex capabilities such as language use, ability to perform complex physical tasks, ability to recognize objects or people, or to construct objects; and
  - personality change; and
- being in *clear consciousness* (i.e., awake and alert).

The definition differentiates dementia from mental retardation, in which there is no *decline* from a previous level. Thus a person with exceptional intelligence might have dementia if his or her intellectual ability declined to average. Similarly, a mentally retarded person can suffer from dementia when his or her intellectual limitations worsen.

That qualification requires that the individual's previous level of function be known. If no one can give a clear account of the person's past, the only way to determine if abilities are declining is to observe the individual over time. That necessity has implications for both epidemiology (7) and policy. If criteria for eligibility for services were to include documentation of change over time, individuals who require immediate assistance might be excluded. If, on the other hand, documentation of decline is not required, persons with lifelong impaired capacity might use limited services intended for persons with dementia. It is usually easy to document decline, based on the family's report. When someone has no close family, it is more difficult.

The next part of the definition, *global*, means that more than one area of intellectual function is impaired. Thus a person suffering only a memory impairment (e.g., caused by Korsakoff's syndrome) or only an impairment in the ability to speak (e.g., caused by some strokes) is usually not said to be suffering from a dementia (26). In practice, these individuals are often similarly handicapped and limited in their ability to function independently. They will need services and resources like those for persons with a dementing illness. In addition, many people with Alzheimer's disease suffer only memory loss at first. It is the expectation that other abilities will be lost that differentiates them from persons with pure amnesia.

The definition also distinguishes dementia from other mental states such as delirium, sleep, coma, stupor, and intoxication. The third major qualification, *in clear consciousness*, means that in contrast to delirium, the person is mentally impaired even when awake and alert. Several criteria distinguish delirium from dementia.

Ž State of consciousness: Persons with delirium have fluctuating or clouded conscious-

ness, while those with dementia areas attentive as they can be.

- **Stability:** With delirium, the individual's ability to pay attention and respond varies over short periods, only minutes or hours, while dementia is relatively stable in comparison.
- **Duration:** Delirium is usually short-lived, while dementia has a more prolonged course.
- **Rate of onset:** Delirium usually appears abruptly, over days or weeks, while dementia, except for some vascular dementia, usually develops insidiously.
- **Cause:** Delirium usually can be traced to a recent source—head trauma, drugs, fever, infection—while dementia may not be linked to another cause.

These distinctions are usually easy to make in young persons, but the borders between dementia and delirium blur with age. Elderly people can remain delirious for prolonged periods and the cause can be obscure. Many of the physical insults that cause delirium in the young can produce symptoms that look very much like dementia in older people.

The elderly delirious patient can exhibit a full spectrum of psychiatric symptoms including delusions, hallucinations, depression, excitement, agitation, fear, anger, and apathy. A cognitive examination reveals disorientation, memory impairment, problems in writing, and inability to sustain a conversation (9). Thus delirious persons can easily be misdiagnosed as having a dementing illness, and the underlying cause of the delirium may be left untreated.

Elderly people are especially vulnerable to delirium caused by illness or reactions to medication. Some may have only a delirium; others may suffer from both a delirium and a dementia. Persons with dementing illnesses are prone to develop additional delirium when they develop any other illness (42). In such cases, the delirium may cause a further decline in the individual's cognitive abilities. Therefore, the presence of an underlying dementia cannot be determined until any concurrent delirium has disappeared (39).

Thus, eligibility for services based on the presence of dementia requires a careful search to exclude delirium. Any assessment of need for services would be difficult to determine for elderly

persons who are acutely ill and confused. That is a particularly significant problem when such persons have been hospitalized. In order to avoid delays, plans for a patient's discharge are begun soon after admission, when the presence and severity of dementia maybe difficult to determine.

### ***Other Diagnostic Criteria***

Several criteria that have been used in defining dementia are omitted from the DSM-III definition. DSM-III does not include any statement regarding the course of the illness (i.e., chronic or acute) or prospects for treatment (i.e., reversible or irreversible). It makes no statement regarding the cause of the dementia (e.g., Alzheimer's disease or stroke) (26). Nor does it require the presence of specific behaviors such as agitation or wandering. Its great advantage is that it allows the description of disabilities along several axes without using unproved assumptions about cause or classification to label an individual.

The absence of such labels has policy implications. In the past, elderly persons with memory loss or changed behaviors were said to be suffering from "(chronic organic brain syndrome"—a label that consigned them to a hopeless category before their condition had been diagnosed, and that discouraged the search for treatable causes of the dementia. Although the most common disorders causing dementia—Alzheimer's disease and multi-infarct dementia—are not curable, that may not always be so. Therefore, a definition that includes irreversibility would be inappropriate. Excluding the cause of the dementia from the diagnosis also permits identification of an individual's characteristics and needs in the absence of a causal diagnosis. Behaviors such as wandering are not necessary for the diagnosis because they may disappear as the person's condition declines or when under treatment.

### ***Variation in Symptoms***

The specific cognitive functions that are lost and those that remain can vary from time to time and from person to person (17). These variations may be due to several factors:

- The progression (stage) of the disease or the length of time the person has had the disease

(18): Over time individuals gradually lose more and more cognitive ability. Because the speed at which these changes occur varies from person to person (from 1 to 20 years) (18), services need to be flexible if they are to meet changing impairments. (The limitations inherent in describing the course of the disease by stages are described later in this chapter.)

- The underlying disease causing the dementia (14): Some dementing illnesses affect gait, bladder control, or mood to a greater or lesser extent; other dementias affect reason, judgment, mathematical ability, and complex thought (26). These variations can affect the equitable distribution of resources. For example, eligibility criteria for Old Age Survivors Disability Insurance include evidence of deterioration of personal habits. One person's coherent speech and appearance of well-being may conceal very poor judgment and inability to hold a job, while another's apathetic and disheveled appearance may make him or her appear much more impaired. Furthermore, Alzheimer's disease and multi-infarct dementia can be difficult to distinguish, making the course of an individual's illness hard to predict.
- The presence of other illnesses or reactions to medication (18): As noted earlier, persons with dementia often experience a further impairment in their intellectual function when they also develop other illnesses or drug reactions. Even minor illness can temporarily cause worsened behavior or greater confusion (20).
- The idiosyncratic characteristics of the individual (19): One person with Alzheimer's disease may be agitated and combative, while another may be amiable and easily managed. The causes of these differences are not understood. The difference affects the services

needed and the individual's ability to use services,

- The uneven impact of the illness on different areas of intellect (19): The ill person will be able to do some things better than others. This seeming paradox of intellectual function often leads to misunderstandings of a person's abilities. Families often mistakenly believe that ability to do one task indicates an ability to do an apparently similar task. For example, one woman could load her elder daughter's dishwasher but not the younger one's. The daughters attributed this to the mother's long-standing preference for the elder daughter, but an occupational therapist found that the elder daughter's dishwasher was old, and the mother had learned to operate it before she became ill. The younger daughter's dishwasher was new and the mother was unable to learn even the simple skill of opening it (19).
- The varied response of different symptoms to intervention: Symptoms vary in their responsiveness to treatment, regardless of whether the underlying disease is treatable. Angry outbursts or hallucinations maybe controlled or prevented, for example, but an increasing memory loss may not be stopped.

Because of these variations, the ability and behavior of individuals with the same disease may differ widely, and the ability of one individual may vary through the day, or from week to week. Neuropsychological tests are being designed that more accurately measure these varied disabilities and changes over time. However, the relationship between the test results and the person's actual ability to function in familiar surroundings has not been standardized. Although useful in research, such tests are not sufficient by themselves to determine eligibility for services (see ch. 8),

## STAGES OF THE DISEASE

The most common cause of dementia, Alzheimer's disease, is a chronic, progressive disorder. Its worsening course has been described in terms of stages of increasing severity. The course of the

disease differs from that of multi-infarct dementia or other diseases, but the problems in accurately diagnosing Alzheimer's disease and multi-infarct dementia make it difficult to develop ways to de-

scribe these stages. This section will discuss the concept of identifying stages only for Alzheimer's disease.

### ***Theoretical Advantages of Staging or Measures of Severity***

The successful definition of a series of discrete and reliable stages describing Alzheimer's disease would have several advantages. Staging would enable a family to plan ahead for an individual's needs. It would enable researchers to compare different individuals at similar points in their illnesses. It would allow researchers to measure the effect of experimental interventions in postponing the next stage. Researchers could test the effects of experimental drugs by comparing treated persons with untreated persons at the same stage.

Staging would also allow planning for appropriate levels of service needed as individuals decline. Average lengths of time in each stage would allow planners to estimate costs of care. The stage of the individual's illness could be used as a criterion of eligibility for specific services,

### ***Staging Instruments***

The effort to develop accurate measures of stages has only begun. One of the classic descriptions of Alzheimer's disease, which has been used by many clinicians, has three stages. The first stage is marked by the onset of memory loss. The second stage is marked by problems in language, motor ability, and recognition of objects. The third or terminal stage shows profound dementia with loss of continence, loss of the ability to walk, and nearly complete loss of language (38).

Several more detailed theories of stages have been developed recently in an effort to characterize more specifically the predictable changes during the course of the disease. Although the validity of scales remains controversial, two examples are included here.

Table 2-1 shows the Brief Cognitive Rating Scale (32), which describes seven stages of the patient's illness on 10 axes: concentration, recent memory, past memory, orientation, functioning and self-care, speech, motor functioning, mood and behavior, practice of an art or skill, and calculation

ability. This scale has the advantage of describing declines in several areas of function. Also it is more detailed and specific than the three-stage model.

Table 2-2 shows the Global Deterioration Scale, which defines seven stages of deterioration, ranging from no cognitive decline to very severe cognitive decline, and their associated clinical phases and characteristics.

The Clinical Dementia Rating Scale (15) (table 2-3) uses five stages and six axes and is designed to measure the severity of major areas of cognition.

### ***Use of Assessment Tools for Staging***

Tests intended to diagnose the presence of dementia, to assess those areas of cognition that are more impaired than others, or to track the decline of individuals can be used to describe stages. These scales may rate person's abilities to perform familiar tasks (3), or several general kinds of functioning (10). Researchers have examined many other specific characteristics of intellect in search of those that show a consistent and reliable pattern of change in dementia (18).

### ***Problems in the Use of Scales and Stages***

Researchers do not agree about the validity of the scales. While some report consistent similarities in persons with dementia, others are struck by the degree of variability. Although one researcher states, "present investigations indicate that seven stages of progressive deterioration in normal aging and Alzheimer's disease can readily be described" (33), another maintains that: "although the patient with Alzheimer's disease or a related disorder undergoes a series of behavioral changes and losses, empirical data are still not available to describe the course of the illness. Cognitive skills and competency in life tasks appear to deteriorate at different rates in different people, but the losses are progressive until the individual ultimately dies" (4).

Alzheimer's disease is a gradually progressive disorder with no noticeable hallmarks that mark a person's passage from one stage to the next. Observers note that some individuals remain un-

**Table 2-1.—Brief Cognitive Rating Scale**

## Part 1

*Axis 1: Concentration*

1. No objective or subjective evidence of deficit in concentration.
2. Subjective decrement in concentration ability.
3. Minor signs of poor concentration (e.g., subtraction of serials 7s from 100).
4. Definite concentration deficit for persons of their background (e.g., marked deficit on serial 7s; frequent deficit in subtraction of serial 4s from 40).
5. Marked concentration deficit (e.g., giving months backwards or serials 2s from 20).
6. Forgets the concentration task. Frequently begins to count forward when asked to count backwards from 10 by 1s.
7. Marked difficulty counting forward to 10 by 1s.

*Axis II: Recent memory*

1. No objective or subjective evidence of deficit in recent memory.
2. Subjective impairment only (e.g., forgetting names more than formerly).
3. Deficit in recall of specific events evident upon detailed questioning. No deficit in the recall of major recent events.
4. Cannot recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favorite TV shows, etc.
5. Unsure of weather; may not know current president or current address.
6. Occasional knowledge of some recent events. Little or no idea of current address.
7. No knowledge of recent events.

*Axis III: Past memory*

1. No subjective or objective impairment in past memory.
2. Subjective impairment only, can recall two or more primary school teachers.
3. Some gaps in past memory upon detailed questioning. Able to recall at least one childhood teacher and/or childhood friend.
4. Clear-cut deficit, the spouse recalls more of the patient's past than the patient. Cannot recall childhood friends and/or teachers but knows the names of schools attended. Confuses chronology in reciting personal history.
5. Major past events sometimes not recalled (e.g., names of schools attended).
6. Some residual memory of past (e.g., may recall country of birth or former occupation; may or may not recall mother's name; may or may not recall father's name).
7. No memory of past (cannot recall country, State, or town of origin; cannot recall names of parents, etc.).

*Axis IV: Orientation*

1. No deficit in memory for time, place, identity of self or others.
2. Subjective impairment only, knows time to nearest hour, location.
3. Any mistake in time of 2 hours or more; day of the week of 1 day or more; date of 3 days or more.
4. Mistakes in month of 10 days or more; or year of 1 month or more.
5. Unsure of month and/or year and/or season; unsure of locale.
6. No idea of date. Identifies spouse but may not recall name. Knows own name.
7. Cannot identify spouse. May be unsure of personal identity.

*Axis V: Functioning and self-care*

1. No difficulty, either subjectively or objectively.
2. Complains of forgetting location of objects. Subjective work difficulties.
3. Decreased job functioning evident to co-workers, difficulty in traveling to new locations.
4. Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances, marketing, etc.).
5. Requires assistance in choosing proper clothing.
6. Requires assistance in feeding, and/or toileting, and/or bathing, and/or ambulating.
7. Requires constant assistance in all activities of daily life.

SOURCE: B. Reisberg, S. Ferris, and M.J. deLeon, "Senile Dementia of the Alzheimer's Type: Diagnostic and Differential Diagnostic Features With Special Reference to Functional Assessment Staging," *Proceedings*, Second International Tropon-Bayer Symposium, 1984.



**Table 2-2.—The Global Deterioration Scale (GDS) for Age-Associated Cognitive Decline and Alzheimer’s Disease**

GDS stage	Clinical phase	Clinical characteristic
1 No cognitive decline	Normal	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2 Very mild cognitive decline	Forgetfulness	Subjective complaints of memory deficit, most frequently in following areas: a) forgetting where one has placed familiar objects; b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
3 Mild cognitive decline	Early confusional	Earliest clear-cut deficits. Manifestations in more than one of the following areas: a) patient may have gotten lost when traveling to an unfamiliar location; b) co-workers become aware of patient’s relatively poor performance; c) word and name finding deficits become evident to intimates; d) patient may read a passage or a book and retain relatively little material; e) patient may demonstrate decreased facility in remembering names upon introduction to new people; f) patient may have lost or misplaced an object of value; g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview conducted by a trained geriatric psychiatrist. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.
4 Moderate cognitive decline	Late confusional	Clear-cut deficit on careful clinical interview. Deficits manifest in following areas: a) decreased knowledge of current and recent events; b) may exhibit some deficit in memory of personal history; c) concentration deficit elicited on serial subtractions; d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: a) orientation to time and person; b) recognition of familiar persons and faces; c) ability to travel to familiar areas. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations occur.
5 Moderately severe decline	Early dementia	Patients can no longer survive without some assistance. Patients are unable during interview to recall a major relevant aspect of their current lives: e.g., the names of close members of their family (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouse’s and children’s names. They require no assistance with toileting or eating, but may have some difficulty choosing the proper clothing to wear.
6 Severe cognitive decline	Middle dementia	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives, but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and sometimes forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance, but occasionally will display ability to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; c) anxiety symptoms, agitation, and even previously non-existent violent behavior may occur; d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.
7 Very severe cognitive decline	Late dementia	All verbal abilities are lost. Frequently there is no speech at all —only grunting. Incontinent of urine; requires assistance toileting and feeding. Lose basic psychomotor skills, e.g., ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.

**SOURCE:** B. Reisberg, “Clinical Presentation, Diagnosis, and Symptomatology of Age-Associated Cognitive Decline and Alzheimer’s Disease,” *Alzheimer’s Disease: The Standard Reference* (New York: Free Press, 1983), pp. 173-187.

changed for long periods while others follow an atypical course (17). It can be difficult to clinically distinguish this disease from other dementing illnesses with slightly different courses; indeed, the term “Alzheimer’s disease” may actually include several diseases, each with a slightly different pattern (see ch. 3). All of these factors limit the use-

fulness of staging instruments. Further, as noted, there are many reasons why persons with Alzheimer’s disease can show worsened symptoms: other illnesses, fatigue, delirium, or an inappropriate environment. The stage of a person’s illness cannot be determined until these factors have been ruled out.

**Table 2-3.—Clinical Dementia Rating (CDR) Scale**

	Healthy CDR 0	Questionable dementia COR 0.5	Mild dementia CDR 1	Moderate dementia CDR 2	Severe dementia CDR 3
Memory	No memory loss or slight inconsistent forgetfulness	Mild consistent forgetfulness; partial recollection of events; "benign" forgetfulness	Moderate memory loss, more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
Orientation	Fully oriented		Some difficulty with time relationships; oriented for place and person at examination but may have geographic disorientation	Usually disoriented in time, often to place	Orientation to person only
Judgment and problem-solving	Solves everyday problems well; judgment good in relation to past performance	Only doubtful impairment in solving problems, similarities, differences	Moderate difficulty in handling complex problems; social judgment usually maintained	Severely impaired in handling problems, similarities, differences; social judgment usually impaired	Unable to make judgments or solve problems
Community affairs	Independent function at usual level in job, shopping, business and financial affairs, volunteer and social groups	Only doubtful or mild impairment in these activities	Unable to function independently at these activities though may still be engaged in some; may still appear normal to casual inspection	No pretense of independent function outside home Appears well enough to be taken to functions outside a family home	Appears too ill to be taken to functions outside a family home
Home and hobbies	Life at home, hobbies, intellectual interests well maintained	Life at home, hobbies, intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores <b>preserved</b> ; very restricted interests, poorly sustained	No significant function in home outside of own room
Personal care	Fully capable of self-care		Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; often incontinent effects

SOURCE C P Hughes, L Berg, W L Donziger, et al., "New Clinical Scale for the Staging of Dementia," *British Journal of Psychiatry* 140 "556-572, 1982

Concepts of staging can be used for different purposes: research, family education, understanding an individual patient, or measuring disability to enable eligibility for services. Scales used for eligibility must correctly screen out those who should not be eligible while not excluding some whose symptoms are atypical. They should be replicable and they should produce the same results as other reliable tests. They should produce

accurate scores regardless of the sociocultural background of the person being tested; they should detect dementia early in the illness and give accurate scores of disability through the full course of the illness. They should be easy to administer and not upsetting to the individual. None of the scales or theories of staging yet meets these criteria.

### **Box B.—Progression of Dementia**

At the beginning of the disease, people experience memory loss and a lack of spontaneity. They may have a change in language or handwriting, or trouble doing mathematics. They lose the ability to make rapid hand and fine motor movements. They may cover up these difficulties, although many become depressed. Individuals may be uncharacteristically moody or exhibit sudden outbursts over trivial issues. They will be able to care for themselves and may be driving a car, cooking meals, or even living alone. The disease may go unrecognized until some event calls attention to the problem: they may get lost coming home from work, be asked to resign from a job, or have a car accident. Some minor additional stressor often precipitates a temporary decline in abilities, so that the individual's difficulty comes to the attention of others.

As the disease progresses, apraxia (problems carrying out purposeful movement) and aphasia (problems with language) appear and worsen steadily. People will be unable to remember new information for even 2 or 3 minutes, but their memory of the past will deteriorate more slowly. These individuals will no longer be able to work or to care for their personal needs independently. Such people cannot be left alone: they do not comprehend their limitations and therefore they are at serious risk of accidents. At this point, most are still physically vigorous and some cause significant problems by trying to walk away from their home or care setting.

During this period persons with dementia may show angry outbursts, sudden shifts of mood, suspicion, fearfulness, or violence. They need help in dressing, in eating, and eventually with using the toilet. Many of these individuals are awake and active at night. They do not recognize their need for care and often vigorously resist help.

The late stages of the disease often begin with the onset of incontinence. Gradually the apraxia progresses until these persons are unable to walk without help. Many are bedfast. They will need to be bathed, fed, dressed, and toileted. They will be essentially mute; language will consist only of one or two words or cries. Behavior problems disappear due to the severity of the physical impairment. Seizures are common. These people become feeble and emaciated. They may refuse to eat or be unable to swallow without choking, so that artificial feeding may be required. They are at risk of developing bedsores, infections, and pneumonia. Pneumonia is a common cause of death. There is significant variability in the symptoms from person to person and some symptoms never appear in some individuals.

## SYMPTOMS OF DEMENTIA

persons suffering from a dementing illness lose cognitive abilities, as manifested in changes in behavior and losses of function (35). These symptoms can be loosely grouped into four categories: cognitive or neurological symptoms; functional symptoms or impairment of the ability to carry out normal daily activities; behavioral or "(psychiatric)" symptoms; and the excess disabilities brought about by outside factors (18). Categorizing symptoms is somewhat arbitrary: Many could as easily fit into one group as into another. Nevertheless, grouping symptoms is useful in describing the kind of care these individuals need.

An understanding of which of the individual's cognitive functions have been spared or impaired can be used by the clinician to explain specific behaviors to the family and is useful in devising ways to assist the person with dementia (30,&I). As noted, social skills, judgment, ability to do mathematics, ability to remember things, or ability to pay attention may all vary independently. One person may still seem gracious and friendly but be unable to remember the context of a conversation from moment to moment. Another may be able to remember how to dismantle a sink but be unable to realize that the sink being taken apart is in someone else's room,

The loss of intellectual function, often combined with the false appearance of normal capability, confuses family members and professional caregivers. Demented individuals may still be able to walk or drive but may get lost or have accidents. That is one way in which these individuals differ from other frail, elderly, or ill persons. They may have no awareness of their impairments and therefore resist assistance. They may argue with caregivers or accuse them of abuse (22).

### ***Cognitive/Neurological Symptoms***

In the early part of the illness, person with dementias typically experience memory loss and aphasia (language problems). That is often followed by apraxia (inability to carry out purposeful movement in the absence of motor or sensory impairment), agnosia (failure to recognize things or people), loss of the ability to learn, and disorien-

tation (41). Other possible neurological symptoms include seizures, shocklike contractions of a group of muscles, changes in reflexes, tremors, and failure of muscle coordination. There is considerable overlap between some symptoms.

Symptoms are thought to correlate with specific areas of brain damage or systems of neurotransmitters (26). In disorders for which medicine now has no cure, such as Alzheimer's disease, these symptoms are quite stable within a given individual at a given time, despite efforts to modify them. That is, when other factors (delirium, nonsupportive environment, unnecessary stress) are removed, most efforts to bring about improvement in these functions have been unsuccessful (29).

Cognitive symptoms can be measured with neuropsychological tests and some can be reliably replicated in the same person. Therefore they are frequently selected as markers to measure change brought about by experimental therapy. There is more general agreement about the sequence or stages in which these cognitive symptoms appear in Alzheimer's disease than there is about other symptoms. Disorders affecting rapid and complex hand movements also may begin early in Alzheimer's disease. Cognitive impairments profoundly affect the way in which a person perceives his or her world and therefore significantly affect behavior.

### Memory Impairment

The hallmark of dementia is impairment of memory, which differs from the normal forgetfulness of healthy individuals. In dementia, memory of important information such as the names of close family members or the way to get home from a familiar place may be lost.

At the beginning of the illness it can be difficult to distinguish between normal forgetfulness and the first signs of a dementing illness. That can cause anxiety among elderly persons who fear they are developing dementia. However, as the disease progresses, the severity of the memory impairment becomes evident, and is clearly different from absentmindedness.

There are several different forms of memory: immediate (remembering for a few seconds), short-term (remembering for a few minutes), and long-term (remembering material learned from year to year). Neuropsychological testing can delineate the types of memory that are spared and impaired in a given person. Most persons with Alzheimer's disease have impaired short-term memory (35), but many retain some long-term memory.

It is difficult to imagine life without a short-term memory. One could not learn from experience. Following a conversation would become impossible. Television would become a meaningless jumble. Individuals who have lost short-term memory cannot remember the question just asked or the answer just given, or even that they have forgotten. These individuals often become fearful and anxious and cling to a trusted caregiver. They may ask the same question many times or fail to do something because they cannot remember what they were asked to do. Such problems often begin before a person looks or acts ill, so that others are not sensitive to the disability.

### Aphasia

Aphasia is impairment in the use of language. In some persons, it is the first symptom of dementia; it eventually occurs in persons with Alzheimer's disease (25). Expressive aphasia is an impairment in the ability to use language, speak, or write, while receptive aphasia is an impairment in the ability to understand spoken or written language. Unlike persons who are deaf, persons whose brains cannot process language cannot use symbols, pictures, or sign language.

Aphasias are further classified by precise types of language impairment, such as the loss of the ability to name items, to put together sentences, to understand and act on what is heard, or to read or write. A person may experience quite selective losses of language. For example, an individual may be able to read aloud a note on the refrigerator to "take your pills at noon," but be unable to carry out those instructions.

Such highly specific impairments frustrate caregivers who reason that a person who can read ought to be able to act on instructions, or that a person who can hold reasonable social conver-

sation ought to be able to remember a spouse's name. But reading and comprehending instructions, participating in casual conversation, and recalling nouns are all different skills, and one can be lost before another.

As dementia progresses, the person loses more language skills. Eventually, these individuals become nearly mute and it is no longer possible to differentiate types of language loss. Loss of communication often means that a person cannot ask for help when his or her memory has failed, and caregivers must then guess at needs. As the disease progresses, individuals become unable to tell caregivers when they are in pain, cold, or *hungry*.

### Apraxia

Apraxia is the inability to carry out purposeful movement or motor acts—buttoning buttons, walking, dressing, eating a meal, or maintaining a sitting position—in the absence of motor or sensory impairment. Unlike the person who is paralyzed or injured, the person with apraxia has "forgotten" a skill. In Alzheimer's disease, apraxia is progressive, beginning with a slight clumsiness and progressing to a dramatic lack of coordination, frequent falls, or the loss of the ability to walk. At first a person may have difficulty with clothing fasteners, whereas later the problem may be getting feet into trousers. Eventually, the person will be unable to participate at all in getting dressed.

Although someone who has lost a hand in an accident can learn to use a prosthesis, and a person who has suffered a paralyzing spinal cord injury may learn to use crutches, individuals with dementia have lost the ability to remember and learn. Therefore, they may be unable to learn to use a walker or other assistive device. The methods of helping a person with a dementia to compensate for a disability are thus different from those used to assist a physically handicapped person. Yet the person's disability is as real as an amputee's (24). Research may lead to the development of devices persons with dementia can use.

### Agnosia

Agnosia is a disorder of perception—that is, the loss of the ability to comprehend the meaning or

recognize the importance of various types of sensory stimulation. That loss is different from the loss of memory, and might be described as an inability to use sensory information to recognize something. Individuals with agnosia may run into the mantelpiece because they do not recognize it as protruding before them. They may urinate in the wastebasket or put their dentures in the refrigerator because they do not correctly recognize the function of the wastebasket or refrigerator.

Some individuals with agnosia insist that the spouse who is caring for them is not their spouse. Such a person may agree that the caregiver looks just like the spouse, but will insist that this caregiver is an imposter. A woman may cease to recognize a mirror image and begin to talk to the "woman in the bathroom ." In some cases, she may regard the woman in the bathroom as a rival or intruder and act on this belief. Such impairments can be terribly distressing to family members, and the peculiarly circumscribed nature of some agnosias can make it difficult for family members to accept agnosia as a symptom of neurological damage (22).

Persons with agnosia maybe unable to put together the various elements of a situation or object. In neurological examination, a person may be asked to copy a simple diagram but be unable to reproduce more than a section of it. At home that individual may be unable to set the table because he or she cannot think of all the elements—china, cloth, and silverware—at one time. The individual may be able to pay attention to only two of four people in a room, and appear to ignore the others.

### Impaired Ability To Learn New Material

Persons with a dementia usually experience a profound impairment in the ability to learn. They may be unable to learn a list of numbers in a test situation or unable to learn information as important as the location of the bathroom in a new residence. (That inability is closely related to other impairments such as loss of short-term memory.)

Someone suffering from a dementia may superficially appear capable in other areas of intellectual function, but at the same time may be unable to learn even basic new material. That impairment

can be disabling to the person who must move to a new residence or who is expected to learn a new, although less difficult, job skill.

Some victims of dementia have been disqualified for payments under Social Security Disability Insurance (OASDI) because they are assumed to be able to work at less demanding jobs (6). However, not only are these individuals unable to learn simple new skills, but they cannot even learn that they are not doing their old job. Thus a former engineer whose intelligence score indicates an ability to work as a janitor may be unable to learn where the brooms are kept but insist that he or she is still an engineer.

At the same time, persons with Alzheimer's disease have not lost all ability to learn. Especially early in the disease, some individuals have learned compensatory techniques or ways to signal the caregiver. Although these are eventually lost, research to clarify the circumstances under which such technique? can be learned would greatly assist care providers.

### Disorientation

Disorientation is the lack of correct knowledge of person, place, or time—where a person is, who the people around you are, or what time of day, day of the week, or month it is. Persons with dementia develop these limitations from disorientation gradually. Some may not be disoriented, especially if the person is in a familiar setting or in the early stages of illness.

### ***Ability To Do Normal Daily Activities***

Persons with dementing illnesses gradually lose the ability to do the tasks of normal daily living. These skills include ones known as the activities of daily living (ADLs), which include basic skills such as dressing or eating, and those known as instrumental activities of daily living (IADLs) such as answering the telephone or making change. (For a full discussion of ADLs and IADLs, see ch. 8.) Checklists provide a score that describes the extent of the person's dependence or independence.

Tables 2-4, 2-5, and 2-6 show the percentage of respondents in a survey, done for OTA, of caregivers who reported that persons with dementia

**Table 2-4.-Ability of Dementia Patient To Do Basic Tasks**

Task	Percent of total respondents			
	Very well	Somewhat	Not at all	No answer
Walk without assistance. . . . .	35	26	35	5
Eat without assistance . . . . .	30	32	34	5
Dress without assistance . . . . .	14	28	52	5
Perform simple household tasks, such as setting the table or simple home repairs. . . . .	6	19	69	5
Cope with small sums of money. . . . .	5	15	73	6

NOTE: This table is percentage horizontally. Also totals may not add because of rounding.

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, 1986

**Table 2.5.—Assessment of Dementia Patient's Eating Skills**

Eating skills	Percentage of total respondents
Eats cleanly, with proper utensils . . . . .	36
Eats messily . . . . .	23
Only eats simple solids, like crackers, by self. . . . .	6
Has to be fed by others . . . . .	28
Is tube fed . . . . .	4
No answer . . . . .	4

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, 1986.

**Table 2-6.—Assessment of Dementia Patient's Toilet Skills**

Toilet skills	Percentage of total respondents
Independent/fully functional. . . . .	23
Has occasional accidents/needs some help or reminder . . . . .	25
Has frequent wet beds or accidents. . . . .	12
Is doubly incontinent (has bowel and urine accidents) . . . . .	36
No answer . . . . .	4

SOURCE: Yankelovich, Skelly, & White, Inc., "Caregivers of Patients With Dementia," contract report prepared for the Office of Technology Assessment, 1986.

had impairments in ADLs and IADLs.<sup>4</sup> That survey encompassed caregivers of persons with dementia in all phases of their illness. Table 2-4 shows

<sup>4</sup>The Yankelovich, Skelly, & White data in this chapter and in ch. 4 differ by a few percentage points from the figures cited elsewhere in this assessment. This is because the Yankelovich report calculated the percents of people answering each question exclusive of the nonresponders. In these two chapters, where the bulk of this assessment is reported, those who completed a questionnaire but did not answer a specific question are shown as a separate column. There are no significant differences between the two sets of data.

that persons with dementia are not uniformly impaired—skills are lost at different times throughout the illness. More can walk independently than can eat or dress without help; few can do household tasks or cope with money. The ability to handle money or do household tasks unassisted is usually lost early in the course of the disease: the ability to walk is lost late. It is also clear that the majority of these people are severely impaired in vital skills. Other studies report comparable levels of impairments (6,11).

The ability to perform various tasks of daily living depends on the severity of cognitive impairments. The ability to brush teeth, for example, is based on the interaction of the ability to remember, to recognize the toothbrush, to perform the motor action, and so forth. An individual's loss of a skill may be partial, and he or she may be able to get dressed but not to select the clothing, or be able to eat independently only if served finger foods.

Persons suffering from nondementing illnesses may also lose these same abilities, although for different reasons. Therefore, the degree or type of impairment does not indicate a specific disease, and the treatment intervention varies with the cause of the condition.

Scores on measures of IADLs and ADLs have been found to be more reliable than diagnoses for predicting the amount of care a person will need in a nursing home (8). In the absence of a diagnosis, however, the use of ADLs to measure disability can obscure an individual's potential for rehabilitation. The type of assistance an individual will need depends on the cause of the impairment: a blind person may need to be told where

food is; a paraplegic may need a prosthesis; a person with dementia may need to have his or her food cut up, be given reminders, or be given fewer foods at one time to reduce confusion.

Although the ability of most persons with dementia to function independently will inevitably decline until the person becomes totally dependent on others, the extent of an individual's ADL handicap sometimes can be reduced, and total dependency postponed. Disability can be reduced in supportive situations and worsened in unsupportive settings (see ch. 7).

Continence illustrates the interlocking issues of decline in ADLs and the potential for improvement. Incontinence may be embarrassing for the individual and upsetting to the caregiver. Some authorities report that it is one of the precipitant for nursing home placement (40). But some report that uncontrolled incontinence is unnecessary in most cases. Problems of incontinence vary from complete loss of bladder or bowel control to occasional "leaking." Incontinence has multiple causes, some of which are reversible. The need for diapers or catheters can sometimes be avoided or postponed with proper treatment of the underlying problem (42).

The true incidence of failure to treat incontinence is unknown. Clinicians report cases in which reversible causes of incontinence have been incorrectly ascribed to the dementing disorder, and their susceptibility to treatment overlooked (21). In addition, individualized schedules, reminders, and assistance can maintain continence even in severely demented persons (42). Thus an individual's ADL score for incontinence may depend on the aggressiveness of treatment and the willingness of caregivers to assist. Since an individual may be continent in one setting and incontinent in another, the measure of his or her independence in ADLs may reflect both the setting and the individual's intellectual ability.

### ***Behavioral or '(psychiatric)' Symptoms***

Behavioral or psychiatric symptoms include angry outbursts, depression, violence, apathy, stubbornness, resistance to care, suspicion and accusations, wandering, incessant repeating of the

same question, being awake and active at night, use of obscene or abusive language, talking to deceased relatives, hallucinations, delusions, rummaging through other persons rooms, stealing, getting lost, urinating in unsuitable places, hiding things, refusing to give up activities that can no longer be performed safely, wearing clothing inside out or in the wrong order, refusing to change clothing or to bathe—the list can go on and on.

The presence or absence of these symptoms by themselves is not necessarily evidence of dementia or any specific dementing illness. Similar behaviors can be seen in persons suffering from a variety of organic and psychiatric disorders, as well as in persons not suffering from any mental illness. It is important, however, to note that the treatment of choice varies with the cause of the problem. Techniques appropriate for treating depression or schizophrenia may or may not help persons with dementia. Also, a person suffering from a dementia may have none of these behavioral disturbances, or the disturbances may be present for only part of the illness (e.g., accusations decline as language is lost; wandering declines as ambulation is lost).

Table 2-7 shows the percentage of caregivers in the OTA study who reported patient behavior problems. Other surveys report even higher rates of disturbed behavior (6,11,31). Variations between the studies can be accounted for in part by differences in the number of persons who were too ill to engage in the behaviors. In a resurvey of one of these populations 2 years later, researchers found a significant decline in disturbed behaviors, which they reported as due at least in part to the subject's continued decline (23). The experience of ADRDA also provides compelling evidence of the prevalence of these behaviors—these problems are frequently discussed in the association's '(how-to)' books and newsletters. From this evidence it can probably be concluded that disturbed behaviors occur for part of the illness in a majority of victims.

Aberrant behaviors can be extremely distressing both for the sufferer and for caregivers. Families and service providers alike report that it is often these behavior problems, rather than the cognitive symptoms or the need for nursing or



Table 2-7.—Frequency of Dementia Patient’s Engagement in Certain Behaviors

	Percentage of total respondents			
	Very frequently	Occasionally	Rarely/never	Don’t know/ no answer
<i>How frequently does patient:</i>				
Have periods of restlessness and agitation? . . . .	39	33	10	18
Become listless and apathetic? . . . . .	32	29	14	26
Get in a depressed mood? . . . . .	27	32	12	29
Wander away from home unless watched? . . . . .	29	24	36	
Have inappropriate angry outbursts? . . . . .	19	32	30	19
Engage in crying episodes? . . . . .	13	26	38	23
Engage in actions (hit, pinch, throw things) that physically hurt people? . . . . .	9	17	53	22

<sup>a</sup>Respondents who are not the primary caregiver may not know the frequency of behavior problems.

NOTE: This table is percentage horizontally. Also totals may not add because of rounding.

SOURCE: Yankelovich, Skelly, & White, Inc., “Caregivers of Patients With Dementia,” contract report prepared for the Office of Technology Assessment, 1986.

personal care, that prove most distressing (40). Recent findings, however, indicate that these behaviors may be more responsive to treatment than previously assumed, and that they can be reduced even in the absence of significant change in cognitive impairment (see chs, 4 and 7’).

The division between behavioral and cognitive symptoms is arbitrary. A person suffering from damage to nerve cells or changes in brain chemistry can be expected to exhibit behavior that results from the neurological illness. It can also be reasoned that persons who cannot communicate their needs or thoughts, who cannot get dressed, or who do not know where they are or who is caring for them might experience depression, fear, anxiety, or anger. Thus these symptoms are not so much “psychiatric” as they are the clear result of the neurological illness. They maybe due both to brain damage and to an understandable reaction to the loss of mental abilities caused by that damage.

Little is known about the relation of many behavioral symptoms to specific locations in the brain. Researchers disagree over whether a given behavior is primarily neurological, is a psychological response to the neurological symptoms, or was a characteristic of an individual’s personality before the onset of the dementing illness. As scientists’ understanding grows about the relationship of these symptoms to the underlying neurological disorder, so will the understanding of the broader relationship of brain to behavior,

Fortunately, many behavioral symptoms of dementia are more responsive to currently available

methods of treatment and intervention than the cognitive symptoms are (30). When the symptoms are not treated, the individual can be more impaired in functional ability than necessary. Medications are often the treatment of choice; however, they are easily overused or misused. The pharmacotherapy of aggressive or agitated behaviors in person’s with dementia has not been extensively studied despite the prevalence of the problem (34).

This section addresses a few of the many behavioral and mood problems that people with dementia may face.

#### problems of Mood and Experience of Distress

Persons with dementia often experience changes in mood or personality. Families may report that a formerly gentle person has become hostile and angry, or that a trusting person has become suspicious. Some persons with dementing illnesses shift quickly from laughter to tears or anger with little or no apparent cause.

**Catastrophic Reactions.**—Persons suffering from a dementia often become angry, irritable, or upset over seemingly minor situations. Families report that such outbursts are a major problem. Clinicians refer to such behavior as a catastrophic reaction (12) to distinguish it from behavior in a person with no brain injury. The episode maybe minor (shouting or stubbornness) or major (hitting, or swinging a weapon). Catastrophic reactions may precipitate placing the individual in a nursing home or other long-term care institution (40).

There is also evidence that when such behavior recurs frequently, however, it may cause the person to be denied admission to nursing homes, day care, home care, or other services, or may cause the person to be transferred to another setting (see ch. 7). The behavior often leads to heavily medicating or physically restraining the patient (28). Medications and restraints can lead to medical complications and severely limit the individual's freedom and quality of life.

Unlike similar behavior in a cognitively well person, catastrophic reaction behavior is thought to be the result of brain damage and largely beyond the control of the person with dementia (19). It may result from failure to understand a request, failure to comprehend a situation, fatigue, or pressure to perform beyond the individual's limited capabilities (19). Persons whose thinking is impaired understandably can become frightened or anxious in situations they cannot understand, and that anxiety may translate into outbursts. These individuals may also have lost the ability to inhibit their behavior.

Caregivers often view such outbursts in the same way they would view it in a well person—deliberate and under the person's willful control. Their response may be restrictions, punishment, arguments, or explanations—responses that further distress the individual and increase anxiety and agitation (22). When catastrophic reactions are properly recognized, however, they respond to a variety of interventions; one of the most successful is making the person's environment more supportive of his or her disability. Training family and professional caregivers in appropriate responses is often a key to controlling these behaviors (30).

Confused, disoriented persons with compromised intellectual function may occasionally become combative or threatening. That is usually an extreme catastrophic reaction. Since these persons may also be strong and mobile, combative behavior can present serious problems to caregivers. A man suffering from dementia may repeatedly push, shove, or knock down his frail, elderly wife who is trying to care for him. The confused person may not know whom he is fighting; he may be frightened or misunderstand the

situation. For example, he may believe that his son is a robber or that the nurse trying to bathe him is attempting to rape him (30).

Respite programs or nursing homes may refuse to care for violent patients, whom they fear pose a threat to staff or other residents. Such behavior is not intentional on the part of the person with dementia and therefore must be treated differently from similar behaviors in persons with normal cognitive functions (22).

Catastrophic reactions and violent behavior are often amenable to nonpharmacological interventions when steps are taken to reduce the stress the individual is experiencing. Judicious use of medication can effectively augment the supportive environment to control frequent or extreme reactions (22,43). Experienced professional caregivers report far less of this behavior than do untrained staff.

**Depression**—Some persons suffering from dementia are also clinically depressed (43). The likelihood of depression secondary to the dementing process may vary with the disease entity (18). The literature presents contradictory data on the frequency with which depression arises in persons with Alzheimer's disease or multi-infarct dementia. Clearly, not everyone with a dementing illness experiences such periods.

Depression responds to a variety of treatments and it should be treated when possible both because it can further impair a person's thinking and because it causes suffering (18,41; also ch. 3). Persons whose primary problem is a clinical depression may also show cognitive impairment. Treatment of the depression may alleviate the cognitive problems. For that reason, persons showing symptoms of both depression and confusion or memory loss should be carefully evaluated.

**Apathy**.—Persons with some types of dementing illnesses may become apathetic, listless, unmotivated to participate in activities, or unwilling to maintain adequate personal hygiene. Such behavior may be misinterpreted by untrained caregivers as laziness or stubbornness (13,22).

Victims of Alzheimer's disease often lack the ability to plan or initiate meaningful activities. In an environment that offers little activity or sensory

stimulation, these persons may lapse into apathy, wandering, or repetitious, meaningless motions. Dramatic changes can occur when such persons are transferred to a special care setting that offers suitable structured activity and sensory stimulation, and that encourages individuals to use remaining abilities (see ch. 7).

**Restlessness.**—Persons with dementia often become restless—pacing, wringing their hands, talking, etc. Pacing in front of the nurse's station or asking the same question over and over for several hours is often reported as a source of distress to caregivers, who may ask that the individual be given tranquilizers, even though the restlessness presents no harm to the person with dementia. Motor restlessness is also a common side effect of medications and is responsive to reduction in dose. Some clinicians do not treat it because they assume it is part of the dementia.

**Subjective Feelings.**—Loss of cognition does not necessarily change a person's ability to experience a range of emotions. Until late in the course of the illness, people probably are experiencing the emotions that are reflected in their behavior (30). Thus, although they may not change how well a person remembers things, interventions can reduce a person's unpleasant feelings (21). Persons with Alzheimer's disease may lose extensive cognitive skills and functions, but their ability to express and give affection remain for most of their illness. They can experience joy and enjoy humor. Caregivers report that these attributes can be elicited through provision of good, supportive care. Also that positive aspect helps to sustain family caregivers.

### Problems of Behavior

**Disruptions of the Sleep/wake Cycle.**—Recent work suggests that nocturnal sleep is disrupted in Alzheimer's disease. Persons suffering from dementia are often awake at night and may dress, pack their clothing, attempt to use the stove, or leave the house and wander the streets. Such behaviors require constant night-time supervision or a secure setting to ensure safety (22). That requirement may lead to nursing home placement when the family caregiver becomes exhausted. However, clinicians report that sleep problems can

be reduced both through careful use of medications (41) and with improved care techniques (5).

**Loss of the Internal Clock.**—Because these individuals have lost their internal sense of time's passage, they may insist that it is time to go home immediately after arriving for a visitor they may accuse others of never visiting or never feeding them. An individual's impaired memory may make it impossible for him or her to understand explanations (22).

**Wandering.**—Cognitively impaired people may pace the floor, or they may wander out of their residence. They may not realize that they are in traffic, or in a high crime area. They may say that they are in a different place or that they are returning to a home or job that existed in the past. They may be inappropriately dressed or they may fall, increasing the risk of injury. Those who realize that they are lost may panic. Unlocked care facilities may refuse to accept individuals with dementia who are known to wander, because they cannot provide adequate supervision.

Wandering and the risks associated with it can be controlled through the use of nonrestraining environmental supports. Simple, unfamiliar latches can keep people with dementia on the premises because they are unable to learn how to operate the new latches (22). Several companies now market electronic monitoring systems for nursing homes. Research Triangle Institute has completed a feasibility study of devices to monitor wandering (36).

**Suspicion and Paranoia.**—Some persons with dementing illnesses may become suspicious; they may believe that they are being robbed, that others are attempting to poison them, or that their families have taken all their possessions and money (35). These individuals may be able to remember unfounded suspicions and fears in detail even when they cannot recall other simple information.

Such suspicion can be understood in part as an aspect of the memory impairment (the individual has forgotten where things are), but for some persons with dementia it goes beyond that. It may be an expression of his or her experience of numerous losses (of memory, friends, freedom, health) or may be a direct result of the disease

process. Family members who devote their lives to the care of such persons are often hurt by this accusatory behavior. In a group setting, the individual's adamant reports of mistreatment or theft may complicate efforts to ensure quality care and patient rights.

**Perseveration**-persons with dementia may repeat a motion or activity over and over, a behavior known as perseveration. They seem to have "gotten stuck" in that activity. They may wash only their left arm, or may repeat the same meaningless phrase all day (22).

**Social Inappropriateness** -As noted, persons with dementing illnesses may act inappropriately because they do not know where they are, who they are, or who is with them. They may mistake children for parents, a nurse for a wife, or another nursing home resident for a spouse. They may think they are in a childhood home. They may be unable to express their need to use the toilet. Such confusion leads to a range of socially inappropriate behaviors that can place an individual with dementia at risk. Some of these behaviors may be interpreted by caregivers as sexually abnormal: a man may take down his trousers because he is searching for a toilet, for example, or may climb into the wrong bed (22).

Although lost, confused, or frightened individuals who have dementia may act inappropriately, persons with certain dementing illnesses may retain for a long time a semblance of social skills that helps conceal the extent of their intellectual difficulty; this can obscure their need for help and assistance. Trained caregivers can take advantage of these retained social skills to improve the quality of life for the individual; in supportive settings, these persons are able to enjoy social groups and make new friends (2 I).

**Sexual Behaviors**-Most studies of patient behavior have shown that individuals who have never had a history of abnormal sexual behavior rarely develop such behaviors with the onset of a dementia (2). Occasionally, institutionalized persons will engage in self-stimulation in the presence of others. They may not realize they are not in private. That behavior seems to occur in persons who are severely demented and also are severely deprived of stimuli, activity, and pleasure,

There is no evidence that persons with dementia pose any sexual threat to children or others (22).

**Impairment of Reason and Judgment.**—Persons with impaired intellectual function often show a loss of reason and judgment (35). That may be due to disorientation, to forgetting information before all the facts of a situation can be thought through, or to the disease process itself, which in Alzheimer's disease and some other dementias afflicts these portions of intellect selectively.

Persons with dementia who can no longer live alone safely because, for example, they continually leave the stove on, may be able to argue effectively they are "fine" and that their families are trying to take away their independence. Such skill in arguing can lead the caregiver to the false premise that an impaired individual is aware of the endangering behavior (22).

A particularly difficult problem is knowing when someone can no longer drive safely. A car is the only available form of transportation for many people. Loss of driving privilege can be demoralizing for the individual with dementia and stressful for the caregiver and physician. However, persons with dementia are at significant risk of accidents. They often have poor judgment and a slow response time. They depend on habit to drive and may be unable to think quickly in an emergency. Most State laws do not require a test of intellectual function for renewal of a driver's license. Uniform guidelines for repeat testing of drivers, particularly over the age of 55, might be beneficial.

Determining the extent of a person's ability to make responsible decisions regarding property may also be difficult (see ch. 5). Because of the selective nature of impairments, the usual tests of legal competency may not reveal the absence of good skills in reasoning and judgment or the ability to remember a decision long enough to think about it.

Individuals with dementia may not realize they are being exploited or abused and maybe unable to remember or report abuse. In addition to being exceptionally vulnerable to poor care, such individuals may fall victim to unscrupulous sales people and to fraudulent business schemes. Other

individuals may erroneously charge that they are being raped or assaulted. These difficulties may be more complicated in special care programs where all the residents have dementia and no one is capable of giving evidence of abuse (see ch. 7).

**Hallucinations.**—Hallucinations are sensory experiences unique to the individual: he or she either hears, sees, smells, tastes, or feels something not experienced by others. When they occur, hallucinations are alarming to the family because of their association with insanity. They create risks for the patient who acts on them. Hallucinations usually respond to medication (37).

People with dementia also have illusions: they misunderstand sensory information so that they have an incorrect perception of reality. A man may believe a nurse is his wife. One man believed that his adolescent son was a boarder renting a room.

**Delusions**—Delusions are false, fixed ideas. As with suspicion, persons with dementia may be able to maintain a delusion for long periods, but at the same time be unable to remember factual information for more than a few minutes. The fixed nature of a delusion may seem to contradict an individual's memory impairment. The caregiver often feels that if the individual can remember a delusion, he or she should also be able to remember facts (22),

**paradoxical Behaviors.** -Persons suffering from dementing illnesses often exhibit seemingly paradoxical behaviors, some of which have been mentioned. A person may be able to play cards but unable to remember a family member's name. A person may be able to remember emotionally loaded material (e.g., being angry with someone) but unable to remember facts (e.g., that the matter that caused the anger has been explained). Someone may be able to do a task one day but not the next. Someone may still be able to work but suddenly get lost driving home from the office. An individual may behave in ways that seem to be deliberate actions to get attention or to control the responses of others, even when cognitive testing shows that the person is too impaired to carry out such manipulative behavior.

Such seemingly paradoxical behaviors are probably due to which specific areas of function have been spared or impaired in the person's intellect

and to the fluctuating and incomplete disruption of neurologic function. Whatever the cause, paradoxical behavior can affect the quality of the relationship between the individual with dementia and caregiver. This relationship can be positive: when much of a person's former personality is intact, a good deal remains that the family loves and enjoys. That retained personality can support the family in continuing to care for the individual (2 I). Yet when it appears that an individual can function well in one way, caregivers may expect an equivalent level of function in others, and, in so doing, may overstress the individual with dementia. When paradoxical behaviors appear to be intentional efforts to hurt or control a caregiver, caregivers sometimes respond as they would to such behavior in a well person. Such paradoxes can also cause confusion in the assessment of an individual's legal competence or ability to remain employed (22).

### ***Excess Disability Brought About by Outside Factors***

The level at which a person with a dementing illness is able to function is affected by other factors than the dementia. The first of these, treatment of secondary psychiatric symptoms, has been discussed. Others include the presence of other illnesses or reactions to medications, delirium, sensory impairments, or external stressors. Modifying or alleviating any of these factors can raise the level of function of the individual with dementia, even when the baseline impairment due to the dementia cannot be modified. The presence of symptoms that can be modified in this way has been labeled "excess disability" (16)—a term used by clinicians because it effectively contradicts the therapeutic nihilism often assumed in the care of persons with dementia (21,37). Unfortunately a worsening of a person's behavior or thinking is often assumed to be evidence of worsening of the dementia, and such persons are not examined for other, potentially treatable conditions which compound their disability (2 I).

#### **Presence of Other Illnesses**

Elderly persons are at risk of many other illnesses: heart disease, arthritis, diabetes, osteoporosis, and so on. The presence of any other con-

dition in addition to the dementia complicates the management of both. Persons with dementia may not be able to learn self-care or compensatory skills (e.g., insulin administration, use of a walker, or diet management) (24). Further, the presence of another illness may further impair the individual's cognitive function. Thus, treatment of the condition may somewhat improve the intellectual function as well (41). Persons with a dementing illness may also suffer from preexisting psychiatric disorders, that can compound their behavioral problems.

### Presence of Delirium

Delirium (also called acute brain syndrome) is a decline in intellectual functioning with clouded consciousness. As discussed earlier in this chapter, persons with dementia frequently develop a delirium from other illnesses or drug reactions. That can further impair their thinking. For these persons, the careful monitoring of health status and the adjustment of treatment regimen can improve the level of function (20).

### Presence of Sensory Impairment

Persons suffering from a dementia may also suffer from sensory impairments (loss or reduction of hearing, vision, taste, or smell) common in the elderly. Such impairment may be overlooked in individuals who are unable to complain of disability or whose behavior is misinterpreted. Sensory loss doubly impairs a person who does not realize the impairment or who lacks the ability to compensate for it (41). A person who suffers from a hearing loss may hear only whispers. If the person is also intellectually unable to realize this impairment, the person may conclude that others are talking about him or her, and become suspicious or hostile (22).

Individuals with dementia who need corrective eyeglasses or hearing aids should be assisted in using them. Caregivers must remind them to use these devices, and must assume responsibility for their maintenance. New eyeglasses, contact lenses, and hearing aids require that the person learn to use them; because they do not exactly reproduce the lost sense, they require that the user adapt to them. (Eyeglasses distort vision; in someone without dementia, the brain quickly learns

to ignore the distortion. Similarly, hearing aids magnify all sounds including those that the brain must learn to filter out.) Some persons suffering from dementia may never learn to adjust to new devices. Research is needed to develop supportive devices that are easier to learn to use.

Sensory deficits can be eased to some extent without the use of eyeglasses and hearing aids. Reducing background noise and glare, improving levels of lighting, and speaking clearly are important aids for confused persons (see ch. 7).

### Presence of External Stressors

When a person suffers from a dementia, seemingly low levels of stress (e.g., the presence of several people in the room, a medical examination, or getting lost) can significantly reduce his or her ability to function (30). Indeed, "whereas stress in the intact individual may enhance the ego, stress in the demented patient may lead to ego disintegration" (41).

The stressors that can precipitate such a drop in cognitive function maybe physical (mild illness, discomfort, or fatigue), exogenous (travel, or a change of environment), or psychological (fear, or discouragement over the inability to do a simple task). Keeping persons with dementia as healthy as possible, supporting sensory impairments, and adjusting demands on them can therefore improve function and reduce behavior problems.

### Terminal Stages of the Illness

As the disease progresses, more function is lost and these individuals gradually become totally dependent on others for care. Damage to the brain is profound and more generalized than in earlier phases. As the apraxia and aphasia progress, disruptive behaviors such as wandering and suspiciousness are lost. Individuals may lose the ability to swallow without choking. Clinicians report that at some point persons with dementia are no longer able to participate in group social activities. Caregivers are often uncertain of the extent to which the individual is aware of their presence.

Physical therapy and nursing care can reduce problems secondary to the dementia, such as contractures (abnormal shortening of muscle tissue),

bedsores, impactions, and dehydration. Sensory stimulation (such as music) and touch can support what function remains. Some individuals can

be kept alive for some time through aggressive medical care and life-sustaining systems, raising difficult ethical questions for caregivers (see ch. 5).

## **CONCEPTUAL ISSUES RAISED BY THE CHARACTERISTICS OF PERSONS WITH DEMENTIA**

### ***Is Dementia a Disease or Normal Aging?***

In the past, the set of symptoms identified as dementia was termed “senility” and assumed to be a part of normal aging. The shift from that belief to another—that dementia is a pathological syndrome caused by a group of diseases—has implications of public responsibility for the care of its victims: physicians have a responsibility to diagnose and treat the condition; caregivers and others must accept abnormal behavior as illness-produced rather than “crazy” or deliberate; research can be expected to improve treatment. Government can be expected to provide the same services for these individuals as for victims of other chronic illnesses such as heart disease or cancer.

In fact, although most authorities agree that dementia is a disease syndrome, the case for its being a concomitant of normal aging has not been disproved. The distinction between mental deterioration that occurs with age and that caused by disease rests on several premises. First, a process that affects all individuals would be considered a part of aging, while one that affects only a fraction of people would be called disease. Second, a condition that is due to aging should not be confused with a factor that is caused by long-term exposures or repeated insults; it should be considered an intrinsic part of the aging process itself. Mental symptoms severe enough to be called dementia do not affect all people, even if they live to a very old age. Third, finding a cause not intrinsic to aging would confirm that dementia is not a part of (“normal” aging). A few dementing disorders have been traced to specific causes (viruses, head trauma, or small strokes that are not due to aging), but the cause of Alzheimer’s disease remains unknown.

The impact of a shift in public attitude toward dementia has already been translated into in-

creased funding for research, proposed legislation, media attention, consumer demand for services, and contributions to the medical literature. Yet existing State and Federal laws and the attitudes of some physicians and nursing home personnel reflect the confusion and ambivalence that result in uneven treatment and access to resources.

### ***Are Persons Eligible for Services on the Basis of Age or Disability?***

The Federal Government offers many services to people not because they are ill but simply because they are over age 64. Persons with dementia often “fall between the cracks”—sometimes eligible for services to the elderly, sometimes eligible for services for the ill, and sometimes eligible for neither (see ch. 11). For example, Federal medical assistance does not provide for service in institutions for the mentally disabled to persons between ages 22 and 65. If institutional care is needed, persons with dementia who are under age 65 must be cared for in a nursing home if they are to receive medical assistance. Nursing homes are often reluctant to accept younger persons with dementia because they fear the potential behavior disorders in a physically able person. Some persons with dementia may have nowhere to go.

### ***Is Dementia a Mental Disorder; an Organic Disease, or Something In-Between?***

Disorders causing dementia lie on the border between traditional conceptions of “mental disorders” and “organic diseases.” Concepts of mental disorders are based on observed behavior; explanations of the cause can include madness incited by emotional stress, alcohol- or drug-in-

duced delirium, or cell surface receptor changes associated with depression. Concepts of organic diseases tend to focus on cancer, heart disease, or some other condition in which a concrete physical disability results from a structural or chemical disruption of normal body function. There has always been a broad and ill-defined gray zone between organic disease and mental disorder; progress in brain research over the last two decades has made the distinction even less defensible for many disorders.

The disorders covered in this assessment are organic diseases caused by changes in the brain, an organ whose cells can suffer damage in much the same way other organs do. The resultant symptoms of such physical damage, however, are behavioral, those most often ascribed to mental illnesses: intellectual decline, cognitive impairment, and emotional instability.

The diagnosis and treatment of persons with dementing disorders reflect that duality. Alzheimer's disease, for example, falls precisely between neurology and psychiatry, and it is treated by both disciplines. Recent recognition of the prevalence of Alzheimer's disease has attracted increased interest from physicians engaged in primary care, such as internists, geriatricians, and family practitioners. The diagnostic and therapeutic care that an individual receives may hinge on which type of practitioner the person sees. That may be advantageous in that different specialty groups may try different approaches, but it can also cause problems because care may be inconsistent or insufficient, depending on the training and competence of the physician in charge.

The distinction between mental and physical illnesses is prominent in public policies. Federal programs for drug abuse and alcoholism, for example, are administratively grouped with programs for diseases such as schizophrenia and manic-depressive illness, and kept separate from programs for heart disease, cancer, or arthritis. Because disorders causing dementia include features of both organic disease and mental debility, they often fall into an administrative limbo: they are sometimes covered by a mental health program, sometimes by a medical program, and often by neither.

An individual maybe excluded from one set of programs (e.g., under rules for determining eligibility for disability benefits), included in another (e.g., in Federal policies on biomedical research), or lost amidst a complex and sometimes contradictory combination of inclusive and exclusionary rules (as in many programs for long-term care). Each of these issues leads to local variations in the amount and type of care available to individuals or their families, based on local interpretations of "normal aging," age-related eligibility, and mental or physical illness. Some community mental health centers offer excellent services for persons with dementia; others do not. Supportive services available to the elderly, such as transportation and meals, may not be available to younger persons with dementia.

### ***What Share of Funds Should Be Allocated to Research Into Patient Care?***

In a setting of limited resources, allocation decisions must be made between funds for research into the cure or prevention of dementing illnesses and funds for research into improved care techniques. The sheer numbers of persons expected to develop dementia and the enormous potential cost of their care argues strongly for additional funding to prevent or cure the condition. However, there are also excellent arguments for research into ways to alleviate the suffering of the victim and the devastation of the family caregiver; more efficient ways to provide care may well affect the long-term costs of care.

Ample precedent exists for treating symptoms and alleviating suffering in persons with chronic irreversible diseases. But several unique problems arise with dementia. First, there is a widely held assumption that "nothing can be done" for persons with dementing disorders. If this were true, then failure to spend funds on unnecessary interventions would be justified. By the same token, a physician's failure to spend time with a patient presenting with dementia would be justified as a responsible conservation of valuable time. If interventions are beneficial, however, persons with dementia and their families are justified in



asking for as much treatment as victims of other chronic illnesses receive.

The second problem is the type of treatment persons with dementia seem to require. Persons with progressive dementing illnesses will experience continual declines in intellect and in their capability for self-care and independent living, and will eventually reach a state of total dependency. But decline in some abilities can sometimes be postponed, and some disturbing symptoms can be treated. The recommended intervention is often not medication or a medical procedure, but modifying the environment. Doing so appears to improve the quality of life for such individuals, and clearly benefits the caregivers. Clinical experience has demonstrated that good medical care and family support can reduce distressing behaviors in the home (30). And pilot projects have shown that persons with dementia function better in specifically designed settings than in traditional nursing homes (see ch. 7). The needs of a person with dementia can be compared with those of the mobility-handicapped person: providing access routes “treats” the mobility-handicapped so that his or her life can be more normal. Yet spending funds on a caregiver’s home is more difficult to justify than spending them on medications for the person with dementia.

Critical questions remain unanswered. Research into improving care is in its infancy, and the effectiveness of specific interventions is not fully understood. Little is known about which individuals would benefit from improved care. Scant research has been done on medications to control certain symptoms or on technologies that would support self-care.

The number of persons with dementia who would actually benefit from new methods of care or who are now overmedicated, undertreated for concurrent illness, restrained, or deprived of needed sensory stimulation is unknown; estimates range from a few to most. Nor are the costs of supporting optimal function well understood. The rate of disease progression when function is maximally supported has not been completely documented. Thus the cost-effectiveness of optimal care cannot be established. Investment in research in patient care and health care delivery is needed to answer these questions. Some estimate that it may be many years before a cure is found. If so, research is urgently needed to tell us how to provide humane care at an acceptable cost.

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