A REPORT TO CONGRESS OF THE
ADVISORY PANEL ON ALZHEIMER'S DISEASE

ALZHEIMER'S DISEASE AND RELATED DEMENTIAS: LEGAL ISSUES IN CARE AND TREATMENT

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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The Advisory Panel on Alzheimer's Disease, congressionally mandated by Public Law 99-660 and reauthorized by Public Law 102-507, was appointed by the Director of the Office of Technology Assessment, a non-partisan analytical agency that serves the U.S. Congress. The Panel was charged to advise the Department of Health and Human Services (DHHS) and its Council on Alzheimer's Disease, as well as the Congress, on Alzheimer's research priorities and policy recommendations. Its chairperson was appointed by the Secretary of HHS, and its activities have been administered through the DHHS. This report is submitted to the Congress, the Secretary of HHS, and the DHHS Council on Alzheimer's Disease; it also is released to the general public.

While the final version represents the advice and effort of the entire membership, the Panel wishes to express appreciation to Thomas V. Trainer, J.D., for his leadership in the development of this report.

The opinions expressed herein are the views of the authors and do not necessarily reflect the official position of the U.S. Department of Health and Human Services or any of its components.

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PREFACE

The Advisory Panel on Alzheimer's Disease, established under Public Law 99-660 (amended by Public Law 102-507), was charged with the following mandate:

> The Panel shall assist the Secretary [of the Department of Health and Human Services] and the Council [on Alzheimer's Disease, an intra-governmental task force also established under the same statutes] in the identification of priorities and emerging issues with respect to Alzheimer's disease and related dementias and the care of individuals with such disease and dementias. The Panel shall advise the Secretary and the Council with respect to the identification of —
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> (1) emerging issues in, and promising areas of, biomedical research relating to Alzheimer's disease and related dementias;
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> (2) emerging issues in, and promising areas of, research relating to services for individuals with Alzheimer's disease and related dementias and their families;
>
> (3) emerging issues and promising initiatives in home and community-based services, and systems of such services, for individuals with Alzheimer's disease and related dementias and their families; and
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> (4) emerging issues in, and innovative financing mechanisms for, payment for health care

services and social services for individuals with Alzheimer's disease and related dementias and their families, particularly financing mechanisms in the private sector. (Sec 922[a])

This report focuses upon legal issues arising in the context of Alzheimer's disease, matters that affect the person with the disorder, his or her family, health care professionals, and society at large. It contains a series of public policy recommendations for actions that are designed to resolve the problems that now arise in the context of judgments of legal competency and medical diagnoses of probable Alzheimer's disease (AD) or other related dementing disorders (ADRD).* These recommendations are highlighted in bold type throughout the body of this report.

The report also marks a departure from previous Panel reporting methods. In past years, the Panel has produced a single annual volume that provided a broad overview of emerging issues and needs in biomedical and health services research, and identified an issue and solutions to a specific problem in ADRD care and treatment, whether in the area of eligibility, provider training, treatment goals and objectives, or care needs of racial and ethnic minority populations. While that method of fulfilling its mandate has been well received by policy makers and

* The abbreviation ADRD is used when referring to the dementias as an undifferentiated group of disorders with similar manifestations, e.g., the population considered to show the cognitive impairments of dementia as a result of either Alzheimer's disease or related disorders. The abbreviation AD is used when referring to features, such as neuropathological changes, thought to be specific to the Alzheimer's disease process rather than true of dementias in general.

the public alike, the Panel has decided to develop and disseminate the products of its deliberations as separate, more focused reports. Thus, over the course of the year, the Panel will be reporting to the DHHS, the Council on Alzheimer's Disease, and the Congress on more than one occasion. However, our objective remains the provision of expert, scientifically based commentary and advice on research and service delivery issues key to understanding the nature of AD and to providing the most appropriate care and treatment to persons with Alzheimer's disease or related disorders.

LEGAL ISSUES IN THE CARE AND TREATMENT OF PERSONS WITH ADRD

INTRODUCTION

Alzheimer's disease (AD) currently affects an estimated 4 million Americans. Manifested initially by mild forgetfulness, this devastating disease eventually erodes all cognitive and functional abilities, leading to total dependence on caregivers and, ultimately, to death. The prevalence of AD increases dramatically with age. Persons age 65 to 74 have a 1 in 25 chance of having AD; for those 85 and older, the likelihood rises to a staggering level, approaching 1 in every 2 persons. Those age 85 and over represent the most rapidly growing sector of the American population, portending a dramatic increase in the overall number of cases of AD in the coming decade.

Persons with Alzheimer's disease and related dementias (ADRD) often are unaware of the toll taken by the multiple effects of the disease process at work within them. Initially, they evidence increasing "forgetfulness"; over time, they find themselves unable to work or to manage home life and personal care. Eventually, the inexorable course of the disease leads to loss of cognition and total dependence. On average, an individual's progressive incapacitation, with the attendant dependency and need for family or other forms of care, may last 6 to 8 years (1,2). At times, it can extend decades. In the progression of the disorder, persons with AD lose their ability to make decisions about even the most basic aspects of daily living: when and what to eat; how to dress; how to groom; how to toilet. They become dependent upon 24-hour supervision and need more intensive therapeutic interventions,

most often aimed not at the disease itself, but at its secondary behavioral and psychiatric symptoms of agitation, wandering, and inappropriate behavior.

Intervention most often first comes from family and other informal caregivers. The families of those with Alzheimer's disease experience increasingly substantial burdens as the result of the caregiving role. In an effort to delay institutional care, spouses and other family members often attend to the AD patient in the home, at the cost of lost wages, lost jobs, and lost time to tend to one's own needs. The incidence of compromised physical and mental health among family caregivers is significant as well (3). While respite care, adult day programs, and other community-based health care services may help reduce the growing pressure experienced by family caregivers, these services are of limited availability in many areas and are not sought by many family caregivers (4).

One of the most common results of this increased caregiver burden is placement in long-term care facilities, adding to the family burden in economic terms. Indeed, AD is one of the late life health problems most greatly feared by American families, due both to the enormous suffering it causes and to the significant costs it incurs. Persons with ADRD often require extended periods of nursing home care; when coupled with their lost income and the lost income of family caregivers, the result may be economic disaster. For many persons with AD, the last years of life are spent in a long-term care facility, the costs of which are borne primarily by today's welfare system (5,6).

In its previous reports, the Panel considered a host of medical, ethical, and health economic issues arising at their interface with Alzheimer's disease. We have examined issues of eligibility, health care financing, and professional training. Panel reports have shed light on the special concerns of ethnic and minority populations facing AD; and we have wrestled with is-

sues of values that control caregiving decisions made by and for persons with ADRD. In this report, we turn to legal issues, another area of growing concern in the care and treatment of AD. Central to the discussion are questions of autonomy and incapacity, medical decisionmaking, and long-term care.[1]

THE LAW AND ALZHEIMER'S DISEASE

Today, the U.S. legal system contains very little codified "law" specific to Alzheimer's disease and related dementias, notwithstanding the fact that these disorders are thought to affect over 4 million AD patients and perhaps again as many family caregivers and to cost nearly $100 billion dollars annually.[2] Relatively few statutes, whether at the Federal, state, or local jurisdictional level, contain any reference to Alzheimer's disease itself. A nationwide computer-based research inquiry conducted by the Panel found that in 1993, only 85 Federal and 200 state statutes in any area of jurisprudence included a

1 A computer search of court cases involving persons with AD yielded a variety of topics central to issues of judgment or what, in law, is referred to as "capacity." They included cases that focused on the capacity of a person with AD to marry; to enter into contracts with professionals; to enter into a durable power of attorney; to be tried for criminal acts; to serve as a witness in trials; to be excused legally for failing to act within a required time in the payment of property taxes, in lease renewal, or in response to a court pleading; and to undertake estate planning, such as the preparation of wills or trusts.

2 The National Foundation for Brain Research, which serves as the clearinghouse for Federal activities concerning the Decade of the Brain, has estimated that the total annual costs of dementia in the U.S. exceed $113 billion (1991 dollars), with direct costs (medical care, nursing home care) estimated at over $18 billion, and indirect costs (caregiver time, premature death) estimated at $94 billion.

specific reference to Alzheimer's disease. A preponderance of these statutes provide only for the establishment or operation of government task forces or panels on Alzheimer's disease[3] rather than for the regulation of a substantive area of law. The research query also searched court decisions of record. Of over one half million decisions recorded by the Westlaw legal computer system, only 260 decisions include any reference to Alzheimer's disease per se. Of these 260 identified cases, 50 contain only passing reference to AD. It should be noted that this figure may be somewhat conservative. A second computer-aided search, using the term senile dementia, a term formerly used to describe what we know today as ADRD, identified an additional 130 cases, again a very small number. The search demonstrates the paucity of legal precedent in the area of ADRD, suggesting also that future decisions or statutes likely will not be based on precedent.

While little statutory, case, or regulatory law deals directly with Alzheimer's disease, a number of general areas of law have a significant effect upon persons with Alzheimer's disease and their families. The balance of this report will focus on those issues, among them legal issues bearing on autonomy and incapacity, and on medical decision-making.

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3 The few statutes dealing with substantive legal matters demonstrate the difficulties that arise when attempting to draft legislation dealing with a specific illness or disorder in the absence of sufficient knowledge of the disease. Thus, a Utah guardianship statute, for example, requires that the proposed ward in a guardianship hearing be present in the courtroom unless there is "clear and convincing" evidence that the ward is "in the fourth level or stage of Alzheimer's disease." While AD is a progressive disease, clinicians have not adopted any type of system or strategy to identify AD by such "stages," and, thus, would be unlikely to be able to present clear and convincing evidence regarding the "stage" of the disease, notwithstanding the statute's clear wish for them to do so.

AUTONOMY AND INCAPACITY

A fundamental principle of the U.S. legal system is that people[4] are autonomous—entitled to make their own decisions, whether in minor matters such as choosing what to eat, read, or wear, or in major issues such as deciding whether to marry, move from one's home, or refuse medical treatment for a terminal illness. To the greatest possible extent, our legal system supports the concept of self-determination. The legal system begins from the presumption that all persons have both the right and the ability to make their own choices and decisions, so long as those determinations are within the law. This legal presumption remains in effect until a court determines otherwise,[5] based on fact finding and due process.

While legal statutes place a premium on autonomy and self-determination, they also recognize that a range of impairments may render a person incapable of independent decisionmaking, causing them to present a potential hazard to themselves or to others. Physical or mental impairments—among them, Alzheimer's disease or related dementias, stroke,

4 "Personhood," for the purposes of the law, most often refers to individuals over 18 years of age; some areas of law extend this definition to include minors of mature judgment.

5 Generally, a court's determination that a person no longer can make his or her own decisions is made prospectively in the conduct of a guardian or conservatorship proceeding [discussed later in this report under the section Involuntary Transfers of Decisionmaking]. While occurring less frequently, courts may review the past actions of an impaired person and determine that the person lacked the capacity to make a particular decision at the time he or she acted. As a result, the legal effect of the past act is set aside, as in the case of contested wills, questioned gifts, and disputed contracts for goods or services. Such legal challenges most often are brought before probate or chancery court, but, depending upon the nature of the dispute, also may be brought in the general trial courts of a particular locality.

mental illness, developmental disability—may limit a person's capacity to make choices or to undertake activities in one or more areas of life. To respond to questions of impaired decisionmaking ability, our legal system has adopted two separate approaches to the problems that arise in the wake of "incapacity" or "incompetence"[6] (hereafter referred to collectively as "incapacity") to make decisions as the result of that impairment.

First, the legal system has established methods through which persons voluntarily may delegate certain of their decisionmaking rights to others. This arises most often when a risk of incapacity is recognized, such as when a medical diagnosis of a mentally disabling disorder is made early in its course (discussed below in Voluntary Transfers of Decisionmaking). For people who have never been alert (unimpaired) or who, when alert, made no provisions for transfer of decisionmaking, the law provides a second means of transfer. Under this alternative approach, an impaired individual's rights are removed involuntarily and given to another (discussed below in Involuntary Transfers of Decisionmaking).

Critical to the voluntary or involuntary transfer of decisionmaking is the legal determination regarding capacity or incapacity. With either approach, the legal system must establish, through a formal set of procedures, whether a person has the ability to make his or her own reasoned decisions. No

6 "Incapacity" and "incompetency" are synonymous legal determinations that identify a person as being unable to care for self or property. The terms "incapacitated" or "incompetent" may be used by lay persons and the medical profession to describe someone as functionally or clinically unable to engage in rational decisionmaking. However, insofar as jurisprudence is concerned, an individual is entitled to retain his or her legal right to make decisions until and unless a court of law holds a hearing and makes a legal finding of incapacity or incompetency.

single standard has been codified for this legal determination. Rather, the courts broadly look to ascertain whether the person in question understands the basic nature of the decision or decisions being made, reaches his or her decision or decisions in a reasoned manner, and understands the consequences of the determination.

Alzheimer's disease presents particularly complex problems for the legal system in efforts to make determinations of capacity or incapacity. The disease is difficult to diagnose in its early stages. To date, a review of court opinions of record suggests that little, if any, uniformity exists in either how the diagnosis of AD is established or how its severity is measured.

In most of the cases reviewed, the sitting judges simply appear to have relied upon physician or psychologist statements regarding the degree of mental impairment. The testifying expert most often was not asked about past experience or education in working with AD patients. More often than not, the expert appears not to have been asked how the diagnosis was reached. In the few cases in which specific information regarding the diagnostic process was elicited from the expert witness, the diagnosis most often was based upon test scores (usually, the Mini-Mental State Examination—MMSE) and on positron emission tomography (PET) and magnetic resonance imaging (MRI) scans.

The Panel observes that **this approach to the assessment of legal capacity in persons with AD poses a number of problems, including: (a) reliance on a medical evaluation in the absence of specifically identified tests; (b) adequacy of the diagnostic screens, if used; (c) the familiarity of the medical witness with current practices in diagnosis and evaluation of potential AD; (d) reliability of determinations made through an evaluation performed at a distinct point in time; and (e) absence of measures of judgment.**

From a clinical perspective, the determination that an individual may be suffering from the early stages of AD cannot be made easily or lightly, given its profound consequences for individuals and families alike. For this reason alone, courts should not be satisfied with a suggested diagnosis of AD in the absence of clear medical evidence to support that diagnosis. As will be discussed in greater detail below, even when the diagnosis of AD has been established, a presumption of incapacity would be premature.

While the MMSE and other mental status tests are useful to distinguish normal from impaired cognitive function, they are not necessarily the best tests against which to evaluate the *specific* cognitive losses and loss of judgment that arise in AD.[7] Research (7) has found that results on this and other similar global measures of mental status may be affected by specific non-cognitive characteristics of the person being evaluated, such as physical health, socioeconomic status, and education. For example, a person with AD who had attained a high level of education may test relatively high on a cognitive screen; yet the score may be low relative to the person's score when healthy. Significant cognitive loss may be present but may not be identified through screening measures since scores from these tests

7 Mental status screens play a valuable role in the rapid evaluation of cognitive status; however, in and of themselves, such screens are not adequate for forming a specific diagnostic opinion regarding a particular aspect of cognitive function, such as language, memory, judgment, or psychomotor skills. Since the primary function of screens such as the MMSE is to assess overall cognitive status in a brief and rapid fashion, the screens lack detail about any single aspect of cognition. Detailed assessment requires the use of additional instruments specific to the area of cognition in question. The Agency for Health Care Policy Research Panel on Early Recognition and Initial Assessment of Alzheimer's Disease and Related Dementia [sic] has developed a bibliography containing what researchers and clinicians agree to be the seminal references for ADRD-relevant cognitive screens.

are judged against a scale that has been set to a relatively low common denominator. Similarly, persons with low education may have relatively low cognitive screen scores, but may not be suffering from AD. Moreover, in AD, particularly in its earlier stages, capacity may vary from day to day or even from morning to night; a single test instrument administered on a one-time basis may not reflect the overall state of impairment or lost judgment.

A host of significant diagnostic advances over the decade have led to the availability of more accurate evaluative techniques to aid in the establishment of a diagnosis of AD, whether for use in clinical care or in court-related evaluations of impairment. The Alzheimer's Association, in collaboration with the National Institutes of Health National Institute of Neurological Disorders and Stroke (NINDS), has developed diagnostic criteria that have been found to have an 80-90% accuracy rate, a standard with a higher degree of certainty than found when relying on standard mental status examinations. (A copy of these criteria is found at the back of this report section.) Recent basic research findings suggest that new and more precise tools may not be long in development.

However, even the most accurate measure of lost cognitive capacity or the diagnosis of AD itself provides insufficient information upon which to make a legal determination of lost capacity.[8] The concepts of cognition and judgment—the latter being the focus of the legal proceeding—are not synonymous. In addition to cognitive and neuropsychological assessment, other aspects of judgment should be evaluated through the assessment of occupational capacity or other measures of the prac-

8 Even with the limited number of legal decisions of record involving Alzheimer's disease, a number of courts have ruled that a diagnosis of AD alone is insufficient proof that a person is unable to make reasoned decisions.

tical aspects of functioning. Moreover, in forming a legal opinion of capacity, courts should evaluate historical evidence from the individual in question and informed others (such as family) as well as direct information regarding the individual's ability to make choices, understand the questions at hand, and to comprehend the outcomes of those choices. Through such means, courts will be able to distinguish more clearly between the loss of memory ("forgetfulness" or early cognitive impairment) and judgment.

Other difficulties in the legal determination of capacity among persons with ADRD extend to the knowledge base of the medical experts and family of the person in question. The expertise and background of the medical witness, oftentimes a family doctor who has treated the patient for years, may not reflect current knowledge of the diagnosis and treatment of AD. This may lead to untoward findings. For example, one of the primary and early effects of the disease—forgetfulness—does not affect a person's ability to make informed decisions in the early stages of AD; yet evidence of forgetfulness may be central in the legal decisionmaking process. Similarly, family caregivers may have conflicting interests in the outcome, particularly if caregiving has become particularly burdensome to them.

Each of these questions arises in the conduct of a legal evaluation of capacity in a person with AD, without regard to the degree to which the disease has progressed. With the exception of the latest stages of the disease, during which time the individual in question most likely has lost the ability to recognize family or to communicate with any clarity, the questions are no easier to answer. The middle phase of the disease—a period that varies widely from AD patient to AD patient, given the 6-20-year span of the disease—is characterized by significant personality change and loss of judgment and memory, notwithstanding the fact that both speech and mobility remain intact. At this stage, courts and family alike may find it difficult to determine whether an AD patient's decisions

are an expression of a desire for continued autonomy, or are a reflection of the disease process itself.

For example, concerned caregivers (family, health care professional, or adult protective services worker) may believe a person with AD to be unable to live alone safely because of the risk of malnutrition, disease, fire, wandering, or other similar hazards resulting from the increased inability to provide self-care or to avoid simple dangers. The person with AD may refuse a move to a supervised living setting, such as a personal care facility or a nursing home. In such cases, a court will be asked to determine whether this person is making a reasoned decision and, therefore, exercising personal autonomy in refusing the move. If the court determines that legal capacity and judgment are present, the person in question will be allowed the risk of self-harm to safeguard his or her personal autonomy. If, on the other hand, the court determines that the person no longer is able to make appropriate decisions, the court will order the person to be placed in the supervised living setting, protecting the person under the state's "parens patriae" or "beneficence" powers.

As discussed in the *Third Report of the Advisory Panel on Alzheimer's Disease*, the Panel believes that, to the extent possible, the autonomy of a person with AD should be preserved for as long as possible. However, the Panel also recognizes that, at varying times in the course of AD in any one individual, the ability to make decisions, to self-direct daily activities, and to conduct one's life becomes so severely impaired that it becomes dangerous or hazardous to self or to others. While it is the responsibility of the courts to determine the point at which people with AD can no longer continue to act autonomously and decisions affecting their lives must be made by others, the Panel has observed that the information upon which these decisions are made is not necessarily complete or based upon state-of-the-art knowledge of the nature of AD. Moreover, little uni-

formity exists in how the legal system manages questions of capacity in persons with AD.

For these reasons, the Panel hopes to bring greater assurance of autonomy for the AD patient for the greatest length of time and greater uniformity and clarity to the process of legal determinations of capacity through a number of recommendations:

- Current best medical opinion holds that **clinical diagnoses of Alzheimer's disease should be established through careful clinical evaluation at several different points in time. That evaluation should include, but not be limited to (a) cognitive screening instruments (such as the MMSE); (b) NINDS/ADRDA Alzheimer's screening criteria, including other neuropsychological assessment tools; (c) measures of practical aspects of functioning, such as occupational evaluations.** In addition, the assessment would be incomplete in the absence of historical evidence provided by the person in question or informed individuals, such as family and personal physician. The same determining procedures and methods should be employed across legal jurisdictions to bring greater uniformity to legal decisionmaking about AD patients' capacity.

- Insofar as medical and legal determinations of cognitive ability and judgment are concerned, it is important to separate the two concepts for the purpose of evaluating capacity. Judgment and cognitive ability are not synonymous terms; there is a difference between lost memory and lost judgment. Thus, **AD's early feature of memory loss alone does not necessarily compromise a**

person's ability to make informed decisions or to express preferences; impairment of judgment arises in the course of the disease, not necessarily at its diagnosis.[9] Courts should weigh this distinction carefully in competence determinations. Families and medical professionals, too, should be better informed about these distinctions.

- The complexity of capacity determinations for persons with AD suggests that **greater uniformity in evaluations and the concomitant need for evaluations at multiple points in time are needed.** A person with AD may be competent for certain purposes at a given time, yet found incompetent for other purposes at the same time.[10] For this reason, the Panel **recommends that courts *consider implementing regularly scheduled reassessments* of the legal capacity of persons with ADRD until such time as verbal and communication skills are irrevocably lost, thereby preserving autonomy in as many areas**

9 Judgment, too, should be distinguished from personality change, a common symptom in AD, but also present in a number of other disorders. While personality changes may provide indications of potential disease progress, such changes, in and of themsleves, are not a proxy measure for judgmental capacity.

10 The law also recognizes that not all types of decision require the same degree of understanding or cognitive capacity. Thus, while a person may be legally unable to make one type of decision, such as a home purchase or the establishment of a financial power of attorney, that person may retain the capacity to make another order of decision, such as writing a will or appointing a medical agent.

as possible for as long as possible. The Panel concurs that when these skills are determined to be lost irrevocably, repeated determinations of decisionmaking ability no longer are necessary. *Given the large number of persons likely to be adjudicated in such a system, states may wish to establish special court diversion programs that utilize a uniform set of criteria and procedures to determine issues of capacity in persons with ADRD.*

Voluntary Transfers of Decisionmaking

All states permit the establishment of voluntary legal arrangements—such as durable powers of attorney and trusts—through which a person can delegate to another the right to make certain decisions on his or her behalf. Historically, such arrangements have dealt primarily with financial matters; more recently, courts have broadened the interpretation of these arrangements to include delegation of broad personal[11] and healthcare decisionmaking as well.

The most useful of these devices is the *durable power of attorney.*[12] All states authorize their use for the purposes of delegating authority to manage financial and property matters.

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11 Certain limits exist regarding the personal rights that may be delegated to another. Clearly, an individual cannot delegate the right to vote or to marry.

12 A power of attorney is a document in which one person designates another to act as his or her agent in certain specified matters. A "durable" power of attorney is one that states specifically that the delegation of authority continues, should the first person become disabled or unable to manage his or her own affairs.

Though more than 40 states further authorize their use for purposes of delegating medical and personal decisions,[13] other states make specific and separate statutory provisions for health care decisionmaking. Under a properly drafted general power of attorney, an agent may pay the bills of the impaired person, manage his or her property, provide for the person's dependents, and maintain his or her affairs to protect the impaired person's post-death estate plan. In states that permit powers of attorney to be used for medical and personal surrogate decisionmaking, the agent of a properly drawn power of attorney also may be able to consent to or to refuse medical treatment, hire medical personnel, and decide where the impaired person will live. (This last issue may require court approval, particularly for nursing home placement. Statutes vary from state to state.)

Trusts,[14] while more complex and used most often for traditional estate planning purposes, also can provide for the complete management of the financial affairs of an incapacitated person and his or her dependents. *Joint asset holdings*[15] not a true delegation of authority but a means of

13 All of the 50 states allow medical decisions to be made under either a general durable power of attorney or a specific medical power of attorney.

14 A trust is an agreement in which a person (usually known as the "grantor") gives his or her assets to a "trustee" who, in turn, uses the assets in a manner consistent with the grantor's instructions to care for various "beneficiaries" designated by the grantor.

15 Assets, such as bank accounts, certificates of deposit (CDs), stocks, bonds, real estate, motor vehicles, and the like, can have shared ownership. For assets, such as bank accounts, CDs, and similar items, either owner generally has the right to deposit or remove funds. Therefore, by placing a second name on a bank account, an individual may establish a partial protection against incapacity. Upon disability, the second owner may continue to withdraw funds and use them to pay for the first owner's expenses.

sharing"ownership" of funds, may provide a means of simple estate planning and protection against incapacity. Through this mechanism, the healthy owner of a jointly held asset, such as a bank account, may be willing and able to use the assets to pay for the care of the impaired "partner." Unfortunately, this may not always be the case. Thus, this mechanism should be used with caution.

The great advantage of establishing these devices is that they allow a person who may later become incapacitated to determine who will act on his or her behalf. The documents upon which these arrangements are based can provide direction as to the decisions the giver wishes to have made. These devices, when properly drawn or established, generally avoid the need for future court intervention. However, these instruments require advance planning, an activity in which many people do not engage for a variety of reasons.[16] Moreover, the person entering into such advance planning must have the legal ability to make his or her own decision at the time the document is executed. The Panel notes again that a person in the early stages of Alzheimer's disease retains the legal right to make his or her own decisions absent a court finding of incapacity and may well have the current ability to establish voluntary delegations of decisionmaking.

The Panel has found that the use of voluntary transfers of decisionmaking is meager, at best, whether used for the purposes of property and finances or for the purposes of medical

16 In the absence of research findings, it is unclear whether this is because people fail to realize the risk of incapacity or the consequences of failing to plan for it, whether people lack access to professionals who may help implement an advance plan (such as attorneys, financial managers, and others), whether people have no reliable agents who can act on their behalf, or whether people fear that engaging in planning somehow may make the feared incapacity more likely to occur (the so-called "ostrich" theory).

and personal decisions. It is unclear whether these devices are not used because people are unaware of them, are unwilling (or emotionally unable) to confront their potential mortality, or perceive them to be too expensive to undertake. Whatever the reason, the Panel believes these voluntary transfers represent an important element in the maintenance of autonomous decisionmaking by persons with ADRD. Decisions made before issues of capacity arise are carried through by others on behalf of the incapacitated person in the manner specified in advance of the loss of judgmental and cognitive capacity. The use of such advance voluntary transfers can help avoid the need for involuntary guardianships once an individual has become incapacitated by AD. For this reason, the Panel makes a series of recommendations regarding this issue.

- As the Panel found in its third report with respect to persons with AD and as held as a key tenet of jurisprudence for the general population, individual autonomy and the right to make decisions should be granted primacy over the desires of others; these personal rights also should be safeguarded for as long as legally and medically possible. For these reasons, the Panel recommends that **the legal and medical communities work together to reach consensus on a specific set of tools through which the legal system may better be able to ascertain whether a person of uncertain cognitive status retains the *legal* capacity to enter into agreements of any sort, including the legal delegation of decisionmaking. Standardization of these procedures nationwide is indicated,** since the incidence and prevalence of AD do not vary widely from state to state. The needs of AD patients in Portland, Maine, are the same as those in Portland, Oregon.

- **Greater education is needed about the utility and appropriateness of voluntary transfers of authority**. Simple descriptions of what these mechanisms are and how they can be undertaken should be provided. Such information should be placed in the context of the nature of ADRD, its course, and its potential consequences on individual autonomy and decisionmaking. As discussed in greater detail later in this paper, material on this subject could be included in the larger public education document that the Panel has recommended be developed for dissemination not only by ADRD-related programs, but also by the Administration on Aging through its legal services programs, Area Agencies on Aging, and multipurpose senior centers.

- **Because persons diagnosed in the early stages of AD often retain the ability to undertake voluntary transfers of decisionmaking, health care professionals working with such persons should provide information about the mechanisms through which such voluntary delegations may be made.** This is particularly important in states in which durable powers of attorney may be used to guide medical decisions at later stages of the disease process. From the perspective of the person with AD, the most important aspect of a voluntary transfer may be the early designation of a trusted, knowledgeable, specific surrogate decisionmaker in the event of incapacity. **Professional societies, continuing education programs, and medical schools should help educate physicians to issues regarding voluntary transfers, since physicians often represent the most significant contact point for older Americans outside the family struc-**

ture. In this way, physicians may help assure patient autonomy for as long as possible, ensuring that patient desires are met even when decisionmaking capacity has been lost. The early establishment of a voluntary transfer can safeguard against the need for such determinations at the point of hospital admission, a time not ideal for patient-centered decisionmaking.

Involuntary Transfers of Decisionmaking

In the absence of a legally binding voluntary arrangement as described above, court intervention is required when a person becomes incapacitated and a decision regarding his or her care or finances must be made. Most often a court's determination that an impaired person has become legally incapacitated is made on a prospective basis; from the moment of the court decision, the impaired person may no longer make decisions that are legally binding. These court actions often are referred to as "protective proceedings," and are divided into two separate categories. When a court determines that a person no longer is able to make personal decisions regarding matters such as where to live, whether to seek medical care (discussed in greater detail below), whether to marry, divorce, or seek other legal action, the court will appoint a surrogate decisionmaker in a *guardianship*[17] proceeding. In contrast, *conservatorships*[18] are legal proceedings to establish incapacity and to identify a

17 All states have statutes that authorize a court both to review the personal decisions of a person alleged to be incapacitated and to appoint a substitute decisionmaker to act on behalf of the incapacitated person. Such statutes generally are referred to as guardianship proceedings, although nomenclature may vary from state to state.

18 Similarly, each of the 50 states has enacted statutes that authorize a court to review the financial decisions of a person alleged to be incapacitated and to appoint a substitute decisionmaker to act on that person's be-

surrogate decisionmaker for a person who no longer can manage financial matters such as bill paying, making investments, or selling realty.[19]

Typically, these legal proceedings are brought before the probate or chancery court of the county in which the impaired person lives or owns property. Some variation exists among the states regarding the rights and procedures under which these hearings are convened. However, in general, the court first determines whether the impaired person can still manage his or her personal and financial affairs. If the court finds the person to be incapacitated, it then appoints either a guardian or conservator—or both—to make decisions on the impaired person's behalf. [20]

In the past, courts generally gave guardians and conservators the authority to make all personal and financial decisions on the impaired person's behalf. More recently, however, a growing number of states have adopted laws that

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half. In some states, these determinations are incorporated into the guardianship proceedings; in other states, they are handled separately as conservatorships. Again, state terminology and procedure may vary.

19 Federal and state government agencies also provide what, in effect, is a limited "administrative conservatorship." A representative or "third party" payee may be appointed to receive and disburse Social Security, Supplemental Security Income, Department of Veterans Affairs, disability or other government benefit check for a beneficiary whose disability has affected the ability to manage funds. (The Panel notes that this arrangement is not always the most satisfactory. Problems regarding the management of patient funds by third parties have arisen in a variety of settings in which conflicts of interest arise, most notably in board-and-care facilities.)

20 In states that bifurcate personal and financial decisions, courts frequently will seek or appoint either a guardianship or conservatorship, not both. It is unclear whether such a decision is based on the belief that the impaired per-

permit courts within the state's jurisdiction to restrict the powers to be granted to guardians and conservators, allowing the impaired person to continue to make specific classes of decisions not yet affected by incapacity. At least in theory, such laws support the Panel's articulated view that, to the extent practicable and for as long as possible, a person should be entitled to the maintenance of autonomy and self-direction. These laws seem particularly appropriate to persons with Alzheimer's disease, especially in view of the disease's relatively slow progression and the varying degrees of capacity that may be accepted by courts in making capacity determinations about different kinds of decisions. However, in the absence of research, the effectiveness of partial guardianships and conservatorships in the maintenance of personal autonomy is untested.

It is clear to the Panel that **the use of voluntary transfers of decisionmaking should be encouraged**. Unless the loss of cognition and judgment inherent in a diagnosis of AD is planned for through the exercise of such voluntary legal arrangements, then the courts, not the person with AD, are likely to decide who will become the surrogate decisionmaker and the range of that person's authority.

MEDICAL DECISIONMAKING

Making decisions about one's own medical matters may be among the most personal of rights. Because the concept of autonomy is at its very roots, the U.S. legal system long has held that patients must be allowed to choose the

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son is still able to manage affairs in the other domain of decisionmaking, whether the person already has made voluntary arrangements in the second area, or whether the person simply has no financial or personal needs demanding the appointment of a guardian or conservator.

medical care and treatment that they will receive. Unfortunately, the nature of Alzheimer's disease is such that patients are faced with a diminishing ability to make decisions at the very time that medical interventions are becoming increasingly complex and more difficult for the lay person readily to understand. When working with AD patients over time, health care providers must determine anew at each visit whether the AD patient retains the ability to decide care and, if not, who should be called upon to make decisions on that patient's behalf. The family and friends of the person with Alzheimer's disease are confronted yet again by the nature of the disease and its inevitable progression when they are asked, perhaps for the first time, to make care decisions.

The Patient or Presumed Patient

The general rule of law states that a person is presumed legally able to make his or her own decisions until a court determines otherwise. While the presumption may be and has been challenged in court, the law strongly suggests that the benefit of doubt should be given to the patient, thereby preserving the right to decide his or her own care or, in medico/legal terms, to give "informed consent," for so long as an opinion can be expressed. Surprisingly, few court cases have discussed precisely what standards should be used to determine a patient's mental capacity to consent to health care. However, the limited case law reviewed by the Panel suggests that the test is whether the patient is of sufficient mind to reasonably understand his or her condition, the nature and effect of the proposed treatment, and the attendant risks in pursuing—and not pursuing—such treatment. Because of our system's preference for autonomy and the very personal nature of the consequences of receiving or refusing medical care, an individual's own decisions about medical care should be given the greatest weight for as long as the patient is able to express a preference.

Advance Directives

At a point in time that varies with the speed of the course of disease, a person with AD will become unable to make his or her own medical decisions. Each of the 50 states now has statutes that permit the establishment of voluntary arrangements to delegate at least some medical decisionmaking rights to others. These arrangements, referred to as "advance directives," are written documents that a patient signs while competent; they direct how health care treatment decisions will be made in the event of future incapacity. Two types of advance directives have been established under law:

- *A Power of Attorney for Medical Care* is a document granting an agent (or "advocate") the right to make some or all medical decisions on the patient's behalf should the patient become ill. All of the states but Alabama have statutes that permit a person to delegate medical decisions to another through a special health care power of attorney or as part of a general power of attorney (discussed earlier in this paper).

- *A Living Will* is a document providing specific instructions to physicians about an individual's wishes regarding medical care in the event the person becomes too ill[21] to articulate such preferences. Forty-eight states have Living Will statutes.

21 All state living will statutes authorize the use of such directives for "terminally ill" people. Some state statutes further permit living wills to be used for persons in permanently unconscious or persistent vegetative states.

- In the new proposed uniform statute, the separate concepts of the living will and the power of attorney for medical care are joined in a single document called an advance directive. That concept has been adopted in statutes in Arizona, Connecticut, Florida, Maryland, New Jersey, Oklahoma, Oregon, and Virginia.

These two types of directive often are combined in a single document that contains both a designation of an agent who will carry out the patient's wishes and a set of instructions to physicians who are about to provide care and treatment.

State statutes are not consistent in the delineation of the range of powers that may be given by a person in an advance directive. In general, however, such directives may authorize decisions regarding *care* (selecting who may provide services to the patient), *custody* (selecting the site at which the care is given), and *medical treatment* (selecting the diagnostic, surgical, therapeutic, or other procedures provided by health care workers at the differing sites). An interesting issue that may arise in the area of treatment advance directives is the question of experimental treatments for persons who might wish to become research participants. Greater attention should be paid to this last issue, particularly with respect to AD patients, whose loss of legal capacity may occur relatively early in the disease course.

Advance directives can be used and often are used to consent to life-sustaining treatment. They also can be used to refuse life-sustaining treatment at an identified point in the course of an illness; most advance directives are created for this very reason. While all states authorize the creation of advance directives, the extent to which they are actually in use is not known. What research has shown is that surrogate decisionmakers often do not choose the course of action

identified as by the patient as preferred. **Thus, given the irreversible nature and destruction of cognitive ability inherent in AD, the Panel believes it critical that people express their wishes regarding care: (1) if they have received a tentative or confirming diagnosis of the disorder in its early stages; or (2) if there is any concern about potential future loss of cognitive ability.**

Refusing Medical Treatment

U.S. law now has clarified that individuals have the right to refuse medical treatment in appropriate circumstances. In the Cruzan v Director, Missouri Department of Health decision of 1991, The U.S. Supreme Court recognized that the right to refuse medical treatment is protected under the Constitution, although it is not an absolute right without qualification. The Court recognized that states do have a legitimate interest in preserving life, preventing suicide, maintaining the integrity of the health care profession, and protecting the rights of minors or other third parties entitled to support and care. These state interests must be balanced against patient autonomy, and often are included in the statutes that permit the creation of advance directives.

In light of these protective but sometimes conflicting interests, states have general freedom to make their own rules regarding treatment refusal. One area in which substantial differences exist among the states is whether the artificial provision of *hydration and nutrition* falls within the definition of medical treatment, and whether, as such, it then can be refused in an advance directive. In the Cruzan case, the Supreme Court drew no distinction between hydration and nutrition and any other forms of medical treatment, leaving the determination a medical one. Nevertheless, a dwindling number of state statutes continue either to limit or to prohibit the right to refuse such treatment.

Health care providers have expressed concerns that honoring advance directives may result in liability. So far, this concern appears to be unfounded. Advance directive statutes often include provisions that release a provider from civil or criminal liability if a directive has been followed in good faith. Extant court cases do not suggest substantial risk to the health care provider, either. Based on information compiled by the State Justice Institute, only one appellate court case was found to involve criminal charges being brought against a provider for heeding an advance directive; moreover, the charges brought in the case later were dismissed.[22] Similarly, the State Justice Institute review found only a single civil suit brought against a provider for honoring an advance directive; five separate cases have been brought against providers for refusing to honor an advance directive and continuing treatment.[23]

The nature of AD can present problems in the use of advance directives. These devices, whether by statutory language or by drafting, may restrict the right to refuse medical treatment to cases of terminal illness. Family members and others who must act on the patient's behalf find it difficult to know how AD falls within this definition, considering the uncertainty regarding its progression. **In the Panel's opinion, AD, today, must be considered a terminal illness; end-stage AD is no less terminal than end-stage cancer or heart disease. The Panel understands that the uniform act on advance directives recently adopted by the National Commissioners**

22 Barber v. Superior Ct of Los Angeles County, 147 Cal App3 1006, 195 Cal Rptr 484 (1983). See Guidelines for State Court Decision Making in Life Sustaining Medical Treatment Cases, Second Edition, Appendix A, West Publishing.

23 See Guidelines for State Court Decision Making in Life Sustaining Medical Treatment Cases, Second Edition, Appendix A, West Publishing.

of Uniform State Law removes the requirement that end-stage disease be certified. However, until the model statute is adopted by each of the 50 states, the Panel believes that determination of what constitutes "end-stage" AD should be the province of the treating physician. The Panel further suggests that individual physicians, courts, and families should be granted broad permission to establish when an advance directive of a person with ADRD should be honored. Dialogue on this issue is key to successful resolution in the best interests of the patient and society as a whole.

Treating in the Absence of Advance Directives

When a patient cannot make his or her own decisions and no advance directive has been set in place, health care providers often are uncertain whether they must seek judicial involvement before providing treatment. In some situations, the patient's condition or behavior may make such a step unnecessary. For example, the law long has recognized that informed consent need not be obtained in an emergency. Similarly, consent may be implied when a patient seeks or manifests a willingness to submit to treatment; however, case law does not elucidate clearly the parameters within which these exceptions are legally acceptable.[24]

In some states, a "family consent" statute further diminishes the need for judicial involvement. In the absence of an advance directive, such a statute typically gives authority to make medical decisions for an incapacitated patient to family members; priority is given to the closest relative.

24 Notwithstanding the latitude, these doctrines do not give health care personnel the right to treat an impaired person contrary to the terms of an advance directive of which they were aware.

Reliance on state statutes and court proceedings to determine the appropriateness of medical treatment in the absence of advance directives occurs less frequently than one would suspect by relying on media accounts (e.g., Cruzan, Quinlan, etc.). To date, most frequently, medical decisionmaking for incapacitated people is made informally by families in the absence of specific legal authority or basis for making decisions except their concern and knowledge of the patient's wishes. While this approach may not be supported by clear legal authority, reliance upon family decisionmaking is widespread, not only acknowledged but approved by some courts.[25] This practice also is supported by the landmark Federal report, *The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: Deciding to Forego Life-Sustaining Treatment,* 1983, and is incorporated in many hospital practice guidelines.

When relying upon informal decisionmakers, health care providers may need to determine who among the family members is the most appropriate to act on the patient's behalf. In most circumstances, the spouse is the preferred first choice. State case decisions often uphold the right of one spouse to act for the other under certain circumstances. The spouse generally also has the highest priority among family members for court appointment as guardian, should legal authorization be sought or required. However, if the spouse is ill or a history of neglect or domestic relations complaints is present, health care providers and courts alike may well question whether the spouse is the best candidate for the role as surrogate decisionmaker.

In the absence of a spouse, adult children generally are the next choice. Unfortunately, the law provides little help

25 For example, Quinlan and Rosebush.

in determining which child to rely upon, should there be disagreement between or among them. Again, health care providers should be alert to possible indications of abuse, neglect, or other family difficulties. As the Panel observed in its third report, it is critical to assure against competing interests when it becomes necessary to rely on family or informal caregiver decisionmaking. For this reason, the Panel emphasizes the need for health care professionals to engage in regular conversations about these difficult medical issues with their patients with suspected or diagnosed AD. By placing greater emphasis upon the importance of advance directives, physicians and other health care professionals might help assure that a patient's desires are articulated before issues of capacity arise and long before the need for medical intervention occurs.

Federal Involvement in Medical Decisionmaking

In 1990, the U.S. Congress adopted the Patient Self-Determination Act, which requires all Medicare or Medicaid certified health care organizations, including hospitals, nursing homes, home health agencies, hospices, and prepaid organizations, to—

i. give all patients written information regarding their rights under state law to make decisions about medical care, including, in particular, the rights to refuse medical treatment and to prepare or have honored written instructions outlining their wishes;

ii. have written policies and procedures about the use of "advance directives";

iii. include the "advance directive" in the medical record of any patient who has made one; and,

iv. educate the facility's staff and the community on issues regarding advance directives.

This law could help increase the awareness and the use of advance directives and not interfere with states' rights to codify state health care law. The statute's laudable goals, however, will be met only if people indeed receive and understand the information regarding their medical decisionmaking rights, and if the means necessary to establish their wishes are readily accessible.

In its Third Report, the Panel identified a number of principles that should guide overall decisionmaking in the care of AD patients:

- Place high priority on the values of patients and families.
- Emphasize quality of life, broadly defined, over mere survival.
- Encourage resolution of value conflicts among patients, families, and care providers through early education and other mechanisms outside the court system.

The Panel believes that these same principles should guide the medical decisionmaking that occurs in the care and treatment of Alzheimer's patients. To that end and as stated earlier in this paper, the Panel recommends that **given the nature and destruction of cognitive ability inherent in AD, people should be encouraged to express their wishes regarding care through the use of advance directives. Such directives are warranted whether the individual is at risk of AD, has received a tentative or confirming diagnosis of the disorder, or if there is any concern about potential loss of cognitive ability in the future.**

However, while patient values—expressed through such advance directives—should be foremost in medical decisionmaking, the Panel concedes that much is not known about how individual decisions about treatment preferences may change over time. For example, an advance directive issued in anticipation of AD may be far different from one that might be issued after confirmatory diagnosis of the disorder. For this reason, the Panel believes that **greater research is warranted regarding the stability of treatment preferences over time.** Such research could help ascertain whether advance directives should be reevaluated and altered at the will of the person with AD at various points in the disease process. Further, by suggesting the use of advance directives, the Panel is also arguing for **further basic and clinical research that may lead to the detection of AD in its very earliest stages**, before questions that could cloud the validity of an advance directive arise, such as issues of capacity or cognitive status.

Yet, even with an advance directive in place, its utility has been limited by the laws governing such documents. Most often, a right to refuse treatment (contained in an advance directive) is limited to cases of terminal illness. Unfortunately, neither case history nor general practice of medicine or law is clear regarding precisely how AD falls within that definition. In the Panel's view, until such time as the uniform act on advance directives is enacted in each state, **both those rendering treatment to AD patients and those defining statutes governing the right to refuse treatment today must consider AD to be a terminal illness. End-stage AD should be treated in the same way as end-stage heart disease or cancer; advance directives should be honored based on the treating physician's determination that the illness has reached its final stage**. As observed in its previous reports, the Panel recognizes the difficulties inherent in linking such policy principles to clinical care or personal decisions by individual patients and families.

Nonetheless, the issue remains one of values, and those of the individual with AD should remain paramount in the medical and legal decisionmaking processes.

CONCLUSION

This report represents the culmination of several years of Advisory Panel deliberations regarding legal issues affecting the care and treatment of people with Alzheimer's disease. The issues are complex, ranging from questions of autonomy and capacity to medical treatment and the right to refuse that treatment. The lengthy trajectory of AD further complicates how decisions regarding the legal rights of a person with AD are to be protected and how that person's safety is also to be maintained. The Panel's Third Report emphasized the role of values in the care and treatment of persons with AD. Values form an overarching theme in this report as well, including the values implied in law and statute, the values inherent in the voluntary transfer of decisionmaking, the values held by formal and informal caregivers, and the values contained in advance directives.

The legal implications of Alzheimer's disease have not been clarified in case law to date. However, as the number of persons with AD rises, the need for more reasoned and medically sound mechanisms to determine issues of capacity and stage of illness is heightened. To that end, the Panel has made a host of recommendations regarding legal capacity and medical decisionmaking in AD care and treatment.

- Medical and legal determinations of cognitive ability and judgment are not synonymous. Courts should weigh this distinction in competence determinations; families and medical professionals should be better informed of the differences.

- Greater uniformity in medical evaluations and the conduct of evaluations at different points in time can help ensure that the autonomy of a person with AD may be maintained for as long as possible.

- The legal and medical communities should work together to reach consensus on specific nationally applicable tools through which the legal system may be able to ascertain whether a person of uncertain cognitive status retains the *legal* capacity to make his or her own decisions.

- The use and appropriateness of voluntary transfers of authority should be the subject of education for older persons and their families, through not only ADRD-related organizations, but programs working with older Americans in general, whether at the Federal, state or local levels. Health professionals, too, should be educated about such mechanisms and should provide information about them to their patients or clients. Professional societies, continuing education programs, and medical schools can be helpful in this effort.

- The use of advance directives should be encouraged for those at risk of or those diagnosed with AD. Through improved methods of early detection of AD the timely issuance of such directives can be facilitated. Until such time as the model uniform act on advance directives is adopted by each of the states, the use of advance directives, however, must be accompanied by acceptance of the Panel's view that there is such a concept as "end-stage" AD and that the trajectory of AD today is no different from that of a patient diagnosed with incurable heart disease or cancer.

The Panel believes that enactment of the recommendations contained in this report will be beneficial not

only to large numbers of ADRD patients and their families, but also to the wider community. It calls upon those in the medical and legal professions to begin to grapple with the legal issues surrounding Alzheimer's disease from the perspective of the patient and family, urging greater education of older Americans and caregivers to legal mechanisms available to preserve individual autonomy in the event of lost cognitive capacity due to ADRD.

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APPENDIX

Clinical Diagnosis of Alzheimer's Disease:

Report of the NINCDS-ADRDA Work Group* under *the Auspices of Department of Health and Human* Services Task Force on Alzheimer's Disease

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Alzheimer's disease is a brain disorder characterized by a progressive dementia that occurs in middle or late life. The pathologic characteristics are degeneration of specific nerve cells, presence of neuritic plaques, and neurofibrillary tangles. Alterations in transmitter-specific markers include forebrain cholinergic systems, and, in some cases, noradrenergic and somatostatinergic systems that innervate the telencephalon.

A Work Group on the Diagnosis of Alzheimer's Disease was established by the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA)+. The group intended to establish and to describe clinical criteria for the diagnosis of Alzheimer's disease of particular importance for research protocols and to describe approaches that would be useful for assessing the natural history of the disease. The need to refine clinical diagnostic criteria has been emphasized because 20% or more of cases with the clinical diagnosis of Alzheimer's disease are found at autopsy to have other conditions and not Alzheimer's disease. Moreover, therapeutic trials can be meaningfully compared only if uniform criteria are used for diagnosis and response to treatment.

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* For Work Group participants and affiliations, see page 943.

+ The NINCDS is now known as the National Institute of Neurological Disorders and Stroke (NINDS). The ADRDA is now known simply as the Alzheimer's Association.

The need for this report was suggested by the National Advisory Council of the NINCDS. The report has been reviewed by workshop participants, representatives of the National Advisory Neurological and Communicative Disorders and Stroke Council, representatives of the ADRDA, and designated reviewers representing professional societies concerned with the diagnosis of Alzheimer's disease. (For list of professional societies and designated reviewers, see page 58.)

The report was developed by subgroups that addressed medical history, clinical examination, neuropsychological testing, and laboratory assessments; the report was then discussed in plenary session. Based on a consensus of the participants, criteria were developed to serve as a clinical basis for diagnosis. These criteria should be useful also for comparative studies of patients in different kinds of investigations, including case control studies, therapeutic trials, evaluation of new diagnostic laboratory tests, and clinicopathologic correlations.

The criteria are not yet fully operational because of insufficient knowledge about the disease. The criteria are compatible with definitions in the current Diagnostic and Statistical Manual of Mental Disorders (DSM-III) and in the International Classification of Diseases. These criteria must be regarded as tentative and subject to change. Additional longitudinal studies, confirmed by autopsy, are necessary to establish the validity of these criteria in comparison with other criteria such as DSM-III.

CRITERIA FOR DEMENTIA SYNDROME. Dementia is the decline of memory and other cognitive functions in comparison with the patient's previous level of function as determined by a history of decline in performance and by abnormalities noted from clinical examination and neuropsychological tests. A diagnosis of dementia cannot be made when consciousness is impaired by delirium, drowsiness, stupor, or coma, or when other clinical abnormalities prevent adequate evaluation of mental status. Dementia is a diagnosis based on behavior and cannot be determined by computerized tomography, electroencephalography, or other laboratory instruments, although specific causes of dementia may be identified by these means.

CRITERIA FOR ALZHEIMER'S DISEASE. Alzheimer's disease is a progressive, dementing disorder, usually of middle or late life. The clinical criteria for the diagnosis of PROBABLE, POSSIBLE, and DEFINITE Alzheimer's disease are outlined in table 1. A clinical diagnosis of probable Alzheimer's disease can be made with confidence if there is a typical insidious onset of dementia with progression and if there are no other systemic or

brain diseases that could account for the progressive memory and other cognitive deficits. Among the disorders that must be excluded are manic-depressive disorder, Parkinson's disease, multi-infarct dementia, and drug intoxication; less commonly encountered disorders that may cause dementia include thyroid disease, pernicious anemia, luetic brain disease and other chronic infections of the nervous system, subdural hematoma, occult hydrocephalus, Huntington's disease, Creutzfeldt-Jakob disease, and brain tumors.

A diagnosis of definite Alzheimer's disease requires histopathologic confirmation. A clinical diagnosis of possible Alzheimer's disease may be made in the presence of other significant diseases, particularly if, on clinical judgment, Alzheimer's disease is considered the more likely cause of the progressive dementia. The clinical diagnosis of possible rather than probable Alzheimer's disease may be used if the presentation or course is somewhat aberrant. The information needed to apply these criteria is obtained by standard methods of examination: the medical history; neurologic, psychiatric, and clinical examinations; neuropsychological tests; and laboratory studies.

Medical history. A medical history should be taken from the patient and from an informant who is well acquainted with the affected individual. This approach is essential to establish a history of progressive deterioration and for identifying tasks that the patient can no longer perform adequately. A diary maintained by an observer may be very helpful in documenting changes in various functions. The history discloses abnormalities including impaired memory and other cognitive functions, impaired activities of daily living, alterations in mood, often delusions and illusions, and sometimes hallucinations. Common complaints of patients or families include forgetfulness about appointments or errands; inability to find the way to an accustomed destination; inability to use money and instruments of daily living such as a telephone; deterioration in work or homemaking performance; difficulty adapting to changes in the workplace; difficulties in dressing, reading, and writing; and inability to recognize previously familiar individuals.

Clinical examination. The clinical examination provides data to fulfill inclusionary and exclusionary criteria for the diagnosis of Alzheimer's disease and to document symptoms such as delusions or depression that identify subgroups of patients important both for research studies and for patient care. Mental status testing, an essential component of the clinical examination, includes specific assessment of orientation, registration, attention, calculation, recent recall, naming, repeating, understanding, reading, writing,

and ability to draw or copy. Because cognitive impairment may occur in depressive syndromes, it is important to inquire about affective state and depressive symptoms, such as disturbed sleep and weight loss, before diagnosing Alzheimer's disease. Inquiry specifically about the presence of delusions and hallucinations is needed to identify subgroups. Both symptoms may be experienced in a variety of neuropsychiatric disorders, which may or may not have known organic substrates.

Quantitative aids to the clinical examination include the Mini-Mental State Examination (1) for cognitive screening; the Blessed Dementia Scale (2) for clinical symptoms and social function; the Hamilton Depression Scale (3) for severity of depression; the Present State Examination (4) for anxiety, depression, delusions, and hallucinations; and the Hachinski Scale (5,6) for estimating the likelihood of multi-infarct dementia. A complete psychiatric evaluation is needed to exclude the various psychiatric disorders.

Complete examination of sensory and motor systems (including cranial nerves, tone, reflexes, coordination, gait, and proprioception) is needed to exclude other neurologic disorders. In early stages, patients are alert and free of other neurologic changes related to the dementia except for the occasional presence of snout reflex, jaw jerk, rigidity, or myoclonus, all of which may be encountered in nondemented elderly people. As the disease progresses, some patients become apathetic or show irritability, agitation, paranoid ideas, sleep disorders, or incontinence. In the very advanced stages, patients may become mute and lose all ability to communicate.

Neuropsychological testing. Neuropsychological tests may provide additional information for the diagnosis of dementia. Because there are no normative population standards for many of these tests, abnormal performance can be determined only by comparison with a normal control group matched for age, sex, and local education. A score falling in the lowest fifth percentile of an individual's normal control group may be designated as "abnormal." One or more abnormal scores will identify an individual for research purposes who is highly likely to be cognitively impaired. Progressive worsening can be established by comparison with the patient's previous performance on these tests. Although there is continued debate about the tests that best measure these functions, the Work Group did make some suggestions (table 2).

Similar series of tests can be used to assess less severely affected patients by increasing the complexity of the neuropsychological tests. Further modification in the test procedure may be needed to detect impairment

in highly intelligent patients. Confirmation of the dementia syndrome by neuropsychological tests should be based on measurable abnormalities in two or more aspects of cognition.

In longitudinal assessment, many patients with Alzheimer's disease show progressive loss of recent memory followed by disorders of language, praxis, or visual perception. In some patients with Alzheimer's disease, however, the first symptoms are difficulty in finding words, impaired visual perception, or apraxia, with memory impairment and other symptoms and signs appearing later.

Although neuropsychological tests are presently used primarily to provide confirmatory evidence for the diagnosis of dementia, these tests are valuable for determining patterns of impairment, for assessing changes in impairment over time and after drug treatment or rehabilitation, and for establishing correlations of abnormal performance with laboratory and neuropathologic examinations.

Laboratory assessments. Clinical assessment and neuro-psychological tests provide information to meet the criteria for clinically probable Alzheimer's disease. At present, there are no specific diagnostic laboratory tests for Alzheimer's disease, but some tests can enhance diagnostic accuracy by identifying other causes of the dementia syndrome. Moreover, as suggested by the Work Group, the laboratory approaches described below used quantitatively in longitudinal studies should help to clarify the natural history of Alzheimer's disease, possibly provide information needed in subtyping the disease, and permit measurement of efficacy of therapeutic interventions. Some of these techniques, particularly positron emission tomography, are strictly investigative tools and not readily available outside of research institutions.

Electrophysiologic methods. The EEG of some patients with Alzheimer's disease shows increased slow-wave activity that may become more pronounced with progression of the disease. Evoked potentials (EP) are brain waves associated with sensory or other events that may be auditory, somatosensory, or visual. Endogenous or cognitive potentials, such as P300, are thought to reflect speed of cognition. The latency of P300 is altered with age, and there appears to be an increased latency of P300 potentials in 50 to 80% of patients with Alzheimer's disease compared with age-matched control subjects. These changes occur in different dementias and are not spe-

cific to Alzheimer's disease. The P300 wave, however, is normal in depressive syndromes and may therefore be useful in differentiating the dementia of Alzheimer's disease from the dementia of depressive syndromes, particularly when adequate normal data become available.

Computerized tomography. CT is useful in the diagnosis of Alzheimer's disease because it permits the exclusion of other disorders such as subdural hematoma, brain tumor, hydrocephalus, and dementia associated with vascular disease. The technique can delineate gyri and sulci and quantitate tissue densities, ventricular size, CSF volume, and brain mass. In Alzheimer's disease the volume of the ventricular system and the width of the third ventricle are increased, gyri are narrowed, and sulci are widened; however, these general patterns may not be particularly useful as diagnostic criteria in individual cases. Furthermore, available data do not indicate how well a qualitative observation correlates with the magnitude of cognitive abnormality or with evidence of progression of disease. There is a pressing need for quantitative CT studies of Alzheimer's disease patients during the course of disease and for correlation of CT images with clinical signs, neuropsychological test results, and autopsy findings.

Regional cerebral blood flow. Measurement of regional cerebral blood flow (rCBF), including (10) xenon clearance, may help differentiate Alzheimer's disease and dementia associated with cerebrovascular disease. In multi-infarct dementia (MID), early changes include decreased autoregulation; in the later stages of MID, rCBF and oxygen consumption are decreased. In patients who have Alzheimer's disease, rCBF and cerebral metabolic rate are decreased; but A-V differences, carbon dioxide responses, and auto-regulation are preserved.

Positron emission tomography. Positron emission tomography (PET) is a research technique that allows quantitative assessment of the rate of glucose utilization, oxygen consumption, and rCBF. With some isotopes, these characteristics can be assessed during neuropsychological testing; moreover, (11) C-markers may permit the use of retest paradigms. Early reports suggest that rCBF determined by PET may be reduced in areas of encephalomalacia. In contrast, most patients with Alzheimer's disease show cerebral hypometabolism when compared with age-matched controls. These changes correlate with disease severity and may be correlated with neuropsychological test performance. For example, speech impairment may be correlated with decreased activity in the left hemisphere, whereas impaired performance on spatial tasks may be more closely correlated with impaired activity in the right hemisphere. Different approaches may be nec-

essary for delineating presynaptic and postsynaptic markers of transmitter systems, as recently achieved with PET images of the dopamine system. Since PET reveals a significant variation even among normal subjects, any change may have to be severe to be detected. The value of PET studies in determining the stages of disease, in documenting progression, and in assessing the effects of treatment is unknown.

Magnetic resonance imaging. The proton nuclear magnetic resonance (NMR) image, or magnetic resonance imaging (MRI), reveals the demarcation of gray and white matter of the brain and has therefore proved useful in studies of demyelinating disorders. Although the method has not been applied systematically to the study of dementia, it has potential for differentiating between Alzheimer's disease, multi-infarct dementia, and low-pressure hydrocephalus. Information should soon be available about the usefulness of MRI in the diagnosis of Alzheimer's disease.

Examination of body fluids and nonneural tissues. In the diagnosis of Alzheimer's disease, studies of blood and CSF are helpful in excluding chronic infections, such as cryptococcal meningitis and syphilis, and other disorders. To date, definitive diagnostic information about Alzheimer's disease from blood or CSF has not been sought consistently, but CSF should be studied to demonstrate neurotransmitters, metabolites, and synthesizing and degradative enzymes. Other techniques, such as sophisticated radioimmunoassays with specific antibodies, may be useful for detecting markers of the disease, such as constituents associated with the development of neurofibrillary tangles and neuritic plaques. Specific abnormalities have not been detected in nonneural tissues.

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Table 1. Criteria for Clinical Diagnosis of Alzheimer's Disease

I.. The criteria for the clinical diagnosis of PROBABLE Alzheimer's disease include:
--dementia established by clinical examination and documented by the Mini-Mental Test, Blessed Dementia Scale, or some similar examination, and confirmed by neuropsychological tests;
--deficits in two or more areas of cognition;
--progressive worsening of memory and other cognitive functions;
--no disturbance of consciousness;
--onset between ages 40 and 90, most often after age 65; and
--absence of systemic disorders or other brain diseases that in and of themselves could account for the progressive deficits in memory and cognition.

II. The diagnosis of PROBABLE Alzheimer's disease is supported by:
--progressive deterioration of specific cognitive functions such as language (aphasia), motor skills (apraxia), and perception (agnosia);
--impaired activities of daily living and altered patterns of behavior;
--family history of similar disorders, particularly if confirmed neuropathologically; and
--laboratory results of:
•normal lumbar puncture as evaluated by standard techniques
•normal pattern or nonspecific changes in EEG, such as increased slow-wave activity; and
•evidence of cerebral atrophy on CT with progression documented by serial observation.

III. Other clinical features consistent with the diagnosis of PROBABLE Alzheimer's disease, after exclusion of causes of dementia other than Alzheimer's disease, include:
--plateaus in the course of progression of the illness
--associated symptoms of depression, insomnia, incontinence, delusions, illusions, hallucinations, catastrophic verbal emotional or physical outbursts, sexual disorders, and weight loss;
--other neurologic abnormalities in some patients, especially with more advanced disease and including motor signs such as increased muscle tone, myoclonus, or gait disorder;
--seizures in advanced disease; and
--CT normal for age.

IV. Features that make the diagnosis of PROBABLE Alzheimer's disease uncertain or unlikely include:
--sudden, apoplectic onset;
--focal neurologic findings such as hemiparesis, sensory loss, visual field deficits, and incoordination early in the course of the illness; and
--seizures or gait disturbances at the onset or very early in the course of illness.

(Table 1, Continued)

V. Clinical diagnosis of POSSIBLE Alzheimer's disease:
--may be made on the basis of the dementia syndrome, in the absence of other neurologic, psychiatric, or systemic disorders sufficient to cause dementia, and in the presence of variations in the onset, in the presentation, or in the clinical course;
--may be made in the presence of a second systemic or brain disorder sufficient to produce dementia, which is not considered to be *the* cause of the dementia; and
--should be used in research studies when a single, gradually progressive severe cognitive deficit is identified in the absence of other identifiable cause.

VI. Criteria for the diagnosis of DEFINITE Alzheimer's disease are:
--the clinical criteria for probable Alzheimer's disease and
--histopathologic evidence obtained from a biopsy or autopsy.

VII. Classification of Alzheimer's disease for research purposes should specify features that may differentiate subtypes of the disorder, such as:
--familial occurrence;
--onset before age of 65;
--presence of trisomy-21; and
--coexistence of other relevant conditions such as Parkinson's disease.

Table 2. Neuropsychological Evaluation

The major cognitive processes that are impaired in Alzheimer's disease, with examples of the kinds of tests used to assess these functions, include:

- orientation to place and time, graded by a test such as the Mini-Mental State Examination;
- memory evaluated by tests such as a free-recall test of concrete nouns, a 3-4 paired-associate learning test (verbal and nonverbal) by use of a recognition paradigm, the Recognition Span Test, and the Brown-Peterson Distractor Test (stopping the task when the patient fails or begins to produce the distractor instead of the stimulus trigrams);
- language skills tested by examination of verbal fluency of the semantic or category type, with the examiner writing responses, and by other tests such as the Boston Naming Test (preferably one of the abbreviated forms), the Boston Diagnostic Aphasia Examination, the Western Aphasia Test, and the Token Test, with Reporter's Test;
- praxis evaluated by tests such as those in which the patient copies a drawing (cube, daisy, clock, or house) or performs the block design subtest of the Wechsler Adult Intelligence Scale;
- attention monitored by tests such as a reaction-time task or by the Continuous-Performance Test;
- visual perception studied by use of a variety of tasks, such as the Gollin Incomplete-Pictures Test and the Hooper Test;
- problem-solving skills determined by tests such as the Wisconsin Card Sorting Test, or the Poisoned Food Problem Task of Arenberg; and
- social function, activities of daily living, and instrumental activity of daily living, assessed by methods similar to those described in the Philadelphia Geriatrics Center Forms.

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