

Approved 4-2-86
Date ed

MINUTES OF THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by Marvin L. Littlejohn at
Chairperson

1:30 /a.m./p.m. on March 26, 1986 in room 423-S of the Capitol.

All members were present except:

Committee staff present:

Emalene Correll, Research
Norman Furse, Revisor
Sue Hill, Secretary to Committee

Conferees appearing before the committee:

Marilyn Bradt, Kansans for Improvement of Nursing Homes
Michele Hind, Kansas State Nurses Association
Joyce Romerso, Secretary Department on Aging
Dick Morrissey, Department of Health and Environment
Elizabeth Taylor, Ks. Assn. of Education of Young Children
Ks. Assn. of Local Health Departments

Visitor's register, (see Attachment No.1.)

Chairman called meeting to order, and invited conferees who would not be heard at previous meeting since meeting ran out of time.

Hearings continued again on SB 690.

Marilyn Bradt, Kansans for Improvement of Nursing Homes gave hand-out yesterday, so it is recorded in minutes of 3/27/86, as Attachment No. 8. She asked members to note her printed testimony distributed yesterday, and she urged for favorable consideration of SB 690, saying this is a good beginning towards helping people with these particular problems. It is a modest beginning, but a beginning.

Michele Hinds, Kansas State Nurses Association gave hand-out, see (Attachment No.2), for details. She spoke in support of establishing an 800 helpline where information related to Alzheimer's disease could be relayed to those who need such information. Social Security administration projects that by the year 2000, the group most at risk of institutionalization will be 60 percent larger than in 1983. The nursing home population can be expected to increase by 49 percent according to National Health Statistics recently compiled. The nursing profession has four main roles she stated, i.e., help those who are ill, regain their health; help the healthy maintain or enhance a state of wellness; offer support to those that are dying; and make life as good as it can be given the disease process. In the case of an Alzheimer's patient, we can't at this time help cure, but we can support the patient, utilize appropriate responses to behavior changes and effect the kind of nursing care that will provide a patient care geared specifically to this particular disease. Perhaps families of the Alzheimer's patient are even more affected, and the program that is spoken to in SB 690 will be of help to them. The Dept. on Aging would be responsible for implementation of SB 690 in providing adequate professional staff and resources to fulfill items detailed in Sec. 1, (c). She urged committee to favorable support SB 690. She spoke to the support of SB 3051 as well, and asked members to note that in her printed testimony this date. Within the Attachment are papers from Nurses Journal that members might find interesting and have some of their questions answered.

Ms. Joyce Romero, Secy. of Department on Aging gave hand-out, see (Attachment No.3), for details. She recommended passage of SB 690, and wanted to assure committee that their Department does not intend to create a new unit as the word "office" implies in Sec. 1, (b) of the bill. The office of Alzheimer's information would be a service delivered by a professional within an existing division of their Department. This person would assist those who call in or write; research national, state and local information for dissemination; publicize the existence and purpose of the helpline; cooperate with local area agencies

CONTINUATION SHEET

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Hearings continue on SB 690.

on Aging in disseminating information and making proper referrals; build a resource file of information; train state and local staff. These duties will require a professional who is knowledgeable about Alzheimer's and related diseases. Kansas needs a Helpline so that family members of Alzheimer's patients will always have a source of information in the future. The House Ways and Means approved \$10,000 and Senate Ways and Means approved an additional \$35,000 for funding this helpline.

At this point, Chairman noted he had discussions with Mr. Harper who testified at meeting yesterday on SB 690, and their Department would not have any problem with amending language in Sec. 1, (b), lines 30-35 that speak to "office"., he said. Motion made by Rep. Runnels to amend SB 690 to make necessary technical changes by removing lines 29-35 through the word "network" on line 35. Motion seconded by Rep. Williams. Discussion ensued, i.e., some objecting to all this language being removed since it describes some duties that shall be performed. Rep. Blumenthal made a substitute motion to change only the word "office" in line 30, to "position". Motion seconded by Rep. Branson. Discussion ensued, i.e., what other language might be more appropriate.

At this time, Rep. Blumenthal and Rep. Branson removed their substitute motion. Rep. Runnels, Rep. Williams withdrew their original motion to amend SB 690.

Possible language to amend was suggested by Ms. Correll. At this point, Rep. Branson made a motion to amend SB 690 by striking language in line 30, after the word an, "office of Alzheimer's information to assist", and to strike in line 31, words, "persons making inquiries through the", and to leave the remaining language intact. Motion seconded by Rep. Runnels.

Chairman invited Ms. Romero to comment on amendment proposed, and she said it was fine. No further discussion. Vote taken, motion carried.

Ms. Romero answered question, i.e., yes, they have one 800 phone number which is called Aging Services in Kansas. The helpline that they had requested funds for, they are just going into that. They are not establishing a whole new number. The present 800 number is highly publicized and currently is mainly used to take complaints against nursing homes, and we plan to have area agency publicize their 800 numbers more, she said. The request we have made will just piggy-back onto what is currently established, she said. When asked when they could begin to utilize a helpline, she replied, as soon as funding is available. Rep. Williams made a motion to amend SB 690 by striking the words, "statute book", and insert in lieu there of, "register", in line 56. Motion seconded by Rep. Hassler, no discussion, vote taken, motion carried.

Questions of Ms. Romero continued, no, there is nothing to prevent them from carrying out this service now, except that it would not be cost effective since they do not have any professionals manning the phones. If SB 690 were passed, it would change that. Radio and TV announcements were mentioned, since the FCC requires stations to air public service announcements be given. Ms. Romero thought this a good suggestion. The staff member that would be placed to work the helpline was discussed, i.e., credentials of said staff member. Ms. Romero said they would hope to get someone with a graduate degree, someone who had worked with Alzheimer's patients, or who had worked closely in the field of gerontology/geriatrics. We have people in mind, she said. There was discussion on related diseases, and presently there are over 100 dementias and Alzheimer's is but one of those. The helpline won't be perfect, but it will serve to educate and assist people and help to lessen some of their burden.

Chair at this point noted that Ms. Romero wished to speak to HB 3051.

HB 3051.

Ms. Romero offered attachment (No.4), in response to questions posed by committee members. Their Department on Aging suggests an amendment to HB 3051, she said, to authorize three demonstration respite care projects. Recommended amendment that speaks to this authority would be to delete Sec. 4 (c) through (h), and Sec. 10. Further, to insert the word, "three" between "that", and "countywide", in Sec. 4. Further, to amend

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Ms. Romero continued on HB 3051.

Section 5, could be amended by adding, "One program shall be established in a city which is a major population center of the state, one program shall be established in a city which in population is intermediate in size and one program shall be established in a city which in population is small in size." She stated their Department estimates these three projects would cost the state \$45,000, total, \$15,000 for each project.

Chair had committee note, this project of 3 programs being established had no funding. The funding was for the helpline only, so this proposed program would have to go through Ways and Means Committee before we could do anything further on it.

There was discussion on HB 3051, and Chair determined to by-pass action on this bill until such time as Rep. Wagnon will be available.

At this point, Rep. Branson moved to report SB 690 out favorably as amended, seconded by Rep. Cribbs, no discussion, vote taken, motion carried.

Hearings began on SB 672:--

Dick Morrissey, Department of Health and Environment spoke to SB 672, gave hand-out, (Attachment No.5), for details. He pointed out several technical changes. Sec. 1, he recommended the changing fee to \$15 for home licensed to care for less than 13 residents. And to change fee to \$75 for home licensed to care for more than 13 residents. In Sec. 3, to establish a fee of \$5 to offset costs incurred. And to remove an archaic requirement in Sec. 2 that would notify judges of all licenses issued or applications withdrawn. (This is no longer wanted or needed by the judges). Sec. 4 proposed changes purely technical, Sec. 5, would amend to establish requirement for annual inspection rather than 2 inspections per year. He urged for favorable passage. He answered questions from members, i.e., difficulty in the age of children authorized and perhaps changing the age to 16 or 18, since some are working age. Discussion on problems in some areas of the state where children are placed by the courts and the number permitted might not be in proper categories of under 13, or over 13. Mr. Morrissey agreed there are problems in both these cases, but their department felt it not best to make recommendations in this regard at this time. Just changing age limitations would not correct the problem in the one case he said. There has been an attempt to make adjustments, some County Attorney offices cooperate, and some do not. Purely in most cases because they too, must follow priority schedules, and this often is not top priority.

Norman Furse then asked members to note that line 64 of SB 672, language changes necessary might need to be made to delete language, "not to exceed".

Elizabeth Taylor, speaking to SB 672 in behalf of two groups, Kansas Association of Education of Young Children, and Kansas Association of Local Health Departments. They are concerned with the education of children under age 8, she said. We support Mr. Morrissey's recommendation of increasing the fees; the number of children; the technical changes suggested, but are concerned with the inspection visits, and do not support changing that from 2 to 1 per year. She answered questions from members, i.e., they feel a small \$5 fee would not discourage anyone from applying for registering a home to care for children. She suggested the legislature might wish to take a look at targeting the \$5 fee into the Local Health departments.

There was discussion in regard to a case in the state where one home was trying to put another out of business are are daily counting the number of children in an established home for children.

Hearings closed on SB 672.

Chairman asked Ms. correll to brief members on HB 3124.

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Ms. Correll stated, it was discovered there were hospital districts around the state who were unlawfully operating as hospital districts, having not operated hospitals for a period of years. There is a specific hospital that does not wish to operate as a hospital any longer, but wishes to operate as an adult care home. Hb 3124 would give authority to say that if a hospital district needs to terminate its hospital activities, it can turn itself into a health care facilities and services hospital district and can continue to operate those other types of health related services that it was operating at the time it was a hospital.

It is a technical kind of bill, and it is my understanding, she said, that the bill will speak to four or so other specific cases in the coming year.

Chair then noted work to be done in committee before deadline date. Tomorrow, Committee will have discussion and action on 9 bills/resolutions, and hold hearings on some.

Meeting adjourned at 3:15 p.m.

GUEST REGISTER

DATE

3-26-86

HOUSE

PUBLIC HEALTH AND WELFARE

Date 3-26-86

NAME	ORGANIZATION	ADDRESS
Eugene M. Carmick	Adult Services / SRS	St. Complex West Biddle Bldg
Michele Hinds	K.S.N.A.	Topeka
JOYCE V. ROMERO	KDOA	610 W. 10 th
Lyndon Drew	KDOA	610 W. 10 th
MARLENE HUGLUND	KDOA	610 W. 10 th
Richard Morrissey	KDHE	TOPEKA
B.J. SABOL	KDHE	TOPEKA
Elizabeth C. Taylor	KAEYC	"
Marek Hutchinson	KMS	Topeka
KEITH R. LANDIS	CHRISTIAN SCIENCE COMMITTEE ON PUBLICATION FOR LANDS	"
Marilyn Bradt	KINH	Lawrence
Andrea Levano	KS Hosp. Assoc.	Topeka
Tom Bell	KS Hosp. Assoc.	Topeka
Luis Jelo	Ks. Action for Children	"

Attachment 1
3-26-86
Hs. PHW

Attn. #2
3-26-86

For Further Information Contact:

Terri Rosselot R.N.
Executive Director
(913) 233-8638

March 25, 1986

SB 690

ESTABLISHMENT OF INFORMATION & REFERRAL NETWORK--ALZHEIMER'S DISEASE

Mr. Chairman, members of the Committee on Public Health and Welfare, my name is Michele Hinds, MN, RN, and I come before you today as the Legislative Chairperson of the Kansas State Nurses' Association. There are currently over 22,000 licensed registered nurses in the state of Kansas. KSNA supports Senate Bill 690 and HB 3051 (Respite care services for caregivers). As nurses we play an important role in patient and family advocacy and we share your concern regarding Alzheimer's and other related disorders. We support the establishment of a 800 Helpline where information related to the disease and resources available to caregivers and family members can be disseminated in a systematic and timely fashion.

The importance of this kind of program will become even more evident in the years to come as the population that is susceptible to dementia orders, that is, those over 65 years becomes much larger in number. Through innovations in medicine and the fact that technology has made hard manual labor less prevelant, Americans live longer, therefore making a larger population pool susceptible to Alzheimer's disease. The Social Security Administration projects that by the year 2000, the group most at risk of institutionalization (the over 85 population) will be 60 percent larger than in 1983. The nursing home population can be expected to increase by 49 percent according to the National Center for Health

Attn. #2
3-26-86
H. PHW

Statistics. The year 2000 doesn't even bring today's baby boomers into the over 65 category--their approach into the age group most susceptible to Alzheimer's disease will bring about increased demands for help and information. Perhaps by that time programs will have uncovered preventative and/or curative methods through research.

The nursing profession has four main roles. We help those that are ill regain their health, we help the healthy maintain or enhance a state of wellness, and we offer support to those that are dying and make life as good as it can be given the disease process. In the case of an Alzheimer patient we can't at this time help cure--we can, though, support the patient, utilize the appropriate responses to behavior changes and effect the kind of nursing care that will provide a patient care geared specifically to this particular disorder. The families of Alzheimer's disease victims are perhaps the most affected. This program will provide much needed education and referral services to those who need it most--the children, the spouses, the friends of Alzheimer disease victims who are seeing their loved ones change and don't know what to do or just need someone to talk to who would understand their crisis. It is also very important that health care providers know and understand the stages of the disease process and how the patient's individual needs should be accommodated.

SB 690 and HB 3051 were two of several recommendations from the Task

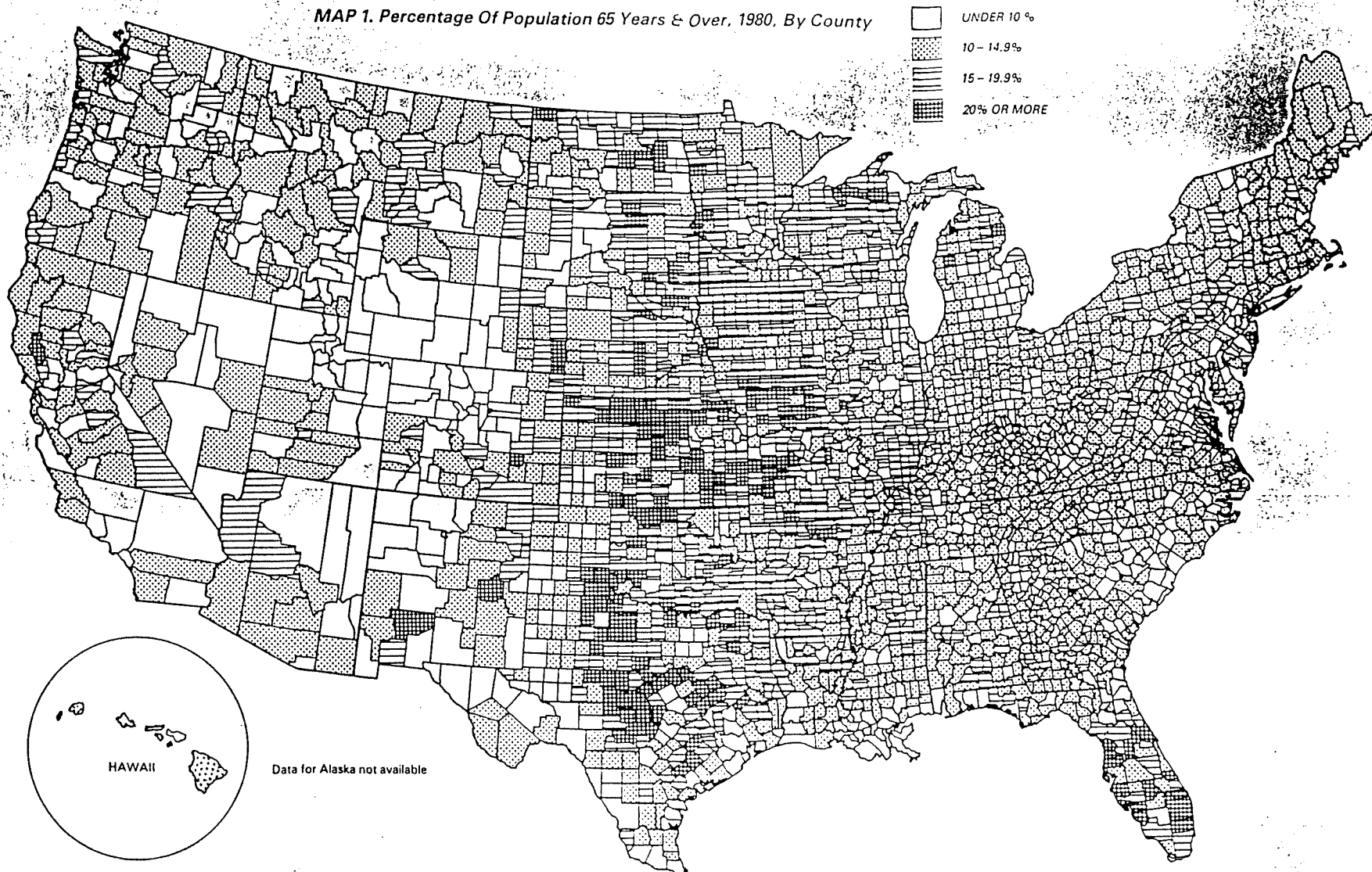
SB 690 Alzheimer's Testimony
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Force Report on Alzheimer's Disease. The Department on Aging would be responsible for implementation of SB 690 in providing adequate professional staff and resources to fulfill the items detailed in (c). KSNA would encourage this committee to support SB 690 and the fiscal note attached to its implementation.

HB 3051 which encourages the development of respite care services for caregivers through state financial assistance is an attempt to provide a much needed system for round-the-clock family members to remove themselves from the constant attention-giving setting that Alzheimers and other related disorders present. Without the availability of such services, family and loved ones tire very quickly of the constant strain of caring for these victims and resign to institutionalizing them. As institutionalized patients many of them become medicaid recipients and the state eventually pays for the services related to their care. Respite care services would encourage families to retain loved ones in the home for longer periods and indirectly reduce the financial strain on the already limited funds of the medicaid system. HB 3051 is one of the two remaining recommendations of the Task Force in this legislative session. KSNA encourages serious consideration to its passage.

Thank you.

MAP 1. Percentage Of Population 65 Years & Over, 1980, By County



SPECIAL COMMITTEE ON AGING · U.S. SENATE

Maps prepared for the Special Committee on Aging in conjunction with the Congressional Research Service and the Inter-university Consortium for Political and Social Research using cartographic software provided by the Statistical Research Laboratory, The University of Michigan. Based on data from the 1980 Census, February 1982.

KSNA

the voice of Nursing in Kansas
Copy of an article from the
American Journal of Nursing
Feb. 1984. It reviews the
stages of the disease process.

Continuing education credit
study of this feature.
e test. See page 232.
and fee.



ILLUSTRATION BY PETER FIORE

ALZHEIMER'S DISEASE

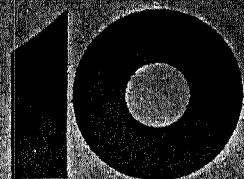
After you have studied the material here, you will be able to:

- Explain how Alzheimer's disease is detected and diagnosed.
- Identify four causes of reversible dementia.
- Explain three current theories on the cause of Alzheimer's disease.
- Discuss three treatment experiments based on the above theories.
- Assess the level of cognitive impairment in an Alzheimer's patient.
- Identify appropriate interventions for caretakers (nurses and others) at each of six levels of cognitive impairment.
- Explain nursing interventions for five functional disabilities common to hospitalized Alzheimer's patients.
- Discuss how family members can approach four common problem areas (sex, nutrition, sleep, and self-care) encountered in home care of Alzheimer's patients.

Jo Kahn, RN, was consultant to this continuing education feature. Ms. Kahn is a volunteer counselor with Alzheimer's disease family support groups in New York City.

Approved for CE credit by the ANA Mechanism for Continuing Education.

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For



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Contact
Hours

CE

ALZHEIMER'S DISEASE

INPATIENT CARE

BY MARILYN PAJK



The man shuffled stiffly, but insistently, down the corridor—the nurse beside him trying to coax him into taking a shower. The more she insisted, the more he resisted, his mask-like face tightening in refusal. Finally, the scene ended as it had every day since he had been admitted: He rigidly braced himself outside the shower room and shouted his refusal. The nurse wondered how this could possibly be the man who, according to his wife, had retired three years before as department chairman at a prestigious university.

Sadly, such tragic behavior changes are all too common among the victims of Alzheimer's disease. People who have the disease are usually cared for at home in the early stages of the disease and often require placement in a nursing home during the late stages. Nurses who work in acute care facilities may also encounter Alzheimer's victims who have been hospitalized for medical and surgical problems. A patient with congestive heart failure or diabetes, for example, may have a secondary diagnosis, senile dementia of the Alzheimer's

Marilyn Pajk, RN, MS, is a medical clinical nurse specialist at Mt. Auburn Hospital in Cambridge, Mass.

type (SDAT). It is this "secondary" diagnosis that often becomes the primary challenge in nursing care.

WHAT IS ALZHEIMER'S DISEASE?

Senility, "senile dementia," "hardening of the arteries," and "organic brain syndrome" have been used interchangeably to describe the cognitive decline of Alzheimer's disease.

Dementia is the term currently preferred to describe a syndrome of intellectual deterioration, disorganization of the personality, and inability to carry out the normal tasks of daily living(1). Dementias are categorized as primary or secondary. Primary dementias arise spontaneously with no known cause and have no known effective treatment. Secondary dementias are reversible and treatable; they may be caused by metabolic disturbances, nutritional deficiency or other acute conditions (see "Is It Alzheimer's Disease?" on the following pages.)

Alzheimer's disease, named after the German physician who first described the condition in 1907, is the most common irreversible dementia. It is estimated that 50-70 percent of all elderly people with dementia have the Alzheimer's type(2-4).

Though the disease has been described, the cause is a mystery, and the diagnosis is made virtually by the process of elimination. Conditions that produce dementia resembling Alzheimer's disease include drug intoxication, depression, head injuries, brain tumors, and nutritional deficiencies such as pernicious anemia. Because many of these disorders may be reversed or cured with appropriate treatment, it is crucial that they be identified and all treatable causes of dementia ruled out through a thorough medical, neurological, and

psychosocial assessment. The diagnostic process can be costly.

After all other disorders have been ruled out, a diagnosis of Alzheimer's disease is usually made on the basis of the type of symptoms and the way the symptoms progress over time. Confirmation, however, is only possible upon postmortem examination of brain tissue. The brain tissue of the patient with Alzheimer's has three hallmarks:

- *neurofibrillary tangles*—pairs of filaments wrapped around each other in the cytoplasm of the neurons;
- *neuritic plaques*—filamentous and granular deposits representing degeneration in the neuronal processes;
- *granulovascular degeneration*—in which fluid pockets and granular material develop in the neurons(4).

While these changes may be seen to some extent in the brains of normal aging people, in patients with Alzheimer's they are found throughout the cerebral cortex and in large concentration in the hippocampus, the short-term memory center of the brain.

EARLY STAGES

Alzheimer's disease can progress quickly, over three to four years, or slowly, over as long as 15 years(5). The first stage of the disease involves almost imperceptible changes(6). Forgetfulness, especially of recent events, is common. There may be difficulty learning or remembering new information. For example, the person may have trouble remembering that he is not supposed to eat or drink anything before a GI series.

The patient may also have trouble remembering hospital routines, how to use the call light, when he had his last medication, or the names of common objects, such as toilet articles. In an

undiagnosed person who is hospitalized, these problems may be mistakenly attributed to the stress of illness and hospitalization.

Deterioration in personal hygiene and appearance may be noted in the early stages. An inability to concentrate on such things as reading or watching television may be interpreted as a lack of interest, apathy, or depression. In fact, depression is not uncommon at this point because the person knows that things are "not quite right." The subtle nature of these changes does not usually interfere significantly with the person's ability to manage. Gradually, though, tasks that require abstract thinking, such as mathematical calculations needed to balance a checkbook, become more difficult. Activities requiring judgment, such as driving a car or following directions, also become harder. The hospitalized patient may be unable to follow directions for filling out the daily menu or to learn how and when to take medications. Friends and family may interpret these changes as carelessness or laziness, thus contributing to the patient's feelings of despair.

Alzheimer's disease is often missed in the early stages. However, a careful nursing assessment obtained from the patient and family may reveal short-term memory problems and inappropriate behavior that were noticed before hospitalization and so may not be related to the patient's illness.

LATER STAGES

The later stages of Alzheimer's disease extend over years, until death. One characteristic is progressive difficulty in communication. Deterioration of the areas of the cerebral cortex that involve memory, language, and motor functions results in a loss of coordi-

NURSING CARE PLAN FOR THE

FUNCTIONAL DISABILITY	NURSING GOAL	NURSING INTERVENTIONS
<p>Altered cognitive and perceptual abilities</p>	<p>Establish effective verbal and nonverbal communication with the patient</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Gently approach the patient with an open, friendly, relaxed manner and expression. Alzheimer's patients mirror the affect of those around them. If you are tense or hurried, the patient may become tense and resistant. EXAMPLE: Mr. Jones is shuffling down the hall toward the exit. The nurse, who is in the midst of administering medications, looks up and calls to Mr. Jones. When he doesn't respond, she dashes down the hall and quickly turns Mr. Jones around. Overwhelmed and frightened, Mr. Jones begins to shout and refuses to return to his room. If the nurse responds by gently and quietly talking to Mr. Jones, he will calm down and, after a few minutes, accompany the nurse back to his room. <input type="checkbox"/> Always identify yourself and look directly at the patient to be sure that you have his attention. EXAMPLE: "Mr. Jones, I am your nurse, Susan." <input type="checkbox"/> Speak to the patient in a clear, low-pitched voice. High-pitched tones convey anxiety and tension. <input type="checkbox"/> Eliminate competing and distracting background stimuli (e.g., radio, TV) when talking to the patient. Too much stimulation overloads and confuses the patient. <input type="checkbox"/> Use short and simple words, sentences, and questions. EXAMPLE: "Are you cold?" "Are you hungry?" "Here is your robe." "Here is your pill." <input type="checkbox"/> Ask only one question at a time. Wait for a response before asking another. If the patient does not respond, ask the question again in exactly the same way. Do not change the wording. EXAMPLE: Instead of "Do you hurt?" (pause) "Show me where you hurt." ask "Do you hurt?" (pause) "Do you hurt?" <input type="checkbox"/> Use yes/no questions as much as possible, and avoid those that require choices or decisionmaking. EXAMPLE: Instead of asking, "Would you like to go for a walk or listen to music?", first ask, "Would you like to go for a walk?" If the answer is no, then ask, "Would you like to listen to music?" <input type="checkbox"/> Break down tasks into individual steps and ask the patient to do them one at a time. EXAMPLE: a. "Here are your eyeglasses." b. "Take them out of the case." c. "Put on the eyeglasses." <input type="checkbox"/> Accompany verbal communication with appropriate nonverbal cues or signals. EXAMPLE: Ask "Do you need to urinate?" and show the patient the unal. <input type="checkbox"/> Physical expressions of caring (e.g., gentle touch, a soothing supportive arm) will usually be understood and may calm an upset patient. Recognize, however, that some patients may misinterpret a reassuring arm around the shoulder as a threat or restraint. <input type="checkbox"/> If the patient reacts catastrophically to a situation, remain calm and remove him from whatever is upsetting him. Also, respond to what you think he is feeling so that he will sense you understand. When verbal communication is lost, the feelings in a situation are usually appropriate but exaggerated so that the behavior is inappropriate. Avoid arguing or reasoning. Use distraction rather than confrontation. <input type="checkbox"/> Carefully assess the patient's nonverbal behavior, since he may not be able to verbalize pain or discomfort. Closely observe body cues such as posture, guarding, grimacing, sudden changes in behavior, and increased restlessness.
	<p>Provide a safe, structured environment</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Provide consistent caregivers for the patient, such as a primary and associate nurse. Consistency is often essential in securing the patient's trust. In addition, it is the best way to determine the patient's limits and how to interpret verbal and nonverbal communication. <input type="checkbox"/> Provide a room for the patient that allows careful observation, such as near the nurses' station. Make sure the patient is properly identified (e.g., by wristband). <input type="checkbox"/> Never leave at the bedside anything that might harm the patient (e.g., scissors, matches, medicine). <input type="checkbox"/> Keep siderails up and bed in low position. Check the patient frequently at night. A low light sometimes lessens anxiety. <input type="checkbox"/> Assess the patient's degree of ataxia; help with walking, if necessary.

PATIENT WITH ALZHEIMER'S DISEASE

FUNCTIONAL DISABILITY	NURSING GOAL	NURSING INTERVENTIONS
		<ul style="list-style-type: none"> <input type="checkbox"/> Establish a schedule of care. It is critical not to alter the patient's routine, so ask the family about the patient's usual schedule at home and try to follow it. If the patient is able to participate in his care, always keep such things as toilet and bathing articles in the same place. <input type="checkbox"/> Orient the patient to person, time, and place frequently. A calendar and clock on the wall are helpful. When possible, label items, using visual cues, such as a picture of a shirt on the closet door.
Alteration in exercise activity patterns	Maintain mobility and exercise as much as possible, appropriate to the patient's level of fitness	<ul style="list-style-type: none"> <input type="checkbox"/> If the patient is able, encourage walking, especially during the day. The activity will help maintain muscle strength, joint motion, and improve sleep. <input type="checkbox"/> Bedridden patients require active and passive range-of-joint movement. <input type="checkbox"/> Avoid restraints, if possible. They tend to disturb the patient and may precipitate a catastrophic reaction.
	Provide cognitive stimulation in the patient's environment	<ul style="list-style-type: none"> <input type="checkbox"/> Avoid isolating the patient. A person with dementia still enjoys the presence of caring people. <input type="checkbox"/> Soft music from a radio or tape recorder may be very soothing. The patient whose short-term memory is impaired often remembers songs and music from the past. <input type="checkbox"/> Some Alzheimer's patients may enjoy television; others find it too stimulating and frustrating to follow.
Altered bowel and bladder patterns	Maintain bowel and bladder continence for as long as possible	<ul style="list-style-type: none"> <input type="checkbox"/> Keep a written record of the patient's continent and incontinent voidings and bowel movements to determine his usual pattern. Then, offer the bedpan or urinal, or walk him to the bathroom, as the pattern indicates. <input type="checkbox"/> Often patients are incontinent because they can't get to the bathroom quickly enough or because they can't find it. Marking the bathroom clearly with a picture of a toilet may help. Some patients may be more successful using a bedside commode or urinal. <input type="checkbox"/> Limit the fluids the patient consumes at bedtime to prevent nighttime incontinence. <input type="checkbox"/> Avoid using laxatives, but encourage a high-fiber diet to help maintain bowel regularity. Since the patient may not be able to tell you about it, observe subtle signs of constipation, such as lethargy, reduced appetite, abdominal distension.
Altered nutritional/metabolic patterns	Maintain optimum nutritional status	<ul style="list-style-type: none"> <input type="checkbox"/> Encourage well-balanced meals appropriate to the eating abilities of the patient. If the patient is unable to manage a fork and knife, encourage "finger foods," such as sandwiches or fruit. <input type="checkbox"/> Plan a high-calorie diet if the patient is hyperactive. Encourage fluids during the day to prevent dehydration. <input type="checkbox"/> Limit the number of foods you place in front of the patient at any one time, as too many foods can be overwhelming. <input type="checkbox"/> Observe for swallowing difficulties that put the patient at risk for aspiration. Be certain the patient is sitting upright with his head forward during meals and that he remains so for a half-hour after eating. Thin liquids are the most difficult to manage for people who have swallowing problems. Thicker liquids or semi-soft foods may be more suitable. <input type="checkbox"/> Patients in the later stage of Alzheimer's may have no appetite or interest in food. Enteral or parenteral feedings may be required.
Altered sleep rest patterns	Maintain normal day/night patterns	<ul style="list-style-type: none"> <input type="checkbox"/> Encourage the patient to stay awake during the day. Naps may disrupt or prevent nighttime sleep. <input type="checkbox"/> If the patient is on tranquilizers to control agitation, periodically assess their effectiveness and look for side effects. Drug dosage may need to be reduced or the schedule may need to be changed if it makes the patient sleepy during the day; on the other hand, some tranquilizers may paradoxically increase agitation and confusion. <input type="checkbox"/> Schedule tests and treatments for the morning and afternoon, so the patient can wind down in the late afternoon and evening. This helps to avoid overstimulation before bedtime. <input type="checkbox"/> If the patient wakes during the night and becomes confused and agitated, reorient him in a soft, soothing manner to avoid precipitating extreme agitation and loss of control.

CE ALZHEIMER'S DISEASE

nation and of the abilities to write (agraphia) or speak (aphasia). Perseveration, the continuous repetition of a word or gesture, is common(7,8). The loss of coordination affects the ability to perform purposeful movements or tasks, such as dressing or eating.

Changes in gait are also common. A stiff, stooped posture and wide-based stance, with slow, shuffling steps are typical. The patient may cup his hands at his sides and limit arm-swing. Constant movement and purposeless pacing are also characteristic. Problems with balance may occur, and this puts the patient at risk for injury.

Because increased activity and movement result in a high expenditure of calories, these patients tend to develop voracious appetites. In addition, they may have a compulsion to put everything in their mouths (hyperorality), whether or not it is edible. Incontinence is also a common problem as the disease progresses. Frequently the patient simply does not recognize the appropriate time or place to urinate or defecate.

In addition to depression, which may have been present at the earlier stage, other personality changes may be seen. Restlessness, irritability, and nocturnal awakenings are common, as are confu-

IS IT ALZHEIMER'S DISEASE?

THE EXAM

History

THE QUESTIONS

What are the specific signs of memory or intellectual impairment? When were they first noticed? Have they grown steadily worse?

Does the patient have other illnesses? What illnesses has the patient had in the past?

What OTC and prescribed drugs does the patient take?

Any exposure to toxins? Industrial hydrocarbons? Any exposure to infected people? Any recent trauma?

Mental Status Exam
(done by a technician and interpreted by a psychologist: \$75)

Are memory and learning really impaired? Objective measurement includes questions on:

- recent memory, by having person recall a name, address or short sentence after several minutes
- orientation to time of day, month, year
- concentration, by asking person to count backward by ones, twos, or threes
- serial reversals, such as asking person to spell a word backwards
- abstract reasoning, by asking for definitions of familiar words or proverbs

CAUSES OF DEMENTIA

Alzheimer's disease is marked by forgetfulness and repetitiveness that have grown steadily worse. The family may report that the patient sometimes gets lost in familiar surroundings. The onset is insidious. Neither patient nor family can recall exactly when the signs began or associate them with a specific event.

By contrast, in the hospitalized elderly patient *reacting to disease* or dislocation**, the symptoms of forgetfulness and cognitive impairment are usually described as being of recent onset, and associated with hospitalization, illness, or trauma.

In the patient with *multi-infarct dementia (MID)*, onset is often abrupt, and the history is punctuated by episodes of sharp decline.

In the *pseudodementia of depression**, the onset is often described as abrupt, and the patient can clearly describe and frequently exaggerates the problems.

- History of *hypertension*, TIAs or CVAs may suggest *MID*.
- History of *cancer* may suggest metastasis or meningeal involvement.
- History of tuberculosis raises the question of *tubercular meningitis**. Medical problems that are known to cause dementia include *chronic hepatic insufficiency**, *hypoglycemia**, *hypothyroidism**, *pernicious anemia**, *pellagra**.
- History of depression and other psychiatric illness may suggest depression-induced *pseudodementia**.

A number of *drugs**, alone or in combination, can impair cognition in the elderly. This is especially true of diuretics, digitalis, propranolol, atropine, oral hypoglycemics, some anti-inflammatory agents, phenothiazines, barbiturates, methyldopa, disulfiram, lithium, and phenytoin.

Toxicity from such *heavy metals** as lead, mercury, and aluminum can cause dementia.

In the elderly, the response to *infection** can be confusion and disorientation without temperature change. Trauma suggests *cerebral hematoma**.

Measurable deficits in memory and cognition are required for the diagnosis of dementia, regardless of cause.

sion and disorientation. Eventually, the Alzheimer's patient may become so disoriented that he can not recognize his own reflection (mirror sign). Finally, the patient can no longer express himself verbally and employs other types of behavior as a means of communication(7). For example, the patient who cannot describe pain in words may signify pain by facial grimacing or by guarding the area that hurts.

A dramatic example of behavioral communication occurs when the patient is asked to do something that is too complex for him: He has a "catastrophic reaction." The term is used to describe

the excessive distress the patient may exhibit in situations that confuse or frighten him. He may, for example, become overwhelmed by the number of questions posed by his caregivers. He may become angry and cry in response to simple questions that are a necessary part of his treatment and care. Or he may show outrage and resistance, like the man who fought the shower. These reactions upset and exhaust the patient, as well as those around him.

As the disease progresses, Alzheimer's patients become physically as well as intellectually disabled. They are very susceptible to infection and have a high

rate of accidents, vascular disease, and neoplasia(5).

Other factors that contribute to illness in the Alzheimer's victim are malnutrition, dehydration, lowered tolerance to stress, and adverse reactions to medications, including the anticholinergic effect of most tranquilizers(3,5).

MR. T, FOR EXAMPLE

The Alzheimer's patient entering the hospital during this period may be very ill and present a serious behavior problem. Howard T, for example, was a 62-year-old retired schoolteacher admitted to a busy medical unit with a

THE EXAM

Psychiatric Exam
(done and interpreted by a psychiatrist: \$100)

THE QUESTIONS

Is there evidence of low self-esteem, depressed mood, or such signs of depression as anorexia or early morning awakening?
Any history or present signs of affective disorder, personality disorder, schizophrenia, mental retardation, unexplained medical symptoms?

CAUSES OF DEMENTIA

May rule in a treatable psychiatric disorder.*

Physical Exam and Lab Studies
(done by an internist: \$200)

Any evidence of systemic diseases known to produce dementia?

- CBC; MCV, MCH, MCHC (mean corpuscular volume, hemoglobin, and hemoglobin concentration); serum vitamin B₁₂; and folate level may reveal a nutritional deficit,* anemia* (especially pernicious anemia).
- SGOT, SGPT, bilirubin to rule out (r/o) hepatic encephalopathy.*
- BUN and creatinine to r/o renal encephalopathy.*
- Sodium and potassium to r/o adrenal disease.*
- Calcium and phosphate to r/o parathyroid disease.*
- VDRL to r/o syphilis.*
- Serum thyroxine and serum-free thyroxine to r/o thyroid disorder.*
- Blood glucose and insulin levels to r/o hyperinsulinism.*
- Electrolytes to r/o encephalopathy due to electrolyte imbalance.*

Neurologic Exam
(done by a neurologist: \$100)

Any neurologic signs associated with the memory loss?

Asterixis (flapping tremor) is common in memory loss associated with metabolic impairment,* but generally absent in AD, MID, and depression.* Slowed relaxation phase in ankle reflex suggests hypothyroidism.*

EEG
(done by technician and interpreted by neurologist: \$75)

Seizure activity? Areas of brain-wave depression?

- In AD, some reduction in beta and fast alpha activity may be noted.
- Very abnormal EEG supports suspicion of drug,* toxin,* metabolic,* or traumatic* cause of the dementia.
- Seizure activity on EEG may support suspicion of temporal lobe seizures.*

CAT Scan
(done by technician and interpreted by neurologist: \$250)

Ventricles enlarged? Any atrophy of cerebral cortex? Any abnormal masses?

- In AD, the CAT scan may show normal or atrophied brain.
- Ventricular enlargement in the absence of cortical atrophy on a CAT scan may rule in hydrocephalus* that can be treated with a shunt.
- Scan may also rule in cerebral infarction or multiple infarction areas, an intracranial abscess,* or slow-growing tumor.*

*A cause of dementia that may be reversed or arrested if treated before neurons are permanently damaged.

Costs are approximate, based on usual New York City charges. This workup will rule out most of the reversible dementias. Some physicians also advise skull x-rays, CSF examination, angiography, and/or cisternal scan. Positive emission tomography (PET) is the most recently developed test. It identifies areas of brain function and dysfunction by measuring glucose uptake. The patient is given an injection of a radioactively marked glucose analogue, and uptake is measured by external counters placed on the skull.

Based on information contained in "Reversible dementia and the misdiagnosis of dementia: a review" by P.V. Robins in *Hosp. and Comm. Psychiatry* 34:830-835, Sept. 1983; "Disorders of Memory" by G.M. McKhann in *The Principles and Practice of Medicine*, twelfth edition, ed. by A.M. Harvey and others, Appleton-Century-Crofts, N.Y., 1980, pp. 1191-1195; and "Senility Reconsidered" by the NIA Task Force in *JAMA* 244:259-263, July 18, 1980.

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ALZHEIMER'S DISEASE

diagnosis of pneumonia. He also had severe seborrhea of the scalp. Small and disheveled, with greasy hair and generally unkempt appearance, he was brought in by his wife, a tiny, neat woman who looked sad and bewildered when she spoke with him. She frankly admitted that it had become more and more difficult to care for her husband at home. Mr. T no longer seemed to recognize her or their children. Often, he resisted the most basic care. His need for constant supervision was becoming an emotional and physical drain.

It took several days for Mr. T to adjust to his new environment and for the nursing staff to understand Mr. T's behavior and plan the best ways to care for him. Communicating was difficult at first. Much of the time he babbled or repeated short phrases, such as "That's enough now!" or "Where's mother?" Every now and then, however, he would say something appropriate and even poignant. "I'm so sad," he might say, and he would truly look unhappy. Since Mr. T could no longer read or write, the staff learned to understand what he was trying to communicate by paying close attention to his body language, as well as the inflection in his voice, even when he was perseverating. They also came to realize that Mr. T would reflect their own emotional states: If a nurse was tense and hurried while caring for Mr. T, he responded by becoming tense and resistant.

Each day Mr. T was required to take a shower and shampoo for his seborrhea. The shower was one of the many things he no longer could recognize and interpret (agnosia). As a result, he was very fearful. "It's raining in there!" he

would shout repeatedly as he tried to push his nurse aside and shuffle back to his room. Occasionally, his reaction would be more extreme—he would become uncontrollably upset and emphatic in his refusal. The nurse learned that the best approach was to remain calm and to take Mr. T back to his room. Distraction, rather than confrontation, proved effective. He would quickly forget the episode and later take his shower with less resistance.

Mr. T was a picture of constant motion. While many patients are reluctant to get out of bed, Mr. T was always up and walking around. Attempts to secure him in a geriatric chair or use any kind of restraint made him agitated. The nurses discovered that it was best to permit him to walk the corridors, as long as he remained in sight. He never went much further than the vicinity of the nurses' station. He seemed to like to be around people, and this allowed all to keep an eye on him. Sometimes he would simply sit quietly at the station next to a nurse who was charting.

Mr. T had a healthy appetite. Sometimes he would help himself to trays that were delivered to the nurses' station for other patients. Because of his constant activity, though, he remained slight and spare.

Night seemed to arouse many fears and compulsions in him. He feared his reflection in the window at night, but would quickly calm down when the shades were drawn. Too, if anyone tried to remove his slippers when helping him into bed, he would become quite upset. He was frequently awake and restless during the night.

Serious illness, hospitalization, or

surgery do not affect the course of Alzheimer's disease, but the stress of these events may exacerbate the patient's dementia for a time. Also, the patient's brain impairment may make it more difficult to adjust after illness(9). Ms. T met frequently with the nurses and the hospital social workers to plan the support services she would need when her husband came home. After much consideration, Ms. T made the difficult decision to place her husband in a nursing home.

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THEORIES AND THERAPIES

KEY THEORIES UNDER STUDY

Neurotransmitter deficiency. In 1976, autopsies of patients with Alzheimer's disease (AD) revealed choline acetyltransferase (ChAT) levels 70-90 percent below normal(1). Since ChAT is an enzyme needed to produce the neurotransmitter, acetylcholine (ACh), it was presumed that AD patients had an ACh deficiency. Researchers have now studied 15 neurotransmitters and discovered only four that are altered in Alzheimer's disease: acetylcholine, somatostatin, substance P and, in some patients, norepinephrine(2,3).

Research questions are: Why are all these neurotransmitters deficient? Is it a cause or effect of AD? Are there ways to increase CNS transmitter functions to compensate for their loss? Are there neurotransmitter enhancers or substitutes?

Aluminum deposits. It is not uncommon to find aluminum deposits in elderly brains, but much higher than normal concentrations have been observed in the brains of AD patients. In 1973, autopsy results on eight patients revealed that none of the three without AD had an aluminum concentration above 2.7 $\mu\text{g/g}$, while each of the five with AD had concentrations of 8.4 to 11.5 $\mu\text{g/g}$ in one or more portions of brain tissue(4). A second study, in Kentucky, where water aluminum levels in water are high, found no increase(5).

Research questions are: How do these aluminum deposits get into the brain? Is their presence related to aging or to disease? Are aluminum deposits a cause or effect of AD?

Heavy metals, such as manganese, have been known to cause dementia in humans. When aluminum was injected into rabbit brains, neurofibrillary tangles formed but they were morphologically different from AD tangles(6).

Virus. It is known that the Creutzfeldt-Jakob dementia is transmitted by a slow-growing virus. In 1978, two researchers reported that laboratory animals developed a progressive neurologic illness within 29 to 40 months after they were injected intracranially and intravenously with brain tissue from Alzheimer's patients(7). This would

support the theory that AD is caused by a slow-growth virus, except that attempts to reproduce and corroborate these findings have failed(8).

The key research question here is whether, indeed, an AD-producing virus exists.

Chromosome defect (heredity). It has been observed that an adult's chance of developing Alzheimer's at age 65 is less than two percent, but if a close relative has the disease, the chance increases fourfold(9). This fact, plus the finding that Down's syndrome patients who survive to adulthood eventually develop Alzheimer's lesions in the brain, have led to speculation that the information on the extra chromosome of a Down's victim might be related to the cause of Alzheimer's(10).

Immunologic defect. Abnormally high levels of antibodies have been observed in Alzheimer's patients. It is suspected that the body's defense system goes awry and attacks the body's own cells. In 1983, researchers reported success in making antibodies to abnormal proteins characteristic of Alzheimer's. The antibodies can be used at autopsy to distinguish brain samples of Alzheimer's patients from brain tissue that is normal and altered by other neurologic diseases. Research in this area may lead to a simple test for AD(11).

Trauma. Serious head injury may predispose to Alzheimer's disease. According to studies in Minneapolis and at Duke University, 15 percent of AD patients had a history of serious head trauma; less than 5 percent of the control group had a similar history(2).

KEY THERAPIES BEING TRIED AND INVESTIGATED

Reports of clinical trials with new and old drugs are proliferating in Alzheimer's research literature. Some substances are intended to attack the pathophysiology—low ACh levels, high aluminum; others are intended to reduce the symptoms—memory loss, decreased attention, and so on.

To promote ACh production. Since *choline* is required in the synthesis of acetylcholine, researchers hypothesized that giving choline salts would boost the body's production of ACh. In

fact, early reports indicated that single doses improved memory in normal subjects. But in 2- to 4-week trials with mild to moderately impaired AD patients, no improvement in mood or cognition was observed(12).

Lecithin, a complex fat found in egg yolks, meat and fish is the dietary precursor of choline. When large oral doses of lecithin were given, serum choline increased more than it had with oral choline salts; some studies reported slight improvement in memory(13).

To substitute for ACh. Just as beef and pork insulins have been found to be human insulin substitutes, some researchers are looking for an ACh substitute. One such substance is *arecoline*, which acts like ACh. The problem is that it causes bladder cancer in rats. Drug companies are trying to develop a less toxic analogue(2).

To slow ACh breakdown. *Physostigmine* slows the breakdown of ACh by blocking the enzyme that destroys it. It has a very narrow therapeutic range(14). An early study revealed some improvement in long-term memory but not in short-term memory in normal subjects(13). The IV form, initially used, was short-acting with effects lasting no longer than 30 minutes(7). Now, an oral form of physostigmine, given with lecithin, has been observed to improve memory with longer-lasting effects in some people(13).

To spur neurotransmitter action. *Deanol*, a substance thought to increase cholinergic activity, has been tried in 14 patients who had mild to moderate cognitive deficits. Four patients experienced no change; 10 improved in such behavior problems as anxiety and depression, but not in memory or cognition(15).

Piracetam represents an effort to alter brain chemistry to compensate for lost acetylcholine. It has been shown to increase brain energy and the inter-hemispheric transfer of information. In animal studies, it increased learning and reduced the amnesia usually associated with hypoxia. Piracetam has no analgesic, sedative, tranquilizing, antihistaminic, anticholinergic, or antisero-tonergic effects. It has been shown to increase memory and cognition in nor-

mal students and in mildly to moderately impaired elderly subjects, but not in severely impaired people. This suggests piracetam may have value in early and middle stages of dementia (i.e., forgetfulness and confusion), but not in late stages(16).

Vasopressin, ACTH, and MSH are brain peptides that have been shown to affect learning in animals. In one study of normal men, 55 to 65 years of age, memory and cognition improved with vasopressin(16).

Enkephalins are another group of endogenous neuropeptides under study to determine their effect on cognition.

Naloxone, an antagonist of endogenous opiate neuropeptides, has been shown to produce at least a temporary improvement in cognition(17). A second large study, however, was unable to replicate these findings(18).

To decrease aluminum. There is no evidence to suggest that people should give up antacids, aluminum pots, or deodorant.

Some study is being done on the use of chelating substances, such as sodium fluoride and deferoxamine, to remove aluminum(8,13). These drugs have produced debilitating and dangerous side effects; clinical trials on human subjects are considered hazardous(8).

Enhancing cerebral circulation. Cerebral vasodilators first were used when dementia was thought to be caused by arteriosclerotic narrowing. They are now given to enhance brain metabolism by increasing oxygen supply. Some of the cerebral vasodilators that have been tried in the treatment of AD include ergoloid mesylate (Hydergine), papaverine (Pavabid), cyclandelate (Cyclospasmol), and isoxsuprine (Vasodilan).

Ergoloid mesylate, an ergot derivative, has been associated with some improvement in mood and cognition. On the Wechsler Intelligence Test, the Hydergine group showed a small improvement compared to the placebo group(16).

Papaverine produced EEG improvement in some patients but no change in others. But in a two-year study, those in the placebo group showed deterioration, while those in treatment were unchanged.

Cyclandelate and isoxsuprine have been given to increase cerebral perfusion in the hope of reducing symptoms of dementia; in general, however, they have been ineffective clinically(16).

Hyperbaric O₂ also has been tried as a cerebral circulation enhancer. Treatment usually consists of 10 to 20 sessions of 1-2 hours in a hyperbaric chamber. No significant effect on cognitive impairment has been shown(13).

Naftidrofuryl and carbonic anhydrase inhibitors (e.g., acetazolamide or Diamox) may enhance cerebral perfusion and are under study(16).

Anticoagulants—bishydroxycoumarin and warfarin sodium, for example—may have some value in slowing deterioration in multi-infarct dementia, but long-term anticoagulant therapy is hazardous and few researchers have studied its use in AD(13).

MAO inhibition. Gerovital H3 (G-H3), also called "Rumanian procaine," is a solution of 2 percent procaine HCl. MAO activity is known to increase with aging; using procaine to block MAO activity may help patients with memory problems related to depression, but there is no evidence that it affects the cognitive impairment associated with AD(13).

Psychostimulation. One theory is that elevating mood may increase attention in Alzheimer's patients. Methylphenidate (Ritalin) and pentylentetrazol (Metrazol), in particular, have been tried in the elderly impaired. No difference in mood or memory has been found between drug and placebo groups. Despite evidence that these drugs are not useful in treating AD, they are still prescribed(16).

To control behavior problems. *Antidepressants* may be used cautiously if depression (as it tends to do) seems to be exacerbating dementia. The tricyclics doxepin and trazodone (Desyrel) may be selected because they have fewer anticholinergic effects than other antidepressants.

Haloperidol (Haldol) may be given as an antipsychotic when a patient becomes violent. Haloperidol is preferred because of its weak hypotensive effect. If extra-pyramidal effects occur, trihexyphenidyl (Artane) or diphenhydramine may be added.

Tranquilizers or sedatives may be used sparingly for insomnia, restlessness, and agitation. Chloral hydrate, triazolam (Halcion) and oxazepam (Serax) are preferred because each has a short half-life(19).

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STAGES OF COGNITIVE DECLINE

BY BARRY REISBERG

Prevalence data indicate that Alzheimer's disease may be the fourth leading cause of death in the United States(1). It is estimated that four to five percent of the over-65 population have severe dementia and 11-12 percent have mild to moderate dementia. This translates into more than three million people(2).

Clearly, every clinician needs to be prepared to work with these patients. Each level of cognitive function is marked by recognizable clinical characteristics, described here and in the table on page 227(3-5).

Level 1: Normal. It is important to recognize that some individuals suffer no subjective or objective changes in intellectual functioning with increasing age. There are people in their 90s who show no cognitive decline.

Level 2: Normal aged forgetfulness. Most people over age 65 have subjective complaints of decline in cognitive functioning: They don't remember names as well as they used to or they have difficulty remembering where they have put things. When these complaints are so slight that they do not interfere with job or social functioning, the prognosis is entirely benign(6). Nevertheless, the symptoms can be very frightening to someone who fears that they represent early Alzheimer's dis-

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ease or some other serious ailment.

PATIENT RESPONSE: Subjective discomfort; no overt emotional symptoms.

IMPACT ON FAMILY: Patient is more troubled by symptoms than are family members or others.

PROFESSIONAL CARE: Reassure the patient that the prognosis is benign.

Level 3: Early confusion. A small but significant number of elderly people experience enough of a decline in cognitive abilities that it begins to interfere at work and in social situations. A teacher who once knew the names of all of her students by the end of a semester may find, for example, that she cannot recall even one and that she forgets important faculty meetings. A salesman, once able to remember hundreds of customers, is unable to recall the names even of his best clients.

In social situations, names of people to whom one has just been introduced are immediately forgotten.

Co-workers may become aware of a deterioration in job performance. Intimates note deficits in a friend's or family member's ability to recall names or select words. They may also be shocked to discover that an object of great value has been lost or misplaced.

PATIENT RESPONSE: Memory loss at this stage frequently is accompanied by a marked increase in anxiety as the person attempts to fulfill social and occupational obligations, a task that becomes exceedingly difficult.

IMPACT ON FAMILY: Family discusses patient's retirement and withdrawal from demanding tasks.

PROFESSIONAL CARE: It is vital to realize that a variety of conditions apart from central nervous system aging and degeneration can produce the symptoms above. Acute and chronic physical ill-

nesses, as well as such mental illnesses as depression, must be ruled out. When all other causes have been eliminated, however, the health professional is faced with the probable diagnosis of age-associated brain disease. The patient and his family can be reassured that the majority of people with these symptoms experience no further decline for several years, if ever(6).

Encourage the patient and family to continue social activities but to withdraw from situations that, by virtue of their complexity, provoke the patient's anxiety. A change to a less demanding lifestyle and retirement should be explored. Anxiety-reducing drugs generally are not suitable. The patient's anxiety is an appropriate reaction to his impaired ability to function.

Level 4: Late confusion. Symptoms in this phase are those of early Alzheimer's disease. Notably, the person loses the ability to handle such routine activities as marketing or managing personal and household finances. Frequently, however, orientation to time and person and recognition of familiar faces and places remain unimpaired.

Prognostic studies have indicated that approximately one-third of these patients decline quickly; they are institutionalized or dead within three years. Another third become worse but can still function in the community, and one-third seem to remain at this level for three years or longer(6).

PATIENT RESPONSE: Denial is the dominant defense mechanism, and the patient withdraws emotionally.

IMPACT ON FAMILY: Arrangements must be made for someone to take over the patient's finances and associated responsibilities and to check on the patient regularly.

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PROFESSIONAL CARE: The person in the late confusional phase often, with help, can continue to function in the community. If the patient has no spouse or other family members, it may be necessary to make arrangements with a bank or other agency for power of attorney to take care of such financial matters as paying the rent. A part-time homemaker and visiting nurses can provide the daily support and personal contact the patient needs. At this stage, the patient tends to get lost or, when under stress, forget his address. An identification bracelet or labels sewn on clothing help ensure his safe return.

Level 5: Early dementia. People at this stage can no longer survive alone in the community. At times, they cannot recall their address, the year, or other major information about their lives. The area of memory lapse varies from moment to moment. Hence, on one occasion a person may recall his correct address but not know the year; on the next visit he may recall the year, but forget the address. Family members frequently interpret this as being "good one day and bad the next." In fact, the person's overall level of cognitive abilities remains unchanged.

You can recognize this stage by querying the family about the patient's functional level. At this point, he has difficulty choosing clothing appropriate to the occasion or season without supervision, and he would wear the same clothing day after day, if not reminded by caregivers to change.

PATIENT RESPONSE: Most of the time, denial mercifully protects the patient from confronting the terrible truth that he is literally "losing his mind." Still, on occasion, anger, suspicion, and transient crying episodes occur.

IMPACT ON FAMILY: The patient's emotional lability can be particularly troubling to family members, but usually the patient's symptoms are not sufficiently severe to require medication.

Care and supervision of the patient begin to become full-time responsibilities. Families who care for patients need at least part-time help. If the patient lives alone, full-time homemaking and personal supervision are needed. The key problems, of course, are finding people who can work with the patient and finding a way to pay for help. The local chapter of the Alzheimer's Disease and Related Disorders Association can help.

PROFESSIONAL CARE: Common queries of family at this stage are "Should I push him to do more?" "If he were more active and used his mind more would that keep him from getting worse as rapidly?" The answer to such questions is no. It is important to explain to the family that the patient's withdrawal from stressful activities is an adaptive response to decreased cognitive capacities: Pushing the person to do more only provokes anger and anxiety.

The family may need guidance in handling the patient's emotional outbursts. Part-time home health care, if it can be arranged, is very useful because the patient needs continuous supervision and frequently must have an escort when he leaves home. The family can be advised that, despite the need for constant supervision, the patient may still enjoy nondemanding social situations such as going to the theater or movies.

Driving an automobile does not seem to become hazardous until this stage. Then, early signs of reduced driving ability include suddenly speeding up or slowing down for no apparent reason, or "absentmindedly" going through a stop signal. Sometimes, the patient realizes the danger and voluntarily abandons driving. At other times, the health professional can help by suggesting that the family arrange for the motor vehicle bureau to retest the patient.

Level 6: Middle dementia. Patients at this stage begin to require assistance with such basic activities of daily life as bathing and toileting. Memory deteriorates to a fragmentary knowledge of address and whereabouts. Patients frequently cannot identify the spouses upon whom they depend for survival; in clinical testing, patients have difficulty counting backward from 10.

Early in this stage, patients develop a

fear of bathing. They forget how to adjust the water for temperature and may become frightened, particularly of the shower. At times, towel washing is all that the patient will tolerate.

Later in the stage, the patient begins to forget the mechanics of toileting and must be given step-by-step instructions for wiping and washing himself. Decreased cognitive capacity eventually results in urinary, and then in fecal, incontinence. The lack of control is not due to infection or physiological change, but simply to lack of memory about toileting. Taking the patient to the toilet frequently and using absorbent bed pads and incontinence briefs can help. For some male patients, condom catheters can be of enormous assistance. While not all men tolerate such devices, catheters can make the difference between being able to accompany family into the community without embarrassment and being homebound smelling of urine.

PATIENT RESPONSE: The world becomes frightening to patients at this stage, and the chemical balance in the brain changes markedly. For these psychological and neurochemical reasons, denial becomes less effective. Instead of withdrawal, the patient is prone to agitation, violence, paranoia and delusions. For example, he may talk to imaginary people or accuse the spouse of being an imposter. Emotional changes in this stage are variable and can also include obsessive symptoms, such as repeating a simple cleaning activity. The patient can show a loss of willpower because he cannot carry a thought long enough to determine an action.

IMPACT ON THE FAMILY: This is the stage at which caregivers usually become overwhelmed by the requirements of the Alzheimer's victim—they literally must devote their lives to helping a patient who can no longer even recall their names much less the kindness shown to him. Caretakers of Alzheimer's victims are forced into a "saintly" role, and this strain must be alleviated.

PROFESSIONAL CARE: The family needs to be taught how to assist the patient with bathing and toileting, and how to manage his incontinence.

Major tranquilizers often become necessary to treat the agitation at this stage. Phenothiazines with a low risk of Parkinsonian side effects may be prescribed. Tranquilizers, if prescribed, should be initiated at very low doses, and monitored regularly.

COGNITIVE FUNCTION SCALE

LEVEL	CLINICAL PHASE	CLINICAL CHARACTERISTICS	FUNCTIONAL CAPACITY
1	Normal	No subjective complaints of memory loss or objective evidence of memory deficit on clinical interview.	No impairment.
2	Forgetfulness (Normal for age)	Subjective complaints of slight memory loss, for example, patient forgets where he has placed familiar objects or forgets names he formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Patient is appropriately concerned about memory loss.	No impairment, but subjective concern about memory loss.
3	Early Confusional (Borderline Alzheimer's disease)	Clear-cut deficits become apparent to others. Patient tends to get lost. Job performance declines. Patient immediately forgets what he reads or is told and develops difficulty finding the right word in conversation. Objective evidence of deficit in memory and concentration obtained only with an intensive interview conducted by a trained geriatric psychiatrist. Patient tries to deny and hide cognitive impairment and develops mild to moderate anxiety about symptoms.	Inability to perform in demanding employment and social interactions evident to intimates and associates.
4	Late Confusional (Mild Alzheimer's disease)	On clinical interview, patient demonstrates cognitive deficit in several areas: • decreased knowledge of current and recent events, • some deficit in memory of personal history, • concentration deficit elicited on serial subtractions. Frequently at this point, there is no deficit in orientation to time and person, recognition of familiar persons and faces, or ability to travel to familiar locations. Denial is the dominant defense at this stage. Patient becomes overwhelmed when confronted with a complex task; flattening of affect and withdrawal from challenging situations is characteristic.	Decreased ability to handle finances and marketing.
5	Early Dementia (Moderate Alzheimer's disease)	During interview, patient is unable to recall his address or telephone number of many years, the names of close members of his family (such as grandchildren), the name of the high school or college from which he graduated, or other major aspects of his life. Frequently, there is 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 facts about themselves and others. They invariably know their own names and generally know their spouses' and children's names.	No assistance required with toileting or eating, but may have some difficulty choosing the proper clothing to wear. May require coaxing to bathe.
6	Middle Dementia (Moderately severe Alzheimer's disease)	Patient occasionally forgets the name of the spouse upon whom he is entirely dependent for survival, but can usually distinguish between strangers and people he knows. Can almost always recall his own name. Will be largely unaware of all recent events and experiences, but usually retains some knowledge of his past life, though it is very sketchy. Generally unaware of his surroundings, the year, the season, etc. May have difficulty counting backward from 10, may not be able to count forward. Occasionally will display an ability to travel to familiar locations, but usually requires travel escort. Diurnal rhythm frequently disturbed.	Personal or hygienic dysfunction, or both, with following progression: • Difficulty putting on clothing properly. • Requires assistance with bathing; may develop fear of bathing. • Inability to handle mechanics of toileting. • Urinary incontinence. • Fecal incontinence.
7	Late Dementia	The brain appears no longer able to tell the body what to do. Verbal abilities are lost. Frequently, there is only grunting. Such basic psychomotor skills as the ability to walk are lost. Patient is incontinent of both urine and feces and requires assistance with toileting and feeding.	Speech and motor dysfunction, with the following progression: • Ability to speak limited to a few words. • All intelligible vocabulary lost. • All motor abilities lost. • Stupor. • Coma.

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notional burden on the family is usually unbearable by the time the patient reaches this stage. Urge the family to join a support group, if they have not done so already. Also, encourage them to maintain outside interests. Full-time assistance is ideal; part-time assistance to allow respite is essential. At this stage, the health professional should be prepared to discuss the option of institutionalizing the patient: Institutions can sometimes provide a higher level of care than can the most devoted family. Crises leading most often to institutionalization are violence and incontinence.

Level 7: Late dementia. Patients at this stage first lose the ability to speak and then to walk. The end stages of Alzheimer's disease are stupor and coma, if death has not resulted from aspiration, infection, or other illness.

The need for tranquilizers evaporates at this stage, and overmedication may occur. As the patient's vocalizations are reduced to grunts or screams, these are frequently interpreted as signs of distress and muted with tranquilizers. Such a procedure, of course, merely serves to dull the remaining consciousness of the patient.

Before the complete loss of ambulation, the patient may be found sometimes on the floor, when he "forgets" that he was walking and sinks to the ground. This process must be differentiated from a stroke, transient ischemic attack, or other cause of syncope.

PATIENT RESPONSE: In most cases, denial again protects patient against much of the emotional impact of the illness. In some patients, denial is so effective in the late dementia phase that the patient may continue to laugh, smile, and appear to enjoy life as much as anyone else. The victim, even at the late stage, is as often kindly and amenable as recalcitrant and angry. There have been patients in this phase who could no longer talk, yet could attend and enjoy such important family events as weddings.

IMPACT ON FAMILY: Much of the suffering falls upon the family and, in particular, the caregiver. Yet, the life of the patient in this late phase continues to be meaningful for the family. Simply having a parent or grandparent alive can be valuable. Very young children may be able, many years later, to conjure up an image of their grandparent.

PROFESSIONAL CARE: Early on, the patient requires someone to help him with

walking. A walker is generally not useful for these patients because they lack the cognitive capacity to use the device properly. Guard rails and soft rugs or matting in the home may help. Geriatric chairs, which confine the patient, are to be avoided; they simply produce agitation. If the family cannot offer full-time care in the home, an institution may be the only answer.

Caregivers must be prepared to deal with eating problems. Early in this stage, food must be carefully cut up for the patient. Later, as the ability to chew is entirely lost, a soft diet may be necessary. Aspiration is a danger and a common cause of death and disability in these patients. Medical or psychological crises may result in the patient's refusal of all oral nourishment, and nasogastric feeding may become temporarily necessary.

The patient's screams and emotional outbursts should be carefully interpreted. They may be attempts to communicate needs, not just expressions of distress. Such attention can prevent unnecessary sedation—an increasingly important issue as consciousness decreases.

As the patient becomes completely unaware, you must be prepared to respond when loved ones ask, "Does it matter if I talk to my father? He doesn't seem to understand me" or "Should I touch my mother?" The answer is, I believe, that human contact continues to make all the difference in the world for the Alzheimer's patient, either in the home or in an institution. A loving voice, attention and touch are enormously important—they keep the patient emotionally and physically alive.

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CE

ALZHEIMER'S DISEASE



HELPING FAMILIES SURVIVE

BY IDA MARLENE BEAM



I still recall my deep hurt when the doctor said, "The reason for your father's confusion is Alzheimer's disease, or senile dementia. There is no cure or treatment, and his confusion will progressively worsen."

No one had noticed changes in my father's behavior, although my mother said he often exhausted her patience by losing things or asking questions and forgetting the answers. I now know that she was seeing the early, subtle signs of cognitive decline. We could not have anticipated the destruction it foreshadowed. After five years, I still grieve when I reflect on this mysterious, victim-wasting, family-shattering disease. My nursing experience provided some knowledge, but we were not really prepared for the problems to come.

Alzheimer's is insidious; the diagnosis often is not made until the person exhibits memory loss, confusion, and sometimes inappropriate behavior. Of-

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ten, it is the latter that prompts the family to seek help. Alzheimer's victims invariably deny or attempt to conceal lost abilities, but often are poignantly aware and afraid. Once, my father was working on my car and he said, "I can't put the air cleaner back in place because my memory is not like it was." Later, watching television films about Alzheimer's disease, he saw patients refusing to dress and demonstrating other behavior problems and said, "That's how I act." The family must know that they cannot expect the patient to "try harder to remember" or to "try to control himself."

They also must learn not to be shocked or surprised by anything the person says or does. The most bizarre behavior is often an attempt to communicate something that his brain can't relate any other way.

The demoralized families often want a reason for the behavior, as they attempt to deal with the resultant chaos. I liken the Alzheimer's patient's brain to a mass of tangled electrical wires that first work with faulty conduction and then not at all. Initially, only thought and sensory functions are disturbed; eventually, however, all functions fail.

The key to understanding the patient's behavior is to know the patient.

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You may find that behaviors of early life are repeated. For example, a former military man may salute relatives and respond to requests with "Yes, sir." Because of their intimate knowledge, families are sometimes better able than skilled professionals to understand and communicate with the patients.

The delusions and suspiciousness of the Alzheimer's victim can be especially trying: Families may feel hurt, embarrassed, and bewildered by the victim's unjust accusations. I try to help them see beyond the behavior, to understand that it is often related to distortions of a failing brain, and to the frightening world that develops as abilities to comprehend and communicate slip away. When my father felt threatened or overwhelmed he would refer to his family as "strangers in the house." If the family can understand this relationship, they will be able to comfort themselves as well as the patient.

Some particularly annoying behavior the family can expect includes clinging, hoarding, perseveration (repetitive motions and words), and excessive fidgeting, rearranging or fondling objects (often called hypermetamorphosis).

The person suffering from Alzheimer's disease clings to family members because they represent familiarity, belonging, and security. My father used to follow me around and watch every move I made. One day, I asked, "Why don't you quit watching me?" He replied, "I like watching you."

Hoarding and hypermetamorphosis (which can be seen as forms of clinging), combined with lack of judgment, can produce shocking behavior. Accidental shoplifting, for example, can occur when the person begins fondling a figurine and decides to hoard it, or would like to purchase it but cannot cal-

RESOURCES

The Alzheimer's Disease and Related Disorders Association, Inc. (ADDA) exists to "offer help in any manner, whenever and wherever needed to those afflicted by the disease and to their loved ones." In only four years, the ADDA has grown from fewer than 10 isolated groups of concerned family members to a nationwide organization with more than 70 chapters in 31 states.

A letter or call to the ADDA National Headquarters, 360 North Michigan Avenue, Chicago, Ill. 60601, (312) 853-3060, brings a packet of information that includes a recent issue of the *ADDA Newsletter*, a fact sheet on Alzheimer's disease, an order form for additional educational materials, and a list of chapters.

A call, then, to your nearest chapter will enable you to find out when and where meetings are held and how family members can become involved in a support group. ADDA does not charge for its educational and support services to families.

Chapter meetings are usually educational sessions open to anyone interested in attending. Often, there is a speaker, on some facet of Alzheimer's and announcements of any new informa-

tion on AD research and treatment.

The organization also sponsors more than 300 support groups led by family members. Groups vary in size and in frequency of meetings, but most are small and meet weekly or biweekly. Regular attendance is encouraged. New members tend to join because they think it will help the AD victim. They want specific information about new drugs, how to manage patient care problems, and so forth. Later, they learn that the family support group has a larger purpose: It is a place where they can safely expose how angry, frustrated, lonely, and disappointed they really feel.

Some useful references for families:

- *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease* by Nancy L. Mace and Peter V. Rabins. The Johns Hopkins University Press, Baltimore, 1982.
- *Alzheimer's Disease: A Guide for Families* by Lenore S. Powell and K. Courtice. Addison-Wesley, Reading, Mass., 1983.
- *A Guide to Alzheimer's Disease for Family, Spouse and Friends* by Barry Reisberg. The Free Press, New York, 1983 (paperback edition).

culate money. Accusations only antagonize the patient, who often has forgotten that he took anything.

At home, the patient may become preoccupied with tying knots in shoelaces, or in the fringed edges of rugs or bedspreads. A pocketful of rocks, toilet paper, nails, pens or pencils can disrupt the laundry. Mail, dentures, wedding bands or eyeglasses disappear in the trash, become buried in dresser drawers, or clog the toilet. I tell families to expect, and prepare for, these problems. I suggest they use a locked box to protect valuables and devise alternative activities for the patient's annoying or destructive behavior. For example, the patient can collect unwanted advertisements or figurines.

Odd behavior can result in social isolation, especially if others do not understand the disease. Families can become double victims: They lose not only the fellowship of the Alzheimer's patient, but that of friends and relatives.

Social isolation also can result from the family's lack of understanding. When a family member has Alzheimer's disease, the impulse is to hide the fact: while disclosure may embarrass, secrecy fosters isolation. Openness and main-

taining social activities as much as possible are vital. Alzheimer's individuals must not be shrouded from society nor excluded from decisions during lucid times.

Yet another burdensome lifestyle change for an Alzheimer's family is role reversal: shifts in who makes decisions, cooks, pays the bills or keeps house.

The degeneration in neurons eventually destroys all verbal skills. To teach families communication guidelines, I again use the example of faulty wires. Overloading the brain's system with compound sentences, complex directions, or shouting can cause a blowout. The Alzheimer's patient will be overwhelmed, confusion will increase, and he will either become more agitated or forget what he has been told.

To illustrate: Suppose my father is in another room, and I shout, "Hurry, your dinner is getting cold. Come in here, pull up a chair, sit down and eat." He would be unable to sort out my many commands and so would probably forget them all. Too, he probably would interpret my loud tone as anger. Thus, he might think that I was angry with him, but not know why. If I don't piece this together, I may *become* angry because

he refuses to come to the table to eat.

Knowing what to do, though, does not automatically mean the family will be able to do it. Even when family members know that a low tone, short words, and simple sentences are important, they may not be able to follow through when patience is thin(1).

Besides what you say to the Alzheimer's patient, what he says to you can be important—even if it seems to be gibberish. Families often complain that it is irritating to listen to an Alzheimer's patient's meaningless chatter. A careful listener, however, may detect hidden messages. "Pins in stomach," for example, might mean abdominal pain, indigestion, or constipation.

In his attempts at conversation, the Alzheimer's patient is easily distracted, and the message may change rapidly. After I told my father about a promotion, for example, he said, "Congratulations for getting so many things done for your requirements." Then, hearing construction workers outside, he went on, "... The big trucks and equipment are digging with all this dirt to keep the wheels turning over."

Sensitivity to nonverbal communication is another way of listening. Wandering and restlessness often mean the person is searching for something or someone. When my father wandered, if I approached him gently and took his hand, he would smile, shake my hand, and go with me calmly. As the disease progresses, nonverbal communication becomes critical. Eventually patients are unable to express physiological

needs or pain other than by moaning, perspiring or grimacing.

An Alzheimer's patient's potential for injury is great: Hazards include look-alikes (apple juice, beer and urine; fruit-shaped soap; poisons that resemble medications), accessible medication, a forgotten cigarette, a lit stove. When Alzheimer's patients wander, they may stray into a blizzard or walk in front of a car. The list can be endless.

Ways to prevent accidents include adequate lighting that minimizes shadows and clearly points the way to the bathroom, fiddle-proof locks so the patient doesn't wander away while the family is sleeping, reality-orientation devices such as clocks, calendars, and picture labels (a man or woman on the bathroom door).

Restless wandering increases if the patient has nothing to do. I become very concerned when I hear of an Alzheimer's patient left idle all day, although the family may do this without harmful intent. Some caregivers must work and have no money for day care. Others do not know that the lack of sensory input increases confusion.

Activities for Alzheimer's patients need not be complex; but the repetition may bore families. Dancing or bouncing a ball seem to reduce the incessant restlessness. Vacuuming, raking leaves, and other repetitive motions make good use of perseverance.

Simplicity is the key. Sensory overload confuses and frustrates Alzheimer's patients. Activities that are complex or require a lost skill terrify them.

My father, for example, was asked to help put a table together. When I came to take him home, he said, "You saved my life." His conversation then drifted, but this small statement told me that he felt threatened by the task.

Activities associated with what the individual did in the past can support a crumbling self-esteem. I advise families to create a photo album of the Alzheimer's patient's past or to play old music. A former trucker may like to take short trips; a former businessman may enjoy attending meetings (even if it is only attending a family support group).

Since many Alzheimer's patients get along particularly well with two- and three year olds, I encourage families to have parties for young children, to have the Alzheimer's patient bat a balloon around with the children, and engage in other play. I found that my father enjoyed amusement parks and zoos. They captured his attention and would provoke the laughter we all need.

Sex and belonging. Neuronal damage blocks self-control, and the exhibitionism common among Alzheimer's patients is often related to forgetfulness. Unable to locate a bathroom, for example, the patient may indicate the need to void by unzipping his pants in the living room or on the street.

Although sexual exposure or open masturbation can be shocking to families, they should understand that the patient's sexual needs persist in spite of Alzheimer's disease. Affection and caring work better than scolding. I find that Alzheimer's individuals crave af-

CE CREDIT FOR HOME STUDY

AJN has been approved as a provider of continuing education offerings for nurses under the ANA Mechanism for the Accreditation of Continuing Education in Nursing through the Eastern Regional Accrediting Committee. This national approval means that you can secure CE contact hours no matter where you are located. In addition, *AJN* is an approved provider under the state boards of nursing in states where CE is mandatory, so that your contact hours can be used toward relicensure in those states (except in Kentucky, where home study

is approved only for licensees living abroad). How it works:

Send for the CE test for this unit on **Alzheimer's Disease** using the coupon on the next page. After you study the material in this issue, take the open-book test and return the answer card as instructed. It will be scored and you'll be notified of the result (pass-fail). If you pass, you will receive a certificate for the contact hours you have earned, and a record will be retained by the *American Journal of Nursing*.

feeling. They may show it by patting the caregiver, or clinging to a lovable animal. The anticipation of needs and use of distraction may divert sexual attention without triggering anger(2).

Sleep. Alzheimer's patients seem to sleep very little and sometimes have day-night sleep reversal, which increases the patient's confusion and depletes the energy of both patient and family. Excessive wakefulness or agitation may require the judicious use of a mild sedative. Families who crave sleep, however, need to be cautioned against being quick to give sleeping medications: Sedatives can increase confusion and have other side effects.

Nutrition. Alzheimer's disease leads to regressive eating behavior and decreased motor skills. Frequently, the patient's behavior is extreme—either a refusal to eat or gorging. Again, nonverbal clues are important. When my father refused steak it was a signal that he could not use a knife. Playing with utensils may signify difficulty in choosing foods on a plate. When a plate is overloaded, the patient may overeat and vomit. I teach families that it is best to give fewer choices and less food, but more frequent meals. When the individual has lost motor skills, I suggest preparing "finger foods," like sandwiches.

Dressing and bathing. Simply getting the patient bathed and dressed can exhaust and depress the family. Activities that most people take for granted

must be broken down, simplified, and slowly presented to avoid overloading the Alzheimer's individual. Trying to rush the person is futile and inevitably ends in battle.

Families also can expect compliance problems—a patient wants to wear pajamas all day, sleep in clothes or wear two sets. Problems in dressing may be born of a fear that clothes are being stolen during the changing. Motor problems are another cause: When the shuffling gait becomes too difficult, the individual may claim, "My shoes are too heavy."

As Alzheimer's disease progresses, incontinence, choking, and seizures become potential problems. Problems in toileting are related to forgetfulness and to misperception. For example, the family may find urine or feces in a trash can or on a valet chair that resembles a toilet. I advise families to limit fluids at bedtime and to label items with pictures that show their use.

Teaching families to understand Alzheimer's disease not only helps in caring for the patient, but also may prevent a fruitless journey from physician to physician. Blindly optimistic globetrotting hastens family burnout and may deplete a lifetime savings in the search for a miraculous cure.

Advertised, unproved medicinal and dietary products may stimulate false hope of a cure for Alzheimer's disease. For example, when families opt for

over-the-counter agents like choline or lecithin (dietary substances required in the synthesis of the neurotransmitter, acetylcholine), I try to ease potential disappointment by pointing out that, even in the favorable studies, many patients have not shown any improvement with these substances.

As I struggled to care for my father, and, in later years, to help other families, I learned that the family often needs as much care as the person with the disease. Knowledge of resources (day care, respite care, family support groups, legal aid or financial assistance) must be acquired and shared with families. Also, as hard as it sounds, as soon as the diagnosis is known, the family should seek legal counsel about such things as planning for wills, before the patient becomes incompetent. Finally, it is important to continually assess the family's ability to care for the patient at home. One ought not suggest institutionalization prematurely. Moreover, I recommend that nurses attend an Alzheimer's family support group and listen to what families say about the help they need.

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Testimony Regarding
S.B. 690 - Helpline

*Attn #3
3-26-86*

Before the
Public Health and Welfare Committee
Kansas State House
March 26, 1986

Presented by
Joyce Romero
Kansas Department on Aging

Rep. Littlejohn and members of the committee, the Kansas Department on Aging recommends passage of S.B. 690, the Helpline bill.

Let me assure you that the Department does not intend to create a new unit as the word "office" implies in Sec. (1)(b). The office of Alzheimer's information would be a service delivered by a professional within an existing division of the Department.

The person who would supply this service would perform the following duties: assist people who call or write; research national, state and local information for dissemination; publicize the existence and purpose of the helpline; cooperate with local area agencies on aging in disseminating information and making referrals; build a resource file of information; and train state and local staff.

Such duties will require a professional who is knowledgeable about Alzheimer's and related diseases.

One caregiving wife testified in a public hearing of the Alzheimer's and Related Diseases Task Force, "We went 6 1/2 years thinking he was the only one in Kansas who had the disease." Kansas needs a Helpline so that family members will always have a source of information in the future.

LD:rd

*Attn #3
3-26-86
Hs. PHW*

Proposed Amendment
H.B. 3051 - Respite Care

*Attn: #1
3-26-86*

Before the
Public Health and Welfare Committee
Kansas State House
March 26, 1986

Presented by
Joyce Romero
Kansas Department on Aging

In response to questions from the committee, the Kansas Department on Aging suggests an amendment to H.B. 3051 to authorize three demonstration respite care projects.

This can be accomplished by deleting Sec. 4(c) through (h) and Sec. 10. If the word "three" is inserted between "that" and "countywide" in Sec. 4, the bill will authorize three demonstration respite care projects.

Sec. 5 could be amended by adding the following sentence: "One program shall be established in a city which is a major population center of the state, one program shall be established in a city which in population is intermediate in size and one program shall be established in a city which in population is small in size."

The Department estimates that three projects would cost the state \$45,000, \$15,000 for each project.

LD:rd

*Attn: #4
3-26-86
Hs. PHW*

KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

Attn. # 5
3-26-86

TESTIMONY ON SENATE BILL 672

PRESENTED TO THE HOUSE COMMITTEE ON PUBLIC HEALTH AND WELFARE

MARCH 26, 1986

This is the official position taken by the Kansas Department of Health and Environment on Senate Bill 672.

BACKGROUND INFORMATION:

Section 1 of the bill authorizes an increase in licensing fees to \$15 for facilities caring for fewer than 13 children and an increase to \$75 for facilities caring for more than 13 children. Establishing the higher fee for facilities caring for 13 or more children will place all licensed day care homes in the lower fee category and includes all child care centers and most group homes and residential programs in the larger fee category.

Section 3 of the bill would authorize a fee for registration of family day care homes. Registered family day care homes currently represent the largest category of child care (3,463 homes) yet do not contribute to the cost of the program. Even though these homes are not routinely inspected, there is a significant cost related to the registration process, including the criminal record and child abuse checks on the providers. The amendment would establish a \$5 maximum fee for registration of a family day care home.

The fee increases authorized by Sections 1 and 3 would generate an additional \$73,500 in revenue. These funds are urgently needed to augment the current appropriation of \$125,000 for county health departments conducting the child care inspections and administering the programs on the local level. A 1981 Statewide Health Coordinating Council study, Public Health Services in Kansas, estimated that the real cost of the county health departments' services in inspecting child care facilities was \$353,000 per year. The increase fee revenue proposed under Sections 1 and 3 will not fully fund the counties; however, it would represent more than a 50 percent increase in current funding to the counties for child care licensure work.

Section 2 of the bill removes an archaic requirement that district court judges be notified of all licenses issued or applications withdrawn. At the present time, as many as 2,000 licenses may be issued per quarter, making it impractical to provide an effective notice to the district judges. Also, the courts have little need for information relating to which day care facilities are currently licensed.

Section 4 of the bill would establish authority for the department to deny an initial application for registration of a family day care home. The current statute authorizes only revocation or refusal to renew an

Attn. # 5
3-26-86
Hs. PHW

application. Applications for registration of a family day care home may be received from applicants who are known to the agency as being neglectful or abusive toward children, who have been unable to meet child care licensing regulations in the past, or who have a criminal record. We are presently issuing denials of initial applications based upon case law authority and because it makes little apparent sense to issue a registration certificate simply to revoke it.

Section 5 of the bill amends KSA 65-512 to establish a requirement for annual inspections of child care facilities. The current requirement is for child care facilities to be inspected every six months. In practice, this frequency of inspection has not occurred for many years and there is little likelihood that sufficient resources will be available to support this frequency of inspections in the foreseeable future. The department is concerned that the state may face increased liability because semi-annual inspections cannot be accomplished within the current and proposed appropriation levels. In addition, it is important to note that other licensing statutes, such as those for nursing homes, hospitals, and food service facilities, typically mandate annual inspections. Should additional resources become available, this amendment would not prevent those resources being utilized to increase the frequency of inspections to more than once a year.

DEPARTMENT'S POSITION:

The department respectfully recommends that the committee report the bill favorably for passage.

Presented by: Barbara J. Sabo, Secretary
Kansas Department of Health and
Environment