

Approved 3-18-86  
Date

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

The meeting was called to order by SENATOR ROY M. EHRLICH at  
Chairperson

10:00 a.m. ~~pm~~ on March 5, 1986 in room 526-S of the Capitol.

All members were present except:

Committee staff present:

Bill Wolff, Legislative Research  
Emalene Correll, Legislative Research  
Clarene Wilms, Committee Secretary

Conferees appearing before the committee:

Jerry Slaughter, Kansas Medical Society  
Richard Morrissey, Bureau Manager, Department of Health and Environment  
Elizabeth Taylor, Kansas Association for the Education of Young Children  
Linda Wright, Member, Kansas Alzheimers Disease Task Force  
Craig Grant  
Diane Bottorff, Member, Board of Directors, Topeka Alzheimers Disease and  
Related Diseases Association  
Robert Guthrie  
Linda Blaser, President, Topeka Alzheimers Disease and Related Disease Assn.  
Marilyn Bradt, Kansans for Improvement of Nursing Homes  
Marguerite Chalmers - written testimony  
Barbara Dailey, Former Research Director for Kansas Alzheimers and Related  
Diseases Task Force  
Susan Miringoff, R.N., KSNA  
Joyce Romero, Secretary, Department on Aging  
Louis Jensen, M.D.  
Dick Hummel, Executive Director, Kansas Health Care Association  
John Grace, Executive Director, Kansas Association of Homes for Aging  
Jane C. McClain

Others attending: See attached list

Jerry Slaughter was recognized by Chairman Ehrlich to speak on SB-690 and SB-691 prior to other hearings due to a scheduling conflict. Mr. Slaughter stated that the Kansas Medical Society is in favor of the concept of both bills.

SB-672 - An Act relating to maternity hospitals or homes and homes for children; concerning license and registration fees; providing grounds for denial of certificate of registration;

Richard Morrissey presented written testimony for Secretary Barbara Sabol. Attachment I. Mr. Morrissey stated that this bill would separate licensing fees for facilities of 13 children or less and facilities over 13 children. This bill would increase licensing fees. Section 2 would remove the requirement of district court judges being notified, the number of applications have increased to a point that makes this impractical. Section 4 would establish authority for the department to deny an initial application for registration of a family day care home. A balloon bill is attached recommending a new section which would change inspections from every 6 months to yearly.

Elizabeth Taylor testified and presented written testimony in support of SB-672. Attachment II Ms. Taylor stated her organization could not support the requested amendment. Under questioning she stated that she had not seen the amendment.

SB-690 - An Act concerning the department on aging; establishing an information and referral network to assist persons with Alzheimer's and related diseases.

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

room 526-S, Statehouse, at 10:00 a.m./~~p.m.~~ on March 5, 1986

SB-691 - An Act establishing regional Alzheimer's disease assistance centers; providing for the designation of such centers; authorizing the development of a state Alzheimer's disease assistance plan; providing grants-in-aid to such regional centers.

Linda Wright testified and presented written testimony in support of SB-690 and SB-691. Attachments III & IV Ms. Wright stated that SB-690 was needed so that an information and referral system could be established to aid families of victims. SB-691 would concentrate research, data collection and planning into one to three centers in the state. \*

Craig Grant testified and presented written testimony in support of SB-690. Attachment VI Mr. Grant stated that people in the situation of trying to help families and victims need aid in securing information on all aspects of Alzheimers disease.

Diane Bottorff testified and presented written testimony in support of SB-690. Attachment VII Ms. Bottorff stated that the Topeka Chapter of Alzheimers Disease and Related Disorders Association which has a 24 hour answering service which provides information and referral services to families of victims, gets calls that are not all from this area and pointed out that people are really searching for help. It was pointed out that people are really searching for help. The Topeka Chapter cannot be of great help to people from other areas due to the fact that they are not familiar with resources in the caller's area.

Robert Guthrie testified and presented written testimony on SB-690 and SB-691. Attachments VIII and IX Mr. Guthrie stated that SB-690 would be very valuable to families facing the catastrophic problems of Alzheimer's disease and related disorders. SB-691 would provide essential services and educate the public concerning this problem.

Wanda Blaser testified and presented written testimony in support of SB-691. Attachment X Ms. Blaser stated that knowledge of prevention and management procedures could lead to cost savings.

Marilyn Bradt testified and presented written testimony in support of SB-690 and SB-691. Attachment XI Ms. Bradt stated that SB-690 would provide needed and helpful systems to patients' relatives and through them to the victims. SB-691 recognizes the need for adequate medical attention to Alzheimers' patients and for the education and training of health care providers and caregivers.

Marguerite B. Chalmers presented written testimony on SB-690 and SB-691. Attachment XII Mrs. Chalmers related her personal story of the difficulties encountered in obtaining a diagnosis in her husband's case.

Barbara Dailey testified and presented written testimony in support of SB-690. Attachment XIII Ms. Dailey stated that in her work answering the telephone for the Topeka Alzheimer's support group she sees the trend for information continuing. Many areas outside the Topeka area are needing help and SB-690 provides assistance. SB-691 would be a great help to the families of Alzheimer's patients if a specified entity could develop and update a resource file for public distribution.

Susan Miringoff testified and presented written testimony in support of SB-690 and SB-691. Attachment XIV Ms. Miringoff stated that as the population ages this kind of program becomes increasingly important. It was also stated that SB-690 and SB-691 would set up the kind of base that will bring about great strides in the expertise of the health care capabilities.

Secretary Joyce Romero testified and presented written testimony in support of SB-690 and SB-691. Attachment XV Secretary Romero stated that both bills are essential in providing information to professional and lay caregivers.

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE,  
room 526-S, Statehouse, at 10:00 a.m./~~P.M.~~ on March 5, 1986

Louis Jensen, M.D. testified and presented written testimony in support of SB-691. Attachment XVI Dr. Jensen stated that he would favor designation and some fiscal support for three centers for diagnosis, education and training and psychosocial research as relates to Alzheimer's and related diseases.

Dick Hummel presented written testimony in support of SB-690 and SB-691. Attachment XVII These bills relate to Alzheimer's disease, its victims and their families and caregivers.

John Grace presented written testimony in support of SB-690 and SB-691. Attachment XVIII Mr. Grace stated in his testimony that in the next 15 years the over age of 75 population will increase by nearly 50% and that it is imperative that we begin to look at developing information and referral networks for those with Alzheimer's disease and related disorders.

Jane McClain presented written testimony urging passage of SB-690 and SB-691. Attachment XIX

Written testimony was presented on SB-690 and SB-691 by Lois Johnson, McDonald, Kansas. Attachment XX

Written testimony from Michaela Stenger, Outreach Counselor, Huntington's Disease. Attachment XXI

\*No Attachment V - attachments misnumbered.

SENATE  
PUBLIC HEALTH AND WELFARE COMMITTEE

DATE 3-5-86

(PLEASE PRINT)  
NAME AND ADDRESS

ORGANIZATION

(PLEASE PRINT) NAME AND ADDRESS	ORGANIZATION
Dorothea Conway	
Jeanne Duest	Dermatology P.A.
Peter Carl	KINH 00
Harriet Nehring	"
Marilyn Bradt	KINH
Craig Grant	
Lee Johnson McDonald, Ks	
Marsha Hutcheson Topoka	Ks Medical Society
Liane Bottorff Topoka	Topoka Chapter ADRDA
SUSAN TANNENWALD-MIRINGOFF TOPEKA	Ks State Nurses Assn
Carolyn Muddendoy	KSNRA
Margaret Anschub	KSNIA
Jessie Beard	Writer
Grace Bullard	in 1st Hand
John Peterson	Ks Hssn Co. Child Care Agency
John Grace	Ks Homes for Aging
Sally Cable Adams	FRS - Div. of Med. Programs
Robert C. Guthrie	Topoka Chapter ADRDA; Ks Juk
Ray Vernon	Topoka Presbyterian Man
Keith V. Brossler	Topoka Chapter ADRDA - U-Pres.
Louis Jensen, M.D.	Rt. 1, Box 31B, Wakarusa, 66546
Val Braun	Ks Medical Society
JOYCE ROMERO	KDOA

SENATE  
PUBLIC HEALTH AND WELFARE COMMITTEE

DATE 3-5-86

(PLEASE PRINT)  
NAME AND ADDRESS

ORGANIZATION

Lyndon Dren  
Barb Reinert  
Theresa Smith  
PAT SCHAFFER

KIDOK  
Planned Parenthood  
Kansas  
DIVISION OF REPRODUCTION

KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

TESTIMONY ON SENATE BILL 672

PRESENTED TO THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE

MARCH 5, 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

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.

Attached to this testimony is a balloon recommending the addition of a new section to Senate Bill 672. This new language would amend 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 amend Senate Bill 672 as suggested and report the amended bill favorably for passage.

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

## SENATE BILL No. 672

By Committee on Public Health and Welfare

2-19

0017 AN ACT relating to maternity hospitals or homes and homes for  
0018 children; concerning license and registration fees; providing  
0019 grounds for denial of certificate of registration; amending  
0020 K.S.A. 65-505, 65-506, 65-519 and 65-521 and repealing the  
0021 existing sections.

0022 *Be it enacted by the Legislature of the State of Kansas:*

0023 Section 1. K.S.A. 65-505 is hereby amended to read as fol-  
0024 lows: 65-505. (a) Except as otherwise provided in this section,  
0025 the fee for a license to conduct a maternity hospital or home, or  
0026 home for children shall be fixed by the secretary of health and  
0027 environment by rules and regulations. Such fee shall not exceed  
0028 ~~\$12.50~~ \$15 except that for a hospital or home which is licensed to  
0029 care for five 13 or more residents such fee shall not exceed \$35  
0030 \$75. Such fee shall be paid to the secretary of health and  
0031 environment when the license is applied for and is not refund-  
0032 able. No fee shall be charged for a license to conduct a home for  
0033 children which is a family foster home as defined in K.A.R.  
0034 28-4-311 and amendments thereto. The secretary of health and  
0035 environment shall remit all moneys received by the secretary  
0036 from fees under the provisions of this section to the state trea-  
0037 surer at least monthly. Upon receipt of any such remittance the  
0038 state treasurer shall deposit the entire amount thereof in the state  
0039 treasury, and such amount shall be credited to the state general  
0040 fund.

0041 (b) The fees established by this section immediately prior to  
0042 July 1, ~~1982~~ 1986, shall continue in effect until different fees are  
0043 fixed by rules and regulations in accordance with subsection (a)  
0044 of this section.

0045 Sec. 2. K.S.A. 65-506 is hereby amended to read as follows:



0046 65-506. The secretary of health and environment shall serve  
 0047 written notice to the secretary of social and rehabilitation ser-  
 0048 vices and to the judge of the district court and to the county,  
 0049 city-county and multi-county department of health in every city  
 0050 and county in which a maternity hospital or home, or home for  
 0051 children is located, of the issuance of a license to conduct such  
 0052 hospital or home, or the revocation of such license; and. Neither  
 0053 the secretary of social and rehabilitation services; the judge of  
 0054 the district court or other officer or nor any other person shall not  
 0055 place or cause to be placed any maternity patient or child under  
 0056 sixteen (16) 16 years of age in any maternity hospital or home, or  
 0057 home for children not licensed by the secretary of health and  
 0058 environment.

0059 Sec. 3. K.S.A. 65-519 is hereby amended to read as follows:

0060 65-519. (a) The secretary shall issue a certificate of registration to  
 0061 any person who applies for registration on forms furnished by the  
 0062 secretary, who attests to the safety of the family day care home  
 0063 for the care of children, *who submits a fee not to exceed \$5*  
 0064 *payable to the secretary of health and environment, and who*  
 0065 certifies that no person described in paragraphs (1), (2), (3), (4),  
 0066 (5) or (6) of subsection (a) of K.S.A. 65-516 and amendments  
 0067 thereto resides, works or volunteers in the family day care home.

0068 (b) The secretary shall furnish each applicant for registration  
 0069 a family day care home safety evaluation form to be completed  
 0070 by the applicant and submitted with the registration application.

0071 (c) The certificate of registration shall be renewed annually  
 0072 in the same manner provided for in this section.

0073 (d) *The secretary of health and environment shall remit all*  
 0074 *moneys received by the secretary from fees under the provisions*  
 0075 *of this act to the state treasurer at least monthly. Upon receipt*  
 0076 *of each such remittance, the state treasurer shall deposit the*  
 0077 *entire amount thereof in the state treasury, and such amount*  
 0078 *shall be credited to the state general fund.*

0079 Sec. 4. K.S.A. 65-521 is hereby amended to read as follows:

0080 65-521. The secretary may deny, revoke or refuse to renew a  
 0081 certificate of registration upon a determination by the secretary  
 0082 that the registrant falsified information on the application or

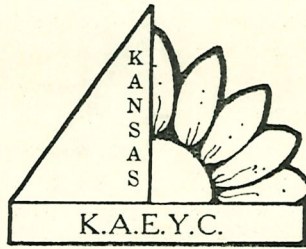
Sec. 3. K.S.A. 65-512 is hereby amended to read as  
 follows: 65-512. Inspections. It is hereby made the  
 duty of the division of health of the department of  
 health and environment to inspect or cause to be inspected  
 at least once every ~~six-(6)~~ 12 months every maternity  
 hospital or home, or home for children, and for that  
 purpose it shall have the right of entry and access  
 thereto in every department and to every place in the  
 premises and shall call for and examine the records which  
 are required to be kept by the provisions of this act  
 and shall make and preserve a record of every inspection.  
 The licensee shall give all reasonable information to the  
 authorized agent of the secretary of health and environment  
 and shall afford every reasonable facility for viewing the  
 premises and seeing the patients residents therein. No  
 patient or resident without his or her consent shall be  
 required to be interviewed by any agent unless the agent  
 shall be an authorized person or a licensed physician.

0083 willfully and substantially has violated K.S.A. 65-516 to 65-522,  
0084 inclusive, and amendments thereto. The secretary shall not  
0085 revoke or refuse to renew any certificate without first giving  
0086 notice and conducting a hearing in accordance with the provi-  
0087 sions of the Kansas administrative procedure act.

0088 ~~Sec. 5. K.S.A. 65-505, 65-506, 65-519 and 65-521 are hereby~~  
0089 ~~repealed.~~

0090 Sec. 6. This act shall take effect and be in force from and  
0091 after its publication in the statute book.

Sec. 6. K.S.A. 65-505, 65-506, 65-512, 65-519 and  
65-521 are hereby repealed.



Kansas Association for the Education  
of Young Children, Inc.

March 5, 1986

TO: Senate Public Health & Welfare Committee  
 FROM: Elizabeth E. Taylor, Legislative Consultant - KAEYC  
 RE: Support for SB 672

Thank you for the opportunity to express our support of SB 672.

The Kansas Association for the Education of Young Children is a state-wide organization of child care professionals including early childhood educators, preschool teachers, child care staff, and parents who are concerned with issues affecting children through age eight. KAEYC is affiliated with the NAEYC which represents 40,000.

During the last couple of legislative sessions, KAEYC has supported several measures which increase the protection of children in out-of-home care. In particular, we have supported the criminal check for employees working or applying to work in child care facilities. We realize that this increased protection for children must be funded. We realize that this fee increase will be easier for the larger facilities to afford and more difficult for small facilities such as family day care homes, but we agree that the services we have supported in the past must be funded.

Therefore, we are supporting the increase in fees and the establishment of a fee for family day care homes.

Again, thank you for allowing KAEYC to express its views.

RE: SENATE BILL NO. 690

Testimony before Kansas Senate Committee on Public Health & Welfare

Submitted by: Linda Wright  
Member, Kansas Alzheimer's Disease Task Force  
Past Chairman, Greater Kansas City Area Chapter  
Alzheimer's Disease & Related Disorders Association (ADRDA)  
Advocacy Chairman, Greater Kansas City Area Chapter  
ADRDA

As a member of the Kansas Alzheimer's Disease Task Force and as a member of the Greater Kansas City Area Chapter of ADRDA, I would like to encourage this committee's support of Senate Bill 690.

Establishment of an information and referral system through the Kansas Department on Aging will centralize information on Alzheimer's disease and related illnesses. Not only will this serve as a focal means of support, now lacking for families of persons with such illnesses, but as importantly will serve as a resource to those person's beginning their search for information and support.

With an information and referral network as outlined in Senate Bill 690, Kansans should benefit in multiple ways. Among these is: the decreased likelihood of inappropriate interventions in areas of diagnosis, treatment and research; supportive assistance for referral to systems for both care and support; an increase in understanding and support on the part of agencies in both the public and private sector; increased access to new information on Alzheimer's disease and related illness.

Thank you for your support of this bill.

RE: SENATE BILL NO. 691

Testimony before Kansas Senate Committee on Public Health & Welfare

Submitted by: Linda Wright  
Member, Kansas Alzheimer's Disease Task Force  
Past Chairman, Greater Kansas City Area Chapter  
Alzheimer's Disease & Related Disorders Association (ADRDA)  
Advocacy Chairman, Greater Kansas City Area Chapter  
ADRDA

As a member of the Kansas Alzheimer's Disease Task Force and as a member of the Greater Kansas City Area Chapter of ADRDA, I would like to encourage this committee's support of Senate Bill 691.

During the public hearings held throughout the state of Kansas by the Alzheimer's Disease Task Force, certain common problems were voiced. Support of Senate Bill 691 would address and help to resolve some of the issues raised in the hearings.

Through implementation of the plan outlined in this bill, the citizens of Kansas would have access to centers for assessment of Alzheimer's disease and related disorders without suffering the stress and frustration that occurs today when seeking such help. Too many tales were told by family members of less than appropriate assessment and diagnosis.

Because persons who have Alzheimer's disease or a related illness have unique care needs whether in the home, adult day care, or nursing home setting, both caregiver education and behavioral research is needed. Through the educational and research aspects suggested in this bill, attention could be given these areas. Unfortunately today families plead for more information on caregiving for themselves as well as for knowledgeable trained caregivers in the community and long term care.

Today no major efforts for research, data collection, and policy planning exists in respect to Alzheimer's disease or related dementias in the state of Kansas. Through Senate Bill 691, research and data collection could exist in a centralized way, encouraging not only better policy direction for the present, but for the future as well.

Because of the wide and diverse impact this bill would have to benefit persons with Alzheimer's disease (and related disorders) as well as those who care for them, I strongly encourage your support of this bill.

Thank you for your support of this bill.

Craig Grant Testimony Before The  
Senate Public Health & Welfare Committee  
Wednesday, March 5, 1986

Thank you, Mr. Chairman. Members of the Committee, my name is Craig Grant and I am speaking as an individual. I appreciate this chance to visit with you about SB 690.

I speak to you today as a part of a family which has had to deal with Alzheimer's disease. My father has been diagnosed having Alzheimer's for about five years now and has been in a nursing care home for three years. Even though there were many services available in Johnson County, I can tell you that my 70+ year old mother felt as isolated as anyone could feel. She was confused and often did not know where to turn for assistance or comfort. It is easy to understand how a person, after 51 years of relying on her spouse, hesitated and even refused to seek help from anyone else other than family. Sometimes our pride just gets in our way. If it had not been for my sister's close proximity, I am sure my mother could not have coped with the trauma. Now, after three years of building her strength (both physical and emotional) since he entered the nursing home, my mom is much better able to cope with the stress associated with her situation. She still goes through periods of depression and needs support of others who are in the same predicament.

I am sure my story is not atypical of many in Kansas. SB 690 would allow a person in a situation similar to my mothers to be able to call and get information on clinics, support groups, care providers, and maybe an Alzheimer's task force which could assist people in need. If people call and feel comfortable in calling, this should provide a much needed service for an ever-growing segment of our population which would be well worth the investment.

I would hope that you report SB 690 favorably. Thank you for your time in listening to my concern.

Testimony before the Senate Public Health and Welfare Committee  
March 5, 1986  
by Diane Bottorff  
Senate Bill 690

Mr Chairman and members of the committee, my name is Diane Bottorff. I am a member of the Board of Directors of the Topeka Chapter of the Alzheimer's Disease and Related Disorders Association. I speak in support of SB 690.

Our Topeka Chapter has a 24 hour answering service which provides information and referral services to families of Alzheimer's victims and professionals who work with these persons. I am one of several professionals who takes a turn responding to these calls. Callers have a variety of questions and concerns. Not all the calls we receive are from the Topeka area. This tells us that there are areas in our state where a source of information and referral is lacking. In fact, callers tell us they did not know whom to call in their area. We are somewhat handicapped in responding to persons from other areas of the state because we are not familiar with their local resources.

If the information and referral network is established as proposed in SB 690, then all areas of the state would have access to a central source of information including specific resources in their area. This network would also be a valuable resource to our Topeka Chapter as we attempt to help those who call us for assistance.

The bill proposes setting up the network within the Kansas Department on Aging. This is a wise move. The Department already has in place much data on Alzheimer's Disease and Related Disorders and knowledge of many resources as a result of the work of the State Task Force. In addition, the Department has an established network across the state with the Area Agencies on Aging.

The report of the Task Force on Alzheimer's Disease and Related Disorders has identified that there is a great need for information and better understanding of the disease. Passage of SB 690 is one way to help meet this need by making help only a phone call away.

SENATE BILL NO. 690  
PUBLIC HEALTH AND WELFARE COMMITTEE  
MARCH 5, 1986

Senator Ehrlich and fellow Committee Members:

My brief remarks are made as a member of the Kansas Alzheimer's Disease Task Force and of the Alzheimer's Disease and Related Disorders Association, Topeka Chapter; as a native Kansan with a deep concern for the tragic problems brought about by this malady; and finally and most sadly, as the husband of a bright, vivacious woman, active in many community, church and civic affairs, who in her sixties has been stricken with Alzheimer's Disease.

When my wife's organic illness was diagnosed about three years ago, I found that Alzheimer's disease was generally considered a mental disorder, not subject to the benefit of Medicare and health insurance. As is now emphatically agreed by medical specialists and research authorities, it is an organic disease just as cancer, cardio-vascular illness, arthritis, diabetes or many other maladies are diseases.

In holding public hearings over the State, the Task Force found much confusion about dementia, its diagnosis and lack of sources of help for the patient and family. Senate Bill No. 690, which would establish an information and referral network through the Department on Aging combined with a toll free telephone information system, would bring a valuable Helpline to families facing the catastrophic problems of Alzheimer's disease and related disorders.

As a concerned citizen, who has served on many Boards for the health and welfare of the less fortunate over the years, I urge favorable consideration by this Committee on Senate Bill No. 690.

Thank you sincerely,

*Robert C. Guthrie*  
Robert C. Guthrie  
3000 West 19th Street  
Topeka, KS 66604



SENATE BILL NO. 691  
SENATE PUBLIC HEALTH AND WELFARE COMMITTEE  
MARCH 5, 1986

Senator Ehrlich and fellow Committee Members:

My brief remarks are made as a member of the Kansas Alzheimer's Disease Task Force and of the Alzheimer's Disease and Related Disorders Association, Topeka Chapter; as a native Kansan with a deep concern for the tragic problems brought about by this malady; and finally and most sadly, as the husband of a bright, vivacious woman, active in many community, church and civic affairs, who in her sixties has been stricken with Alzheimer's Disease.

Speaking as a layman (my business career has been in banking), I nevertheless see the urgent need for the establishment of regional Alzheimer's disease assistance, education and service demonstration centers. Senate Bill No. 691 would designate the University of Kansas Medical Center along with other centers established under Section 4 of the Bill, to provide essential service including professional staff specially trained in diagnosis, geriatric nursing, medicine, neurology, psychiatry, and other professional specialties. The education and service provided with the demonstration units would address the major needs as heard at the public hearings conducted by the Task Force.

As a concerned citizen, who hopes future generations will not suffer the same grief as some of us are at present enduring, I urge favorable consideration by this Committee on Senate Bill NO. 691.

Thank you sincerely,

*Robert C. Guthrie*  
Robert C. Guthrie  
3000 W. 19th Street  
Topeka, KS 66604

Testimony in Support of SB 691

My name is Wanda Blaser. I am a registered nurse and have my master's degree in nursing. I teach for the University of Kansas and currently serve as president of the Alzheimer's Disease and Related Disorder's Association (ADRDA), Topeka Chapter.

From my work as a support group leader and at the task force hearings I have heard family concerns for improved patient care as well as the need for increased knowledge on the part of health and social service providers. From my work in the hospital and nursing home setting I have seen numerous examples of poor quality care to Alzheimer's patients and families due to lack of knowledge about Alzheimer's and suitable models of care to follow. I speak in support of SB 691 for the following reasons:

1. Provides Workable Solution. This bill does not create new agencies but allows enhanced functions of those agencies already in existence. Research, education, and clinical care are entwined to meet the needs of Alzheimer's patients, Alzheimer's families, and health and social service providers. Teaching and demonstration units within university settings, nursing homes and service agencies such as adult day care provide needed care for patients and families, models of care for agencies and practicing service providers, and education for students. Models similar to those designed for work with the elderly population in other states such as the Teaching Nursing Homes Projects of the Robert Wood Johnson Foundation, Beverly Enterprises, and the National Institute of Aging present good examples of expected outcomes for similar Alzheimer's programs. (Schneider et al, 1984)

2. Demonstrates large potential savings. Studies of prevention and management of AD behaviors such as incontinence, decubitus ulcers (bed sores), and contractures (immobilized joints), can lead to cost savings. I have seen numerous situations in hospital and nursing home settings where lack of knowledgable supportive care for patients lead to increased complications and increased costs of care. One example would be that of the Alzheimer patient inappropriately labeled with nontreatable incontinence with its accompanying embarrassment and increased cost of supplies, laundry, and labor. Appropriately educated personnel often find the incontinence is a problem of the environment that can be remedied such as lack of easily accessible bathrooms, poorly structured clothing for the Alzheimer patient, or poorly scheduled medications.

Expensive costs of decubitus treatment and the debilitation of contractures should be able to be entirely limited with appropriately instituted activity plans for the Alzheimer patient. These are interventions that require no more time than is already being provided by caregivers, just more knowledgable, thoughtful use of time.

The nature of Alzheimers disease leads in almost all cases to eventual nursing home placement. The majority of Alzheimers victims are elderly. The costs of nursing home care rapidly deplete the funds of the average elderly couple and medicaid reimbursement becomes necessary. As we are a rapidly aging population, it makes sense to determine the most cost effective modes of care now.

3. Promotes accurate diagnosis. A gentleman called me last week from western Kansas and said his mother had just been diagnosed with Alzheimers. The rapidity of onset of symptoms and the acute situation which brought on the symptoms caused concern on my part that it might have been an inappropriate diagnosis. When questioned about the diagnostic work-up he replied he had done the best he could. He never called back. According to a recent article in the Journal of the American Medical Association, 26 out of 136 patients with a diagnosis of Alzheimers or a related disorder actually had a treatable problem. (Sabin et al, 1982) Since there is no cure for Alzheimers in essence 26 patients were wrongly given a death sentence. Multidisciplinary centers could provide a reassurance to families of thorough investigation for any treatable disorders.

4. Promotes maximum function of patient. With a structured environment and simplified tasks an Alzheimer patient can function at a relatively high level for extended periods of time. Models of care must be provided that demonstrate the specific structuring of these types of environments. As I hear of nursing homes developing special Alzheimer units I am hopeful for progress, but also concerned that some agencies might simply lock a unit and say they are specialized. I have had experiences with nursing homes that call themselves adult day care centers while doing nothing more than charging a patient to come in and wander about their facility for the day. Multidisciplinary centers could provide models and consultation to other Kansas facilities in developing a safe, supportive environment for Alzheimer patients.

5. Promotes safety. Wandering behaviors are common for AD patients and models of care are needed to demonstrate that tying a patient to a chair is not the safest and least restrictive environment. I read about the Alzheimer patient who wandered off from a Topeka nursing home last year and died of exposure before he was found. Approaches can be developed and implemented for a safe, relatively nonrestrictive environment for Alzheimer's patients. It is time this be done.

6. Promotes decreased burden for the family. Families have repeatedly expressed their frustrations about lack of information and access to resources to ease their caregiving burdens. "What do we do?" and "what is available?" are two of the most common questions voiced in our support groups. Multidisciplinary centers could provide this much needed coordination role in returning families to their local communities, as well as serving as resources to communities in developing their own additional services.

We need the multidisciplinary centers described in SB 691 to offer immediate assistance and provide models that can be replicated in communities across our state. This proposal provides a positive approach for patients, families, educators, and health and service providers. I ask for your support of SB 691 with the hope that you will consider the long term gains all would receive.

Schneider, E., et al. (1985). The Teaching Nursing Home. New York: Raven Press.

Sabin, T., et al. (1982). Are Nursing Home Diagnosis and Treatment Adequate. Journal of the American Medical Association: 248.



**Kansans for Improvement of Nursing Homes, Inc.**

913 Tennessee, suite 2 Lawrence, Kansas 66044 (913) 842 3088

March 5, 1986

STATEMENT REGARDING SB 690: ESTABLISHMENT OF AN INFORMATION AND REFERRAL NETWORK TO ASSIST PERSONS WITH ALZHEIMER'S AND RELATED DISEASES

(Testimony for Kansans for Improvement of Nursing Homes was prepared by Harriet Nehring, Executive Director of KINH)

Mr. Chairman, Members of the Committee: As a member of the task force on Alzheimer's Disease and a former family caregiver, I have a background of knowledge and experience concerning the needs of Alzheimer's patients and of the family members responsible for their care. I believe SB 690 would provide needed and helpful assistance to patients' relatives, and through them, to the victims also.

In the past, a typical experience--and for those who have been through it, an all too familiar one--is the necessity of coping with the symptoms and diagnosis of Alzheimer's with little or no information, assistance, or support. The caregivers are overwhelmed by a feeling of helplessness; they have no idea where to get information or help. Fortunately, that experience is gradually changing, with growing availability of community services and programs such as respite services and family support groups. The need now is to link individuals who need services and information to their providers.

The existing toll free line in the Department on Aging's information and referral network is the necessary link. It is an established service available to Kansas citizens. What needs to be added is the gathering of data, and information on existing support services. An important factor to

cont.--

3/5/86

Attachment XI

S. PH&W

XI

STATEMENT REGARDING SB 690 cont.

the success of the added function of the statewide telephone network will be effective publicity so that all who need assistance will find it accessible. It would greatly reduce the burden and worries of Alzheimer's caregivers, and allow them more effectively to care for their loved ones. KINH enthusiastically supports SB 690 and requests that it receive the Committee's favorable report.



**KINH Kansans for Improvement of Nursing Homes, Inc.**

913 Tennessee, suite 2 Lawrence, Kansas 66044 (913) 842 3088

March 5, 1986

STATEMENT REGARDING SB 691: ESTABLISHING REGIONAL ALZHEIMER'S  
DISEASE ASSISTANCE CENTERS

(Testimony prepared by Harriet Nehring, Executive Director  
of Kansans for Improvement of Nursing Homes)

Mr. Chairman and Members of the Committee:

SB 691 recognizes the need for adequate medical attention to Alzheimer's patients, and for the education and training of health care providers and caregivers. Again, in the pragmatic approach to solutions offered by the Alzheimer's Task Force, existing health resources are utilized to meet this identified need.

It is recognized that the cost of immediate implementation of the assistance centers would be prohibitive in the present state financial crisis. SB 691, however, provides for a less costly, and we hope, more affordable and supportable idea of beginning to plan for the centers now through established health planning procedure in the Department of Health and Environment. The plan, according to the legislation, is to be prepared in the next two years, and can only be implemented within the limits of appropriations, thus protecting the Legislature's fiscal responsibility.

This is a reasonable and practical recommendation which gives Alzheimer's patients and their families further hope for improvement in future services, while laying a foundation for meaningful attention to real need in the present.

We recommend favorable consideration be given to SB 691.

TO: STATE LEGISLATORS  
REGARDING: WILLIAM R. CHALMERS (ALZHEIMER'S PATIENT)  
FROM: MARGUERITE B. CHALMERS (MRS. W. R. CHALMERS)

Bill Chalmers is a 1931 graduate of Kansas State University. He worked for the Kansas Highway Commission for thirty-five years, one year for Roy Finney, Consulting Engineer and four years for the Christopher Iron Works in Wichita. During the time he worked for KDOT, he was on a Core Drilling Party, in the Road Department and the last twenty-five years he was a Squad Chief in the Bridge Department. He retired April 1, 1974.

Because of throat trouble in December 1980, he was referred to an Ear-Nose-Throat doctor by his Cardiologist. He went the ENT doctor for six months and the only test he run was to see if Bill had throat cancer.

In June of 1981, I took Bill to Dr. Robert Holmes, who is a 1978 graduate of the K. U. Medical School. He immediately had tests run and then entered Bill into Stormont Vail for more testing. At the end of the testing, he told me he thought he knew what Bill's trouble was but asked if he could call in another doctor for a second opinion. Dr. Holmes called Dr. Stein a Neurologist from Menningers. Both diagnosed it as Alzheimer's Disease. Dr. Holmes continued to find out what caused Bill's regurgitating. Dr. Ricci examined him and did more testing. When this did not help, Dr. Holmes contacted Dr. Wanless and he performed surgery on Bill's neck and this helped.

At that time, the only hospitals doing research on Alzheimer's Disease were on either the East or West coast. We were financially unable to make the trip to one of them. Also there was very little literature about Alzheimer's Disease. When I told friends about the disease they usually asked "What's that". Now five years later people are better informed and there is more literature and TV specials regarding Alzheimer's Disease.

Bill entered a nursing home February 23, 1984. He has lost 53 pounds, walks constantly and does not know any of his family or friends.

Bill's family, a son and two daughters, and I urge you to pass Bills 690 and 691. We need to have a hospital centrally located so more people could go there and be diagnosed earlier than Bill was. Also, there could be some kind of educational classes for doctors, nurses, LPN's and family members. We have some now but we need more.

*Marguerite B. Chalmers*

Barbara L. Dopyera Daley  
6912 Towerview Lane  
Topeka, Kansas 66619  
862-2092

SENATE BILL 690- HELPLINE

Chairman Ehrlich and members of the Senate Public Health and Welfare Committee:

Thank you for the opportunity to tell you why I support the passage of Senate Bill 690. In my experience I have found a tremendous need for a centralized source of information and a helpline to access this information source.

While I worked as Research Director for the Kansas Alzheimer's and Related Diseases Task Force, I was swamped with telephone calls requesting written information about Alzheimer's disease and information about appropriate services on the local level.

Because of the number of information requests we had, we decided to put together a resource packet on Alzheimer's disease. We had 300 requests for the Resource Packet before my term ended in January.

In addition to telephone calls and written requests for information, the Task Force heard testimony from hundreds of Kansans. People repeatedly testified that they had need for information on Alzheimer's and had difficulty obtaining information about the disease and services for caregivers and victims of Alzheimer's.

For example, a Wichita man stated:

I talked with 17 attorneys to find one who would accept the case; there is no one place or phone number that can answer specific questions.

An El Dorado woman expressed her concern for more information in her area. She said:

The Task Force should help get more support groups and more information to the public. There should be a publicity drive in my town, they thought I started Alzheimer's disease there.

I am currently answering the telephone for the Topeka Alzheimer's Support Group and I see the trend in the need for information continuing. The majority of the phone calls I have are information requests. People either want written information or information about services. I find it particularly interesting when someone calls to find out if something is available in Hays for example, or Southern Kansas. I think these examples further illustrate the need for a centralized information source.

Lastly, I would like to point out that the information about Alzheimer's disease is rapidly changing. New research is being conducted that involves diagnostic procedures and treatment. Ways of dealing with the behavior of Alzheimer's patient are being

- 3/5/86

Attachment XIII  
S. PH&W



Page two- Testimony on SB 690-Helpline

developed and local services for the caregiver and victim of Alzheimer's are implemented from time to time.

It would be a great help to the families of Alzheimer's patients if there was a designated office that could keep track of all these changes. It is essential that someone develop and continually update a resource file for public distribution. In addition, this professional could learn about Alzheimer's specific local services.

For these reasons I encourage the committee's support of Senate Bill 690. I urge you to consider the tremendous need for this helpline in your deliberations.

Respectfully submitted,

Barbara L. Dopyera Daley



3-5-86  
For Further Information Contact:

Susan Tannenwald-Miringoff, R.N.  
Assistant Director  
(913) 233-8638

March 5, 1986

SB 690 and SB 691

- \* Establishment of Information and Referral Network--Alzheimer's Disease.
- \* Establishment of Regional Alzheimer's Disease Assistance Centers.

Mr. Chairman, members of the Committee on Public Health and Welfare, my name is Susan Tannenwald-Miringoff and I am a registered nurse here to speak to you on behalf of the Kansas State Nurses' Association. KSNA supports Senate Bills 690 and 691. 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 as well as regional Alzheimer's disease assistance centers in the state of Kansas.

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 disorders, 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 prevalent, Americans are living 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 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 increase demands for help and information.

Attachment XIV  
- 3/5/86 S. PH&W -

SB 690 &amp; 691

March 5, 1986

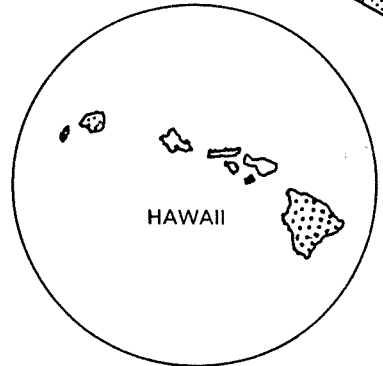
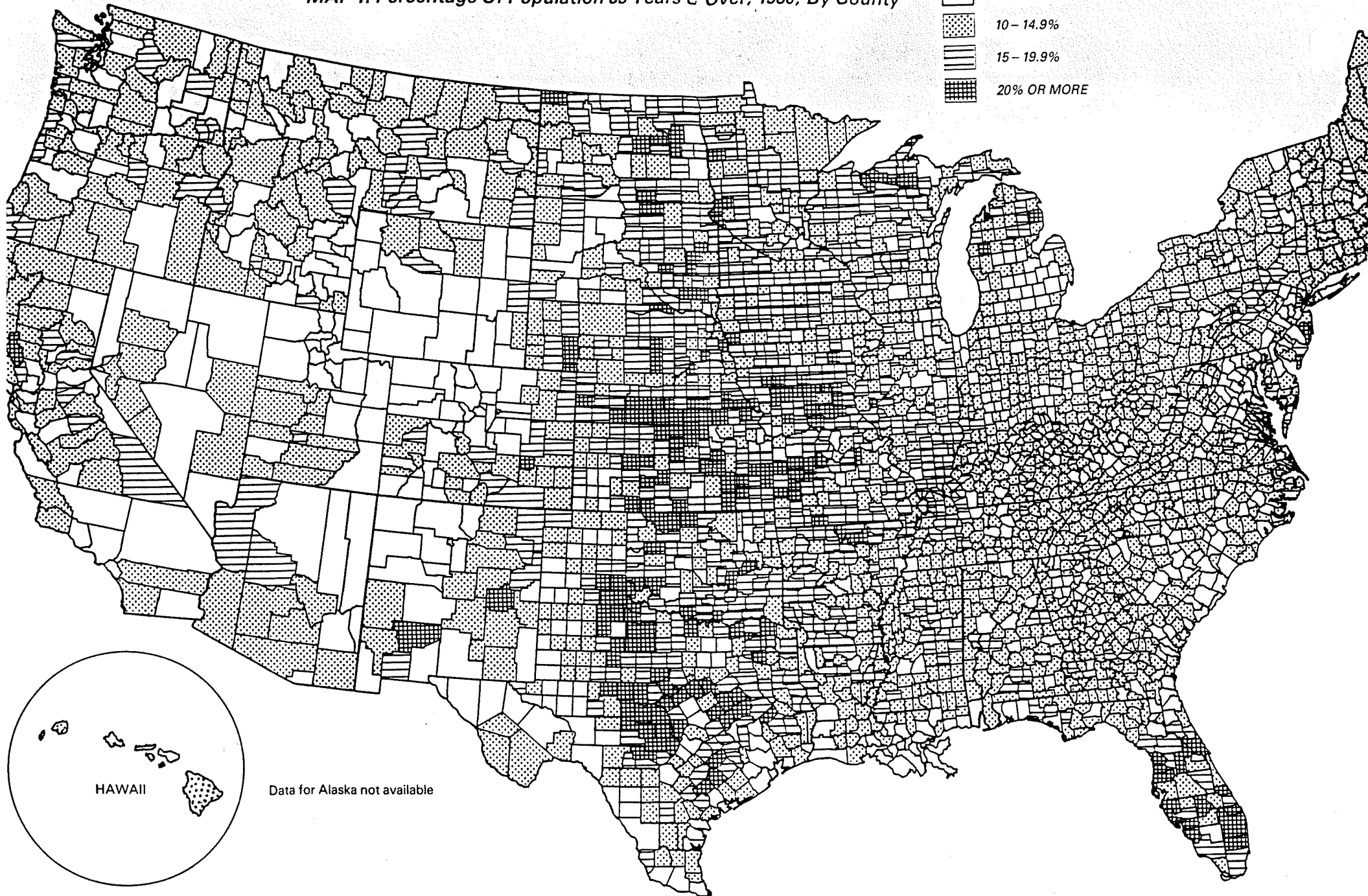
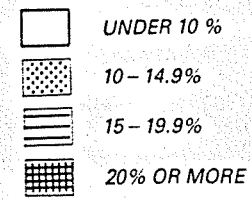
Perhaps by that time programs such as those proposed by SB 691 will have uncovered preventative and/or curative methods through research at Kansas' regional ADA centers.

The nursing profession has four basic 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 his particular disorder. The families of Alzheimer's disease victims are perhaps the most affected. These programs will provide much needed support, education, and referral services to those who need it the 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. In order to be health educators ourselves, we need the knowledge gained from the research programs that SB 691 will provide. We need the training and continuing education that SB 691 spells out so that nurses and others across the state will have access to the most recent approaches to these debilitating diseases. These two bills set up the kind of expertise base that will bring about great strides in health care delivery capabilities that Kansas health care consumers need and deserve.

Thank you.

Attached to this testimony is a copy of an article from the "American Journal of Nursing" of February, 1984. It reviews the stages of the disease process of Alzheimer's disease and demonstrates the role of Nursing with these patients.

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



Data for Alaska not available

# 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, University of Michigan. The University of Michigan. Based on data from the 1980 Census, February 1983.

# CE

To earn continuing education credit for home study of this feature, send for the test. See page 232 for coupon and fee.

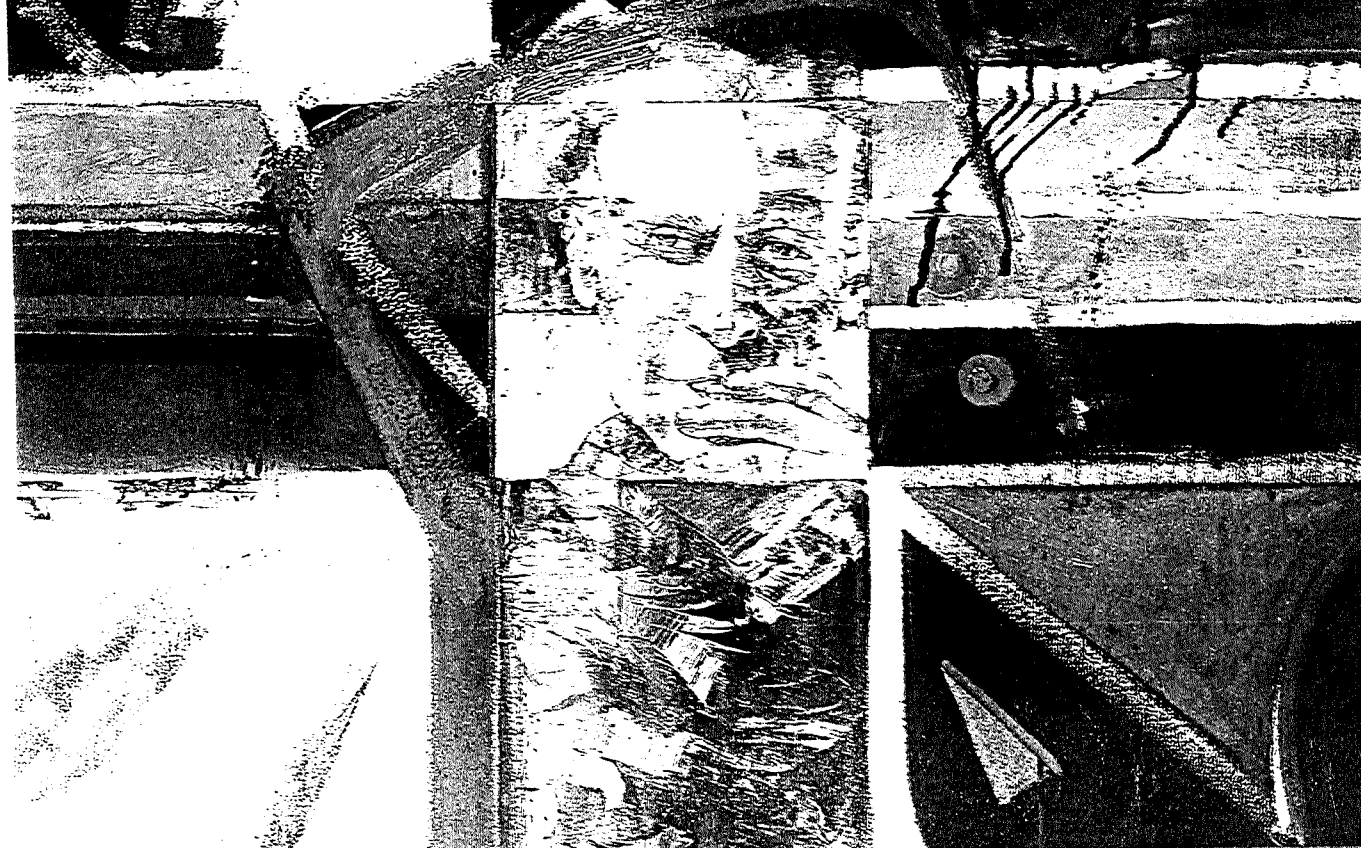


ILLUSTRATION BY PETER FIORE

# 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.

*Ma 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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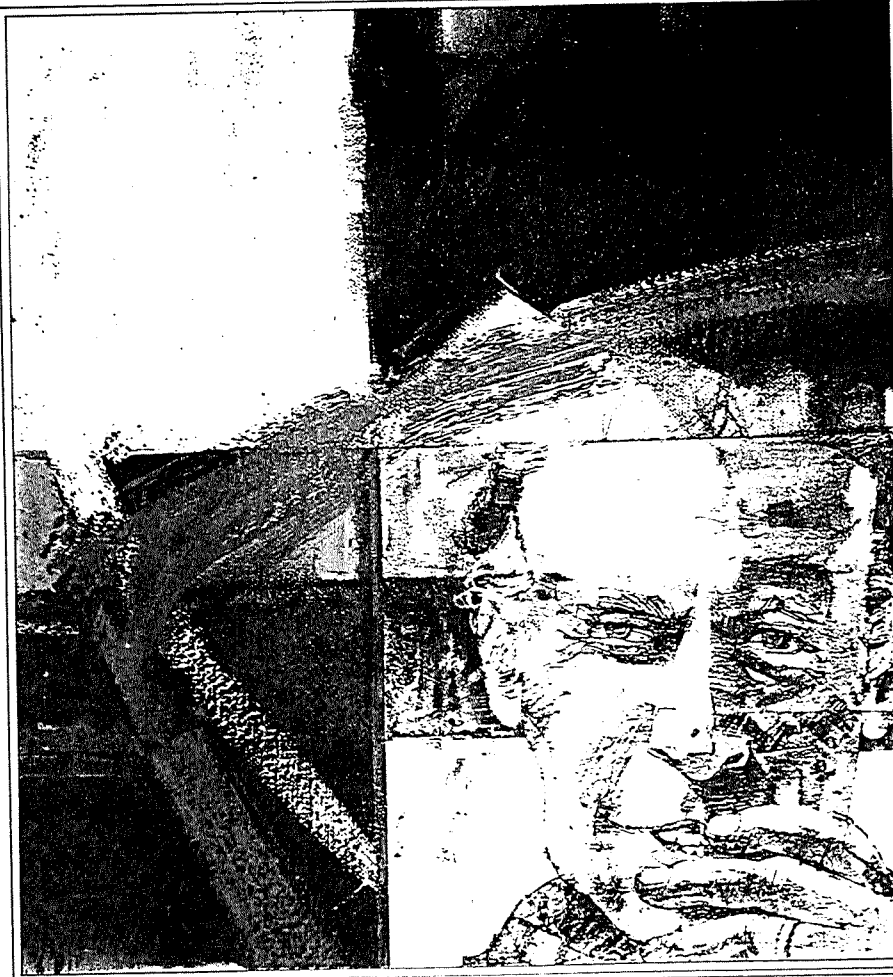
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# CE

## ALZHEIMER'S DISEASE

# INPATIENT CARE

BY MARILYN PAJK



**T**he 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?

**S**enility, "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

**A**lzheimer'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

**T**he 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 T

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"> <li><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.</li> <li><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."</li> <li><input type="checkbox"/> Speak to the patient in a clear, low-pitched voice. High-pitched tones convey anxiety and tension.</li> <li><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.</li> <li><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."</li> <li><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?"</li> <li><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?"</li> <li><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."</li> <li><input type="checkbox"/> Accompany verbal communication with appropriate nonverbal cues or signals. EXAMPLE: Ask "Do you need to urinate?" and show the patient the urinal.</li> <li><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.</li> <li><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.</li> <li><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.</li> </ul>
	<p>Provide a safe, structured environment</p>	<ul style="list-style-type: none"> <li><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.</li> <li><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).</li> <li><input type="checkbox"/> Never leave at the bedside anything that might harm the patient (e.g., scissors, matches, medicine).</li> <li><input type="checkbox"/> Keep siderails up and bed in low position. Check the patient frequently at night. A low light sometimes lessens anxiety.</li> <li><input type="checkbox"/> Assess the patient's degree of ataxia; help with walking, if necessary.</li> </ul>



# PATIENT WITH ALZHEIMER'S DISEASE

FUNCTIONAL DISABILITY	NURSING GOAL	NURSING INTERVENTIONS
		<ul style="list-style-type: none"> <li><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.</li> <li><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.</li> </ul>
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"> <li><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.</li> <li><input type="checkbox"/> Bedridden patients require active and passive range-of-joint movement.</li> <li><input type="checkbox"/> Avoid restraints, if possible. They tend to disturb the patient and may precipitate a catastrophic reaction.</li> </ul>
	Provide cognitive stimulation in the patient's environment	<ul style="list-style-type: none"> <li><input type="checkbox"/> Avoid isolating the patient. A person with dementia still enjoys the presence of caring people.</li> <li><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.</li> <li><input type="checkbox"/> Some Alzheimer's patients may enjoy television; others find it too stimulating and frustrating to follow.</li> </ul>
Altered bowel and bladder patterns	Maintain bowel and bladder continence for as long as possible	<ul style="list-style-type: none"> <li><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.</li> <li><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.</li> <li><input type="checkbox"/> Limit the fluids the patient consumes at bedtime to prevent nighttime incontinence.</li> <li><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.</li> </ul>
Altered nutritional/metabolic patterns	Maintain optimum nutritional status	<ul style="list-style-type: none"> <li><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.</li> <li><input type="checkbox"/> Plan a high-calorie diet if the patient is hyperactive. Encourage fluids during the day to prevent dehydration.</li> <li><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.</li> <li><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.</li> <li><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.</li> </ul>
Altered sleep rest patterns	Maintain normal day/night patterns	<ul style="list-style-type: none"> <li><input type="checkbox"/> Encourage the patient to stay awake during the day. Naps may disrupt or prevent nighttime sleep.</li> <li><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.</li> <li><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.</li> <li><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.</li> </ul>

# 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 sign 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, methyl dopa, 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**

**T**he 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)

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

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

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

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

**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?

Any evidence of systemic diseases known to produce dementia?

Any neurologic signs associated with the memory loss?

Seizure activity? Areas of brain-wave depression?

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

**CAUSES OF DEMENTIA**

May rule in a treatable *psychiatric disorder*.\*

- CBC: MCV, MCH, MCHC (mean corpuscular volume, hemoglobin, and hemoglobin concentration); serum vitamin B<sub>12</sub>; 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*.\*

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*.\*

- 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*.\*

- 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.

# CE

## 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 O<sub>2</sub>**, 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, trihexphenidyl (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

**P**revalence 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-

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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# CE

## ALZHEIMER'S DISEASE

**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: <ul style="list-style-type: none"> <li>• decreased knowledge of current and recent events,</li> <li>• some deficit in memory of personal history,</li> <li>• concentration deficit elicited on serial subtractions.</li> </ul> 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: <ul style="list-style-type: none"> <li>• Difficulty putting on clothing properly.</li> <li>• Requires assistance with bathing; may develop fear of bathing.</li> <li>• Inability to handle mechanics of toileting.</li> <li>• Urinary incontinence.</li> <li>• Fecal incontinence.</li> </ul>
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: <ul style="list-style-type: none"> <li>• Ability to speak limited to a few words.</li> <li>• All intelligible vocabulary lost.</li> <li>• All motor abilities lost.</li> <li>• Stupor.</li> <li>• Coma.</li> </ul>

Adapted with permission from *Amer. J. Psychiatry* 139:1138, Sept. 1982. © American Psychiatric Association.

The emotional 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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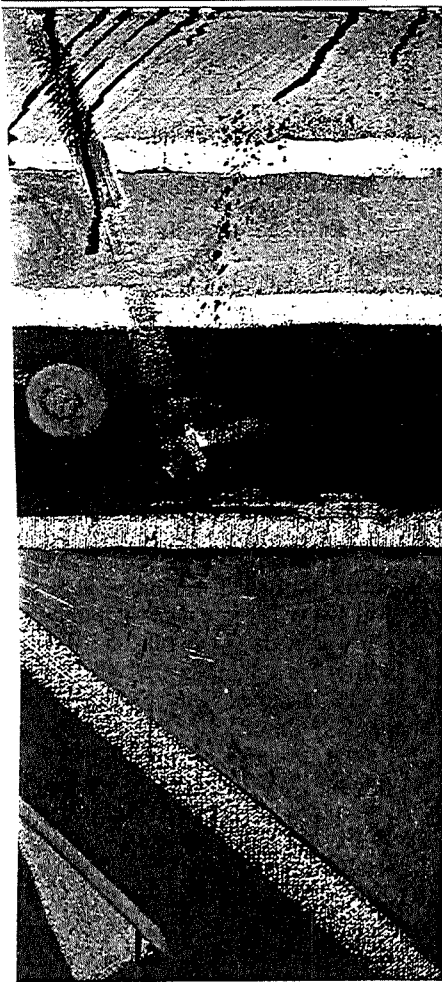
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# CE ALZHEIMER'S DISEASE



# 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 suprised 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.

# CE

## ALZHEIMER'S DISEASE

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. (ADRDA) 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 ADRDA 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 ADRDA National Headquarters, 360 North Michigan Avenue, Chicago, Ill. 60601, (312) 853-3060, brings a packet of information that includes a recent issue of the *ADRDA 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. ADRDA 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 them 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 perseveration.

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

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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*.

fection. 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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KDA

Testimony Regarding  
SB 690 - Helpline  
SB 691 - Multidisciplinary Centers

Before the  
Public Health and Welfare Committee  
Kansas State Senate  
March 6, 1986

Senator Ehrlich and members of the Senate Public Health and Welfare Committee, the Kansas Department on Aging endorses SB 690 and 691 and urges their adoption.

The six month study by the Task Force discovered a need to know more about Alzheimer's and Related Diseases in Kansas.

Resource Packet

One measure of this need is the response to this resource packet. Barbara Daley, one of the Task Force staff members, prepared a resource packet on Alzheimer's and Related Diseases. The packet reprinted 23 articles and a list of support groups in Kansas.

Over 300 packets were requested when the Department issued a press release on November 7. These articles have informed both professional and lay caregivers.

The following examples illustrate the impact of the resource packet:

- A registered physical therapist at a visiting nurses association requested 5 additional copies for staff members after reading the initial copy.
- A president of a Larned pharmacy requested a packet. He consults with three area nursing homes.
- An individual in Prairie Village gave his copy of the packet to a friend whose mother has Alzheimer's Disease. He called back and reported, "I find that I need it for reference and am wondering if you would be kind enough to send me another packet. I surely would appreciate it."
- A woman who formerly lived in Topeka but now lives in Texas requested a packet this way, "I am sure that I have some of the symptoms of the disease, so would appreciate a book as soon as possible."

One packet announced in one press release has informed these people. The Kansas Department on Aging shares with you a satisfaction in being a part of this educational effort.

## Final Report

The Department will continue to distribute copies of the final report by the Task Force. Not only does the report contain the recommendations which you are considering, it also contains an extensive appendix of information including a list by county of services for Alzheimer's victims.

The Task Force has given us a valuable tool for education.

- The report was used in February for workshops in Topeka and Pratt. It will be used this month for workshops in Chanute and Colby.
- A social worker from a Rossville nursing home has requested four additional copies of the final report for family members and staff.
- The director of resident and community services at a Newton nursing home requested a copy of the report. The home has opened the first Alzheimer's unit in Kansas.
- The following request came from a family member, "My mother died two years ago now and was diagnosed as having Alzheimer's Disease through a brain autopsy conducted after her death. My two brothers and I would appreciate reading such a report as to the latest research, etc. being done concerning this devastating disease.

## SB 690 and 691

Both bills, SB 690 and 691, are essential in providing information to professional and lay caregivers. The need revealed by the Department's experience with the resource packet and final report is supported by testimony at Task Force hearings.

One caregiving wife testified, "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.

A woman from Coffeyville lived with and cared for her husband for eight years before a clinic in Tulsa diagnosed the problem as Alzheimer's Disease.

Kansas needs clinics of its own where victims can be diagnosed and caregivers educated.

I feel that Senator Ehrlich and the other Task Force members have given us reasonable proposals which can and should be approved by the 1986 Kansas Legislature.



# Green Jade Swallow

LOUIS JENSEN, M.D.

March 5, 1986

Route 1, Box 31B  
Wakarusa, KS, 66546

(913) 671-2131

TESTIMONY ON SENATE BILL NO. SB 691.

PRESENTATION BY LOUIS JENSEN, M.D., MEMBER, ADVISORY COUNCIL TO ALZHEIMER'S TASK FORCE.

POSITION: FAVOR DESIGNATION AND SOME FISCAL SUPPORT TO THREE MULTIDISCIPLINARY CENTERS FOR DIAGNOSIS, EDUCATION AND TRAINING AND PSYCHOSOCIAL RESEARCH AS RELATES TO ALZHEIMER'S AND RELATED DISEASES.

## BACKGROUND:

### I. Many diseases simulate Alzheimer's Disease:

#### A. Some diseases that have been mistaken for Alzheimer's Disease:

1. May be highly, favorably responsive to specific treatment. An example is severe depression which may present with slowing of thought, complaints of impaired memory and episodes of feeling disoriented.
2. The course of certain other diseases (such as low pressure hydrocephalus, brain tumor, and even certain infections of the central nervous system such as with syphilis, tuberculosis, etc.) may be slowed or arrested by appropriate specific treatment once correct diagnosis is established.
3. At least one very formidable disease with progressive dementia and a neurological syndrome of myoclonic jerking and, often, marked startle reaction (Creutzfeldt-Jakob's slow virus spongiform encephalopathy) may be transmitted to other human beings by such tissue-donor processes as corneal transplant, etc.
4. Symptoms due to thyroid and pituitary disease may go undiagnosed. Other endocrine, digestive and circulatory disease of the brain may be mistaken for one of the dementias, resulting in needed treatment being omitted. Zinc deficiency, heavy metal poisoning and poisoning from industrial solvents, etc. need to be diagnosed, when present, to permit prevention of other family members or co-workers from the same hazards.
5. In my experience, dementias due to brain damage incurred in periods of cardiac arrest tend to have a quality of pervasive restlessness and of the victim perpetually on the go, with rapid development of tranquilizer tolerance.
6. The list seems endless! The reasons for desperately needing qualified multidisciplinary centers to establish ACCURATE diagnoses for the elderly citizens of Kansas are legion!.. To identify treatable conditions, to protect others from communicable illness or from toxic hazards of the community and to create better opportunity to anticipate the course of each illness at hand.

Attachment XVI

3/5/86

S. PH&W

XVI

TESTIMONY ON SENATE BILL NO. 691 (continued)  
PRESENTED BY: LOUIS JENSEN, M.D. (continued)

II. Resources for education and training:

- A. Currently, new information on the various organic brain diseases is being developed more rapidly than previously in this nation's history. From patient to patient the treatment challenges may vary greatly! Both the family members who care for loved ones at home and the health care personnel at nursing homes (including physicians, nurses, social workers, home administrators, etc.) need to have resources for augmentation of training and training materials.
1. Ongoing compassionate care requires attention to sustaining (to the extent consistent with the patient's condition) independence, self-determination, dignity, privacy, safety and prevention of such usual complications as fractures (from falls), bed sores (from extended periods of pressure on the same areas of the skin), pneumonia (from immobilization and reduced resistance to infection), blood clots (from inadequate promotion of ambulation with resulting stagnation of circulation), etc.
  2. It takes time, training and concern to learn to grasp how the patient's limited perception of his ongoing life events, including his illness, progressively change his/her adjustment, attitudes and expectations.
- B. The specialized training in these centers will, hopefully, teach how it is that the tendencies to restrain confused and forgetful patients increases the risks for debilitation, blood clots and other complications. Similarly, most psychiatric medications, through slowing and dulling brain functions, tend to aggravate the very problems that are central to dementia... the problem of remembering.. and of putting it all together. Much, much more is now known about the care-needs in general and also in the face of specific challenges, that needs to be organized and made more available to those caring for our elderly in Kansas, today.

III. The geriatric diseases that have mental symptoms due to organic brain disease have had surprisingly limited research as to treatment and psychosocial aspects of management. I believe this to be the result of our American culture having a strong tendency to unconsciously identify advanced age as being a part of dying. Most of us have not come to terms with our own dying so we, and our private and public institutions are strongly inclined to avoid dealing with death OR the realistic needs, rights, dynamics, problems and limitations of advanced age. Looked at in a wider perspective,

TESTIMONY ON SENATE BILL NO. 691 (continued)

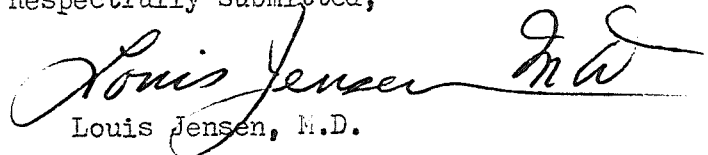
PRESENTED BY: LOUIS JENSEN, M.D. (continued)

III. NEED FOR RESEARCH RESOURCES AND COMMITMENT AT SELECTED CENTERS (CONTINUED):

our neglect of these areas seems as though we were diligently committed to lining our PERSONAL retirement nests with THORNS!!! What we do, to-day, to enhance the knowledge and practice of care of OUR elderly offers hope that the care that we and our children receive in our twilight years may be enhanced by the knowledge and compassion and resources made possible by the commitments made this day. THROUGH RESEARCH, MUCH REMAINS TO BE DISCOVERED TO ENHANCE:

- A. Knowledge about the diagnosis, causes, prevention and dynamics of the various senile dementias.
- B. Treatment, environmental enhancement and other aspects of care of these patients.
- C. Gathering, discovering and compiling information in such format as to be meaningfully contributory to the Centers' functions of education and training.

Respectfully submitted,

  
Louis Jensen, M.D.

LOUIS JENSEN, M.D. - BACKGROUND:

Retired from Colmery-O'Neil V.A. Medical Center 3-30-85 after over 38 years' Federal service (Navy, Army & VA)  
Born: Ya-an, Sichuan, China 1-21-24 of missionary parents.  
AB degree - Colgate University, Hamilton, NY. 1944.  
MD degree - University of Rochester School of Medicine. 1948.  
Internship: Albany Hospital, Albany, N.Y.  
Certified in Psychiatry by American Board of Psychiatry & Neurology. 1955  
Chief, Psychiatry Service, V.A. Hospital, Hines, Illinois. 3-6-56 to 11-30-65.  
Chief of Staff, VAMC, Knoxville, Iowa. 12-26-68 to 12-31-77.  
Staff Physician, Intermediate Care, VAMC, Topeka, KS. 9-1-78 to 3-30-85.  
Became Fellow, Gerontological Society, Inc. 9-6-52.  
Became Fellow, American Geriatric Society. 4-26-60.  
Member, American Psychiatric Association since 4-30-56.  
Other relevant memberships:  
Shawnee County Advocacy Council of Aging.  
National Council on Aging.  
American Association of Retired Persons.  
Covenant Baptist Church.

Member of  
Care Association **ahca**

Kansas Health Care Association

March 5, 1986

SUBJECT: SUPPORT FOR S.B. 690 AND S.B. 691 -- ALZHEIMER'S DISEASE

Senator Ehrlich and Members of the Senate Public Health and Welfare Committee:

This is to convey this association's support for the two bills captioned above which relate to Alzheimer's Disease, its victims, their families and caregivers.


S.B. 690 provides for an informational, telephone network within the Department on Aging. The other measure, S.B. 691, establishes regional assistance centers and training and demonstration units.

These bills were recommendations from the Kansas Alzheimer's and Related Diseases Task Force, which spent an inordinate amount of time last year hearing the concerns and suggestions from those associated with this crippling and incurable disease.

The Kansas Health Care Association is a voluntary non-profit organization which represents over 200 licensed adult care homes in Kansas, both proprietary as well as not-for-profit interests.

Your favorable consideration of these bills is respectfully requested.

Sincerely,

  
*Dick Hummel*  
Dick Hummel  
Executive Director

DH:jn

Attachment XVII

3/5/86

S. PH&W

*"We Care"*



The Organization of  
Nonprofit Homes and  
Services for the Elderly

Kansas Association of Homes for the Aging  
One Townsite Plaza  
Fifth and Kansas Avenue  
Topeka, Kansas 66603

913-233-7443

March 5, 1986

Testimony for the Senate Public Health and Welfare  
Committee

Re: Senate Bills No. 690 & 691

John R. Grace, Executive Director  
Kansas Association of Homes for the Aging

Chairman Ehrlich and Members of the Committee.

The Kansas Association of Homes for the Aging is the organization of community, governmental and religious sponsored homes and services for the aging of Kansas. We have 73 members located in all regions of the state.

We support Senate Bills No. 690 & 691

During the next 15 years, the over age 75 population will increase by nearly 50%. As this growth occurs, it is imperative that we begin to look at developing information and referral networks for those with Alzheimer's Disease and related disorders. In addition, the establishment of regional disease assistance centers for providing assistance to families and professionals in the field of aging, would be most helpful in addressing this public concern.

Thank you for the opportunity to comment on these Bills.

3/5/86

Attachment XVIII

S. PH&W

XVIII

March 1, 1986

Dear Legislator,

As the daughter of an Alzheimer's victim I urge you to vote for Helpline (Senate Bill 690) and Multidisciplinary Centers (Senate Bill 691).

This legislation would represent money well spent to assist the victims and families of those afflicted with this tragic disease.

Sincerely,

*Jane McClain*  
Jane C. McClain

Attachment XIX

3/5/86

S. PH&W

XIX

TESTIMONY ON S.B. 691  
BY LOIS JOHNSON, MCDONALD, KANSAS  
MARCH 6, 1986

Senator Ehrlich and Committee Members:

I support bill 691.

My husband was stricken with Alzheimer's disease four years ago. We started seeking help for him through our local doctor when we notice his personality changes. He thought it might be a stress problem and gave him a series of testing. At our insistance, our local doctor sent him to Denver and more testing was done, including CT scan, heart catheter, and psychological testing. We were then told to seek help from a psychiatrist. The closest one was 150 miles. A lot of the same tests were run at additional expense to us. He was diagnosed at having depression. He spent seven weeks on a mental ward under heavy medication until we were able to get him in a VA hospital in Topeka. As the medication was removed, they were able to do more complete testing and we were given the diagnosis of organic brain syndrome probably Alzheimer's. We wish there had been a multi-disciplinary center in Kansas, not only because of the expense, but because of the time we could have been spending with him before he lost his personality and was no longer able to communicate with us.

Thank you.

TESTIMONY ON S.B. 690  
BY LOIS JOHNSON, MCDONALD, KANSAS  
MARCH 6, 1986

Senator Ehrlich and Committee Members:

I support bill 690.

My husband was stricken with Alzheimer's disease at age 49. We live in Northwest Kansas at least 200 miles from any major medical services. I had no idea where to start searching for the doctors that we need to accurately evaluate what was going wrong with my husband. As the disease progressed, I needed legal counseling, support services, day care and again this was all by trial and error as I had no place to seek advice on these services. A "Helpline" as the bill proposes would help with the worry and frustration that goes with this disease, especially in rural Kansas. As a member of the advisory board for the Alzheimer's and Related Disease Task Force, I heard this same remark all across the state, "Where do we go for help?"

Thank you.





# HUNTINGTON'S DISEASE

Foundation of America  
**KANSAS CHAPTER**

2721 Boulevard Plaza  
Wichita, Kansas 67211  
316-684-0593

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*John Martin*

**Executive Director**

*Nan Emmett Godfrey*

March 5, 1986

The Honorable Roy Ehrlich  
State Capital, Room 138H  
Topeka, KS 66612

Dear Senator Ehrlich:

I understand that in the Wednesday hearing on S.B. 690 and S.B. 691, a question was asked about international programs.

I am therefore sending you this information on the Arthur Preston Centre in Australia. This centre was established in 1981 specifically to care for sufferers of Huntington's Disease.

Per a recent phone conversation with the centre, I learned that their efforts have been very successful in educating the public to facilitate programs for the overall benefit of victims of Huntington's Disease.

I strongly support both bills, S.B. 690 and S.B. 691 for the same purpose. Only through available and massive education can we help those who so desperately need it.

Sincerely,

Michaela Stenger  
Outreach Counselor, Huntington's Disease

kr

Attachment XXI  
3/5/86 S. PH&W

Help Put An End To A Family Tradition

Non-Profit — Tax Exempt — Participating Member of the National Health Agencies in combined Federal campaign

Attachment XXI

HUNTINGTON'S DISEASE  
FOUNDATION OF AMERICA, INC.  
250 W. 57th STREET  
NEW YORK, N.Y. 10107

ARTHUR PRESTON CENTRE  
AT MARY'S MOUNT  
25 YARBAT AVE.  
BALWYN 310

## A CARE CENTRE FOR HUNTINGTON'S DISEASE: CONFRONTING ATTITUDES TO CHRONIC TERMINAL ILLNESS.

Alison Ball  
Social Worker  
Arthur Preston Centre, Melbourne

### Abstract

This paper first describes the Arthur Preston Centre at Mary's Mount in Balwyn, Victoria and what Huntington's Disease is. It then discusses the old attitudes to this chronic, terminal illness and the confrontation with these attitudes presented to sufferers and families. The type of care offered at the Centre is described and the ways in which the experience at the centre calls into question the old professional attitudes and assumptions relating to the sufferers of this disease. Finally a challenge is made for the adoption of a new viewpoint.

### Introduction

The Arthur Preston Centre at Mary's Mount in Balwyn Victoria, was officially opened by the Governor General of Australia, Sir Zelman Cowen on October 25th 1981. Wesley Central Mission of the Uniting Church in Australia have thus provided the world's first centre specifically devoted to the care of sufferers from Huntington's Disease. Wesley's help came in response to the needs expressed by the Australian Huntington's Disease Association and the professional work already done in the field by Mrs Betty Teltcher and Dr. Edmond Chiu through the University of Melbourne Department of Psychiatry. The spacious property and residence purchased for the Centre had been owned by the Catholic Church and had been built in the early 1930's by the late Oliver Gilpin. With the assistance of the Commonwealth Government, it now comprises a Deficit Funded Nursing Home for up to 25 permanent residents aged 32 to 73 years and has four other beds which are used for short term family relief care. Additionally, sufferers who live at home or in other institutions attend on a daily basis for socialization groups and approved para-medical services.

Huntington's Disease is an inherited disease which, after onset, results in rapid, progressive degeneration of brain cells. It is characterised by uncoordinated, involuntary movements, speech difficulties and varying degrees of physical and cognitive incapacity. Onset is usually in the middle years of life though childhood forms are known and some sufferers are not diagnosed until as late as their seventies. The disease does not skip generations and each child of a sufferer has a 50% chance of inheriting or not inheriting the gene which causes this disease. At this time there is no cure and no test can predict which children will inherit the illness. Death, generally through pneumonia or heart failure usually occurs some 15 to 20 years or more after onset.

### The Old Attitudes

In the past in Victoria, and still in most places in the world, sufferers from Huntington's Disease have been the forgotten people, housed in the back wards of Mental Institutions; the skeleton almost literally in the cupboard for hundreds of families and shunned as frightening and hopeless by communities and professionals alike. Sufferers themselves have been given no hope and families have felt shamed by this disease which has often wrecked their marriages and their lives. They have felt angry that their parents may have passed it on to their children. The community and the professionals have reinforced their shame, and, in the face of their own helplessness in combating this disease have in the main, turned their backs on sufferers as being untreatable because their illness is incurable.

Communities, families and sufferers follow the lead of professionals in attitudes toward particular illnesses and, all too often right to this moment, the attitudes of professionals exude helplessness and hopelessness when this disease is mentioned. In much the same way as they do at mention of Senile Dementia many professionals still literally turn their backs and lose all affect as they say "Huntington's Disease? They can't be treated." Where the old attitudes prevail the assumption is that it is not worth treating someone who has a limited time to live or whose quality of life seems poor. In the case of this devastating, chronic, terminal illness it is thought rather better or kinder to withhold any treatment which may prolong that life.

Teltcher (1) and Chiu (2) have long expressed their challenges to such attitudes. The establishment of the Arthur Preston Centre represents the testing ground of new attitudes derived from their ten years of interactions with Huntington's Disease sufferers and their families.

### A Concrete Confrontation

A building, even a very large one, with sometimes up to thirty-six sufferers of Huntington's Disease together under the one roof does represent a very strong experience of this illness and a very concrete confrontation with all the old attitudes and assumptions. At our centre our people are not treated as sick, dying people. During the day they are up and about unless they have a specific other illness at the time. They are up because they have work to do. Their work is to take part in the program of activities which is aimed at keeping their minds and bodies active, and which is, in our view, the only and the best way that we

can help them. Our people swim, pot plants, do craft activities, play word games, discuss current affairs, take part in relaxation sessions, music and movement therapy. Our physiotherapists who began work only a short time ago clear their chest congestion and put unused muscles back to work. They are excited by what their assessments of these advanced patients might mean in the future for new sufferers. We do not pretend that our people can be cured or that we can even lengthen the span of their lives. All we say is that we hope to improve the quality of their lives, to help them to live each day to the full and, with a realistic acceptance of the limitations, aim to promote their optimum level of functioning at any particular time.

### The Sufferers

The confrontation begins with the sufferers themselves. Daily they find themselves in the presence of others in much more deteriorated states than themselves, bringing into sharp focus all their worst fears of what the future might hold for them. Many do not want to identify with the group but there is a sense of relief in not being the odd one out and isolation is being replaced by caring for one another and by a growing self-esteem. Sufferers have expectations placed upon them and, in an atmosphere which treats them as responsible human beings, are now, in turn, beginning to assert themselves and take pride in their accomplishments.

### Families

Families too, and particularly those at risk of contracting Huntington's Disease have also been confronted with this visible evidence of all their worst fears. Evidence of physical deterioration, loss of speech, brain and motor function, peculiar gait and accompanying loss of role and productive ability all combine with distress and grief to drive home the realities of this disease. Very often, for the first time, sufferers and families have realised that this disease cannot be dismissed as a disease of old age but that quite young people can contract this illness and they comprehend at last that this is what may await themselves or their children. At the same time their children will grow with a knowledge their parents did not have. Future decision making for them will be all the more difficult because they will not be ignorant and a choice to have children will be all the more agonizing. In the past families have been sheltered from such confrontation but at the same time have been isolated and left alone to cope with their fears and their anger. At our centre they are brought face to face with the worst but, at the same time, they see hope for a better quality of life for sufferers and find support amongst friends.

### The Professionals

The old attitude amongst professionals are not a feature of the past. Every week we hear and see further evidence of the strength and depth of the myths. The old attitudes meant that once labelled with the

diagnosis, sufferers were placed in the long-term chronic wards, treated lovingly perhaps, but with no stimulation for their minds or activity for their bodies. The old attitudes meant that it was not much use buying day clothes, testing eyes for reading glasses, fixing teeth or fitting dentures. The old attitudes left gynaecological problems unattended and they meant that it was hardly worth the trouble to rehabilitate an elderly sufferer who had broken a leg nor could it have been conceivable to treat the heart condition of an older man. The old attitudes meant that the paramedical services have had no experience at all of working with sufferers of Huntington's Disease and that participation in the community was discouraged because of the problems. The old attitudes said sufferers were incontinent, that they wasted away, that they were violent or aggressive. The old attitudes said that because speech was incoherent then there was no thinking and, most damning of all, the old attitudes said that sufferers were demented or dementing.

### The Reality

Huntington's Disease does have gross effects upon its victims and many of these effects are a direct consequence of the disease. Brain cells do die off at a rapid rate, functioning in many areas is greatly reduced and for many sufferers some of the problems above are prevalent for some of their years with this disease. But, by writing off sufferers from almost the beginnings of this disease because their illness is incurable, many of the attendant complications have long been ignored and untreated, dismissed as an inevitable concomitant of this disease.

Living day by day with our people forces us to question the old professional assumptions. Do Huntington's sufferers really have to waste away? We encourage as many as possible to continue to feed themselves even if much of the food ends up on the floor. None of our residents as yet eat vitamised food even though some came in doing so and other day-patients return to nursing homes to eat vitamised food after a normal lunch. Great vigilance must, of course, be exercised in the dining room but most of our residents have maintained weight or gained in weight. Is the supposed incontinence really an integral part of this disease? Our experience suggests that it is rather more a feature of lack of speech clarity which makes it difficult to express needs or in other cases the acting out of anger which is not able to be verbally expressed. Is the aggression and violence we so often hear about also an inherent part of this illness? Our sufferers at Balwyn, in the main, are no more aggressive than you or I. The very few who sometimes are seen to be acting out of fear of what may be happening to them or sometimes it seems the anger attached to the grief which is naturally felt when one is afflicted with any chronic, terminal illness. Often, too, it seems a reaction to finding oneself totally dependent upon others for even the most basic needs.

And it is true that sufferers from Huntington's Disease are demented or dementing? Certainly the

functioning of our people deteriorates in many ways, but dementia? Do demented people listen to the football or cricket, discuss the scores and compare them with previous years? Do demented people co-operate, concentrate and follow instructions to the letter for sometimes up to three or four hours when being examined and assessed by optometrists or physiotherapists? Do demented people laugh at our jokes or, having been absent for two months, ask us how was our two week holiday which we had said we would be taking when last we met? And do demented people show care, concern and grief for the suffering of one of their friends whose brother or son has died? Dementia may be the medical, technically correct term to describe death of brain cells but, when used in conjunction with the old attitudes it is a pejorative term which, in one foul swoop, is used to write off whole categories of people as not worth bothering about. Chiu (3) has coined a new term 'Dysmentia' which expresses a more positive approach to the intellectual deterioration of our Huntington's Disease sufferers.

### The Challenge

The reality of this disease can, indeed, be frightening but our advanced sufferers at Balwyn are an inspiration. The battles against the old attitudes which are being fought are not new although they are new for the sufferers of this particular disease. Professional and community attitudes have changed in relation to many disadvantaged groups in our society but that the battles must be fought for our people is indicative of how far along the road we still must travel. We do not want extra-ordinary measures or excessive medical interventions used to resuscitate a sufferer when a heart attack or pneumonia will give a quick and easy release from this world. Our sufferers themselves may well

think it a blessing when the lingering has ended. But we do want our people to be given reasonable care for what ails them, we do want to ask the physiotherapists, the occupational therapists, the speech therapists and the doctors to do their best to help the sufferer to maintain whatever may be their optimum level of functioning at any particular time. At the Arthur Preston Centre we are in the business of helping people to live each day to the full. Most will presumably reach a point beyond which they will never improve and certainly most could not survive outside a protected environment. All will eventually deteriorate and die no matter what we do. But we are in the business of trying to abolish the sense of helplessness and hopelessness which has accompanied this disease. Our sufferers are people again; people who have rights and responsibilities; people who are able to stand up for themselves and people who are beginning to realise that they still may have a contribution to make to this world. Our sufferers from Huntington's Disease may be dying; so are we all. At the Arthur Preston Centre they are showing us how to live with a chronic terminal illness. We have the challenge to offer realistic hope and all of us have a responsibility to look not at a disease, a sick organ, at old age or chronic illness but at the person who, in the presence of established disabilities, still has 'a lot of living to do'.

#### REFERENCES

1. Teltscher, B., Huntington's Disease. Some Recent Developments, Australian Social Work, March, 1981 Vol.34, No. 1
2. Chiu, E., Notes on The Management of Huntington's Disease: A Brief guide for family physicians, Australian Family Physician Vol.8 February 1979.
3. Chiu, E. & deL. Horne, D. J. Dysmentia in Huntington's Disease; Paper presented at the first Australian Huntington's Disease conference, 1979.

Distributed by: Huntington's Disease Foundation of America (formerly Committee To Combat Huntington's Disease)