ALASKA LEGISLATURE COMMITTEE FILES 1985-1986 8672

3924 SHES SB 117

800

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James O. Smith
Signature of Camera Operator

10/31/89
Date

2-519 (REV 8/78)

SB

117

## Senate Health, Education and Social Services Committee

### Legislation Checklist

Bill number: SB 117

Sponsor: V. Fischer

Date referred to committee: 2/1/85

Synopsis completed: 2/4

Fiscal note:

Further referrals: Finance

Teleconference Sites: Fbx, Anch, Juneau, Nome, Kotzebue, Mat-Su, Anch Pioneers Home

CONTACTS:

✓ Fischer Steve Kadisch 278-3654

Eleanor Kelley, Fbx coordinator - 479-5999
Alzheimer's Support Group

Becky Clemens, Statewide Coordinator 344-6707
Alzheimer's Support Group

✓ Ruth Brown, Planner for the Older
Alaskans Commission 465-3250

Rod Betit, Director, Division of
~~Medical Assistance~~ 465-3355
Dave Bruce, Div Public Health.

~~Dean Tirador~~, MD., Health Services
Specialist, Division of Public Health
465-3090

## What is DAY BREAK?

DAY BREAK is an adult day care center for individuals with Alzheimer's disease and related disorders. DAY BREAK provides:

- Relief to families --- allowing time for those who are caring for a loved one at home to carry on the other activities in their lives.
- A safe, caring environment for clients — enhancing their lives and maintaining their highest level of functioning.

## Who Comes to DAY BREAK?

DAY BREAK clients include those who:

- Have memory impairments and need supervision
- Are seeking an alternative to nursing home care
- Are lonely or isolated
- Have limited opportunities for participation in community activities

## What Services Are Offered at DAY BREAK?

DAY BREAK offers a variety of services depending on the client's needs and abilities:

- Recreation
- Relaxation
- Exercise
- Counseling
- Socialization
- Arts and crafts
- Health and medication maintenance
- Occupational therapy
- Group and individual activities
- Participation in community projects

*DAY BREAK works closely with the **Alzheimer's Disease Family Support Group** in providing support to clients' families.*

## Location:

9210 Jupiter
Anchorage, Alaska 99508

## Cost:

Fees are based on a sliding scale according to the client's ability to pay.

## Hours:

Monday-Friday
8:00 a.m. to 5:00 p.m.
Closed on holidays

Days of attendance are arranged in advance.

## For More Information

on the DAY BREAK program or on Alzheimer's disease and related disorders call:

**The DAY BREAK Office**
346-2234

**The Alzheimer's Disease Family Support Group**
346-2366

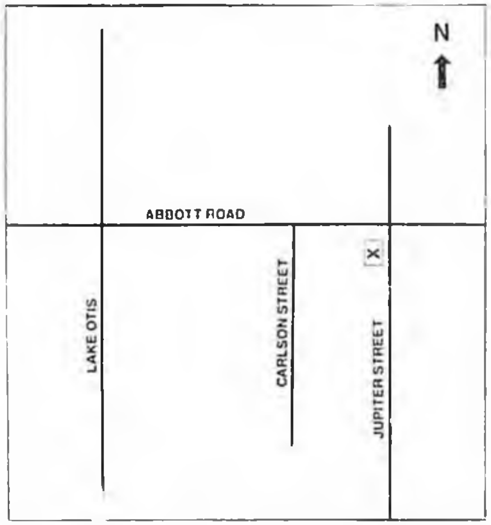
**Southcentral Counseling Center Geriatric Services**
563-1000

SB 117

**Funding for DAY BREAK** is provided by: Older Alaskans Commission; Municipality of Anchorage; Salvation Army Senior Citizens' Programs — food services; The Alzheimer's Memorial Fund of Southcentral Counseling Center — equipment and special programs.

The **Alzheimer's Memorial Fund** of **Southcentral Counseling Center** was established to provide ongoing care for those persons having Alzheimer's disease and related disorders.

Those wishing to contribute to this fund should contact DAY BREAK or Southcentral Counseling Center.



# DAY BREAK

## *A day care program for individuals with Alzheimer's disease and related disorders*

DAY BREAK is located in the
Nellie Johanson Memorial Center
9210 Jupiter
Anchorage, Alaska 99508
(907) 346-2234

*A Service of*

Southcentral
COUNSELING CENTER

# COMMITTEE REPORT
# SENATE

FURTHER: FINANCE

3/1/85

Date 3-17-85

Mr. President

The Committee on HESS considered SS SB 117

relating to Alzheimer's disease and related disorders.

and (a majority of the committee) (the committee) reports it back with the following recommendations:

☐ do pass

☐ do pass with attached amendment(s)

☑ replace with/or adopt CS for SS SB 117
☐ new title
☑ same title and recommends Do Pass

☐ and attached a "LETTER OF INTENT" ☐ NEW FISCAL NOTE

☐ reports it back without recommendation

☐ recommends referral to ______ Committee

MEMBERS SIGNING
DO PASS

Joe Josephson

Edna DeVries

MEMBERS HAVING
OTHER RECOMMENDATIONS

Chairman

Chairman recommendation

Senator FAHREMKAMP
Atten: SANDRA

Senator Vic Fischer
Alaska State Legislature
Pouch V • Juneau, Alaska 99811 • (907) 465-4954

January 28, 1986

file

To: Senator Jan Faiks, Co-Chair
Senate Finance Committee

From: Senator Vic Fischer

Re: Request for hearing SB 117 - Alzheimer's disease

Attached is a file of background information on SB 117, an act relating to Alzheimer's disease, that has been pending before the Senate Finance Committee since early last session. I would greatly appreciate your at least scheduling a hearing on SB 117 at your earliest convenience.

SB 117 was introduced early last year and referred to the Senate HESS and Finance Committee. The HE&SS Committee heard SB 117 on March 20 and unanimously passed the CS currently before the Finance Committee.

SB 117 is endorsed by the Alzheimer's Family Support Group, along with hundreds of other concerned Alaskans, and is supported by the Older Alaskans Commission and the Department of Health and Social Services.

The Finance Committee heard considerable testimony this last year about the growing number of Alzheimer victims in Alaska and the tremendous costs associated with treatment of Alzheimer-related illnesses. The Department and others have endorsed the approach outlined in SB 117 as the most cost-effective way to address this problem.

Alzheimer's is a devastating disease that presents incredible hardships for both the victim and the family that tries to help them. SB 117 would give those families a fighting chance. It truly is the very least we can do.

*During Interim • 1024 W. 6th Avenue, Suite 204C • Anchorage, Alaska 99501 • (907) 278-3654*

If there are any problems preventing an early hearing on SB 117, please let me know. Should you have any other questions, or need additional background information, please contact me or Ginger Baim at 4954.

cc: Senator Bettye Fahrenkamp
Commissioner John Pugh
Becky Clement - Alzheimer's Family Support Group

BILL SHEFFIELD, GOVERNOR

**DEPT. OF HEALTH AND SOCIAL SERVICES**

*OFFICE OF THE COMMISSIONER*

POUCH H 01
JUNEAU, ALASKA 99811
PHONE: 465-3030

Document No. 86-5

January 20, 1986

The Honorable Vic Fischer
Alaska State Senate
P.O. Box V
Juneau, AK 99811

Dear Senator Fischer:

I appreciate your candid response to my July 5 letter regarding adult day care for Alzheimer's victims.

Since my July letter, I have studied the long-term care needs of Alaska's elderly in considerable depth. As you know, I am chairman of Governor Sheffield's task force on long-term care. It is well documented that a significant element of the growing demand for long-term care services, including residential care, is Alzheimer's disease. As you well know, the dimensions of the problem are far from clear at this point.

I am convinced of the growing severity of this problem. Availability of community based services such as adult day care and personal care would provide the most desirable approach to provide the needed services. The department has requested the Governor introduce a bill to add personal care to the medicaid program. The fiscal note on the bill is $500.0. In addition, two weeks ago I approved a Certificate of Need for Camai Center in Palmer because of their willingness to develop a special program for Alzheimer's patients.

I definitely agree that Alzheimer's is a significant problem, and I am eager to support your efforts to secure passage of Senate Bill 117. I would like to discuss this further with you as soon as your schedule permits.

Again, thank you for your letter.

Sincerely,

John R. Pugh

John R. Pugh
Commissioner

Senator Vic Fischer
Alaska State Legislature
Pouch V • Juneau, Alaska 99811 • (907) 465-4954

November 15, 1985

John R. Pugh, Commissioner
Dept. of Health and Social Services
Pouch H 01
Juneau, Alaska 99811

Dear John:

On June 17, I wrote asking that the Department make legislation providing adult day care centers for Alzehimers victims a priority. Frankly, your lukewarm response of July 5 was a great disappointment.

Saying "the department's position papers endorsed the concept of the bill and indicated our willingness to serve on a task force..." simply isn't good enough. And it avoids a direct response to a direct question: Will the Department make treatment and care of Alzheimers victims a priority?

John, I'm fully aware of the financial crunch facing the state, and the particular hardship that presents to DHSS - a department grossly underfunded even in times of relative wealth. However, Alzheimer's, like most of the issue you deal with, will not go away if we ignore it, nor will the cost of treatment be less if we fail to actively pursue the least costly treatment alternatives available.

I truly don't care whether its my bill, or the House bill, or legislation yet to be introduced that provides a vehicle for identifying Alzheimer's victims and providing treatment alternatives. The critical thing is for the Department to became an active and agressive advocate for dealing with the current and anticipated "crisis" of Alzheimer-type illnesses in Alaska.

The Department has designated certain issues as priorities in the past. A case in point is the monumental effort expressed in support of programs dealing with physical and sexual abuse of children. This effort resulted in a substantial increase in our understanding of the problem and in developing better methods to deal with it.

*During Interim • 1024 W. 6th Avenue, Suite 204C • Anchorage, Alaska 99501 • (907) 278-3654*

I believe the time is overdue for the Department to take a similar lead in advocating for treatment programs for Alzheimer's victims. Sometimes it's necessary to review existing programs and make room for newly recognized needs and priorities. I believe this is one of those times.

I will be in Juneau on December 12 on personal business. Assuming the weather and flights are cooperative, I will try to meet with you then to discuss this issue. My staff will confirm times with your office the first week in December.

Best regards,

Senator Vic Fischer

cc: Thelma Langdon & Becky Clement
Alzheimer's Family Support Group

STATE OF ALASKA

**DEPT. OF HEALTH AND SOCIAL SERVICES**

*OFFICE OF THE COMMISSIONER*

*BILL SHEFFIELD, GOVERNOR*

*POUCH H 01*
*JUNEAU, ALASKA 99811*
*PHONE:* 465-3030

Document No. 85-165

July 5, 1985

The Honorable Vic Fischer
Alaska State Senate
600 Barrow
Anchorage, AK 99501

Dear Senator Fischer:

Thank you for your letter of June 17, 1985 regarding legislation authorizing adult day care centers for Alzheimer's disease patients.

As you know, the Department had some reservations regarding the requirement in the original bill for establishment of a diagnostic center in Anchorage to serve the entire state. This requirement was removed in the committee substitute for the original senate bill. Subsequently, the department's position papers endorsed the concept of the bill and indicated our willingness to serve on a task force to investigate problems relating to diagnosis and care of people with the disease.

I am very interested in the comparisons of day care costs versus nursing home costs made by the Alzheimer's Family Support Group. I would be happy to discuss this bill with you or your staff at your convenience.

Sincerely,

John R. Pugh

John R. Pugh
Commissioner

Senator Vic Fischer (907) 465-4954

Alaska State Legislature
Pouch V • Juneau, Alaska 99811 • (907) 465-4954

June 17, 1985

John Pugh, Commissioner
Department of Health and Social Services
Pouch H-01
Juneau 99811

Dear John,

As you know legislation creating adult day care centers for Alaskans afflicted with Alzheimer's disease was introduced in both the Senate (SB 117) and House (HB 279) this year. I am writing to request that you make this legislation a Department priority for the next session.

Day care centers for Alzheimer's patients have proven to be inexpensive, efficient, and effective programs that provide critically needed service. It is estimated that there are as many as 2000 Alzheimer's victims in the state.

Alzheimer's Family Support Group claims that for every year that long-term institutional care is put off for each person by the availability of adult day care saves the state a minimum of $40,000. The state is obligated to cover through Medicaid the expenses of institutional care at a minimum of $140/day per person, equal to $51,000 a year, compared to approximately $35/day for day care. In other words, for every one dollar the state spends for adult day care means a hard cash savings of six dollars to the state.

The bills are now in their respective Finance Committees. Your help and leadership on this issue could really make a difference. Please let me know when you would like to discuss this further.

Best Regards,

Senator Vic Fischer

file SB 117
JAN 17 1986

TO: Eleanor Andrews, Commissioner, Dept. of Administration
Joyce Munson, Director, Division of Pioneers' Benefits
John Pugh, Commissioner, Dept. of Health & Social Services

FR: Frank Port, Anchorage Pioneers' Home Resident

DATE January 13, 1986

SUB: Alzheimers Daycare Centers with care wings for ten incontinent patients

Relative to the Alzheimers and geriatric caregroups turning down the use of the State facility known as Harbor View located at Valdez. It has taken some time for the Dept. of Health and Social Services and the Dept. of Administration to come up with a viable option to meet the exigency of the time no matter how it is considered remote and it should be used beyond its planned purpose until a joint meeting of the Legislature to consider the Honorable Vic Fischer's Bill and the Honorable Nilo Kaponen's Bill to provide diagonistic services, treatment, and Daycare centers. I suggest that in addition to the Daycare centers that a unit of each consisting of ten rooms to take care of incontinent patients. I also suggest a fee for Daycare patients of $15.00 per day and $25.00 per day for incontinent patients. This also serves notice upon family members that they cannot shun off their responsibilities upon the State. Over all costs should come from fees derived from mental health lands that have been ceded over to the State by the Federal Government.just for this stated purpose. Medicaid would be a further source of funding, plus matching funds from the Federal Government.

I do hope this reasoning will add to the solution of the problem facing us in a situation that can only grow worse with each passing day. The cost for private institutions will be prohibitive regardless of whether they are run by a religious or a private corporation.

CC: Each State Legislator
Dr. Glade Birch and Charles Mundorf, S.C. Counseling Center
Governor William Sheffield
Ms. Thelma Langdon, Alzheimer Support Group
Roberley Potter, Anc. Pioneers' Home Manager
Nancy Bourne, Director of Nurses, Anc. Pioneers' Home
President, Greater Anchorage Ministerial Group

cc V. Fischer

file SB117 etc

# STATE HEALTH NOTES

## Alzheimer's Initiatives Advance

Alzheimer's disease—a debilitating form of senile dementia afflicting an estimated 1.5 million of the nation's elderly—is becoming an increasingly important state priority. So far this year, the legislatures in at least five states have enacted laws aimed at promoting further study of the disease and providing help to Alzheimer's patients and their families. They join **CALIFORNIA**, which approved several initiatives, including a $1 million grant to create diagnostic and research centers, in last year's session.

One of the most far-reaching efforts this year came out of **ILLINOIS**, where the legislature enacted a package of eight bills relating to Alzheimer's. According to the sponsors, as many as 111,000 **ILLINOIS** citizens may be suffering from the disease and 50 percent of all nursing home admissions are linked to Alzheimer's or related disorders.

re to Medicaid costs

The centerpiece of the **ILLINOIS** package is the Alzheimer's Disease Assistance Act (SB 388), which creates regional centers (one serving the Chicago metropolitan area and at least one other conveniently situated for residents in the rest of the state) to provide comprehensive diagnosis and treatment of the disease, in conjunction with other providers in the state.

The centers, which will be located at higher education institutions having a medical school affiliated with a medical center, are to be staffed by professionals trained in geriatric medicine, neurology, psychiatry and pharmacology. Under the law, they must provide a broad ranges of services including transportation, consultation, referral and training and continuing education for caregivers, including family members, as well as doing research and serving as a clearinghouse for data collection and processing.

In addition, the law directs the Department of Public Health, by January 1, 1987, to develop standards for conducting research and for identifying, evaluating, diagnosing, referring and treating victims of the disease through the regional assistance centers and other providers. By that date and every three years thereafter, the department will also be required to prepare an Alzheimers's disease assistance plan to coordinate research, diagnosis, referral and treatment services within each service area of the state. An advisory committee will be created to assist the department in implementing and administering the plan.

Finally, the law authorizes grants-in-aid to the regional centers to conduct research and maintain services for victims of the disease, in accord with the triennial plan.

The other parts of the package build on that base. SB 386, for example, directs the Public Health Department to establish policies, procedures and standards for collecting, maintaining and exchanging the confidential personal and medical information needed to identify and evaluate Alzheimer's victims. The information will also be used for consultations, referrals and treatment of patients through their personal physicians and the new regional assistance centers. Under the new law, physicians and other health personnel at hospitals, nursing homes and clinics will be required to report any diagnosis of Alzheimer's to the department; in turn, the department will release the information to organizations doing research into the disease, protecting the privacy of patients.

SB 385 creates an Alzheimer's task force to evaluate the state's health and medical assistance programs and suggest ways of improving those programs to better serve the needs of patients and their families. Within a year, the task force will be required to sponsor a statewide conference to explore the progress of new programs and services, identify future needs and make recommendations on how to meet those needs.

Alternative to SB117!

SB 391 amends the definitions of disabled people under the state's rehabilitation act to include Alzheimer's victims, making them eligible for state-financed services such as home health and home nursing care, chore and housekeeping services, home-delivered meals, adult day care and respite care. Similarly, SB 384 extends eligibility for a state respite care demonstration program to the families of Alzheimer's disease victims.

SB 392 authorizes the Department of Public Aid to create and implement a pilot project to determine the feasibility of authorizing state medical assistance payments for the cost of diagnosing and treating Alzheimer's. SB 390 will give incentive payments to nursing homes that develop special programs for Alzheimer's patients, by considering the cost of such programs in setting prospective payment rates for skilled nursing and intermediate care facilities.

Finally, SB 62 creates the Alzheimer's Disease Research Act, providing a voluntary tax checkoff for **ILLINOIS** residents who wish to contribute a portion of their refund to Alzheimer's research. The act also sets up a special fund within the state treasury to finance research.

**FLORIDA'S** legislature also moved on Alzheimer's in its recent session. HB 77 (Chapter 85-145) establishes an Alzheimer's disease advisory committee as well as a research trust fund to award grants to institutions that run programs intended to control the disease as well as prevention, and research programs.

The new law also authorizes funds to create memory disorder clinics at each of the state's three medical schools and at a major private, non-profit research oriented teaching hospital and/or any other affiliated teaching hospitals. The clinics' purpose will be to conduct research and training in a diagnostic and therapeutic setting for Alzheimer's patients. Further, the law requires the Department of Health and Rehabilitation Services to contract for three specialized model day care programs in conjunction with each of the clinics.

Finally, it directs the department to contract for respite care programs. The programs are to be used by the medical schools and teaching hospitals as a resource to compile research and statistical data on Alzheimer's.

Three other states have also committed resources to further study Alzheimer's. **CONNECTICUT** SB 582 (Special Act 85-81) creates a task force to assess the needs and problems of victims of Alzheimer's and related disorders as well as the needs of the family members who care for them. The task force is to report its and recommendations to the General Assembly next February 1. A **KANSAS** law (SCR 1618) directs the Secretary of Aging to set up a task force to determine the incidence and prevalence of Alzheimer's and review program options. And **VIRGINIA** HJR 309 creates a Commission on Alzheimer's Disease and Related Disorders to study the need for and feasibility of developing a network of four to six regional dementia centers. The centers would be based in academic or health care centers and operated in coordination with local chapters of the Alzheimer's Disease and Related Disorders Association. The 20-member commission has been directed to study areas such as support activities for patients and their families by volunteer peer counselors and continuing education and training activities for medical, mental health and social service workers.

Finally, the **TEXAS** legislature, in HCR 88, express its "wholehearted support" of the state Health Department's efforts to develop support and educational programs to help patients, their families and nursing homes in their efforts to manage Alzheimer's disease. The resolution also encourages the department to continue its efforts to develop a network of associations, family members and other concerned individuals to deal with what it describes as a "serious health problem."

Meantime, **CALIFORNIA** is in the process of implementing several Alzheimer's programs enacted last year and is on the verge of approving several other bills. The $1 million appropriated in 1984 has been allocated, with $250,000 going to four research programs and the remainder to diagnostic and treatment centers. The Department of Aging is in the final stages of implementing two other of last year's initiatives: one to establish a day care resources center and the other to set up a statewide conference on Alzheimer's. That conference is tentatively scheduled for April of 1986.

This session, the Assembly has already approved three bills and the Senate one. AB 99 calls for a three-year demonstration project for three Alzheimer's disease institutes, combining traditional programs with specialized strategies to meet the needs of Alzheimer's victims. Applicants would be expected to finance the projects themselves but could apply for state or federal funds available for Alzheimer's disease programs. Another bill (AB 1305) directs a 1984 Alzheimer's task force to study a means for making private insurance available to victims of the disease. And AB 2470 authorizes grants to local organizations to provide or arrange for in-home care and respite care for patients and their families. Finally, SB 1113 seeks to appropriate another $1 million for Alzheimer's research. **CALIFORNIA's** session is scheduled to end on September 13. Supporters say they are optimistic that all the bills will win the legislature's approval but fear money considerations may cause the the Governor to veto one or more of them.

# Medicaid and Indigent Care Survey Released

*Recent and Proposed Changes in State Medicaid Programs* (July 1985) is now available from IHPP. The survey summarizes the major state Medicaid policy changes—both legislative and administrative—that have been initiated through July of 1985. It also includes an appendix on 1985 proposed and adopted legislation affecting indigent care.

A review of the July 1985 survey indicates a continuation of the trend of states expanding program eligibility. So far in 1985, 19 states have expanded eligibility by extending coverage to new categories, creating limited medically needy programs or increasing the income eligibility levels. This compares with 17 states that expanded eligibility in 1984 and 15 others in 1983.

Some of the surveys highlights include:

## Services

- As of July 1985, 13 states have expanded their benefit coverage. This compares with 25 states that expanded services in 1984 and 26 in 1983. Conversely, only two states reduced their coverage in 1985, while six did so in 1984, and 12 in 1983. The types of new services covered were quite diverse although three states—Hawaii, New Jersey and North Carolina—all added personal care services.

## Eligibility

- Seven of the 19 states that expanded eligibility did so to comply with the requirements of the Child Health Assurance Program of the Deficit Reduction Act of 1984 (DEFRA). New Jersey and Texas adopted limited medically needy programs, while Oregon expanded its limited medically needy program.

## Reimbursement

- States continue to demonstrate a willingness to try new prospective payment systems for inpatient hospital services. Washington and Michigan became the fifth and sixth states to implement a reimbursement system based on diagnosis-related groups for Medicaid payments. The other four states using the DRG system are New Jersey, Ohio, Pennsylvania and Utah; four other states—Minnesota, Montana Oregon and South Dakota—have proposed adopting DRGs within the year.
- Florida adopted legislation that authorizes the state to contract for services under competitive bidding. By implementing ICARE—the Illinois Competitive Access and Reimbursement Equity program—Illinois joined the Medicaid programs of Arizona (AHCCCS) and California (Medi-Cal) in utilizing a competitive bidding approach to reimburse inpatient hospital services.

## Administration and Management

- Nine states considered and two states adopted legislation that prohibits discrimination against Medicaid nursing home residents. California's law prohibits discrimination against a Medi-Cal patient on the basis of source of payment and also prohibits evicting residents who change from private insurance to Medi-Cal. Oregon's law also bars discrimination based on source of payment and against requiring a fee from Medicaid patients in excess of the Medicaid payments.

**Other**

- So far in 1985, eight states—Kentucky, Maine, Michigan, Minnesota, Nevada, Texas, Utah and Virginia—are or will be studying at least one component of the Medicaid program. For example, Minnesota will study the feasibility of creating a home equity conversion program to finance long term care services and insurance.

**Indigent Care**

- In 1985, states continued to devote a large amount of attention to the issue of providing care to the medically indigent. Thirty states considered legislative proposals that would have either mandated improvements in state or county indigent care programs or would have required establishing a commission to examine the issue.
- Eight states altered their indigent programs, and four—Arkansas, Nevada, South Carolina and Texas—adopted legislation creating new state indigent care programs. Texas enacted legislation that clarified county responsibility; created a maternal and infant health improvement program; established a primary health services program; and amended the hospital licensure law by inserting minimum standards governing the transfer of patients for nonmedical reasons. South Carolina created a medically indigent assistance program, financed by an assessment on general hospitals and on counties that will reimburse hospitals for providing treatment to the medically indigent. And Nevada mandated that counties must establish a fund to finance medical assistance for indigents.
- Nine states adopted legislation requiring a study of the indigent care issue. Of that group, six states—Louisiana, Nebraska, New Hampshire, North Carolina, Tennessee, and West Virginia—will focus exclusively on the indigent care issue, while in three—Colorado, New Mexico and Oregon—indigent care will be only one component of the health care issues that will be studied.

Single copies of the survey are available without charge to state and federal officials. Others may obtain a copy by sending $9 to IHPP.

## Transplant Activities Continue

write state health notes & Oregon for info on [illegible] other states laws

State legislatures have continued to be very active in promoting and facilitating organ donation and procurement. In their recent sessions, New York and Oregon enacted laws intended to alleviate the chronic scarcity of organs available for transplantation by requiring hospital administrators to ask relatives to donate the organs of patients who have died in the hospital. The new laws, which mark a major departure from current policy, are designed to overcome physicians' and hospitals' reluctance to approach grieving families about organ donation. Under New York's AB 6849 and Oregon's HB 2902, hospital administrators must ask the relatives of all deceased persons who, in accordance with medical criteria are determined to be suitable candidates for organ donation, if they are willing to donate organs. Exception will be made if the hospitals have clear indications that the deceased person or family members opposed organ donations or if the practice conflicts with their religious beliefs.

New York also enacted another bill, AB 6635, designed to ease the shortage of corneas and pituitary glands for transplant. Coroners and medical examiners were reluctant to provide the names of deceased persons under their jurisdiction or the names of their relatives to organ procurement agencies, believing that they lacked statutory to do so. AB 6635 grants them specific authority to release these names, thus paving the way for organ procurement agencies to ask family members for organ donations.

★ ★ ★ ★ ★ ★ ★ ★ ★ ★

The Intergovernmental Health Policy Project and the U.S. Health Care Financing Administration recently reported findings from a fifty state review of Medicaid coverage and payment policies for organ transplants. According to the survey, great diversity and uncertainty exists in Medicaid policies governing payment for organ trans-

SS SB 117

1) WOULD AUTHORIZE THE OLDER ALASKANS COMMISSION TO MAKE GRANTS FOR THE OPERATION OF DAY CARE CENTERS. THE FISCAL NOTE IS FOR $496,300 AND WAS COMPUTED BY ESTIMATING THE NUMBER OF POTENTIAL ADULT DAY CARE CLIENTS IN TARGET COMMUNITIES:
Fairbanks, Anchorage/Chugiak expansion, Kenai, Nome, Juneau, Palmer/Wasilla

2) WOULD AUTHORIZE THE OLDER ALASKANS COMMISSION TO PROVIDE FOR IN-HOME SERVICES TO VICTIMS OF ALZHEIMER'S DISEASE. THE COSTS ARE INCLUDED IN THE ABOVE FISCAL NOTE

3) WOULD ESTABLISH AN ALZHEIMER'S DISEASE TASK FORCE. THE FISCAL NOTE IS FOR $13,000

4) WOULD AUTHORIZE THE DEPT. OF HEALTH AND SOCIAL SERVICES TO OPERATE OR CONTRACT FOR A STATEWIDE ALZHEIMER DIAGNOSTIC CENTER IN ANCHORAGE. THE FISCAL NOTE IS $253,800.

---

* THERE IS ONE ADULT DAY CARE FACILITY IN ANCHORAGE THAT PROVIDES PSYCHOLOGICAL AND MEDICAL CARE TO ALZHEIMER VICTIMS. AS PART OF THEIR DAILY PROGRAM THEY KEEP THE VICTIMS PHYSICALLY ACTIVE AND USE TECHNIQUES TO ENCOURAGE MEMORY.

* SINCE MOST ALZHEIMER VICTIMS ARE OTHERWISE HEALTHY AND AMBULATORY, SUPERVISION AND 24 HOUR CARE IS DIFFICULT TO PROVIDE IN A NURSING HOME WHERE MOST PATIENTS ARE RESTRICTED IN MOVEMENT.

* RESPITE FOR THE FAMILY, AND PSYCHOLOGICAL AND PHYSICAL ACTIVITIES FOR THE VICTIM UNTIL THE FINAL STAGES OF THE DISEASE, MUCH LIKE TREATMENT FOR THE DEVELOPMENTALLY DISABLED, IS RECOMMENDED OVER INSTITUTIONALIZATION.

* ADULT DAY CARE COSTS AVERAGE $35 A DAY. NURSING HOME CARE AVERAGES $140 A DAY

## QUESTIONS:

DO WE KNOW HOW MANY ALASKANS HAVE ALZHEIMER'S DISEASE?

413 senior citizens in the state of Alaska have been identified as having Alzheimer's Disease or a Related Disorder according to the Alzheimer's Disease Family Support Group.

WHY DO WE NEED A DIAGNOSTIC CENTER? DON'T WE HAVE THE TECHNOLOGY AVAILABLE PRESENTLY TO IDENTIFY ALZHEIMER'S DISEASE?

Technology is available for diagnosis. However, because of the similiarity to other disease's symptoms, there have been many instances of misdiagnosis. Many would-be Alzheimer's victims actually have another illness that may be treatable, or may just be showing normal age-related forgetfulness. Proper diagnosis is needed, in order to reassure these older Alaskans that these symptoms are benign and to properly diangosis Alzheimer's and other diseases.

WHAT KIND OF CARE IS REQUIRED FOR ALZHEIMER'S DISEASE?

Until the final stages of the disease, most victims are ambulatory. The victim and families need a variety of in-home support services in order to continue to care for their loved ones at home as long as possible. Because it is important that they be given every opportunity for physical movement and social interaction, day care facilities provide that opporunity and use techniques which help the victim retain memory as long as possible. As with the families of the developmentally disabled, day care centers also provide respite for the family.

WHAT KIND OF CARE DO WE PRESENTLY HAVE FOR ALZHEIMER VICTIMS?

There is one adult day care facility in Anchorage. 252 identified victims are living in institutions around the state. However, it is the opinion of the families that the traditional skilled nursing home does not meet the needs of the ambulatory victim. Day care services and in-home services will provide needed financial and emotional relief for those Alaskans and their families that are neither rich enough to afford thousands of dollars a month for essential care, poor enough to be eligible for state Medicaid, or lucky enough to have the Alzheimer's victim living in a Pioneer Home.

Senate HESS staff

SB 117 authorizes the Older Alaskans Commission to make grants for the operation of adult day care centers, or to provide for in-home services, to victims of Alzheimer disease, and to establish an Alzheimer's disease task force. It also authorizes the Department of Health and Social Services to operate or contract for a statewide center in Anchorage for the diagnosis of Alzheimer's disease and related disorders.

Alzheimer's disease is a progressive, degenerative erosion of the cells of the brain causing loss of memory and serious mental deterioration. It is not known what causes it and there is no known cure for it or no known way of stopping its progression. The disease affects middle aged and older people. The number of known or presumptive cases of Alzheimer's in Alaska is not known but the Alzheimer's Disease Family Support Group in Anchorage knows of 130-150 cases.

Diagnosis is important to exclude treatable forms of dementia. A diagnostic center in Anchorage is suggested because many families have had to go out of state for diagnosis and because the facilities for some of the more sophisticated diagnostic procedures such as CT scanning are available there. Competent diagnostic services are essential for proper treatment and for financial planning for the patient and his or her family.

The only service that presently exists is the Daybreak Center in Anchorage, a subsidiary of the Southcentral Counseling Center, and the Alzheimer's family support group. As the disease reaches its final state, nursing home facilities are desirable. Since most Alzheimer victims are ambulatory, 24 hour care is difficult to provide in a nursing home where most patients are bedridden and relatively easy to supervise. Further, the average annual cost for adult day care is $9,100 in comparison to the average cost of nursing home care at $44,326. The type of care required for the developmentally disabled would be more appropriate for the Alzheimer victim until the final stage of the disease.

# Alaska State Legislature

BETTYE FAHRENKAMP, Chairman
ARLISS STURGULEWSKI, Vice Chairman
JOE JOSEPHSON
PAUL FISCHER
EDNA ARMSTRONG-DE VRIES

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STATE CAPITAL
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(907) 465-3834
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## Senate
## Committee on
## Health, Education and Social Services

March 19, 1985

Senator John Sackett, Co-Chair
Senator Jan Faiks, Co-Chair
Senate Finance Committee
Pouch V
Juneau, Alaska 99811

Dear Senator Faiks and Senator Sackett:

Sponsor Substitute for SB 117 would give the Older Alaskans Commission the authority to make grants to nonprofit organizations for the operation of adult day care centers that provide supervision, custodial care and psychological and physical activities for persons afflicted with Alzheimer's disease and related disorders. It also requires the Older Alaskans Commission to establish an Alzheimer's disease task force to investigate problems related to the care and diagnosis of people with the disease. Finally, it would require the Department of Health and Social Services to operate or contract for the operation of a statewide Alzheimer diagnostic center in Anchorage.

The Senate Committee on Health, Education, and Social Services held a public hearing on SSSB 117 on March 6th. While testimony provided was supportive, there was recognition that funding for all aspects of the proposal may not be available. In an effort to retain the essential services, CSSSSB 117 (HESS) excludes the diagnostic center from the bill. However, as we feel this information may prove useful to the Senate Finance Committee, the following serves as a prioritization of the proposed services based on oral and written testimony:

(1) grants for the adult day care centers ($496,300 for FY 86)
(2) the Alzheimer's disease task force ($9,300 for FY 86)
(3) the diagnostic center ($253,800 for FY 86)

Senator John Sackett
Senator Jan Faiks
March 19, 1985
page two

Senators, thank you for taking these comments into consideration. We would be pleased to assist you in any way during your deliberations.

Sincerely,

Bettye Fahrenkamp
Senator Bettye Fahrenkamp
Chairman

Paul Fisch
Senator Paul Fischer

Senator Arliss Sturgulewski
Senator Arliss Sturgulewski
Vice Chairman

Edna DeVries
Senator Edna DeVries

Joe Josephson
Senator Joe Josephson

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May, 1988

Copies of minutes listed below were originally included in this file. The minutes are available on the STAIRS database CMPR. In order to save space copies of minutes have not been left in the files.

Mary Van Nimwegen

HESS 3-14-85 1:35pm
3-19-85 1:34pm

# Helping Families Cope With Alzheimer's Disease

J. Paul Teusink, M.D.
Susan Mahler, M.S.W., A.C.S.W.

*Many families of patients with Alzheimer's disease seem to undergo an intense five-stage reaction process and to face several specific problems when coping with the onset and progression of this debilitating illness. Mental health professionals must provide families with education about Alzheimer's disease and with supportive guidance, so that family members will successfully work through their reactions and be able to mourn their loved one, make necessary decisions for his care, and reestablish family equilibrium. The authors describe the reaction process and how mental health professionals can help during each stage, present a case example of a family coping with the disease, and discuss the specific problems that families must face and work through.*

Alzheimer's disease is the most common of a number of diseases known as dementia. Since most medical authorities and the public do not distinguish between the presenile onset and the senile onset of this primary degenerative dementia, and refer to the majority of Alzheimer patients as one group, we shall do the same in this paper.

Dr. Teusink is assistant professor of psychiatry at New York Hospital–Cornell Medical Center, Westchester Division, 21 Bloomingdale Road, White Plains, New York 10605. Ms. Mahler is a psychiatric social worker at the center.

According to several studies cited by Wells (1), Alzheimer's disease accounts for approximately 51 percent of dementia cases, vascular disease (multiinfarct dementia) for approximately 10 percent, a combination of Alzheimer's disease and vascular disease for 8 percent, normal pressure hydrocephalus for 6 percent, alcoholism for 6 percent, and multiple other causes for less than 20 percent.

More than three million Americans are affected to some degree by Alzheimer's disease, and more than one million, or 5 percent, of the elderly over age 64 are severely affected by it (2). All mental health professionals who work with elderly patients, in general hospitals or clinics, but particularly in long-term care facilities, are frequently involved with Alzheimer patients.

Dementias are unique diseases, not only because they are not curable, but because they cause a progressive impairment of memory and orientation with generalized deterioration in intellectual functioning and eventually in physical health. Roth and Myers' definition of dementia (3) stresses the progressive failure of the patient in the activities of everyday life, the failure of memory and intellect, and the disorganization of the personality. A patient's intellectual impairment may lead to emotional changes, to deterioration in self-care, and even to delusions and hallucinations.

The tremendous burden that dementia patients create for their caretakers is therefore magnified because these patients are, in a sense, intellectually dying. In addition, many of the caretakers of Alzheimer patients are members of what has been called "the sandwich generation"—middle-aged adults whose relief at having just finished caring for their own children is shattered by the new responsibility of caring for their aging parents. It is therefore no surprise that families have strong, and often varied, reactions to the development of Alzheimer's disease in family members.

Despite the variability in family reactions that we have seen in our work with Alzheimer patients at New York Hospital–Cornell Medical Center, we have found that the reactions of families coping with the disease may be similar to the reactions of families coping with death. Thus although the reactions of family members may seem abnormal at times, they may actually be normal steps in a process of coming to terms with this overwhelming illness.

In this paper, we will characterize what we have seen to be a normal series of responses to Alzheimer's disease, consisting of initial denial that there is anything wrong, followed by overinvolvement of the family with the patient in an attempt to compensate for the illness, anger when the compensation fails, guilt that is created by the anger, and, finally, resolution or acceptance of the problem. It is not difficult to note the similarity of the process we will describe to the mourning process described by Kubler-Ross (4), which also consists of five stages: denial and isolation, anger, bargaining, depression, and acceptance.

Because Alzheimer's disease requires such an enormous adjustment by families and because any one of the stages of acceptance can become abnormal or problematic

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if it is not worked through, we will provide some guidelines for working with the family members of Alzheimer patients as they go through the reaction process. We will provide a case example to illustrate how one family member went through the five stages of the process and how staff were able to help him. Finally, we will discuss some of the specific problems that the individual in the case example faced, and that many other families face, when coping with Alzheimer's disease.

## The reaction process

*Stage one—denial.* Family members will often first notice memory losses in the patient, but may explain these away by saying that they're "just senility." Although this reaction might partially be explained by the family's lack of education about aging, it may also represent a wish on the part of family members to deny what they are seeing. Some memory loss with aging is common, but when memory loss exceeds mild forgetfulness, it is a sign of abnormal cognitive functioning secondary to dementia or some other physical or metabolic disease.

Some denial may be a normal reaction to memory loss and forgetfulness, but we have seen many families who were able to carry this reaction to a remarkable extreme. At times families even fail to recognize grossly disturbed behavior and marked deterioration in memory and cognitive functioning. Their denial in this case may be aided by the common finding that recent memory fails with age while remote memory remains somewhat well preserved. Thus the family may focus on the still well-functioning remote memory and ignore the patient's inability to keep track of recent time or events.

Denial may be a way of defending against the pain of loss and the family disruption that results from illness; it may also allow the family to postpone dealing with their grief. In that case denial can make realistic assessment, decision making, and treatment planning impossible. Families that exhibit excessive denial must be helped, through education and at times through confrontation, to recognize the extent of the disability of their family member. Only then can they make realistic plans for treatment and move on to an acceptance of their loved one's illness.

Although the reactions of family members may seem abnormal at times, they may actually be normal steps in a process of coming to terms with this overwhelming illness.

*Stage two—overinvolvement.* As the deterioration of the sick family member becomes more obvious to the family, family members may become more involved with the patient in an effort to compensate for his or her losses. This may involve a realistic adjustment, such as taking over the family's financial responsibilities. When involvement with the patient's needs is carried to an exaggerated degree, however, family members may sacrifice many aspects of their personal lives, such as their social relationships, their freedom to come and go, and even their sleep. Although these families recognize that there is a problem, they may not seek help from the medical profession or other agencies; out of intense loyalty to their loved one, they feel they must deal with the illness themselves.

Certain aspects of overinvolvement seem to be culturally motivated. Our experience has shown us that in some very close Italian and Jewish families, for example, sons or daughters are raised to believe that they must care for their parents without regard to their own needs. If they do not do so, they fear they will be ridiculed by the community. Eventually, overinvolved family members may react in anger to feeling unable to shoulder the tremendous burden of caring for an Alzheimer's patient.

To deal with overinvolvement and to arrange for appropriate care, the treating professionals must be able to differentiate between a pathological reaction and a normal reaction within each family and its cultural group. The relatives can then be helped to see their overinvolvement as a hindrance rather than a help in realistically dealing with the patient's problem. One helpful approach is to confront the relatives with the specific difficulties that their overinvolvement is creating for the patient and for the rest of the family.

*Stage three—anger.* Anger among family members develops not only as a reaction to the added physical burden of caring for a demented person and to the embarassment caused by the frequent behavioral problems presented by that person; it also results from the feeling of having been abandoned by the still-living but now afunctional parent or spouse.

When anger predominates within a family, it is often projected or displaced onto the very people who are trying to help the family deal with their overwhelming sense of helplessness—the mental health professionals. If the professionals do not help the family to actively confront their anger and to realize that they are displacing their own painful feelings about the situation, family members may become so dissatisfied that they remove the patient from treatment or accuse staff of neglecting the patient and therefore causing the deterioration that naturally occurs with this illness. Countertransference issues in staff must be similarly addressed, since the normal reaction to being accused of neglect is defensiveness or anger, either of which will further alienate the relatives.

*Stage four—guilt.* As anger lessens, guilt may become more obvious. Some feelings of guilt among family members may be a normal reaction to recognizing feelings of anger or wishes that the demented patient would die. Family members may feel guilty for many other reasons, such as feeling that they delayed in bringing in the patient for evaluation and thus may have contributed to the illness, feeling that they were not attentive enough to their parent or spouse earlier in their lives, for unexpressed anger from past times and events, or for needing to make decisions objected to by the patient.

Mental health professionals must deal with the family members' guilt by discovering its cause and by taking corrective steps to alleviate it. One step can be simply to educate the family about the illness itself, thereby providing reassurance that the family has not harmed the patient. More extensive counseling may be needed to help the family make difficult but necessary decisions, some of which may be objected to by the patient.

*Stage five—acceptance.* Acceptance comes only after relatives have understood the disease process that is affecting their loved one, have found sufficient resources within themselves and the community to deal with the increased burden of care for the patient, have worked through their anger and guilt, and have recognized that their loved one is no longer the person they once knew. Acceptance is made more difficult by the disease's insidious onset and often long progressive course, as well as by the patient's relative preservation of normal physical vigor and appearance during the early stages of the illness.

## Case examples

Mrs. K, a profoundly demented 76-year-old Jewish widow, was transferred from a long-term-care facility to the Cornell Medical Center for an evaluation of agitated behavior including constant pacing, verbal abusiveness, and at times combativeness. Although Mrs. K had had symptoms of Alzheimer's disese for approximately one and a half years, she had worked in her family's garment manufacturing business until one year before her transfer to the center.

In the transfer summary, the nursing home complained of difficulty with the patient's 50-year-old son, who was running his mother's business. During the initial phase of his mother's hospitalization in our facility, Mr. K was unable to accept his mother's progressive deterioration and was insistent that certain signs, such as intact long-term memory, were proof that she was less impaired than he had been told. He believed that his mother's wandering stemmed from her boredom at not having work to do and from the lack of staff initiative in engaging her in activity.

Mr. K visited his mother nightly and brought her dress patterns to cut. When she was unable to perform the tasks he expected of her, he displaced his disappointment and anger onto the nursing staff in a hostile, abusive, and accusatory fashion, thus engendering staff defensiveness and resistance to empathizing with his pain. Mr. K was critical of all aspects of his mother's treatment and expected the hospital to find a miracle cure for her illness.

Engaging Mr. K in family therapy was difficult since he saw both the doctor and social worker (JPT and SM) as his adversaries. He was seen in weekly sessions, where he was encouraged to talk about his frustration at our inability to make his mother well. At the sa[illegible]ne, we educated him abo[illegible]zheimer's disease—its manifestations, course, and treatment.

Mr. K eventually revealed his concerns that the illness was hereditary or contagious and his feelings of helplessness in caring for his mother. He had attempted to have her live with his family before placing her in a nursing home, but he and the family were unable to control her wandering and disruption of family life.

As Mr. K began to discuss his family history and his feelings about his mother, it became clear that he had a conflict-ridden, ambivalent relationship with her. Mrs. K had worked long hours in the family's business since Mr. K was a young child and had left his care to an older sibling. Mr. K had felt neglected and abandoned, and had developed angry feelings toward his mother. Having to put his mother into a nursing home reawakened these repressed feelings of anger and abandonment, and aroused concerns that he was now abandoning her. He was still unable to see his mother as anything other than the strong, capable, working woman he had known in the past, and although he was capable of running the family business, he was experiencing self-doubts. In addition, he was furious at his sibling, who lived out of town and was not involved with his mother's care.

Mr. K's reminiscences about his mother helped him to realize the source of his angry feelings and he became less critical of the staff. His lessened anger enabled him to understand the symptoms of Alzheimer's disease, to more realistically assess his mother's illness, and to mourn her loss.

When Mrs. K was discharged from our facility, we talked with the social worker in the long-term-care facility where Mrs. K would return, so that we could apprise her of Mr. K's conflicts and encourage her to provide him with continued support.

## Specific problems in reaching acceptance

Many of Mr. K's reactions resulted from his attempts to cope with some specific problems that arise when families must face the onset of Alzheimer's disease in a family member. By recognizing the likelihood that these problems will occur and by providing supportive guidance, mental health professionals can help ease families through the reaction process.

*Role reversal.* One of the most difficult adjustments that a family member must make is to assume the patient's former family role when he or she is no longer able to function as in the past. Frequently the family member must become a parent to his or her own parent, and that adjustment can be particularly difficult when the previously

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dependent child must make decisions for the previously more dominant parent. The adjustment can be equally difficult when a previously dependent spouse assumes the role of the more dominant spouse.

It is important for staff to help the responsible relatives of Alzheimer's patients see that a reversal in roles is occurring and to help them accept the necessary change in their concept of themselves and their loved one. By helping relatives to express their fear, anger, and disappointment, and by showing them that there is someone who is sharing their burden, staff can help relatives be more accepting of the necessary reversal in roles.

*Reactivated interpersonal problems.* As seen in our case example, long-standing interpersonal problems between the patient and relative may be reawakened when the relative is forced to assume more responsibility and become more involved with the deteriorating patient. A son or daughter may even move to another part of the country to avoid dealing with their demanding, unsatisfied parent and with any problems that may have resurfaced.

When it becomes obvious that an immediate relative does not want to be involved with the patient, the helping professional must decide if he or she can change the relative's mind without causing further alienation. Frequently, counseling to help resolve the reactivated problems or even family therapy with the demented patient, although unlikely to improve the patient's condition, may be necessary to keep the alienated relative involved. In other cases, the professional must firmly insist that the relative has a responsibility to participate in the evaluation and disposition planning, although this approach is not always successful.

*Lack of understanding about the illness.* Most relatives of Alzheimer's patients know little or nothing about this common disease. It is unlike any other disease they have encountered. To make decisions about the patient's future, they may need considerable education about their loved one's symptoms and the progression of the illness. The doctor may need to meet with the relatives personally to reassure them that the patient does not have other illnesses that could explain his symptoms. They must be educated regarding what resources are available for the care of the patient. They may need to be encouraged to seek legal advice or to take legal responsibility for the patient should they have to make decisions that the patient opposes.

Unresolved interpersonal problems between a patient and a relative may be reactivated when the relative is forced to become more involved with the deteriorating patient.

*Fears about heredity.* Many family members fear that heredity may be involved in the dementia of their parent and may either directly or indirectly inquire about whether they too will be afflicted by such an illness. They may talk about their own failing memory and need reassurance and education about normal memory loss with aging and dementia. Education can therefore play an important role in working with families' reactions to this disease. For example, it may be reassuring for a family member to know that although there is a fourfold increase in dementia among first-degree relatives of Alzheimer's patients, Alzheimer's disease is still a relatively uncommon disorder. Thus a relative's chances of developing Alzheimer's disease may be increased from only 1 percent in the general population to 3.8 percent (5).

*Shopping for cures.* Relatives of patients with dementia are understandably gullible about treatment promises made by unscrupulous persons or even well-meaning physicians. These persons may suggest, among other treatments, nutritional supplements, medications such as vitamins and vasodilators, and physical therapy and physical stimulation programs. Although some of these treatments may be helpful in preventing deterioration, they will also not cure dementia.

Again, families must be educated about Alzheimer's disease so that they will not develop unrealistic hopes that some new treatment will cure the dementia. Fad therapies are usually more harmful than beneficial. Improved therapies may be found in the future, but they will be the result of careful and laborious research.

## Discussion

Unlike many other illnesses, Alzheimer's disease is a progressive illness. Families of Alzheimer patients must therefore endure an ongoing grief process, and they may need ongoing intervention and support to cope with the illness. Many authors (6–9) have shown that education and support can be effectively provided through relatives' discussion and support groups.

The stages of the reaction process discussed in this paper need to be recognized and addressed by mental health professionals. Although every family will cope with Alzheimer's disease in its own way, there are several common experiences and problems that most families must deal with and work through so that they can mourn their loved one, make necessary decisions for his or her care, and reestablish family equilibrium.

Mental health professionals should make the assessment of family reactions to Alzheimer's disease an important part of any thorough case evaluation (10), and family members must be helped to recognize and deal with their reactions. Until they do so, until they have been educated about the disease and know what to expect, and until they are reassured that the mental health professionals under-

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# Alzheimer's Disease
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## A Family Information Handbook

# Alzheimer's Disease
## A Family Information Handbook

Published by authority of the
Minister of National Health and Welfare
Mental Health Division
Health Services Directorate
Health Services and Promotion Branch
in cooperation with
the Alzheimer Society of Canada
(Société Alzheimer du Canada)

Également disponible en français
sous le titre
La maladie d'Alzheimer:
renseignements à l'intention des familles

March, 1984

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# Introduction

Alzheimer's disease (pronounced altz'hi-merz) is a little-known but remarkably common disorder that affects the cells of the brain. It is a disease that produces intellectual impairment in adults. While experts formerly believed that the disease occurred mainly in persons under age 65, this disorder is now recognized as the most common cause of severe intellectual impairment in older people as well.

The changes most commonly associated with Alzheimer's disease (A.D.) occur in the proteins of the nerve cells in the cerebral cortex — the outer layer of the brain — leading to an accumulation of abnormal fibers. Under the ordinary microscope these changes appear as a tangle of filaments. These "neurofibrillary tangles" were first described in 1906 by Alois Alzheimer, a German neurologist.

New and highly sophisticated instruments and techniques — such as the electron microscope, which can magnify cells more than a hundred thousand times — have revealed other changes in the brain that are characteristic of the disease. Scattered throughout the cortex, groups of nerve cell endings degenerate and disrupt the passage of electrochemical signals between the cells. These areas of degeneration have a special appearance under the microscope and are called plaques. The larger the number of plaques and tangles, the greater the disturbance seems to be in intellectual function and memory.

## Some Statistics

The fact that many people have never heard of Alzheimer's disease does not mean that it is a rare illness. Many individuals who have the disease never receive a precise diagnosis.* The best current estimates indicate that more than three million North Americans may suffer from it. In Canada, it has been estimated that at least 10,000 deaths a year are attributable to this disease, and as many as 100,000 to 300,000 may be affected to a varying degree. After cancer, heart disease and stroke, it is thought to be the fourth or fifth most common cause of death in Canada; however, this is difficult to verify because A.D. is not always listed as an official cause of death on death certificates, which all too often record only the events immediately prior to death.

## Causes

Alzheimer's disease is an inexorable, degenerative, neurological disorder for which there is currently no known method of prevention or cure. Why plaques and neuro-fibrillary tangles develop in the cortex of the brain has yet to be determined.

It seems clear that the illness is not caused by hardening of the arteries. Nor is there any evidence that it is contagious. Although emotional upsets and stress may temporarily affect the person's mood and behaviour, they do not *cause* the disease but are more likely its effect.

The disease occurs in two to three per cent of the general population over 60 years of age, and in more than 20 per cent of those over 80. The probability of its occurrence within the same family is about one in six, if one's parents have been victims, and about one in twelve if brothers or sisters have had the disease. This represents a slight hereditary disposition in some families, possibly combined with undetermined environmental factors.

Scientists are applying the newest knowledge and research techniques to the study of human brain tissue removed at autopsy. Although there are now a number of promising clues, determination of the actual cause of A.D. must await much more extensive scientific investigation.

## What Are the Symptoms?

At first, the individual experiences only minor and almost imperceptible symptoms that are often attributed to emotional upsets or other physical illnesses. Gradually, however, the person becomes more forgetful, particularly about recent events. The individual may neglect to turn off the oven, may misplace things, may continually recheck to see if a task was done, may take longer to complete a chore that was previously routine, or may repeat already answered questions. As the disease progresses, memory loss worsens and other manifestations such as confusion, irritability, restlessness, and agitation are likely to appear, as well as changes in personality, mood, and behaviour. Judgement, concentration, orientation, and speech may also be affected. Eventually, the disease renders its victims totally incapable of caring for themselves.

There are many different patterns in the type, severity, and sequence of changes in mental and neurological functioning that result from A.D. The symptoms are progressive, but there is great variation in the rate of change from person to person. In a few cases, there may be a rapid decline; but more commonly, many months — even years — may pass with little change. Limitations in physical activity during the later stages may cause the person to have less resistance to pneumonia and other physical illnesses that may shorten remaining life expectancy by as much as one-half.

Although the person with A.D. may deny or be unaware of the full extent of his or her limitations — especially later in the course of the illness — the seemingly unexplainable changes in essential functions are a source of deep frustration, both for those afflicted and for the caregivers.

## Early Indications

In the early stages, the disease is very difficult to detect. The changes are subtle. Patients may struggle to cover up their mental difficulties through hard work and altered personal patterns. Moreover, many of the early signs can easily be confused with depression, drug or alcohol induced dementia, or other acute and potentially reversible mental impairments. Early symptoms of A.D. involve an inability to learn new things, a memory loss for recent events, poor judgement, difficulty in communication and coping with decisions or new situations, a suspicious attitude, and possible outbursts of temper resulting from frustration, any of which may not alert family members to suspect a possible illness. And since memory for much earlier events is usually well preserved, the family may attribute forgetfulness of recent events to fatigue, depression or other causes.

Eventually it becomes apparent that there really is a problem. It is likely to be the spouse or other close family member who will realize it. But

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* Strictly speaking, final confirmation of the diagnosis of Alzheimer's disease requires a post-mortem examination of the brain.

it could also be someone more removed from the situation such as an employer, neighbour, friend or doctor. Such a person would not have witnessed the minor day-by-day changes, and would more readily recognize the effects of months of deterioration.

Many people are reluctant to consult a doctor, especially when the changes are behavioural and there are no obvious physical problems. Therefore, it may take considerable urging by others before they will consider this as a possible medical problem.

## How Is Diagnosis Made?

Before a diagnosis of Alzheimer's disease is made, other illnesses which may cause the same symptoms must be excluded. The condition must be differentiated from the mild and occasional forgetfulness that sometimes occurs during normal aging. Depression, which is fairly common in elderly individuals facing a variety of stressful situations, may also present symptoms.

More than one-half of elderly men and women with severe intellectual impairment are victims of A.D. About another fourth of the overall group suffer from vascular disorders, especially multiple strokes. The remainder have a variety of other conditions; for example, brain tumors, abnormal thyroid function, infections, pernicious anemia, adverse drug reactions, and abnormalities in the spinal fluid system (a type of hydrocephalus). The specific diagnosis is very important since many of these other causes of mental malfunctioning can be readily treated.

Each person suspected of having A.D. should have thorough physical, neurological, and psychiatric or psychogeriatric evaluations. Comprehensive blood studies, including tests for detecting metabolic disorders, must be carried out as part of the evaluation. The electroencephalogram may show a general slowing of the brain waves and may help confirm the presence of A.D. Computerized tomography (CT scan), electroencephalography (EEG), and occasionally special studies of the spinal fluid system are required for more accurate diagnosis.

After other diseases have been ruled out, in particular the dementia associated with previous strokes (multi-infarct dementia), a diagnosis of A.D. can usually be made on the basis of medical history, mental status, and the course of the illness. Periodic neurological examinations and psychological testing are very useful in confirming the diagnosis and evaluating the stage of the disease.

## Misconceptions

The average person knows very little about dementia (so-called "senility"), and the myths which have developed about such disorders have prevented an accurate education of Canadians.

*"Senility is just part of growing old."*

If this were true, all old people would suffer severe memory loss, physical immobility and considerable intellectual impairment. In fact, only one in 10 over age 60 suffer from states of confusion; of these cases, about 70% are probably A.D. Secondly, this disease is not confined solely to the elderly; people as young as 40 have been diagnosed.

***"The person doesn't suffer as a result of his/her condition because he/she doesn't know that anything is wrong."***

There are indications that people with this disease may realize that something is wrong, well before anyone else becomes aware of a persistent change.

***"The disease is contagious."***

There is no evidence for this statement.

***"It is the result of excessive strain or emotional stress."***

Although emotional upsets and stress may temporarily affect the person's mood and behaviour, they are not the cause of the illness.

***"Declining mental ability is due to laziness — people not using their brains."***

While withdrawal from mentally stimulating activity could contribute to apparent intellectual decline, the loss of memory and changes in personality that A.D. patients show are due to physical changes in their brains; it is an actual disease of the brain.

## Stages of Deterioration

Alzheimer's is a disease in which functions of the brain gradually and progressively deteriorate over a period of years — sometimes even months.

The *first stage* is manifested by slow, subtle changes in the person's ability to learn, problems in communication, memory loss for recent events, impaired judgement, difficulty in making decisions, coping with new situations, suspiciousness, and possible outbursts of temper resulting from frustration.

For example:

- *Mrs. V. of Victoria, B.C. relates that the first thing she noticed in her 55-year-old husband* *was "poor memory, slow movements and occasional weak legs."*

- *Mr. M. of Montreal, Que., when asked what symptoms or signs were first noticed, answered that his 61-year-old wife "could no longer add up a short and simple column of figures."*
- *Mrs. P. of P.E.I., reported "memory loss" as the first symptom in her 57-year-old husband. "The family doctor thought it was a case of early senility," she adds.*
- *Mr. L. of Toronto, Ont., said he and his 50-year-old wife just thought she had a hearing problem because she didn't seem to understand what was being said.*

In the *second stage*, while memory functions continue to deteriorate, other aspects of intellectual abilities also decline, including language and the ability to communicate and to conduct daily activities without supervision or guidance.

The person may respond to people or objects in an aggressive way, due to misperceptions of what is happening. For example, someone approaching quickly to help with dressing may be seen as a threat, particularly if the approach is from behind or from one side (at the edge of the person's field of vision).

Increased disorientation to time and place occurs, and the person may be unable to recognize him/herself in the mirror. There may be inability to write or understand and use language. Often there is a struggle to maintain bodily functions, and some will be retained longer than others. The person may become restless, especially at night. There is a loss of dexterity, which may interfere with tasks such as dressing and other self-care routines. Body movements may begin to slow down and the person physically resists being helped. Some loss of bowel and urine control (incontinence) may begin.

For example:

- *Mrs. G. of Gananoque, Ont., said that her father now "forgets where he has placed articles but he can remember tunes and lyrics to hymns. (He) forgets names of grandchildren, has loss of balance . . . (and) has difficulty in walking."*
- *Mrs. S. of B.C., said that her 53-year-old husband showed an "inability to concentrate and to work on figures." She added that "he seems a different person but is not too hard to handle." Later, however, she reported that he had visual and speech impairment, as well as loss of bladder and bowel control.*
- *Mrs. L. of Lachine, Que., said that her brother now shows so much impairment that "comprehension (is) too poor to determine if there is still any memory." She added that he is "fearful, suspicious, has episodes of depression and weeping — and sometimes of giggling. He needs to be guided for he has just fallen and broken his hip."*

In the *final stage*, 24-hour nursing care is usually necessary. In addition, hospitalization may be required to treat the increasing occurrence of physical disabilities and illness. The ability to speak or communicate disappears, along with increased immobility. Loss of bowel and urine control greatly increases. Twitches or jerking may develop, and seizures may occur. There may be an almost complete absence of any spontaneous movement or reaction to people or other stimuli. In some cases, a general, gradual stiffening of muscles can leave the person increasingly less mobile. Reflexes develop, such as one that causes sucking of anything put in the mouth. At this stage the person is prone to pneumonia, and to bed sores because of immobility.

As physical health deteriorates, there is increasing susceptibility to other conditions. Records indicate that between two and 19 years after the onset of the disease, death will occur. However, because the diagnosis often occurs late in the course of the disease, the length of survival after a doctor has made the diagnosis averages about five to eight years — a significant reduction from normal life expectancy. There is usually a secondary immediate cause of death which appears on the death certificate, such as pneumonia or heart disease. Two Alzheimer Society members, each with a spouse in a long-term care hospital, made these observations:

- *Mr. G. of Guelph, Ont., stated that his 69-year-old wife is now showing a "general slowing of movements and recently has become bedridden due to a complete loss of mobility."*
- *Mrs. G. of Edmonton, Alta., reported that she had been nursing and caring for her 65-year-old husband at home for about two years "but finally I could no longer stand the physical and emotional strain and was able to have him placed in a nursing home — three months before he died!"*

These stages illustrate a general trend of the disease. Every patient gradually deteriorates and the lost functions and abilities will never be restored, but the speed of the deterioration, and the symptoms which are manifest, will vary with each person.

# Caring for Someone with Alzheimer's

This section provides a number of practical suggestions for coping with the problems and disabilities of the person with Alzheimer's. Some of these may or may not be relevant to your situation.

## Overview

As the disease progresses, disabilities increase. Somehow, the caregivers must find that fine line where they are helping the person perform to the best of his/her ability, while recognizing that there are some things the afflicted person is just not capable of doing.

Caring effectively for an increasingly dependent person, yet still someone whose pride can be easily injured, is a tremendous challenge. The frustration of trying to help someone who at times seems bent on defeating every effort, can drive the caregiver "up the wall."

A general helping rule is to provide a consistent routine for the person. A regular rhythm of familiar household events, and of people who come and go, provides a reassuring structure on which the person can depend.

## Coping with Emotional and Behavioural Problems

*Patient's Awareness of Inabilities.* A person with A.D. is often aware of lost abilities. This can result in frustration, tears, anger, embarrassment or humiliation — even in depression. When this occurs, remember that this is caused by the neurological disease and the person needs quiet reassurance and support, plus the message that he/she is still loved.

Some families have tried explaining the disease to the person. While this can sometimes help the family to feel better, and to know that they are doing the best they can, it is nevertheless true that persons with A.D. vary greatly in their ability to comprehend these explanations.

*Memory Loss.* The loss of short-term memory, a common early symptom of the disease, will cause those who suffer from it to forget things they have done just a few minutes ago. They may forget answers to their questions, and so ask them over and over again. They may forget names, addresses and other bits of information we use to orient ourselves. This can be as frustrating or humiliating to them as it is irritating for those taking care of them.

People suffering from a loss of memory tend to perform better with a consistent daily routine. They will need frequent and patient reminders that may be in the form of spoken words, calendars, clocks, diagrams, lists, schedules, and so on. It may be that simply laying out clothes in the morning will be enough to get them to dress themselves. It is a test of creativity and patience to guide someone with memory loss through the many daily routines we usually take for granted. Repeated instructions will be necessary. If the response is delayed, try it again five or ten minutes later.

It often requires more time and effort to remind them to do the task themselves than it does to do it for them. The extra effort, however, allows them to function to the best of their ability and feel better about themselves, particularly in the early stages. This is as important for their health as it is for the health of the caregiver. Sometimes they will try to hide their memory loss, or compensate for it in some other way. In these situations, for example, be sure that his or her teeth really *are* brushed, that lunch is *really* eaten, or your letter *really* mailed.

*Poor Judgement.* Mental disabilities involve more than memory loss. Poor judgement and/or erratic thought process also occur. Some actions and choices based on poor judgement may lead to unforeseen, even dangerous situations. It is important to watch for these behaviour changes, which tend to be subtle and are often disguised. You may notice a mistake playing cards, an unnecessary purchase from a salesman, or some unreasonable decision. The person may wander out alone. These things may be a response to a loss of orientation, or a searching for some type of satisfaction.

*Wandering.* No one knows precisely what causes a particular person to wander. It is very difficult to control and can be dangerous (e.g., there is the risk of getting mixed up in traffic, or getting lost). Certainly it is a constant source of worry and frustration to families and to institutions.

Generally, the most effective solution to wandering is to install a lock that the patient can't operate. Any locksmith can help with this. But there is no need to panic if the person does wander away; just have an action plan ready for finding him/her. For example, let two or three of your family neighbours know that he/she is a wanderer and ask if perhaps they would be willing to look after the person in their home if they see him/her wandering and you are out for a while.

If the person is found wandering, it is important not to startle or frighten him/her by a sudden approach. Also, you may want to sew an address label — not too conspicuously (perhaps on the back of the collar of the wanderer where it can't easily be removed) — or have him/her wear an identification bracelet which is hard to take off. By taking the person on frequent walks, or arranging for lots of exercise, the wandering may be reduced.

*Repetitious Behaviour.* Being asked a question repeatedly by someone who does not understand or remember the answer can try anyone's patience. A short, simple reply is often sufficient. Some A.D. persons may pace continuously. There seems to be no clear explanation for this. Whatever the cause, there is no real solution to repetitious behaviour. In some cases, comfort and support may be substituted for answers to questions. In other cases, repeated questions or other repetitious behaviour may be ignored in the hope that it will not persist. It is this kind of thing that is so trying and makes it necessary for caregivers to seek periods of respite.

*Sleep and Night-time Problems.* Manifestations of A.D. are often prominent at night. Some wander only at this time, others may not be able to sleep, or may be fearful at night, while still others may be prone to hearing or seeing things which aren't really there. Obviously, disruptions of this kind in the home can deprive caregivers of much-needed rest. But the A.D. person who has been physically active during the day is more likely to sleep at night. (See "Recreation," p. 12. Activities and exercises should be matched to individual abilities in various stages of the illness.) Neuroleptic medication, under the advice of a doctor, may have a role in helping to relieve confusion at night or to modify sleep patterns.

Remember that the A.D. person who is just waking up is subject to the same kinds of confusion and disorientation other people feel at that time — and even more so. Always try not to be too loud, or move too quickly, when approaching the A.D. person, and approach from the front so that he/she may feel less threatened. Also, identify yourself, explaining the time of day and what is expected of the person.

Night lights in the bedroom and bathroom are useful too. In some cases, shades which hide a street light can make the person sense it is sleep time.

Sometimes a simple reminder that it is still nighttime will keep the person from trying to get up. At other times, a change of location may help. If you go into the bedroom at night, remember to address the person by name, identify yourself, and mention the time of night it is. This helps the person to more quickly orient him/herself. If all this fails, consult a health professional for other possible suggestions.

*Fear.* This disease often creates considerable fear in A.D. persons. When individuals are unable to learn or recall their surroundings, it must seem very strange and threatening to them if the environment is cluttered or continually changing. Objects and events become misconstrued, since they are perceived through a sort of "damaged brain filter." Anxiety makes for tension and irritability, so that some responses are exaggerated.

Gentle reassurance, preferably by a touch or hug, or in words, or simply by being present, can sometimes help. Simplified and consistent surroundings also help to keep the person secure and calm. Knowing that these fears and behaviours are a result of the disease often makes it easier for families to cope with them.

*Aggressive Behaviour.* A.D. persons can have quick changes of mind and angry outbursts. Some family members and professionals fail to recognize that these are due to the person's damaged grasp on reality. Because they misperceive what is happening, they react to misperceived threats, dangers or insults, or they explode with frustration that has been simmering beneath the surface. It is seen as rudeness or unacceptable behaviour, and is particularly disturbing to someone who is devoting so much attention to the person's care.

This emotional instability, when combined with some of the physical problems discussed later (e.g., a person who jerks away when guided or assisted) makes the life of the caregiver extremely difficult. Arguments can result, with frustration and anger building up, often for both parties.

Whenever possible, these outbursts should be dealt with calmly. You simply cannot use logic with someone who usually is quite unable to grasp an explanation. Raising your voice will only amplify the reaction. Therefore, trying to remain calm helps the A.D. person maintain composure as well.

But it is just not possible always to remain in control. Whey you feel this way, try calling a friend or another Alzheimer caregiver. This often helps to restore calm and get back in control. But remember, no caring person need feel inadequate or guilty for losing control or feeling angry under such circumstances. When other approaches fail, psychotropic medication under the advice of a doctor may play a part in relieving anxiety and fear that can lead to irritability and apparent aggression. It may also, to some degree affect the thought disorder that contributes to the development of anxiety.

*Communication.* As has already been noted, the capacity to use and understand language deteriorates slowly and seriously, making other forms of communication gradually more important. Non-verbal means, such as facial expression, body position, or tone of voice, should help to convey ideas. Similarly, as speech may change to a stream of words, interspersed with only a few appropriate ones, the person will convey something through stance, tone, or facial expression. Yet feelings still remain, and the person may express his/her need for reassurance or complaints of pain without words. Remember always to look for the meaning behind behaviour that is puzzling.

When talking to the person, listen and observe the reaction carefully; from his/her words and actions you can sense the possible degree of understanding. In this way you can continue to communicate at the appropriate level of understanding and not make false assumptions. This prevents "talking down" and helps maintain dignity and respect for the individual.

Use short, simple sentences, spoken slowly and clearly. Present one statement or question at a time, allowing plenty of time for response. If necessary, repeat your question exactly as you did before. Sometimes questions requiring an answer may confuse the person. Even the answer "yes" or "no" may be difficult, or may not really convey his/her wishes. An affirmative statement such as "Here is your fruit" may be preferable to "Would you like some fruit?" Where possible, "either-or" questions should be avoided. Suggestions should be made very clearly.

Whenever possible, the speaker should be in front of the person to maintain eye contact. Calling him/her by name should direct attention to your verbal exchange. Whenever practical, reinforce the spoken message using real objects and demonstration.

If there is hearing loss, clarity of speech, facing the person, and lowering the pitch of the voice are more important than speaking louder.

Follow through on promises, or make explanations if for some reason a promise cannot be kept. Continue to bear in mind that the person's feelings are still sensitive and can be hurt just like anyone else's!

You should also share with other caregivers any and all effective ways of communicating. This will make things easier for all concerned.

*Social Situations.* While the social life of family members is dealt with elsewhere, that of A.D. persons deserves special attention. Some may retain many of their social skills for years, while others deteriorate in their ability to relate to others and to participate in social activities.

Careful thought should be given to the type of social situation in which the A.D. person can participate. Sometimes the disabilities make a formal situation uncomfortable for everyone. In other cases, a formal situation may remind the person to behave particularly well. Response is usually best in the kind of social situation in which the person was formerly comfortable — e.g., family or church groups, where repetition of earlier social patterns may be entered into quite naturally.

The family will also have to judge how much socializing the person wants, and with whom. But the lack of responsiveness to visiting, etc., does not necessarily imply a lack of interest. Try to watch for overall behaviour during a visit. Staff in hospitals and nursing homes have reported that even profoundly brain-damaged patients seem somewhat better on days they receive visitors.

## Hygiene and Personal Care

A.D. persons gradually lose their ability to care for themselves. In encouraging them, families and professionals who care for patients must strike a balance between what they can and what they cannot do. In some cases, simple reminders may suffice; in others, tasks may need to be simplified and broken down into small steps so that the person can still manage them by him/herself. A medical social worker, occupational therapist, or public health nurse should be able to help with this. (See the "Who Can Help?" section on how to contact them, p. 15).

Here is a list of some things that might make hygiene and personal care easier:

- Install special hand grips for the toilet and tub so the person can lift him/herself more easily and safely.
- Watch the person in the tub, and be sure the tub has a rubber mat or non-slip strips. Use just a few inches of water and check the temperature to avoid burns. Colour indicator thermometers are available.
- Check the person frequently for red areas that can be the result of prolonged sitting or lying.
- Use clothes that can be put on and taken off easily. Avoid laces and buttons. If the patient

can't operate them, velcro strips can be used to replace buttons and zippers.

- If he can't tie a tie, use a clip-on; if that doesn't work, use a turtleneck or open-neck shirt.
- Help the person select clothing to avoid unnecessary confusion and inappropriate choices.
- Make sure that teeth are brushed. When the person is no longer able to do this, it needs to be done for him/her, gently and reassuringly.
- If the person has toilet accidents, see if there is a pattern to such incidents, then try to establish a regular toilet schedule by giving reminders. For example, someone may have "an accident" regularly an hour after meals. By giving toilet reminders you will be replacing the signals that the body no longer sends to him/her. Special pads in the underwear can be a reassurance for some persons, as well as a big help to caregivers.
- Try to keep such things as hairbrushes, toothbrushes, electric razors and so on, in a regular, visible place, so that the person will see them and be reminded to use them. Regular gooming is particularly important to maintain and enhance self-esteem and overall health.

## Diet and Eating Tips

A well-balanced diet is essential for good health. The person may simply forget to eat, lose the ability to use a knife and fork, and become incapable of making proper choices of what to eat.

A doctor, nutritionist, or a public health nurse can help you in planning a balanced diet, or you may follow Canada's Food Guide*. It is very important to consult the doctor if you notice any major change in appetite or eating patterns, for this may indicate a medical problem.

If the person is responsible for feeding him/herself, don't just assume he/she is eating properly. See that the right foods are available and verify that they have been eaten. Programs such as "Meals on Wheels" should be considered where shopping or preparation is a problem.

The person may forget he/she has eaten and want to eat all over again. Also try to limit between-meal eating to such things as melba toast and fresh vegetables, or plan a number of very small meals per day.

As the disease progresses, a loss of table manners is normal. This will influence planning meals and setting the table. Notice which foods the person has trouble with. If he/she is using a knife and fork poorly, slices of meat should be cut up. If the person is not chewing properly, avoid foods that are easily choked on, and be sure that all servings are bite-size. All of this is important because of the effect the disease has on swallowing. If eating is mostly with the fingers, try to prepare foods that are easy and convenient to grasp.

The table setting should be as simple as possible. Unnecessary cutlery, flatware and condiments should be removed to avoid distraction. Use plastic placemats and spill-proof cups. Consistency may help at meals. Setting the table the same way, sitting the person at the same place, and eating at the same time each day, may help him/her to act more appropriately.

Eating habits should determine the kind of clothes to be worn at mealtime. Some people may want to use a smock or apron; others prefer easy-to-wash clothes. You can explain to guests or hosts that the person has difficulty eating because of the illness. With the proper selection of food (non-messy) and cutlery, the person may be able to join the others at mealtime. A restaurant is strange for the person but he/she might surprise you by falling into earlier patterns of eating and enjoy the change, especially in the early stage of the disease.

Those who eat regularly with an A.D. person should be familiar with basic first-aid in the event of choking. Your local Red Cross, St. John Ambulance or Public Health Department can help you with this.

The temperatures of all foods, drinks and serving dishes should be watched so that the person doesn't burn him/herself. Ensuring that cups are not filled too full, and plates are not crowded, helps to prevent spilling.

## Safety Suggestions

The impairment of judgement and memory creates many safety hazards. One of the hardest tasks facing family members is to help the person avoid potentially hazardous activities.

*Driving*. As soon as indications of deteriorating driving ability appear, the person must no longer be permitted to drive. The driver who forgets where he or she is going, or how to get there, is a hazard both to him/herself and others.

*Smoking*. Ideally, A.D. persons should be helped to give up smoking, if not for health reasons, then because of the fire hazard. They may forget they are smoking, and a smouldering cigarette could start a fire. If they are unable to give up smoking, then stay with them while they smoke.

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* Available without charge, in English or French, by writing to: Health Promotion Branch, Department of Health and Welfare, Ottawa, Ont. K1A 1B4.

*Stairs*. To keep a family member from going up or down the stairs, place a wrought iron or wooden expanding gate at the top or bottom of the stairs. A fairly sturdy gate, at least waist-high, provides the best protection.

*Door Knobs*. Safety knob can be very helpful in keeping your doors and cupboards closed.

*Mirrors*. These can frighten the person, so you may want to turn them around, cover them up, or remove them entirely.

*Breakable Objects*. Move these out of the way because they can injure the person if broken.

*Dead Bolts*. If you need to use a dead bolt lock without a turn latch, be sure to keep a key close by in case of emergency.

*Cooking*. You may want to consult your hydro or gas company about making your stove inoperative when no one else is around. It is too easy to turn on an unlit burner, or to put flammable materials in the oven, or to create a number of other fire hazards.

*Hot Water*. Adjust your water heater so that the temperature is low enough to prevent scalding.

*Small Appliances*. Essential electrical appliances should be used under supervision, and other small but potentially dangerous ones should be safely hidden away.

*Poisons and Medications*. The person may have poor judgement in handling these. Hide or lock them up, or get hard-to-operate lids.

*Safety Devices*. An occupational therapist or a public health nurse should be able to provide you with information on a whole range of clever safety devices and procedures. These include proper assists and handrails for balance in the bathroom and elsewhere, difficult-to-use latches and numerous other items.

## Recreation

Recreational activities should be related to past interests and abilities which remain intact. Often, music and dancing are pleasurable, as are simple woodwork, knitting, crochet work, painting, food preparation and other simple household tasks. Again, speak to an occupational or recreational therapist for additional suggestions.

When particular leisure activities seem to frustrate the person, simplify them or try different ones. Since memory for much earlier events remains, reviewing and talking about them may be pleasurable. Photographs and treasured objects may stimulate enjoyable discussion and help with a "life review" of significant past events. Physical activity will keep the person in better health, possibly reduce wandering, and help him/her sleep better at night. Adequate exercise and activity can often reduce the need for medication. For those who are still mobile, a daily walk may be the easiest and most enjoyable form of exercise. For others, including even those who are bedridden, information about different exercises is available from physiotherapists or public health nurses.

## Physical Problems

***Problems of Balance and Coordination.*** Patients with this disease often suffer from loss of balance and coordination. Speak to the doctor about this. You may want to request a referral to a physiotherapist who can teach you how to lift the person without hurting yourself, and also tell you about handrails and other aids.

Beware of scatter rugs, carpets with curled up ends, sharp corners on furniture, steep stairs, loose handrails, icy walks and slippery floors.

*Seizures*. Some A.D. persons tend to have seizures. But remember, seizures are much harder on the observer than the victim.

Ease the person to the floor and loosen his/her clothing. Move any sharp or hot objects out of the way to prevent injury. If necessary, wipe away excess saliva. To prevent possible choking on the tongue, the person should be turned on his/her side. This can also be accomplished by simply turning the head to one side. Do *not* insert anything in the mouth, or interfere with the seizure in any way. When the seizure is over, call the doctor, since many types of seizures can be controlled by medication.

# Impact on the Family

When someone suffers from Alzheimer's, it has an impact on the entire family.

Because it is usually one of the older members who is affected, and because the need for care and attention increases, all family members may have to take on new responsibilities and make changes in their lifestyle, which can be extremely stressful, both physically and emotionally, depending on the degree of involvement and the level of disability.

Each family will find its own way of coping. In some cases, the spouse will bear primary responsibility for the care of the person, while in others it will likely be the children. Eventually most, but not all, A.D. persons are institutionalized because of their chronic nursing care needs.

## Coping with an Invisible Disease

One of the most difficult aspects for family members is that there are often no physical signs of anything being wrong, at least in the first two stages.* This makes it hard for family members to recognize or accept that the person is ill, rather than moody, depressed or "being difficult." It also means that outside sympathy and support, which friends and relatives normally provide for the spouse or child of the ill person, may not be forthcoming. However, after increasing their understanding of the disease, and realizing that the various changes in behaviour and the progressive loss of judgement and memory are characteristic of the illness, the family may also find it helpful to share this understanding with friends and relatives so that they, too, can realize the real cause of the disabilities and erratic behaviours.

## Anger, Guilt and Other Feelings

Coping with someone who has Alzheimer's is an intensely emotional experience. Family members can resent the fact that it requires so much of their time; or resent other family members who don't seem to be pulling their weight. They may even feel guilty because they think they are not doing enough, or because they get impatient with the person. Discussing these feelings with family and/or friends, or seeking professional counselling, can often help. But it should be remembered that caregivers must somehow find ways to attend to their own physical and emotional needs.

## Responsibility for Care

Caring for an A.D. person becomes a 24-hour-a-day job that is more demanding as time goes by. Some have even called it a 36-hour day! Each person must assess just how much she or he can do, and at what point to seek assistance — for caregivers must not lose sight of their own needs and push too far, overextending their energy and emotional reserves.

Assistance may take many forms: e.g., a relative helping out once in a while to give the caregiver a break; a friend doing some cooking or laundry; seeking professional or volunteer help in the home; arranging some sort of special day for caregivers to be on their own; or seeking residential relief or respite care. Additional information on these and other available services is discussed in the chapter "Who Can Help?" (p. 15).

Chronic illness tends to isolate family members from other people just when they need them most. Visiting and being with others is greatly reduced because of the time taken up with caring for a spouse or parent; or the family may be embarrassed to have others in the house; or the person may not wish to go out. Moreover, friends might not understand or know how to empathize with the family — at least until they have been helped to understand the nature of the illness. Yet, to emphasize again, it is essential for family members to seek assistance and support.

## Role Changes in the Family

As pointed out earlier, this disease usually strikes older family members. Persons with A.D. and their spouses will require increasing help from their children, reversing the life-long pattern of parents helping their children. As well, a husband who had not previously been involved in helping to get the meals may find himself entirely responsible for this; or wives who had not previously managed the family finances may have to learn to pay the bills, balance bank accounts, and so on. This role reversal can be very stressful for both partners — even strongly resented by one or the other. Some, of course, will find ways of adjusting to it through family meetings, support from friends, etc.; others may need professional counselling. But however these changes are struggled with, they must be faced.

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* See "Stages of Deterioration," p. 6.

## Sex and Alzheimer's

One of the issues for some A.D. caregivers, but certainly not all, is a diminishing expression of sexual interest by the affected partner. This may occur earlier, later or not at all, depending on the onset of the disease. The caregiving partner may easily feel that he/she has become less stimulating or undesirable or unattractive. Why does the A.D. person no longer look at the caregiver with pleasure, or touch or embrace? Has he or she lost interest in the partner — or perhaps in sex? They used to respond with so much joy and excitement to touching, stroking and other sexual activities. But now there is little or no response. Is their sexual loving to end?

At some stage, and for this kind of loving, unfortunately the answer is "yes," at least in many cases. Nevertheless, although there may be little or no response, you may be sure that this is *not* a message to keep away. The need for warmth, tenderness and closeness remains. Just as with all of us, your partner continues to need caring and intimacy.

In other cases, where a somewhat greater erotic response is experienced, use your intuitive feelings drawn from your earlier lifetime style of response. For example, where the woman has usually tended to await her partner's initiative, her role may have to be reversed. She will need to take the lead — whether or not her guiding leads to intercourse — which is certainly not "the be all and end all" of an intimate relationship. Loving is loving, and can take many forms.

Two other aspects. *First*, sometimes an A.D. partner may mistake a friend or housekeeper for his/her spouse, leading to inappropriate sexual behaviour. Others may mistake a lingering handshake, or friendly embrace, as an erotic gesture. To avoid embarrassment, explain A.D. to the person and how this kind of thing can happen.

*Second*: For some afflicted persons, whether male or female, their sex drive increases. But, because of their neurological impairment, they are unable to perform adequately. They may clumsily reach out or awkwardly try to fondle or kiss. Not achieving satisfaction, their frustration and anger increases. As their partner understandably resists, they may respond with angry and unfair accusations, perhaps concerning an alleged mistress or boyfriend. In other cases, the A.D. partner may try to have sex two or three times a day. Of course, all of this is very difficult to handle without becoming quite upset. Try to comfort and give reassurance that you care, which may help your partner relax and sleep.

## Changes in the Present and Future

When one partner has the disease, the relationship is drastically altered for the other. In many respects, the one with the illness becomes lost to his or her partner, lost as a friend, a confidant, a companion and lover. This adds immeasurable grief to the existing complexity of their relationship so that "mourning" often occurs, sometimes for the duration of the entire illness. At the time of death, the surviving partner may feel a sense of relief. Such feelings are not uncommon and should not be a cause for guilt, particularly if the partner has been mourning for some time.

Reflecting on the effects of having had to care for such a partner, and stressing the need to take future life into account, one person observed:

> *One can end up socially isolated, emotionally drained, and physically exhausted. But one should think about what lies ahead. What happens after your partner has become so ill that he or she must be placed in a nursing home, or after he or she dies? Will you have become isolated, without other interests, lonely, used up, and find yourself in a tight little world all your own? You must not let this happen! You need your friends and hobbies now more than ever. You must have a change of pace to relieve your job of caretaker, for this will bolster and carry you through that long night of never-ending illness. More than that, it will sustain the strength you will need when the time comes for you to be left alone.*

# Who Can Help?

Anyone caring for an A.D. person may need a wide variety of assistance throughout the course of the disease. That assistance may come from family and friends, health professionals and social workers, community services, nursing homes or homes for the aged, church or synagogue, social clubs, and of course, local Chapters of the Alzheimer Society. At some time during their illness most patients eventually are moved to a nursing home, home for the aged, or hospital. For many with a family member at home, a range of community support services is absolutely essential. These include: geriatric assessment services, social work, visiting nurses, visiting homemakers, physio and/or occupational therapists, transportation, day care, temporary respite care, personal or family counselling, and last — but not least! — Alzheimer Family Support Group services.

## Family Doctors

It is important to remember that at all times the family physician is your major professional contact, and you should keep in touch with him or her regularly. Also remember, however, that there are no fool-proof signs to help the doctor recognize the disease. He or she will probably need as much help from you as possible. Consequently, he or she will be greatly assisted if you, and/or any of the friends who are close to the person, can describe, in as much detail as possible, the sequence of events which brought you to the doctor. He/she may well need extensive tests to help distinguish possible A.D. from a great number of treatable conditions which also cause mental dysfunction. Quite aside from whatever referrals the doctor may make to other medical specialists for additional assistance in the diagnosis, you should continue to keep in close touch with him/her, and report any and all changes which you observe in order that the doctor may discover any additional physical problems which should also be attended to.

The doctor should also communicate regularly with the caregiver(s) and explain the patient's progress to them. Some doctors may only give as much information as asked for. Consequently, do not hesitate to discuss with him/her any other questions which you may have. And if for any reason you feel the doctor is not a sufficiently understanding person, you should consider changing doctors, because throughout the entire course of the illness, medical consultation and guidance are so important — not only for the patient, but for you!

You may also want to put the doctor in touch with your local Chapter of the Alzheimer Society, or at least supply him/her with information about its functions and possible Family Support services.

## Neurologists

The neurologist is a physician who has specialized in diseases of the nervous system and acts as a consultant to your family physician. He/she, or a geriatric psychiatrist, should nearly always be involved in the diagnosis of this disease, and may also do periodic assessments to evaluate changes. The family physician will get a full report from him/her indicating the diagnosis and how it was obtained.

The family doctor may assist the family, where necessary, by suggesting questions to ask the neurologist in order to obtain a clear understanding of the implications of any findings and the status of the patient.

## Psychiatrists

Your doctor may refer the patient to a psychiatrist in order to determine whether changes in memory and other functions result from an organic disease process or are the result of stress, depression, or personal problems. Another reason for referral could have to do with understanding the personality changes seen in the patient, or emotional disturbance seen in the caregiver.

The psychiatrist uses more specialized methods to assess mental function than those used by the family physician. Medication may be prescribed by the psychiatrist to relieve anxiety, regulate sleep patterns, or to control other distressing symptoms, if and when they develop.

## Psychologists

A psychologist may be called on to administer psychological tests, particularly assessments of the patient's mental capabilities, to help the psychiatrist and family physician distinguish between organic disease and emotional problems, and to determine the severity of any dementia. This can help in planning for the future, and can assist both the family and the patient in making the best use of their capabilities at any stage of the disease.

## Social Workers

Most general or acute care hospitals have social workers on their staff. The family doctor or neurologist who diagnoses the patient can probably refer you to a social worker in the hospital or in other agencies such as local Family Service Associations, municipal or provincial social services, centres for seniors, or homes for the aged.

The social worker provides personal or family counselling and advice, or can refer you to the particular community service you may need. Social workers who know about and understand A.D., or who are associated with the Alzheimer Society, can help the whole family cope with and understand the changes in the patient, and the disruptions of family life that may be due to the stresses of caring for the patient.

## Public Health Services

Public health nurses are available virtually everywhere in Canada. They can help families of patients by doing an assessment of the home environment, and by providing advice and assistance regarding other community services. They can also help you plan the daily care of the patient and assist with any health problems which may occur.

Families may ask the public health nurse about medical care, diet, bathing, dressing, relief care, first-aid, or any other health-related problems. The nurse should be able to secure an answer to many of your queries — if she doesn't already have them!

Many other services, such as Visiting Homemakers, are obtainable on referral by the local Public Health Unit, Department of Health, or Department of Social Service.

## Community Information and Referral Centres

These centres usually exist in larger urban communities. They are a source of information on most services available in the community and can advise you about local resources and what to expect from them. Consult the Yellow Pages of your telephone book — usually under the heading "Social Services".

## Other Voluntary Organizations

First, consult your local Chapter of the Alzheimer Society. In communities where there is no Chapter, senior citizens' groups may be able to provide information on available resources. In many parts of the country, organizations of friends and relatives of patients in a variety of care facilities have been formed; these organizations should be able to provide some information on different kinds of institutional care.

## Home Support

In the provision of health care and social services, there recently has been increased awareness of the need for services to help the A.D. person remain at home. For various reasons, Canadians sometimes tend to place people in institutional care sooner than is the case in other countries. This is changing as home support services, at varying rates, are becoming more available. These services may be rather expensive and, unfortunately, can be used by most families only as and when they become chargeable to Medicare or other insurance programs.

## Visiting Nurses

These nurses will provide any nursing care required by the patient (e.g., changing dressings, teaching skills, etc.). They can also help with advice on health counselling and household management.

## Visiting Homemakers

Homemakers help keep the household operating when family members are unable to do so themselves. They provide personal care, household assistance and emotional support. In some areas they are also beginning to provide short-t relief or respite care for family members who badly need brief periods of time away from the A.D. person: time for shopping, going to the doctor or dentist, or visiting a neighbour or friend for a short while.

## Occupational Therapists

Such a therapist can help the family to find ways of dealing with the patient's disabilities. This can include adaptation of the house to accommodate disabilities, techniques for simplifying tasks, minimizing the stress on caregivers, and teaching them how to help the A.D. person with eating and personal grooming, as well as referring you to other agencies when needed. Occupational therapists are available through hospitals, through home care or home support programs, or through referral by your physician.

## Meals-on-Wheels

This service provides a meal for people who would not otherwise be able to prepare one. This may be appropriate for those who are still well enough to remain alone during the day but who might not otherwise eat properly. It can also be helpful when the partner or spouse is unwell, too tired, or otherwise unable to shop or prepare a meal.

## Respite or Relief Care

This is perhaps the most essential service for caregivers of an Alzheimer patient. It provides substitute care in order to give the caregiver a break. Unfortunately, this service is as yet very limited on any formally organized basis and depends mainly on personal arrangements.

Currently, there are three kinds of respite care: in-home services, day care and vacation care. In such situations, the regular caregiver should remain with the patient long enough to allow him/her to become comfortable with the respite caregiver.

In-home (or "sitter") services are limited and usually are run for a profit. With such an arrangement someone comes into the home to be with the person and to allow the caregiver to get away for a few hours. In some cases such a service may be provided by Visiting Homemakers or Visiting Nurses.

Day care centres and day hospital care provide activities for patients in a supervised setting away from the home. While day care programs for senior citizens are becoming more common, they often are not set up to cope with Alzheimer patients who may wander or become a bit agitated. These programs are usually attached to chronic care hospitals, homes for the aged or senior citizens' centres. Sometimes, however, specially adapted programs and a larger well-trained staff are provided to accommodate the mentally impaired within their existing program.

Short-term stay may sometimes be arranged with some nursing homes, homes for the aged, or chronic care and convalescent hospitals, to give the caregivers a rest or vacation. The length of stay permitted will vary. Locating this kind of service becomes more difficult for patients who are A.D. patients and who, it is assumed, are difficult to care for. Nevertheless, it is worth investigating, as a few weeks respite is a tremendous boon to anyone responsible for full-time care.

## Home Care Programs

In some areas of the country, comprehensive home care health programs are being developed to offer a full range of services to ill or disabled people in the community. Unfortunately, a number of these programs provide only limited periods of service and, unless the service is renewable, the help may be of limited duration (e.g., 15 or 30 days). However, the Home Care Programs of each province should be checked, since these are now a priority in health care. As with other services, there are certain eligibility rules which vary from province to province, as do the various professional and other services which are provided.

## Institutional Care

Most A.D. persons ultimately require some type of institutional care. Understandably, many families find this a very difficult decision to face. However, there is a limit to how long the caregiver can cope with the exhausting emotional and physical strain. Eventually it becomes much better for the patient to be in a setting that can provide care and safety on a 24-hour basis.

## Assessing the A.D. Person's Needs and Abilities

There is a variety of situations in which residential care must be seriously considered. The person may live alone and become incapable of providing for his/her own needs. He/she may live with a spouse who becomes unable to provide the care that is essential. The person may live with other family members who, even in spite of outside community support, can no longer stand the strain of disruptive behaviour, incontinence, etc. The move may be prompted by the need for increased medical attention, or by other complications.

A social worker, public health nurse, or occupational therapist will be very useful in helping to assess the person's needs and abilities. They may also be able to find ways of communicating with the patient, and can help family members with the very difficult and stressful decision of placement.

## Assessing the Family Situation

Families and individuals will need to assess periodically their ability to continue providing care. Personal limits of physical and emotional strength must be recognized and, if the stress becomes too great and health and family relationships are likely to suffer, it is time to consider institutional care.

Of great importance is a free and open discussion of the situation by everyone in the family, including any relative and close friend who may be involved. While their participation is important in discussions of the future care and the selection of an appropriate institutional facility, the feelings of the main caregiver must receive primary consideration.

## Institutional Care Options

Options for institutional care differ in each community, but it is essential to plan in advance, since desirable facilities usually have long waiting lists. This means there may be a delay of six months or longer. Facilities that accept patients with advanced mental impairment may be limited in your community. Whenever possible, professional assistance should be obtained from your local Health or Social Services Department, or from a Community Information Centre, where there is one.

The types of residential facilities which may be needed are: homes for the aged, nursing homes, chronic care hospitals and psychiatric institutions.

*Homes for the aged* are intended for seniors (60 years and up), but exceptions for underage applicants are sometimes made. These operate under provincial legislation but are administered by a municipal or non-profit agency, which may be a religious or ethnic organization. Specific admission policies of each institution must be ascertained to determine if the care provided will meet the requirements of the ill person. Some homes are for those who require only minimal supervision; others will accommodate the patient for life, unless some acute condition develops requiring alternative care. Some institutions employ the term "special care" for a unit in which the care and programs are adapted for patients with mental impairment.

*Nursing homes* are intended to care for those who require medical and nursing care, and the need for such is medically determined. They are usually privately owned and, while operating under provincial legislation, may vary greatly in the type of patients they admit and in the level of care they provide.

When deciding on institutional placement, check these important features:

- What is the philosophy of care? Since you know best the likes and dislikes of the patient, it is you who can best interpret these to the institution. Do you sense that they will be taken into consideration? In other words, will the staff be taking care of the patient as well as the disease?
- Do you see the staff talking to the patients and residents, rather than ignoring them?
- Check whether the home is licensed under provincial authority, or incorporated under provincial legislation and subject to inspection and accreditation by the Canadian Council on Hospital Accreditation.
- What are the eligibility requirements for admission, e.g., level of care, medical examination, age, residence requirement, etc.?
- Financial arrangement and cost of care: check for requirement of any contract or written agreements. Inquire about government subsidy, and what services are and are not covered by the daily rate.
- Enquire whether the medical, nursing care and supervision are provided during the day and at night. Also, is it a safe environment, i.e., are there smoke detectors, fire drills, etc.?
- See that resources are available for maintenance of maximum well-being; e.g., is there on staff a consultant occupational therapist and physiotherapist? Is staff leadership given for appropriate physical, religious and social activities?
- Is there provision of well-balanced diets?
- Are there special services and comforts available, such as hairdressing, dental service, foot, teeth and eye care?
- Are there pleasant, clean, comfortable surroundings? Does the setting lend itself to bringing in personal possessions or pets so as to help retain a sense of identity and familiarity?
- Do the staff appear to be open and reassuring to residents? Discover if they orient new patients and families to what happens or is going to happen in the institution.
- Note the location for ease of visiting.
- Is there an active Residents' or Patients' or Family Council that speaks to the Administrator on behalf of the residents, and whose proposals and suggestions are considered seriously?
- The home should be a member of the provincial association of Nursing Homes or Homes for the Aged.

*Chronic care hospitals* provide medical and rehabilitative treatment where a mentally impaired person may, in some circumstances, be cared for. *Psychiatric institutions* may be appropriate for diagnostic or continuing care purposes.

Because mentally impaired persons may not fit neatly into the normal admission process of one of the above types of institutional care, there is an urgent need for more long-term care facilities for ambulant patients which provide constant supervision in appropriate surroundings, and which have activity programs geared to individual abilities.

Decisions and choices regarding placement are made based on a particular setting's ability to provide the best services available. These services should meet those needs felt to be the most important in the particular situation. Even with family conferences to share the decision, the admission of a loved one to a care facility can cause considerable feelings of anxiety and guilt. Social work or other professional counselling may help with this. A transition period of visits to the facility prior to final admission can be very helpful for both patient and family, and such an arrangement should be made.

### Your Local Alzheimer Society Chapter

Be sure to contact and join your local Chapter of the Alzheimer Society of Canada. These Chapters can be a source of considerable help and emotional support. Here you will be able to meet others who face many of the same problems that you encounter. Moreover, the Society needs your support in its efforts to bring about greater public understanding of the disease, promote even more research into its causes and prevention, and to work actively for the many improvements in facilities and programs which are so badly needed in local communities. Your participation in the Society's collective struggle to achieve these ends is not only needed, but will protect you — at least to some extent — from that inevitable sense of isolation and helplessness which is the lot of so many A.D. caregivers.

### Family and Caregiver Support Groups

In a growing number of communities, Chapters of the Society are operating a service known as Family Support Groups. The purpose of these self-help groups is to help families or other caregivers share with one another ideas and methods of coping with an A.D. patient. The groups, which consist of about five to ten or twelve persons, usually meet every other week, depending on the particular community. The "program" is usually quite informal and the group is led by someone skilled in working with and leading groups, often a health professional or a person particularly knowledgeable about A.D. These Support Groups provide an opportunity for participants to discuss their problems, recieve suggestions from group members, share ideas and work out practical ways of helping one another, as well as the A.D. person for whom they are caring. To date, these groups have been found to be very stimulating and helpful. If you are not already a member or associated with the Alzheimer Chapter in your community, this does not matter at all. You will be most welcome to join one of their Family Support Groups.

## Drugs

*A word of caution!* Whenever drugs are prescribed for an A.D. patient there is the risk of side effects, some of which could cause further mental impairment. Most elderly people have several medical conditions for which medication may be prescribed, and the drugs in question may interact — whether they are prescribed or bought "over the counter." Consequently, it is essential that you discuss with your physician the degree of risk which will be involved should he or she wish to prescribe drugs, for you will be faced with a trade-off:

a) either you decide to take this risk because the behaviour for which the drugs are prescribed is just too much for you and your family to cope with; or

b) you decide not to take the risk — at least for the time being.

In any case, the potential risk should be seriously considered.

Should you consent to the use of drugs, be sure to monitor their effects and, if you observe *any* changes in the patient's behaviour, other than those for which the drugs were prescribed, report them *immediately* to the doctor. Also, it is equally important to find out from the doctor about how long it should take before you can expect to observe the results for which the drugs were prescribed. On this basis, advise the doctor if the expected changes do not occur.

## Legal Aspects

In addition to medical concerns, A.D. raises many legal issues which require careful consideration, including mental incompetency proceedings, contractual liability, liability in "tort," testamentary capacity, power of attorney effectiveness, and medical consent liability, to name a few. For the purpose of this manual, the discussion of the legal aspects of the disease will be restricted to the issues of guardianship (in most jurisdictions, this is referred to as "committeeship") and power of attorney.

**First, seek legal counsel.** Laws and procedures vary significantly from province to province. This manual provides only a brief and general discussion; it cannot substitute for the services of a lawyer.

### Guardianship or Committeeship

Persons with A.D. may suffer to such an extent that they are incapable of managing their own affairs. Consequently, they will require the assistance of a person or corporation to manage their assets on their behalf, or to exercise certain personal rights on their behalf, such as giving consent to medical treatment. The person or corporation selected legally to do so is called a "guardian" or a "committee." (The term "committee" is used in what follows.)

There are two alternative ways in which a committee may be appointed to manage the estate of a mentally incompetent person. First, a disabled person receiving treatment in a psychiatric facility may be certified as incompetent without a court order if the attending physician examines the disabled person and declares him/her incapable of managing his/her affairs, pursuant to the provisions of the particular province's Mental Health Act. When such a declaration is processed under the province's Mental Health Act, the committee of the estate is the province's Public Trustee. In some provinces, he/she is referred to as the Estate Administrator or Curateur Publique. (In Ontario, the procedure and process are also applicable to residents of mental retardation facilities under the Developmental Services Act, and to outpatients of psychiatric facilities who reside in Homes for Special Care. Laws and procedures governing such declarations may vary in other provinces.)

The Public Trustee's jurisdiction is limited to property matters and does not extend to personal rights. The Public Trustee is a special corporation created by statute, and one individual is appointed by the provincial government to fill the office of Public Trustee. The staff of the Public Trustee administers the estate under the Public Trustee's care, with the Trustee him/herself having the final authority in all decision-making. As committee of an incompetent person's estate, the Public Trustee has all the rights over such property that the incompetent person would have if competent, including the right to prosecute or defend court actions in the incompetent person's name.

A second method of appointing a committee is pursuant to a court order and involves either those individuals who are not under the care of a psychiatric facility or those patients for whom a private committee is to be appointed to substitute for the Public Trustee. For a private individual to obtain such an appointment, his or her lawyer must bring a "motion" to a judge, a motion being the legal term for a request or application. It will include medical evidence of the disability, a recital of facts, the application by the person or corporation who wishes to be committee, an inventory of all property (money, goods, land, etc., of the incompetent person), and a scheme of managing such property, including plans for the disabled person's care and maintenance. All facts on the application are confirmed by sworn statements. Under this procedure, the court generally has authority to grant the committee personal rights over the incompetent person (e.g. the right to make decisions regarding the care of the person), and this authority varies from province to province.

A committee (whether the Public Trustee or a private committee) is entitled to compensation for services provided in administering an incompetent person's estate. However, a committee who is the spouse or relative of the incompetent person often waives any claim to such compensation, and the Public Trustee may waive compensation, in whole or in part, if economic hardship is evident.

Whether the committee be an individual, a trust company, or the Public Trustee, when it is making investment of the funds in the incompetent person's estate, such investments must be proper investments at law. For committeeships arising from court appointments, the investment scheme is supervised by the court. For committeeships by the Public Trustee under the provincial Mental Health Act legislation, the investment of funds follows the guidelines described with that legislation. Generally speaking, the investments permitted by the court are more limited than those provided by the provincial Mental Health Acts.

The question of who should be named the committee is one that must be examined carefully. Should it be the next-of-kin, a corporation, or the Public Trustee? There are advantages and disadvantages in each choice. An individual named as a committee of the estate of a mentally incompetent individual will be required in many cases to post security in the form of a bond to guarantee to the court that the incompetent person's estate will not be depreciated by improper management. Any committee must keep clear records of the property of the incompetent person, and of all income, expenses, investments, and reinvestments of estate property. A trust company or the Public Trustee has the experience and business know-how to manage an estate, but will not have the same individual appreciation as the spouse or next-of-kin of the incompetent person. You can obtain valuable assistance with respect to the most appropriate choice by speaking to your lawyer, and with representatives of trust companies and the Public Trustee. The best choice will depend upon each person's circumstances.

### Power of Attorney

The concept of power of attorney involves the legal ability of a duly delegated person (called an "attorney") to exercise certain property rights on behalf of another (called a "donor"). The basic element of a power of attorney is this delegation of authority. By signing a power of attorney, a person bestows upon another the right to handle some or all of his/her business affairs, as specified in the power of attorney (for example, banking, signing legal documents, selling property, etc.).

Only a person who is legally competent to manage his/her affairs may grant a power of attorney to another. The question is often asked: "If the donor of the power of attorney becomes incompetent after giving power of attorney to his friend, can the friend continue to act pursuant to the power of attorney?" The answer varies. In most provinces of Canada, the friend can only exercise the rights given by the power of attorney so long as the donor is mentally competent. However, Alberta and Ontario, with the proper wording of the power of attorney, allow the friend to continue exercising it up to the time when a formal declaration of incompetence is made. In any event, a person cannot delegate more authority than he/she has.

## Brain Tissue Banks

Brain Tissue Banks have been established in Canada. Their purpose is to provide needed biological material for medical research that seeks the causes, develops treatments, and searches for cures for the many devastating neurological and psychiatric disorders affecting so many people today, including A.D. and related disorders.

### Why a Brain Tissue Bank?

Human brain banks are necessary because several serious neurological and psychiatric conditions affect only humans, and animal models are not available for study. Clues to the cause and treatment of these disorders can be found only through analysis of human brain tissue that has been removed at autopsy. Scientists now have powerful new research techniques, and human central nervous system tissue is essential to them in order to understand and, ultimately, prevent or alleviate these distressing illnesses. There is no substitute. Tissue stored in the Bank will be available to all competent neuro-scientists carrying out studies of brain diseases, both in Canada and abroad. Autopsies must be performed very promptly after death occurs.

### Everyone Can Help Brain Research

If the person for whom you are responsible is affected by a neurological or psychiatric disorder, you may wish to help thousands of others who are similarly affected by arranging for donation of brain tissue for research. By arranging now for donation of the A.D. person's brain tissue, you will be giving a unique and priceless gift.

The Alzheimer Society actively cooperates with three Canadian Brain Banks. For more information about these Banks, and to arrange for future donation of brain tissue for medical research, write to:

Canadian Brain Tissue Bank
Banting Institute, Room 128
100 College Street
Toronto, Ont. M5G 1L5
(416) 977-3398

or

Brain Tissue Bank
Douglas Hospital Research Centre
6875 LaSalle Blvd.
Verdun, Que. H4H 1R3
(514) 761-6131 Ext. 310

or

Brain Tissue Bank
Dementia Study Office
University Hospital
London, Ont. N6A 5A5
(519) 663-3384

## For More Information

If you need more information on Alzheimer's disease, or wish to secure the address and telephone number of the nearest Chapter of the Alzheimer Society, contact the national office:

Alzheimer Society of Canada
185 Bloor Street East, Suite 222
Toronto, Ont. M4W 3J3
(416) 927-1580

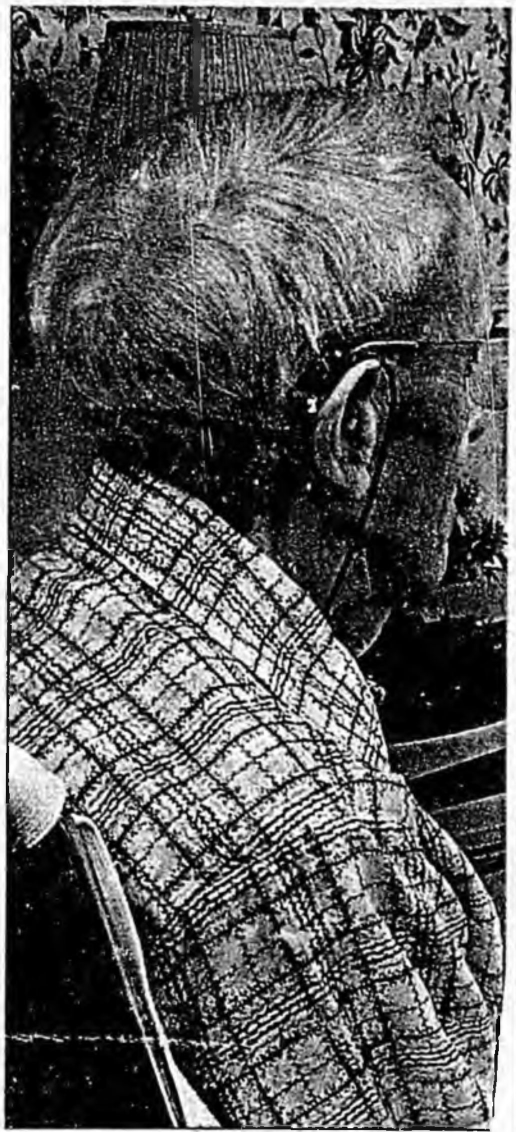
## Additional Reading

- **The 36-Hour Day**, by *Nancy L. Mace* and *Peter V. Rabins, M.D.*, Johns Hopkins University Press, Baltimore/London (1981) 233 pp. (available from Alzheimer Society of Canada, 185 Bloor Street East, Suite 222, Toronto, Ont. M4W 3J3). Price: $10.00 (Can.) including postage and handling.
- **Journal of Geriatric Nursing (U.S.)**, Vol. 8 #2, Feb. 1982; and Vol. 9 #2, Feb. 1983.
- **Generations**, Fall, 1982. A journal of articles published by, and available from, the Western Gerontological Society, 833 Market Street, Room 516, San Francisco, Calif., U.S.A., 94103. Price: $4.00 (U.S. funds) including postage and handling.

file SB 117

# A Slow Death of The Mind

## Devastating for victims and families, Alzheimer's is now being recognized as 'the disease of the century.'



*Memory aids: At Charlwell House, Alzheimer's*

*The part where your memory is gone, it's dead. I don't know what's missing. Your thoughts come to a void, and then there's nothing.*

—Mildred, a 53-year-old victim of Alzheimer's disease

Of all the incurable diseases, the degenerative brain disorder known as Alzheimer's may be the cruelest, because it kills its victims twice. In Alzheimer's, the mind dies first: names, dates, places—the interior scrapbook of an entire life—fade into mists of nonrecognition. The simplest tasks—tying a shoelace, cutting meat with a knife, telling time—become insurmountable. Then, the body dies. No longer able to walk or control elemental functions, the victim lies curled in a fetal position, gradually sinking into coma and death. On average, the decline occurs in six to eight years, although some sufferers linger as long as 20. "To lose your mind, your ability to live a constructive life, is worse than cancer," says Elizabeth Reno. "At least cancer is a tangible pain. This disease quietly consumes you." Reno can speak with special insight—she has suffered from cancer, and now has Alzheimer's (box, page 60).

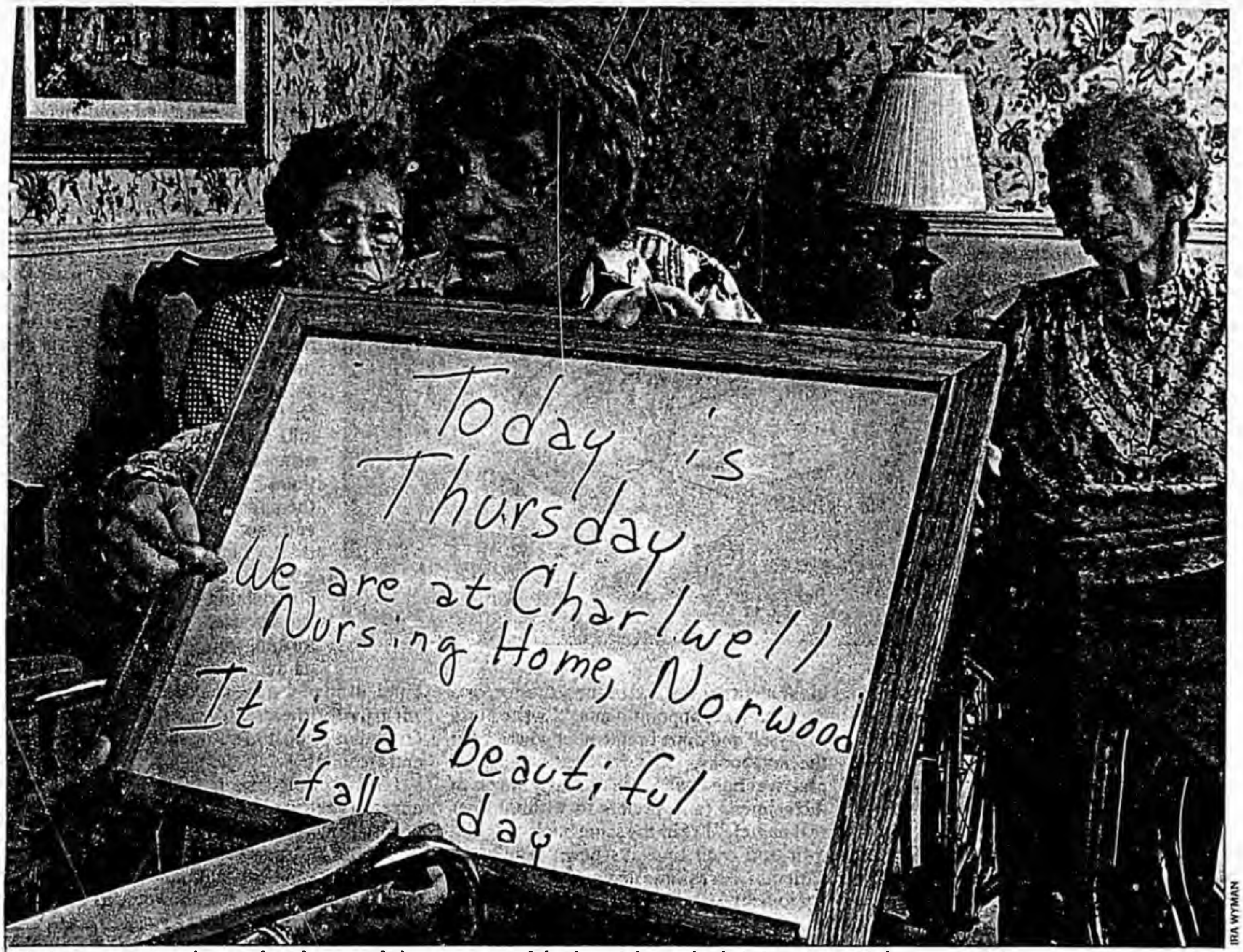
Experts now call Alzheimer's "the disease of the century." It afflicts up to 3 million Americans—about 7 percent of the 27 million people over 65 in the United States are severely disabled by the disease. Actress Rita Hayworth, movie director Otto Preminger and actor Edmond O'Brien all suffer from Alzheimer's, and it has claimed the lives of mystery writer Ross MacDonald and artist Norman Rockwell. The causes are unknown. And while medical scientists are beginning to make strides in analyzing the chemical processes of the brain, Alzheimer's remains irreversible. It strikes people of every ethnic and socioeconomic group and the number of cases is expanding apace with the rapid growth of the nation's elderly population. It claims more than 120,000 lives a year, making it the fourth leading cause of death among the old, after heart disease, cancer and stroke.

LESTER SLOAN—NEWSWEEK

*Respite: Patients gather for meeting at Alzheimer's Family Center in San Diego*

**Anguish:** Alzheimer's may be even more devastating for the families of victims. They drive themselves to physical and emotional exhaustion while rendering continuous care, and experience the anguish of seeing a loved one turn into a witless stranger who no longer even remembers who they are. And amid all this, they may see their life savings consumed in the crushing task of caring for a doomed patient. "There's no hope at the end of the tunnel," says Flora Richter, of Palo Alto, Calif., whose 80-year-old husband, Julius, has had Alzheimer's for three years. "It's only going to get worse."

Yet Alzheimer's is a disease that health policymakers somehow overlooked in their grand planning. Neither Medicare nor most private health-insurance programs pay for the "custodial" care its victims need. Before



*victims scan prompting cards to buttress their awareness of the day of the week, their location and the season of the year*

IRA WYMAN

qualifying for federal-state Medicaid, a family must spend its way into virtual poverty. Occasionally, spouses become divorced in order to protect what's left of their savings. "You either have to be very wealthy or very poor," says Jerome Stone of Chicago, founder of the Alzheimer's Disease and Related Disorders Association (ADRDA). "The middle class is absolutely wiped out." And even those who can afford to pay $20,000 or more a year for a nursing home are often turned away because Alzheimer's patients are too much trouble. "My mother would run up and down the halls and knock on all the doors," says Mary Hunter of San Diego. "Finally, they threw her out."

Until recently, Alzheimer's was considered an exotic disorder. When he learned that his wife had the disease in 1970, Stone was appalled to find that a 680-page neurology textbook devoted only one, sparse page to it. But as the disease has relentlessly continued to strike older Americans—and the families who must care for them—it has started to get the public attention it deserves. Since 1976, for example, federal research spending on Alzheimer's has increased almost tenfold, from less than $4 million to $37.1 million this year. And just last month, the National Institute on Aging designated five medical schools—including Harvard, Johns Hopkins, the University of California, University of Southern California and New York's Mount Sinai School of Medicine—as Alzheimer's research centers with a grant of $16.6 million.

*Davies: New hope in the lab*

BERNARD GOTFRYD—NEWSWEEK

Now there are glimmers of hope that medical science is beginning to unravel the Alzheimer's riddle. Within the last decade, refined investigative techniques have provided new clues about what causes memory and judgment to break down in the brains of victims. These discoveries raise the possibility, for the first time, that specific treatments can be found.

**Twisted Nerve Fibers:** The typical "senile dementia" of the elderly used to be blamed largely on impaired blood circulation to the brain and was thought to be an inevitable part of growing old. In 1906, Alois Alzheimer, a German neurologist, encountered a woman who showed all the signs of severe dementia—memory loss, disorientation and hallucinations—even though she was only 51. After her death, Alzheimer examined her brain and discovered that parts of it contained clumps of twisted nerve-cell fibers that he called "neurofibrillary tangles." For decades afterward, physicians regarded cases of the kind Alzheimer described as rather rare and confined to the relatively young. In fact, they called the syndrome "presenile dementia." But in the 1960s, researchers armed with electron microscopes discovered the same neurofibrillary tangles in brain tissue from elderly patients with dementia. It soon became clear that the disease is neither "presenile" nor rare.

Alzheimer's accounts for more than half of all cases of senile dementia. The other cases are most often caused by a succession of "small strokes" that knock out increasingly large amounts of brain tissue, or by a variety of conditions, some of them treatable, that produce mental confusion. These include depression, thyroid disease, deficiencies in certain vitamins, adverse drug reactions, anemia and alcoholism. Therein, of course, lies comfort for many people who fear they have Alzheimer's. "I've seen some spectacular misdiagnoses," says Dr. Barry Reisberg of New York University Medical Center. "One-third to one-half of the patients referred to me have some other illness, or normal aging."

**Memory Loss:** Alzheimer's usually occurs after 65, although it can strike in the 40s. But according to Reisberg, even elderly people who have trouble remembering where they put their glasses or can't recall names as quickly as they once did may just be showing normal age-related forgetfulness. "They need to be reassured that these subjective symptoms are benign and consistent with good health," he says.

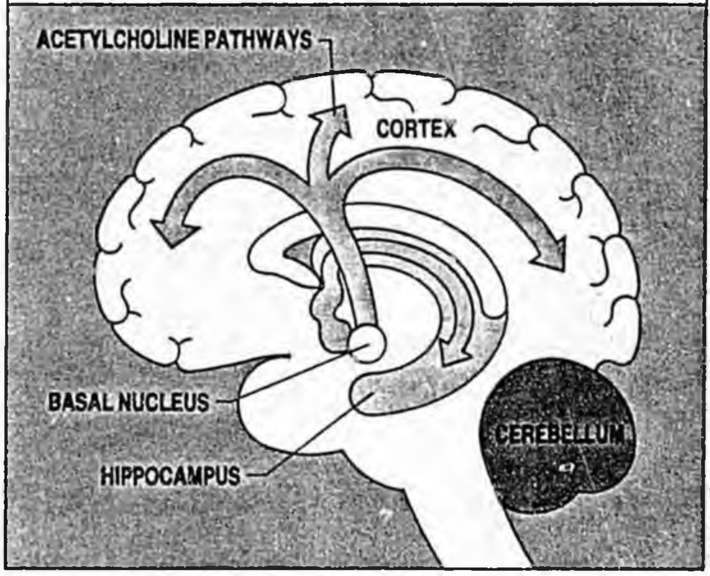
Signs of real trouble come when memory loss begins to affect a person's work or social life—a teacher can't remember the names of his students at the end of the semester, or a doctor forgets appointments. "I write notes to myself and hope I remember where I put the notebooks," says Mildred, a licensed practical nurse who is in the early stages of Alzheimer's (and prefers to withhold her real name). "I read the same book over and over and each time it's new." Typically, patients in this phase deny their problem or try to belittle it. When Rita Hayworth forgot once that her daughter, Yasmin Khan, had told her about having some singing engagements, she exclaimed, according to Yasmin: "Oh, silly mother, silly me to forget."

Although fading memory is the most common early sign, trouble with language or personality changes may be among the first symptoms. Some patients believe the trouble is with their eyes because they aren't able to follow words on a page. Or they may go for a glass of milk and end up in the bedroom instead of the kitchen. "Sometimes I find myself standing in the middle of the dining room and not knowing why I'm there, or how I got there," says Elizabeth Reno of Detroit. Another dominant symptom may be "apraxia," difficulty in performing rote gestures such as hair combing. "We think these different manifestations come from different parts of the brain," says Dr. John H. Growdon of Boston's Massachusetts General Hospital.

Later, the first signs of true dementia appear. The victim has trouble making appropriate judgments; typically he may dress for winter in midsummer. As the disease worsens, the patient may confuse the hot and cold handles in the shower and burn

## UNLOCKING THE SECRETS OF THE BRAIN

Researchers are investigating cell abnormalities in Alzheimer's victims, focusing on the cortex, the basal nucleus and the region next to the hippocampus.



BOB CONRAD

## Days in the Life

Ruth Conroy is grateful for all the traveling she and her husband, Bill, did together—hiking and camping all over New England, sailing their boat from Massachusetts to Long Island, skiing in Austria, touring Pakistan and Russia. "I'm glad we did those things without waiting to retire," the 56-year-old Brighton, Mass., woman says. "You never know what life is going to hit you with."

Bill, a handsome 57-year-old Harvard graduate, was diagnosed as having Alzheimer's three years ago at Massachusetts General Hospital. He stays home now while Ruth holds down a part-time job in Boston. Before she leaves each morning, she neatly lays out plates and silver on the kitchen counter and leaves his breakfast in the refrigerator. She also puts handwritten notes around the house—"Get name and phone number," "Turn gas off," "Don't go out—back at 2:30." Occasionally, Bill takes walks by himself, but for the most part he stays home and aimlessly passes the time. When his wife asks if he listened to music or watched television while she was away, his reply is usually something like "Can't do anything now. Dropped everything."

After Ruth comes home, they occasionally take walks around the reservoir near their condominium or watch football practice at Harvard. But she finds it increasingly difficult to think of things for them to do together. "Dinner gets to be earlier and earlier," she says. And recently, communication between the two has become difficult because Bill often speaks in cryptic, fractured sentences. "I don't want to burn myself," he said one day recently. "I found myself; I was gone. I have to go back again. Everything bang! Right out of me." Ruth wonders if he was referring to his disease. When she asks him if he's talking about Alzheimer's, he replies: "It's the same thing. I can't

PHOTOS BY IRA WYMAN

*Conroy being tested*

himself. Finally, the sufferer becomes incontinent, forgetting where to relieve himself. By this time, the patient may not know where he lives, or the season of the year, and may even have forgotten the name of his spouse. "One day my husband threatened to leave home because he wanted to go off to call his wife," recalls Lillian Lewis of San Diego. "He cried and begged me to let him call 'Lil.' I told him I was Lil—it was devastating."

**Full-Time Care:** Some victims may become agitated and even sociopathic. One San Diego man was nearly picked up as a sex offender because he pulled down his pants and urinated on the sidewalk in front of some children. Another patient, a woman, was prosecuted for shoplifting by a California grocery chain, though her son, her doctor and the police explained that she didn't even know she was in a store. A retired Air Force officer recalls that his wife suddenly began pummeling him while they were driving along a highway at 55 miles an hour. "I'm driving with one hand and holding her back with the other. A man in a van next to us almost crashed. I'm sure he thought I was beating her." At this point, the patient obviously needs full-time care. "The spouse is forced literally to become a saint," says Reisberg.

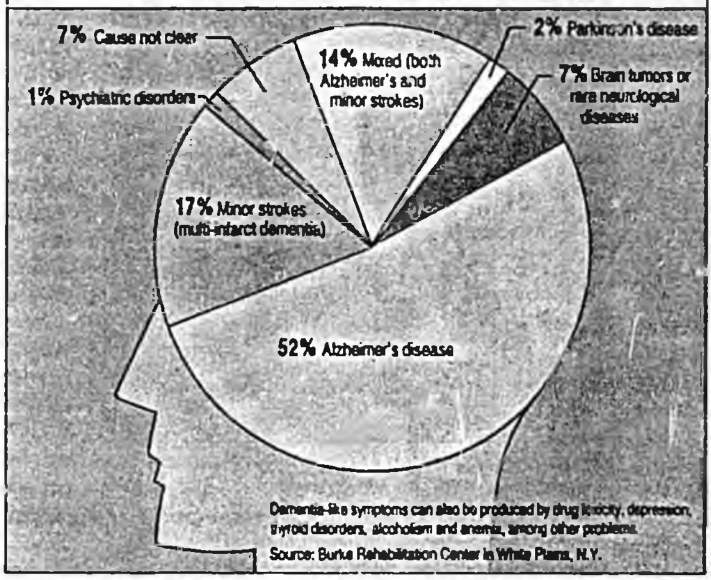
In the last stage of Alzheimer's, the victim loses the ability to speak much at all, just saying "yes" or "OK" to everything. Gradually, he becomes unable to walk and may develop contractures of the face, arms and legs. Primo Nini, 68, of Dearborn, Mich., lies curled up fetuslike in the final throes of the disease. His wife, Dorothy, whom he hasn't been able to recognize for three years, patiently changes his urinary catheter and puts sheepskin pads between his legs to prevent bedsores. "The decline goes at a fairly consistent rate," says Dr. Michael A. Jenike of Mass. General. "If there was a rapid start, then it continues rapid. If the start was slow, it continues slow." Often, death is the result of pneumonia, which may be caused by inhaling food into the lungs.

**Diagnosis:** The only sure way to diagnose Alzheimer's is to take a biopsy of brain tissue, which might disclose the telltale neurofibrillary tangles. But most doctors rely on less drastic tests. Often, these eliminate other possible causes of a patient's symptoms, rather than simply show the presence of Alzheimer's. Blood tests may indicate anemia, thyroid abnormalities or vitamin B-12 deficiencies that could be the source of trouble. CAT scans and the more recently developed nuclear-magnetic-resonance (NMR) technique for looking inside the skull will reveal signs of strokes or brain tumors.

As part of the workup, patients are given tests of memory, attention span, language, spatial ability and abstract reasoning. In

**THE CAUSES OF SENILE DEMENTIA**

Current research shows that more than half of all senile dementias are caused by Alzheimer's, the degenerative disease that afflicts up to 3 million Americans.



Dementia-like symptoms can also be produced by drug toxicity, depression, thyroid disorders, alcoholism and anemia, among other problems.

Source: Burke Rehabilitation Center in White Plains, N.Y.

BOB CONRAD

*Written reminders guide Conroy through his daily routine, and a bond of affection helps him cope*

figure." He sometimes can't remember the names of his stepchildren, or even his wife, but he may try to cover such lapses. When groping for a name, he'll stall by saying, "Wait a minute, I want to hear what they are saying." Sometimes he asks Ruth when they are going home, even though they are sitting in their own living room.

Ruth has begun to show the stress. Once, she rushed to the emergency room, complaining of severe chest pains, afraid she was having a heart attack. But she was told the symptoms were simply the result of being on edge. Now and then, she blows up. "Last night, he brought me a can of beer, and I reminded him I like it in a glass," she says. "He must have gone back and forth to the kitchen four times and returned with the same can of beer. I yelled at him, then I felt terrible."

But most of the time, a bond of deep affection helps both of them cope. "He tries so hard to please me," says Ruth. "He is so grateful." Occasionally, Bill will take her hand and, looking into her face, he will say simply, "I would be dead by now." As much as possible, Ruth strives to make their present life together resemble what it was before Bill's illness. "I am taking every good thing that I can now because I know it's not going to last," she says. "But I don't dwell on what's ahead."

one such exam, they are asked to name the year, season, day of the week and month and to count backward from 100 by sevens. A considerable number of Alzheimer's victims display a trait called "intrusion" in replying to the questions. They may, for example, give the number of the year when they were asked the day of the week. Patients may also be asked to follow a three-point instruction such as "Take a paper in your right hand, fold it in half and put it on the floor." Taken together, such tests not only can suggest a diagnosis, but also indicate remaining abilities that can be used effectively in care. "Many patients have trouble talking," says Marilyn Albert of Mass. General, "yet we find they understand speech. The family should know that."

*Hands on: Researcher Davis comforts patient*

BERNARD GOTFRYD—NEWSWEEK

**'Crutches':** Although the disease is irreversible, Alzheimer's patients are by no means beyond help. In the early stages, when depression is often a major symptom, treatment with conventional antidepressant drugs can not only help but even postpone the need for institutionalization. "Many physicians overlook depression and don't treat it aggressively," says Mass. General's Jenike, "but we find that if we really go after it, it can make a tremendous difference." Behavior therapy can also slow down the inexorable process of mental deterioration. "Memory crutches" in the early phase might include keeping a simple list of routine chores. Worried that their 81-year-old mother might wander out at night or forget to take her medication, one family took turns calling her in the morning to remind her about the drugs and put a sign on her door warning her not to leave her apartment after 5 p.m. "With memory patchwork, she was able to stay on her own for two more years," says Dr. Gene Cohen of the National Institute of Mental Health.

The bible for the relatives of Alzheimer's patients is "The 36-hour Day," by Dr. Peter Rabins and Nancy Mace of Johns Hopkins. The book provides tips on such matters as how to keep a stubborn victim from continuing to drive his car (remove the distributor cap), and how to prevent accidents in the home by taking such precautions as turning down the hot-water heater, or installing gates at the top of the stairs.

**Self-Help:** But the pressure of 24-hour care eventually becomes too great for most people, however loving, to withstand. To give family members much needed respite, ADRDA now has 120 chapters across the country and sponsors 300 self-help groups. One highly esteemed prototype of an Alzheimer's care center was started two years ago by a longtime researcher in the disease, Dr. George Glenner of the University of California, San Diego, and his wife, Joy.

At a charge of $25 a day, the center takes care of Alzheimer's patients Monday through Friday. Besides helping victims with mundane tasks like going to the bathroom, staff volunteers take patients on walks, conduct "current events" classes and show old movies. Dances are organized featuring records by Glenn Miller and the

## Keeping the Facade

Elizabeth Reno crosses the dates off on her calendar and writes notes to herself to jog her memory. "I try to trick myself into remembering," says the 46-year-old Detroit woman. But the tricks don't work so well anymore. Reno immediately forgets the plot of the last television show she watched and she has trouble reading newspaper articles because she loses the gist of the story after two or three sentences. She has long since forgotten the names and phone numbers of relatives, and no longer cooks or drives a car because she can't remember how. "Can you imagine the embarrassment of an educated woman not knowing who the president is or having to ask where the bathroom is in your own house?" she asks in frustration.

Having already survived breast and cervical cancer, Reno learned that she had Alzheimer's disease only last March. And like many patients in the early stages of the illness, she is engaged in an often-futile attempt to mask her condition. "I rehearse and rehearse," she says, "conducting conversations with myself, anticipating what might be said. Every word I speak I have to think about very carefully." As a result of that effort, she is misleadingly articulate. But when she is tired, the façade disappears and she shows the full signs of her disability. Last August she was forced to retire from her job as a phone-company supervisor. "After work, I would collapse because I had to muster all the strength I could to make it through the day," she recalls.

**Volunteer:** Married 26 years, the Renos have three children. Nowadays, Elizabeth tries to avoid socializing and depends on her husband to make excuses for her. "I am conscious that I am a burden," she says. Richard, a Michigan Bell Co. engineer, does all the housework when he gets home. Fortunately, the couple's job benefits will cover the financial burdens that will accrue when Elizabeth finally goes to a nursing home. In the meantime, both Renos attend meetings of a support group twice a week, and Elizabeth is a hot-line volunteer for the local chapter of ADRDA. Strong Irish Catholics, the couple radiate confidence that they will somehow endure. "We pray for determination and the will to do instead of sitting and crying," Elizabeth says. "Remember, we had already accepted cancer."

*Patient Reno and husband: 'I am conscious that I am a burden'*

ANDREW SAKS

other big bands that might stir a faint memory of another, very different time in the patients' lives. "Music is familiar to them emotionally even if their memory is gone," says activities aide Madelyn Lewis-Long. "Even if they can't remember the words, they can tap their feet or whistle."

The Respite Care Program in Portland, Ore., puts volunteers in the homes of Alzheimer's patients to give their families much-needed periods of rest. Program volunteers undergo an unusual training course. They are asked to perform such tasks as threading a needle while wearing vision-distorting glasses, or shuffling cards while wearing gloves, to illustrate the physical burdens of both the patients and the elderly spouses who must care for them.


JAMES D. WILSON—Newsweek

*Simulation: Volunteers experience for themselves*

But in the end, most patients need the full-time attention of a nursing home. Charlwell House, a 124-bed home in Norwood, Mass., deals with many patients in advanced senility. The home stresses "patterning," an individually tailored program in which the patient bathes, dresses and eats according to the schedule he followed at home. "Alzheimer's patients are much more comfortable in a structured setting," says administrator Lorraine Ryan. Equally important, patients are kept out of bed and engaged in activity as much as possible. They attend group sessions in which they are reminded of familiar objects, like autumn leaves, and listen to music. "If we can keep them physically well and active, we can bring them further along and stave off the last stage of vegetation," says Ryan.

Although the cause of Alzheimer's remains elusive, researchers are turning up clues at an accelerating pace. In 1976, scientists at three labs in Britain simultaneously found that Alzheimer's victims show a marked lack of an enzyme responsible for synthesizing acetylcholine, one of the brain chemicals, or neurotransmitters, responsible for carrying impulses between nerve cells. "This gave us a real handle for research, an enormous impetus," says Dr. Peter Davies, one of the researchers, who is now at New York's Albert Einstein College of Medicine. Although there is evidence that other neurotransmitters, such as noradrenalin, may also be involved, reduced levels of acetylcholine seem to be a hallmark of Alzheimer's and can account for many of the characteristic symptoms of the disease. For example, volunteers given scopolamine, a drug that blocks the action of acetylcholine, show lapses in memory. And recently, Dr. Donald Price and his co-workers at Johns Hopkins University School of Medicine found that the brains of Alzheimer's victims exhibit a dramatic loss of neurons in the basal nucleus, a small area deep within the brain, where, as it happens, most acetylcholine is normally produced.

In recent years, researchers have found other clues to the pathology of Alzheimer's. Among the most promising:

**Tangles and Plaques.** Dr. Robert Terry, now at the University of California, San

## Facing the Inevitable

Just a few years ago, Carl Sandstrom was a successful attorney with an oil firm. Today, at 55, he wanders around his house in suburban Denver, vacuuming, doing dishes and watching television. "It's heartbreaking to see him unable to decide what to wear in the morning," says his wife, Barbara.

With the onset of Alzheimer's, she recalls, her husband became depressed and withdrawn and began losing his temper with their five children at the slightest provocation. At one point, in a fit of anger, he disowned his 21-year-old daughter. "We began to walk on eggs in order not to ruffle Dad," his wife says. Eventually, she had to take away his driver's license, because his reaction time had become too slow, and his money—he was leaving as much as $20 in change in stores and restaurants. "I've become a controlling, interfering wife and I don't like it," she says.

**'Difficult':** Barbara's burden is made heavier by the fact that three of the children are away at college and can't see what their mother is going through day in and day out. Even worse, her parents and in-laws don't fully appreciate her problem and wonder if she isn't exaggerating the situation with Carl. "They tell me he's looking better than ever, and that's difficult to bear," she says. "He doesn't look sick, so people don't think he's sick."

Typical of Alzheimer's victims, Carl has lost track of night and day, and often wanders about the house at odd hours. "Every time he's up, I awaken and wonder what he's going to do next," Barbara says. Yet when she looks tired the next day, her husband will ask her why. "He won't remember that he kept me up." To make matters worse, neighbors have begun to shun the Sandstroms. A church group occasionally sends a volunteer to take Carl for a walk, but only if Barbara calls for help. "They forget to come back again," she says.


JAMES A. COOK—PICTURE GROUP

*Sandstrom and family: 'We began to walk on eggs'*

The pressure is taking its inevitable emotional toll on Barbara. Two weeks ago she quit her job as a paid staffer at the Denver chapter of ADRDA so she could spend full time with her husband. But should that prove too great a burden, she intends to send him to a nursing home 60 miles from Denver. "I don't want to feel obligated to visit him daily, which I would if he were nearby," she says candidly. "Somehow, I have to have some kind of a life." The home will cost $1,500 to $1,800 a month, to be paid for by Carl's pension and a lot of belt tightening. Barbara dreads the change in life-style, both for herself and her husband. "I've always been optimistic," she says, "but I don't look forward to tomorrow anymore. I don't look forward to having to put him into a nursing home; in fact I pray that he'll die."

Diego, discovered some years ago that the neurofibrillary tangles originally described by Alzheimer consist mostly of minute threads twisted into the shape of a double helix, and he called them paired helical filaments (PHF). Outside the nerve cells, Alzheimer's brains show a formation called plaques, knobby patches of dying nerve fibers that are clustered around a core of material called amyloid. Whether the accumulating tangles and plaques are the cause or the result of the disease process is one of the tantalizing mysteries of Alzheimer's. Researchers are trying to determine the molecular composition of these abnormal structures to see what led to their development. They have found that the PHF, for example, are made of cementlike proteins that can't be broken down by ordinary techniques in the lab, which may explain why the disease is irreversible.

**Hippocampus Blockage.** One of the key areas of the brain for processing new information and putting it into the human memory bank is the hippocampus, below the cerebral cortex. Three months ago, researchers at the University of Iowa College of Medicine reported highly specific areas of damage adjacent to this region in five Alzheimer's patients. "If the input and output to the hippocampus are blocked, your brain will simply not be able to acquire new memories," says Dr. Antonio R. Damasio, a member of the Iowa team. "We think this is a superb way to explain some types of memory loss patients get in the early stages."

**Reduced RNA.** In the normal brain, protein is being synthesized continuously, and a key chemical in the making of protein is RNA. But Dr. Charles A. Marotta of MacLean Hospital in Belmont, Mass., has discovered that the regions of the brain in Alzheimer's patients where the plaques and tangles seem to be particularly numerous show a marked reduction in RNA and protein synthesis. After RNA has done its job of making protein, it is removed by an enzyme. Recently, Marotta and his colleague, Elizabeth M. Sajdel-Sulkowska, found evidence of excessive activity of this enzyme in Alzheimer's brains, which may account for decreased protein synthesis.

**Genetics.** Inheritance clearly plays a role in about 10 to 15 percent of Alzheimer's cases: the children of these victims have a 50 percent risk of developing the disease. Symptoms usually develop earlier than age 65 in these cases and the progress of the disease is unusually rapid and severe. Even among the rest of Alzheimer's victims, as many as a third have had a close relative with the disease. The younger the relative is when he gets the disease, the greater the risk for others in the family. "But if a parent got Alzheimer's after age 70, there's very little increased risk," says Dr. Leonard L. Heston of the University of Michigan.

Another indication of genetic involvement lies in the fact that virtually anyone with Down's syndrome—a form of mental retardation caused by an extra chromosome in the body's cells—develops what seems to be Alzheimer's after the age of 35 or 40. Heston has found that families with an Alzheimer's victim are three times more likely than others to also have a member with Down's syndrome. Since an extra chromosome is the culprit in Down's, that's where scientists, using the new recombinant DNA technology, are looking for the gene that may cause Alzheimer's.

LESTER SLOAN—NEWSWEEK

*Remembering: Dancing to the big-band sound at San Diego center*

**'Slow Viruses.'** Several neurological diseases that produce dementialike symptoms are known to be caused by "slow viruses," organisms that lie dormant for long periods before causing any symptoms. So far, however, attempts to transmit such a putative virus to experimental animals by inoculating them with brain tissue from Alzheimer's victims have been unsuccessful, leaving the issue unresolved.

Researchers concede that taken together the Alzheimer's evidence to date resembles a jigsaw puzzle. In fact, the disease might have not one, but several interlocking causes—viruses, toxins or genes. Still, using the clues available, doctors are taking the first hopeful steps in testing treatments for the disease. The discovery that patients have a deficiency of acetylcholine prompted researchers to try drugs that would raise levels of the neurotransmitter. The most effective of these has been a drug called physostigmine. It increases levels of acetylcholine by blocking the action of an enzyme that normally removes it from the brain. Dr. Kenneth L. Davis of New York's Mount Sinai School of Medicine reports clinically significant improvement in 3 of 11 patients taking oral doses of physostigmine. "The best were made to look like they had looked 1½ years earlier," says Davis. Drugs that raise acetylcholine levels may not work in patients with advanced Alzheimer's, researchers suspect, simply because they don't have enough acetylcholine-producing brain cells left.

So far, the most promising results have been obtained by Dr. Robert E. Harbaugh of Dartmouth-Hitchcock Medical Center, Hanover, N.H. Perhaps, he reasoned, not enough of a drug gets into a patient's brain when it is given orally. So he and his colleagues implanted a small pump under the skin of the abdomen in four Alzheimer's victims. By means of a catheter inserted through a tiny hole in the skull, the pump delivered a continual flow of an acetylcholinelike drug called bethanechol directly into the ventricles of the brain. As judged by their own families, the patients have shown improvement in such previously impaired activities as reading, personal hygiene, conversation and social activity for as long as a year. Harbaugh hopes to test the infusion pump on more patients, and using a variety of other more promising drugs. "We are very pleased," he says.

**'Exciting Times':** Scientists compare the current status of Alzheimer's to the challenge they faced with heart disease three decades ago. It, too, was once thought to be an inevitable part of aging. Then came drugs to control high blood pressure and recognition of the role of diet in atherosclerosis, both of which may help account for the present decline in coronary mortality. So, researchers hope, it might eventually go with Alzheimer's. "These are exciting times," says Mass. General's Growdon. "More is known than ever, and more will be known next year."

In the meantime, what seems needed is to keep the Alzheimer's tragedy in the public eye and make sure there is no slackening of the research effort. "The way I deal with my grief is by sharing it, talking to people about Alzheimer's, trying to get funding for research," says Yasmin Khan, who is on the national board of ADRDA and makes public appearances to tell her mother's story. "There's an enormous need to come out of the closet," she says, "and to share the information, the awareness and the pain."

MATT CLARK with MARIANA GOSNELL and DEBORAH WITHERSPOON in New York, JANET HUCK in San Diego, MARY HAGER in Washington, DARBY JUNKIN in Denver, PATRICIA KING in Chicago, AMY WALLACE in San Francisco and TRACEY L. ROBINSON in Detroit

It is imperative that the person be under the care of a physician. The physician may be a neurologist, a psychiatrist, or the family physician or internist who can consult with a neurologist. Most important, the physician selected should have the time and interest to closely monitor treatment and to answer the many questions that arise during the variable course of the illness. The physician will also need to treat various other physical ailments that may complicate the course of the disease.

Tranquilizers can lessen agitation, anxiety and unpredictable behavior. Medication can also improve sleeping patterns. If depression accompanies the illness, it can be treated with appropriate drugs. Proper nourishment and fluid intake are important, but special diets or supplements are usually not necessary. Appropriate exercise is of value and physical therapy can help if difficulties arise in physical functioning. Alcohol should be avoided since it may add to the patient's confusion.

Activities should be maintained at as normal a level as possible. The daily routine, physical activities and social contacts should be encouraged. It may be helpful, when necessary, to provide simple memory aids to assist the individual in day-to-day living: a prominent calendar, lists of daily tasks, written reminders about routine safety measures, and directions to and labeling of frequently used items.

Although it is best to maintain an ordered environment so that a person does not have to continuously learn new things, it is important not to restrict him or her from trying something new. For example, an individual with Alzheimer's Disease may do very well on a trip if accompanied by a supportive family member or friend.

Understandably, the person afflicted with Alzheimer's Disease finds it difficult to comprehend the changes that are taking place in thinking and behavior. Family and friends may also have questions about the course of the illness, the activities that can be engaged in with safety, how to encourage the person to carry out familiar activities that have become painfully frustrating and how to explain the memory loss to neighbors. Answers to such questions vary according to the individual and the particular phase of his or her illness. The physician or one of his associates–a psychologist, nurse or social worker–can be helpful in meeting these needs.

**An Information Booklet Prepared by**
**The National Institute on Aging**
**Distributed by**
**The Collaborative Case-Control Study**
**of Alzheimer's Disease**

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# Alzheimer's Disease

A Description of the Illness
for the Family and Friends
of Patients with this Disorder

Reprinted by:

**Alzheimer's Disease**
**and Related Disorders Association, Inc.**
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**(In Illinois)**

## What is Alzheimer's Disease?

Alzheimer's Disease (pronounced Altz'-hi-merz) is a little-known disorder of the brain causing loss of memory or serious mental deterioration. It was first described by Alois Alzheimer, a German neurologist, in 1906. Until recently, it was believed that only persons under age 65 developed this illness. However, new laboratory techniques have revealed that identical changes in the brain also occur in persons age 65. It is estimated that the disease affects from 2 million to 2.5 million middle-aged and older Americans.

In this disease, groups of nerve endings in the outer layer of the brain (the cortex) degenerate and disrupt the passage of electrochemical signals between the cells. These focal areas of degeneration have a characteristic appearance under the microscope and are called "plaques". Changes also occur in the nerve cells of the cortex, leading to an accumulation of abnormal fibers called neurofibrillary tangles. The larger the number of these two abnormalities–plaques and tangles–the greater the disturbance in intellectual function and memory.

The terms pre-senile and senile dementia are used to describe any kind of severe mental impairment in older individuals. Approximately one-half of such persons are victims of Alzheimer's Disease; about another quarter have diseased blood vessels and the remainder suffer from a variety of other conditions such as brain tumors, thyroid dysfunction and pernicious anemia. Diagnosis of the specific type of senile or pre-senile dementia is very important since some types, other than Alzheimer's Disease, can be effectively treated.

## What Are Its Symptoms?

At first, Alzheimer's Disease exhibits only minor and almost imperceptible symptoms that are often attributed to other illnesses. Gradually, however, the person becomes more forgetful. As memory loss increases, changes also appear in personality, mood and behavior. The person may neglect to turn off the oven, misplace things, take longer to complete a chore that was previously routine or repeat already answered questions. Judgement, concentration, speech and physical coordination may also be affected. Some individuals show confusion and restlessness and require special assistance.

There are many patterns in the type, severity and sequence of mental changes in this illness. The symptoms are usually progressive, but there is great variation in the rate of change from person to person. In a few cases, there may be a rapid decline, but more commonly, there are long periods with little change.

Although the person with Alzheimer's Disease is often unaware of, or may deny the full extent of his or her limitations–especially late in the course of the illness–the development and course of the illness are a source of deep frustration for those afflicted and for their loved ones.

## What Causes Alzheimer's Disease?

Alzheimer's Disease, as mentioned earlier, affects the cortex of the brain resulting in the development of plaques and neurofibrillary tangles. These changes are not caused by hardening of the arteries. Nor is there evidence that the disease is contagious. Although emotional upsets and stress may temporarily affect the person's mood and behavior, they are not the cause of the illness.

Alzheimer's Disease occurs in two to three percent of the general population over sixty years of age. Within the same family, there may be an additional increase in its occurrence up to four or five percent. This may represent a slight hereditary disposition or an undetermined environmental factor. However, Alzheimer's Disease does not usually affect more than a single member of the family.

Scientists are now applying the newest knowledge and research techniques to the study of human brain tissue removed at autopsy. Although there are a number of promising clues as to possible virus infections, immune processes and biochemical disturbances, the actual cause of Alzheimer's Disease is unknown and further scientific investigation is required.

## How is the Diagnosis Made?

The diagnosis of Alzheimer's Disease is made only after other illnesses, which also result in memory loss, are excluded. Each person suspected of having this disease must have a thorough neurologic evaluation. The condition must be differentiated from forgetfulness that occurs during normal aging and from depression which may also affect memory. The presence of brain tumors, strokes, infections and abnormalities in the spinal fluid system (hydrocephalus) must be eliminated. Diagnostic techniques such as computer tomography (CT scan), electroencephalography (EEG) and studies of the spinal fluid system are usually needed to differentiate the various causes of dementia. Comprehensive blood studies, including tests for several metabolic disorders, must also be carried out.

After other diseases–many of which may be easily treatable–have been excluded, a firm diagnosis of Alzheimer's Disease can usually be made on the basis of history, mental status and the course of the illness. Periodic neurological and psychological examinations are useful in evaluating the progress of the disease.

## What Is The Treatment?

As yet, the prevention or cure of the disease is not known. However, medical care can relieve many of its symptoms and proper guidance can assist the person and family in coping with the illness.

SCIENCE '84 (October)

Alzheimer's Disease Information
ADRDA — ASIST
P.O. Box 77031
Seattle, WA 93177
(206) 542-7488

*Time drags the frame on through its changes*
*but the body just stumbles along behind . . .*
*A fine practical joke by sun and moon*
*but I ask you who's going to laugh?*
Fan Ch'eng-ta, Chinese 12th-century poet

# THE CLOUDED MIND

## When a key brain enzyme disappears, so does memory.

**by Michael Shodell**

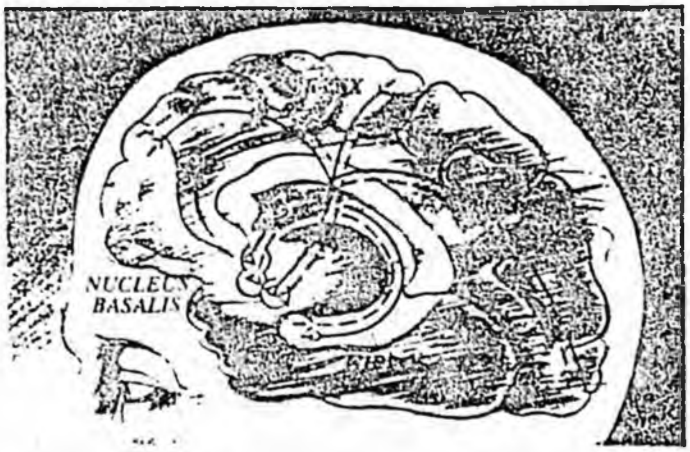
Old age, even in cultures where it is venerated, is often viewed with ambivalence. And as living standards and medicine continue to improve, more and more of us will be the butts of Fan Ch'eng-ta's fine joke. For with an increased life-span, afflictions that once were rare have become common. Among the gravest of these is Alzheimer's disease, an illness that destroys the mind, leaving the body behind as a grim reminder of the person who once was there. As cancer, another all-too-familiar companion of the later decades, has become a relentless reminder of the urgency in seeking the secrets of the cell, so Alzheimer's disease has left us with another pressing challenge—uncovering the mysteries of the mind.

Alzheimer's disease is one of the most fearsome and devastating aspects of aging: It has no known cause, no prevention, no cure. It afflicts about a million people, roughly five percent of the population over 65. By the year 2000 an estimated three to four million Americans, or one of every 10 adults over 65, will be a victim. Hundreds of scientists around the world are dedicated to understanding this affliction. Some are isolating Alzheimer's biochemical defects in the brains of victims, others are comparing these to similar ones in other dementias, while still others are looking at rare dementia-causing diseases from distant parts of the globe.

In this way, they hope to pin down Alzheimer's cause, which is as elusive today as it was in 1906 when the German neurologist Alois Alzheimer first described the disease in a report entitled "Concerning a unique illness of the brain cortex." Alzheimer was the first to show that senile dementia was not just a natural wearing out of the mind, a belief common then as it had been through the centuries. Shakespeare reflected that conviction when he described the last age of man as "second childishness and mere oblivion." While severe dementia may be caused by a number of illnesses, such as brain tumors, alcoholism, or arteriosclerosis of brain blood vessels, Alzheimer's disease is by far the single most prevalent cause of mental deterioration in the elderly.

Victims initially have trouble remembering recent events. Gradually, as their minds deteriorate, they become more confused and forgetful, repeating questions asked moments before, for example, or getting hopelessly lost while traveling to previously familiar places. Disorientation grows, and memories of the past disappear, sometimes accompanied by paranoia, hallucinations, and violent mood swings. Patients can no longer cook, drive, or use tools. Later, they lose their ability to read, write, eat, walk, or talk. Finally the disease culminates in a full dementia, the undoing of the mind.

In his seminal paper Alzheimer first described one of the two physical characteristics of the disease: the clumping of fibers within nerve cells, called neurofibrillary tangles. The other—the so-called senile plaques—are filled with knobby, abnormal nerve axons and terminals wreathed around amyloid, a waxy, translucent protein that looks like rippled pasta. These structures nest among the mass of normal brain cells and fibers in the cerebral cortex, the outer layer of the brain in which higher thought processes and abilities originate, and the hippocampus, which seems to play a special role in learning and memory. The plaques and tangles can easily be seen with a low-power microscope.



*Solid green lines represent the path of a normal amount of enzyme that is produced in the nucleus basalis and travels to the cortex, where it aids in manufacture of the neurotransmitter acetylcholine. In Alzheimer's patients, a reduced amount of the enzyme, dotted green lines, reaches the cortex, impairing mind and memory. A similar enzyme deficit, dotted red lines, may affect short-term memory in the hippocampus.*

disease of kuru, which means fear or trembling. Through a combination of anthropological, medical, and epidemiological creativity and tenacity, D. Carleton Gajdusek of the U.S. National Institutes of Health was able to show that this illness, which appeared to be a classic chronic degenerative disorder, was actually caused by an infectious agent. The kuru agent was not passed from person to person, but rather from the dead to the living as the mothers and children handled the infected brains of the deceased as part of their mourning ritual. The disease progressively attacks the brain and nervous system of its victims, who first shiver, stagger, slur their speech, eventually can neither walk nor sit up without assistance, and, finally unable to chew or swallow, die.

The discovery of this agent, and the establishment of its ability to have infected years or even decades before its devastating effects have become unleashed upon the brains of its victims—effects that include dementia and probably the senile plaques in victims' brains as well—brought a new perspective to the consideration of degenerative neurological disease. Such kurulike agents are now known to occur in a variety of species, including the widespread scrapie disease of sheep, and another human affliction known as Creutzfeldt-Jakob syndrome that occurs virtually worldwide. Named after the German scientists who discovered it in 1920, Creutzfeldt-Jakob syndrome causes a severe form of senility that strikes people in their middle to later decades and progresses far more rapidly than Alzheimer's. It is also a disease, although far rarer than Alzheimer's, for which family inheritance patterns have been demonstrated in some instances. But even in these cases, infectious slow viruses—similar to the kuru and sheep scrapie viruses—are the actual cause.

Another seemingly isolated incidence of disease on a remote Pacific island offers yet another possible candidate as the cause of Alzheimer's—the environment. A tribe known as the Chamarros, living in a relatively underdeveloped region on Guam, develop extremely high incidences of Lou Gehrig's disease (amyotrophic lateral sclerosis or ALS)—the progressive wasting of muscles that killed baseball's "iron man"—as well as Parkinsonlike ailments and dementia accompanied by Alzheimerlike neurofibrillary tangles. It turns out that the region of Guam where the tribe lives is almost entirely devoid of such essential minerals as calcium and magnesium. Neuropathologist Daniel Perl of the University of Vermont believes that these deficits combined with and possibly leading to unusually high accumulations of heavy metals, especially aluminum, seem to play a role in the genesis of the illnesses of the Chamorros. In addition, Perl has shown that the tangles in the brains of victims of Alzheimer's disease also contain aluminum and that this metal, when injected into the brains of experimental animals, can also lead to the formation of similar, although not identical, tangles.

This discovery has caused people to worry about using aluminum pots, pans, foil, deodorants, and Rolaids for fear the metal will accumulate in the brain. Perl says that the evidence available is not sufficient to warrant these concerns. Aluminum is the most ubiquitous metal on Earth, and it is impossible to avoid it. Although it is definitely toxic to the nervous system, most people luckily have efficient barriers to prevent aluminum from getting into the brain. Perl says he is now trying to find out what the barrier mechanisms are that keep aluminum out. He is also studying the potential effects of advancing age, slow viruses, and other factors on the integrity of the barrier system.

The list of suspects implicated in Alzheimer's disease, then, is distressingly broad: genetics, infectious agents, and environment—either acting alone or in concert. Should the cause be infectious or environmental, researchers might be able to eliminate or inactivate it. But what if it should be something more fundamental and far-reaching—a genetic program for senility that is part of the aging process—one of the seven stages of man? Were that so, Alzheimer's would not be a disease at all. There would be no cure. Doctors could only make the affliction more bearable.

By comparing Alzheimer's to known diseases such as Parkinson's, kuru, and Creutzfeldt-Jakob, however, it seems likely that Alzheimer's is a true disease. As such there is hope for seeking its causes and its possible cures. Then aging need not portend Shakespeare's "mere oblivion" after all, but rather a stage of life to be appreciated for its own strengths as well as for its weaknesses—a stage as legitimate and no more pathological than any other.

*Michael Shodell is a contributing editor of* Science 84

A special report

# The mystery of ALZHEIMER'S disease

Photo by S. J. Birdsall

By S. J. Birdsall

Nine years ago Rebecca Clement did not know about Alzheimer's disease. But she did know that something was wrong with her mother.

"At first it seemed as though she was getting to be hard of hearing," Clement said. "She didn't seem to quite catch what I would say. Then she began writing little notes to herself about what my name was, what my sister's name was, and about things around the house. And she began making poor decisions concerning her business.

"I thought that she was going crazy."

Five years and a long, confusing search later, Clement's mother was finally diagnosed properly. She had Alzheimer's disease.

"The doctor told us 'This is what she has, we don't know much about it, you'll have to live with it,'" Clement said.

Alzheimer's disease is a progressive, degenerative erosion of the cells of the brain that deal with thought and memory. It is not known what causes it, and there is no known cure for it or no known way of stopping its progression.

The disease progresses from an almost unnoticable lack of sparkle and spontaneity in the victim to an almost complete loss of memory, an inability to perform simple daily functions, and an inability to recognize family members and other individuals.

Alzheimer's kills, but the road traveled by its victims and their families from that first forgotten name or mishandled business transaction to the grave is long and slow, lasting from five to 15 years.

"It's like a funeral that never ends," Clement said, echoing other families who have had to deal with Alzheimer's. "The grief is always there."

During the course of the disease, the financial and emotion-

Continued on page 16

# ALZHEIMER'S

A Special Report

## The families: lifetime savings spent on care

Continued from page [illegible]

…costs to the victim's family can be devastating.

Clement, an Anchorage woman who has independently studied the disease since her mother's diagnosis, said that very often the caregiver, usually a family member, will die before the Alzheimer's victim will.

"Caring for an Alzheimer's victim is very, very stressful," Clement said. "Caregivers have heart attacks, high blood pressure – all the things you can get from stress.

"'Caregiver's Disease' is what the families get. Depression, higher use of drugs and alcohol go along with it. Because a person is so busy taking care of the Alzheimer's victim, there's a lack of outside activities and a loss of one's own feelings. It's easy to become an unidentified person. The Alzheimer's person can take over your life."

According to Clement, most Alzheimer's victims need 24 hour supervision.

"In the beginning I was teaching school and was afraid to leave Mother by herself," Clement said. "So I got permission to take her to school with me, and afterwards I would bring her home to my house or take her to my sister's for the evening."

Clement and her sister, Beverly Tallman, eventually hired Louise Bates to spend the nights at their mother's.

"It's a very hard thing to do, to work out all the details and still keep Mother happy," Clement said. "If she thought we were moving someone in with her, she would be offended. So we gave Louise money to give to her, as if she were paying for the room, when in actuality we were paying Louise to stay with her.

"You end up telling a lot of lies, even if you've never told a lie to your mother before in your life. You have to [illegible] to get through."

In 1981 Clement and Tallman each quit their jobs in order to care for their mother.

"For about two years Sunday was one of my days to take care of Mother," Clement said. "I would have her all day, in addition to my small children. By the time Sunday was over I would be a wreck.

"You have to watch her every minute. Alzheimer's victims are liable to do anything – take a bite out of a bar of soap – run away – one time my sister left a bottle of peroxide on the counter and Mother began drinking it."

Clement's mother now spends about seven and a half hours each day at the Daybreak Elderly Daycare and Alzheimer's Center in Anchorage. The center was created two years ago.

Care cost at the center is on a sliding scale, ranging from $2 to $25 per day.

Because of the length of the disease, the cost of care for Alzheimer's victims can financially ruin them and/or their families.

"Insurance companies, Medicaid and Medicare exclude custodial care," Clement said.

Continued on page [illegible]

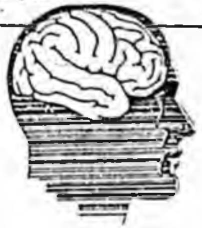
## Four phases mark Alzheimer's symptoms

The course of Alzheimer's disease has been divided into four phases:

- Phase one: This phase is described as "[illegible]." The symptoms at this point are extremely subtle and may go unnoticed. Characteristics of this phase may include a lessening of spontaneity, sparkle, energy, and drive in the victim. The victim also may learn and react slower than before, may become angry easier and may shun the unfamiliar.
- Phase two: In this phase the victim is still functioning normally in many ways. However, the victim may be much slower in understanding and in speech, may have great difficulty in making decisions and plans, and may be unable to calculate. The victim may become increasingly self-absorbed and insensitive to the feelings of others.
- Phase three: In this phase the victim is obviously disabled, and his or her behavior will probably be markedly changed. The victim's memory of the recent past may be poor or failing, while memories of the distant past may be astonishingly clear. The victim may lose orientation to time and place, invent words, misidentify people, and have little personal warmth.
- Phase four: Victims in this final phase will need increasing help with the simple activities of daily living. The victim may be apathetic and incontinent, may have poor remote and recent memory, and may have no recognition of individuals, including family members.

Symptoms may vary from person to person, and diagnosis is not a sure thing. The above symptoms can be caused from reversible, treatable disorders such as trauma, tumors, neurological or circulatory disorders. Symptoms may also be caused from malnutrition.

**Stories by**
**S. J. Birdsall**
**and**
**Rebecca Goodman**



## Studies unravel clues to Alzheimer's disease

by Rebecca J. Goodman

No cure for Alzheimer's disease has burst upon the medical scene as yet, but researchers are cautiously optimistic that they will one day unlock the mystery of the brain-destroying neurological disorder responsible for severe memory loss in some two million Americans.

What causes Alzheimer's disease is still unknown but recent research has unraveled some clues to the possible causes and mechanisms of the disease.

Several factors are suspected of playing a major role in the onset of the disease and researchers are studying their leads. These leads include:

- Tissue breakdown in the brain cells;
- genetic factors;
- pathogens such as "slow" viruses or virus-like agents, and
- environmental toxins such as trace metals.

Tissue breakdown – Autopsies of Alzheimer's victims at some of the new research center "brain banks" indicate that the disease causes significant damage to brain tissue.

Some of these changes include shrinkage of the brain, "tangles," a spaghetti-like mass of abnormal protein fibers in the brain tissue, and "plaques," clumps of deteriorated nerve endings.

Recent research from several medical centers in the U.S. suggests that there is a strong link between these brain tissue changes and the severity of mental impairment.

There is still no answer to how the tissue damage is caused but chemical deficiencies in the brain are suspected.

For instance, one group of medical studies reports that the brains of Alzheimer's victims show deficiencies of a chemical called acetylcholine – a nerve impulse-transmitting chemical responsible for conveying nerve "communications" between cells.

Research efforts have shown that in addition to chemical deficiencies, the Alzheimer brain uses less glucose than the normal brain.

Glucose is the main "fuel" for brain energy and it is a vital chemical link in the body's manufacturing pathway for acetylcholine.

Some scientists have suggested that future treatment possibilities for Alzheimer's patients in the beginning stages of the disease could include use of compounds that would enhance the levels of acetylcholine transmission through the brain's nerve cells.

Genetic factors – Investigators are also pursuing the incidence of Alzheimer's disease in families. Research studies have been sparse, but what is available suggests that there is clearly a risk of developing Alzheimer's disease if a parent or sibling was affected by the disease at an early age.

As yet, no one can answer the questions posed by family members of an Alzheimer's victim. No one knows what the chances of getting the disease are for sons or daughters of affected patients.

**Pathogens: "slow" viruses** – Another research effort that aroused much attention explored the possibility that Alzheimer's disease is caused by a "slow" virus or virus-like agent.

A few years ago researchers at the University of California medical school in San Francisco discovered a tiny infectious agent – dubbed "prion" – which appeared to be associated with several kinds of degenerative brain diseases.

According to researchers, the characteristics of the "prion" are similar to the chemical compounds found at the core of degenerated nerve tissue in Alzheimer's victims' brains.

The "prion" is called "slow" because it is suspected of a long developmental stage – perhaps as long as 20 years. By contrast, most viruses are fast-acting and display detrimental effects within hours after initial infection.

Environmental toxins: trace metals – Canadian researchers were among the first to explore the effects of environmental toxins such as aluminum and other trace metals on brain cell metabolism.

Early investigators experimentally caused brain tissue damage in lab animals by injecting aluminum salts. The tissue damage to the protein fibers that resulted from the experiment was similar to the "tangles" found in Alzheimer's brains.

More recently, research teams studying aluminum concentrations in Alzheimer's victims reported finding brain tissue concentrations of aluminum 10 to 30 times greater than in normal brains.

Scientists caution that there is no evidence that aluminum actually causes the development of Alzheimer's disease. And there is still no evidence that consumption of foods cooked in aluminum or use of products containing aluminum (certain deodorants, baking powders, pickling compounds, antacids, etc.) result in high concentrations of aluminum in the brain.

Aluminum has long been viewed as a "friendly" element because it is so widespread in the earth's crust.

Exploring the aluminum-brain deterioration link further, Canadian researchers recently undertook a pilot study using aluminum-removing drugs called chelating agents on Alzheimer's patients.

Initial results were reported as encouraging, but long-term studies are now necessary to determine the risks and benefits of using chelating agents known to be dangerous to humans.

Research continues to explore the questions of how aluminum enters the brain tissues, at what levels it becomes toxic and why, as brains age, there is a general increase in aluminum concentrations in the tissues.

The pace of research into Alzheimer's disease has dramatically quickened over the past 10 years, but much remains to be unraveled about the disease.

One important question investigators have yet to answer is whether Alzheimer's is actually one disease or two.

In the meantime physicians and medical researchers are refining diagnostic techniques to define the underlying characteristics of this mysterious Alzheimer's disease.

> ***Research continues to explore the questions of how aluminum enters the brain tissues and at what levels it becomes toxic and why, as brains age, there is an increase in aluminum concentrations in the tissues***

# Help for Alaskan Alzheimer's victims

by S. J. Birdsall

During the course of Alzheimer's disease it may become necessary to place the victim in a nursing home or other care facility.

Nursing homes in the state of Alaska will generally accept the Alzheimer's victim for care provided he or she meets the normal requirements for admittance.

Nursing homes in the state who say they will accept Alzheimer's victims include:

- St. Ann's Nursing Home, Juneau;
- Wesleyan Nursing Home, Seward;
- Our Lady of Compassion Care Center, Anchorage;
- Denali Center in Fairbanks;
- Pioneers' Home in Fairbanks, Ketchikan, Palmer and Sitka.

The Anchorage Pioneers' Home has in the past admitted people who are suffering from Alzheimer's disease, but the home is currently not admitting Alzheimer's victims, according to Donna Stephens, manager of the Anchorage Pioneers' Home.

"We don't have the space or the staff for them," Stephens said.

According to Stephens, the Anchorage home is planning to increase services in order to provide the Alzheimer's victim with the "best possible" care.

"Our staff has been studying this disease," Stephens said. "We're in the process of training and improving our program in this area."

Alzheimer's victims may also find long-term nursing care in some Alaskan hospitals. These hospitals include:

- Ketchikan General Hospital;
- Wrangell General Hospital and Long Term Care Facility;
- Nome Hospital, and
- Petersburg General Hospital.

According to Yvonne Foster, director of the Daybreak Elderly Daycare Center in Anchorage, in the past two years about 50 percent of Day Break's clients who have Alzheimer's have had to go Outside in order to find placement in a nursing home.

"It's very hard on the families to send their loved ones Outside," Foster said. "And unless the Alzheimer's victim is in the very last stages of the disease, the move to the states means more confusion and another loss."

Foster said that many families try to care for their failing family member until a "breaking point" is reached and immediate placement into a home is necessary.

"Since many places in Alaska have waiting lists, families have to turn to nursing homes outside the state in order to find immediate placement," Foster said.

According to Foster, the Southcentral Counseling Center, of which Daybreak is a subsidiary, is working to create a cottage-type care center specifically for Alzheimer's victims.

Foster said the center hopes to construct the first of four care cottages in 1985 but, she said, the cottage concept is "still a dream."

# Alzheimer's victim: healthy body, failing mind

Continued from page 16

"Most families cannot afford to keep the Alzheimer's victim in his or her home." Therefore, Clement said, many Alzheimer's victims end up living with their children or other relatives.

According to Clement, care for her mother costs $3,000 a month, which has so far been paid for with her mother's assets.

"My mother was widowed at 33 and was left with four children to raise," Clement said. "She was a very sharp business person. She took what money there was and bought and sold real estate."

Clement said that her mother has enough money left to pay for two more years of care, and that before the end of those two years Clement intends to "see to it" that Alaska has a "quality place" for her mother to live.

"Her body is still very healthy, and she could live many more years," Clement said. "Most families have to send their people Outside to nursing homes, and it's a real potluck affair as far as knowing where's the best place to send your loved one."

**'Caregiver's Disease' is what familes get. Depression, higher use of drugs and alcohol go along with it . . . The Alzheimer's person can take over your life - R. Clement**

Clement said that after "nine years of grieving" she and Tallman decided to set their grief aside and "do something to make it better for anyone else who may have to go through this."

In addition to forming Alaska's only Alzheimer's family support group in Anchorage, Clement and Tallman are members of the nationwide Alzheimer's Disease and Related Brain Disorders Association based in Chicago.

According to Clement, the association's goals include:

- Research — getting the government to realize that Alzheimer's is the fourth leading cause of death in the United States and to put money where it is needed.
- Public Education — inform the public on the symptoms of Alzheimer' disease and what it takes to take care of its victims.
- Caregiver's rights — establish a "Bill of Rights" for those who care for family members who have Alzheimer's disease.
- Homes — establish quality low-cost care facilities for Alzheimer's victims.

Clement is Alaska's contact person for the association, and people with questions about Alzheimer's disease can call her at 344-6706 or Tallman at 563-6503. The association's toll free number is 800-621-0379.

The family support group meets on the second and fourth Tuesday of each month at 10 a.m. at the Anchorage Senior Center, and on the first Thursday of the month at 7 p.m., also at the senior center.

Clement's mother is now entering the fourth and final stage of the disease. She can speak only a few nonsensical words, and, except for an occasional glimmer of reality, she does not know her daughters. Soon she will be unable to perform the simplest of functions for herself — eating, going to the bathroom, changing her clothes . . .

"She was only 52 when she got Alzheimer's," Clement said.

According to Clement, research suggests that the younger a person is when they initially get the disease, the greater the chance that their offspring may have a hereditary tendency toward getting it.

"Of course I worry about getting it," Clement said. "Maybe not as much as I should, I guess. I just don't believe that the Lord would do it to us twice. I just don't believe that He would put us through hell twice."

## References for families

Several useful references are available for families or spouses coping with an Alzheimer's victim.

- *Alzheimer's Disease: A Guide for Families* by Lenore S. Powell and K. Courtice. Addison-Wesley, Reading, Mass., 1983.
- *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.
- *A Guide to Alzheimer's Disease for Family, Spouse and Friends* by Barry Reisberg. The Free Press, New York, 1983.
- *The Nursing Home Rating Project, Citizens for Improvement of Nursing Homes*. 1305 NE 47th, Seattle, Washington 98105 (206) 634-2349.
- *Q & A: Alzheimer's Disease*, U.S. Department of Health and Social Services reprinted by Alzheimer's Disease and Related Disorders Association, Inc., 360 N. Michigan Avenue, Suite 601, Chicago, Illinois 60601.

The Alzheimer's Disease and Related Disorders Association (ADRDA) will also send upon request a fact sheet on the disease, a recent newsletter by ADRDA and an order form for other educational materials.

Write the above Chicago address or call ADRDA at (800) 621-0379.

## Alzheimer's Glossary

Acetylcholine—A chemical compound active in the transmission of nerve impulses. In the brains of Alzheimer's victims, the level of choline acetyltransferase, an enzyme that stimulates production of acetylcholine, is abnormally low.

Alzheimer's disease—A disorder of the cells of the brain, the most common cause of severe intellectual impairment in older individuals.

Alzheimer, Alois—(1864-1915) A German physician who studied the relationship of changes in the structure of the nervous system to disease, and who first described the changes in the disease that carries his name.

Brain enzyme—A protein that accelerates a specific chemical reaction in the brain.

Nerve cell—A neuron, the basic unit of the nervous system consisting of a cell body and its threadlike extensions for receiving and transmitting impulses.

Plaque—A localized abnormal area found in the brain of a person with Alzheimer's disease.

Tangle—An accumulation of abnormal fibers in the nerve cells in the cerebral cortex.

*Adapted from. Q & A Alzheimer's Disease, U.S. Department of Health and Human Services, 1981.*

### Teleconference on Alzheimer's Disease set July 31

A conference and a state-wide teleconference sponsored in part by the Alzheimer's Disease Family Support Group will be held July 31 beginning at 8:30 a.m. at the Anchorage Senior Center located at 1300 E. 19th. For more information call 344-6706.

## Article 4. Older Alaskans Commission.

Section
200. Older Alaskans Commission
210. Meetings
220. Compensation

Section
230. Powers, duties, and limitations
240. Definitions

**Sec. 44.21.200. Older Alaskans Commission.** (a) The Older Alaskans Commission is established in the Department of Administration. The members of the commission include

(1) the commissioner of the Department of Administration or the commissioner's designee;

(2) the commissioner of the Department of Community and Regional Affairs or the commissioner's designee;

(3) the commissioner of the Department of Health and Social Services or the commissioner's designee;

(4) the chairman of the Pioneers' Homes Advisory Board appointed under AS 44.21.100 — 44.21.130; and

(5) seven Alaskans selected on the basis of their knowledge and demonstrated interest in the concerns of older Alaskans, appointed by the governor in accordance with (b) of this section.

(b) After requesting from senior citizens' organizations the names of persons who are qualified for and interested in serving on the commission, the governor shall appoint the members of the commission under (a)(5) of this section. Appointments shall be made by the governor to assure representation of low-income persons and minorities, and representation from rural and urban areas of the state, and to secure statewide geographical representation on the commission. At least six of the persons appointed by the governor shall be 60 years of age or older. At least two of these persons shall be 65 years of age or older. Each member appointed by the governor shall be a resident of the state.

(c) The persons appointed under (a)(5) of this section serve overlapping four-year terms, and serve at the pleasure of the governor. A member may be reappointed, but a member appointed under (a)(5) of this section may not serve more than two consecutive terms or eight consecutive years, whichever is longer.

(d) If a person appointed under (a)(5) of this section fails to attend three consecutive meetings of the commission, a majority of the members of the commission may request the governor to terminate the membership of the member and to fill the vacancy.

(e) A vacancy in the membership of persons appointed under (a)(5) of this section shall be filled by appointment by the governor. The person appointed shall serve for the unexpired portion of the term. (§ 2 ch 79 SLA 1981)

**Cross references.** — For provisions related to the commission's initial membership, see § 13, ch 79, SLA 1981, in the Temporary and Special Acts

**Editor's notes.** — Section 13, ch. 79, SLA 1981, provides: "INITIAL MEMlimitations

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BERSHIP AND MEETING OF COMMISSION. (a) Of the seven public members first appointed by the governor to the Older Alaskans Commission under AS 44.21.200(a)(5),

(1) three shall serve a term of two years;

(2) two shall serve a term of three years;

(3) two shall serve a term of four years.

(b) In making appointments of the first public members of the Older Alaskans Commission under AS 44.21.200(a)(5), the governor shall designate an expiration date of the terms of members first appointed in accordance with (a) of this section.

(c) The governor shall determine the date and place of the first meeting of the Older Alaskans Commission; however, that meeting shall be held not later than September 13, 1981.

**Sec. 44.21.210. Meetings.** (a) The commission shall meet at the call of the chairperson, at the request of a majority of the members, or at a regularly scheduled time as determined by a majority of the members. The commission shall meet at least six times each year.

(b) The members of the commission listed in AS 44.21.200(a)(1) — (4) may not vote on matters before the commission. A majority of the members of the commission listed in AS 44.21.200(a)(5) constitutes a quorum for conducting business and exercising the powers of the commission.

(c) The commission shall elect one of its members as chairperson, and may select other officers it considers necessary. (§ 2 ch 79 SLA 1981)

**Sec. 44.21.220. Compensation.** Members of the commission receive no compensation for their services, but are entitled to per diem and travel allowances authorized by law for other boards and commissions under AS 39.20.180. (§ 2 ch 79 SLA 1981)

**Sec. 44.21.230. Powers, duties, and limitations.** (a) The commission shall

(1) formulate a comprehensive statewide plan that identifies the concerns and needs of older Alaskans and, with reference to the plan adopted, prepare and submit to the governor and legislature an annual analysis and evaluation of the services that are provided to older Alaskans;

(2) make recommendations directly to the governor and legislature with respect to legislation, regulations, and appropriations for programs or services that benefit older Alaskans;

(3) encourage and aid the development of municipal commissions serving older Alaskans and community-oriented programs and services for the benefit of older Alaskans;

(4) employ an executive director who serves at the pleasure of the commission;

(5) help older Alaskans lead dignified, independent, and useful lives;

(6) request and receive reports and audits from state agencies and local institutions concerned with the conditions and needs of older Alaskans;

(7) administer, with the approval of the commissioner of administration, federal programs as provided under 42 U.S.C. 3001 — 3045i (Older Americans Act), as amended; and

(8) administer, with the approval of the commissioner of administration, state programs as provided under AS 47.65.010 — 47.65.060.

(b) To accomplish its duties, the commission may

(1) review, evaluate, and comment upon state programs concerned with the problems and the needs of older Alaskans;

(2) collect facts and statistics, and make studies of conditions and problems pertaining to the employment, health, financial security, social welfare, and other concerns that bear upon the well-being of older Alaskans;

(3) provide information about public programs that would be of interest or benefit to older Alaskans;

(4) appoint special committees, which may include persons who are not members of the commission, to complete necessary studies;

(5) promote community education efforts regarding the problems and concerns of older Alaskans;

(6) contract for necessary services;

(7) consult and cooperate with persons, organizations, and groups interested in or concerned with programs of assistance to older Alaskans;

(8) advocate improved programs of benefit to older Alaskans; and

(9) set standards for levels of services for older Alaskans for programs administered by the commission.

(c) The commission may not investigate, review, or undertake any responsibility for the longevity bonus program (AS 47.45.010 — 47.45.170) or the Alaska Pioneers' Homes (AS 47.25.010 — 47.25.100). (§ 2 ch 79 SLA 1981)

**Editor's notes.** — Section 14 of ch. 79, SLA 1981, provides: "TRANSFER OF PROGRAM RESPONSIBILITIES. The following are transferred to the Older Alaskans Commission in the Department of Administration:

(1) the programs conducted under the Older Americans Act, P.L. 89-73, as amended, and the persons who administer those programs in the division of adult and aging services, Department of Health and Social Services;

(2) the programs conducted under AS 47.65.010 — 47.65.060, and the persons who administer those programs in the division of adult and aging services, Department of Health and Social Services; and

(3) the Governor's Advisory Committee on Aging."

Section 15 of ch. 79, SLA 1981, provides: "CONTINUING RESPONSIBILITY OF THE DEPARTMENT OF ADMINISTRATION. This Act does not affect the responsibility of the Department of Administration for the Alaska longevity bonus program (AS 47.45.010 — 47.45.170) or the Alaska Pioneers' Homes (AS 47.25.010 — 47.25.110)."

**Sec. 44.21.240. Definitions.** In AS 44.21.200 — 44.21.240, "commission" means the Older Alaskans Commission. (§ 2 ch 79 SLA 1981)

Anchorage Daily News
Monday Monday Jan. 21, 85

# Elderly care expensive in Alaska

By RONNIE CHAPPELL
Daily News reporter

Only the rich, the poor and the lucky can afford the $48,000-a-year cost of nursing home care in Alaska.

Almost everyone else must leave Alaska to find affordable long-term care, said Rod Betit, director of the Division of Medical Assistance.

The rich pay their own bills. Medicaid takes care of the poor. The lucky gain admission to state-run Pioneer Homes.

Middle-class Alaskans are caught between their retirement incomes and constantly increasing nursing home costs that now average $4,000 a month, Betit said. And even when family members contribute to the cost of care the gap often is too wide to overcome.

"It's a national problem," Betit said. "But the gap is smaller in other states" where nursing home care is half as expensive as it is in Alaska.

For that reason, lots of middle-class families end up placing grandpa or grandma in a nursing home thousands

See Back Page, NURSING

# Nursing home cost dilemma

Continued from Page A-1

of miles from home.

No one knows how many are forced to leave the state, Betit said. All that is certain is that few are turning up at Alaska nursing homes.

There are 550, non-Pioneer Home long-term care beds located in hospitals and nursing homes around the state. Almost all — 90 percent — are filled with Medicaid patients.

According to Betit, the other 10 percent are filled with patients who will be Medicaid-eligible once they have used up their assets paying their medical bills.

Some middle-class senior citizens do make it into state-run Pioneer Homes. Many, however, can't meet the 15-year residency requirement and others must compete with indigent patients — who would be Medicaid-elgible if they sought care at privately operated facilities — for the 300 or so "skilled nursing beds" available within the Pioneer Home system.

For middle-class senior citizens, Betit said, "there aren't a lot of choices."

That fact has Betit and other state officials taking a hard look at proposals to build new nursing homes in Homer and Soldotna. Sixty-bed facilities are planned in both cities.

"Why build the beds if there are not enough Medicaid-eligible people to fill them?" Betit asked hospital supporters at a hearing in Homer earlier this month.

Mike Herring, administrator at South Peninsula General Hospital in Homer anticipates little difficulty filling the $5 million facility that his hospital hopes to open in 1988. The Homer health-care facility just added 15 long-term beds and all are filled, Herring said.

"People who need the care will become indigent," he said. "What happens now is that the system requires people to pauperize themselves to be eligible for it. They give their assets away to their children."

Liquidating assets isn't always enough. People who earn more than $975 a month cannot qualify for Medicaid-funded nursing home care. A survey of 1982 federal tax returns revealed that about 60 percent of Alaska's elderly residents had monthly income above that standard, Betit said.

To meet the needs of that 60 percent, health care providers must search for ways to make nursing home care affordable, said Richard Waller of the Lutheran Homes and Hospital Society.

Lutheran Homes wants to open a nursing home in Soldotna next year.

"We're looking at alternatives to inpatient care," he said. Under one program, working people could leave elderly family members in the morning and pick them up at night.

Another option, Betit said, would be to require companies writing medical insurance in Alaska to provide coverage for long-term care.

That way the expense could be spread over a large number of policyholders. The policy might not pay the entire cost of a nursing home stay but it could narrow the gap enough to allow middle-class families to keep elderly Alaskans close to home, Betit said.

Companies are being forced to provide coverage for long-term care in other states, Betit said. "It appears to be financially successful."

# Pioneer Homes and Alzheimer's an uneasy combination

**Support group seeks answers**

by Margaret Haight

The Alzheimer's Family Support Group of Alaska brought both good news and bad to a workshop held at the Senior Citizen's Center in Kenai last week: Senility is not an inevitable part of aging; but by the year 2,000 an estimated one in ten adults over 65 will suffer from Alzheimer's type dementia.

Dementia, meaning "deprived of mind", is the most frightening aspect of Alzheimer's for the victim and the most painful for the family. Labelled senility, the dimming of the mind was long considered a normal part of aging.

Today, however, medical professionals and researchers insist it is natural to be clear-headed until the monent of death. "Senility is not normal, senility is a disease called Alzheimer's" is the sentiment echoed by family support groups around the nation. The perspective is an important

(Continued on Page 9)

# Pioneer Homes and Alzheimers: an uneasy combination

(Continued from Page 1)

one. Given a glimmer of hope, people will fight for a cure instead of accepting mental deterioration as a sympton of aging. The cause ofAlzheimers is as yet undefined. What is certain is tht it strikes the elderly from all walks of life, indiscriminantly.

Beverly Tallman and Becky Clement, sisters from Anchorage, watched helplessly as their mother's mind slowly clouded for five years before she was diagnosed as having Alzheimer's. Frustrated by the lack of financial and emotional support available to Alaskans afflicted with the disease, Tallman and Clement established a non-profit support group six-months ago and embarked on a rigorous campaign to educate the public about Alzheimer's disease. "This is the only thing we can do for our mother now," Clement said.

Though about two million middle-aged and elderly Americans suffer from Alzheimer's, most insurance polices and medicare benefits exclude custodial care in their health coverage. An Alzheimer's victim may live more than 15 years after the onset of the disease becoming increasinly helpless. Because of the length of the disease, and the costs of respite care, Alzheimer's often financially ruins both victims and their families.

Clement and Tallman said they learned early on that those holding the purse strings of the state coffers knew little or nothing about the disease and the plight of the victim's families. Even Alaska's five Pioneer Homes were unequipt to give the 24-hour attention required by the Alzheimer's suffer, and routinely turned them away.

In theory, the Pioneer Homes of Alaska provide state subsidized care impartially to all elderly Alaskans who meet the age and residency requirements. But in reality Alzheimer's victims fit poorly into the Pioneer Home system as it operates today. For those elderly who are capable of self-care residence halls are available. Nursing units serve those that require skilled nursing or are bedridden. But for the mentally infirm, many many of whom continue to be ambulatroy and may be a danger to themselves or others, neither alternative is optimal.

Nelda Wythe, member of the Alaska support group, said that part of her mission to the Peninsula Wednesday was to urge Kenai residents to plan for some kind of intermediate care facility if and when a Pioneer Home becomes a reality in the area. Wythe said the Pioneer Home system unintentionally, but effectively, excludes the mentally disabled. She told workshop participants that due to limited space and high demand for housing in the Pioneer Homes, a priority system governing admittance was designated by state law.

As space becomes available applicants with the greatest financial need are accomodated first, second priority goes to the physically disabled, and third to those in the residentail wing that are in need of mare intensive care, Wythe said.

Unable to gain entry into the Pioneer Home system, Wythe said many Alzheimer's sufferes are placed in private homes at an average cost per day of $121 in Alaska. "The nature of the system simply pauperizes the individual and the care-giving families," Wythe said. She said financial assistance to minimize the discrepancy in cost between the Pioneer Home and private care would alleviate much of the problem and might prove more economical than trying to establish special care units for the mentally impaired in existing Pioneer Homes.

"Significant numbers of the least capable elders in the state are excluded from state aid," Wythe said of

(Continued on Back Page)

# Pioneer Homes are split on Alzheimer's

the current system.

She said the Alzheimer's victim might eventually find placement in a Pioneer Home, but only after a tragic series of events.

"You place your elderly relative in a private home until that individual's resources are exhausted, the family's reources are exhausted, medicaid is exhausted, then---delcared indigent---they'll go to the head of the priority list for Pioneer Homes," Wythe said. "It's a catch-22."

Donna Stephens, manager of the Anchorage Pioneer Home, said the system has never discriminated againest the mentally infirm. She said 15 of the current Anchorage residents have Alzheimer's type disabilities. Stephens said priority over beds in the facility is governed first by financial need and secondly on overall need including social, mental, physical and emotional considerations.

"But there are only a finite number of resources. If a person's safety cannot be insured they can't be accepted," Stephens said.

When Stephens became manager of the home in February she said she attempted to evaluate how well different groups of people were being cared for. She concluded that better services were needed for those with Alzheimer's type disabilities. During the 1985 fiscal year Stephens said she will petition the legislature for additional funding to increase nursing care throughout the home. She said one of her specific requests will be for funding of an Alzheimer's special care facility. Stephens said the space for such a facility is already available, but staffing is expensive. Stephens said the Anchorage home will continue to accept those with dementing illnesses as staffing allows.

Last year the Divsion of Pioneer Benefits came under fire from advocates for the mentally disabled elderly. Regulations were being drafted goverining all aspects of the Pioneer Home system, but a preliminary draft of a clause con

*of services to others.*

Keller said following a public hearing and input from many individuals the language of the clause had been modified. Keller declined to be specific about changes in the wording but he said, "We have heard those people, and their concerns have been addressed in the final draft."

Keller said his department has been attacked by those on three separate sides of the issue of whom Pioneer Homes should serve. He said some feel it is immoral for the homes to serve those that are not in need of financial or medical assistance. Others feel the homes should be reserved for seniors who are somewhat independent, as these living in the residence units. They argue that the Pioneer Homes should not be turned into nursing homes. And lastly, there are those who believe some sort of special accomodations should be established for the mentally infirm

"At no point can we make a choice without offending at least two of these groups," Keller said. "We're not going to try to do it (make decisions) on a disease-of-the-month type concept."

Keller pointed out that the current appeal process for applicants who are not accepted into a Pioneer H[illegible] clearly spelled

illness can't wait. Clement said since June three people from the 60 member Alaskan support group have given up on receiving help in their home state and gone outside.

The latest of these emigrants, she said, involved an extreme but not unusual situation. Clement said she had been trying to aid a man whose wife was in the advanced stages of Alzheimer's. Grace had been on a Pioneer Home waiting list for two years and her husband Joe had meanwhile exhausted all other avenues in seeking care for her in Alaska. Grace had frequent vilent outbursts and Joe had padlocked all the the cupboards, doors and the refridgerator to restrain her destructive impulses.

"I went to bed at night wondering if one of them would be dead in the morning," Clement said. The last time she phoned the home to ask how things were going, Joe said he had locked himself in his bedroom to escape his wife.

Clement phoned a Seattle support group and explained the emergency situation. The Seattle group placed Grace in a home within three days and the couple moved from Alaska after nearly four decades of residence.

Sen. Paul Fischer and

Kenai Peninsula Cheechako News

10/31/84

# A history of Alzheimer's

Alois Alzheimer, a German scientist, first described the disease in 1906. A 51-year-old woman had come to him seeking treatment for her increasing disorientation and memory loss. Her problem was later complicated by depression and hallucinations, and eventually, in a severly demented state, she died.

The patient's brain was found to be atrophied and the outer layer of the brain showed microscopic tangles of fibers in the nerve cells. These jumbles of filaments have since become the telltale sign of Alzheimer's disease.

Little is known about what causes the brain to begin to deteriorate. Diagnosis is most often based on the presence of symptomatic behavior. Specific diagnosis of Alzheimer's is possible through biopsy, done by removing a piece of the skull and extracting a sample of brain tissue to be examined for the hallmark neurofibrillary tangles. While elimination of other possible causes is important, positive diagnosis of Alzheimer's is costly and of little use since no cure in currently available.

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## Alzheimers History

(Continued from Front Page)

The Cat scan, a monumental breakthrough for neurology, allows medical professionals to examine the patients brain, section by section, through the use of x-rays, and to eliminate brain tumors and other disorders as possible causes of mental impairment. Another exciting new tool which promises to prove invaluable in Alzheimer's research, is called positron emission tomography (PET). Glucose

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## Alzheimers History

(Continued from Page A4)

(sugar) is the primary source of brain energy, according to Louis Sokoloff of the Laboratory of Cerebral Metabolism, at the University of Pennsylvania. The rate of cerebral uptake of glucose, therefore, is a direct measure of activity in any given region of the brain. In a PET scan, the subject is injected with a radioactively marked analogue of glucose that becomes trapped in the brain because it cannot be metabolized. External counters on the skull measure the small amounts of emitted gamma radiation, indicating the amount of brain activity during sleep, sensory stimulation, and disease states.

Post-mortem examination of brains ravaged by Alzheimer's has shown lower than normal quantities of chlorine actyltransferase, an enzyme used in manufacturing acetylcholine. Acetylcholine is an important neurotransmitter for the functioning of memory.

Dr. Peter Davies, of the Albert Einstein College of Medicine in New York City traced the source of acetylcholine to a portion of the brain called the neucleus basalis. He found that in autopsies of people believed to have suffered from Alzheimer's about 75 percent of the acetylcholine producing cells in the neucleus basalis had been destroyed. Researchers were encouraged by the similarities of Alzheimer's and Parkinson's disease, which is caused by deficiency of the neurotransmitter dopamine. Doses of the enzyme L-Dopa have resulted in significant improvements in the neural functioning of Parkinson's victims. Though results have not been as dramatic in the case of Alzheimer's sufferers, the drug physostigmine has been shown to increase brain. levels of acetylcholine by about 10 to 25 percent in one. out of three victims, with corresponding improvments in memory functioning.

Lecithin, an enzyme with many similarities to choline, occurs in many foods and has also been examined as a possible nutritional treatment for Alzheimer's. To date there is little evidence that memory, mood or behavior of Alzheimer's patients is improved by lecithin.

The quantity of aluminum particles in the brain rises in most people with age, but higher than expected levels are found in the brains of Alzheimer's victims, leading researchers to speculate on the relationship between aluminum and mental functioning. Aluminum is present in large quantities in the natural environment, making exposure inevitable; but studies indicate that aluminum exposure does not lead to dementia. Experimental use of drugs which eliminate aluminum from the body have had little preliminary success as Alzheimer's treatment. Many researchers now believe high levels of aluminum are the effect rather than the cause of Alzheimer's type dementia.

Another theory of Azheimer's causation is a malfunctioning of the body's immunological system. Some of the proteins used by the body to fight infection have shown abnormal levels in Alzheimer's patients. Scientists suspect the body's defense system, designed to battle alien cells, sometimes goes awry and attacks body tissue.

Perhaps the most consistently sighted cause of Alzheimers, heredity, has offered researchers some clues. An adult's chances of developing Alzheimer's are about one or two in a 100 at age 65, but odds increase four-fold if a close relative has the disease. With stepped up research on the family histories of Alzheimer's patients, another enetic link has become ragically visible. lzheimer's family members

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## Alzheimers History

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are found to have up to 10 times greater risk of giving birth to a Down's Syndrome child. The syndrome is known to be the result of a genetic deficiency, and victims who live to the age of 35 show neurofibulary tangles similar to those found in Alzheimer's

Speaking on a video tape shown at a recent Alzheimer's workshop in Kenai, Dr. Davies estimated that the cause of Alzheimer's disease would be clearly delineated in about five years and a cure in sight within ten.

Kenai Peninsula Cheechako News
10/31/84

# Alzheimer's creates emotional and financial burdens

by Margaret Haight

"I put locks and dead bolts on the door, not to keep burglars and strangers out, but to keep John in," Marion Hylen said, averting her eyes momentarily and groping for strength to talk about an illness that steals a bit of her husband day by day.

John had not been himself for nearly 15 years. But last fall, at her wits end, Marion took him to Seattle where he was diagnosed as having Alzheimer's disease; a life sentence characterized by a relentless and irreversible deterioration of the mind.

As a young man, John came to Alaska in 1929. He traveled around the state immersing himself in the things he loved best, freedom and the outdoors. Marion was employed as a nurse in Anchorage when she met John. "He was a good looking man," Marion said, with an inscrutable smile hinting simultaneously at happiness and sorrow.

They were married and came to Ninilchik in 1948 to homestead 160 acres and raise two boys. Sometimes John still talks coherently of those early days and mentions Marion's name, as though she too is just a memory of the past. He does not connect his pioneer wife with the older woman who now cares for him constantly, but is an unknown stranger in his house.

John and Marion Hylen came to Ninilchik in 1948.

"He knows my face, he knows I belong there, but he doesn't really know who I am," she said.

John was good with his hands. He could fix anything. He built his family's home and filled it with elegant hand-crafted furniture. The walls are decorated with oil paintings done by John during a younger era.

Sometime in the early seventies, Marion recalled, John put away his paints and brushes without explanation. In her mind the day is marked as the beginning of the end.

John became less and less himself, friends stopped coming to visit, and Marion shouldered an increasing burden of responsibility which had once balanced between her and John. All property and assets were listed in both their names, but John could no longer sign his.

"I was on my own and there was no one to talk to," she said. Marion hesitated in seeking full power of attorney over John's affairs. "It was like saying he was gone," she said.

Alzheimer's victims often remain physically well long after they have become mental invalids. John would wander away from the house at any time of day or night. Marion couldn't leave him alone, yet something as simple as a trip to the grocery store had become an ordeal. If she turned her back for a second he would disappear and Marion would give up the shopping trip in frustration.

John was equally frustrated. Sometimes he would struggle to tell Marion something, but only manage to utter, "I just can't say it." Sometimes he cried. Many Alzheimer's victims vent their frustrations in violence, and though John had never harmed her, Marion was frightened by his unpredictability. Locked in the house with him at night she sometimes slept in a living room chair to avoid letting herself be cornered when he stood in a doorway.

Finally, Marion decided to combat the loneliness and exhaustion brought about by her 24-hour vigil.

"I said to myself, either you're going to go under or you're going to survive; and you better make up your mind."

Five years ago at the age of 67, Marion began a career as a real estate broker. She set-up a small office next door to the house, found a caretaker for John, and hired a secretary; as much for someone to talk to as anything else, she said.

"Well, it saved me, that I had something else," Marion said. But the downhill course of Alzheimer's marched on. John began to imagine he saw people in the house. He could describe them in vivid detail and when Marion came home to have lunch with him he might ask, "Aren't you going to feed these other people?"

One night on his way to bed John informed her there were three strangers sitting on the couch in the living room and said, "Why don't you throw those bums out." Until recently she had insisted to John that there was no one there, but one day John said to his caretaker, Nikki, "Marion tells me those people aren't there, but I know better." Deciding that her denials only confused him and caused him to mistrust her, Marion now pretends with him. "What difference does it make now," she said.

John had been an avid gardener for years, but last season he left the weeds and pulled up healthy plan-

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## Alzheimers Victim

(Continued from Front Page)

ts instead. In his attempts to fix broken machinery that used to present no challenge to him, John began to ruin expensive tools.

Stripped of his talents one by one, he began to spend most of the day indoors sleeping or looking at magazines. One of the cruelest tricks of Alzheimer's is the momentary lifting of the fog. "Sometimes he actually reads," Marion said. But the clarity is always temporary. Marion might find him later holding a book upside down and looking at it blankly - the caprices of the disease making a cruel mockery of a once dignified man.

Marion does what she can to salvage the vestiges of what he once was. She makes sure he always has some cash and a knife in his pocket to remind him of decades of self-reliance. "He loses one (knife) and I buy him another one," she said. "You just can't take those things away."

Last Autumn John embarked on one of the severe mental plunges that are typical of Alzheimer's disease. He had difficulty feeding and dressing himself. "If he couldn't get a button open he would use his knife and cut it off," Marion said. "Zippers are horrendous; if he can't make them work, he'd just-as-soon rip them out." He began to misjudge the position of chairs, falling when he tried to sit down. He was sometimes incontinent. Marion took John to Virginia Mason in Seattle. "They put a name to it," she said, after years of not knowing why her husband's mind was slipping away.

During a recent afternoon visit John sat quietly in his living room, surrounded by the lovely artifacts of his once active mind and hands. His eyes are the same striking blue as Cook Inlet which forms a backdrop to the view from a window behind him. He rises, shakes the visitor's hand and smiles warmly...a convincing mirage of the person he was. But Marion said just that morning he had come to her weeping and asked her to zip his coat. She asked him what was the matter and he replied, "I want to go home."

The stress and constant demands of the disease often usher the spouse into death years before the victim. John has been on a waiting list for a pioneer home for two years. But even with his 55-year residency status, Marion said she has little hope of his being admitted with his need for round-the-clock care. Her sons urge her to consider a private home. One of them told her recently, "I don't want to lose both of you, Mom."

John still shows glimmers of recognition when his family is around him and he is calmer in the house where things have remained purposely unchanged for years. But, Marion said, when she is sure he no longer derives any comfort from the familiarity of his family's faces...it may be time.

Kenai Peninsula Cheechako News
10/31/84

SB 117

Senator Vic Fischer
Alaska State Legislature
Pouch V • Juneau, Alaska 99811 • (907) 465-4954

Date: 2/26/85

To: Senator Bettye Fahrenkamp

From: Senator Vic Fischer

Re: Scheduling for SB 117 - Alzheimer's Disease

I am requesting that you schedule a hearing for SB 117 at your earliest convenience. Attached are fiscal notes from the Older Alaskans Commission and the Department of Health and Social Services, a recently completed report from the Alaska Alzheimer's Family Supporrt Group, and other descriptive back-up materials.

This bill calls for the development of daycare centers to provide quality care for Alzheimer's victim and respite for families of victims. Daycare centers are inexpensive and efficient programs that can provide needed stimulus, social interaction, and care for the disease victim. The Older Alaskans Commission would provide Alzheimer's daycare centers in various parts of the state.

This program provides needed financial and emotional relief for those Alaskans and their families that are neither rich enough to afford thousands of dollars a month for essential care, poor enough to be eligible for Medicaid, or lucky enough to have the Alzheimer's victim reside in a Pioneer Home.

A diagnostic service, based in Anchorage, is also proposed. Because of the similiarity to other disease's symptoms, there have been many instances of misdiagnosis. Many would-be Alzheimer's victims actually have another illness that may be treatable, or may just be showing normal age-related forgetfulness. Proper diagnosis is needed, in order to reassure these older Alaskans that these symptoms are benign and to properly diagnosis Alzheimer's and other diseases.

The states of Washington and California have adopted similiar programs. Washington has funded demonstration projects for adult daycare. California has in place a $4 million program that provides diagnostic services, daycare centers, and funding for Alzheimer family support groups.

Alzheimer's is a disease that we must take action on today to relieve not only the patient, but also the family. The types of preventative health care described in SB 117 are critical to the dignity and lifestyle that the state government can provide to our older citizens.

*During Interim • 1024 W. 6th Avenue, Suite 201C • Anchorage, Alaska 99501 • (907) 278-3654*

# PROBLEMS AND NEEDS OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS VICTIMS AND THEIR FAMILIES IN ALASKA

BY

REBECCA CLEMENT

FEBRUARY 19, 1985

Alzheimer's disease is a little- known but remarkably common disorder that affects the cells of the brain. This disease produces intellectual impairment in adults. The experts use to believe that the disease occurred mainly in persons under age 65. However since the late 1970's researchers began to recognize it as the most common cause of severe intellectual impairment in older people as well.

The fact that many people have never heard of Alzheimer's disease does not mean that it is a rare illness. Many individuals who have the disease never receive the precise diagnosis. The only sure way to diagnose Alzheimer's disease is by preforming an autopsy . Pathologists find scattered throughout the cortex, groups of nerve cell endings degenerate and disrupt the passage of electrochemical signals between the cells. The areas of degeneration have a special appearance and are called plagues . Another change in the brain occur in the proteins of the nerve cells , leading to an accumulation of abnormal fibers called tangles. The larger the number of plaques and tangles, the greater the disturbance seems to be in the intellectual function and memory .

## NATIONAL STATISTICS

The best current estimates indicate that more than three million North Americans may suffer from this disease. After cancer, heart disease and stroke, it is thought to be the fourth most common cause of death.

The problem is that A.D. is not usually listed as an official cause of death on death certificates, which leads to inaccurate statistics about the incidence of Alzheimer's Disease. This disease occurrs in three percent of the population over age 60, and in more than 20 per cent of those over age 80. It is estimated that in just fifteen years (by the year 2000) one person in ten over the age of 65 will be a victim of Alzheimer's Disease or Related Disorder.

## THE SYMPTOMS

In the beginning the symptoms are almost imperceptible and are often mistaken for emotional upsets or other physical illnesses. However, the person becomes more forgetful, especially when asked to remember most recent events. As the disease progresses, memory loss worsens and confusion, irritability, restlessness, and agitation begin to appear. Personality , mood and behavior changes also take place. Judgement, concentration, orientation, and speech is affected. The symptoms are progressive, and show many different patterns in the type, severity, and sequence of changes from person to person. Most commonly the decline is over many years, 2 to 20 years, in some cases.

# ALZHEIMER'S DISEASE IN ALASKA

During the period March 1, 1984 through February 25, 1985, The Alzheimer's Disease Family Support Group of Alaska has identified three major areas of concern.

1. How many victims of Alzheimer's Disease and Related Disorders are living in the state?
2. What are the living situations of these victims?
3. What will the needs be for the future?

During the period March 1, 1984 through February 25, 1985, 413 senior citizens in the state of Alaska have been identified as having Alzheimer's Disease or a Related Disorder (ADRD). Of the 413 seniors identified as having ADRD, it is signficant to note that 161 seniors are residing in their communities while 252 seniors are living in institutions throughout the state. ( see attachments)

Let us for a moment consider what are some of the needs of the victims and their families.

1. Most know little or nothing about the disease.
2. Victims of this disease are subject to safety hazards, malnutrition, elder abuse and neglect, financial exploitation, and medical inattendance.
3. The victims who are living alone are especially vulnerable to all of the above. " Mother was diagnosed in 1979, I was teaching school at the time. I checked on her each morning and then went off to school wondering if she would leave the stove on and burn up her house. I worried about who might come to the door and how she might be influenced by strangers. I was afraid because she still wanted to drive her car. Would she get lost and where would I look for her? Finally I was able to talk to my principal about the problem. Mother came to school with me every day until school was out and began doing simple tasks in my classroom. The next fall I resigned from teaching after nine years. authors personal experience.
4. The victims who are living with spouse or family present worry and untold stress to those who are caring for them.
   " 78 year old man roams around village causing worry on the part of the neighbors. He lives with son and daughter-in-law and teenage children and this is causing resentment on the part of the children." From rural questionaire - Cordova

5. The victims need to have a proper diagnosis in order to rule out psuedo dementias and proper medical attention by a doctor who knows and understands the behaviors exibited by these individuals. See attached - List of reversible causes of Mental Impairment

6. Families need assistance to prevent elderly abuse. Caregivers are not educated about the disease and therefore do not understand behavior patterns and the ways of dealing with the abusive situations that can occur. Most victims are isolated and the families become confined to a home that is half prison and half nursing home. One daughter reports about her 82 year old father. " He often wants to tear up things, move things around and break things. From questionaire Juneau.

7. Victims must have a stable, consistant living situation that will help preserve the dignity, security and independence of life . "I knew I could no longer care for my husband in our own home in Kenai. He was so confused and I was under tremendous stress trying to meet his needs. We applied for residence in the Anchorage Pioneers' Home. Nick can go to the Daybreak Day care Center during the week . I am so thankful that I did not have to place Nick in a nursing home . This arrangement allows us to still be independent and offers security to me. Elsa Weiler - Pioneers' Home Anchorage.

8. The ADRD victim and families need a variety of in-home support services in order to continue to care for their loved ones at home as long as possible. In-home care services could reduce the cost of in institutionalization to the state significantly. ' Consider the example of adult day care . Adult day care service for a full year costs approximately $ 9,100. In comparison, 80% of Alaska's nursing home residents are Medicaid eligible and the February 1983 average per diem rate for nursing home care totaled slightly over $44,326 per year. Jon Wolfe , Older Alaskans Commission, Testimony on HB 124. Feb. 8, 1985

9. Families find it very difficult to get through the bureaucratic madness in order to receive the badly needed in-home support services. "Disabled and elderly persons who do not live in institutions find they must interact with the funding bureaucracy of different funding sources for every service they receive. This entails meeting different eligibility requirements, completing separate application, and often undergoing multiple assessment evaluations. In Anchorage, a disabled person needing assistance might apply for social security disability at the Social Security Office, food stamps at the local State Public Assistance Office. Homemaker support is available after it is authorized by a State Social Worker at the Family Youth Services Office and an assessment of need is completed both by the Social Worker and the Homemaker program. Authorization to use the transportation system for senior transportation system would be obtained at the Municipality of Anchorage Senior Program office. The individual might also put his or her name in at the local Alaska State Housing Authority office to be put on the waiting for subsidized, barrier-free housing. If physician services and medications are required, Medicare or Medicaid might assist with the bill of the eligibiltity criteria are met and the appropriate forms are filed. The problem is not the number of programs available, but rather accessing the service in time of need. Unfortunately, the requirements and criteria for medical and social services do not intermesh, but instead overlap or leave huge gaps between services" Donna Stephens reports in "The Continuum of Long Term Care in Anchorage, October 1982"

10. When the victim can no longer stay at home and be cared for by the family, care facility which would meet the needs of the ADRD victim is not available in Alaska at this time. It is the opinion of the families that the traditional skilled nursing home does not meet the needs of the ambulatory ADRD person in particular. " When Mother went to live in the nursing home, she could walk and talk. She could play the piano and sing. After two months, she had no glasses and no teeth, and each time I went to see her she was restrained in her wheel chair or so over medicated that she was unable to talk with me . These feeling were expressed during an interview - Anchorage

11. The financial burden which comes with the cost of institutionalization is very excessive for all those families when the victim does not qualify for state Medicaid benefits. " My father lives with us now. He could not take care of my mother any longer. We tried to have them both live with our family, but then we couldn't take care of her either, after about six months. My father pays $6,000 a month for my mother to stay at the hospital here in Kodiak. They have a few beds for long-term care. The thing that bothers me most is that she is so restricted all the time.' A daughter of an Alzheimer's victim conveyed her feeling during a telephone interview. - Kodiak

12. Another major area of concern is that there seems to be no facility that is able to take an ADRD victim in an emergency. If the family comes to a crisis point in caring for the ADRD person, there needs to be some facility that could meet this immediate need. " One elderly man had been caring for his wife for three years. She became very combative and was no longer able to attend the adult day care with other ADRD persons. The elderly husband was forced to keep his wife at home with him 24 hours per day. the husband had to put locks on all the cupboards and the refrigerator. He had to lock her in her bedroom at night for fear that she would wander out of the house during the night. She had been picked up by the police several times and taken to API. It was not unusual to see scratches and bruises where she had struck out at him in her confusion. The husband was not able to find placement in Alaska even though she was a long-time Alaskan. The only help that the man received was from his sister and the Alzheimer's Family Support Group of Alaska and Seattle. A placement for the with was finally made in Seattle because of the cooperation between the two support groups." Personal Experience, author.

13. When families have presented their financial concerns as well as expressed their frustration about adequate placement for Alaskans in nursing home or Pioneers' home, to those official in high level state positions, they frequently are asked, "Don't you have family living outside who can help you find placement where the cost of long term care is not as great?" telephone interview Seward Alaska.

A recent article in the Anchorage Daily News further illustrates the growing financial needs concerning elderly care.

" Only the rich, the poor and the lucky can afford the $48,000-a- year cost of nursing home care in Alaska. Almost everyone else must leave Alaska to find affordable long-term care, said Rod Betit, director of the Division of Medical Assistance. The rich pay their own bills. Medicaid takes care of the poor. The lucky gain admission to state-run Pioneers' Homes.

Middle- class Alaskans are caught between their retirement incomes and constantly increasing nursing home costs that now average $4,000 a month. Betit said. And even when family members contribute to the cost of care the gap often is too wide to overcome. " It's a national problem." Betit said. " But the gap is smaller in other states where nursing home care is half as expensive as it is in Alaska."

For that reason, lots of middle-class families end up placing grandpa or grandma in a nursing home thousands of miles from home.

No one knows how many are forced to leave the state, Betit said. All that is certain is that few are turning up at Alaska nursing homes." January 21,1985 by Ronnie Chappell

# Alzheimers Disease and Related Disorders in Alaska

## A Summary of Needs

by
Rebecca Clement

The needs of the Alzheimer's and Related Disorder Victims are great. The families who care for them are being asked to bear the stress and the exhaustion as well as the full financial resposibility for the care that is required. No family should be made to keep the ADRD victim at home with them longer than they can physically and well as mentally cope , just because of the great financial costs. It becomes a breading ground for elder abuse. The incapacitated victim is also abusing the caregivers and this creates a vicious cycle of abuse in the family. **"The rich pay their own bills. Medicaid takes care of the poor. The LUCKY gain admission to the state run Pioneers' Homes."**

Families find it very difficult to get through the bureaucratic madness in order to receive the badly needed in-home support services, if they are available in the community. Any time the ADRD person, frail elderly or the handicapped can remain in the home, it is of emotional benefit to the victim as well as financial benfit to the state. Some of the following could be very helpful to the victims and families : Adult Day Care, Chore Service, Client Finding ,Escort Service, Health Maintenance Activities, Homemaker Services, Meal (Home Delivered and Congregate), Outreach, and Referral. It is the hope of many ADRD families that a boost in the budget for the Older Alaskans Commission , which provide the financial support for these services, will happen during the 1985 session.

When the ADRD victim is institutionalized, it is the sincere feeling of families that the ambulatory victims' needs are not being met within the traditional skilled nursing home setting. Far ~~to~~ frequently, they are restrained in wheelchairs, or are being over-medicated so they will not wander around. **They are made to conform to the needs of the facility, rather than the facility responding to the needs of the ADRD victim.**

It is evident when reviewing the data collected by the Alzheimer's Family Support Group, that the incidence of ADRD is found throughout the state . Information from 29 communities indicates that there are 161 persons afflicted with ADRD who are living in their communities with caregivers and families. Data also indicates that 252 possible ADRD victims are living currently in institutional settings around the state. These current numbers safely tells us that indeed there are at least 413 probable cases of ADRD in the state. These figures do not include areas of the state that the Family Support Group has not been able to survey. These areas include some of the following; Northslope Borough other than Barrow, Bethel and outer villages of the area, Dillingham and King Salmon area ,Aleution Chain, Outer villages of the Nome area, Southeast other than Juneau. I would estimate finding another 20 to 30 victims in these areas.

The Family Support Group conducted Alzheimer's Disease Educational Workshops in Juneau, Anchorage, Fairbanks, and Kenai in an effort to find out how many victims were living in the state, what were the living situations, and to determine the needs of the future concerning ADRD victims.

This year the Alzheimer's Family Support Group will be conducting ten more workshops around the state. This is supported by a grant from the Older Alaskans Commission. These workshops will be located at Tok, Kodiak, Cordova, Kotzubue, Sitka and Ketchikan, Sand Point and Unalaska, Pribilof Islands and Kotzebue , with updates in Anchorage and Fairbanks. It is hard to estimate just how many afflicted persons the Family Support Group will find after presenting these workshops . I would estimate finding another 100 ADRD or more during the coming year. We will also be paying close attention to the needs of the Frail Elderly who are living in the communities and need the support of families as well as community based services in order to remain at home .

The time has come when families are asking the public and private sectors for more help ( financially as well as emotional support) in caring for their loved ones. Families will be insisting that their family members be allowded to remain in this state when institutionalization is required. Also families will become more in need of in-home support services and adult day care programs.

Alaska now has approximately 24,000 person age 60 and older. We must start planning now for the care these individuals will require in the future. The October 1984 edition of Science 84 states. "By the year 2000 one of every 10 adults over the age of 65 will be a victim Of Alzheimer's Disease and Related Disorder."

# ALZHEIMER'S DISEASE FAMILY SUPPORT GROUP OF ALASKA

During the period March 1. 1984 through February 25, 1985, 413 senior citizens in the state of Alaska have been identified as having Alzheimer's Disease or a Related Disorder.

These individuals were identified through a public awareness campaign conducted by the Family Support Group. The support group grew out of the local ADRD Day Care program. In March 1984, three individuals from the group paid for an ad which requested that people who knew someone with ADRD to call. That ad resulted in calls from interested people from all over the state. This interest generated an enthusiasm and awareness for the need for up-to-date and ongoing information , support and services. Since March 84, a core group of six individuals have spent 1776 volunteer hours in providing information, referral and client advocacy. The six individuals are all in the position of being a primary caregivers to ADRD victims.

## SOURCES AND RESOURCES

1. Newspaper advertisements, March 1984
2. Referrals from Daybreak Alzheimer's Disease Day Care Center
3. Referrals from Senior Ombudsman, Older persons Action Group, Public Guardian's Office
4. Responses from notices placed in Pioneers' Homes, Nursing Homes and letters to physicians
5. Television talk show programs, Channels 2, 11, 13, and 7
6. Newspaper articles, Senior Voice, August 1984
7. Questionaires received from rural areas after the July 29th teleconference, Alzheimer's Disease, Now What Do We Do? See Addendum D.
8. Questionaires received from workshops presented in Anchorage, July 29, 1984; Juneau, August 29, 1984; Fairbanks, September 21, 1984; Kenai, October 24, 1984
9. Meeting with Cindy Lincoln, nursing supervisor, in Kotzebue, AK
10. John Mason, Social Worker, Pioneers' Home, Ketchikan
11. Charge Nurse, Sitka Pioneers' Home
12. Kathleen Sutcliff, Aleutian Pribilof Island Association
13. Phone calls made to all Pioneers' Homes, nursing homes, and several community hospitals