

THE GOVERNOR'S TASK FORCE ON ALZHEIMER'S DISEASE

"What is Alzheimer's like? It's a living hell for the spouse and family . . . there gets to be a need to do everything exactly like it's done before, and any change causes confusion . . . he laid his hand on the hot stove burner and didn't know he'd burned it, but still complained about his knee, constantly . . . on his good days, it seemed that his facial expression would be more full and relaxed, and the bad days, more pinched and drawn. His eyes also seemed to change. It was living with a five year old child in the body of your husband, and him not aware that there was anything at all wrong with him."

"She still knows our daughter and me and appreciates every little thing we can do for her. At times she is negative, but mostly she cooperates and her kindness and concern for others comes through . . . she refuses to eat much of anything and is getting weaker and weaker. The nurses and aides love her and are taking good care of her. I never argue with her and find that if I wait a few minutes she will let me take care of her. As you would suspect she remembers past events but not recent ones. We have taken her to our daughter's home and a few hours later she cannot recall having been there."

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Definition and Scope

Alzheimer's Disease is a progressive, irreversible neurological disorder that affects an estimated 2.5 million American adults. It is the most common form of dementing illness. Over 100,000 die of Alzheimer's Disease annually which makes it the fourth leading cause of death in adults, after heart disease, cancer and stroke.

The Disease, first described by Alois Alzheimer in 1906, knows no social or economic boundaries and affects men and women almost equally. Most victims are over 65; however, Alzheimer's Disease can strike in the 40s and 50s. Most Alzheimer's Disease victims are cared for at home, although many persons in nursing homes have dementia. Alzheimer's Disease is devastating for both victims and their families and has been called "the disease of the century."

Symptoms

Symptoms of Alzheimer's Disease include a gradual memory loss, decline in ability to perform routine tasks, impairment of judgment, disorientation, personality change, difficulty in learning, and loss of language skills. There is variation in the rate of change from person to person. The disease eventually renders its victims totally incapable of caring for themselves.

Cause(s) and Research

The cause of Alzheimer's Disease is not known and is currently receiving intensive scientific investigation. Suspected causes include a slow virus or other infectious agent, a genetic predisposition, environmental toxins such as aluminum, and immunologic changes. Other factors also are under investigation.

Scientists are applying the newest knowledge and research techniques in histology, virology, immunology, toxicology, neurology, psychiatry, pharmacology, biochemistry, molecular genetics and epidemiology to find the cause, treatment, and cure for Alzheimer's Disease and related dementias.

Diagnosis

There is no single clinical test to identify Alzheimer's Disease. Before diagnosis of the disease is made, other conditions must be excluded. These include potentially reversible conditions such as depression, adverse drug reactions, metabolic changes, nutritional deficiencies and head injuries.

Each person with possible Alzheimer's Disease symptoms should have a thorough evaluation. Recommended tests include physical, neurological, psychological and psychiatric examinations, and laboratory studies including blood studies, computerized tomography (CT scan), electro-encephalography (EEG) and occasionally studies of the spinal fluid. While this evaluation may provide a clinical diagnosis, confirmation of Alzheimer's Disease requires examination of brain tissue, which is usually performed at autopsy.

Treatment

Although no cure for Alzheimer's Disease is available at present, good planning and medical and social management can ease the burdens on the patient and family. Appropriate medication can lessen agitation, anxiety and unpredictable behavior, improve sleeping patterns and treat depression. Physical exercise and social activity are important, as are proper nutrition and health maintenance. A calm and well-structured environment may help the afflicted person to maintain as much comfort and dignity as possible.

Economic Impact

The course of the disease is usually several years, some of which may require total care regarding daily activities such as eating, grooming and toileting. It is estimated that more than \$40 billion is spent annually on the costs of caring for Alzheimer's Disease victims both in nursing homes and at home.

¹Alzheimer's Disease and Related Disorders Association, Inc., *Fact Sheet on Alzheimer's Disease*, Chicago, IL.

FORMATION OF THE TASK FORCE



Left to right: Former Minnesota Department of Human Services Commissioner, Leonard Levine and Governor Rudy Perpich announcing the formation of the Alzheimer's Disease task force.

On July 10, 1986 Minnesota Governor Rudy Perpich announced formation of a task force on Alzheimer's Disease.

"During April and May I attended ten of the public hearings held around the state conducted by the Minnesota Board on Aging. Among the matters discussed at these enlightening hearings was that of Alzheimer's Disease.

This difficult to diagnose disease is estimated to afflict approximately 2 million men and women in the United States and about 35,000 Minnesotans, mostly persons over 65 years of age.

This progressively debilitating disease causes the gradual mental decline of its victims and is ultimately fatal. Spouses and other loved ones feel helpless as this tragic disease process continues.

Fortunately much is already underway in Minnesota regarding Alzheimer's Disease.

Today I am announcing the formation of a task force on Alzheimer's Disease which is made up of a number of Minnesota authorities. I want to publicly thank all these individuals for graciously agreeing to serve on this panel.

I have asked the task force to report directly to me within 90 days concerning the statewide Alzheimer's Disease effort. I have also asked this group to make recommendations regarding unduplicated research studies we should pursue and other appropriate courses of action."

The task force was comprised as follows:

Frederick Ferron, M.D., Medical Director, Minnesota Department of Human Services, who served as chair;

Gerald Bloedow, Executive Secretary, Minnesota Board on Aging; and Director, Aging Division, Department of Human Services;

V. Katherine Gray, Ph.D., Director of Medicare and Individual Products, PHP of Minnesota;

Ruth Haas, R.N., Associate Executive Director, Minnesota Nurses Association;

William Hargis, President, Minnesota Association of Health Care Facilities;

Richard Heaney, Past President, Metro-Minneapolis/St. Paul Chapter, The Alzheimer's Disease and Related Disorders Association, Inc.;

Thomas Mackenzie, M.D., Department of Psychiatry and David Knopman, M.D., Department of Neurology, University of Minnesota Hospitals;

Gabe Maletta, Ph.D., M.D. and Ken Hepburn, Ph.D., Geriatric Research, Education and Clinical Center (GRECC), Veterans Administration Hospital;

Peter Miller, M.D., Human Development Center, Duluth;

Todd Monson, R.N., M.P.H., Program Supervisor, Hennepin County;

Steve Nielsen, Representative, Minnesota Association of Homes for the Aging;

Valentine O'Malley, M.D., Deputy Commissioner, Minnesota Department of Health;

Ronald Petersen, M.D., Department of Neurology, The Mayo Clinic;

Kathy Righino, Director, Adult Services, Central Mesabi Medical Center;

Jane Royse, M.S., Amherst H. Wilder Foundation;

Bruce Snyder, M.D., Department of Neurology, St. Paul-Ramsey Medical Center.

Between July 29 and October 14 the task force met six times.

In addition to studying eleven basic questions with respect to the disease, the task force heard testimony from Representative Wes Skoglund, Kathleen Davis of Legal Aid, and Pamela Parker who is the director of the interagency task force between the Department of Health and the Department of Human Services. The members spoke by teleconference with Nancy Mace, author of

The 36 Hour Day, a source of information for families regarding Alzheimer's Disease. The task force also received communications from other experts in the field.

A press release was distributed widely in the state asking for written feedback from people with respect to their experiences with the disease. Excerpts from material received are included throughout the report. Public hearings were not scheduled because of the recent hearings on aging and mental health.

RECOMMENDATIONS

"When time is available, I do try to work with my husband at home using techniques employed by our day activity people. If these methods were applied consistently, I feel they could be effective . . . there is little or no respite, little sleep, and no escape . . . victim's caretakers are often not able to attend [support groups] because their freedom is as restricted as the victim's."

"I have seen Alzheimer's Disease support groups and meetings set up. But they are usually 30-40 miles away and usually start at 7:00 p.m. That is too early for me to go. I am sure my mother would go to some of these meetings, but she doesn't like to drive alone and I can't get away that early. What I would like to see is more local meetings. Meetings that would be closer to home and not start so early. I think that even an afternoon meeting might be helpful."

"Professional caregivers as are found in hospitals and nursing homes should have an understanding of the illness and attendant eccentricities of their patients."

1. People in all regions of the state must have access to adequate diagnosis of Alzheimer's Disease, and also to information about services provided in their own regions. Continuing education for health care providers also should be available in each region.

Toward this end, the state should sponsor model education and information resource centers in at least two areas — one urban and one rural. We suggest the hiring of two public health nurses, each as coordinator for one of these models.

2. There should be caregiver support services to provide relief to the primary caregiver from the daily responsibilities of caring for a disabled family member. The proposal of the Minnesota Coalition on Caregiver Support Services is a good model.
3. Requirements must be increased for the educational component of training all persons working with Alzheimer's Disease patients. Curriculums need to include but not be limited to behavioral problems of the patient, communicating with a person with Alzheimer's Disease, and involving the family in continued care. Mandating ongoing nursing home staff inservices around Alzheimer's Disease issues would continue this educational process.
4. Statewide epidemiologic studies or Alzheimer's Disease along with other brain impairments must be developed and initiated in order to understand better the incidence and prevalence of the disease.

5. Minnesota foundations should be enlisted for additional support of Alzheimer's Disease research and pilot service projects, specifically those projects applicable to caregivers and epidemiologic data. Foundations with a special interest in the neurosciences should be contacted first.

6. The autopsy program for brain research should be extended to include the metro Twin Cities area. An advisory group of major investigators should be assembled to further develop this program, e.g. tissue banks.

7. Research should include comparison studies on the efficacy of medications widely used by practitioners in the treatment of behavioral symptoms and signs in patients with Alzheimer's Disease.

8. A standing task force on Alzheimer's Disease and other dementias should be created to provide policy makers with a periodic "state of the state" report on these issues as well as new trends and developments etc. This might also be a conduit for groups like ADRDA and private citizens to transmit their thoughts and concerns. In lieu of such a specific task force, a broader standing task force on chronic illnesses may be beneficial.

9. Health insurance coverage should be changed to cover in some limited way those under 65 years of age who are diagnosed with Alzheimer's Disease.

10. Health and social service agencies should develop all services used by Alzheimer's patients and their families on a sliding fee scale. Where this is not legally possible attempts to change the law should be made.

11. Further discussion is necessary on the risks and benefits of mandated long term health care insurance.

"The root cause, or source, that implants this insidious condition in the brain is going to be difficult to identify until the history of many victims is studied and comparisons are made . . . all routes of investigation must be traveled."

"Recently my father-in-law has had to administer tranquilizers to keep her from wandering and becoming agitated . . . It has become impossible to view TV with her around as the noise upsets her or she thinks they can hear what is happening in her home."

"Fortunately however, they did develop a regimen of medication which kept her well under control so I returned her home."



AUTOPSY BILL SIGNING. Left to right: R.J. Heaney, ADRDA Past President, Metro. Mpls./ St. Paul Chapter; Rep. Wes Skoglund, Dist. 61B; William Frey, Ph.D., Research Director, Alzheimer's Treatment & Research Center, St. Paul Ramsey Med. Center; John Scanlan, M.D., Past Executive Vice-President, Ramsey Clinic, St. Paul Ramsey Medical Center; Senator Eric Petty, Dist. 62; Rep. Karen Clark, Dist. 60A and Governor Rudy Perpich, seated.

ALZHEIMER'S DISEASE: FINDINGS

"Recognize this neurological brain deterioration as a disease, not 'senility'. Otherwise high functioning, intelligent persons don't suddenly become 'senile' in two or three years at ages in the 40's, 50's and 60's. My wife is 60, not 95!"

1. How is the diagnosis of Alzheimer's Disease made; what, if any, changes or improvements can we make in this area?

There is no specific test which can prove the diagnosis of Alzheimer's Disease; only autopsy examination of brain tissue can absolutely confirm the diagnosis, and even then there are cases which are difficult to classify. Alzheimer's Disease typically causes an individual to develop a gradual memory loss which worsens progressively. As months and years pass, impairment of judgment, loss of intellectual abilities, disorders of mood with irritability (and at times aggressiveness) and severe personality change are seen. Eventually self-care is no longer possible; the victim becomes incontinent and loses the ability to identify close family members who provide most of their care.



Jane Royse and Gabe Maletta, M.D. at a Task Force meeting.

The physician with expertise in Alzheimer's Disease must conduct a careful interview and examination and order a variety of laboratory tests in order to rule out other conditions which can resemble Alzheimer's Disease. Some conditions such as severe depression, syphilis, thyroid disorders and uncertain brain tumors may be treatable and their effects reversible. An evaluation will generally include a series of blood tests, an electroencephalogram, CAT scan, and detailed neuropsychological testing. A psychosocial and self-care assessment of patient and family are usually needed as well to arrive at a detailed plan of care.

After completing these examinations and tests, a diagnosis of the cause of a patient's dementia can be made with a high degree of reliability and treatment can be instituted. Ten to twenty percent of people with dementia have a treatable, correctable illness. The results of treatment are much better the earlier it is begun. This means that early diagnosis is important.

There is an urgent need for a specific diagnostic test for Alzheimer's Disease. Such a test should not require an invasive procedure such as a lumbar puncture, brain biopsy or biopsy of any other internal organ. It is conceivable that rather than a single test, a battery of tests may be useful in this regard.

In order to increase the detection of dementing illnesses in general and Alzheimer's Disease in particular, it will be necessary to communicate to medical

personnel, paramedical personnel, and lay people the need for early diagnostic assessment of individuals with memory impairment and personality change. Currently, patients wait until relatively late in their disease before they are seen, and a diagnosis is established. Many physicians are not aware that there is a value in providing a diagnostic assessment, counseling, treatment and support to the dementia patient and his or her family. This attitude can no longer be justified in light of current knowledge of these conditions.

Finally, in order to precisely understand Alzheimer's Disease there will have to be support for basic research in the study of the dementing illnesses. A number of research initiatives are underway in Minnesota at the present time.

2. What is the extent of Alzheimer's Disease in Minnesota; incidence, prevalence, and other epidemiologic data?

Our current estimates of the prevalence of dementia and dementia of the Alzheimer type come from large community studies in northern Europe. These studies have been done in Sweden, Denmark, England and Scotland. Most of these studies focused only on those 65 or older, usually to assess the proportion of older people who are compromised intellectually and need care. Some of these studies included everyone in isolated areas — islands, small rural parishes — others sampled from large metropolitan areas. These studies ranged in size from a few hundred to three thousand people. A few additional points need to be made. The prevalence of dementia and dementia of the Alzheimer type in such studies depends on care definition (how strict one is in the diagnosis of dementia), case finding efforts (how hard one searches for cases of dementia), and the age distribution of the populations studies (the prevalence of dementia increases with age). Taking all these factors into consideration, the consensus of the studies to date, is that 4-5% of people over age 65 are **moderately to severely demented**¹ (4.15% — Epidemiology of Dementia, Oxford University Press, 1981). This 4% includes senile dementia of the Alzheimer type and other dementias.

One further step is necessary to arrive at the proportion of the dementias that can be attributed to different causes. Studies have provided an assessment of the proportion of those demented with Alzheimer's and other dementing illnesses. In these studies there is a careful clinical assessment of a group suffering from dementing illnesses; the group is followed until death and then the autopsy results are carefully correlated with the clinical findings. Such studies have found that 50-60% of the patients have senile dementia of the Alzheimer type.

When conventional methods of estimating the number of individuals over 65 with dementia of the Alzheimer type are used, they suggest that perhaps 10,000 to 13,000¹ of those over 65 in Minnesota are suffering from this disease. The studies on which these estimates are based took place in Northern Europe in areas from which much of the state's population is derived. In addition, there is little evidence to support racial or ethnic differences in the prevalence of dementia of the Alzheimer type, so one is led to believe that these are good estimates for Minnesota. Again, 4% of the population over 65 years of age would be expected to be moderately or severely demented, and 50% of these would be expected to have dementia of the Alzheimer type. This is considering all of those over 65 as a group. Considering this disease from the perspective of those who live to great age, the predictions are more ominous (cumulative morbidity risk — see *Epidemiology of Dementia*, Oxford University Press, 1981). It has been predicted by some that the probability that a person who lives to 80 years of age will become severely demented may be as high as 20%.²

¹Cases of "mild" dementia are difficult to document and have, consequently, not been included in these calculations.

²Additional information and estimates available from L. Ronald French, Ph.D., Minnesota Department of Health.

3. What other studies and task forces have been done on Alzheimer's Disease and what were their outcomes?

The state of Maryland forwarded to the Governor a task force report on June 30, 1985, which made several recommendations relevant to service resources, education and training, financial release, data collection, and follow through and coordination.

The Maryland report highlighted several components of support such as a pool of respite caregivers to relieve family caregivers, encouraging and assisting nursing homes and hospitals to be receptive to short term respite stays by dementia patients, expanding and extending adult day care centers, extending the network of mutual help support groups, providing legal and financial counseling through existing channels, improving and extending diagnostic resources, and excluding from state documents, references to Alzheimer's Disease and multi-infarct dementia as "psychiatric disorders," since they are in fact organic disorders.

In terms of promoting education and training they suggested several steps. One was to develop dementia training centers of excellence, another to incorporate dementia content in all professional education, in the state curriculum for geriatric aid training, and in state mandated inservice education by long term facilities. They suggest engaging the Alzheimer's Disease and Related Disorders Association of Central Maryland to conduct informational and educational activities including a clearinghouse of informational materials, a statewide telephone hotline, and public education forums and professional continuing education programs.

Several financial reliefs were suggested including seeking the easing of eligibility and service restrictions in federal and state programs. They also suggested furnishing financial incentives to families averting institutionalization costly to the state and inducing the insurance industry to develop long term care coverage.

Under data collection they suggested representative data on dementia be developed including its extent, demographic distribution and epidemiologic factors. Further they suggested finding how services are organized and utilized.

Finally they recommended charging a state agency with coordinating and monitoring progress and the recommendations of the Task Force on Alzheimer's Disease and Related Disorders.

In December of 1985 a study committee report on Alzheimer's Disease from the Georgia Department of Human Resources, Office of Aging, was issued. The report begins with a profile of the disease and its impact and goes on to study the effects of the

disease on patients and their families, and much like the Maryland report subcommittees were organized in order to study specific responsibilities. These included in the case of Georgia, data on demography, resources and services, training and education, and financing and funding. This study met from July through November of 1985. They used questionnaires and survey instruments.

They further suggest the adjustment of current Medicaid nursing home reimbursement schedules to take into account the special needs of patients with Alzheimer's Disease and related disorders.

In areas of education and training they suggested the Office of Aging be established as a clearinghouse to collect, analyze and disseminate information on Alzheimer's Disease and related disorders. They also felt education should occur at the level of the Georgia Medical Association to provide continuing education to physicians on the diagnosis, treatment and management of individuals with dementia, and that this should occur at the level of the state licensing board as well.

Concerning research and services, an ongoing data base on individuals with Alzheimer's Disease and related disorders should be established. Use of existing state-wide annual questionnaires on nursing homes, hospitals and home health agencies provide opportunities to gather this information if they're modified to include this data. Many recommendations were made in this area, however one was a need for the establishment of regional diagnostic and treatment centers for Alzheimer's Disease and related disorders in Georgia. Functions of these centers would include diagnosis and treatment, consultation and referral, research and training and education.

Under legal concerns the Georgia study suggested that both the Disabled Adults Protection Act and the Bill of Rights for Residents of Long Term Facilities need to be more stringently enforced.

Like the Maryland study the Georgia study strongly suggested follow up.

The **Kansas** Alzheimer's and Related Disease Task Force final report was issued in 1986. Their recommendations were similar to those of Maryland and Georgia. The Kansas report urged passage of a division of assets law to prevent the abject poverty of the well spouse in his or her attempts to provide for the care of the ill spouse. They also suggested a diagnostic protocol be developed by a subcommittee of the task force on Alzheimer's

Disease and related disorders, which includes suggested guidelines and should be used by physicians for evaluation and diagnosis of demented patients. This protocol should be disseminated through state and county level medical societies.

The Kansas study suggested three multidisciplinary education and service demonstration centers be established for the benefit of patients afflicted with organic dementing illness and their families. These centers should be established in existing state hospitals and university medical centers and would work cooperatively with the Kansas Gerontological Consortium. The function of these centers would be to provide diagnosis, counseling and referral, education, teaching and demonstration units in both nursing homes and adult day care centers, and concise definitions of care for Alzheimer's Disease and related diseases.

The four priority areas of concerns derived from hearings on Alzheimer's Disease were need for financial assistance, need for respite, need for education and information and need for accurate diagnosis.

The state of **Illinois** in July of 1985 published a report on Alzheimer's Disease. The legislative initiative with regard to Alzheimer's Disease in Illinois began in October of 1983.

The **Rhode Island** Legislative Commission on Dementias Related to Aging report was published in May of 1984. Its commission met on 15 occasions in 1983 and 1984 and interviewed 57 witnesses in the course of the sessions. They also assembled and supervised a teaching session on senile dementias on December 2, 1983 with over 100 state health care workers in attendance. They suggested that the executive and legislative leadership of Rhode Island must come to terms with the social enormity of the problem of Alzheimer's Disease. Sufficient resources for the identification and continuing care of its citizens with this disease was seen as imperative. They went on further to state that Alzheimer's Disease has not reached unmanageable proportions, and the state must intervene to provide assistance until such time as research renders this disease manageable.

The commission recommended that there be legislative enactment providing for state income tax abatement for those families carrying the financial burden of caring for patients with verified Alzheimer's Disease.

The commission recommended that the provisions of the Rhode Island Catastrophic Health Insurance Plan be modified so as to

include as legitimate medical compensation the determined fraction of the extended care expenses either incurred within the home or in licensed institutions which are needed for the care of patients with Alzheimer's Disease. The Commission recommended that the state of Rhode Island provide encouragement to Blue Cross-Blue Shield of Rhode Island in their current attempts to design and ultimately provide the citizens of Rhode Island with an actuarially sound policy which would reimburse the cost of chronic diseases such as Alzheimer's Disease which require extended nursing care.

The **Florida** Committee on Aging addressed long term care, Alzheimer's Disease and other forms of senile dementia in January of 1986. They recommended policy initiatives in areas of long term care and research.

There are studies of this type going on in at least five other states presently, and it would seem useful for the Board on Aging to keep current of these developments as they become available.

4. What are the current treatment strategies for Alzheimer's Disease?

Alzheimer's Disease is irreversible and incurable. This does not mean that treatment is unavailable. There are a number of different aspects to the treatment of Alzheimer's Disease as outlined below.

A. Counseling and psychological support — for the patient, early in the disease, there is tremendous anxiety, often depression and a tremendous blow to self-image and self-esteem. Supportive counseling and possibly psychotropic medications for anxiety and depression may be very useful. The patient's family often experiences a great deal of stress as they attempt to provide financially and personally for the increasing need of the patient. Secondary illness in these caretakers is common, and often involves depression, marital stress, financial difficulty, isolation and exhaustion. Again, appropriate support, medical surveillance, counseling, legal and financial services and provision of community services are essential for these individuals.

B. Behavioral control — in certain stages of the disease, the Alzheimer's patient may experience irritability, aggressive

outbursts and possible paranoia with hallucinations. The careful use of tranquilizing medication can decrease and in some cases eliminate this behavior, allowing the patient to remain safely at home for much longer periods of time and to co-exist comfortably with their families. Conversely, these patients are very sensitive to medication. The injudicious use of drugs quickens deterioration, and leads to complications and early institutionalization. Physicians experienced in the care of these patients must guide and advise the therapeutic team in the use of medications.

C. Bladder and bowel control — a number of techniques are available to aid in preventing or at least controlling these problems. These techniques include devices such as disposable absorbent underwear, urinary collecting devices, medications for slowing the emptying of the bladder, the treatment of urinary tract infection or the use of bowel programs to elicit a bowel movement at a predictable time.

D. Stability of walking — a number of appliances such as canes, walkers and braces, as well as the use of certain medications can improve the mobility and stability of these patients. Again this may assist in keeping the patient in a home setting for a longer period of time.

E. Sleep disturbance — patients who are not sleeping at night and who are restless and wandering about the house can be helped to readjust their sleep pattern through the use of increased daytime activity and possibly certain medications.

F. Other symptomatic treatment — drooling can be diminished if necessary through the use of certain medications. Occasionally seizures are a problem and anti-seizure medication can be prescribed. Physical therapy, daytime activity program, and possibly certain rehabilitative programs can help maintain patient's functioning and general well being. Caretakers should receive some instruction in communicating with and working with the demented patient. This can be helpful in decreasing stress and prolonging the patient's ability to remain at home.

G. Specific memory improvement — a number of medications are being studied for their ability to improve the memory function of the Alzheimer's patient. Thus far, however, there has been little success in this area. There has been little progress in identifying a medication which can cure or arrest the underlying disease and this

reflects our lack of knowledge of the cause of Alzheimer's Disease. There is a great need for further research in all these areas.

H. Institutional care — patients with Alzheimer's Disease and other dementing illnesses become more confused and agitated in unfamiliar settings. This is particularly true in the early and middle phases of the disease when they are still able to identify close and cherished family members and surroundings. Therefore most authorities in the field agree that patients should be kept in a familiar setting for as long as possible, that evaluations are best done in an outpatient setting. It will be important to educate physicians and other health care personnel to the special needs of the Alzheimer's patient in the hospital. These include a high degree of sensitivity to a number of commonly prescribed drugs, a tendency to become more confused and agitated in an unfamiliar setting which may result in injury and other complications. Similarly, nursing home placement is often poorly tolerated until the patient has reached such a point of deterioration that they can no longer recognize family and surroundings at all. Nursing home staff must be educated and supported in the care of these difficult patients, techniques for behavioral management and the design of suitable environments may be of value as well.

"My wife, 56 years old, has Alzheimer's Disease and is disabled but is still living at home. In two or three years I'm sure she'll require nursing home care. No one acknowledges that Alzheimer's Disease is a disease: There is no Medicare, or insurance coverage for nursing home care. Who will pay? I'm sure I'll be unable to pay."

5. What are the important financial considerations in the approach to Alzheimer's Disease?

There is no other question that has more far reaching implications than this one. Every recommendation made must be viewed in light of the cost to implement that specific recommendation. Currently, since most Alzheimer's patients are not covered under Medicare or private insurance any additional coverage (direct health care services, education, or support to families) will cost the state of Minnesota more than it is costing now. This is not to say that Minnesota should do nothing because the need of those patients and families affected by Alzheimer's Disease is *very great*. It is simply to say that all recommendations must be viewed in terms of the cost to the public in order to determine what the probability is of the recommendation being enacted.

One consideration would be to change health care insurance coverage in order to cover in

some limited way those under 65 years of age who are diagnosed with Alzheimer's Disease. Health insurance in general does not cover any care for those under 65 years old who develop Alzheimer's Disease, because the disease is "not treatable." This lack of coverage can be especially difficult for the family if the victim is a woman who has been a homemaker and still has children at home. If one were to have this type of coverage there would be financial implications for the health insurance industry and consequently those who buy health insurance, but the incidence of Alzheimer's Disease in the under 65 year old age group is relatively rare. One might consider insurance covering less than full custodial care for the rest of the person's life; it is perhaps that there be limited coverage for example for respite care, or partial reimbursement for adult day care.

Another financial consideration is that along the lines of health and social service agencies developing services used by Alzheimer's patients on a sliding fee scale. Many services are available to those with Alzheimer's Disease who qualify for Medical Assistance at no cost to the patient, but if an individual is not eligible for Medical Assistance these services must be paid for in full and usually out of pocket. The recommended strategy of having services on a sliding fee schedule should extend a family's financial resources prior to reaching the spend down level that makes one eligible for Medical Assistance.

Finally, if long term care insurance were required of all those 65 and over who are Minnesota residents it would allow for coverage by carriers. This option appears to be desired by those people over age 65.

The problem for carriers is that they do not know what the actuarial data are for this type of coverage and they are concerned that any long term care insurance must be widely subscribed to in order to avoid adverse selection. If Minnesota implemented such a policy then demand would be created for the coverage in the private marketplace and insurance carriers would be less concerned about adverse and uncontrolled risk. If such a scheme still produced monthly premiums too high for individuals in general to afford, then there is little hope of any private mechanism meeting the long term care needs of Alzheimer's Disease patients.

The task force could not reach a conclusion on this issue because of its complicated nature. Further study was recommended.

6. What are the important research areas in Alzheimer's Disease?

The Task Force on Alzheimer's Disease strongly supports ongoing research. Basic research funding usually comes from federal and private sources. Minnesota should be a leader in research, particularly in the areas of service delivery and epidemiology.

Research initiatives can be divided into the following categories:

- A. Ongoing studies with respect to epidemiology and prevalence of the disease — these are critical and could very possibly be done at the state level by the Department of Health.
- B. Pathogenesis (medical origin) of dementia — it is important to study what happens neuropathologically to the brain in order to better understand the signs and symptoms patients exhibit. This may or may not be linked to the etiology of the disease.
- C. Therapeutic trials — specific biological approaches are presently unclear. While diagnosis is extremely important, nonetheless we must focus attention on what therapies work with respect to this disease. Rehabilitation therapies should be studied as well. Specific treatment environments might prove to be extremely important.
- D. Management of secondary problems — problematic behavior may be responsible for a patient cared for out of the home prior to what would be necessary otherwise. It is very important to research the drugs that we are currently using in order to treat specific behaviors with respect to the disease.
- E. Health care systems are a critical research area, and should be looked at very carefully by this state — how does one take available resources and give them to people in need? This might include looking at staffing ratios and acute and chronic levels of care. Is the treatment afforded to patients adequate for their disease?
- F. Development of a test or panel of tests for diagnosis of the disease — as is pointed out frequently, the ability to diagnose Alzheimer's Disease in life would allow us to establish whether or not the disease has a prolonged prodromal phase, in other words, whether people have the disease for months or years before they actually

begin to lose their memory and become obviously ill. Diagnostic tests would allow us to determine whether a treatment can actually stop the progression of the disease or even cure it. Diagnostic tests of this sort would allow us to clearly map the inheritance of Alzheimer's Disease which is another very important issue.

7. How can we improve agency coordination in meeting the needs of persons with Alzheimer's Disease?

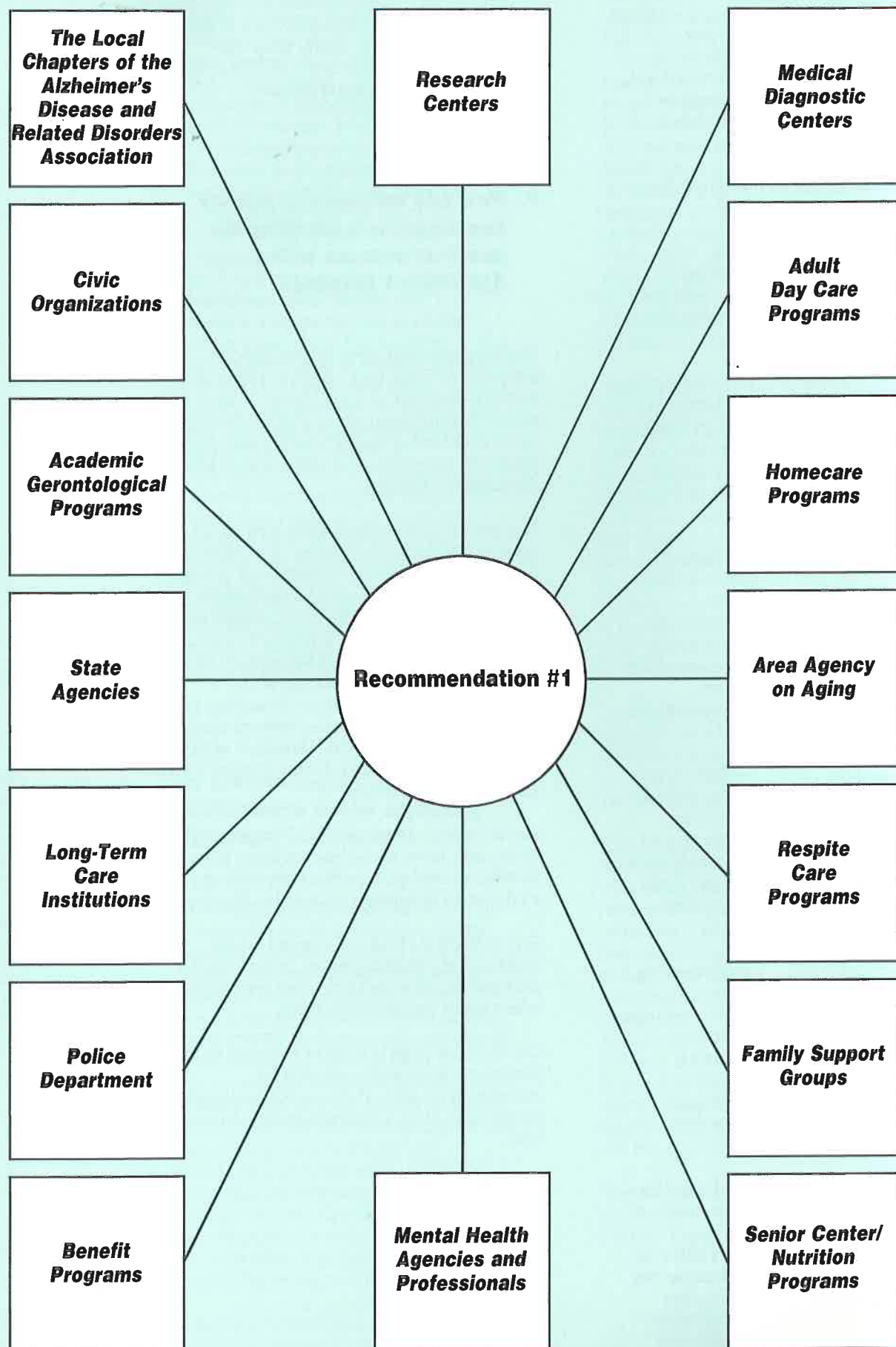
The agencies and services involved in support of Alzheimer's patients providing services and research are many. A basic reason for the appointment of the Task Force on Alzheimer's Disease was to learn what is presently happening in Minnesota related to Alzheimer's Disease.

The next step is to determine how these resources can work together in a collaborative way. Administrative integration of this wide variety of organizations and agencies is not possible. Some mechanism is needed to provide a forum that will promote mutual understanding and faster agreement as to how the planning aspects, services, education, medical services, financing and research will work together toward common goals and objectives. Collaborative efforts are especially important at the local agency and service delivery levels.

A mechanism that can insure implementation of the task force recommendations as well as to educate and gain public support especially of the state legislators should be developed.

The collective efforts of a broad based coalition of public agencies, private sector and community organizations are needed to effect these recommendations.

On the next page is a list of some services and programs that can be affected by coordination and collaboration, as suggested by the task force's recommendation number one.



8. What legislative initiatives are important?

The following items are opportunities for legislative change based on a review of other state reports as well as input of a subcommittee of the task force.

- A. Respite care: in home, out of home day care, volunteer programs all need to be affordable and accessible. They should provide for a sliding fee scale for persons able to pay at least part of the cost. A program should be developed of short term respite care utilizing excess hospital beds. In general, the alternate care grant is simply not enough.
- B. Education: require all educational institutions responsible for education of professionals who may be involved in treating dementia patients to include information about Alzheimer's Disease, etc. and its effect both on patients and caregivers in the curriculum of study for these groups.
- C. Develop an ongoing resource directory of programs to assist caregivers and others in social service and health agencies in making choices for the care of their Alzheimer's patient.
- D. Require the state Departments of Human Services and Health to consider and plan for the unmet needs of Alzheimer's patients and caregivers in their state plans for 1988.
- E. Work for the passage of a joint House and Senate resolution urging the U.S. Congress to give favorable consideration at the earliest possible time to a federal catastrophic health insurance program.
- F. Tax incentives for families providing care for Alzheimer's Disease patients should be available. Some of these expenses presently qualify as a medical deduction on both federal and state tax returns. Unfortunately, under the new federal tax reform bill, the deduction will be less — only amounts over 7% of the gross income can be excluded.
- G. Support regional dementia diagnostic facilities in parts of the state not now covered by Alzheimer's Disease clinics. Start up funds or demonstration projects in two or three sites might be most useful.
- H. A small appropriation for a demonstration project to work with police in the metropolitan area; to train police in the

special needs and problems of Alzheimer's patients, that is wandering, lack of communication and skills, etc.

9. How can we improve public awareness of issues with respect to Alzheimer's Disease?

General public interest in the problems of Alzheimer's Disease and other dementias seems to be in an early phase in Minnesota, as in much of North America. Even at the professional and scientific level worldwide, it is only recently that Alzheimer's Disease has received large amounts of interest and efforts. Thus the need to improve awareness seems clear.

Nevertheless a broad scale public education campaign could be quite costly and its benefits difficult to assess. The most sensible approach would be to identify target groups for specific educational efforts. Likewise the most efficient efforts would, as much as possible, utilize existing organizations and existing governmental agencies. Many target groups could be identified. Four large target groups would include the general public, families and caregivers, professionals involved with the elderly, and governmental officials such as lawmakers and administrators. State and local agencies should collaborate with the Alzheimer's Disease and Related Diseases Association. It may in fact often be more economical to provide state support for specific activities to be carried out through ADRDA rather than to generate the entire process from its beginnings.

A. THE GENERAL PUBLIC: The general public is our constituency; they need information upon which to make informed decisions as citizens, not just as potential patients or caregivers. Thus some specific efforts need to be made. For example:

- 1) Declare a statewide Alzheimer's Disease/Dementia Week. During such a week public service announcements on radio and television could be coordinated, newspaper stories or ads done, and public forums might also be held.
- 2) A brief informational leaflet mailed to postal patrons in some or all areas of the state.



University of Minnesota researcher Muriel Ryden presented her findings on aggressive behavior in Alzheimer's patients to a seminar of professionals and family members.

- 3) Regional Alzheimer's Disease/dementia informational centers could be developed in conjunction with the development of regional clinical centers for assessment and treatment. These centers could provide information to the public as well as helping to serve the educational needs of health professionals.

B. FAMILIES AND CAREGIVERS: Most of us become much more interested and receptive about a health problem once it has touched us in a personal way. For this reason alone, efforts to improve the awareness of this group probably should receive a larger share of funds than those aimed at the general public. More importantly, families of those with dementias have specific needs, and the need for dependable information is a major one.

C. PROFESSIONALS INVOLVED WITH THE ELDERLY: The report of the Kansas Alzheimer's Disease Task Force defines these professionals as including, but not limited to, "physicians, registered nurses, LPNs, attorneys, social workers, physical therapists, pharmacists, and clergy." We should certainly include police, psychologists, nurse aides, health administrators, and chemical dependency counselors. There is a clear need for better and more education about Alzheimer's Disease/dementia in all of these groups.

D. GOVERNMENTAL OFFICIALS (LAW-MAKERS AND ADMINISTRATORS): Those at various levels of government who make and implement decisions regarding these issues also need dependable information. This task force represents one very important effort in this direction. We need to consider ways to continue to keep our various public servants up to date. We may wish to employ ADRDA to provide some sort of continuing education service along these lines.

At present, the largest need seems to be a coordinated letter writing campaign, along with some well-targeted public forums to consider the initial recommendations of this task force. Also, coordinating efforts with the existing brain-impaired task force is important.

10. What are the important ethical and advocacy questions associated with Alzheimer's Disease?

The care of persons with Alzheimer's dementia and other dementias raises a multitude of complex ethical questions. This section of the task force report attempts to identify those questions in a comprehensive manner. Answers will not be advanced as they can only reasonably emerge through dialogue involving a broad spectrum of concerned citizens.

Consideration of these ethical issues will be presented under four headings: the individual and society, the individual and the family, the family and society; and society and society.

For the purposes of this section, ethics will be considered the discipline dealing with what is good and bad and with moral duty and obligation. Advocacy will mean speaking on behalf of the patient with Alzheimer's Disease.

A. THE INDIVIDUAL AND SOCIETY.

1) Society's obligation to the individual:

What obligation does society have to an individual to ensure that their care is humane, minimally restrictive, not exploitative, and meets medical standards for effectiveness?

What is society's obligation to monitor the application of the diagnosis of dementia in order to ensure that it is not inadvertently or deliberately abused? What role should the state have in confirming the existence of the diagnosis?

Does society have an obligation to ensure that an individual with advanced dementia unable to recognize next of kin does not endure protracted suffering solely based on the legal and moral principle that respect for life irrespective of quality is always paramount? This issue arises in relationship to medical and nutritional care in advanced cases and involves procedures such as placement of gastrostomies for feeding.

What is society's obligation to ensure that the dementia patient is not exploited or endangered in relationship to biomedical research on dementia?

This involves adequate consent procedures and review processes that guarantee that the research is of such quality that it should meaningfully contribute to scientific knowledge about the disease.

What is the role of living wills, and "do not resuscitate" with respect to our elderly citizens?

2) The individual's obligation to society:

What is the correct balance between individual freedoms and public risk? At what point does the right of someone with dementia to operate a motor vehicle or handle burning or heated materials (matches, cigarettes, stoves) need to be abridged to protect public safety? This involves a risk-benefit analysis, but the question of how much risk is tolerable has important ethical dimensions.

B. THE INDIVIDUAL AND THE FAMILY.

Which member of the family should represent the individual when he or she cannot make competent decisions? How are disagreements among family members resolved?

What obligation does the family have to the individual to keep them in familiar surroundings cared for by members of the family?

What role should each member of the family play (financially, emotionally and physically) in caring for the member with dementia?

C. THE FAMILY AND SOCIETY.

1) The family's obligation to society:

What obligation does the family have to care for the patient with dementia in order to minimize the public expense of housing and treatment?

What obligation does the family have to society to make sure an autopsy is performed in order that others with the disease or who will get the disease may benefit?

2) Society's obligation to the family:

What obligation does society have to minimize the financial, physical and emotional burdens on the family attendant to caring for someone with dementia?

What obligation does society have to ensure that the cost to each family for the care of an individual with Alzheimer's Disease or a related disorder is proportional to the family's resources?

D. SOCIETY AND SOCIETY.

What obligation does society have to the general public welfare to support biomedical research (including autopsy) in order to advance knowledge of the disease?

What obligation does society have to the general public welfare to monitor those at high-risk for dementia in relationship to potentially dangerous activities such as driving or cooking? In ambiguous cases should the balance tip toward individual freedom or public safety?

11. What are the important issues for families involved with Alzheimer's Disease?

Over 80% of all home care is provided to the elderly by family caregivers. To Alzheimer's victims' families this means the provision of personal care, initiation of all activities, and provision of mobility assistance. The financial burden on the family is enormous. The stress caused by all this results in family dysfunction manifested as physical problems, depression, and family conflicts.

Since Alzheimer's Disease moves so slowly in most cases, the durability and quality of care provision by the family can deteriorate without extensive family support networks. Education about the disease and training for the caregiver is also paramount for healthy family functioning.

Family support groups are extremely important but there is a desperate need for services such as respite care, in-home personal care, adult day care, legal assistance and transportation.

It is a generally accepted fact that families provide the vast majority of the care that is required to help a person with Alzheimer's Disease remain at home. Thus the issues of public policy relate to the ways in which the motivation of these families can be maintained and enhanced. Because these families have varying amounts of financial, emotional and social resources, governmental policy must cover a wide range of family demands from the need simply for information to the need for public

"There is a great need for any help that can be made available to families, like respite care grants or any type of help that can be given because this disease causes a physical, emotional and a big financial burden on the families. Many families' life's savings are going to pay for the care of a loved one and leaving the caregiver to struggle through the 'golden years'."



A teen-age support group and facilitator discuss their parent's affliction with Alzheimer's Disease and its effect on them.

subsidization of home care. In some instances government funds are required and in other cases government must stimulate the private sector to act. Two broad areas of family need that require increased governmental action are listed below:

- A. INFORMATION:** Families seeking help and information often face a labyrinth of sources of information. To help families, government should:
- 1) Designate specific places where current, accurate information regarding Alzheimer's Disease and community resources is available, then families who have the capacity to solve their own problems have the necessary information to do so.
 - 2) Make publicly funded case management available to families so that case managers can give these families professional assessments, advice and advocacy; this service should be available on a sliding fee scale.

B. SERVICES: Governmental responsibility can be divided into the following areas:

- 1) **Quality Assurance:** State laws are needed to ensure that community-based care, which is either privately or publicly purchased, meets minimal standards of safety. Currently there are no such Minnesota state laws or rules.
- 2) **Financial Subsidization:** In order for some families to provide care for the years that Alzheimer's victims remain at home, the families need relief or respite care. These families cannot necessarily afford to pay fully for respite care, so some government funds are needed to provide services on a sliding fee scale.
- 3) **Development of New Services:** Government should work to stimulate the creation of new services that meet the needs of families.

Government can directly fund the service development and it can do the market research that will encourage the private sector to develop services. Some of the community-based services that need attention are in-home respite care, caregiver support groups, mental health counseling for caregivers, private case management, and financial/estate planning.

- 4) **Changes in Nursing Home Care:** Families who finally must have their Alzheimer's victim enter a nursing home are abruptly denied any continuing role in the care of their loved ones. Most nursing homes don't give family members specific responsibilities for ongoing care, yet some families want to remain involved. Through changes in state law and rules that govern nursing home care, families could elect to provide some care to their institutionalized family member and receive financial remuneration.

1. David Drachman, M.D., Professor and Chairman, Department of Neurology, University of Massachusetts Medical School, and Chairman of the Medical and Scientific Advisory Board of the Alzheimer's Disease and Related Disorders Association.

Dr. Drachman pointed out that there are multiple goals in the overall approach to Alzheimer's Disease. He said that if there was a specific etiology for the disease or a specific cure much of the conversation would be obsolete, however this is not the case. He said that research should be carried out at many levels, which are elucidated under questions and answers of number six earlier in this report.

He suggested that goals for a task force such as this one are to provide information to patients and families, specifically with respect to such options as day care and respite care. He also pointed out that institutional beds are dwindling, and "at the end of the road these must be available".

He pointed out that the Massachusetts Task Force is still in existence, meets frequently and has managed to get some funds allocated for respite care and day care.

Dr. Drachman said that he felt eventually Alzheimer's Disease was going to be shown to be a molecular/genetic disease. He thinks that gene regulation is the key issue, and that what down regulates or activates these genes is going to be important. He says there is no change in the pathology of the Alzheimer's patient's brain that doesn't occur in normal aging except that it occurs earlier and in much larger numbers in Alzheimer's Disease. He feels that to understand the mechanics of gene regulation will take several decades.

At a second level he suggested appropriate treatments are very possible which would include appropriate provisions of care. He emphasized the fact that personal, social, legal, and financial aspects of Alzheimer's Disease can't be ignored, and need research.

2. Nancy Mace, member of the Maryland Task Force on Alzheimer's Disease, as well as co-author of the book *The 36 Hour Day* spoke to the task force via teleconference.

She talked about the Maryland Task Force and suggested that the Minnesota task force should contact all interested groups, particularly where legislation is contemplated. She felt that there is a need for better coordination of existing agencies and suggested that volunteer organizations are often helpful. She suggested that things such as respite care are certainly very important but can fail if they are not done in conjunction with other programs. She stressed that families must know what services are available.

Ms. Mace pointed out that Maryland did fund research with respect to state issues such as health care delivery. She agreed that catastrophic health insurance was an issue of major importance. She spoke of the Office of Technology Assessment report on Alzheimer's Disease available nationally and strongly suggested that this be reviewed.

3. Wes Skoglund, State Representative, Minnesota Legislature. Representative Skoglund pointed out that the human costs to Alzheimer's Disease are incalculable and went on to describe the legislative process to the task force. He suggested carefully selecting authors for bills and said it would be important to request a fiscal note early. He offered whatever technical assistance the committee would like in getting their findings to the level of the Legislature.

4. Kathleen Davis, Legal Aid. Ms. Davis is involved with Alzheimer's Disease with respect to education. She said that her clients are frequently family members who are not only dealing with shock and guilt but have deep financial problems. She recommended that concerned individuals such as spouses should seek legal advice and advice regarding what social services are available.

Ms. Davis pointed out that health insurance will not adequately allow home health care or long term care. She felt clarification should occur in HMO contracts which should be in simpler language. She asked that options be carefully laid out for people with respect to home health care and suggested that it was a problem that assets must be reduced to \$3,000 to apply for MA.



Dr. Ronald Petersen discusses input from Dr. Drachman.

5. Pamela Parker, Executive Director of the Interagency Board for Quality Assurance, Minnesota Departments of Health and Human Services. She spoke of long term care services to numbers of people with Alzheimer's Disease. She suggested trying to build a sensible system which would not force divorce of a spouse. She said presently the state is paying approximately one half of nursing home revenues and is looking very closely at increasing funding for home care. She passed out a recently published DHS book on long term care.

Ms. Parker said that the state is currently applying for a waiver for adult disabled, people 21 to 65 years old, and hopes for approval by December of 1986.

She also suggested that preadmission screening documents should have some uniformity and that diagnoses are not always consistent throughout the state. She added that training is important and also pointed out the eleven care levels that are looked at in reimbursement.

6. L. Ronald French, Ph.D., Minnesota Department of Health. Dr. French spoke about epidemiology and passed out some work being done in this area. He said that the diagnosis of Alzheimer's Disease is one of exclusion with an insidious mode of onset. Measures of incidence are not good. Prevalence studies suggest that 4 to 5% of the population over age 65 is moderately or more demented. If we apply this to 1980 Minnesota census of just over 4 million people, this would leave 480,000 65 and over, 19,000 demented and 9500 of these with Alzheimer's Disease. He said that statistics of people over age 80 find that approximately 1 in 5 may have Alzheimer's Disease.

7. Thomas Mackenzie, M.D. reported on Leonard Heston's work at the University of Minnesota with respect to research. He suggested at first that his interview with Dr. Heston indicated that there are no promises for a quick cure. There are certainly pilot projects which would be useful with respect to respite care but also pointed out the necessity for a neuropathological lab and spoke of autopsies on all state hospital patients which were done in the past, and which were quite useful.

These past studies have allowed Dr. Heston to follow at risk families and carefully assess his basic research interest. He is looking at high risk families and has

suggested that "DNA banks," that is tissue related to genetic research, should be saved. Collecting samples of blood cells such as lymphocytes would help. Then we could look for a genetic predisposition of the disease. He added that looking at Down Syndrome is important.

8. Robert G. Riedel, Ph.D., Professor of Psychology, Southwest State University. Dr. Riedel has had a specialized interest in aging over the past 16 years and was chief psychologist on the first Alzheimer's unit in the VA hospital in Tacoma, Washington. He was in Washington when the Alzheimer's Disease and Related Disorders Association was founded.

He said that when the numbers of elderly in our country grow Alzheimer's Disease grows as well. When the "baby boom" generation enters its final one-third of life in 2020, the problems with Alzheimer's Disease will reach a very serious stage.

He feels as though Minnesota is the leader in the United States in treatments associated with Alzheimer's Disease, that is with respect to nursing homes, hospitals, and programs for the elderly. He suggests this state take pride in its accomplishments, but forge ahead nonetheless. Dr. Riedel suggested that rural Minnesota has a unique problem in terms of lack of specialists and lack of access to services. He suggested that the committee review Dr. Brian Breuer's efforts with Good Neighbor Homes in the southwest part of the state.

He also suggested that geriatric specialists be hired centrally and dispersed on an as needed basis to more rural parts of the state.

Specialized programs can work and support groups and ancillary services for families are important. It's important, Dr. Riedel said, that overall stress levels be minimized.

1. Alzheimer's Disease and Related Disorders Association (ADRDA). In the summer of 1979, five family caregivers of patients diagnosed as victims of Alzheimer's Disease met in Minneapolis to discuss problems of mutual concern, and to support one another in facing the ravages of this and related dementing illnesses. Later in the Fall of the same year, a group of some twenty-five caregivers and professionals from across the United States met in a downtown Minneapolis hotel, and from this meeting the National Alzheimer's Disease and Related Disorders Association had its beginning. From a nucleus of six charter chapters, of which the Metro-Minneapolis/St. Paul chapter was one, the national organization has grown to 150 some chapters across the nation. From the beginning, both our chapter and the national association have had three principal goals: family support, education and public awareness, and research.

There are now 28 active support groups in the metropolitan area and throughout the state. These groups meet once each month to share information about their experiences in caring for their family member, to hear speakers discuss such topics as handling stress and grief, finances, and home nursing care. Current literature is available to bring members up to date on new developments in the field. A quarterly newsletter goes to more than 4,000 family members, friends, and professionals, and is a vital link to many hundreds of families who are unable to attend support group meetings.

The metro-Minneapolis/St. Paul chapter has supported research activities at the University of Minnesota, and through National ADRDA's Medical and Scientific Advisory Board. Family members are encouraged to participate in various research studies and to arrange for an autopsy prior to the death of their loved one.

2. William R. Frey II, Ph.D., Research Director at the Alzheimer's Treatment and Research Center at St. Paul Ramsey Medical Center. He pointed out in a paper to the task force that the Alzheimer's Treatment and Research Center at St. Paul Ramsey is actively engaged in both basic and clinical research on Alzheimer's Disease and other forms of dementing

illness. It has focused on developing methods of treating and preventing this devastating illness. In addition they are actively pursuing the development of a blood test for Alzheimer's Disease which currently can only be diagnosed with certainty by neuropathological examination of brain tissue usually performed after the death of the patient. He notes assistance in research by a national network of over 180 pathologists who helped to establish a St. Paul Ramsey Alzheimer's Brain Bank which is the largest human brain bank specifically devoted to the study of Alzheimer's Disease. The state of Minnesota became one of the first states in the union to support research on Alzheimer's Disease when in 1985 Governor Rudy Perpich signed into law legislation introduced by Representative Wes Skoglund to support Alzheimer's research.

Dr. Frey noted recently reporting a discovery of alteration in the nerve growth promoting factor in the brains of individuals with Alzheimer's Disease. This discovery suggests a new treatment direction for this disease. As a result they are collaborating with the major pharmaceutical producer of this special nerve growth factor to initiate the clinical trial with Alzheimer's patients at the end of the year. They are hopeful that this and other research at the Alzheimer's Treatment and Research Center could increase the level of functioning of individuals with Alzheimer's Disease and enable these patients to continue to live independent, productive lives in the community.

3. Nursing home pre-admission screening/alternative care program. All 87 counties in Minnesota have pre-admission screening programs that screen all nursing home applicants. Thus counties have contact with many Alzheimer's patients and their families at the time of nursing home application.

The screening program provides assistance to nursing home applicants and their families by making professional assessments of each of the applicant's living situations, discussing the services available in the community, and when appropriate, preparing a plan of care. For people 65 years old and older, who are on Medical Assistance (MA) or would be on



Family support group members discuss the "36 Hour Day" faced by caregivers of Alzheimer's patients.

MA within 180 days of admission to a nursing home, the social worker/public health nurse will also arrange for the provision of community-based services. In arranging for these services, the social worker/public health nurse has alternative care funds available which can be used to supply seven services: home health aide, homemaker, adult foster care, adult day care, respite care, personal care, and case management.

4. The University of Minnesota has several different groups actively involved in research in Alzheimer's Disease and related areas. In addition to Dr. Len Heston and Dr. Harry Orr working in the area of molecular genetics in patients with familial Alzheimer's Disease, Dr. Ashley Haase in the Department of Microbiology is studying the molecular biology of slow virus diseases and their relationship to Alzheimer's Disease. He recently published an article in the journal *Science* in which his laboratory showed that there are molecular similarities between diseases caused by slow viruses and Alzheimer's. In addition, Dr. Jack Shepherd of the Dight Institute is working with blood samples of patients with Alzheimer's Disease in order to develop a blood test for Alzheimer's based on the detection of an enzyme necessary to preserve the integrity of cells. From the clinical viewpoint, Drs. David Knopman and Thomas Mackenzie direct an Alzheimer's Disease Clinic that has been in operation for over four years. Three hundred patients with memory disorders have been evaluated. The clinic has also been involved in three experimental drug studies. One is currently ongoing. Finally, the University of Minnesota is working in collaboration with Presbyterian Homes of Minnesota and has recently opened an Alzheimer Unit in the nursing home at Langton Lake Place for research and education in Alzheimer's Disease.

5. The Mayo Clinic is actively engaged in the diagnosis and care of patients with Alzheimer's Disease and other forms of dementing illnesses. Mayo has a team of neurologists, psychiatrists, internists with training in geriatrics, neuropsychologists, speech pathologists, and social workers who assess the patients, establish a diagnosis and care for the patients through all stages of the illness. Primary care physicians with special training in geriatrics care for 85 percent of nursing home residents in the Rochester area. Mayo is also conducting research on the

epidemiology of Alzheimer's Disease with emphasis on determining age specific incidence rates for the disorder. Due to the unique nature of the medical record system at the Mayo Clinic and the availability of autopsy data for all of Olmsted County, Mayo is able to generate reliable data concerning the scope of Alzheimer's Disease and related dementias. To the extent that the figures from Olmsted County are representative of Minnesota, accurate figures regarding the scope of the disorder are available from the Mayo data.

Additional research on refining the clinical diagnosis through neuropsychological testing is also underway. While no specific treatments for Alzheimer's Disease are currently available, Mayo plans to begin pharmacologic trials to assist in the diagnosis and to evaluate several possible treatment alternatives. The Mayo Clinic also cooperates with local agencies such as the Alzheimer's Disease and Related Disorders Association in dealing with the social issues for the families of patients with Alzheimer's Disease.

6. The Minneapolis VA Medical Center has extensive resources available to eligible veterans who are victims of dementing illnesses and to the family caregivers of these veterans. Through the GRECC (Geriatric Research, Education, and Clinical Center) program, veterans may receive a multidisciplinary evaluation and diagnosis of confusion; this, typically, is done on an outpatient basis, but it may be done on an inpatient basis if the situation demands. GRECC will provide outpatient management assistance to veterans who are diagnosed with dementing conditions and who continue to reside in the community. This management assistance includes consultation with the veteran's primary physician, case management support from nursing and social work services, and caregiver education. Inpatient placement can also be arranged to deal with specific behavioral disorders that might occur during the course of the disorder. In addition, a limited amount of respite care can be provided. GRECC will also provide periodic examinations, on an outpatient basis, to demented veterans residing in nursing homes.

The VA Medical Center provides, in addition to acute care services, a complete continuum of extended care services to all eligible veterans, including those afflicted with demented conditions. These extended care services include: hospital-based home care; adult day health

care; community health nursing service; and contract nursing home services. With the opening of the replacement hospital in the Fall of 1987, the Minneapolis VA will be able to provide direct nursing home care.

The Minneapolis VA works closely with the St. Cloud VA to provide services to demented veterans. St. Cloud has recently opened an Alzheimer's Unit, to provide both respite care and behavioral training to afflicted veterans. The St. Cloud program also emphasizes work with family caregivers.

7. The Duluth Human Development Center (HDC) established in 1938, is a community mental health center serving southern St. Louis County, Lake County, and Carlton County. Psychiatrist Peter S. Miller, M.D., is active in the diagnosis of dementias, including Alzheimer's Disease. As well, HDC has improved services to the elderly in general, including a special team to coordinate psychotherapy, medication management, and outreach work. Their other psychiatrist, Gregory P. Bambenek, M.D., consults weekly with the special Alzheimer's-dementia unit in the nursing home at Nopeming.

They are in the process of developing, along with Miller-Dawn Hospital, an outpatient dementia assessment clinic. Dr. Miller and neuropsychologist Katherine Wright are participating in this project and beginning to consult with nursing homes and to offer home visit assessments.

"I've tried to sum up and generalize. It would be impossible to tell you the effect on our family. Short, brief occasional glimpses of the real person my mother-in-law once was only accentuates the loss and grief we feel every day. She was a special lady."

"My fervent wishes for Task Force success in the program now being undertaken."

ACKNOWLEDGMENTS

Department of Human Services
Commissioner Sandra S. Gardebring's
continued interest in this Task Force and its
mission is gratefully appreciated.

Thank you to all the individuals and groups
that provided information for this report.
Thank you, too, to Colleen Wieck and Susan
Burns for their contributions of time and
effort in the preparation of the report.

Funding for and coordination of the design
and printing of this report was provided by
the Minnesota Department of Human
Services.

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