REPORT OF THE
COMMISSION ON

Alzheimer's Disease and Related Disorders Pursuant to HJR 309

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

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Report of the
Commission on Alzheimer's Disease
and Related Disorders
Pursuant to HJR 309
To
The Governor and the General Assembly of Virginia
Richmond, Virginia
January, 1986

To: Honorable Gerald L. Baliles, Governor of Virginia,
and
The General Assembly of Virginia

PURPOSE

The 1985 Virginia General Assembly established, via House Joint Resolution No. 309, a Commission on Alzheimer's Disease and Related Disorders to determine the needs of Alzheimer and other dementia victims and their families and to determine the feasibility of establishing regional dementia centers throughout the Commonwealth.

ALZHEIMER'S DISEASE

Alzheimer's disease was first described in 1906 by the German neurologist, Alois Alzheimer, who recounted the story of a 51-year-old patient with loss of memory and disorientation, and whose condition was later complicated by depression, hallucinations, severe dementia and death. Upon death, her brain was found to show severe atrophy (shrinkage) and the cerebral cortex (outer layer of the brain) was marked by a clumping and distortion of fibers in the nerve cells. Alzheimer called these jumbles of filaments neurofibrillary tangles, and they have since become the hallmark of Alzheimer's disease.[1]

Today, Alzheimer's disease is labeled Senile Dementia of the Alzheimer's Type (SDAT). "It is a neurological disorder characterized by a progressive and irreversible deterioration of cognitive functions such as memory, attention and judgment." [2] Alzheimer's begins subtly and gradually with the loss of memory and ends in a terminal vegetative state. Though there is substantial variation in the duration and the rate of progression of the disease - Alzheimer's may last a few years to a few decades - younger patients tend to have worse cases which progress to vegetation more rapidly.

In defining Alzheimer's disease, it is important to state that it is not hardening of the arteries, the natural course of aging, the aftermath of a stroke, the result of alcoholism or blows to the head, depression, or a communicable disease.[3]

Diagnosis

Alzheimer's disease is difficult to diagnose because there is no simple diagnostic test. Usually, it is diagnosed on the bases of medical history, mental status and the course of the illness after other causes of memory loss or dementia have been excluded through thorough physical, neurological and psychiatric evaluations.[4] However, the Alzheimer's diagnosis can be confirmed only by postmortem microscopic examination of brain tissue.[5]

Possible Causes

There is no agreement within the medical community on the causes of Alzheimer's disease. Nevertheless, current medical research has discovered that Alzheimer's disease is associated with a deficiency in the amount of an enzyme, choline acetyltransferase, which is normally present in the brain. Other factors being explored by medical researchers include genetic defects, slow viruses, accumulation of aluminum or other trace metals in the brain, and cell regulation of calcium.

Incidence of Alzheimer's Disease

Because precise information on the prevalence of Alzheimer's disease remains sparse, statistical data regarding the incidence of Alzheimer's disease is conservative. The best estimates available indicate that Alzheimer's disease affects five to fifteen percent of Americans (1.2 to 4 million people) over sixty-five, though the disease has stricken persons as young as forty years of age. The disease becomes more common with advancing age, affecting more than twenty percent of persons aged eighty and over. Alzheimer's disease accounts for nearly fifty percent of admissions to nursing homes and long-term care mental hospitals and may be the single most important cause of institutionalization for long-term care. It is believed that the disease accounts for approximately fifty to seventy-five percent of senility with the remaining portion attributed to atherosclerosis, stroke-related disease, and many treatable dementias.[6]

Treatment of Alzheimer's Disease

Although at present there is neither a prevention nor a cure for Alzheimer's disease, it is imperative that the Alzheimer's victim be under the care of a physician. Therapeutic courses include appropriate drugs, proper nourishment, carefully guided exercises and physical therapy, consistent day-to-day living in an ordered environment, and care appropriate to the severity of the disease. Experimental therapy and research are being conducted on many types of drugs, such as lecithin, physostigmine, naloxon, sodium fluoride and deteroxamine, to combat the effects of the disease.[7]

The Victims

Although each individual and family is different and each individual responds to his condition differently, the following is a profile of the average victim and a description of the effect of the disease upon the victim's family, excerpted from "Alzheimer's Disease: Joint Hearing" before the subcommittees of the Committee on Energy and Commerce of the U.S. House of Representatives in 1983.

Alzheimer's is a disease of insidious onset and devastating course. Its initial symptom is a loss of recent memory. Early in the course of the disease the patient is often acutely aware of his losses and may become depressed or anxious. Patients often lose their jobs or have several automobile accidents. The person often seeks to cover up his failures, and to his family he may only appear to be vaguely upset, discouraged or more irritable. As the disease progresses, the memory loss becomes more profound and the person will need constant supervision. These patients often pace for hours or wander away from home and get lost. They are at risk for many kinds of accidents. They cannot live alone because they forget to feed themselves, take their medications or turn off the stove. They may become highly suspicious or injudiciously give away their money. The person may become unable to locate the bathroom in his own house or to find his way about in his own neighborhood. He may forget the names of his children and may not recognize his own spouse.

Alzheimer's victims develop a language disorder which makes it increasingly difficult for them to understand what is said or to communicate their needs and thoughts. They develop difficulties in coordination so that they gradually become unable to dress themselves or feed themselves without assistance. They develop a stooped posture and a shuffling gait. They may fall frequently. In the latter stages of the disease they will be unable to remember one word for one minute. They will lose control of their bowel and bladder functions and have significant difficulty in walking. They may become unable to walk and be confined to bed. They will become completely unable to communicate, and may produce only occasional words or cries.

The disease is inexorable and fatal. The average person will die seven years after onset. However, the course is quite variable; in some people it will progress much more rapidly and many other patients linger for fifteen years or more.

Throughout the course of the illness the impaired intellectual function often makes these individuals prone to irritability, stubbornness, argumentativeness, and sudden explosive bursts of temper. Alzheimer's victims may also become apathetic, unresponsive, depressed or moody.

At present, there appears to be no relationship between Alzheimer's disease and sex, race, occupation, socioeconomic level, residence or age, since the disease can strike as early as age forty. What is known about the disease is that it is prevalent and that wherever there are old people, there is senile dementia of the Alzheimer's Type (SDAT).

The Family: Caregivers

The tragedy of a dementing illness is not limited to the patient himself. Contrary to social myth that Americans "dump" their elderly in long-term care institutions, most elderly dementia victims live with families. As a result, the patient's family suffers as well and has been called the "other victim of dementia." Although any chronic and fatal illness can have a tremendous impact on the family, the very nature of a brain disease adds significantly to the family's burden. Family members report the effects of the almost overwhelming burden of caring for a person with a dementing illness. They struggle to provide physical care, to find their way through often uninformed agencies, to accept the loss of communication and changes in personality and to grieve as the patient gradually declines. Family members who are themselves elderly or suffering from chronic illnesses are faced with many restrictions which compound the demands of care. Adolescents who have a parent stricken with the disease at an early age struggle to accept this devastating illness in a parent.

Families of brain-injured adults feel frustrated, trapped, isolated, abandoned by the extended family and sometimes abused by the brain-injured patient. There are special problems of spouses whose sexual and affectional needs are frustrated and who cannot properly mourn the loss of the person who has changed so drastically and yet who remains alive.

In light of all these problems the truly amazing thing is that most families soldier on and find creative methods of surviving and caring for their ill family member.

Of course, there are some families who abandon, abuse, or mistreat the demented elderly person. Some families are unable or unwilling to understand and accept the nature of the person's cognitive impairment and may take financial advantage of the impaired person. However, abuse, when it does occur, is often the result of fatigue, frustration, lack of understanding, and a sense of isolation.

We must understand that the long-term demanding nature of Alzheimer's disease can exhaust a family's emotional, physical and financial resources, thus devastating the family as well as leaving patients unsupported. Therefore, any programs which assist caretakers, families and institutions to maintain their support of patients are vitally needed.

Financing Treatment

Financing the medical care and other related services for chronic illnesses is costly. In 1981, "the Health Care Financing Administration estimated the annual cost of nursing home care at $19.4 billion, and about fifty-eight percent or $11.2 billion of this amount was attributed to the care of demented persons. Since it is believed that Alzheimer's disease represents one half of the cases of dementia, the annual cost of nursing home care of such patients would be about $5.6 billion. When the costs of hospitalization, professional office visits and home care are added to this cost, total estimates for the care of Alzheimer's patients approach $20 billion yearly." [8] It should be noted that in spite of the large sums of money that are provided through public and private third-party payors, the families of dementia victims bear the major burden of paying for the patient's medical care. The financial and emotional impact of caring for dementia patients cannot be quantified. These families suffer great financial and psychological stress, and frequently do not have access to public assistance programs until their financial resources have been exhausted.

The primary means of financing third-party payor medical care for Alzheimer's patients are Medicare, Medicaid, Veterans' Administration, Medicare Supplemental Insurance Programs, and Disability Insurance.

- Medicare - the federal medical assistance program administered by the Health Care Financing Administration which is designed primarily to cover medical payments for the elderly, persons with end stage renal disease, and certain disabled persons.[9]

  It is the position of some that Medicare's requirements essentially rule out assistance for Alzheimer's patients since coverage is acute care oriented and generally related to periods of hospitalization and because Medicare views treatment for Alzheimer's as largely custodial, e.g. assistance in walking, bathing, dressing, taking medication, and supervision. Although Medicare does not pay the full cost of some covered services, its hospital insurance component (Part A) covers inpatient hospital care, inpatient care in a skilled nursing facility, home health care, and hospice care. The medical insurance component (Part B) covers medically necessary doctor's services, outpatient hospital services, home health services, and other medical services and supplies that are not covered by the hospital insurance component.[10]

- Medicaid (State Medical Assistance Program) - the federal medical assistance program administered by the states to provide health care services to individuals who meet certain financial and categorical eligibility criteria.

  "Medicaid's most significant contribution to the care of Alzheimer's patients is the provision of nursing home care. Medicaid may pay for nursing home services that are not covered by Medicare. In addition to the limitation on coverage, Alzheimer's families are also confronted with the problem of the unavailability of beds, the expense and location of the facility and policies restricting placement of Alzheimer's patients.

Because Medicaid is geared to provide subsidized medical services to the poor, many Alzheimer's patients are not eligible until the family has been reduced to poverty.

It has been estimated that Medicaid expenditures for Alzheimer's patients exceeded $6.5 billion in fiscal year 1982." [11] It is necessary to point out that (1) financial need and medical need for Medicaid are assessed separately, (2) laws governing Medicaid programs vary from state to state, and (3) changes and reinterpretation of regulations occur almost daily.

- Veterans Administration - medical care services are provided by the Veteran Administration's Medical Facilities to honorably discharged veterans who have "service connected" injuries, illnesses or disability without regard to the ability to pay. Those honorably discharged veterans who do not have a "service connected" disability or illness, but who require medical treatment, are provided medical care services if they are unable to pay for such services in the private sector.

- Medicare Supplementary Insurance Policies - policies sold to cover services not covered by Medicare generally do not provide coverage for Alzheimer's disease and exclude payment for "custodial" services. In a few instances in which the policy would have provided a benefit, insurers have claimed Alzheimer's was a pre-existing condition, undiagnosed, and not covered by the policy.

- Disability Insurance - generally available under Social Security, employment and private insurance programs. Alzheimer's patients have frequently experienced difficulty in qualifying for these benefits.[12]

Other Related Dementias/Brain Disorders

The dementias are brain diseases that result in the progressive loss of mental faculties - loss of memory, impeded learning, short attention span and impaired judgment. Some types of dementia are curable, while most common dementing illnesses are not. In time, an unrelenting dementia will erode all aspects of thought, feeling and behavior, and lead to death. It is important to realize that demented persons are not insane in the sense of suffering a psychiatric disorder, but are "deprived of mind," deprived of the use of parts of the brain associated with a range of intellectual skills and activities unique to human beings. Though dementia is associated with aging, dementing disorders (pre-senile dementias) can occur earlier in life.

Pseudodementias

Among the disorders which can simulate dementia are depression and manic-depression. The depressed person is frequently passive and unresponsive. He may appear slow, confused and forgetful. The manic-depressive may experience mood swings between depression and mania, an excited state in which the person feels powerful, and acts recklessly or foolishly.

Reaction to drugs rivals depression in mimicking dementia. Often the reaction to drugs can cause disorientation, memory lapses and speech difficulties. Cessation of the medication is effective in reversing the dementing symptoms.

Chemical imbalances and organic diseases in individuals can also produce dementing symptoms. Because the brain demands many nutrients, poor eating habits or problems in food absorption can seriously affect the brain. Pernicious anemia, hypothyroidism, hypoglycemia, heart and lung diseases, head injuries, brain tumors, certain hereditary disorders, lead poisoning, and sodium or calcium imbalances are other problems that can induce disturbing personality changes.

All of the pseudodementias are treatable and, if the brain has not suffered permanent damage, the symptoms should abate.

True Dementias

Multi-infarct dementia is the mental deterioration due to blood vessel disease in the brain. It is thought that multi-infarct dementia accounts for twelve to twenty percent of dementia in the elderly and that sixteen to twenty percent of dementia patients have both infarcts and Alzheimer's disease. Multi-infarct dementia is distinguished from Alzheimer's disease in that multi-infarct patients usually have a history of high blood pressure, vascular disease or previous stroke. It is also the result of events that may occur months or years apart. The symptoms of infarcts are limited as these patients may have only one part of the brain affected as opposed to the "global" symptoms witnessed in Alzheimer's patients.

Multiple sclerosis is another disorder in which mental and physical deterioration can occur. This disease is characterized by destruction of the insulating material covering nerve fibers. It progresses through a series of acute episodes and partial recovery.

Parkinson's disease is distinguished by tremor and difficulty in initiating voluntary movements. The disease primarily affects older adults. Medication is administered to relieve the symptoms, but it cannot stop the progression of the disease. Resulting dementia may occur in severe or advanced cases.

Children with a parent who has Huntington's disease have a fifty percent chance of inheriting the disease. The symptoms, which may appear in early middle age, include personality change, mental decline, psychotic symptoms and movement disturbance. Restlessness and facial tics may progress to severe uncontrollable flailing of head, limbs and trunk while mental capacity deteriorates to dementia.

Pick's disease is a disorder very similar to Alzheimer's. The distinguishing feature between the two is different changes in brain tissue.

Creutzfeldt-Jakob disease is thought to be caused by an unusual virus that may lie dormant in the body for years (slow virus). When activated, the virus produces a rapidly progressive dementia with muscle spasms and changes in gait.[13]

Research on Alzheimer's Disease

Over the past decade, Alzheimer's disease has become a priority in federally funded research. Studies have focused on the use of drugs in treating cognitive impairments and secondary psychiatric symptoms such as depression, anxiety, paranoia, obsessionalism, and impaired sleep; psychosocial interventions and management techniques to improve attention, memory, cognition, language usage and behavior; the role of the family;[14] biological mechanisms; and molecular pathology, e.g., biochemistry, trace metals, slow viruses, immunology, biology and epidemiology of viruses, and genetics.[15]

Activities in Virginia, in Other States and at the Federal Level

A. Virginia

The most recent information available indicates that there are four chapters of the Alzheimer's Disease and Related Disorders Association (ADRDA) in Virginia, one each in Falls Church, Richmond, Roanoke and Virginia Beach. There is one such chapter in Washington, D.C., and two regional chapters of which Virginia is a part located in Pennsylvania. ADRDA is an advocacy association which disseminates educational materials and information on Alzheimer's disease to the families of victims and to the public, provides services and support to the families, publicizes the needs of the affected population and promotes the need for continued research into the causes, diagnosis and treatment of dementias.

The Virginia General Assembly in 1982 (§ 2.1-373.9, Code of Virginia) established the Alzheimer's and Related Diseases Research Award Fund. The Fund is administered by the Virginia Center on Aging at Virginia Commonwealth University. Awards are made to scientists in the Commonwealth to support research into the causes, methods of treatment of Alzheimer's and support services for such families. The appropriation for the 1985-1986 fiscal year is $40,000 the first year and $40,000 the second year (1985 Acts of Assembly, C. 619; § 1-75; Item 292).

Another appropriation was made for the 1985-1986 fiscal year to the Dementia Center of the Eastern Virginia Medical Authority, $52,000 the first year and $139,800 the second year (1985 Acts of Assembly, c. 619, § 1-92, Item 365). In addition, the 1985 Legislature also passed House Joint Resolution No. 309, which established a commission to study the need for and the feasibility of establishing a network of regional dementia centers in the Commonwealth and to recommend appropriate activities for such centers.

B. Other States

Recent information compiled by the Commission's staff indicates substantial activity regarding Alzheimer's disease in many states, specifically in California, Rhode Island, Illinois, and Maryland. Legislative activity in these states has primarily addressed the financial needs of Alzheimer victims, family support services and research.

C. Federal

A substantial number of measures on Alzheimer's disease have been introduced in both the U.S. House and Senate during the 98th and the 99th Congresses. A review of the bills and a brief summary of each was prepared by the Commission's staff. The focus of much of this legislation concerned tax incentives, research, medical care, and services to veterans who are Alzheimer victims.

ACTIVITIES OF THE COMMISSION

The Commission was briefed by the staff at its organizational meeting in Richmond regarding Alzheimer's disease and related dementias, factors which affect Alzheimer patients and their families, and the status of legislative activities in other states and the Congress on Alzheimer's disease and related dementias. The staff also prepared and presented a proposal for the conduct of the study which included pertinent issues for investigation and a schedule for the timely completion of the study.

In addition, the Commission received testimony from representatives of the Virginia chapter and the national office of the Alzheimer's Disease and Related Disorders Association (an advocacy organization), the Department on the Aging, the Virginia Center on Aging and a member of the State of Maryland's Task Force on Alzheimer's Disease.

At this meeting, the Commission identified the issues it would address during the course of its study. These issues included reimbursement mechanisms, demographics, autopsy, needs of victims and caregivers, funding for research, education of professionals and public awareness, and medicolegal issues.

To ascertain the views of experts in the area and the public regarding Alzheimer's disease, the Commission held four public hearings throughout the Commonwealth, one each in Christiansburg, Arlington, Richmond and Virginia Beach. The consensus reflected in the testimony received at the hearings can be summarized as follows:

There is a need for

- basic, updated information on the causes, effects, treatment and community resources
- funds for education and information for caregivers, the public and professionals who work with Alzheimer's victims
- funds for existing services to the elderly to provide more in-home, long-term care services to victims and their families
- day care centers for the elderly and demented patients
- respite care
- research
- innovative funding mechanisms to provide necessary health and medical care to victims and to ease the financial burdens on families
- regional dementia centers
- community support services
- access to quality medical care
- coordination of services to the elderly offered by the Departments of Mental Health and Mental Retardation, Office on Aging, Social Services and the State Health Department
- third-party insurance coverage for the chronically ill or long-term care patient
- changes in the Medicaid, Medicare and Veterans' Administration programs to provide increased coverage and availability of medical care and related health/homemaker/rehabilitative services.
- autopsy

To provide the Commission with information concerning the funding of health care and Virginia's statutory requirements concerning anatomical gifts, autopsies and definition of death, the staff prepared two papers for the Commission's review: Overview of the Health Care Industry and the Funding of Health Care, and the Status of the Law: The Natural Death Act, Anatomical Gift Act, Uniform Donor Document and Authorization of Autopsies.

To facilitate an analysis of the issues reviewed in the literature, those identified by the Commission and concerns expressed during the public hearings, the Chairman appointed four subcommittees: Service Gaps/Demography, Education, Finance and Medical/Legal. The staff prepared an issues paper for use by each subcommittee. The subcommittees' findings are embodied in the Commission's recommendations.

RECOMMENDATIONS

SERVICE GAPS/DEMOGRAPHY

Findings

Testimony presented to the Commission by professionals and families of victims indicates that the psychosocial service needs of Alzheimer's disease victims and their families pose a complex problem admitting no easy solution. Of the many and varied needs of victims and families attested to, one of the most significant was an array of services to assist families in maintaining their patients outside of an institution for as long as possible. However, services to accomplish this goal, e.g., respite care and home health care, appear to be relatively few in some localities or lie beyond the means of many victims' families.

The Commission also believes that to effectively serve the needs of Alzheimer victims and their families, the number of Virginians so afflicted must be determined.

A. Demographics

1. The Commission recommends that an epidemiological study be conducted or a mechanism be established to determine the number of Virginians affected with Alzheimer's disease and other dementing disorders.

Discussion

Consultation with representatives of non-profit and for-profit homes for adults, the nursing home association and other such entities in the Commonwealth revealed that data on the number of patients with a dementing disorder in these facilities were not available because such statistics are not compiled, disclosure of such information violated the Freedom of Information Act and the entry of diagnosis was incomplete. However, it was estimated that nearly three to four hundred patients in non-profit homes for adults suffered from Alzheimer's or some form of dementia.

One problem in determining the number of Alzheimer victims in Virginia is the reimbursement mechanism for medical care. As a result, estimates are skewed by variations in diagnosis. For example, a physician may enter the diagnosis as "organic brain syndrome" to assure that he is paid for his services. This makes it difficult, if not impossible, to obtain an accurate count of patients with Alzheimer's or some other dementia.

In an attempt to estimate the number of Alzheimer's victims in Virginia, the staff noted that three percentages (5%, 10%, 15%) are used in determining the number of such persons in the nation. Congress estimates that ten to fifteen percent of the population age sixty-five and older is affected. These percentages, when applied to the 1980 Census for Virginia, result in wide variances. The Commission concludes that such dramatic ranges in estimates substantiate the need for an epidemiological study. However, the Commission is aware of the cost and intricacy of an epidemiological study and proposes that should it be determined that an epidemiological study is not financially feasible, a mechanism be developed to catalog the number of diagnoses of Alzheimer's disease and to facilitate health planning for the victims and their families. It is envisioned that a central registry, such as that suggested by the Medical/Legal Subcommittee, may accomplish these goals. Funding for an epidemiological study or other mechanism might be available through the Health Block Grant, the Alzheimer's Research Award Fund or by an appropriation for this purpose.

2. The Commission recommends that the State Health Department amend the Death Certificate and related regulations in a manner that establishes an accurate account of the deaths attributed to Alzheimer's disease and related dementias.

Discussion

In obtaining information concerning the low number of deaths due to Alzheimer's disease and related dementias in Virginia, the State Health Department advised the Commission that the number of deaths for a given condition is determined by the "immediate cause" of death entered on the death certificate by the physician. For example, it is possible that an individual may have been an Alzheimer's victim, but actually died of pneumonia. Consequently, the individual's death would be included in the total for pneumonia. Likewise, the number of deaths due to Alzheimer's disease represents those cases in which the "immediate cause" of death is entered as Alzheimer's disease. However, the State Health Department indicated that based on National Center for Health Statistics data, the total number of deaths for the Commonwealth in 1983 due to Alzheimer's disease (Code 331.0) and pre-senile dementia including Alzheimer's disease (Code 290.1) was 434 and 475, respectively. Based on the Center's data, the rate of death for Alzheimer's disease is 16.1 per 100,000 persons nationally and 16.2 per 100,000 persons for the state. The Commission believes that a more complete and accurate filing of death certificates will assist the Commonwealth in determining the number of deaths in Virginia attributable to Alzheimer's disease or a related dementia.

B. Service Gaps

3. The Commission recommends the creation of five regional dementia centers throughout the Commonwealth.

Discussion

The Commission believes that better coordination of services only will not address the needs of victims and their families, since services provided through various community agencies are often sporadic, fragmented and ill-equipped to deal with the needs of dementia patients. A more effective means of delivering services to families is to create five regional dementia centers throughout the Commonwealth which will focus primarily upon meeting the psychosocial needs of patients and families through direct service delivery unavailable from other sources. These centers would provide information and referral services, in-home or center-based respite care services, professional training and community awareness, and information and support to families regarding autopsies. It is proposed that a center would be located in each of the state's five health systems areas (HSAs): Norfolk, Fairfax County, Richmond, Charlottesville and Roanoke/Salem or Blacksburg. These centers would be operated jointly by local health care or academic institutions and local chapters of the Alzheimer's Disease and Related Disorders Association, staffed by paid personnel and assisted by volunteers of local chapters of the Alzheimer's Disease and Related Disorders Association. Administrative responsibility for the centers would belong to the Department of Mental Health and Mental Retardation. Centers would work cooperatively with local health care or academic institutions, but would operate independently.

Testimony submitted to the Commission points to a lack of informational and community support services which professionals and caregivers believe are essential to the care of the patient and the support of caregivers. Caregivers need a resource where they can obtain information on the diagnosis, course and treatment of Alzheimer's disease and respite from the long, tedious and emotionally draining periods of caring for patients. Respite, for the purposes of clarification of such services to be provided by the regional dementia centers, is the temporary care of the patient in his home or other appropriate setting in order to provide a respite for the caregiver. In providing programs and services for Alzheimer's victims and their families, it is recommended that the dementia centers determine the needs of this population and the demand for certain services before creating new programs or augmenting existing services which would result in an expensive duplication and fragmentation of programs and services.

To provide affordable educational and psychosocial services to the families of Alzheimer victims, the Commission recommmends that $1,125,000 be appropriated annually to the Department of Mental Health and Mental Retardation for the operation of the dementia centers.

EDUCATION

Findings

The Commission agreed to assess the need of the lay community for information about the dementias, the dissemination of information and the academic preparation of medical and allied health professionals, geriatric nursing assistants, lawyers, the clergy and professional counselors. To determine the accessibility of information on dementias to the general public, the staff reviewed the Union Catalog List to ascertain the holdings of public and private libraries in the Commonwealth. The Commission requested the staff to investigate disseminating such information on a massive scale via the Department of Taxation, the Department of Motor Vehicles, the Alcoholic Beverage Control Board, the Medical Society of Virginia, and the State Chamber of Commerce. The Department of Motor Vehicles, the Alcoholic Beverage Control Board, the Medical Society of Virginia and the State Chamber of Commerce responded favorably to the Commission's inquiry.

Information on the education of professionals who provide care and services to Alzheimer's patients was obtained through testimony before the Commission from representatives of the medical, nursing, geriatric nursing assistant and patient counseling professions. In response to the Commission's concern about the preparation of undergraduate and graduate medical students to care for and treat demented persons, it was the consensus of representatives of the state's medical schools that medical education administrators are aware of the need to improve instruction in this area and that much of the instruction on the dementias occurs in neurology courses. There was agreement that "seed" money to fund research and to attract and retain the ablest of clinicians in this area is a tremendous need. It was also their belief that more effort should be given to providing information on the dementias to practicing physicians.

Nursing representatives assured the Commission that the training of prospective nurses emphasizes the importance of caring for each patient and providing for his particular needs. In this light, such an approach would include the unique needs of the Alzheimer patient. Instruction is provided on the dementias in required courses for the completion of the program. At the graduate level, specialization is offered in psychiatric nursing.

Information provided the Commission regarding the professional preparation of pastoral counselors indicates that they are specifically trained to provide care and counseling to assist patients and their families in coping with crises. It is the Commission's opinion that the very nature of the training of these professionals would enable them to deal effectively with the needs of Alzheimer patients and their families.

The Commission was unable to assess the full range of informational needs of the general public, short of testimony presented by providers and caregivers that there is a need for basic information on dementias. The Commission recommends that a survey be conducted to solicit data on the informational needs of professionals, caregivers and the general public.

A. Legislation

4. The Commission recommends that the study on Alzheimer's Disease and Related Disorders be continued.

Discussion

The Commission identified many issues which are pertinent to its study that it did not have sufficient time to explore. To more adequately address the issues which have been included in this report and to investigate those which were not addressed, an extension of the Commission's study is required.

B. Professional Preparation

5. The Commission recommends that professional and para-professional groups which provide education, treatment, care and supervision of persons with dementias reevaluate their respective academic and clincial programs to ensure adequate instruction on the dementias.

Discussion

Victims of dementia and their families require services from varied professionals, e.g. physicians, nurses, attorneys, the clergy, geriatric nursing assistants, many of whom are unaware of the needs and problems of demented patients and their families. Effective interaction of these professionals with such patients and their families requires that these professionals possess the skills necessary to meet the needs of these individuals and develop an understanding of the problems they face, as well as attain knowledge about the dementias. It is the Commission's belief that the academic and clinical programs for these professionals are capable of accommodating instruction to prepare such persons to meet the needs of demented patients and their families. The State Council of Higher Education is therefore requested to apprise the relevant colleges and universities of the Commission's opinion regarding this issue.

6. The Commission recommends that the eighty-hour curriculum for the geriatric nursing assistant program be increased.

Discussion

The chronic nature of Alzheimer's disease neccesitates the institutionalization of many patients. It has been estimated that Alzheimer's disease accounts for nearly fifty percent of admissions to nursing homes and long-term mental hospitals in the nation. Consequently, it is the geriatric nursing assistant that provides the routine daily care of such patients. Thus, the responsibilities of the geriatric nursing assistant require that these individuals possess knowledge of the nature of dementias and proper care and management of such patients.

The geriatric nursing assistant program is offered by public schools, proprietary schools and community colleges. Licensed nursing homes also offer this program to meet their individual needs and are required to have the program approved by the State Health Department. The standards for the program are jointly developed by the Department of Education, the Board for the Virginia Community College System and the State Health Department, though the programs are regulated by the State Health Department. Based on a review of the standards and on testimony regarding the program, the Commission determined that the current standards were minimal and that an increase in the standards would produce personnel better prepared to provide appropriate and quality care and to cope with the demands of caring for demented patients. An increase in the current eighty-hour curriculum would accommodate comprehensiveness, additional content on the dementias and a practicum.

C. Dissemination of Information

7. The Commission recommends that the Board of Education include instruction on the dementias in the health education program.

Discussion

The tragedy of Alzheimer's disease is not limited to the victim, but the victim's family also suffers. The great majority of chronically ill persons in this nation are cared for in the home by their families. Family members who are responsible for the care of a member who is suffering from a dementing illness are overwhelmed physically, emotionally and financially by the burden of providing such care.

Testimony before the Commission revealed that school children are beset with many perplexing problems when a dementing illness strikes a parent, often causing them to feel trapped, frustrated, isolated and abandoned. In many instances, these children must assume the role and responsibilities of the parent, an emotionally difficult role for children to assume. They have little or no control over family situations and many times the problems and unresolved emotions may manifest themselves as failure in school, discipline problems, substance abuse and other deleterious habits and activities.

In the school setting, it is imperative that school personnel be knowledgeable of the dementias and their effects upon the family in order that they might promptly detect and adequately respond to the needs of such children.

8. The Commission recommends that licensed physicians be encouraged to participate in education programs on the dementias.

Discussion

It has been determined that individuals who are suffering from a dementing disease, and their families, have unique and specific medical and informational needs. Consequently, the skills necessary to meet the needs of these individuals require that physicians stay informed of new medical and research breakthroughs on the dementias and become sensitized to the problems and needs of the victim and the caregivers.

Many programs being presented by health facilities and professional medical associations to provide continuing education for physicians increasingly focus on the dementias. It is recommended that licensed physicians participate in continuing education programs, as physicians who possess more definitive information of the dementias would be better prepared to meet the needs of both victims and their families.

9. The Commission recommends that the state agencies and interested civic and community associations cooperate to disseminate information on Alzheimer's disease and related disorders.

Discussion

The Commission has determined that thousands of Virginians, age sixty-five and over, are afflicted with Alzheimer's disease or a related disorder, such as Pick's disease, Huntington's disease and Creutzfeldt-Jakob disease. The Commission has also identified a need for greater public access to information about these diseases and the medical and support services available in the community. It is the Commission's belief that the expeditious dissemination of such information could be accomplished through a collaborative effort by both public and private agencies which maintain contact with great numbers of the citizens of this Commonwealth. The agencies of the Commonwealth are encouraged to work with civic and community organizations and advocacy groups for the elderly and on the dementias in disseminating information on the dementias to the public. It is necessary that those civic and community organizations and advocacy groups interested in participating in this effort provide the information and materials at their expense and in a manner consistent with agencies' policies.

MEDICAL/LEGAL

Findings

The Commission deliberated on problems related to the treatment of dementia patients, the course of the disease and its effects on the patients' and families' daily lives, and research into the etiology of dementias. Also discussed were issues related to the clinical symptoms of cognitive decline, such as when guardianship is appropriate and intermittent competency and how it affects the individual's ability to render voluntary informed consent, give power of attorney and conduct the activities of daily living, e.g., driving. It was agreed that determining when guardianship is appropriate is a difficult task which can only be resolved on a case-by-case basis and that the families of dementia patients should seek the advice of attorneys if guardianship becomes an issue. Guardianship requires a legal procedure which can be expensive and it was noted that a family member frequently obtains power of attorney in order to conduct the patient's financial and property affairs.

It must be emphasized that a power of attorney must be obtained during a period of lucidity. Further, a power of attorney obtained from a patient diagnosed as having progressive dementia should be sought during the early stages of the disease and should include the statement "This power of attorney shall not terminate on disability of the principal" (See §11-9.1 of the Code of Virginia).

Although dementia patients have many problems in carrying out the activities of daily living, many families have expressed particular concern for the difficulty in removing driving privileges. As the disease progresses, the patient's ability to find his way or to remember traffic rules may diminish. The families have voiced their fear for the safety of the patient and the public. Section 46.1-383 of the Code of Virginia provides that on a written request to the Department of Motor Vehicles an individual will be required to submit to an examination which can include a medical examination. If the written request is submitted by a relative of the individual, the Department cannot release the identity of the individual supplying the information. It was concluded that the provisions of this law are not widely known or used and that the families of dementia patients should be informed of the protections afforded by this mechanism.

Discussed at length were the difficulties in obtaining voluntary informed consent for treatment of Alzheimer's disease and related disorders. Virginia's human research statute states: "notwithstanding consent by a legally authorized representative, no person shall be forced to participate in any human research." Dementia patients often become paranoid and belligerent as the disease progresses. At this time, there are no cures for these diseases; therefore, experimental therapies are used. During periods of paranoia, dementia patients often come to view their physicians with suspicion and are prone to refuse treatment. Physicians frequently find it necessary during these crises forcibly to administer therapy which is still considered experimental to alleviate such paranoid and contentious behavior. Because these situations are viewed as emergencies by the medical community, many physicians do not feel that informed consent is an issue. However, the potential exposure to liability for nonconformance with the human research statute does exist.

Issues related to research in and diagnosis of Alzheimer's disease and related disorders such as the need for additional grant funds, the efficacy of an Alzheimer's disease and related disorders registry, needed revisions to the present laws on anatomical gifts, determination of death, and authorization of autopsies, and the need for methods to procure tissue for research and confirmation of diagnoses were the subjects of extended discussion by the Commission. It was the consensus of the Commission that the grants awarded by the Alzheimer's and Related Diseases Research Award Fund serve a valuable function in "seeding" dementia research in Virginia and promoting a competitive edge for acquiring national grants from the National Institutes of Health and the National Science Foundation.

The Commission believes that a functional registry could benefit the families of patients, researchers and practitioners by providing essential data. Such a registry would serve the primary purpose of collecting data on the incidence of Alzheimer's disease and related disorders in Virginia and the demography of these diseases. These data are essential as the bases for cost-effective planning and implementation of needed services for the victims of dementias and their families.

A registry could be developed which would also include a mechanism for confirmation of diagnoses through random autopsies or, if a test becomes a reality, through the test. This registry could also include a mechanism for the distribution of tissue to researchers.

The Commission agreed that there is a need for statutory authority for antemortem consent to autopsies because frequently family members are not available at the time of death and it is difficult to predict when death will occur. Such a statutory provision would complement a state registry by allowing families to consent to autopsy before the death of the disease victim, thereby assuring the family of a confirmation of the diagnosis.

The Anatomical Gift Act and the Determination of Death Statute were also analyzed because of the potential for interaction between these statutes and a state registry and antemortem authorization of autopsy. The Anatomical Gift Act authorizes several groups to perform recoveries of various organs and tissues; therefore, it appeared to the Commission that an inexpensive means of obtaining an autopsy of the brain would be to allow technicians trained by neuropathologists to recover brains which could then be evaluated by pathologists. A registry which includes random autopsies would be cost-effective if such technicians, rather than pathologists, could be used for this purpose. Further, authorizing trained technicians to recover the brain could make it easier for families to obtain an autopsy through mechanisms other than a registry at less cost because pathologists are not always available to perform this service. It is the Commission's opinion that, although dementia patients seldom suffer brain death, any potential for suspicion related to antemortem authorization of autopsies could be averted by clarifying the determination of death statute to assure that two physicians are required to declare brain death.

Another set of issues addressed by the Commission was related to the civil liability of the individual and institutional provider of care, such as methods of securing dementia units and restraining dementia patients and the physician's or institution's potential responsibility to detect caregiver stress which could lead to abuse of the patient.

Public awareness of abuse of disabled and elderly adults has been heightened in recent years by media reports of such events. Some providers do not feel that they have an obligation to monitor caregiver stress. However, others state that when counseling the caregiver, they consider that individual a patient and tailor the advice accordingly. The Commission recognizes that in the usual case the provider is not in a position to monitor the condition of the caregiver. However, if severe symptoms of stress are displayed, special caution should be used in counseling the caregiver.

Dementia patients frequently wander in facilities, causing disruptions and disturbing other patients. Further, these patients sometimes wander outside the facility. While wandering dementia patients often appear lucid to the public, they may not be able to or may not want to find their way back to the facility. For these reasons, the security of dementia units is a matter of serious consideration. The Commission strongly emphasizes that every possible structural method, e.g., alarms, cameras, etc., should be used to secure dementia units rather than physical or chemical restraints of the patient. The Commission also believes that the requirements of the BOCA Code and local building codes should be examined to determine if they are realistic as applied to units for dementia patients.

Issues related to the commitment procedure in Virginia, such as the inadequacy of the public and professional understanding of the requirements of the law and the role of the crisis intervention centers, were also discussed by the Commission, though it did not complete its deliberations on these issues. It appears at present that the commitment procedure in Virginia is operating adequately. The Commission intends to investigate the responsibilities of the crisis intervention centers and to determine any needs in this area in the next year of this study. At this time, it appears that education of the public and professionals is needed to inform them of the procedures for involuntary commitment in Virginia and the services available from the local community services boards and crisis intervention centers.

Issues related to graduate medical education, such as the apparent deficiencies in the quality of care in remote areas of the state and the need for curricular revisions, continuing education for practicing physicians and additional information services were also examined. It is the opinion of the Commission that there is a need for a more cohesive, coordinated approach to dissemination of information on dementias to professionals. There also appears to be a need to increase expertise in some areas of the state in order to improve the quality of care for dementia patients. Some patients demonstrating symptoms of dementias suffer from reversible disorders. In view of the fact that Alzheimer's disease has been described as a "waste basket" diagnosis, the Commission believes that more information and instruction for the medical community are important issues for future consideration during the next year of this study.

The Commission acknowledges, relative to the dementia center concept and issues related to this concept, the Medical/Legal Subcommittee's belief that the development of a model multidisciplinary system of services appears to be a feasible and cost-efficient means of providing services, utilizing existing resources, tailoring services to the needs of localities and substantiating the need for and effectiveness of regional dementia centers.

A. Cognitive Decline

10. The Commission recommends that the statute on human research be amended to clarify the requirements for informed consent.

Discussion

This amendment is essential to alleviate the potential for liability for nonconformance with the prohibition against force when no accepted therapies are available for incompetent patients. The difficulties related to voluntary informed consent and the various understandings of the meaning of the statement in the law related to "force" prompted the Commission to study this law carefully. The Commission believes that the recommended amendments more accurately reflect actual practice and provide additional protections for competent patients. No competent individual is "forced" to participate in human research. However, borderline cases involving young, preverbal children and other incompetent individuals occur on a daily basis when there is no accepted treatment or cure, but there is an experimental therapy which would, in all probability, be beneficial. It is believed that the revisions protect the individual's right to "determine what shall be done with his own body" (Schloendorff v. Society of New York Hosp., 211 N.Y. 125, 129, 105 N.E. 92 (1914)), while providing the medical community with a legal mechanism for instituting treatment under these difficult circumstances.

B. Human Research

11. The Commission recommends that the Commonwealth's funding of the Alzheimer's and Related Diseases Research Award Fund be increased from $40,000 to $100,000 per year and that this increase be allocated for medical and biomedical research.

Discussion

Currently, the appropriations for this fund are $40,000 per year, a sum which will fund only a few research projects. The Commission felt strongly that this sum should be increased to $100,000 per year, that increased "seed" funding would attract additional national research funding, that the additional funds should be dedicated to medical and biomedical research and that the benefits of this increase would be substantial to the research community, the research institutions and the patients.

C. Autopsy

12. The Commission recommends that authorization of antemortem consent to autopsies be provided.

Discussion

A diagnosis of Alzheimer's disease and other dementias can only be confirmed by autopsy. It is difficult to predict the time of death for even seriously ill dementia patients, who often rally when death appears imminent. Often family members express the desire to obtain an autopsy, but are not present to give consent at the time of death. Further, in some areas of the state, it is difficult to arrange for an autopsy and antemortem authorizations will allow the families the time to plan and alleviate anxiety related to the possibility of "never knowing for sure" if the diagnosis was correct.

13. The Commission recommends that the Anatomical Gift Act be revised to allow technicians trained by neuropathologists to recover the brain.

Discussion

In many areas of the state, autopsies have become expensive and even difficult to obtain because pathologists may not be available and changes in reimbursement systems have contributed to the decline in the use of autopsies. Confirmation of diagnoses of dementias can only be obtained through autopsy. It is anticipated that trained technicians could provide an inexpensive recovery mechanism for a registry and other systems established to assist the families of Alzheimer's disease and related disorders in obtaining autopsies.

D. Registry

14. The Commission recommends that a functional registry be established which would include a mechanism for confirmation of diagnoses through random autopsies and a mechanism for distribution of tissues to researchers.

Discussion

To help collect essential data on the demography and incidence of dementias in Virginia, assist families with confirmation of diagnoses and promote the development of research on the etiology and treatment of dementias, the Commission discussed the concept and structure of a multidimensional registry. It is believed that such a registry is the best method of obtaining accurate data on dementias and that incorporation of autopsy and tissue distribution mechanisms in this registry will create a unique benefit to the families of dementia patients and medical and scientific researchers in Virginia.

E. Determination of Death

15. The Commission recommends that the determination of death statute be amended to clarify the requirement for two physicians to declare brain death.

Discussion

Presently, the brain death provisions are subject to various interpretations. Some physicians who are neurospecialists believe that this law should be interpreted to mean that in instances in which the attending physician is a neurospecialist, no second attestation is required. Most experts interpret this statute to require two attestations of brain death. To ameliorate any concerns about antemortem authorizations of consent for autopsies before these concerns are voiced, the Commission recommends that the brain death law be clarified.

F. Continuing Medical Education

16. The Commission recommends that funds be appropriated to the state's medical schools for the establishment of model multidisciplinary systems of services for patients with organic brain diseases or cognitive disorders.

Discussion

To develop cost-effective, coordinated approaches to delivery of medical and other services to patients with organic brain diseases or cognitive disorders in tertiary institutions, the Commission proposes that each of the three medical schools be appropriated a small sum of money for the development of a multidisciplinary system of services for patients with organic brain diseases or cognitive disorders. These systems are to be developed using existing resources, e.g., departments of neurology, geriatrics, general medicine, psychiatry, etc. The structure of these systems is left to the administrators of the medical schools. The one element of these delivery systems believed by the Commission to be valid for all three medical schools is the implementation of a toll-free number through which all physicians in the Commonwealth could have access to specialized medical advice on organic brain diseases and cognitive disorders.

G. Facilities

17. The Commission recommends that medical facilities and institutions which provide care for demented patients implement, wherever possible, structurally secure environments for such patients rather than using chemical or physical restraints.

Discussion

An environment that provides both security and maximum opportunity for free movement of ambulatory patients appears to be the most sensible, humane and feasible way of providing for the needs of both physically disabled and demented patients within the same facility. Such structural security measures allow demented patients more opportunity for interaction with staff and residents, especially during periods of lucidity, while protecting them from outside dangers and insulating other residents from possible disruptive behavior.

CONCLUSION

The Commission worked diligently throughout its study and has identified many needs of Alzheimer victims and their families, the general public and the medical community. It is recommending certain legislative action, where appropriate, to address these needs. Nevertheless, there remains much to be accomplished relative to estimating the number of Virginians afflicted with Alzheimer's disease, determining the number and needs of individuals afflicted with other dementias, and developing alternatives to the dilemma of financing the medical care of such individuals. The medical/legal and research factors also require further deliberation. Therefore, legislation which requests the continuation of this study has been appended.

The Commission extends its appreciation to all who assisted in its study.

Respectfully submitted,

Kenneth R. Plum, Chairman

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FOOTNOTES

[1] Proposed Report on Senile Dementia of the Alzheimer's Type, Department of Health and Human Services, Public Health Service, National Institutes of Health (Washington, D.C.: Government Printing Office, 1981).

[2] Alzheimer's Disease: Joint Hearing before the Subcommittee on Health and Long-Term Care of the Select Committee on Aging and the Subcommittee on Health and the Environment of the Committee on Energy and Commerce, House of Representatives, 98th Congress, 1st Session, August 3, 1983 (Washington, D.C.: Government Printing Office, 1984), pp. 4-6.

[3] Alzheimer's Disease: An Information Paper Prepared for the Use of the Subcommittee on Health and Long-Term Care of the Select Committee on Aging, House of Representatives, 98th Congress, 1st Session (Washington, D.C.: Government Printing Office, 1983) p. 5.

[4] Questions and Answers: Alzheimer's Disease, Department of Health and Human Services, Public Health Service, National Institutes of Health (Washington, D.C.: Government Printing Office, 1980).

[5] Alzheimer's Disease: Joint Hearing, p. 4.

[6] Alzheimer's Disease: An Information Paper, p. 13.

[7] Ibid., p. 17.

[8] Alzheimer's Disease: Joint Hearing, p. 4.

[9] Your Medicare Handbook, Department of Health and Human Services, Health Care Financing Administration (Washington, D.C.: Government Printing Office, 1985), p. 3.

[10] Alzheimer's Disease: An Information Paper, p. 19.

[11] Idem.

[12] Ibid. p.20.

[13] The Dementias: Hope Through Research, Department of Health and Human Services (Washington, D.C.: Department of Health and Human Services).

[14] Alzheimer's Disease: Report of the Secretary's Task Force on Alzheimer's Disease, Department of Health and Human Services (Washington, D.C.: Government Printing Office, 1984), pp. 34-47.

[15] Progress Report on Alzheimer's Disease: Volume II, Department of Health and Human Services, Public Health Service, National Institutes of Health (Washington, D.C.: Government Printing Office, 1984), pp. 5-24.

APPENDICES

A. Legislation

B. Section 11-9.1, Code of Virginia

Section 46.1-383, Code of Virginia

APPENDIX A

LD1961548

HOUSE BILL NO. 633

Offered January 21, 1986

A BILL to amend the Code of Virginia by adding in Chapter 1 of Title 37.1 an article numbered 6, consisting of sections numbered 37.1-62.1 and 37.1-62.2, relating to the establishment of five dementia centers.

Patrons--Plum, Almand, Munford, Crouch, Mayer, Harris, Byrne, Saunders, Stambaugh, Marshall, McDiarmid, and Van Landingham; Senators: Holland, C. A., DuVal, Waddell, Babalas, and Lambert

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Referred to Committee on Health, Welfare and Institutions

Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Chapter 1 of Title 37.1 an article numbered 6, consisting of sections numbered 37.1-62.1 and 37.1-62.2 as follows:

Article 6.

Dementia Centers.

§ 37.1-62.1. Dementia centers established; Board to monitor; respite, other psychosocial and educational services to be provided.--From such funds as are appropriated for this purpose, there are hereby established five dementia centers, one to be located in each of the five health service areas of the Commonwealth.

For the purposes of this section, the term "dementia center" shall mean a facility administered by a licensed health care facility or an accredited institution of higher education to deliver educational and psychosocial services to patients with dementias and their families. These services shall include, but not be limited to, respite care services to families caring for dementia patients, information and referral services to families caring for dementia patients, professional and community education and information on obtaining brain autopsies for confirmation of diagnoses.

"Respite care" shall mean temporary care for the patient in his home or in a center or other appropriate setting in order to provide a rest for the caregiver.

Each of the centers shall coordinate its activities with the local chapter of the Alzheimer's Disease and Related Disorders Association. The centers shall collaborate with other disciplines within the health care or academic institution as appropriate, but shall be independent of any and all other activities. Volunteers drawn primarily from the local chapter of the Alzheimer's Disease and Related Disorders Association and any other support group shall be utilized by the dementia centers to maximize the use of staff resources.

The Department of Mental Health and Mental Retardation shall contract with the licensed health care facilities or accredited institutions of higher education for the provision of the services described in this section and shall monitor the fiscal and substantive activities of the dementia centers. The Department may require such reports from the centers and promulgate such regulations as it deems necessary and appropriate. The Department of Mental Health and

Mental Retardation shall also provide technical expertise and administrative oversight pursuant to the regulations and reporting requirements of the Board.

§ 37.1-62.2. Alzheimer's Disease and Related Disorders Commission; membership; oversight responsibilities.–The Alzheimer's Disease and related Disorders Commission shall, until July 1, 1989, monitor the development and operations of the dementia centers.

The Commission shall consist of twenty members appointed by the Governor, four of whom shall be members of the House of Delegates, three of whom shall be members of the Senate of Virginia, five of whom shall be providers who are member of the Alzheimer's Disease and Related Disorders Association, and eight of whom shall be professionals, one each from the fields of medicine, nursing, mental health, aging, social services, forensic medicine and two other areas related to the healing arts.

The Commission shall monitor the activities of the dementia centers and make recommendations to the centers for improving services to dementia patients and their families.

LD1226548

HOUSE BILL NO. 635

Offered January 21, 1986

A BILL to amend the Code of Virginia by adding in Chapter 2 of Title 32.1 an article numbered 9.1, consisting of sections numbered 32.1-71.1 through 32.1-71.4, establishing the Statewide Alzheimer's Disease and Related Disorders Registry.

Patrons--Plum, Callahan, Munford, Crouch, Mayer, Almand, Byrne, Saunders, Stambaugh, Marshall, McDiarmid, and Van Landingham; Senators: DuVal, Holland, C. A., Waddell, Babalas, and Lambert

---

Referred to Committee on Health, Welfare and Institutions

Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Chapter 2 of Title 32.1 an article numbered 9.1, consisting of sections numbered 32.1-71.1 through 32.1-71.4 as follows:

Article 9.1.

Statewide Alzheimer's Disease and Related Disorders Registry

§ 32.1-71.1. Statewide Alzheimer's Disease and Related Disorders Registry established; records of hospitals, clinics, individual practitioners and others may be supplied to Commissioner.--A. In order to collect data to evaluate the incidence of Alzheimer's disease and related disorders in Virginia, promote research on dementias, particularly Alzheimer's Disease, improve and validate the diagnosis of dementias, improve treatment of dementias, establish a mechanism for quality assurance and psychometric validation and provide a mechanism for informing patients and their families of available health care resources, there is hereby established the Statewide Alzheimer's disease and Related Disorders Registry. Each hospital, clinic, individual practitioner or other agency or facility providing health care may participate in this registry by making available to the Commissioner or his agents abstracts of their records of patients who have been diagnosed as having Alzheimer's disease or a related disorder. Such abstracts may include the name, address, sex, race and any other pertinent identifying information regarding each patient.

From the abstracts received, the Commissioner shall establish and maintain a Statewide Alzheimer's Disease and Related Disorders Registry. The purpose of the state registry shall include, but not be limited to:

1. Determining means of improving the diagnosis and treatment of patients with Alzheimer's disease or related disorders.

2. Determining the need for and means of providing better long-term, follow-up care for dementia patients.

3. Assisting in the training of professionals and other personnel providing care for patients with Alzheimer's disease and related disorders.

4. Providing tissue to validate diagnoses and support research on Alzheimer's and related *disorders.*

5. Collecting data to evaluate the incidence and causes of Alzheimer's Disease and related disorders.

6. Providing data to support research on Alzheimer's Disease and related disorders.

§ 32.1-71.2. Advisory Committee to be appointed; contract for quality assurance.–The Commissioner shall appoint an advisory committee to assist in the design and implementation of this registry which shall include, but need not be limited to, the Commissioner of the Department of Mental Health and Mental Retardation or his designee and one representative of each of the following groups: practicing physicians treating patients with Alzheimer's disease and related disorders; neuropathologists; researchers engaged in clinical investigations related to dementias; basic science researchers engaged in studies related to dementias; nursing home administrators; the Medical College of Virginia; the University of Virginia School of Medicine; Eastern Virginia Medical School; and the Alzheimer's Disease and Related Disorders Association.

The advisory committee shall assist the Commissioner or his agents in developing protocols, choosing necessary psychometric validation instruments and other technical mechanisms.

From such funds as are appropriated, the Commissioner shall contract with one or more of the three medical schools in the Commonwealth for diagnostic quality assurance of a random sampling of patients. The contractor shall report the results of the postmortem examination or other conclusive test to the family of the deceased and to his attending physician and shall make tissue available to any researcher conducting approved human research in the Commonwealth. The contractor shall hire on a consulting basis and train as necessary an individual or individuals to procure tissue.

§ 32.1-71.3. Fees for nonparticipants for informational services and providing tissue for research.–The Board shall establish and periodically review a schedule of fees to be charged for data or tissue requested by nonparticipating institutions, agencies or individuals. The fees shall be based on the actual cost of producing the data or providing the tissue. Agencies or political subdivisions of the Commonwealth shall be exempt from the payment of any such fees.

The schedule of fees for providing tissue shall be developed in cooperation with the contractor or contractors pursuant to § 32.1-71.2. The contractor or contractors shall keep records and periodically transfer such funds as are collected for providing tissue to nonparticipants to the Department.

§ 32.1-71.4. Confidential nature of information supplied; publication.–The Commissioner and all other persons to whom data is released or tissue provided pursuant to § 32.1-71.1 shall keep all patient information confidential. No publication of information, biomedical research or medical data shall be made which identifies the patients. However, the Commissioner may contact the families and physicians of patients diagnosed as having Alzheimer's Disease or a related disorder to collect relevant data and to provide them with information about available public and private health care resources.

HOUSE JOINT RESOLUTION NO. 105

House Amendments in [ ] - February 10, 1986

Requesting the Board of Education to include [~~a unit~~ , where appropriate, study] on the dementias in the [~~Family Life~~ Health] Education Program and in in-service education programs for all instructional, administrative and pupil services personnel.

Patrons—Munford, Plum, Crouch, and Miller, Y. B.; Senators: Holland, C. A. and Lambert

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Referred to Committee on Education

WHEREAS, Alzheimer's disease, a neurological disorder characterized by a progressive and irreversible deterioration of cognitive functions such as memory, attention and judgment, is estimated to afflicit 1.2 to 4 million people in the United States; and

WHEREAS, the tragedy of Alzheimer's disease, one of the dementing illnesses, is not limited to the victim, but the victim's family also suffers; and

WHEREAS, contrary to popular belief that most chronically ill persons are "dumped" in long-term care institutions, it has been found that the majority of such persons are cared for in the home by their families; and

WHEREAS, families caring for a member suffering from a dementing illness are overwhelmed physically, emotionally and financially and by the burden of caring for the member; and

WHEREAS, testimony before the Commission on Alzheimer's Disease and Related Disorders revealed that school children are beset with many perplexing problems when a dementing illness strikes a parent, often causing them to feel trapped, frustrated, isolated and abandoned; and

WHEREAS, often, these children must assume the role and responsibilities of the parent in the home, and this is an emotionally difficult role for children to assume; and

WHEREAS, these multiple problems and unresolved emotions may manifest themselves as failure in school, discipline problems, substance abuse and other deleterious habits, and activities; and

WHEREAS, children burdened by family situations over which they have little or no control may pose a problem to the orderly conduct of the school; and

WHEREAS, to promptly detect and adequately respond to the needs of such troubled children, school personnel need to be knowledgeable of the dementias and their effects upon the family; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Board of Education is requested to include [~~a unit~~ , where appropriate, study] on the dementias in the [~~Family Life~~ Health] Education Program and in in-service education programs for all instructional, administrative and pupil services personnel in order that they may be prepared to understand and respond to the needs of and the educationally related problems presented by children whose families may be caring for a member with Alzheimer's disease or a related dementing illness.

The Clerk of the House of Delegates shall prepare a copy of this resolution for presentation to the Board of Education in order that the Board members may be apprised of the sense of this body.

LD2226530

HOUSE JOINT RESOLUTION NO. 106
AMENDMENT IN THE NATURE OF A SUBSTITUTE

(Proposed by the House Committee on Education on

February 7, 1986)

(Patron Prior to Substitute--Delegate Munford)

Requesting the Department of Education, the Board for Virginia Community Colleges and the State Department of Health to study the Geriatric Nursing Assistants Program.

WHEREAS, due to the chronic nature of Alzheimer's disease many victims of this disease frequently require long-term health care, usually through institutionalization; and

WHEREAS, it has been estimated that Alzheimer's disease accounts for nearly fifty percent of admissions to nursing homes and long-term mental hospitals in the nation; and

WHEREAS, within these health facilities, it is the geriatric nursing assistant who most often administers the routine daily care of the patient; and

WHEREAS, it is necessary that these individuals possess knowledge of the nature of dementias and proper care and management of such patients to provide appropriate and quality care; and

WHEREAS, there are available in Virginia three types of preparatory programs for the geriatric nursing assistant: those offered by public schools, proprietary schools, and community colleges, all regulated by the State Department of Health; and

WHEREAS, the Department of Education, the Board for Virginia Community Colleges and the State Department of Health jointly developed standards for the geriatric nursing assistant program, which is being revised; and

WHEREAS, the Commission on Alzheimer's Disease and Related Disorders determined that the current standards were minimal and that an increase in the standards would produce personnel better prepared to cope with the demands of caring for such patients; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Department of Education, the Board for Virginia Community Colleges and the State Department of Health are requested to study the geriatric nursing assistants program to ascertain the need for increasing the eighty-hour curriculum, increasing the content on the dementias, and requiring that the curriculum be comprehensive and include services to dementia patients in the practicum.

The Clerk of the House shall prepare copies of this resolution for presentation to the Department of Education, the Board for Virginia Community Colleges and the State Department of Health and order that they may be apprised of the sense of this body.

LD1218548

HOUSE JOINT RESOLUTION NO. 140

Offered January 21, 1986

Requesting educators of professionals who care for or serve those suffering from dementias to reevaluate their programs to ensure adequate instruction in the dementias.

Patrons--Plum, Callahan, Munford, Stambaugh, Marshall, Almand, Crouch, and Van Landingham; Senators: Babalas, DuVal, and Lambert

Referred to Committee on Education

WHEREAS, victims of dementias and their families require services from many types of professionals, such as social workers, professional counselors, the clergy, physicians, nurses, and attorneys; and

WHEREAS, the Commission on Alzheimer's Disease and Related Disorders has found that individuals suffering from dementias and their families have specific service and informational needs; and

WHEREAS, many professionals are unaware of the problems faced by victims of dementia and their families; and

WHEREAS, the skills necessary to meet the needs of these individuals require that professionals develop an understanding of the problems faced by the patients and their families and become knowledgeable about the symptoms, treatment and courses of these diseases; and

WHEREAS, programs for professionals are capable of accommodating instruction to prepare such persons to serve the elderly and those suffering from dementias by incorporating more definitive information on the dementias; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That educators of professionals who care for or serve those suffering from dementias reevaluate their programs to ensure adequate instruction in the dementias.

The Clerk of the House of Delegates is hereby requested to send a copy of this resolution to the State Council of Higher Education for Virginia to be transmitted to the relevant colleges and universities.

LD4087548

HOUSE JOINT RESOLUTION NO. 134

House Amendments in [ ] - February 10, 1986

Continuing the Commission on Alzheimer's Disease and Related Disorders.

Patrons--Plum, Callahan, Munford, Crouch, Mayer, Almand, Harris, Byrne, Saunders, Stambaugh, Marshall, McDiarmid, and Van Landingham; Senators: Holland, C. A., DuVal, Waddell, Babalas, and Lambert

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Referred to Committee on Rules

WHEREAS, the Commission on Alzheimer's Disease and Related Disorders was established by the 1985 Session of the General Assembly to determine the needs of the victims of Alzheimer's disease and related dementias and to determine the feasibility of establishing regional dementia centers throughout the Commonwealth; and

WHEREAS, the Commission determined that thousands of Virginians age sixty-five and over are afflicted with Alzheimer's disease or a related disorder; and

WHEREAS, a cause or a cure for Alzheimer's disease has not yet been discovered; and

WHEREAS, the Commission has found that there exists a need to adequately inform the public of the nature of the disease; and

WHEREAS, exploration of the relationship between the preparation of medical and health-related professionals and the care of victims and their families would provide information regarding the adequacy of the training of such professionals; and

WHEREAS, testimony presented to the Commission indicates a lack of appropriate community and support services for the families of these victims; and

WHEREAS, the development of a clinical base to promote research, the formulation of alternatives to finance the medical care of victims, and the address of medicolegal problems inherent with the care of victims are issues which are critical to effective treatment of Alzheimer's disease; and

WHEREAS, the Commission has not had sufficient time to complete its work in the aforementioned areas; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Commission on Alzheimer's Disease and Related Disorders created pursuant to House Joint Resolution No. 309 of the 1985 Session is continued.

The membership of the Commission shall remain the same. In the event of a vacancy, such vacancy shall be filled in the same manner as the original appointments.

The Commission shall be funded in the same manner as other interim legislative studies. The Office of the Clerk of the House of Delegates shall provide administrative staffing, and legal and research staffing shall be provided by the Division of Legislative Services. Agencies of the Commonwealth shall provide assistance upon request and as the Commission deems appropriate. The Virginia Center on Aging shall provide consultative services to the Commission. The Commission shall complete its work [~~in sufficient time to have its legislative recommendation introduced into the 1987 Session of the General Assembly~~ prior to November 15, 1986].

All direct and indirect costs of this study are estimated to be [~~$25,000~~ $13,060].

LD1222548

HOUSE JOINT RESOLUTION NO. 148

Offered January 21, 1986

Requesting the State Board of Medicine and the Medical Society of Virginia to encourage licensed physicians to participate in education programs on the dementias.

Patrons--Plum, Munford, Stambaugh, Almand, Crouch, Van Landingham, Marshall, and McDiarmid; Senators: Babalas, DuVal, and Lambert

Referred to Committee on Health, Welfare and Institutions

WHEREAS, Alzheimer's disease is one of insidious onset and devastating course, characterized by a progressive and irreversible deterioration of cognitive functions, such as memory, attention and judgment; and

WHEREAS, it is estimated that 1.2 to 4 million people age sixty-five and older in the United States are stricken with this disease, some as young as forty years of age; and

WHEREAS, individuals suffering from dementias and their families, have specific medical and informational needs; and

WHEREAS, the skills necessary to meet the needs of these individuals require that physicians stay informed of new medical and research breakthroughs regarding the diagnosis, treatment and management of the victims of dementia, and become sensitized to the problems and needs of caregivers and the victims' families; and

WHEREAS, programs being developed by health facilities and professional medical associations to provide continuing education for physicians increasingly focused on Alzheimer's disease and the related disorders; and

WHEREAS, physicians who possess more definitive information of the dementias would be better prepared to meet the needs of both victims and families; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the State Board of Medicine and the Medical Society of Virginia are hereby requested to encourage all physicians licensed to practice in the Commonwealth to participate in continuing education programs on the dementias.

The Clerk of the House of Delegates shall prepare a copy of this resolution for presentation to the State Board of Medicine and to the Medical Society of Virginia in order that these groups may be apprised of the sense of the General Assembly.

HOUSE JOINT RESOLUTION NO.....

Requesting Virginia Commonwealth University's Department of Biostatistics of the Medical College of Virginia to conduct an epidemiological study on Alzheimer's disease.

WHEREAS, Alzheimer's disease, a neurological disorder characterized by a progressive and irreversible deterioration of cognitive functions, is estimated to affect 1.2 to 4 million people age 65 and older in the nation; and

WHEREAS, this disease afflicts people of all economic, social and racial classes; and

WHEREAS, though there is no agreement within the medical community on the causes of Alzheimer's disease, there is yet no cure for it; and

WHEREAS, because of the lack of precise information about the disease, an accurate measurement of its prevalence is impeded; and

WHEREAS, to formulate effective health policy and to plan effectively for the needs of Virginians suffering from this dread disease, an epidemiological study is necessary to determine the prevalence of the disease in the Commonwealth; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Virginia Commonwealth University's Department of Biostatistics of the Medical College of Virginia is requested to conduct an epidemiological study on Alzheimer's disease.

All agencies of the Commonwealth shall provide assistance upon the request of the Department and as it deems appropriate.

The Department is requested to submit its findings to the 1987 Session of the General Assembly.

HOUSE JOINT RESOLUTION NO....

Requesting certain public and private agencies to participate in increasing the public awareness of Alzheimer's disease and related disorders.

WHEREAS, the Commission or Alzheimer's Disease and Related Disorders found that there is a need to inform the public of Alzheimer's disease and the related disorders, such as Pick's, Huntington's disease and Creutzfeldt-Jakob disease; and

WHEREAS, the need is for basic, up-to-date information on the possible causes, the course of the diseases, treatment and community resources; and

WHEREAS, the public's access to such information would facilitate greater understanding about these diseases and provide individuals with the information needed to determine the kinds of related medical and support services available in the commmunity; and

WHEREAS, the expeditious dissemination of this information could be accomplished through a collaborative effort by both public and private agencies which maintain contact with great numbers of the citizens of this Commonwealth; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Departments of Motor Vehicles, Mental Health and Mental Retardation, Social Services, and Health, the Department on the Aging, the Virginia Center on Aging, the State Library Network, the Medical Society of Virginia and the State Chamber of Commerce, and other public and private educational, social and professional associations and agencies are hereby requested to work cooperatively with civic and community organizations and advocacy groups for the elderly and on the dementias in disseminating information on Alzheimer's disease and the related disorders to the public.

These public and private agencies and associations are requested to cooperate in the dissemination of such information that is provided by and at the expense of the civic and community organizations and the advocacy groups, and in a manner consistent with such agency's policies.

The Clerk of the House of Delegates shall prepare a copy of this resolution for presentation to the aforementioned agencies and associations in order that they may be apprised of the sense of this body.