

## CHAPTER 76

AN ACT establishing the New Jersey Alzheimer's Disease Study Commission and supplementing Title 26 of the Revised Statutes.

**BE IT ENACTED** by the Senate and General Assembly of the State of New Jersey:

C.26:2M-16 Findings, declarations relative to Alzheimer's Disease.

1. The Legislature finds and declares that:

a. Alzheimer's disease is a progressive, degenerative, and irreversible neurological disease. It is one of a group of dementias referred to as Alzheimer's disease and related disorders that: develops over a period of years; is of undetermined origin; and is characterized by a progressive decline in intellectual or cognitive functioning that begins with gradual short-term memory loss and progresses to include a deterioration in all areas of cognition and executive functioning, such as analytical ability and reasoning, language and communication, perception and judgment, personality, and eventual inability to perform physical functions, including, but not limited to, activities of daily living such as ambulation, dressing, feeding, and bathing;

b. According to the report of the Alzheimer's Association, *2009 Alzheimer's Disease Facts and Figures*, it is estimated that 5.3 million persons in the United States currently have Alzheimer's disease. Every 70 seconds someone develops Alzheimer's disease; by mid-century someone will develop Alzheimer's disease every 33 seconds. Men 55 years of age or older now have a one in eight chance of developing Alzheimer's disease; and women 55 years of age or older now have a one in five chance of developing Alzheimer's disease. By 2010, there will be nearly a half million new cases of Alzheimer's disease each year; and by 2050, there will be nearly a million new cases per year, and between 11 and 16 million persons with Alzheimer's disease;

c. Currently in New Jersey, by extrapolation based on age and demographics, the conservative estimate is that there are 150,000 residents with Alzheimer's disease. Because of the progressive deteriorative nature of the disease, it is necessary when considering its impact, to include a minimum of at least one primary caregiver for each person with Alzheimer's disease as also being directly impacted by the disease; accordingly, the current number of New Jersey residents directly impacted by Alzheimer's disease is 350,000;

d. Alzheimer's disease is the sixth leading cause of death in the United States. However, this ranking may be an underestimate due to both the failure to properly diagnose the patient's condition and the failure for the disease to be noted on the death certificate as the primary contributing factor to death;

e. Since a diagnosis of Alzheimer's disease cannot be determined definitively until an autopsy is performed, the disease is determined through a process of differential diagnosis that includes a comprehensive medical history and a physical examination and assessment, including blood testing, brain scans such as computerized axial tomography (CT), positron emission tomography (PET), and magnetic resonance imaging (MRI), and psychological and neurological testing;

f. Alzheimer's disease generally progresses over time in a gradual and insidious manner. Typically, persons with dementia (PWD) can live from eight to 10 years after receiving their diagnosis, but depending on the overall health status, some individuals live up to 20 years after receiving their diagnosis;

g. During this time, PWD and their families need continuous support, education, and assistance to help them identify and access proper care and support services. These specialized services can be difficult to find and very expensive, especially when the length of

time the services are needed is taken into consideration. As the needs of the PWD intensify with the disease progression, there is a direct correlation to the associated burden and expense for the PWD and the person's family caregivers. Family caregivers become overwhelmed and emotionally and physically taxed by the heavy demands associated with providing care 24 hours per day, seven days per week for their family member with Alzheimer's disease. Caregiver stress and associated health decline become of paramount consideration;

h. Frequently, family caregivers develop chronic and life impacting illnesses; older spouses may frequently pre-decease the PWD for whom they are caring. And, if caregivers are working outside the home, they may have difficulty managing family life and work responsibilities, and may lose time from work or become unable to perform their responsibilities at the level they were once able to, which can result in employment termination and loss of family income;

i. The direct and indirect costs of Alzheimer's disease and other dementias amount to more than \$148 billion annually. In 2004, total per-person payments from all sources for health and long-term care were three times higher for Medicare beneficiaries 65 years of age or older with Alzheimer's disease than for other Medicare beneficiaries in this age group; and

j. It is in the public interest for the State to establish a commission, similar to the one which was established under P.L.1983, c.352 but which has since expired, to study the current issues in the State associated with Alzheimer's disease in order to help raise awareness about one of this country's most significant health epidemics, to facilitate the continued development of integrated and responsive community-based services, and ease the burden of the disease on persons with Alzheimer's disease and their family members and caregivers through expanded support.

#### C.26:2M-17 New Jersey Alzheimer's Disease Study Commission.

2. a. There is established the New Jersey Alzheimer's Disease Study Commission in the Department of Health and Senior Services.

b. The commission shall consist of 15 members as follows:

(1) the Commissioners of Health and Senior Services and Human Services, or their designees, who shall serve ex officio;

(2) two members of the Senate, to be appointed by the President of the Senate, who shall not be of the same political party;

(3) two members of the General Assembly, to be appointed by the Speaker of the General Assembly, who shall not be of the same political party; and

(4) nine members appointed by the Governor, as follows: two persons recommended by the Alzheimer's Association, one of whom shall be a representative of the Greater New Jersey Chapter and one of whom shall be a representative of the Alzheimer's Association Delaware Valley Chapter; three health care professionals who are currently involved in the provision of direct services, one of whom shall be a representative of an agency that provides home care services to persons with dementia, one of whom shall be a representative of an assisted living facility that provides specialized services to persons with dementia, and one of whom shall be a representative of a licensed nursing home that provides specialized services to persons with dementia; one representative from the clergy who has experience providing emotional and spiritual care and support for persons with Alzheimer's disease and their families; two persons who by reason of family relationship or legal guardianship bear or have borne responsibility in caring for a person with Alzheimer's disease; and one attorney who is

currently licensed and practicing in New Jersey, has expertise in legal and financial planning and elder care issues, and has extensive community-based experience working with persons with Alzheimer's disease and their families.

c. Vacancies in the membership of the commission shall be filled in the same manner provided for the original appointments.

d. The commission shall organize as soon as practicable following the appointment of its members and shall select a chairperson from among the members. The chairperson shall appoint a secretary who need not be a member of the commission.

e. Members of the commission shall serve without compensation, but shall be reimbursed for necessary expenses incurred in the performance of their duties as members of the commission, within the limits of funds appropriated or otherwise made available to the commission for its purposes.

f. The commission shall be entitled to call to its assistance and avail itself of the services of the employees of any State, county, or municipal department, board, bureau, commission, or agency as it may require and as may be available to it for its purposes.

g. The Department of Health and Senior Service shall provide staff support to the commission, as necessary.

#### C.26:2M-18 Duty of the commission.

3. It shall be the duty of the commission to:

a. study the current impact and incidence of Alzheimer's disease among State residents, and make projections about the future impact and incidence among State residents;

b. study the State's role in long-term care, family caregiver support, and assistance to persons with early stage and early onset of Alzheimer's disease;

c. consider the capacity of public safety and law enforcement officials to respond to persons with Alzheimer's disease and for these officials to have proper education and training;

d. study the needs of persons with Alzheimer's disease and their family members and caregivers, assess the availability and affordability of existing services, programs, facilities, and agencies to meet those needs, and make recommendations for improving, expanding, or changing such services, programs, facilities, and agencies, as appropriate;

e. gather and disseminate data and information relative to the care of persons with Alzheimer's disease in order to provide health care professionals and governmental policymakers, as appropriate, with accurate data about the disease and its impact on these persons and their family members and caregivers;

f. identify the adequacy, appropriateness, and best practice-based geriatric and psychiatric services and interventions; and

g. consider such other issues as the commission may identify as necessary to ease the burden for persons with Alzheimer's disease and their family members and caregivers in the State.

#### C.26:2M-19 Hearings, report, recommendations.

4. The commission may meet and hold hearings at such places and times as it shall designate, and shall report its findings and recommendations to the Governor, and to the Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1), within two years of the appointment of a majority of the public members of the commission.

5. This act shall take effect immediately and shall expire upon the submission by the commission of its report.

Approved June 21, 2011.