

The Future of Dementia Care: What the U.S. Can
Learn From Norway

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I. INTRODUCTION

Dementia care is a primary concern for the retiring “baby boom” generation both in the United States and abroad. As this spike in population begins moving into older age, there is a host of medical issues confronting governments. An expensive issue amongst seniors is the prevalence of dementia, which costs society approximately \$172 billion a year.¹ Dementia is not a new disease; rather, as the population is living longer, it is becoming more prevalent, as it typically occurs later in life.² In the U.S., there are approximately 5.2 million people over the age of sixty-five suffering from Alzheimer’s, and by 2030, that number is expected to increase by fifty percent to 7.7 million.³ Currently, Alzheimer’s disease is the sixth-leading cause of death in the U.S., and for those over sixty-five years of age, it is the fifth-leading cause of death.⁴ The challenges presented by those suffering from dementia include expensive personalized care for both the government and individuals,⁵ along with a lack of housing

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1. ALZHEIMER’S ASSOCIATION, FACT SHEET: NATIONAL ALZHEIMER’S PROJECT ACT (2010) available at <http://www.kintera.org/atf/cf/%7BB96E2E84-AF7D-4656-9C86285306F00E19%7D/NAPA%20Fact%20Sheet%209-16.pdf>.

2. See ALZHEIMER’S ASS’N, 2011 ALZHEIMER’S DISEASE FACTS AND FIGURES 17 (2011), available at http://www.alz.org/downloads/Facts_-_2011.pdf.

3. *Id.*

4. *Id.* at 20.

5. See *id.* at 35.

equipped to host dementia patients.⁶ There is no cure for dementia, but research continues, making many prescriptions experimental.⁷ Often referred to as “the long good-bye,”⁸ patients suffering from dementia can live up to twenty years with the disease before dying, resulting in a heavy burden on their caregivers and government subsidized health programs.⁹ Government action can help provide quality care and reduce the costly impact of this disease.

This article will first examine dementia and its impact on the population. Next, it will look at the health care system in Norway and provide a brief history of its development. This article will then describe how Norway’s health care system has responded to the epidemic of dementia. Finally, this article will assess the action of the United States and apply lessons that can be learned from Norway’s Dementia Plan 2015.

II. WHAT IS DEMENTIA?

The term dementia is an umbrella, under which several types of the disease fall.¹⁰ Approximately 60-70% of those suffering from dementia have Alzheimer’s disease, while 15-20% suffer from vascular dementia, which is typically the result of a stroke.¹¹ The remaining cases are from less frequently occurring brain diseases.¹²

The brain of an Alzheimer’s patient begins to fail due to a breakdown of

6. See Claudia Kalb, Aging: Small is Beautiful, *The Daily Beast*, <http://www.thedailybeast.com/newsweek/2005/07/31/aging-small-is-beautiful.html> (last visited February 19, 2012).

7. ALZHEIMER’S ASS’N, *supra* note 2, at 9.

8. Chris Matthews, *Your Mom’s Not What She Was*, *THE SHRIVER REPORT* (Mar. 24, 2012, 3:56 PM), <http://www.alz.org/shriverreport/matthews.html>.

9. ALZHEIMER’S ASS’N, *supra* note 2, at 23.

10. *Id.* at 5.

11. NORWEGIAN MINISTRY OF HEALTH & CARE SERVS., *DEMENTIA PLAN 2015* 11 (2008), available at <http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/DementiaPlan2015.pdf>.

12. *Id.*

communication between synapses located in the brain.¹³ The brain's synapses decline in number, leading to the death of the neurons that host the synapses.¹⁴ Patients with dementia suffer from impaired memory, thinking skills, communication, and orientation.¹⁵ They have trouble performing daily tasks and "coping with everyday problems."¹⁶ Personality changes are common, resulting in aggression, poor judgment, "anxiety, depression, suspiciousness, delusions and compulsive behaviors."¹⁷ Dementia is a degenerative disease,¹⁸ and those suffering from it will become progressively more dependent on assistance from unpaid caregivers, primarily family, or friends.¹⁹

III. NORWAY'S HEALTH SYSTEM

Norway has a reputation for one of the best health systems in the world; in 2000 it was ranked by the World Health Organization as having the eleventh best health care system.²⁰ The cornerstone of Norway's health system is the policy that "all inhabitants should have the same opportunities to access health services, regardless of social or economic status and geographic location."²¹ Since shortly after its independence in the nineteenth century, Norway bases its health system on the response of the states and the municipalities to public health needs.²² A step towards universal coverage came in 1967 with the passage of the National Insurance

13. ALZHEIMER'S ASS'N, *supra* note 2, at 8.

14. *Id.*

15. NORWEGIAN MINISTRY OF HEALTH & CARE SERVS., *supra* note 11, at 11.

16. *Id.*

17. *Id.*

18. *Id.*

19. ALZHEIMER'S ASS'N, *supra* note 1, at 25.

20. WORLD HEALTH ORG., THE WORLD HEALTH REPORT 2000 154 (2000), available at http://www.who.int/whr/2000/en/whr00_en.pdf.

21. JAN ROTH JOHNSEN, HEALTH SYSTEMS IN TRANSITION: NORWAY 1 (Vaida Bankauskaite ed., European Observatory on Health Systems and Policies, 2006), available at <http://www.euro.who.int/document/e88821.pdf>.

22. *Id.* at 13.

Scheme, which provides a public universal insurance and a minimum of social security for everybody regardless of income.²³ Also, in 1969, The Hospital Act introduced a unified system for all medical institutions, placing counties in-charge of “planning, building, and managing hospitals . . .”²⁴ The national government sets policies and doles out block grants to the five health regions for specialty care and the 431 municipalities for primary care.²⁵

IV. NORWAY’S DEMENTIA PLAN 2015

In 2008, the Norwegian government recognized the growing epidemic of dementia and it implemented the Dementia Plan 2015.²⁶ The number of dementia patients is expected to double in the next thirty-five years, with the largest growth in the next ten to fifteen years.²⁷ Norway recognized that eighty percent of residents in nursing homes were suffering from some sort of dementia, and yet hardly any of these facilities were equipped to care for dementia patients.²⁸ The cost for caring for dementia patients in 1995 was fourteen billion NOK (Norwegian Krone) with gross expenditure for the entire health system on the municipal level around forty-five billion NOK.²⁹ The plan emphasizes three main areas of focus: day programs; living facilities better adapted to patient needs; and increased knowledge and skills.³⁰ The plan sets out to provide “a good quality of life . . . and . . . a meaningful day-to-day existence . . .” for dementia patients.³¹

Current care for dementia patients lacks services in the areas of social

23. *Id.* at 14.

24. *Id.*

25. *Id.* at 1, 51.

26. *See*, NORWEGIAN MINISTRY OF HEALTH & CARE SERVS., *supra* note 11, at 7.

27. *Id.*

28. *Id.*

29. *Id.* at 13.

30. *Id.* at 7-8.

31. *Id.* at 9.

and cultural care.³² Amongst dementia patients, approximately fifty percent live inside the home, yet only four percent of those patients have day programs adapted to their needs.³³ Day programs take place at an adult day center away from the primary residence where dementia patients have the opportunity to interact with others in a structured environment.³⁴ Daily activities at a center may include music or recreation, while having the convenience of a nurse or social worker on staff.³⁵ Day programs can provide a needed respite to family caregivers who often become overwhelmed by caring for their loved one.³⁶ There is a strong economic incentive for day programs as well. These programs allow dementia patients to remain living with primary caregivers, postponing institutionalization of the patient, which is paid for by the government.³⁷ The goal is to boost the capacity and quality of these programs “. . . with a greater emphasis on social education, occupational therapy, physiotherapy and social work.”³⁸

A substantial shortfall has been identified in the amount of residences equipped to provide quality care for dementia patients.³⁹ In Norway, it is estimated that approximately half of dementia patients are living in an institution; seventy-five percent of institutionalized patients have some sort of dementia disorder; and only a fraction of those institutions have adapted to care for these patients.⁴⁰ The Norwegian government estimates that approximately 37,000 housing units need to be constructed or renovated by

32. *Id.* at 11.

33. *Id.*

34. ALZHEIMER'S ASSOCIATION, CARE FINDER: FINDING THE CARE THAT'S RIGHT FOR YOU 7 (2010) available at http://www.alz.org/national/documents/brochure_carefinderguide.pdf.

35. *Id.*

36. NORWEGIAN MINISTRY OF HEALTH & CARE SERVS., *supra* note 11, at 11.

37. *Id.*

38. *Id.* at 20.

39. *Id.* at 7.

40. *Id.* at 12.

2030 to properly care for these patients.⁴¹ The ideal institutional dwelling for a dementia patient consists of small living groups that accommodate four to eight patients.⁴² The “small is beautiful”⁴³ concept includes stable staffing, shared social activities, direct access to adapted outdoor space, and easily navigable floor plans.⁴⁴ The Norwegian State Housing Bank has designed and will administer a new grant scheme to encourage investment in these small-scale facilities.⁴⁵

There is certainly greater expertise needed by health care providers, but also by caregivers and society at-large.⁴⁶ A stigma exists for those with dementia and their families, causing the disease to be hidden instead of seeking proper care.⁴⁷ When families are given guidance in dealing with dementia and caring for their loved ones, they themselves have a higher quality of life.⁴⁸

The greatest challenge could be recruiting health and social services personnel into geriatrics.⁴⁹ The first key strategy is to retain current staff and invest in their development via professional training and schooling.⁵⁰ The government decided to add to the municipal care services an additional 10,000 new man-years (amount of time one person works in a year) equipped with professional training in dementia care.⁵¹ In order to achieve this goal, the government aims to improve the professional status of working with the elderly, and producing better equipped health-care professionals by having all social service and health care educational

41. *Id.*

42. *Id.*

43. *Id.* at 9.

44. *Id.* at 12.

45. *Id.* at 17.

46. *Id.* at 8.

47. *Id.*

48. *Id.* at 12.

49. *Id.* at 13.

50. *Id.*

51. *Id.* at 17.

programs adapt their curriculum to include caring for dementia patients.⁵² For those who have already obtained college-level degrees, the government will provide continuing professional education to those practicing in the areas of elder care and mental health, with the goal to reach 6,000 persons.⁵³

V. CURRENT STATUS IN THE UNITED STATES

The United States lags behind other modern countries in developing a national plan that addresses preparing to care for the population growth of those suffering from dementia.⁵⁴ In 2011, dementia care in the U.S. constituted \$183 billion worth of aggregate payments for health, long-term, and hospice care, with that number expected to grow to \$1.1 trillion by 2050.⁵⁵ Seventy percent of dementia patients in the U.S. live at home, usually with family or friends, which is a greater percentage than the dementia patients in Norway.⁵⁶ Day programs for dementia patients averages \$69 per day, assisted living averages \$38,596 per year, and nursing home care ranges from \$74,239 to \$82,113 per year.⁵⁷ In 2009, the average cost of nonmedical home care was \$160 per day.⁵⁸ Medicaid is the only federal program that covers the costs of a long-term nursing home stay, however, Medicaid requires beneficiaries to meet certain financial requirements demonstrating need before they can obtain coverage.⁵⁹

In response to the growing epidemic of dementia, Congress unanimously passed, and the President signed into law, the National Alzheimer's Project

52. *Id.*

53. *Id.* at 18.

54. ALZHEIMER'S ASS'N, *supra* note 1.

55. ALZHEIMER'S ASS'N, *supra* note 2, at 35.

56. *Id.* at 39. NORWEGIAN MINISTRY OF HEALTH & CARE SERVS., *supra* note 11, at 12.

57. ALZHEIMER'S ASS'N, *supra* note 1, at 39.

58. *Id.* at 40.

59. *Id.* at 39.

Act (NAPA) on January 4, 2011.⁶⁰ NAPA was passed with the purpose of guiding federal agencies as they make policy decisions, improving early diagnosis of Alzheimer's and related dementia, and improving the coordination of care and treatment of patients.⁶¹ However, in creating a strategic plan for the U.S. to tackle dementia, perhaps we should look to the strategies that other countries are employing to battle this disease—namely Norway.

The challenges that the U.S. health care system faces are not identical, but the goals can be aligned. As opposed to Norway, ninety-five percent of adult day centers in the U.S. provide care for people with dementia.⁶² However, at an average of \$69 per day, the cost could be a barrier for use.⁶³ As discussed above, day centers can provide needed respite for caregivers and allow them to continue to function in the economy and society, while postponing the need for the patient to enter into an out-of-home facility.⁶⁴ The U.S. should adopt a policy that would extend access to these day programs because they greatly benefit people with dementia and can reduce the overall cost to public and private payers.⁶⁵

Pertaining to assisted living facilities and nursing homes, some believe that an entire culture shift is necessary to affect positive change for dementia patients.⁶⁶ Of the thousands of care facilities, the vast majority of them follow a traditional hospital type model of long corridors, impersonal

60. ALZHEIMER'S ASS'N, FACT SHEET: NATIONAL ALZHEIMER'S PROJECT ACT (March 2011), <http://www.kintera.org/atf/cf/%7BB96E2E84-AF7D-4656-9C86-285306F00E19%7D/2011%20NAPA%20Factsheet.pdf>.

61. National Alzheimer's Project Act, 42 U.S.C. § 11225 (2011).

62. ALZHEIMER'S ASS'N, *supra* note 2, at 43.

63. *Id.*

64. NORWEGIAN MINISTRY OF HEALTH & CARE SERVS., *supra* note 11, at 11.

65. THE NAT'L ALZHEIMER'S STUDY GROUP, A NATIONAL ALZHEIMER'S STRATEGIC PLAN 34 (2008) http://www.pioneernetwork.net/Data/Documents/NewPressRelease/National_Alzheimers_Strategic_Plan.pdf

66. Kalb, *supra* note 6.

surroundings, and decades old buildings.⁶⁷ The Norwegian model of small facilities has a strong following in the U.S. as well, advocating that residences should accommodate no more than ten patients.⁶⁸ Patients respond positively to smaller environments with personal touches and opportunities for personal interactions and relationships.⁶⁹ However, this smaller, more personalized environment comes at a higher price tag, ranging from \$4,300 to \$5,500 per month.⁷⁰ In addition to a higher cost, these facilities are often considered assisted living facilities, not nursing homes, and are thus ineligible for government reimbursement.⁷¹

The NAPA advisory panel needs to take these matters into consideration when deciding how to ensure adequate housing for dementia patients. Reimbursement eligibility for these facilities needs to be expanded under Medicare and Medicaid. Also, to begin steering patients away from the traditional hospital model for living facilities, NAPA needs to include incentives for developers to adopt these smaller scale facilities. Norway has made it a priority to provide residences that put the dementia patient's care first, and the U.S. should follow this example.

Maintaining quality personnel to assist with daily activities and provide quality medical care is an enormous challenge. In the U.S., care providers are typically underpaid and receive little or no training, which leads to high turnover rates.⁷² These working conditions will make it a national challenge to recruit the additional 3.5 million health care providers needed by 2030 to care for these patients.⁷³ NAPA should include funding that will provide investments in human capital; thereby establishing a labor

67. *Id.*

68. *Id.*

69. *Id.*

70. *Id.*

71. *Id.*

72. ALZHEIMER'S ASS'N, *supra* note 2, at 31.

73. *Id.*

foundation for the future of the health care industry. For those care positions where there is no high degree of medical training necessary, there should be affordable avenues for training, including programs at high schools and junior colleges. However, this shortfall exists on the professional side of the spectrum as well - only four percent of social workers, and one percent of registered nurses, physician assistants, and pharmacists identify themselves as specializing in geriatrics.⁷⁴ A condition of on-going certification for these professionals should be continued education that includes training in geriatrics and dementia. The elderly will represent the majority of health care consumers, and it is a national priority to ensure that those providing care are adequately equipped. Norway recognized this as a priority when it demanded continuing education and training for dementia, and the U.S. should consider doing the same.

VI. CONCLUSION

The passage of NAPA is a great first step towards committing the United States to providing the level of care and attention to dementia patients that is consistent with the respect and dignity that they deserve. Although the challenges of the U.S. are somewhat unique to our country, we can learn a great deal from the other countries that have already committed themselves to action in dealing with dementia. The U.S. should not avoid systemic changes that require investments today to bring about long-term savings and an elevated level of care. The one thing that the U.S. certainly cannot afford to do is nothing; inaction is dementia's greatest ally.

74. *Id.*