

**Report to  
The Vermont Legislature**

**Annual Report on Commission on Alzheimer's Disease  
and Related Disorders**

**Fiscal Year 2015**

In accordance with Act 28 (2015), an act related to the membership of the  
Commission on Alzheimer's Disease and Related Disorders.

**Submitted to:** **Senate Committee on Health and Welfare**  
**House Committee on Human Services**

**Submitted by:** **Martha Richardson, Chair**  
Commission on Alzheimer's Disease and Related Disorders

**Prepared by:** **Martha Richardson, Chair**  
Commission on Alzheimer's Disease and Related Disorders

**Assisted by:** **David Yacovone**  
Department of Disabilities, Aging and Independent Living

**Report date:** **December 31, 2015**

**Governor's Commission on  
Alzheimer's Disease and Related  
Disorders**

**2015  
Annual Report**

**January 15, 2016**

Alzheimer's disease is the only cause of death, among the top ten leading causes of death in America that cannot be prevented, cured or slowed.

Alzheimer's disease is the fifth leading cause of death in Vermont, and Vermont has the fourth highest death rate due to Alzheimer's in the nation.

Despite this sobering news, we are hopeful. We are hopeful that with the approval of the \$350 million targeted by Congress to fund the research to help establish a cure for Alzheimer's disease, the future will be different for Vermonters in the years to come.

Still, awareness and readiness to address the impact of Alzheimer's Disease and related disorders is lacking within Vermont. Our State Plan on Dementia, initially created in 2009 is in dire need up updating. Priority activities specific to Vermont are needed with benchmarks in place to move priority activities forward in a timely manner.

## **OUR ACTIVITIES 2015**

The composition of the Commission on ADRD was addressed during 2015 and the statute pertaining to the Commission was updated. Representatives from the Center on Aging at UVM, SASH Program and Vermont Department of Health were added, term limits were put in place and the required membership of a representative from both the house and senate was removed.

As a new initiative Commission members chose to launch three workgroups to focus energies on the following Commission identified priority areas:

- a) Advocacy, Public and Leadership Education
- b) Early Detection and diagnosis
- c) Caregiver Support

Attachment A includes the reference material from each workgroup.

# **Governor's Commission on Alzheimer's Disease and Related Disorders**

## **2015 Work Group Reports**

### **Advocacy, Public and Leadership Education Workgroup**

Concern and awareness about ADRD continue to be the primary areas of focus for our workgroup. Over the last several years, concern about the rise in ADRD and its significant costs to our healthcare system has been growing dramatically. Nationally indicators show that awareness and concern about Alzheimer's is nearly as high as for cancer. Still significant stigma and misunderstanding around ADRD exists. Our workgroup has focused activities in the following areas in 2015 to help our leadership and general public understand the impact the Alzheimer's tsunami is having and will continue to have on our state.

- Successfully advocated for the inclusion of the Cognitive Impairment module in the 2016 Behavioral Risk Management Surveillance Survey (BRFSS) – a telephone survey conducted annually among adults 18 and older. The Vermont BRFSS is completed by the Vermont Department of Health in collaboration with the Centers for Disease Control and Prevention. With the information provided through surveillance our state can gain a better picture of the current impact of cognitive impairment and plan for the needs of our constituents in the future.
- Increased awareness of Alzheimer's in Vermont through testimony to House Human Services and Senate Health and Welfare Committees, meeting with Blue Print for Health leadership, Community Health Teams and VDH Commissioner Harry Chen.
- Hosted Alzheimer's Advocacy and Awareness Day at the Vermont Statehouse February 12, 2015. More than 35 Alzheimer's advocates and Commission members met with their senators and representative to share their stories and raise awareness of the impact of Alzheimer's in their communities. See Legislative message points on page 4.

## Make Vermont a Dementia Capable State

February 2015

[alz.org/vermont](http://alz.org/vermont)

### Growing Public Health Crisis

Alzheimer's disease is a growing public health crisis, in Vermont and across the nation.

- It is the sixth leading cause of death in the United States and affects 11,000 Vermonters.
- The average per-person Medicaid spending for seniors with Alzheimer's is 19 times more than for seniors without Alzheimer's and there are nearly 30,000 family caregivers in Vermont providing 34 million hours of unpaid care for their loved ones living with Alzheimer's disease, valued at more than \$400 million.
- By the year 2025, 17,000 Vermonters will be living with Alzheimer's disease, an increase of 55%.
- According to the 2013 Cognitive Module of the Behavioral Risk Factor Surveillance System (BRFSS), 9% of adults aged 18 and older are experiencing increased confusion or memory loss that is getting worse. Of those aged 45 and older reporting memory issues, 26% had to give up household activities/chores and 30% say their cognitive problems interfered with their ability to work, volunteer, or engage in social activities.
- A study released by the *New England Journal of Medicine* reports that Alzheimer's disease is now the most expensive disease in America, surpassing both cancer and heart disease, and the costs are expected to skyrocket.
- It is the only cause of death among the top 10 in America without a way to prevent it, cure it or even slow its progression.

### WHAT Can State Officials Do?

Work with the Governor's Commission on Alzheimer's Disease and Related Disorders to Implement the Vermont State Plan on Dementia to:

- 1.) Enhance early detection and diagnosis efforts in Vermont.
  - Work with Vermont Blueprint for Health to assure healthcare planning and implementation includes specific strategies for encouraging early detection and diagnosis of dementia as well as referral to community resources.
- 2.) Allocate \$500,000 to support the Dementia Respite program.
  - This allocation will provide grants to families to help them pay for respite care and create a coordinated system of support that connects Vermonters with the community resources and services they need to navigate all stages of the disease.
  - Caregiving for a person with memory loss can be stressful and take a toll on the caregiver's own health. Dementia Respite Grants can be used for a range of services that give family caregivers a break from their caregiving responsibilities.
- 3.) Request that the Cognitive and Caregiver modules be used in the 2016 Behavioral Risk Factor Surveillance System (BRFSS).
  - Continuous surveillance through the Cognitive and Caregiver modules of the Behavioral Risk Factor Surveillance System (BRFSS) collects essential public health information.
  - Vermont has not yet used the Caregiver module. Use of both modules will provide valuable data on the burden of cognitive decline among adults as well as the impact of caregiving for someone with dementia (or other conditions) on caregivers' health and wellbeing.

## Early Detection and Diagnosis Workgroup

For years ADRD has been viewed as a disease of the elderly that is rarely addressed until chronic symptoms begin to affect activities of daily life. However, research continues to emphasize the importance of early intervention for the effective development of disease modifying therapies.

The Early Detection and Diagnosis Workgroup has focused on increased messaging to the general public, primary care community and Community Health Team network to emphasize the benefits of early detection and diagnosis.

Dr. Walter Gundel, Commission member and retired cardiologist has worked closely with the Vermont Department of Health 802Quits program to incorporate messaging about the increased risk of Alzheimer's due to smoking, which led to this video that was developed and widely disseminated to the primary care community.

<https://vimeopro.com/wearehmc/tcp-provider> (password = TcP802Pro)

Additionally, commission members and volunteers have attended conferences focused on the primary care audience - including BluePrint for Health and AHEC - to share information about the importance of early detection and diagnosis and promote the [Alzheimer's Disease Pocket App and resources to support primary care physicians](#)

an article has been drafted and is under review for submission to *Primarily*, an AHEC newsletter for Primary Care Physicians. It is intended to raise awareness and promote conversation on the use of the Mini-Cog(dementia screening tool) during the annual Medicare Wellness Check-Up on a regular basis, much as checking other vital signs.

The Alzheimer's Association has put together the following factsheet outlining the importance of early detection.

# factsheet

FEBRUARY 2013

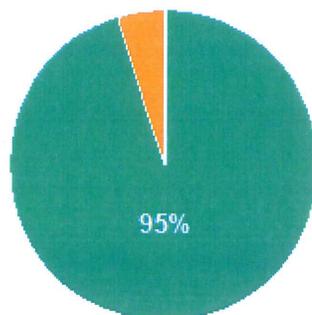
alz.org

## Early Diagnosis: The Value of Knowing

### Americans view Alzheimer's as a major health threat.

- Alzheimer's disease is the second most feared disease – behind only cancer. Nearly 22 percent of Americans rate Alzheimer's as the disease they are most afraid of getting.
- This fear is even prevalent among younger adults. More than one in seven Americans aged 18-34 fear getting Alzheimer's more than any other disease. And one in 10 Americans in this younger age group are very worried that they will get Alzheimer's themselves.
- Nearly three-quarters of Americans know or have known someone with Alzheimer's; 42 percent of Americans have or have had a family member with the disease.

### Americans aged 60 and over who would want to know if they had Alzheimer's



### Most Americans want to know if they have Alzheimer's disease.

- Nearly 89 percent of Americans say that if they were exhibiting confusion and memory loss, they would want to know if the cause of the symptoms was Alzheimer's disease.
- Of those aged 60 and over, 95 percent say they would want to know.
- Over 97 percent say that if they had a family member exhibiting problems with memory loss, they would want them to see a doctor to determine if the cause was Alzheimer's.

### But, half or more of Americans with Alzheimer's do not know they have the disease.

- The convergence of evidence from numerous sources indicates that as many as half of people with dementia have never received a diagnosis.
- Some evidence suggests that it could be more than 50 percent.

*Poll data come from a survey of public perceptions and awareness of Alzheimer's disease conducted by the Harvard School of Public Health. The poll was commissioned by Alzheimer Europe through a grant provided by Bayer.*

## Caregiver Support Workgroup

National and state information indicates that as many as half of families receiving a dementia diagnosis receive little or no information or support for addressing the disease and its impact on the person and their family. In Vermont, there are an estimated 30,000 family and friend caregivers for persons with dementia providing 34 million hours of unpaid care valued at \$413 million dollars ([alz.org/facts](http://alz.org/facts)). Due to the immense burden that family caregiving can put on a person, and the lack of adequate education and support services, caregivers are utilizing healthcare services at additional costs of over \$21 million statewide ([alz.org/facts](http://alz.org/facts)).

The Governor's Commission on Alzheimer's Disease and Related Dementias implemented an Enhancing Caregiver Support Workgroup (ECSW), with the goal of addressing the needs of these caregivers. The goal of the ECSW is to identify strategies to promote and implement caregiver support therefore decreasing the physical, emotional, and financial toll incurred while providing care to a person with dementia.

Providing a set of services and supports statewide, that offer the opportunity for person and family centered care, relies first on a person and family centered assessment of needs. Without a statewide assessment of caregiver reported needs, the creation, implementation, and reductions in services could be incongruent with long term effectiveness and ultimately cost saving outcomes.

Over the past year the ECSW worked diligently, and in collaboration with Kelly Melekis, MSW, PhD at the University of Vermont, on a proposal for implementing a statewide assessment of caregiver needs. This proposed plan was submitted for grant funding to meet the projected budget of about \$40,000; funds that would be recouped in both savings to healthcare related expenditures, as well as savings related to funds and resources being allocated to the areas of need as identified by a strategy which holds the person and family in the center.

The ECSW recognizes the need to be inclusive and aware of diversity and therefore, has discussed and continues to move forward with additional efforts to explore means of retrieving data by way of focus groups, telephone interviews, and community forums. An analysis of data collected will provide professional stakeholders, in particular the Commission, with the information necessary to better identify what are currently viewed as viable and accessible resources, and what are

the gaps and needs of caregivers in our communities.

The ECSW was successful in FY15 facilitating the allocation of awarded dementia respite grants which served 245 care recipients. The breadth and depth of needs among people with dementia and their caregivers, is vast and ever changing. The ECSW recognizes that there are significant unmet needs that once identified clearly, can be addressed by policy changes and the resulting development and implementation of effective programs and services. The ECSW plan for fiscal year 2017 is for the continued seeking out of grant monies to fund a statewide assessment, but also to focus efforts on smaller scale assessment of needs including focus groups and community forums.

# ATTACHMENT A



## Vermont Alzheimer's Statistics

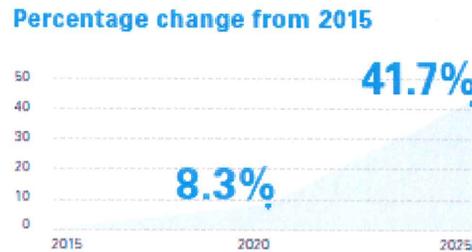
alzheimer's association  
THE BRAINS BEHIND SAVING YOURS™

Over **5 million Americans** are living with Alzheimer's, and as many as **16 million** will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$226 billion** in 2015, increasing to **\$1.1 trillion** (in today's dollars) by mid-century. Nearly **one in every three seniors** who dies each year has Alzheimer's or another dementia.

### 65+ Number of people aged 65 and older with Alzheimer's by age

Totals may not add due to rounding

Year	65-74	75-84	85+	TOTAL
2015	1,800	4,000	4,900	12,000
2020	2,300	5,000	5,300	13,000
2025	2,600	7,000	6,100	17,000



### % Percentage of seniors with Alzheimer's disease



# 11%

### # Number of deaths from Alzheimer's disease in 2012

# 269

- 5<sup>th</sup> leading cause of death in Vermont
- 4<sup>th</sup> highest Alzheimer's death rate in America
- 101% increase in Alzheimer's deaths since 2000

### \$\$ Number of Alzheimer's and dementia caregivers, hours of unpaid care, and costs of caregiving

Year	# of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care	Higher Health Costs of Caregivers
2012	30,000	34,000,000	\$416,000,000	\$20,000,000
2013	30,000	34,000,000	\$422,000,000	\$20,000,000
2014	30,000	34,000,000	\$413,000,000	\$21,000,000



For more information, view the *2015 Alzheimer's Disease Facts and Figures* report at [alz.org/facts](http://alz.org/facts).



Commissioner's Office  
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Voice (802)871-3350  
Fax (802) 871-3281

December 16, 2015

Dear Members of the Governor's Commission on Alzheimer's Disease and other Related Disorders:

Currently in the State of Vermont, there are an estimated 12,000 individuals living with Alzheimer's Disease and other related disorders. If the current trend continues, by 2025, we should expect to see a nearly 42% increase. While these numbers themselves are staggering, they cannot even begin to do justice to the thousands of friends, family members, and caregivers whose lives are also profoundly touched by the disease. I know that no person, however well-intentioned, can reverse this trend alone. For this reason, I am asking for your help.

I am asking the Commission to help me to identify and rank the very best evidence-based programs across the nation aimed at serving those with Alzheimer's, and to help DAIL determine which of those programs might best be replicated in Vermont within our unique service system. This is not an easy undertaking. It will require considerable research and analysis on your part. There may even be value to assessing current Vermont practices and weighing those against those national best practices. I will ask Dave Yacovone, our Older Americans Act Director, to assist you in this effort. I believe that this type of research could assist us in charting a realistic and attainable course forward and could be invaluable in prioritizing steps on that course.

Thank you for considering this request. My hope is that as you prepare your annual report to the Vermont Legislature that you will, if you decide to accept this assignment, highlight this request and this partnership as the next logical step in assisting Vermonters to address the impacts of Alzheimer's disease and other related disorders. The report could indicate that you plan to report back to them next year with your findings.

Again, thank you for considering this request. I wish you and your families the very best this Holiday Season.

Sincerely,  
  
Monica Caserta Hutt  
DAIL Commissioner

## Governor's Commission on Alzheimer's Disease and Related Disorders Commission Members

	Ending Date	Position
<b>APPOINTED BY GOVERNOR</b>		
Peter Cobb	Appt. pending	Home Health Rep
Christina Cosgrove	Appt. pending	Social Worker
Ellen Gagner	4/21/2017	Family Caregiver
Walter Gundel	4/21/2016	Physician
Glenn Jarrett	4/21/2016	Legal Profession
Constance Moser	4/21/2017	Clergy
Laura Murphy	4/21/2017	AAA Rep.
Paula Patorti	4/21/2016	Residential Care Home Rep
Martha Richardson	4/21/2018	Alzheimer's Association
Roberta Rood	4/21/2016	Mental Health Rep
Susanne Shapiro	4/21/2016	Registered Nurse
Patrice Thabault	4/21/2017	Business Rep.
Vacant		Nursing Home Rep
Vacant		Adult Day Care
Janet Nunziata	Application pending	University of VT Center on Aging Rep
Molly Dugan	Application pending	Support & Service at Home (SASH) Rep
Rhonda Williams	Application pending	Vermont Department of Health
David Yacovone	Application pending	Commissioner's Designee DAIL