

Testimony of Eric Colchamiro Director of Government Affairs Alzheimer's Association®

Before the

City Council of the District of Columbia Committee on Health

On

Budget Oversight Hearing: DC Health

Good morning, Chairman Gray and Health committee members. I am Eric Colchamiro, Director of Government Affairs for the Alzheimer's Association in the District of Columbia. Thank you for the opportunity to testify.

I want to begin by touching on the COVID-19 pandemic. In particular, the impact on our seniors is undeniable; data shows that roughly 30 percent of the District's COVID-19 fatalities have occurred in long-term care facilities.

As we move forward on safely re-opening DC, I want to recognize that the separation of seniors in long-term care facilities from their loved ones has had a significant impact; this social isolation has led to loneliness, depression and anxiety. One study showed that loneliness had similar health effects as smoking 15 cigarettes a day.

DC Health must consider parameters under which individuals can see their loved ones again. In Massachusetts, regulations were just announced to allow for scheduled visits at nursing homes and assisted living facilities; these visits will be outdoors, require strict social distancing and PPE for all involved. Seniors and their loved ones are suffering from the lack of connection in their lives. And they do not have time to wait.

I want to shift now to the Alzheimer's State Plan, and the position the Council put in place to implement it, the Dementia Services Coordinator. Thank you for your question during Friday's budget hearing about what the DSC is doing; we look forward to meeting her. More broadly, I want to note what DC Health did not mention in its response to you:

- 1. Organizing dementia services within the District;
- 2. Implementing and updating the District of Columbia State Plan on Alzheimer's Disease;
- 3. Assessing and analyzing dementia-related data collected by the District;
- 4. Evaluating the District's dementia services;

# 5. Identifying and supporting the development of dementiaspecific trainings;

These areas are the five core, legislatively mandated responsibilities of the DSC. And none of them were mentioned in Friday's testimony.

I will add that—to address DC Health's comments about the state plan—while Alzheimer's is 85 percent of diagnosed dementia, we welcome a Plan that covers all forms of dementia, and we are not wedded to calling it an "Alzheimer's State Plan". We can also include language that the next Plan which focuses on brain health across the lifespan; prevention is a core part of any effective state plan. Yet the District's government is hindered by the lack of a Plan and the coordinated strategy that emanates from it; for example, the CDC BOLD grant mentioned in response to your questions last Friday—which the District and other jurisdictions recently applied for—limited the amount of funding a government can attain, if they did not have an active state plan.

And let me emphasize, section 7-744.01 of DC Code makes a new state plan a mandate. As such, we urge the Council to codify a multi-stakeholder Commission, staffed by the Dementia Services Coordinator, to help make that mandate a reality.

All told, as we navigate this moment, we need a clear vision to aid our seniors. Thank you again for the opportunity to testify, and I am happy to answer any questions.



# Executive Office of Health and Human Services Department of Public Health Bureau of Health Care Safety and Quality 67 Forest Street, Marlborough, MA 01752

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#### Memorandum

**TO:** Nursing Home and Rest Home Administrators

FROM: Elizabeth D. Kelley, MPH, MBA, Director

Bureau of Health Care Safety and Quality

**SUBJECT:** Limitations on Visitors in Long-Term Care Facilities during the COVID-19 Outbreak<sup>1</sup>

**DATE:** June 1, 2020

The Massachusetts Department of Public Health (DPH) continues to work with state, federal and local partners on the outbreak of Coronavirus Disease 2019 (COVID-19), caused by the virus SARS-CoV-2, and we continue to appreciate the essential role you have in responding to this evolving situation.

This memorandum replaces the memorandum issued on March 16, 2020 and is effective as of June 3, 2020.

#### **Limitations on Long-Term Care Visitors:**

Long-term care facilities may allow visits with residents to occur, provided that the physical distancing and protection requirements described in detail below are followed. As much as possible, long-term care facilities should continue to use alternative electronic methods for communication between residents and visitors, such as Skype, FaceTime, WhatsApp or Google Duo.

#### **Designated Outdoor Visitation Space:**

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<sup>&</sup>lt;sup>1</sup> This guidance applies to all Long-Term Care Facilities other than those that are operated by the state.

A long-term care facility may allow in-person visitation in a designated outdoor visitation space, provided that the long-term care facility implements all of the following safety, care, and infection control measures:

- A resident who is suspected or confirmed to be infected with COVID-19 cannot be visited. A
  resident who has recovered from COVID-19 may be visited.
- Prior to transporting a resident to the designated outdoor visitation space, the long-term care
  facility must screen the visitor for fever or respiratory symptoms. Any individuals with symptoms
  of COVID-19 infection (fever equal to or greater than 100.0 F, cough, shortness of breath, sore
  throat, myalgia, chills or new onset of loss of taste or smell) will not be permitted to visit with a
  resident.
- Transport of a resident to and from the designated outdoor visitation space must be safe and orderly. At a minimum, safe transport means that the resident cannot be transported through any space designated as COVID-19 care space or space where residents suspected or confirmed to be infected with COVID-19 are present.
- A long-term care facility staff member trained in such patient safety and infection control measures must remain with the resident at all times during the visit.
- Visitors must be limited to no more than two individuals. A visitor must remain at least 6 feet from the resident and attending staff member(s) at all times during the visit.
- Staff and residents must wear a surgical face mask and visitors must wear a face covering or mask for the duration of the visit.

Visits with a resident in a designated outdoor space must be scheduled in advance and are dependent on permissible weather conditions, availability of outdoor space, and sufficient staffing at the facility to meet resident care needs, and the health and well-being of the resident.

A long-term care facility may limit the length of any visit, the days on which visits will be permitted, the hours during a day when visits will be permitted, and the number of times during a day or week a resident may be visited.

#### Compassionate Care Visitation:

For compassionate care situations, including but not limited to an end-of-life situation, long-term care facilities must limit visitors in the facility to a specific room: either the resident's room, if the resident has a private room, or another location designated by the facility. Long-term care facilities must require visitors to perform hand hygiene. Decisions about visitation during an end of life situation should be made on a case-by-case basis, which should include careful screening of the visitor (including clergy, bereavement counselors, etc.) for any symptoms of COVID-19. Individuals with symptoms of a respiratory infection (fever, cough, shortness of breath, sore throat, myalgia, chills or new onset of loss of taste or smell) should not be permitted to enter the long-term care facility at any time.

For those who are in end-of-life situations, visitors should be allowed a time limited visit and be given a face mask if they do not have a face covering or mask. For those visitors who are permitted to visit in compassionate care situations, the visitors must be restricted to the resident's room or other location designated by the facility. They must also be reminded to frequently perform hand hygiene.

Any individual who enters the long-term care facility and develops signs and symptoms of COVID-19 such as fever, cough, shortness of breath, sore throat, myalgia, chills, or new onset loss of smell or taste within 2 days after exiting the long-term care facility or designated outdoor space must immediately notify the long-term care facility of the date they were in the facility, the individuals they were in contact with, and the locations within the facility they visited. Long-term care facilities should immediately screen the individuals who had contact with the visitor for the level of exposure and follow up with the facility's medical director or resident's care provider.

#### **Exceptions to Visitor Limitations:**

<u>Health care personnel:</u> Long-term care facilities should follow CDC guidelines for the management of health care personnel who may have been exposed to COVID-19 which can be found at <a href="https://www.cdc.gov/coronavirus/2019-ncov/hcp/guidance-risk-assesment-hcp.html">https://www.cdc.gov/coronavirus/2019-ncov/hcp/guidance-risk-assesment-hcp.html</a>

The nursing home or rest home must confirm that health care personnel do not have any signs or symptoms of COVID such as a cough, shortness of breath, or sore throat, myalgia, chills, or new onset loss of smell or taste and a fever by taking each healthcare personnel's temperature upon arrival. The health care worker's temperature must be below 100.0 °F for him or her to enter the facility and provide care.

Screening and temperature checks also apply to other health care personnel, such as hospice workers, dialysis technicians, nursing students or Emergency Medical Service (EMS) personnel in non-emergency situations that provide care to residents. They should be permitted to come into the facility as long as they meet the CDC guidelines for health care personnel.

In emergency situations, EMS personnel should be permitted to go directly to the resident.

#### **Dining and Group Activities:**

All long-term care facilities should continue to suspend communal dining, as well as internal and external group activities.

#### **Ombudsman Program and Legal Representation:**

Residents have the right to access the Ombudsman program and to consult with their legal counsel. When in-person access is not available due to infection control concerns, facilities must facilitate resident communication (by phone or another format).

DPH strongly encourages all long-term care facilities in Massachusetts to monitor the CMS and CDC website for up-to-date information and resources:

CMS website: <a href="https://www.cms.gov/About-CMS/Agency-">https://www.cms.gov/About-CMS/Agency-</a>
 Information/Emergency/EPRO/Current-Emergencies/Current-Emergencies-page

• CDC website: https://www.cdc.gov/coronavirus/2019-ncov/healthcare-facilities/index.html

Additionally, please visit DPH's website that provides up-to-date information on COVID-19 in Massachusetts: <a href="https://www.mass.gov/2019coronavirus">https://www.mass.gov/2019coronavirus</a>.

### Before the

#### District of Columbia Council

Committee on Health

Testimony of
Dean R. Brenner
5044 Macomb Street, NW
Washington DC 20016

Budget Oversight Hearing

District of Columbia Department of Health

June 10, 2020

Chairman Gray and Committee Members, my name is Dean Brenner. I live in Ward 3. I am an Alzheimer's advocate and a member of Board of the Alzheimer's Association's National Capital Area Chapter.

Today, I am focusing on two important provisions I urge for this year's budget: 1) maintaining funding for the Dementia Services Coordinator (the DSC); and 2) amending the law passed last year, which required the DSC to produce and implement an updated DC Alzheimer's State Plan, to establish a process for doing so. DC currently lacks a plan and lacks any process to compose a new plan.

First, it is crucial that DC continue to fund the DSC.

There are about 9,000 DC residents with Alzheimer's and

29,000 DC family caregivers. The health care cost of Alzheimer's is enormous—it costs DC over \$122 million in Medicaid alone. African Americans are twice as likely, and Hispanics one and one-half times as likely, to get Alzheimer's as Whites, and two-thirds of the people with Alzheimer's are women. Researchers cannot explain these disparities.

Until passage of last year's legislation, the DC government did not have a point person to address this public health crisis. No one was coordinating Alzheimer's programs, support, and initiatives not just for thousands of DC residents in need now, but also to synthesize the efforts of service providers all over DC (including the DC government). As we now have our

DSC in place—her name is Tina Chamiso—we must develop the enormous potential for this role, so please maintain the funding for our DSC.

Second, DC currently lacks an active state plan to address Alzheimer's and other forms of dementia. The District had a plan prepared in 2013, but it expired last year, which is why last year's legislation required the DSC to update the 2013 plan. The exact language of the law, DC Code Section 7-744.01, which established this as one of the DSC's duties is attached to my written testimony.

An updated DC plan should focus on many important issues, including the racial and gender disparities I described and other forms of dementia, neither of which

are even mentioned in the 2013 plan. To fulfill the requirements of last year's law, the work on an updated plan needs to start now.

The Alzheimer's Association has proposed legislation to amend Section 7-744.01 by creating a commission which, after widespread community participation, would write a new plan. I urge that this legislation be included in this year's Budget Support Act.

As you know, my mom Marilyn Brenner was a long-time, dedicated public official who died from Alzheimer's. My mom had no interest in anything that was symbolic or meaningless. I believe that Section 7-744.01 is not symbolic or meaningless, but we need to amend it to ensure that the law is implemented in a timely

manner by adopting a new DC state plan in a comprehensive process, as we have proposed. Working together, we can save and improve so many lives.

Thank you.

# **District of Columbia Code**

# § 7–744.01. Dementia Services Coordinator.

There is established within the Department of Health the position of the Dementia Services Coordinator

("Coordinator"), who shall be a full-time employee of the District. The Coordinator shall be responsible for:

- (1) Organizing dementia services within the District;
- (2) Implementing and updating the District of Columbia State Plan on Alzheimer's Disease;
- (3) Assessing and analyzing dementia-related data collected by the District;
  - (4) Evaluating the District's dementia services;

- (5) Identifying and supporting the development of dementia-specific trainings; and
- (6) Carrying out such other duties relevant to the support of individuals with dementia as may be assigned by the Director of the Department of Health.

## Before the

District of Columbia Council

Committee on Health

Testimony of
Emma L. Berry

1814 Belmont Rd NW, Apt A

Washington DC 20009

Budget Oversight Hearing

District of Columbia Department of Health

June 10, 2020

Good afternoon Chairman Gray and Committee Members. My name is Emma Berry and I am a resident of Ward 1. I'm also the Advocacy Chair of the YoungNationAlz, a group of young professionals within the Alzheimer's Association National Capital Area Chapter.

I moved to the District of Columbia four years ago, the same year my grandmother passed away from Alzheimer's after living with it for 14 years. After Nana was diagnosed, my grandfather was her primary caregiver; however, he had emphysema from years of smoking, which made it increasingly difficult for him to support her. Both are chronic conditions; health deteriorates from them over time. Yet, while rates of emphysema have dropped dramatically thanks to an abundance of public health data on the dangers of smoking, we have so much more work to prevent Alzheimer's and aid individuals with dementia.

There must be a similar emphasis on collecting data around Alzheimer's and other forms of dementia in order improve outcomes for patients and caregivers. To support this, I ask that within DC Health, you maintain 2020-level funding for the Behavioral Risk Factor Surveillance System. The BRFSS is the nation's premier system of health-related telephone surveys to collect data about US residents regarding their health-related risk behaviors, chronic conditions, and use of preventative services.

This funding allows DC Health to conduct two invaluable modules. The Cognitive Decline module measures how often cognitive decline causes individuals to give up activity, whether individuals request and receive aid they need, and whether they have discussed their condition with a medical professional. As early detection and diagnosis and effective care planning are so fundamentally important to our health, this module captures essential data for our understanding of dementia.

Similarly, data collected from the Caregiver Module, which helps identify caregivers and assess their health, can aid the individual receiving care, and delay costly alternatives such as placement in long-term care facilities. For example, the BRFSS helped Alzheimer's researchers learn the District has 29,000 family caregivers providing \$433,000,000 in unpaid care. Given the economic impact this has on families and the District, information like this is essential for crafting effective public policy.

The data collected through these modules directly supports the development of resources like the Alzheimer's Association's Annual Facts and Figures report, which increase public understanding of dementia care, as well as the impact of Alzheimer's on caregivers. In the midst of a global pandemic, this information is more critical than ever, as how we care for our loved ones with dementia has changed. For example, many long-term care facilities have restricted family visits for their residents; while this limits the spread of COVID-19, it may also isolate dementia patients. We need to understand the long-term impact of these changes during the pandemic on people living with dementia and those caring for them.

The BRFSS is a tool that allows the District to continue to improve public health, as well as provide material contributions to the discourse on dementia care. We need DC Health to collect this data, display it effectively on their website, and work with community partners to get the word out about it. I urge the Council to continue its funding for the BRFSS and, in turn, improve our understanding of Alzheimer's and other forms of dementia.

On behalf of myself, my family and the DC Alzheimer's community, thank you.



# DISTRICT OF COLUMBIA

ALZHEIMER'S STATISTICS

# 65 + NUMBER OF PEOPLE AGED 65 AND **OLDER WITH ALZHEIMER'S BY AGE\***

Year	65-74	75-84	85+	TOTAL
2020	1,400	3,800	3,700	8,900
2025	1,300	4,100	3,600	9,000

\*Totals may not add due to rounding

Estimated percentage change



# NUMBER OF DEATHS FROM ALZHEIMER'S DISEASE (2018)

**105** 



29,000 Number of Caregivers

33,000,000 Total Hours of Unpaid Care

\$433,000,000 Total Value of Unpaid Care



26.8%



of people in hospice have a primary diagnosis of dementia



MEDICAID



MEDICARE -



More than 5 million Americans are living with Alzheimer's. The cost of caring for those with Alzheimer's and other dementias is estimated to total \$305 billion in 2020, increasing to more than \$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.

For more information, view the 2020 Alzheimer's Disease Facts and Figures report at alz.org/facts.

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