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May 1, 2020

Mayor Muriel Bowser
Government of the District of Columbia
1350 Pennsylvania Avenue, NW
Washington, D.C. 20004
VIA EMAIL

Dear Mayor Bowser:

As the District prepares to release and negotiate its budget, the Alzheimer's Association's National Capital Area Chapter asks that your Administration take the urgent actions set out below to protect this vulnerable population within the fiscal year 2021-2022 budget.

It is estimated that there are 8,900 people living with Alzheimer's in the District of Columbia in 2020 - a figure that is expected to increase with the aging population. We respectfully ask that the District of Columbia continue to consider the needs of this population and their families as policies are being developed.

First, protect funding for the Dementia Services Coordinator (DSC) within the District of Columbia Department of Health (DC Health). This innovative new position--one of only eight DSCs nationwide--was established as part of DC Health's fiscal 2020 budget [public law § 7-744.01]. This role is tasked with responsibilities including: organizing dementia services within the District; implementing and updating the State Plan on Alzheimer's; analyzing dementia-related data; and evaluating the District's dementia services. The Alzheimer's Association is thrilled that DC Health has hired the DSC, and she has begun her vital work. *The potential for this position is extraordinary; an essential point-of-contact and coordinator within government for the District's seniors, caregivers, and individuals with dementia.*

Second, maintain FY 2020-level funding for the Behavioral Risk Factor Surveillance System (BRFSS) survey within DC Health. The BRFSS is the nation's premier system of health-related telephone surveys that collects state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. For individuals with Alzheimer's or other dementia, and their caregivers, there are two studies within the BRFSS that provide invaluable data to researchers; the cognitive decline and the caregiver modules. *This funding allows DC Health to conduct both of these invaluable modules.*

The Cognitive Decline module was developed, according to the CDC, because of the importance of understanding cognitive impairment as a public health issue. Dementia--like other BRFSS focus areas such as heart disease, cancer, and stroke--is a chronic disease for which effective data collection is essential. This BRFSS module measures how often subjective cognitive decline (SCD) causes individuals to give up activities outside the home, whether individuals request/receive aid they need, and whether they have discussed SCD with a medical professional. As early detection and diagnosis and effective care planning is so fundamentally important to our health, this module captures essential data for our understanding of dementia.

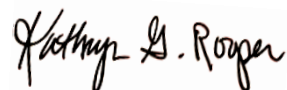
This caregiver module--which helps policymakers identify caregivers and assess their health--can aid the individual receiving care, and delay costly alternatives such as placement in long-term care facilities. This data can help understand factors such as: the percentage of adults who have been caregivers; the length and intensity of work by caregivers; and the health conditions and behaviors of caregivers. *The BRFSS helped Alzheimer's researchers understand that, in 2019, the District had 29,000 family caregivers providing \$433,000,000 in unpaid care* (see Alzheimer's Association's Facts and Figures for the District on page 7). Information like this is essential for crafting effective public policy.

Third, include language—within District of Columbia Code § 7-744.01, (2)—to form a commission which will update the District of Columbia's Alzheimer's State Plan. The fiscal year 2020 budget included language which requires the DSC to implement and update the District of Columbia's State Plan on Alzheimer's Disease, an important planning tool currently enacted in all 50 states.

This proposed provision sets up a multi-stakeholder vehicle--a mayorally appointed commission on Alzheimer's Disease and Dementia--to work with the DSC, to effectively review the prior State Plan (which ran from 2014 to 2019), and chart a course for the next iteration. Please see proposed language, below beginning on page 4, for your consideration.

If you have any questions about these requests, please contact Eric Colchamiro, Alzheimer's Association Director of Government Affairs, at ercolchamiro@alz.org or 202-365-6612

Thank you,



Kate Rooper
Chapter President and Chief Executive Officer
Alzheimer's Association, National Capital Area Chapter

CC: **Mr. Wayne Turnage**, Deputy Mayor for Health and Human Services and Director of the District of Columbia Department of Health Care Finance
Jenny Reed, Budget Director, Office of Mayor Muriel Bowser
LaQuandra Nesbitt, Director, Department of Health

Jennifer Budoff, Director, Budget Office of the Council of the District of Columbia
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Proposed Language:

District of Columbia Commission on Alzheimer's Disease and other Dementia

1. The District of Columbia Commission on Alzheimer's Disease and other Dementia (the Commission) is established as an advisory commission in the executive branch of state government, presiding within the DC Department of Health, to assist people with dementia and their caregivers;
2. The Commission shall include the following members:
 - a. One Member of the Council of the District of Columbia, or their designee;
 - b. The Director of the DC Department of Health, or their designee;
 - c. The Director of the DC Department of Aging and Community Living, or their designee;
 - d. The Director of the DC Department of Healthcare Finance, or their designee;
 - e. The DC Healthcare Ombudsman, or their designee;
 - f. The following members, appointed by the Mayor:
 - i. A District resident with personal or professional experience working on social determinants of health and community outreach in medically underserved communities within the District of Columbia;
 - ii. The Executive Director of the Alzheimer's Association, National Capital Area chapter, or their designee;
 - iii. A caregiver who is a family member of an individual with Alzheimer's Disease or a related dementia;
 - iv. Two research professionals, whose expertise can include addressing racial and ethnic disparities, or research in Alzheimer's Disease and other dementia
 - v. Two healthcare professionals, with experience working with patients who have Alzheimer's or other dementia
 - vi. Three representatives of the District's long-term care industry;
 - vii. At the recommendation of the Council, any other Member necessary to fulfill the duties of the Council;
3. To the extent practicable, the members appointed to the Council shall reflect the geographic, racial, ethnic, cultural, and gender diversity of the District.
4. Members shall be appointed for a term of three years. Appointments to fill vacancies, other than by expiration of a term, shall be for the unexpired terms. All members may be reappointed; however, no member shall serve more than two consecutive three-

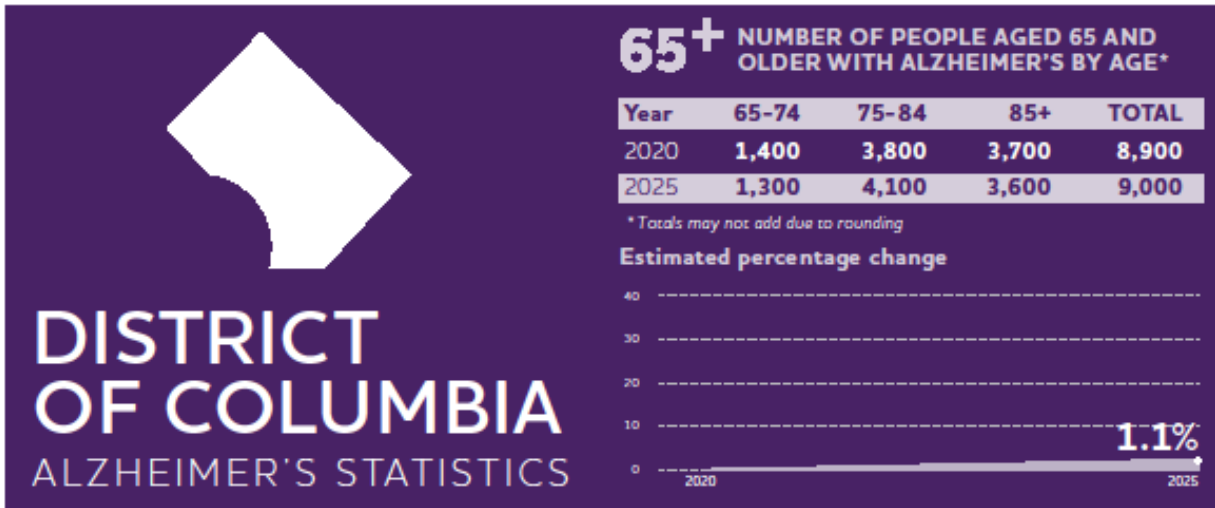
year terms. The remainder of any term to which a member is appointed to fill a vacancy shall not constitute a term in determining the member's eligibility for reappointment. Vacancies shall be filled in the same manner as the original appointments.

5. Members of the Commission shall elect a chair and vice-chair from among its membership; these leadership positions shall be voted on annually. A majority of the voting members shall constitute a quorum. The Commission shall conduct at least four in-person meetings each year; meeting locations should rotate throughout the District's four quadrants, and as a means of encouraging broader community engagement, in the offices of government and non-governmental organizations.

The meetings of the Commission shall be held at the call of the chair or whenever the majority of the voting members so request; meeting announcements shall be sent out to the full committee—and posted on the social media platforms of the DC Department of Health, the DC Department of Aging and Community Living, and the DC Council—no less than seven days prior to the meeting being held;

6. All members shall be reimbursed for reasonable and necessary travel expenses incurred in the performance of their duties. Funding for the expenses of the members shall be provided by the Department.
7. The Commission shall have the responsibility to:
 - a. Review, develop and update the District's plan for meeting the needs of patients with Alzheimer's disease and dementia, along with their caregivers, and advocate for such plan. Such plan shall include:
 - i. An examination of the needs of people with dementia (PWD) and their caregivers;
 - ii. Methods that District's government can most effectively and efficiently respond to the needs of PWD and their caregivers, including an examination of best practices for dementia screening, and how screening can happen more equitably across the District;
 - iii. Strategies to support prevention and early detection of Alzheimer's disease and dementia, including early stage identification;
 - iv. Addressing chronic disease factors contributing to disparities in Alzheimer's disease and dementia;

- v. Processes to increase access to home and community-based services, allowing for seniors to age in place, and for the District's government to provide more person-centered community care;
 - vi. An examination of the District's data collection capacity on Alzheimer's disease and dementia, and recommendations for the more effective display of that data;
 - vii. Strategies to enhance the quality of care focusing on:
 - 1. Developing a workforce to care for and treat Alzheimer's disease and dementia;
 - 2. Educating primary care providers on best practices, including early detection and diagnosis; and
 - 3. Promoting Alzheimer's disease and dementia care guidelines and patient-centered approaches in all care settings
 - 4. Development and promotion of strategies to encourage brain health and reduce cognitive decline;
 - 5. Establishment of priorities for programs among state agencies related to Alzheimer's disease and dementia and criteria to evaluate these programs.
 - viii. Advise and issue recommendations to the Mayor and the DC Council on policy, funding, regulatory, and other issues related to persons with Alzheimer's disease and dementia, along with their caregivers;
 - ix. Submit to the Mayor and DC Council, by October 1 of each year, an electronic report regarding the activities and recommendations of the Commission. This report document shall be posted on the websites and social media platforms of the DC Department of Health, the DC Department of Aging and Community Living, and the DC Council within 14 business days of the Commission approving its annual report.
8. The Dementia Services Coordinator, residing in the DC Department of Health, shall provide staff support to the Commission in coordination with the DC Department of Aging and Community Living. All District agencies shall aid the Commission, upon request.
9. This section shall go into effect on November 1, 2020. This section shall expire on September 30, 2026.



<p>CAREGIVING (2019)</p> <p>29,000 Number of Caregivers</p> <p>33,000,000 Total Hours of Unpaid Care</p> <p>\$433,000,000 Total Value of Unpaid Care</p>	<p>HOSPITALS (2017)</p> <p>1,699 # of emergency department visits per 1,000 people with dementia</p> <p>15.8% Increase in emergency department visits since 2007</p> <p>26.8% dementia patient hospital readmission rate</p>	<p>HOSPICE (2017)</p> <p>263 # of people in hospice with a primary diagnosis of dementia</p> <p>18% of people in hospice have a primary diagnosis of dementia</p>	<p>MEDICAID</p> <p>\$126 MILLION Medicaid costs of caring for people with Alzheimer's (2020)</p> <p>6.8% change in costs from 2020 to 2025</p>
		<p>MEDICARE</p> <p>\$31,993 per capita Medicare spending on people with dementia (in 2019 dollars)</p>	

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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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