

March 31–April 2

alz.org/forum
#alzforum



WELCOME



Dear Alzheimer's Advocate,

Welcome to the 2019 Alzheimer's Impact Movement Advocacy Forum! Thank you for joining us in Washington for the nation's premier Alzheimer's advocacy event. During the next three days of networking, training and education, you'll experience what it truly means to be part of the Alzheimer's advocate community.

Last year was another remarkable year in the fight to end Alzheimer's. Your advocacy efforts led to two historic federal research funding increases, the passage of the BOLD Infrastructure for Alzheimer's Act, as well as the RAISE Family Caregivers Act and Kevin and Avonte's Law. State governments across the country developed, updated and implemented state Alzheimer's plans and passed legislation to improve the lives of all affected by Alzheimer's. And, public health departments — guided by the *State and Local Public Health*

Partnerships to Address Dementia: The 2018-2023 Road Map — began implementing proven strategies to address cognitive decline.

These achievements are due to the power of your advocacy not just here in Washington during the Advocacy Forum, but to the work you do throughout the year.

But we know, more work remains.

In this Advocates Guide, you'll find everything you need to make the most of your Advocacy Forum

experience, including detailed information about our federal and state priorities, and tips and resources on how to successfully advocate on Capitol Hill and at home.

We hope you'll share your Advocacy Forum experience with people unable to come to Washington. Be sure to follow our social media accounts and use #alzforum and #ENDALZ to continue the conversation online.

Alzheimer's is one of the most critical health issues in America today. That's why we work tirelessly to secure public policies that advance research and improves access to care and support services. Thank you for joining us in the fight.

Sincerely,
The Alzheimer's Association
AIM Public Policy Team

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2019 ALZHEIMER'S DISEASE FACTS AND FIGURES

ALZHEIMER'S
DISEASE IS THE

6TH

leading cause of death
in the United States



82% of seniors say it's important to have their thinking or memory checked

BUT ONLY

16%

say they receive regular cognitive assessments

5.8 MILLION Americans are living with Alzheimer's

BY 2050, this number is projected to rise to nearly 14 MILLION

MORE THAN 16 MILLION AMERICANS

provide unpaid care for people with Alzheimer's or other dementias

These caregivers provided an estimated 18.5 BILLION HOURS valued at nearly \$234 BILLION

IN 2019, Alzheimer's and other dementias will cost the nation \$290 BILLION

BY 2050, these costs could rise as high as \$1.1 TRILLION



EVERY 65 SECONDS

someone in the United States develops the disease

Between 2000 and 2017 deaths from heart disease have decreased

9%



while deaths from Alzheimer's disease have increased

145%



1 IN 3

seniors dies with Alzheimer's or another dementia

It kills more than breast cancer and prostate cancer

COMBINED

FACTSHEET

MARCH 2019

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2019 Alzheimer's Disease Facts and Figures

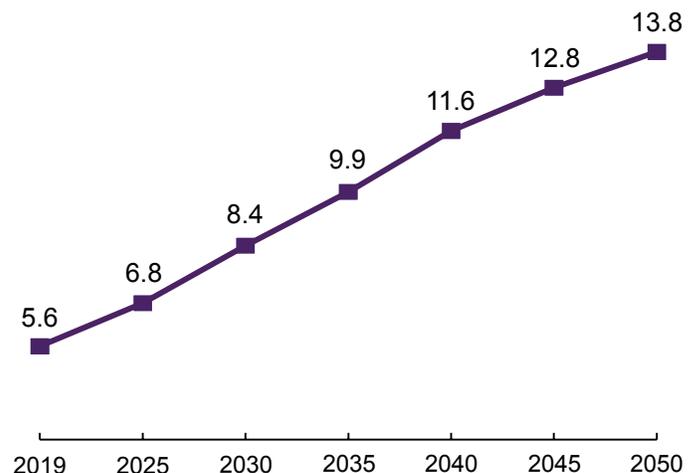
The number of Americans living with Alzheimer's is growing—and growing fast.

- Today, 5.8 million Americans are living with Alzheimer's, including an estimated 200,000 under the age of 65.
- Nearly two-thirds (3.5 million) of seniors with Alzheimer's are women. African Americans are twice as likely and Hispanics are about 1.5 times as likely as whites to develop Alzheimer's.
- The number of people living with Alzheimer's is expected to reach nearly 14 million by mid-century.

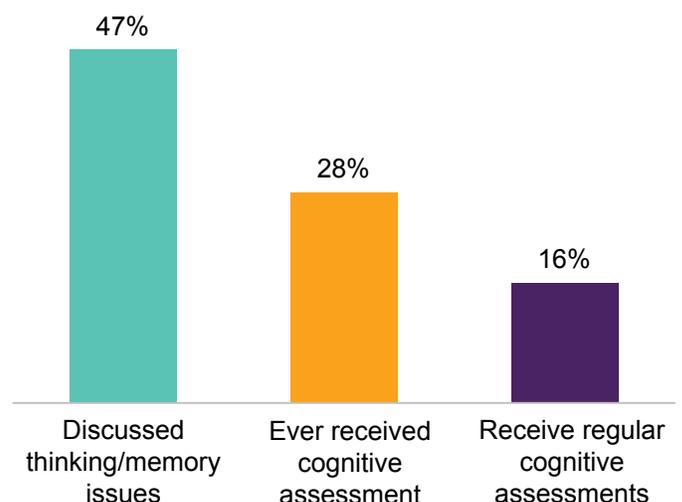
A large number of those living with Alzheimer's are not diagnosed—and most seniors are not even being assessed.

- Less than half (47 percent) of seniors have ever discussed their thinking or memory abilities with a health care provider.
- Only 28 percent report ever having received an assessment for cognitive problems. And even less—16 percent—receive regular cognitive assessments during routine health checkups.
- Almost all seniors (93 percent) say they trust their doctor to recommend testing if needed. But less than half of primary care physicians say it is their standard protocol to assess seniors for cognitive impairment, many indicating they wait for patients or their family members to bring it up first.

Millions of Americans Aged 65 and Older with Alzheimer's



Percentage of Seniors Receiving Cognitive Assessment from a Health Care Provider



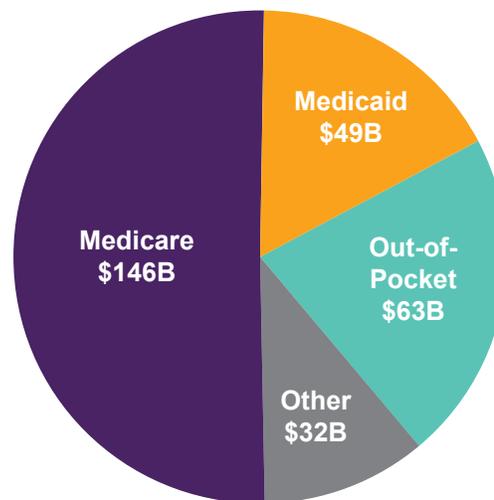
The growing number of people living with Alzheimer's is placing a huge burden on the health care system.

- In 2019, the direct costs to American society of caring for those with Alzheimer's will total an estimated \$290 billion, with \$195 billion of it paid by Medicare and Medicaid.
- Average per-person Medicare spending for those with Alzheimer's and other dementias is more than three times higher than average per-person spending across all other seniors. Medicaid payments are 23 times higher.
- Unless something is done, in 2050, Alzheimer's will cost more than \$1.1 trillion (in 2019 dollars).

Alzheimer's also places a huge burden on families.

- In 2018, 16 million family members and friends provided 18.5 billion hours of unpaid care to people with Alzheimer's and other dementias, at an economic value of \$234 billion.
- Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families—either through out-of-pocket health and long-term care expenses or from the value of unpaid care.
- The annual out-of-pocket spending incurred by dementia caregivers—including on household and personal care expenses—is nearly twice as high as that incurred by caregivers of people with other conditions.
- The physical and emotional impact of caregiving on Alzheimer's and other dementia caregivers resulted in an estimated \$11.7 billion in increased caregiver health costs in 2018.

2019 Costs of Alzheimer's = \$290 Billion



Alzheimer's is not just memory loss. Alzheimer's kills.

- In 2017, 121,404 people in the United States died from Alzheimer's disease, making it the sixth leading cause of death in the United States and the fifth leading cause of death for those aged 65 and older.
- Deaths from Alzheimer's increased 145 percent from 2000 to 2017, while deaths from other major diseases (including heart disease, stroke, and HIV/AIDS) decreased.
- This year, about 1 in every 3 seniors who dies—an estimated 700,000 people—will have Alzheimer's.

Facts in Your State

The 2019 *Alzheimer's Disease Facts and Figures* report also contains state-by-state data on the impact of the disease. Find the full report and information on your state at alz.org/facts.

PUBLIC POLICY VICTORIES

The Alzheimer's Association, the Alzheimer's Impact Movement (AIM), and our dedicated network of advocates are leading the fight to end Alzheimer's!



MAKE YOUR STORY COUNT

LET'S



Human beings (and yes, that includes members of Congress) are hard wired to learn through stories. Statistics simply aren't enough to challenge preconceptions of this disease; it takes authentic stories from constituents like you. That's the whole reason you're an Alzheimer's advocate! But how do you convey your own Alzheimer's story in a way that's brief yet compelling enough to support our legislative asks?

Simply remember:

“Let's CHAT!”

CONNECT

Explore these approaches to find common ground.

- » **“Have you known somebody with Alzheimer's?”**
Give them a moment to tell their story or, say how lucky they are.
- » **Find shared interests/history.**
Research how your story and asks might relate to their background and policy interests.
- » **All politics is local!**
Highlight statistics and events that illustrate the impact on your community.
- » **Say thank you!**
There's always something. Say how it matters to YOU.

HOOK

Grab their attention by putting them in your shoes.

- » **Focus on a single anecdote.**
You only have a minute or two. Share one moment of struggle or realization.
- » **Paint a picture.**
Use all five senses and present tense to put them in the moment.
- » **It's OK to get emotional.**
You're not a lobbyist, but a constituent with a genuine need.
- » **Bridge to the legislative ask.**
Highlight one statistic illustrating the broader impact of your experience.

ASK

Show how they can help. Ask for a commitment.

- » **Let the Advocates Guide be your guide.**
Walk through our materials to make each ask.
- » **Don't bluff!**
“I don't know, but we will get back to you” is a great excuse to follow-up.
- » **Define next steps.**
Ask what they need to reach a decision. Make a plan to follow-up.
- » **Share additional stories as time allows.**

THANK

Thank yous are key to building a lasting relationship.

- » **Thank them for the meeting.**
- » **Thank them for agreeing to our asks.**
- » **Find SEVEN WAYS TO SAY THANK YOU on page 34.**

TIPSHEET: SPARK SOCIAL MEDIA CONVERSATIONS

Social networks enable direct interaction with your legislators. Today, the vast majority of legislators run (or at least monitor) their own social media accounts and are eager to gather feedback from their constituents. With just a handful of simple actions you can make a big difference in the fight to end Alzheimer's.



Mentioning & Tagging

Mentioning or Tagging is an easy way to engage legislators online. On most major social networks, simply mention their “handle” (i.e. @SenatorName) in your post.



Retweeting & Commenting

Legislators use social media to reach their constituents. Reply and comment on their posts to make your voice heard and raise the issue of Alzheimer's. You can also share their posts adding your thoughts. You can also share posts from AIM, your chapter or fellow advocates and tag your legislator to bring them into the conversation.



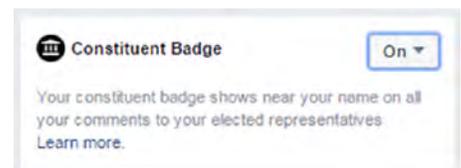
#Hashtags

Hashtags link together a conversation and help you find relevant information. Some commonly used examples are: **#ENDALZ #alzforum #Ask4Alz #Every65Seconds**. Please make sure the hashtag matches the message you are sending.



Remember the “Rule of Three”

Mentions, tags and hyperlinks are all interactive and clickable parts of a social media post or Tweet. While we encourage you to make use of these tools, it is a best practice to include no more than three in a single post. Including too many can distract from your primary message.



Identify yourself as a constituent

Legislators want to hear from their own constituents but it can be difficult to verify constituents on social media. Visit fb.com/townhall to turn-on Facebook's “constituent badge.” On other platforms, mention your town/neighborhood in your profile and include photos from recognizable local events or landmarks.

TIPSHEET: SPARK SOCIAL MEDIA CONVERSATIONS



Find political events on Facebook

Facebook's events feature is a great way to find opportunities to connect with your elected officials and other advocates in your community. After following your elected officials, visit fb.com/events and check out the "popular with friends" category. Select "interested" for any local political events you see and Facebook will notify you of similar events in the future. Make sure to go early and stay late to network and discuss the Alzheimer's crisis. And don't forget to wear your purple!



Expand Your Network with LinkedIn

Elected officials aren't your only audience. In many cases you can connect with legislative staff, local influencers, other advocates and community allies via your professional network. LinkedIn is the most prominent professional social network. You can share AIM posts, your own letters-to-the-editor and relevant Alzheimer's information. linkedin.com/company/alzheimer-s-impact-movement/



Share the Picture

Posting an image or video increases the likelihood your post will be noticed. Whenever possible include a photo and tag the individuals, organization and location. If your photo includes an elected official or their staff, be sure to get their permission before posting. If you have more than one great photo, try posting them together as an album.



Broadcast yourself.

Consider sharing a "live" video stream on Facebook, Twitter, or Instagram. Make sure you have a steady device and you promote it in advance so your followers know to tune in. Save video clips so you can share highlights later for those who missed it.

Worksheet: Get Connected

Do some homework by finding your legislator and your team members on leading social media platforms. "Follow" or "friend" them on each platform to engage them, learn about upcoming events, and to make tagging them easier in future posts and photos.



	Facebook	Twitter	Instagram
Legislator's official account:	_____	_____	_____
Legislator's campaign account:	_____	_____	_____
Any key staff account(s)?:	_____	_____	_____
Alzheimer's Impact Movement:	fb.com/alzimpact	@alzimpact	@alzimpact
Alzheimer's Association:	fb.com/actionalz	@alzassociation	@alzassociation
Your Chapter:	_____	_____	_____
Your Chapter Policy Staff:	_____	_____	_____
Yourself!	_____	_____	_____
Your team/Fellow Advocates:	_____	_____	_____

Would you believe 10% of Congress is active on Snapchat?

Note other platforms that your legislator uses:

LinkedIn: _____ **Snapchat:** _____

Pinterest: _____ **YouTube:** _____

LEGISLATIVE MEETING TIPS



SHOW YOUR COLORS

Wear something purple (tie, scarf, sash, pin, etc.) to indicate that you are an Alzheimer's Association or Alzheimer's Impact Movement advocate.

PLAN YOUR PITCH

Planning is everything. Take the time to develop, rework and refine your stance in advance. In other words, be prepared.

LISTEN

Let the elected official or staff member express his or her point of view.

BE COURTEOUS

Even those who vehemently disagree with your message may support our future efforts. It's important not to burn any bridges.

BE BRIEF

Get in and out of an official's office quickly. Show that you know the value of his or her time.

KEEP IT SIMPLE

Don't be too technical, too detailed, too complex or too oblique. Be direct, cover the basics and make sure the official understands your main point.

KEEP YOUR GROUP SMALL

An unwieldy group can make everyone uncomfortable, distract from your message and waste valuable time getting set up. Make certain that the group has already chosen a spokesperson and stick with that decision.

NEVER TELL A LIE

Your reputation is everything. You lose credibility if you lie. If you don't know the answer to a question, tell them you don't know, but offer to find out and then follow up. Be sure to let the D.C. Public Policy office know so that we can help.

DON'T FORGET TO CLOSE

Always ask for the official's vote or support. Remember to pause and wait for a response.

EXCHANGE INFORMATION

When meeting with staff be sure to exchange contact information or business cards.

SAY THANK YOU

Remember to call or send a note to your elected official to remind them of your visit, and thank them for their time and support.

SHARE YOUR EXPERIENCE

Upload and post pictures of your meeting to your social networks and blogs. Remember to tag and share with your elected officials.

REPORT YOUR ACTIVITY

Please make sure to enter your meeting report on the Alzheimer's Impact Movement (AIM) website.

alzimpact.org

LEGISLATIVE MEETING CHECKLIST

Below are some suggested ways to successfully plan a group meeting with elected officials.

OFF SITE PRE-MEETING

Assign Roles and Assignments

- » Who is responsible for bringing materials to the meeting?

- » Who is going to handle introductions? Ex. Who we are, why we're here?

- » Who will deliver the opening line and show the legislative guide on the state of Alzheimer's?

- » Who is going to tell their story and show how it relates to the first issue?

- » Who is going to make the first "ask"?

- » Who is going to tell their story and show how it relates to the second issue?

- » Who, if applicable, is going to make the additional ask(s)?

- » Who is going to conclude the meeting and ask for a photo?

Logistics

- » Meet with other advocates from your state in the room listed in the the Blue Sheets provided in your Registration Bag.
- » Get your Capitol Hill meeting schedule from your chapter staff contact.
- » Have the meeting time and location been confirmed?
- » Do all attendees have the legislative office's contact information?

ON SITE PRE-MEETING

- » Are all meeting attendees present and accounted for?
If so, quickly reconfirm assigned roles before entering office.

POST-MEETING

- » Who will post a photo from the meeting to Twitter and Facebook?

- » Who will submit the meeting report to **alzimpact.org**?

- » Who will follow-up with the legislative office? Ex. Provide answers to pending questions, additional materials.

- » Who will update/debrief participants and provide next steps?

2019 FEDERAL PRIORITIES

Alzheimer's is a growing crisis for our families and the economy. The federal government must address the challenges the disease poses and take bold action to confront this crisis now.

1

Increase the commitment to Alzheimer's research and public health response

An estimated 5.8 million Americans are living with Alzheimer's, and by mid-century, the number of people with the disease is set to nearly triple. Already the most expensive disease in America, with costs reaching an estimated \$290 billion in 2019, these costs are projected to more than quadruple to \$1.1 trillion by mid century.

- » Consistent with the National Plan to Address Alzheimer's, Congress has bolstered support for research funding at the National Institutes of Health (NIH). Nevertheless, current funding levels continue to fall short of the total funding scientists and the U.S. Alzheimer's Advisory Council, created by Congress, believe is needed to meet the goal of finding a treatment or effective treatments for Alzheimer's and other dementias by 2025. Congress must continue its commitment to the fight against Alzheimer's and other dementias by increasing funding for Alzheimer's research by an additional \$350 million in fiscal year 2020.
- » As scientists continue to explore new areas of research for prevention, treatment and a cure, public health plays a critical role in promoting cognitive function and reducing the risk of cognitive decline. The bipartisan Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406) directs the Centers for Disease Control and Prevention (CDC) to strengthen the public health infrastructure across the country by implementing effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations. The BOLD Infrastructure for Alzheimer's Act will accomplish this by establishing Alzheimer's and Related Dementias Public Health Centers of Excellence, providing funding to state, local, and tribal public health departments, and increasing data analysis and timely reporting. To ensure the law's successful implementation, Congress must fully fund the \$20 million authorized in the law for CDC in FY20.

2

Support education and outreach on Alzheimer's care planning services covered under Medicare

For individuals living with Alzheimer's and their caregivers, care planning is essential to learning about medical and non-medical treatments, clinical trials, and support services available in their community. As of January 2017, Medicare reimburses providers for care planning. However, too few providers and patients are aware of this benefit. *The Improving HOPE for Alzheimer's Act* would increase education and outreach to providers about Alzheimer's and dementia care planning services through Medicare and give clinicians the knowledge and the tools to better help their patients and families living with dementia.

3

Improve access to services for individuals with younger-onset Alzheimer's

An estimated 200,000 Americans under the age of 65 are living with Alzheimer's disease. However, because of their young age these individuals are not eligible for support and service programs available to older Americans. *The Younger-Onset Alzheimer's Disease Act of 2019* would allow individuals living with dementia under the age of 60 to access supports and services from programs under the Older Americans Act (OAA). Those programs include nutritional services, supportive services, the National Family Caregiver Support program, and other services that enhance quality of life.

FACTSHEET

MARCH 2019

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Fiscal Year 2020 Alzheimer's Research Funding

The escalating Alzheimer's epidemic has profound implications for government budgets.

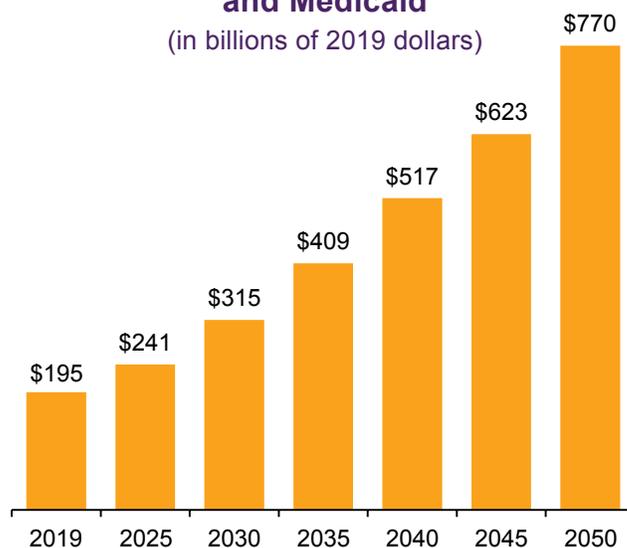
- Alzheimer's is the most expensive disease in America, costing more than heart disease and cancer.
- In 2019, caring for people with Alzheimer's and other dementias will cost the United States an estimated \$290 billion. Cumulatively between now and 2050, it will cost \$20.2 trillion (in 2019 dollars)—two-thirds of which will be borne by Medicare and Medicaid.
- One in every 5 dollars of Medicare spending is spent on people with Alzheimer's and other dementias.

Despite the recent increased investment in Alzheimer's research, funding still falls short of the need.

- For fiscal year 2019, Congress provided an additional \$425 million in Alzheimer's research funding at the National Institutes of Health (NIH).
- With this increase, along with previous research investments, the NIH is expected to spend \$2.3 billion on Alzheimer's research in 2019.
- However, this is still short of the total funding scientists and the federal Alzheimer's Advisory Council have indicated is necessary for continued progress.

Alzheimer's Costs to Medicare and Medicaid

(in billions of 2019 dollars)



Congressional action is needed to stay on the path to discovering scientific breakthroughs.

- The National Alzheimer's Plan has established a goal of developing preventions and effective treatments for Alzheimer's by 2025.
- Under the Plan, the NIH has established timelines and milestones for Alzheimer's research.
- To achieve the timeline and eventual goal, Congress must continue its commitment by increasing funding for Alzheimer's research by an additional \$350 million in fiscal year 2020.

NIH APPROPRIATIONS BACKGROUND

ASK: Please send a letter to the Chair and Ranking Member of the House/Senate Appropriations Committee supporting an additional \$350 million in Fiscal Year 2020 (FY20) for Alzheimer's research activities at the National Institutes of Health (NIH).

Background

Congress unanimously passed the bipartisan National Alzheimer's Project Act (P.L. 111-375) in 2010. The law requires the Secretary of the Department of Health and Human Services (HHS) to create and annually update a national Alzheimer's plan to overcome the disease. The National Plan to Address Alzheimer's Disease, reported to Congress annually, must include recommendations for priority actions both to improve health outcomes for individuals and to lower costs to families and government programs.

To achieve a core goal of the National Plan of preventing and effectively treating Alzheimer's by 2025, Congress has bolstered support for Alzheimer's research at the NIH. In September 2018, Congress appropriated a \$425 million increase for Alzheimer's research funding in FY19, bringing the annual allocation to \$2.3 billion. This significant increase is an important investment in research. However, the current funding level is still short of the total funding scientists and the U.S. Alzheimer's Advisory Council created by Congress believe is needed to meet the goal of finding a treatment or cure for Alzheimer's and other dementias by 2025.

Making the Case for Research Funding

- » According to an NIH-funded study in the *New England Journal of Medicine*, Alzheimer's is the most expensive disease in America.
- » In 2019, the cost for caring for those with Alzheimer's will be \$290 billion, with \$195 billion of that amount paid by Medicare and Medicaid. The annual costs are set to increase rapidly to \$1.1 trillion (not adjusted for inflation) by 2050.
- » According to a 2015 report, a treatment that simply delayed onset of Alzheimer's by five years would lower Medicare spending on those with the disease by one-quarter in 2050 — and the federal government would recoup its research investment in less than three years.
- » The National Plan to Address Alzheimer's Disease has resulted in notable accomplishments, including the NIH creating a blueprint for Alzheimer's research. However, for the progress this disease requires, scientists need the necessary funds to carry out the blueprint.
- » Congress must continue its commitment to the fight against Alzheimer's by increasing funding for Alzheimer's research by an additional \$350 million in FY20.



Share Your Story

Tell your personal story. Congress continues to be focused on deficit reduction and reducing government spending. If you are comfortable doing so, please share your experience with the economic pressures created by the disease including unnecessary hospitalizations, out-of-pocket costs, and complications with other conditions.

NIH APPROPRIATIONS TALKING POINTS

Frequently Asked Questions

During the course of your meetings with members of Congress and their staffs, you may encounter some common questions. We have addressed some of these questions below.

Q. Is this a programmatic request?

Suggested Response:

- » This is not a programmatic request.
- » This is an individual letter of support for an increase in the overall level of funding for Alzheimer's research at the NIH. Letters of support can be sent up until the Labor-HHS Appropriations bill is passed.

Q. NIH already receives funding for Alzheimer's; why the additional \$350 million?

Suggested Response:

- » Recent funding increases have been critical to progress toward the primary research goal of the National Plan to Address Alzheimer's Disease of effectively treating or preventing Alzheimer's by 2025.
- » The "Milestones" leave-behind highlights some of the important research advances made with these funding increases, including research into new biomarkers to detect the disease before the onset of symptoms and ways to build better animal

models to replicate the disease and enable preclinical testing of promising therapeutics.

- » The Alzheimer's Bypass Budget, released annually by the NIH, specifies the resources scientists need to fulfill the primary research goal of the National Plan and the U.S. Alzheimer's Advisory Council. An additional \$350 million would allow the NIH to invest in collaborations that speed discovery, groundbreaking prevention trials, the testing of new therapeutics and many other opportunities.
- » Alzheimer's is the only one of the leading causes of death in the U.S. without a way to prevent, cure or even slow its progression. The primary reason this remains true is that we have put toward Alzheimer's only a fraction of what's been applied over time to address other major diseases.
- » If a treatment became available in 2025 that delayed onset of Alzheimer's for five years (a treatment similar to anti-cholesterol drugs), savings would be seen almost immediately, with Medicare and Medicaid spending reduced by \$47 billion in 2030.

Q. The FY2020 Bypass Budget requests an additional \$477 million for Alzheimer's research at the NIH. Why are you advocating for a \$350 million increase?

Suggested Response:

- » The NIH based its FY20 request of a \$477 million increase on the assumption that Congress would enact the multi-million dollar cut in the President's FY19 budget proposal, therefore starting with a lower baseline number.
- » The Alzheimer's Association and AIM based our FY20 request of a \$350 million increase on the assumption that Congress would approve a multi-million dollar increase for FY19, which Congress did in September 2018.
- » So while our requested increase is a lower dollar figure than the Bypass Budget, it represents a similar overall funding level for Alzheimer's research at the NIH.

NIH APPROPRIATIONS TALKING POINTS

Q. Congress doesn't earmark money by disease. Why should Alzheimer's be different?

Suggested Response:

- » The Alzheimer's Association and Alzheimer's Impact Movement agree that Congress should not pick the specific research projects to be funded — that is a job for scientists.
- » Congress enacted the bipartisan Alzheimer's Accountability Act as part of the Fiscal Year 2015 omnibus appropriations bill (P.L. 113-235) to require the scientists at the NIH to submit a Bypass Budget, which is an annual Alzheimer's research budget proposal.
- » This ensures that Congress hears directly from scientists on what they will need to meet the nation's goal of finding a way of preventing or treating Alzheimer's by 2025, and equips Congress with the best information to determine necessary Alzheimer's research funding levels each year.

Q. How would recent initiatives to address biomedical research funding, like the 21st Century Cures Act, impact funding for Alzheimer's research?

Suggested Response:

- » The Alzheimer's Association strongly supported the 21st Century Cures Act (P.L. 114-255). The legislation has the potential to accelerate Alzheimer's research projects at the NIH.
- » The 21st Century Cures Act directs nearly \$1.6 billion to the BRAIN Initiative over 10 years, which works to accelerate the development and implementation of innovative technologies. While this research may have an impact on Alzheimer's, it is not a substitute for the basic biomedical and translational research conducted by the National Institute on Aging that is so critical to advancing what we all hope will one day be an end to Alzheimer's.

NOTE: If your member of Congress or their staff asks you a question you do not know the answer to, that is not a problem. Do not feel any pressure to provide an answer. Simply ask them to contact a member of the Alzheimer's Impact Movement's Federal Affairs Team at 202.393.7737. Also indicate the interaction at alzimpact.org so a member of the Federal Affairs team can follow up with that office.



FACTSHEET

MARCH 2019

alzimpact.org

BOLD Infrastructure for Alzheimer's Act

How is Alzheimer's a public health issue?

- While Alzheimer's has been viewed as an aging issue, it also has an effect on a community level.
- Specifically, Alzheimer's meets the three-point criteria for identifying a public health issue: (1) the burden is large; (2) the impact is major; and (3) there are ways to intervene.

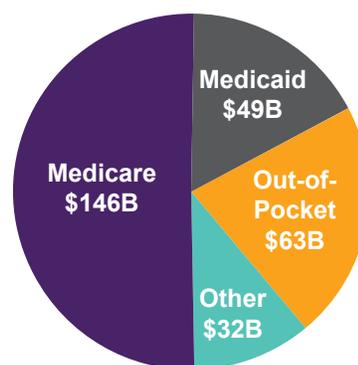
How large is the burden?

- More than 5 million Americans have Alzheimer's.
- It is the most expensive disease in America; costs now exceed a quarter of a trillion dollars per year.
- And the burden is growing larger. The number of people living with Alzheimer's is projected to triple to as many as 16 million in 2050, and the costs are expected to rise to more than \$1.1 trillion.

What Is Public Health?

Health care primarily involves medical treatment and care for particular individuals—that is, the prevention, treatment, and management of illness among individuals by medical professionals. Public health, on the other hand, works on a community level to protect and improve the health and safety of an entire community or group of people. Public health promotes healthy lifestyles, prevents illnesses and injuries, and detects and controls diseases. By working with diverse communities, public health expands the reach and impact of health care efforts.

2019 Costs of Alzheimer's = \$290 Billion



How major is the impact?

- Due to the toll of caring for someone with Alzheimer's, caregivers have more than \$11 billion in additional health care costs each year.
- Among people with dementia, 1 in every 4 hospitalizations is preventable.
- Alzheimer's imposes a significant cost on federal and state budgets:
 - Two-thirds of the health and long-term care costs of caring for those with Alzheimer's are borne by Medicare and Medicaid.
 - One in every 5 dollars spent by Medicare is spent on people with Alzheimer's and other dementias.
- And the impact is growing larger. By 2050, more than 1 in every 3 Medicare dollars will be spent on someone with Alzheimer's and other dementias.

How can the public health community intervene?

- Public health officials can use the traditional tools and techniques of public health to improve the quality of life for those living with Alzheimer's and to reduce the costs associated with it.
- Public health interventions include primary prevention, early detection and diagnosis, data collection, and access to quality care and services.

How specifically can these interventions be applied to Alzheimer's?

- **Primary Prevention:** A growing scientific consensus has concluded that healthy living—regular physical activity, attention to heart health, and preventing head injuries—can reduce the risk of cognitive decline and may reduce the risk of Alzheimer's. Public health can integrate brain health messages into existing, relevant public health campaigns.
- **Early Detection and Diagnosis:** As many as half of people living with Alzheimer's have not been diagnosed. Public health can undertake public awareness campaigns to promote early detection and diagnosis and can educate medical professionals about assessment tools.
- **Data Collection:** Working with the Centers for Disease Control and Prevention (CDC), states can collect data on cognitive decline and Alzheimer's caregiving using tools such as the world's largest continuous public health survey, the Behavioral Risk Factor Surveillance System (BRFSS).
- **Access to Care and Services:** For people with Alzheimer's, public health can encourage health professionals to follow evidence-based clinical care guidelines, create tools to aid in the delivery of care, and report on quality care dementia practices.

An Under-Recognized Crisis

"Alzheimer's is the most under-recognized threat to public health in the 21st century."

– *Dr. David Satcher,
former U.S. Surgeon General
and Director of the Centers for
Disease Control and Prevention*

What does the BOLD Infrastructure for Alzheimer's Act (P.L. 115-406) do?

- The bipartisan BOLD Act was unanimously approved by the Senate and passed in the House of Representatives by a vote of 361-3. It was signed into law on December 31, 2018.
- As enacted, the BOLD Act:
 - Establishes Alzheimer's Centers of Excellence around the country to expand and promote innovative and effective Alzheimer's interventions.
 - Provides funding to state, local, and tribal public health departments to implement those interventions and to carry out the *Public Health Road Map*, including promoting early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations.
 - Increase the analysis and timely reporting of data on cognitive decline and caregiving to inform future public health actions.

What are the next steps?

- The BOLD Act authorized \$100 million over five years to carry out the various public health activities addressing Alzheimer's and other dementias.
- Congress must fully fund the law by providing \$20 million in fiscal year 2020 for the CDC.

INCREASE THE COMMITMENT TO ALZHEIMER'S PUBLIC HEALTH RESPONSE BACKGROUND

ASK: Please send a letter to the Chair and Ranking Member of the House/Senate Appropriations Committee in support of \$20 million in Fiscal Year 2020 (FY20) to implement the BOLD Infrastructure for Alzheimer's Act at the Centers for Disease Control and Prevention (CDC).

Background

The bipartisan Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406) was unanimously approved in the Senate and passed by a vote of 361-3 in the House of Representatives. President Trump signed the bill into law on December 31, 2018. The law directs the Centers for Disease Control and Prevention (CDC) to strengthen the public health infrastructure across the country by implementing effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations. The BOLD Infrastructure for Alzheimer's Act will accomplish this by establishing Alzheimer's and Related Dementias Public Health Centers of Excellence, providing funding to state, local, and tribal public health departments, and increasing data analysis and timely reporting.

As scientists continue to search for a way to prevent, cure, or slow the progression of Alzheimer's through medical research, public health plays an important role in promoting cognitive function and reducing the risk of cognitive decline. Investing in a nationwide Alzheimer's public health response will help create population-level improvements, achieve a higher

quality of life for those living with the disease and their caregivers, and reduce associated costs.

BOLD was introduced by Senators Susan Collins (R-ME), Catherine Cortez Masto (D-NV), Shelley Moore Capito (R-WV), and Tim Kaine (D-VA) in the Senate and Representatives Brett Guthrie (R-KY-2), Paul Tonko (D-NY-20), Chris Smith (R-NJ-4), and Maxine Waters (D-CA-43) in the U.S. House of Representatives.

Making the Case for the BOLD Infrastructure for Alzheimer's Act

- » Former Surgeon General and Director of the Centers for Disease Control and Prevention Dr. David Satcher has said, "Alzheimer's is the most under-recognized threat to public health in the 21st century."
- » Alzheimer's is already a public health crisis because it affects so many people around the country — over 5 million Americans — and has a major impact on our health care system and our government with Medicare and Medicaid bearing two-thirds of the cost of caring for those with the disease.
- » Over half of Congress cosponsored the authorizing

law, so it is clear there is strong bipartisan support in both the House and Senate.

- » BOLD will establish Alzheimer's and Related Dementias Public Health Centers of Excellence, provide funding to state, local, and tribal public health departments, and increase data analysis and timely reporting.
- » This important public health infrastructure will implement effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations.
- » The next step in BOLD's implementation is for Congress to fully fund the \$20 million authorized in the law for CDC in FY20.

Share Your Story

Tell your personal story. Congress continues to be focused on deficit reduction and reducing government spending. If you are comfortable doing so, please share your experience with the economic pressures created by the disease including unnecessary hospitalizations, out-of-pocket costs, and complications with other conditions.

INCREASE THE COMMITMENT TO ALZHEIMER'S PUBLIC HEALTH RESPONSE TALKING POINTS

Frequently Asked Questions

During the course of your meetings with members of Congress and their staffs, you may encounter some common questions. We have addressed some of these common questions below.

Q. Is this a programmatic request?

Suggested Response:

- » This is not a programmatic request.
- » This is an individual letter of support for an increase in the level of funding for Alzheimer's public health efforts at CDC. Letters of support can be sent up until the Labor-HHS Appropriations bill is passed.

Q. How much of the \$20 million for BOLD will go toward Centers of Excellence, versus public health departments or data analysis and timely reporting?

Suggested Response:

- » The final BOLD legislative language did not specify how much of the \$20 million per year will go toward the different activities authorized in the law.
- » CDC will determine how the \$20 million breaks down between the Centers of Excellence, public health departments, or data analysis and timely reporting.

Q. Is the funding in BOLD the same as funding for the Healthy Brain Initiative?

Suggested Response:

- » No, the funding authorized by BOLD is separate from the funds already appropriated for the Healthy Brain Initiative (HBI).
- » The Alzheimer's Association and AIM are requesting \$17 million for HBI funding and \$20 million for BOLD funding in FY20.

Q. How will the Centers of Excellence be determined?

Suggested Response:

- » Once Congress appropriates funding for BOLD in FY20 and CDC receives that funding, it will issue a notice of funding opportunity.
- » After reviewing all applications, CDC will determine which applicants are awarded funding to become regional Alzheimer's and Related Dementias Public Health Centers of Excellence (COEs).
- » While it is up to CDC's discretion to determine the COEs, Congressional preference is that COEs be institutions of higher education, state, local or tribal public health departments, Indian tribes, tribal organizations, associations or other appropriate entities.
- » While certain states may already have existing Alzheimer's centers of excellence, these are not the same as the COEs authorized by BOLD, although CDC could designate one as such.



INCREASE THE COMMITMENT TO ALZHEIMER'S PUBLIC HEALTH RESPONSE TALKING POINTS

Q. How will awards to Public Health Departments be determined?

Suggested Response:

- » Once Congress appropriates funding for BOLD in FY20 and CDC receives that funding, it will issue a notice of funding opportunity.
- » After reviewing all applications, CDC will make the determination on which public health departments will receive funding.
- » CDC will give preference to applications that focus on addressing health disparities, including populations and geographic areas that have the highest prevalence of Alzheimer's disease and related dementias.

Q. How will awards for the data analysis and timely reporting be determined?

Suggested Response:

- » Once Congress appropriates funding for BOLD in FY20 and CDC receives that funding, CDC will decide if it will issue a notice of funding opportunity.
- » CDC has the option on whether or not to issue funding for data analysis and timely reporting because Congress gave that flexibility to CDC.
- » If CDC does issue a notice of funding opportunity, eligible applicants will be public or nonprofit private entities, including institutions of higher education, state, local, and tribal health departments, Indian tribes, and tribal organizations.

NOTE: If your member of Congress or their staff asks you a question you do not know the answer to, that is not a problem. Do not feel any pressure to provide an answer. Simply ask them to contact a member of the Alzheimer's Association's Federal Affairs Team at 202.393.7737. Also indicate the interaction at alzimpact.org so a member of the Federal Affairs team can follow-up with that office.



FACTSHEET

MARCH 2019

alzimpact.org

Improving HOPE for Alzheimer's Act

What is CPT® billing code 99483?

- The bipartisan HOPE for Alzheimer's Act from the 114th Congress would have created a care planning benefit for Medicare beneficiaries with Alzheimer's and other dementias.
- By 2016, more than two-thirds of Congress supported the bill. There were 310 cosponsors in the House of Representatives and 57 in the Senate.
- Since January 1, 2017, the Centers for Medicare and Medicaid Services (CMS)—through CPT® billing code 99483—allows clinicians to be reimbursed for providing a comprehensive set of care planning services to cognitively impaired individuals and their caregivers.

Why is care planning necessary?

- Care planning allows diagnosed individuals and their caregivers to learn about medical and non-medical treatments, clinical trials, and support services available in the community.
- Individuals receiving dementia-specific care planning have fewer hospitalizations, fewer emergency room visits, and better medication management.
- Alzheimer's and related dementias complicate the management of other chronic conditions. Care planning is key to care coordination and managing those other conditions.

How many have received the care planning benefit?

- In 2017, fewer than 1% of seniors living with Alzheimer's disease received the care planning benefit.
- This low rate of usage shows that while care planning results in a higher quality of care and life, patients and providers are generally not aware of the existence of the benefit.
- However, over the course of the year, as more people became aware of the benefit, the utilization of the care planning code increased.

What would the Improving HOPE for Alzheimer's Act (S. 880 / H.R. 1873) do?

- The Improving HOPE for Alzheimer's Act builds on the care planning benefit by addressing the low usage of the benefit.
- The legislation includes provisions of the original HOPE for Alzheimer's Act not implemented by CMS when it created the new billing code.
- Specifically, the Improving HOPE for Alzheimer's Act would require HHS to:
 - Educate clinicians on care planning services available under Medicare and on the care planning billing code.
 - Report on the barriers to individuals receiving care planning services and how the rate of usage can be increased.

IMPROVING HOPE FOR ALZHEIMER'S ACT BACKGROUND

ASK: Please cosponsor the bipartisan Improving HOPE for Alzheimer's Act (S. 880/H.R. 1873), which would help educate clinicians on Alzheimer's and dementia care planning services through Medicare.

Background

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) strongly support the bipartisan Improving HOPE for Alzheimer's Act, which was introduced by Senators Debbie Stabenow (D-MI), Susan Collins (R-ME), Ed Markey (D-MA), Shelley Moore Capito (R-WV), Bob Menendez (D-NJ) in the Senate and Representatives Paul Tonko (D-NY-20), Jackie Walorski (R-IN-2), Earl Blumenauer (D-OR-3), Brett Guthrie (R-KY-2), Maxine Waters (D-CA-43) and Chris Smith (R-NJ-4) in the House.

First introduced in 2009, the bipartisan Health Outcomes, Planning, and Education (HOPE) for Alzheimer's Act was designed to provide comprehensive care planning services following a dementia diagnosis with the services available to both the diagnosed individual and a caregiver. By 2016, when the Centers for Medicare & Medicaid Services (CMS) proposed the new care planning billing code, support for the bill had grown to more than two-thirds of Congress — 310 cosponsors in the House and 57 in the Senate.

As of January 1, 2017, CMS allows for clinicians to be reimbursed for providing care planning to cognitively impaired individuals.

With the code, 99483, clinicians can have the time and resources to provide a comprehensive set of care planning services to people with cognitive impairment and their caregivers.

Making the Case for the Improving HOPE for Alzheimer's Act

For individuals living with Alzheimer's and their caregivers, care planning is essential to learning about medical and non-medical treatments, clinical trials, and support services available in their communities. Access to these services results in a higher quality of life. Thankfully, Medicare covers care planning for individuals with cognitive impairment.

However, patients and medical providers are often not aware of this resource. In the first year the care planning reimbursement was available (2017), fewer than 1% of seniors living with Alzheimer's received the care planning benefit.

In 2015, the Alzheimer's Association convened an expert workgroup to develop timelines and milestones to create an optimal care and support system for those with dementia by 2025. Some of these experts noted that of all the milestones, the most important thing that could be done to improve the care of those

with Alzheimer's was to have care planning after a diagnosis.

The Improving HOPE for Alzheimer's Act would educate clinicians on Alzheimer's and dementia care planning services available through Medicare. This will give clinicians the knowledge and tools to better help their patients and families living with dementia. The legislation also requires the Department of Health and Human Services (HHS) to send a report to Congress on the provider outreach conducted, the utilization rates of the care planning code, and any barriers Medicare beneficiaries encounter when receiving care planning services.

Association Efforts to Promote the Care Planning Code

- » Following CMS's adoption of comprehensive care planning services for dementia, the Alzheimer's Association released the Cognitive Impairment Care Planning Toolkit aimed at providing clinicians with the necessary tools to use the code.
- » While the Association has conducted outreach to clinicians, hospitals, and beneficiaries on this code, we need CMS's help to reach the full range of Medicare and Medicare Advantage providers.

IMPROVING HOPE FOR ALZHEIMER'S ACT BACKGROUND

Importance of Diagnosis and Disclosure

Only about half of those with Alzheimer's have been diagnosed. And of those people who have been diagnosed with Alzheimer's disease, most are not aware of their diagnoses.

- » Among those seniors who have been diagnosed with Alzheimer's, only 33 percent are aware they have the disease.
- » Even when including caregivers, 45 percent — less than half — of those diagnosed with Alzheimer's or their caregivers are aware of their diagnosis.
- » For other types of dementia, the disclosure rate is even lower — only 27 percent.
- » Comparatively, 90 percent or more of those diagnosed with cancer or cardiovascular disease, or their caregivers, are aware of their diagnoses.
- » Studies have found one of the reasons physicians do not diagnose Alzheimer's disease in the first place — or do not disclose a diagnosis once it is made — is because of the lack of time and resources to provide this information and support to patients and caregivers.

Benefits of Comprehensive Care Planning Services

Care planning allows diagnosed individuals and their caregivers to learn about medical and non-medical treatments, clinical trials, and support services available in the community — resulting in a higher quality of life for those with the disease.

- » Individuals receiving dementia-specific care planning have fewer hospitalizations, fewer emergency room visits, and better medication management.
- » Alzheimer's and related dementias complicate the management of other chronic conditions. Care planning is key to care coordination and managing those other conditions.



HOPE For Alzheimer's Act (114th Congress)

The HOPE for Alzheimer's Act from the 114th Congress worked to ensure access to care planning services by:

- » Requiring the Secretary of Health and Human Services (HHS) to conduct provider outreach to inform practitioners about the services under the HOPE benefit; and,
- » Requiring HHS to report to Congress and the Advisory Council on Alzheimer's Research, Care, and Services on barriers beneficiaries face in accessing the services, as well as recommendations to eliminate those barriers.

Additionally, the HOPE for Alzheimer's Act took steps to implement the *National Plan to Address Alzheimer's Disease* by educating and supporting individuals with Alzheimer's disease and other dementias and their families upon diagnosis, educating health care providers, and enhancing assistance for people with Alzheimer's disease and their caregivers to prepare for care needs.

IMPROVING HOPE FOR ALZHEIMER'S ACT TALKING POINTS

Frequently Asked Questions

During the course of your meetings with Members of Congress and their staff, you may encounter some common questions regarding the Improving HOPE for Alzheimer's Act. We have addressed some of these common questions below.

Q. Why do we need the Improving HOPE for Alzheimer's Act if providers are already getting reimbursed for these services?

Suggested Response:

Initial data from CMS shows fewer than 1% of seniors with Alzheimer's received the care planning benefit in 2017. This legislation would give clinicians the knowledge and tools to better help their patients and families living with dementia.

Q. Why is provider outreach necessary?

Suggested Response:

Currently, there are no long-term, effective treatments for Alzheimer's disease. Studies show that one reason doctors don't disclose an Alzheimer's diagnosis to their patients is due to a lack of such treatments. Outreach on the availability and elements of the care planning code will educate providers on what **can** be done after a diagnosis, as well as assure them that they will be reimbursed

for their time. This will improve patient access to these critical services and lead to more patients being informed of their diagnoses.

Q. What does the care planning visit include?

Suggested Response:

To receive reimbursement, clinicians must provide detailed, person-centered care planning. This includes several services: evaluating cognition, function, and neuropsychiatric symptoms; evaluating safety, including driving ability; identifying and assessing the needs of a primary caregiver; developing advance care directives; and planning for palliative care needs. All of these services are ultimately used to develop a detailed care plan — with referrals to community resources — that is shared with the beneficiary and the caregiver.

Q. Is the care planning visit just for Alzheimer's and other dementias?

Suggested Response:

Individuals who are cognitively impaired are eligible to receive the services under CPT code 99483. This includes those who have been diagnosed with Alzheimer's, other dementias, or mild cognitive impairment. It also includes those individuals without a clinical diagnosis who, in the judgment of the clinician, are cognitively impaired.

Q. Who is eligible to bill for the care planning code?

Suggested Response:

Physicians, physician assistants, nurse practitioners, clinical nurse specialists, and certified nurse midwives can currently be reimbursed by CMS.

IMPROVING HOPE FOR ALZHEIMER'S ACT TALKING POINTS

Q. What types of provider education campaigns does CMS conduct?

Suggested Response:

The Centers for Medicare & Medicaid Services is responsible for outreach and education on a variety of topics including Medicare, physician reimbursement, Medicaid, quality of care, and special populations. Outreach and education includes, but is not limited to, fact sheets, toolkits, and webinars.

NOTE: If your member of Congress or their staff asks you a question you do not know the answer to, that is not a problem. Do not feel any pressure to provide an answer. Simply ask them to contact a member of the Alzheimer's Association's Federal Affairs Team at 202.393.7737. Also indicate the interaction at [alzimpact.org](https://www.alzimpact.org) so a member of the Federal Affairs team can follow-up with that office.

Q. How much would the Improving HOPE for Alzheimer's Act cost?

Suggested Response:

The bill has not been scored by the Congressional Budget Office (CBO) and there is no cost estimate for the bill. However, the Alzheimer's Association and AIM will continue to work with the bill's sponsors to determine the impact it would have on federal spending.



FACTSHEET

MARCH 2019

alzimpact.org

Younger-Onset Alzheimer's Disease Act

What is the Older Americans Act?

- The Older Americans Act (OAA) was enacted in 1965 to expand and improve the services available to Americans aged 60 and older.
- The law focuses on delivering home- and community-based programs and supports, including nutritional programs, in-home services, transportation, legal services, elder abuse prevention, and caregiver support.
- OAA services are targeted at older individuals who have the greatest economic and social need, have low income, are members of low-income minority groups, reside in rural areas, have limited English proficiency, or are at risk of entering a nursing home.

The National Plan and the OAA

The Advisory Council on Alzheimer's Research, Care, and Services, which advises the Department of Health and Human Services on updating and implementing the National Alzheimer's Plan, has noted that those with younger-onset Alzheimer's face unique challenges in accessing care and support services.

In 2017, the Advisory Council made a series of recommendations to help address the needs of family caregivers. One of those recommendations was that Congress amend the Older Americans Act (OAA) to ensure that younger individuals living with dementia have access to OAA services.

Are individuals with Alzheimer's covered under the Older Americans Act?

- Yes, many individuals with Alzheimer's and other dementias receive vital assistance and support under the OAA—and many Alzheimer's caregivers receive respite care. These services help maintain an individual's independence. But they are available only if the person with Alzheimer's disease is aged 60 or older.
- Approximately 200,000 individuals in the United States have younger-onset Alzheimer's (sometimes referred to as early-onset Alzheimer's).
- Those with younger-onset Alzheimer's face unique challenges when it comes to family, work, and finances. Also, the stigma associated with younger-onset Alzheimer's can have a significant impact on their well-being and quality of life.
- These individuals who are under 60 are not eligible for OAA programs. Additionally, programs and supports largely do not exist elsewhere because there are relatively few people with younger-onset.

What does the Younger-Onset Alzheimer's Disease Act do?

- The Younger-Onset Alzheimer's Disease Act would make individuals with younger-onset Alzheimer's who are under 60 years old eligible for all OAA programs and services.
- In addition, the Administration on Community Living would submit a report to Congress identifying gaps in services provided to the younger-onset population.

YOUNGER-ONSET ALZHEIMER'S DISEASE ACT OF 2019 BACKGROUND

ASK: Please cosponsor the bipartisan Younger-Onset Alzheimer's Disease Act (H.R. ____/S. ____), which would allow individuals diagnosed with younger-onset Alzheimer's disease (AD) under 60 years of age to be eligible to access programs in the Older Americans Act.

Background

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) strongly support the bipartisan Younger-Onset Alzheimer's Disease Act, which was introduced by Senators Susan Collins (R-ME), Bob Casey (D-PA), Shelley Moore Capito (R-WV) and Doug Jones (D-AL) in the Senate and Representatives Kathleen Rice (D-NY-4), Pete King (R-NY-2), David Trone (D-MD-6), Elise Stefanik (R-NY-21), Maxine Waters (D-CA-43), and Chris Smith (R-NJ-4) in the House.

AIM and the Alzheimer's Association have been strong supporters of this legislation when introduced in the House in previous Congresses.

Making the Case for the Younger-Onset Alzheimer's Disease Act

This legislation would allow individuals living with younger-onset Alzheimer's disease (also known as early-onset) to access supports and services from programs under the Older Americans Act (OAA). Those programs include nutritional services, supportive services, and respite care through the National Family Caregiver Support program.

Additionally, this legislation requires that the Assistant Secretary for Aging submit a report to Congress about Alzheimer's-related programs and program performance, and any gaps in the programs for the needs of individuals living with younger-onset Alzheimer's disease.

What is the Older Americans Act?

The Older Americans Act is a federal law enacted in 1965 that established a federal, state, and local infrastructure to organize and deliver home- and community-based programs and supports including nutritional programs, in-home services, transportation, legal services, and caregiver support. Under current law, to be eligible to access OAA programs, an individual must be over the age of 60. While there is no income or means test, services are targeted to older individuals who have the greatest economic or social need, have low income, are members of low income minority groups, reside in rural areas, have limited English proficiency, or are at risk of institutionalization.

Why is the Younger-Onset Alzheimer's Disease Act needed?

Currently, only Americans over

the age of 60 are eligible for programs through the Older Americans Act. Individuals living with younger-onset face unique challenges when it comes to family, work and finances. They may be parenting young children at home, or still be working as the primary income provider for their family. Due to their young age, they may have more trouble receiving an accurate diagnosis, and even family and friends might question their diagnosis. The stigma associated with younger-onset Alzheimer's can have a significant impact on their well-being and quality of life.

What services would be available to qualifying individuals living with younger-onset AD under the OAA?

The services provided under the OAA are particularly helpful for individuals with younger-onset AD and related dementias who need assistance with activities of daily living. Services also provide vital assistance, support and respite to family caregivers through the National Family Caregiver Program and help to maintain the independence of the individual living with AD.

YOUNGER-ONSET ALZHEIMER'S DISEASE ACT OF 2019 CONGRESSIONAL TALKING POINTS

What does the National Plan to Address Alzheimer's Disease say about OAA?

The Younger-Onset Alzheimer's Disease Act is consistent with the National Plan to Address Alzheimer's Disease. The Advisory Council on Alzheimer's Research, Care, and Services, which is responsible for updating and implementing the Plan, has noted that persons living with younger-onset Alzheimer's face unique challenges in accessing care. In the 2017 National Plan, the Advisory Council recommended that Congress amend the OAA to allow additional services to be provided to younger adults living with dementia.

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Frequently Asked Questions

During the course of your meetings with Members of Congress and their staff, you may encounter some common questions regarding the Younger-Onset Alzheimer's Disease Act. We have addressed some of these common questions below.

What are examples of services provided by the OAA?

Suggested Response:

The OAA programs are divided primarily into four areas: supportive services, nutrition and meals services, disease prevention and health promotion and the National Family Caregiver Support Program. Examples of the services include the long term care Ombudsman program; transportation, outreach, and case management services; and in-home services such as home health aides and chore maintenance.

Why should younger-onset Alzheimer's Disease be included in the OAA when many other diseases also impact people younger than 60?

Suggested Response:

Since 97 percent of all people living with Alzheimer's are age 65 or older, current Alzheimer's support infrastructure focuses exclusively on seniors. As a result, few supportive

services are available to those with younger-onset. With other diseases — like heart disease, diabetes, and even cancer — many people living with them are middle age and there is a large support structure available to them. Those same support structures are not available for the individuals living with younger-onset Alzheimer's disease. Opening up the OAA to people living with younger-onset will allow them access to the existing support structure in the private and non-profit sectors for people under age 60.

How much would the Younger-Onset AD Act cost?

Suggested Response:

The bill has not been scored by the Congressional Budget Office (CBO) and there is no cost estimate for the bill. However, the Alzheimer's Association and AIM will continue to work with the bill's sponsors to determine the impact this bill would have on federal spending.

2019 PUBLIC HEALTH PRIORITIES

Alzheimer's is a growing crisis for our families and the economy. The federal government must address the challenges the disease poses and take bold action to confront this crisis now.

1 Increase the commitment to Alzheimer's research and public health response

An estimated 5.8 million Americans are living with Alzheimer's, and by mid-century, the number of people with the disease is set to nearly triple. Already the most expensive disease in America, with costs reaching an estimated \$290 billion in 2019, these costs are projected to more than quadruple to \$1.1 trillion by mid century.

- » Consistent with the National Plan to Address Alzheimer's, Congress has bolstered support for research funding at the National Institutes of Health (NIH). Nevertheless, current funding levels continue to fall short of the total funding scientists and the U.S. Alzheimer's Advisory Council, created by Congress, believe is needed to meet the goal of finding a treatment or effective treatments for Alzheimer's and other dementias by 2025. Congress must continue its commitment to the fight against Alzheimer's and other dementias by increasing funding for Alzheimer's research by an additional \$350 million in fiscal year 2020.
- » As scientists continue to explore new areas of research for prevention, treatment and a cure, public health plays a critical role in promoting cognitive function and reducing the risk of cognitive decline. The bipartisan Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406) directs the Centers for Disease Control and Prevention (CDC) to strengthen the public health infrastructure across the country by implementing effective Alzheimer's interventions focused on public health issues such as increasing early detection and diagnosis, reducing risk, and preventing avoidable hospitalizations. The BOLD Infrastructure for Alzheimer's Act will accomplish this by establishing Alzheimer's and Related Dementias Public Health Centers of Excellence, providing funding to state, local, and tribal public health departments, and increasing data analysis and timely reporting. To ensure the law's successful implementation, Congress must fully fund the \$20 million authorized in the law for CDC in FY20.

2 Support education and outreach on Alzheimer's care planning services covered under Medicare

For individuals living with Alzheimer's and their caregivers, care planning is essential to learning about medical and non-medical treatments, clinical trials, and support services available in their community. As of January 2017, Medicare reimburses providers for care planning. However, too few providers and patients are aware of this benefit. *The Improving HOPE for Alzheimer's Act* would increase education and outreach to providers about Alzheimer's and dementia care planning services through Medicare and give clinicians the knowledge and the tools to better help their patients and families living with dementia.

3 Improve access to services for individuals with younger-onset Alzheimer's

An estimated 200,000 Americans under the age of 65 are living with Alzheimer's disease. However, because of their young age these individuals are not eligible for support and service programs available to older Americans. *The Younger-Onset Alzheimer's Disease Act of 2019* would allow individuals living with dementia under the age of 60 to access supports and services from programs under the Older Americans Act (OAA). Those programs include nutritional services, supportive services, the National Family Caregiver Support program, and other services that enhance quality of life.

2019 STATE POLICY PRIORITIES

Alzheimer's is a growing public health crisis and state governments must take bold action.

Effectively implementing and updating State Alzheimer's Plans and supporting other policies will reduce the long-term impact of the disease on state budgets, and improve the lives of individuals living with dementia and their family caregivers.

1 Increase public awareness, early detection and diagnosis

Most people who have been diagnosed with Alzheimer's disease are not aware of their diagnosis, and only about half of those with Alzheimer's have been diagnosed. Diagnosis — and disclosure of that diagnosis — is necessary for care planning, which is critical to improving outcomes for the individual. State officials must work to educate health care providers and the public about the importance of early detection and diagnosis, and improve access to and awareness of resources such as the Medicare Annual Wellness visit. Through public health campaigns and data collection via the Behavioral Risk Factor Surveillance System (BRFSS) state governments can further address Alzheimer's in their states.

2 Build a dementia-capable workforce

As our nation ages, more people will develop Alzheimer's and need quality care. However, a shortage of qualified health care workers could jeopardize care for individuals living with Alzheimer's and other dementias. State governments need to implement policies that will create incentives and career pathways to recruit and retain health care professionals, require competency-based dementia training for all involved in the delivery of care, and require training of adult protective services workers and law enforcement about how to recognize and interact with individuals living with dementia.

3 Increase access to home and community-based services

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as is manageable. In fact, 70 percent of people with Alzheimer's live in the community. State governments can reduce long-term costs and increase access to person-centered care in home and community settings including respite and adult day care, regardless of age or financial status through Medicaid and other state-supported programs.

4 Enhance the quality of care in residential settings

Alzheimer's requires a wide range of evolving care and services, and as the disease advances individuals often need to move into residential settings for more specialized care. In fact, among individuals with Alzheimer's, 75 percent will be admitted to a nursing home by the age of 80. It is important that state governments have in place laws to protect people with dementia from improper displacement in residential settings. State governments must also increase Medicaid reimbursement rates to reflect the higher cost of care for individuals living with Alzheimer's and other dementias to ensure residential care settings remain accessible to the population and their needs.

STATE ADVOCACY 101

State advocacy is vital to the work the Association does to meet the care and support needs of individuals living with Alzheimer's and their families. State officials determine regulatory and statutory standards for dementia training; control spending on state respite care dollars; determine spending for state long-term care services; and control Medicaid spending, and in some cases, eligibility and scope of benefits. All of these can have a direct effect on families for whom the Association provides care and support.

Get to Know Your State Legislators

Visit state legislators while they are in their districts. State legislators are generally more accessible than members of the U.S. Congress, and are even more so when session is out and they are at home in their districts. For part-time legislatures, mid-summer, fall, and early winter are ideal times to schedule in-district visits. For full-time legislatures, recesses come at intervals throughout the year.

Join the mailing list for your state legislators. This will allow you to find out about and attend local community events, especially town halls where you can speak publicly on Alzheimer's issues and raise awareness.

Attend Your State Advocacy Day

Your state advocacy day provides an opportunity to increase the Association's presence in the state capital and to build relationships with state policymakers. This event brings advocates together to ask lawmakers to support critical policies impacting those living with Alzheimer's. Learn about your state advocacy day and priority legislation at alzimpact.org/fact/state_center.



Become an Alzheimer's State Champion

By cultivating deep one-on-one relationships with every member of Congress, Alzheimer's Ambassadors have been instrumental in quadrupling federal Alzheimer's research funding since 2011. Alzheimer's State Champions are volunteers working to replicate that successful model in every state by developing multifaceted, year-round relationships with targeted state officials.

Alzheimer's State Champions attend their state advocacy day and have at least two more in person interactions with their assigned legislator each year. They also stay in touch year-round through social media posts, letters-to-the-editor and other personal communications with their legislators. You can be the voice for thousands of families living with dementia in your community and can help ensure that our leaders stand up for the vital programs and services that they rely on.

Visit alzimpact.org/volunteer to learn more.



SEVEN WAYS TO SAY THANK YOU

Frequent thank yous, particularly in public settings, are the key to building lasting and mutually beneficial relationships with your legislators. Thank them for meeting. Then thank them for agreeing to your asks. There's always something to thank them for.



Be Social

Ask for a photo and promptly post on social networks, “tagging” or “mentioning” your legislator.



Handwritten Notes

ALL attendees should send cards to each legislator/staffer they met. Add a personal story and/or photo!



Coffees & Walk

Work with chapter staff to plan a “Coffee with Congress” event or invite your legislators to the Walk to End Alzheimer’s.



Local Media

Work with chapter staff to submit a letter-to-the-editor or write something for your company/community newsletter.



District Meeting

The second district meeting of our District-Forum-District program is your chance to say thank you in person.



Report Your Meetings

Please remember to report each meeting at alzimpact.org/action so our staff can follow-up as well!



Follow-up Email

One attendee should send a prompt follow-up email with requested information, a summary and your thanks.



ABAM & TLD

Join drop-by visits during June’s Alzheimer’s & Brain Awareness Month or invite legislators/staff to attend events on The Longest Day.

ADVOCACY ENGAGEMENT PLANNER

Take a moment to plan your advocacy over the next few months. Consider the follow-up activities and local events that provide opportunities to engage elected officials and fellow advocates.

APR

MAY

JUN

JUL

AUG

SEP

OCT

NOV

DEC

TAKE THE NEXT STEP IN ALZHEIMER'S ADVOCACY

Could you be an Alzheimer's State Champion? Know somebody with skills and interests to round out your Alzheimer's Congressional Team? Visit alzimpact.org/volunteer to learn more and apply online.



Join Our Advocacy Team

With help from advocates like you, we've passed critical legislation and quadrupled federal research funding since 2011. But our work isn't done and we need dedicated advocates like you to build on this success in Congress and in every state capital.

We'll train you to advocate in a variety of ways, some of which take just an hour or two every few months. Whatever your experience and availability, we're eager to have you on our advocacy team!

Will you join us?

Alzheimer's State Champions cultivate multifaceted, year-round relationships with targeted state officials.

Alzheimer's Ambassadors develop deep, one-to-one relationships with their assigned members of Congress.

Alzheimer's Congressional Team members bring their own unique stories, relationships and skills to complement the work of an Ambassador.

Alzheimer's Advocacy Volunteer Application

Please select the advocacy activities that interest you. Depending on your interests, skills and location, we'll reach out to discuss an Alzheimer's State Champion, ACT member and/or Ambassador role that makes sense for you.

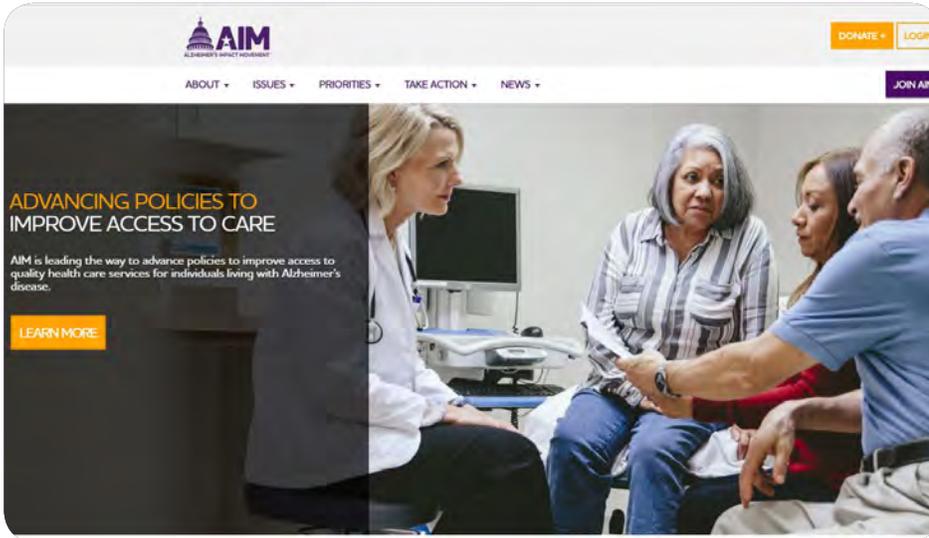
- Meet with elected officials**
Lend your voice in district offices, state capitols and at the Advocacy Forum in D.C.
- Raise awareness through local media**
Partner with chapter staff to draft letters-to-the-editor and pitch stories.
- Spark social media conversations**
Engage online, inspire novices, recruit new advocates and monitor legislator accounts to comment/tweet.
- Coordinate events and volunteers**
Recruit and mobilize volunteers, organize events and work with event committees.
- Support the Alzheimer's Impact Movement (AIM)**
Promote AIM membership. Engage with campaign staff, donors and events.
- Call on your connections**
Use your relationships with legislators and partner organizations to make calls at key moments.
- Share your unique perspective as a...**

(person with dementia, researcher, young person, etc).

Apply online today:

alzimpact.org/volunteer

GET CONNECTED AT ALZIMPACT.ORG



Your Gateway to Alzheimer's Advocacy



Learn

Find fact sheets, guides, sample materials and upcoming events in your personalized "My Advocacy Resources" section. alzimpact.org/resources



Connect

Learn about your legislators and connect with your Alzheimer's Congressional Team. alzimpact.org/congress/search



Act

Take action on AIM/Alzheimer's Association federal policy priorities and get signed-up for mobile alerts. alzimpact.org/take_action/act_now



Report

From your Forum meeting to a simple tweet, please report all your legislative interactions so your team and our staff are in the loop. alzimpact.org/action

Download your AIM Power of Ten Referral Cards



Power of Ten

Have your friends joined AIM? Take the Power of Ten Challenge!

The Alzheimer's Impact Movement (AIM) is the advocacy arm of the Alzheimer's Association. With help from AIM and its members, research funding has more than quadrupled since 2011!

Persuading 10 friends to join AIM for just \$20 is one of the best ways you can influence how leaders in Washington and in state capitals address the Alzheimer's crisis.

List 10 friends you could ask to join AIM:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Find your personal Power of Ten Referral code, instructions, incentives and other tools in the Power of Ten Challenge Kit, available at: alzimpact.org/recruit.

LETTER TO THE EDITOR TALKING POINTS

The following talking points (TPs) can be used to help you write a personal and compelling letter to your editor for placement in your local paper, either **before or immediately following** the March 31 – April 2 Advocacy Forum. As always, please coordinate your efforts with your local chapter to avoid duplication. *NOTE: Please check to see if your member was a cosponsor of the BOLD Infrastructure for Alzheimer's Act; if so, adjust language accordingly to acknowledge and commend their support before submitting.

TPs to COMPEL EDITORS IN OPENING (choose or create your own)

- » There are more than 5 million Americans living with Alzheimer's, including [NUMBER] here in [STATE]. I am one of those Americans.
- » More than 16 million Americans provide unpaid care for loved ones with Alzheimer's or other dementias, including [NUMBER] here in [STATE]. I am one of those Americans.
- » There are more than 5 million Americans living with Alzheimer's disease and more than 16 million unpaid Alzheimer's caregivers. Among them are the [NUMBER] living in [STATE] and their [NUMBER] caregivers. As an Alzheimer's advocate, it is my honor to represent them.

TPs to SUMMARIZE YOUR ADVOCATE STORY & 2019 ADVOCACY GOALS

- » I just returned from Washington, D.C. for the Alzheimer's Impact Movement Advocacy Forum convening more than [ESTIMATED ATTENDEE TOTAL] Alzheimer's advocates from across the nation on Capitol Hill.
- » While on Capitol Hill, I met with [[MEMBER TITLE/S (Rep./Sen.) + FULL NAME/S], [PARTY

APPREVIATION] - [AP STYLE STATE ABBREVIATION]

ex. Rep. Earl Blumenauer, D-Oregon; Sen. Mitt Romney, R-Utah]] to explain why Congress must continue to prioritize legislative action against Alzheimer's.

- » I asked [MEMBER TITLE/S, LAST NAME/S] to support legislation that will provide researchers, healthcare professionals, caregivers and individuals with the educational tools and resources necessary to meaningfully combat Alzheimer's disease.
- » Specifically, I urged them to support funding for increased Alzheimer's disease research at the National Institutes of Health (NIH), as well as funding to implement the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (P.L. 115-406) which Congress passed into law late last year.

TPs to MAKE YOUR CASE WITH STRONG STATISTICS

(choose a few or highlight others)

- » Alzheimer's is the 6th leading cause of death in the United States.
- » Barring increased research funding to uncover and develop medical breakthroughs needed to prevent, slow or cure the disease, the number of people aged 65 and older with

Alzheimer's or other dementias could grow from 5.6 million to 13.8 million by 2050, according to the Alzheimer's Association **2019 Alzheimer's Disease Facts and Figures report.**

- » Alzheimer's is not only the 6th leading cause of death in the country, it also ranks as America's most expensive disease, with total costs nationwide on track to surpass a quarter of a trillion dollars (\$290 billion) in 2019, an increase of nearly \$13 billion just from last year.
- » Alzheimer's costs taxpayers more than \$22 million dollars every hour.
- » It is only through adequately funding research and policies like the BOLD Infrastructure for Alzheimer's Act that we can meet the goal of the National Plan to Address Alzheimer's Disease to prevent and effectively treat Alzheimer's by 2025.

TPs to CONCLUDE WITH CALL TO ACTION

- » Please join me in urging [MEMBER TITLE/S, LAST NAME/S] to invest in policies that address Alzheimer's disease as the national public health crisis it is.
- » To learn more about this disease and how you can join the fight to end Alzheimer's, visit **alzimpact.org.**

LETTER TO THE EDITOR WRITING TIPS

Tips for Writing Printable Letters to the Editor

Writing a letter to the editor (LTE) is an effective way to call attention to an issue. **Below are tips for writing an LTE that gets published and read.**

1. KNOW THE RULES.

Do your homework about how to submit a letter and what information you need to include in order to get it printed. Usually this information is located on the opinion page of the newspaper or you can find it on the newspaper's website. Pay attention to word count submission requirements and instructions on the best way to submit the document.

2. MAKE IT RELEVANT.

Following these tips, we have provided LTE message points and blocks of suggested text for your use. Tailor and modify them with your personal details so that it becomes a piece reflecting your authentic voice, while always staying consistent with Alzheimer's Association messaging.

3. KEEP IT BRIEF.

Most letters to the editor should be 200 words or less. Any longer and it may not get printed.

4. HIGHLIGHT LOCAL STATISTICS.

Include relevant local and/or state information —

the number of people with Alzheimer's in your state, the projected number of individuals age 65 or older with Alzheimer's in your state, mortality data, costs related to caregiving in your state, etc. This information localizes the impact and can increase interest in publishing the letter. Alzheimer's-related information from your state can be found in the *Alzheimer's Association 2019 Facts and Figures report*.

5. BE CLEAR.

While you may be an expert on this issue, not everyone knows about it. Avoid jargon or acronyms that are not common. Have someone proofread the document before you send it.

6. USE LANGUAGE CUES TO EMPHASIZE YOUR POINT.

For instance, conclude with "The important thing is..."

7. DON'T OVERLOOK THE SMALLER OUTLETS,

like neighborhood weeklies or local newspapers, websites and blogs. These media

outlets are intensely important within the area they're published and they also may have more room for letters than a bigger publication.

8. INCLUDE A CALL-TO-ACTION OR SOLUTION.

Include information about what people can do to help. For example: "Visit alz.org or alzimpact.org to learn more about this year's Alzheimer's Association Facts and Figures report," or "Visit alz.org or alzimpact.org to get involved with the fight against Alzheimer's."

9. BE PASSIONATE, BUT NOT POISONOUS.

We appreciate your passion about the issue (and so will the editors), but we also implore you to be respectful in your commentary.

10. CONSIDER THE ONLINE EDITORIAL PAGE.

Many newspapers are moving to just online versions or have an extended letters section in their online versions. Research your local news media outlets to see if there is a way to be included in these sections as well.

PHONE2ACTION ALERT

SIGN UP TO ACT

Text **AIM** to
52886
to join the fight



Message and Data Rates May Apply. Reply STOP to optout, HELP for help.



ALZHEIMER'S ASSOCIATION ALZHEIMER'S IMPACT MOVEMENT

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