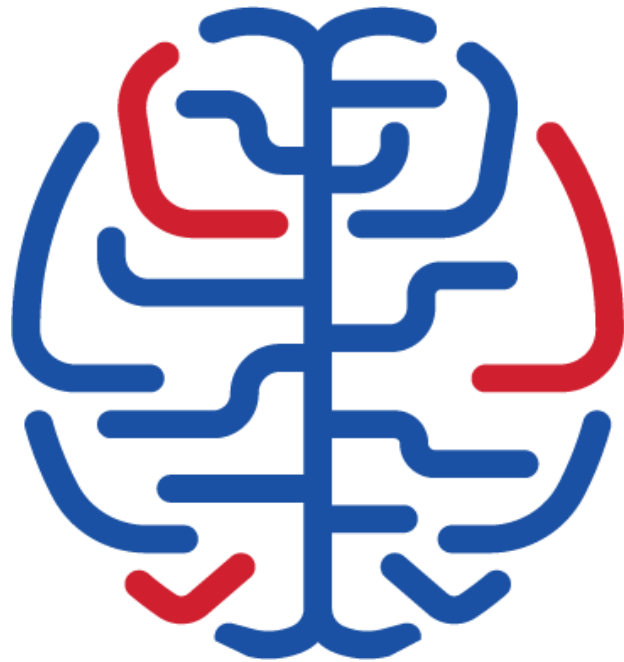


UsAgainstAlzheimer's

Virtual Advocacy Toolkit



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What is Advocacy?

Simply put, advocacy is having your voice heard. Traditionally, constituents advocated through in-person meetings. However, after Capitol Hill began restricting visitors due to COVID-19, advocates quickly pivoted to a virtual environment, calling, video chatting, and emailing lawmakers and their staff with calls to action. This document serves as your toolkit for virtual constituent advocacy.

Relationship Building

Relationships are the cornerstone of effective advocacy in Washington. Fortunately, you have the most important relationship of all — that of a constituent. Even so, you will need to build rapport with Hill and District staff, and that takes time. Building relationships starts with requesting a meeting, and grows the more you stay in contact with staff. Your representative may not take action immediately, and that's ok. It gives you the opportunity to follow up and foster that relationship further, building trust and credibility on the issue. You should seek ongoing opportunities to be a resource for staff. Periodic emails, attending virtual town halls, and grassroots advocacy, such as letter-writing campaigns, exemplify these opportunities. Over time, the staff may start to contact you about legislation and other issues.

Education

Hill staff often have a wide range of issues in their portfolio. Education makes up the bulk of advocacy. You may need to take the time to teach staff about Alzheimer's policy needs. Some staffers may be more knowledgeable than others. When speaking with staff, you should gauge their familiarity with the subject by asking questions like "how familiar are you with Alzheimer's disease" or "do you have family members with Alzheimer's?"

Issue Advocacy

Issue advocacy focuses on policy, not politics. This is an important distinction for an advocate to understand because you want to avoid politics when talking with Hill staff. When advocating for legislation, you should stick to the policy and your personal experiences with the issue. Alzheimer's is not a partisan issue.

Advocacy Mechanisms

In 2020, hand waves over webcams have replaced handshakes. However, virtual advocacy has opened the door to several alternatives.

Phone

Nowadays, because of COVID-19, phone calls are the preferred medium for meetings with Hill staff. Many Hill offices do not allow staff to meet via video conference due to privacy and security concerns. We recommend that you ask the staff about their preferred mode of communication. You may need to provide the staff with your cell phone or a conference line. If you do not have a conference line, contact UsAgainstAlzheimer's staff at summit@usagainstalzheimer.org and they will provide you with a line.

Video Conference

Unlike staff, Members of Congress may meet with you over a video conferencing platform like Zoom. If you choose to go this route, use a trusted platform like Zoom, Google Meet, or Skype. Carefully evaluate the pros and cons of using a waiting room feature. While this feature may be good for security purposes, it can cause confusion and delay the meeting. Some offices prefer to host the video conference, whereas others do not. You should be prepared to provide a video conference (e.g. Google Meet is free if asked).

Social Media

Social media has become a useful tool to promote your advocacy remotely. In fact, according to the Congressional Management Foundation, 75% of Hill staff believe social media enables more meaningful constituent interactions. If using social media, take the time to tag your Member of Congress on social media and let them know the important issues to you.

Suggested Posts

- Detecting Alzheimer's sooner is critical for families to seek help. @Congressman, the CHANGE Act (HR. 2283/S. 1126) would allow us to detect Alzheimer's sooner.
- Paid family leave for caregivers can alleviate much of the burden when a loved one gets diagnosed with Alzheimer's.. @Congressman, please support paid family leave for caregivers.

Interacting with Hill Offices

Members of Congress genuinely care about constituent feedback. All you have to do to have a successful meeting is follow a few simple guidelines.

How to Find your Members of Congress

The simplest way to find your Members of Congress is to visit the website for either the [House of Representatives](#) or the [Senate](#). If on the House website, the site will prompt you to enter your zip code. If your zip code has more than one Representative, you may be required to enter your street address later. For the Senate, simply select your state from the dropdown menu available at the top of the page.

How to Find the Staffer for your Member of Congress

The best way to find out who you should email in your Member's office is to visit this [spreadsheet](#) which has every health hill staffer and their email listed. If your Member of Congress does not appear in this spreadsheet, it likely means they do not have a registered Health staffer. In that case, contact UsAgainstAlzheimer's staff at summit@usagainstalzheimers.org and we will provide you a different point of contact.

Hill Meetings

How to Set up a Meeting

Setting up a Hill meeting is easy! It starts with an email to the staffer and/or the Scheduler for your Member of Congress. We recommend using the following script for your initial outreach.

Email Script to Request a Meeting.

Subject Line: Constituent Request to Meet about Alzheimer's Legislation

Body: Dear [[FIRST NAME]],

I live in [[TOWN]] and I was hoping to schedule a time we can talk over the phone about some important topics regarding Alzheimer's — namely, the CHANGE Act (HR. 2283/S. 1126) and paid family leave for caregivers of people with Alzheimer's.

These issues are important to me because I am a [[CAREGIVER, ADVOCATE, PHYSICIAN OR RESEARCHER]],

I am available to meet with you the following days and times [[]]. Please let me know your availability so we can discuss these topics further.

Thank you,

[[YOUR NAME]]

Following-up on Your Outreach

Sometimes Hill staff won't reply right away, and may need a second nudge. In this case, we recommend altering the first paragraph of the previous script accordingly:

Subject Line: Following-up on Constituent Request to Meet about Alzheimer's Legislation

Body: Dear [[FIRST NAME]],

I am just following up on my previous email. I am still hoping to schedule a time we can talk over the phone about some important topics regarding Alzheimer's — namely, the CHANGE Act (HR. 2283/S. 1126) and paid family leave for caregivers of people with Alzheimer's.

I am available to meet with you the following days and times [[]]. Please let me know your availability so we can discuss these topics further.

Thank you,

[[YOUR NAME]]

Meeting Preparation

You need to thoroughly prepare for your meeting. To get ready, you should research your Member of Congress as described in this section. You should also take the time to review your talking points.

Preparing for every possible question you might receive is impossible. That's ok. You're not expected to be a policy expert. If you're asked a question to which you don't know the answer, tell the staffer that you aren't sure of the answer and will get back to them. Forward that question to UsAgainstAlzheimer's staff and we will follow up with the Hill staff.

Researching Your Member of Congress

Committee Assignments

After a Member of Congress introduces legislation, the bill is referred to a committee of jurisdiction. Committee members and their staff are typically experts in areas of jurisdiction. Knowing which Members sit on which committees is critical to understanding how influential or knowledgeable the Member and staff may be on your issue. You find the committee memberships by clicking any of the links below.

The CHANGE Act, for example, is before the [Senate Finance Committee](#) and is before both the [House Ways and Means](#) and the [House Energy and Commerce](#) Committees.

Paid family leave issues are usually heard before the [Senate Health, Education, Labor and Pensions \(HELP\) Committee](#) and the [House Committee on Education and Labor](#).

Biographical Information

Learn about your Member's background. First you should look at the official biography that the Member of Congress has on his or her website. These websites are usually the member's lastname, followed by the chamber, and .gov (i.e. [pallone.house.gov](#) or [alexander.senate.gov](#)).

After reading their official biographies, we recommend you enter your Member's name into a search engine to see what else might be pertinent. You should look for things you have in common, like whether you went to the same school, grew up in the same town, or have a similar professional background.

Past Support Alzheimer's Legislation

It's important to know if your Senator or House member has already cosponsored the CHANGE Act which impacts the cosponsor request. Also, past support for Alzheimer's legislation is the best indicator for future support. You should visit [www.congress.gov](#), and enter in the following bill numbers and check the lists of cosponsors to see if your Member has taken action before.

- **CHANGE Act:** 116th Congress, HR. 2283/S. 1126.
- **Improving HOPE for Alzheimer’s Act:** 116th Congress, HR. 1873/S. 880.

Meeting Structure/Logistics

Usually, meetings will follow a four-part structure:

1. Introductions

- First and foremost, thank the staff for his or her time.
- In about 2 minutes introduce yourself and your personal story with Alzheimer’s.
- Indicate where you live.
- Give the staff the chance to introduce themselves as well.

2. Discussion on the issues

- In about 5 minutes per issue, explain the talking points for both key issues.

3. Questions

- Ask the staff if they have any questions. Answer the questions you can, and pass along the ones you can’t to UsA2 Staff.

4. Closing

- Review any outstanding questions and restate the action items that came up during the meeting.
- Provide additional contact information if necessary.
- Thank the staff again for his or her time.

Example Meeting Script

Staff: “Hi, I’m Jane Doe with Congressman Jim Smith, it’s nice to meet you.”

You: “Hi, Jane! Nice to meet you, as well, and thanks for taking the time to talk today. I live in Springfield, and I appreciate what the Congressman has done for the district. [[PROVIDE YOUR STORY]] This is why I would like to talk about the CHANGE Act (HR. 2283/S. 1126). Passing this bill would help countless families get the help they need sooner. The bill directs the Centers for Medicare and Medicaid Services (CMS) in a Medicare Annual Wellness Visit to require use of cognitive impairment detection tools that have been identified by the National Institutes of Health (NIH). Use of these tools will incentivize clinicians to detect and diagnose Alzheimer’s sooner. The bill also requires CMS to lead, create, adopt, and recognize quality measures and incentives to promote detection and diagnosis of Alzheimer’s as well as promote appropriate care planning services, including potential clinical trial participation.

Staff: That's helpful, thanks! Would you like to talk about anything else?

You: Yes, paid family leave for caregivers. A recent poll of usaz's online Alzheimer's community found that nearly two-thirds of dementia caregivers think Congress should make paid family leave a priority. Any paid family leave policy must include caregivers for loved ones with serious, chronic health concerns, provide relief for at-home caregivers, contain meaningful income replacement benefits and job protection, and include workplace policies that allow caregivers the flexibility to accompany their loved ones to medical visits, including clinical research visits.

Staff: I understand that, I'll definitely talk to my boss about supporting that in legislation.

You: Well, that's about all I wanted to cover today, but I hope to keep in touch. Do you have any questions for me? Please let me know if there's anything I can do to help you with these issues and again please consider supporting the two items we discussed. Thanks again for your time.

Staff: Definitely! Please contact me anytime.

Virtual Meeting Checklist

- Conference line, cell phone, or video conference information sent to staff via calendar notice
- Attend USA2 Webinar
- Talking points/script in front of you during the meeting
- Hill Materials sent to staff prior to meeting
- Have fun!

Talking Points

The CHANGE Act

- Alzheimer's is the sixth leading cause of death in America making it the biggest ongoing healthcare crisis in our nation — economically, socially, and medically.
- The economic burden of Alzheimer's is close to \$200 billion annually; and rising.
- The CHANGE Act (HR. 2283/S. 1126) is bipartisan and bicameral legislation that encourages early detection, diagnosis, and access to interventions.
- The bill directs the Centers for Medicare and Medicaid Services (CMS) to require use of cognitive impairment detection tools that have been identified by the National Institutes of Health (NIH).
 - Use of these tools will incentivize clinicians to detect Alzheimer's sooner and refer patients for diagnosis and treatment..

- The bill also requires CMS to lead, create, adopt, and recognize quality measures and incentives to promote detection and diagnosis of Alzheimer's as well as promote appropriate care planning services, including potential clinical trial participation.

Paid Leave

- A poll conducted by UsA2 found that nearly two-thirds of dementia caregivers think Congress should make paid family and medical leave a priority.
- Congress should support a paid family leave policy that covers the spectrum of caregiving, from children to older adults.
- A paid family leave policy must:
 - Include caregivers for loved one with serious chronic health conditions.
 - Provide relief for at-home caregivers.
 - Contain meaningful income replacement benefits and job protections.
 - Include workplace policies that allow caregivers the flexibility to accompany their loved ones, including clinical research visits.

Following up After a Meeting

The most important thing to do after a meeting is to follow-up and thank the staffer for his/her time and if enough time has passed ask if they have taken the action requested. Use the script below:

Script for Thank you Email

Subject Line: Thanks for the meeting

Body: Dear [[FIRST NAME]],

Thanks for taking the time to talk about the CHANGE Act (HR. 2283/S. 1126) and paid family leave for caregivers of people with Alzheimer's. I really appreciate the chance to meet with you and share my story, and I hope to stay in touch. Please let me know if your boss has decided to support the CHANGE Act and/or family lead legislation and if I can be a resource to you in any way in the future.

Thank you,

[[YOUR NAME]]

Closing the loop

Let UsA2 staff know how the meeting went and whether follow-up is needed.

Capitol Hill Etiquette

1. Be on time.
 - a. Time is limited. You will likely have between 10 and 25 minutes for your call.
2. Be understanding of the staff.
 - a. Understand the context they work in now. They speak to constituents all day, so be mindful of their schedule. If more than one advocate is on a call at the same time, quickly introduce yourself and your experience with Alzheimer's. Hit your key messages first, and emphasize COVID where appropriate.
3. Be prepared.
 - a. Have a specific Call-to-Action or Ask. Practice it, especially if multiple constituents join a meeting. Determine in advance who takes specific roles.
 - b. If there are multiple constituents on the call, decide beforehand who will lead the conversation.
4. Be polite, courteous, calm, and professional.
 - a. Start each meeting by thanking the staff for their time. Staff are just as important as the Member of Congress for whom they work.
 - b. Listen carefully to what they have to say, don't interrupt, and be flexible.
5. Do not reference politics.
 - a. Do not talk about politics or political contributions. These meetings are about policy and should stay in that arena. Alzheimer's is a nonpartisan issue.