



Advocacy Resources for Family Caregivers

Families, not institutions or other paid providers, provide the majority of care for people with chronic illness and/or disabilities. These families are the primary providers of long-term care, care that often goes beyond what they can do when they may also be raising their own families, have jobs, and/or live far away. Caring for someone with Alzheimer's or Parkinson's disease, stroke, traumatic brain injury, or other long-term conditions can be challenging, especially if it is difficult to locate needed information, services, and/or respite.

Families have first-hand experience with community agencies, providing round-the-clock care, and the financial hardships often associated with caring for a loved one. This personal experience puts these families in a unique position to act as advocates; helping elected officials charged with development of public policy and funding priorities to understand the needs of family caregivers.

This resource document offers families tips and resources to help them get involved in local, state, or federal advocacy efforts.

How Families Can Help Effect Change

Elected officials rely on communications from their constituents to keep them informed and to know where their constituents stand on critical issues. There are many different ways family caregivers can connect with the policy makers who represent them. How you choose to connect is less important than making the decision to connect. Find a method below that works for you.

Methods & Tips for Communicating with Your Legislators

Advocate Phone Calls

- When calling about a particular issue, always be ready to provide basic information, such as a bill number and title, if you are asking for support for a specific bill. This information is often available to you through action alerts provided by the Greater Wisconsin Agency on Aging Resources, Inc. (GWAAR), the Wisconsin Aging Advocacy Network (WAAN), AARP Wisconsin, the Alzheimer's Association Wisconsin Chapter, or other state and federal advocacy partners. Be prepared to explain your position in your own words. Remember to ensure the message you are delivering is your own, not anyone else's. You can call any Member of Congress using the Capitol Switchboard—202-224-3121 (Senate)/202-225-3121 (House). You can also find phone numbers for your federal legislators at: www.house.gov (U.S. Representatives) and www.senate.gov (U.S. Senate). There is also a complete list of contact information on the GWAAR website at: [Wisconsin Members of the 117th Congress](http://www.gwaar.org/wisconsin-members-of-the-117th-congress). To contact your state legislators go to: <https://docs.legis.wisconsin.gov/2021/legislators/senate> (State Senators) and here <https://docs.legis.wisconsin.gov/2021/legislators/assembly> (State Representatives). To find out

who represents you go to: <https://legis.wisconsin.gov/> and enter your home address in the box under “Who Are My Legislators?”. The following tactics will help you put together a winning call!

- Identify yourself as a constituent and the issue about which you are calling.
- Keep your call brief and to the point.
- Express your opinion and the reasons you feel the way you do.
- Be specific about what you wish the official to do.
- Be courteous and understanding of reasonable differences of opinion.
- Always ask for a response.

Format for Advocate Letters

The following format is recommended to ensure advocates’ letters effectively communicate their message. Letters should be legibly written, typed, or sent by email. Try to keep your communication to one page.

First Paragraph

- Identify yourself as someone who is a constituent.
- Identify the reason for writing and the issue(s) you wish to address. Highlight any relevant experience/expertise you have related to the issue(s).
- Include any related information about the issue(s) (i.e., who is affected, how are they affected, how many are impacted).

Second Paragraph

- State your views on the issue in your own words.
- Include a statement about the impact specific policies or funding are having on you and/or those you are caring for (include a bill number/title, if applicable).

Third Paragraph

- Clearly state what you would like the official to do. Give a reason for your position. A personal experience is powerful in establishing your case.

Closing Paragraph

- Thank the official for his or her attention to this matter and offer to be available for any questions.
- Include your name and address on the letter and the envelope or within your e-mail message. Legislators will give the most attention to letters from their own constituents.
- There are times when a bill is to be heard in a particular committee/subcommittee that you may need to communicate with the committee leadership (Chair/Co-chair). In these circumstances, explain that while you are not a member of the legislator’s district, you hope the needs of all citizens will be considered in reaching a decision on the bill. Note: Time the sending of your letter so it is received prior to any scheduled vote on the bill.

Social Media Approaches

- Like/Follow your legislators on Facebook
- Comment (positively) on their blogs
- Follow legislators on Twitter

- Use Linked-In to find potential partners in your efforts to reach out (search on the legislator's name to see who already knows them)
- Subscribe to legislators' YouTube channels
- All these approaches will help you learn more about the elected officials you're seeking to influence. With this background information you'll be able to craft messages that resonate.

Effective Meetings

Plan your visit carefully. Decide in advance what you hope to achieve and who you need to meet with to achieve your goal. Pay close attention to the legislative calendars in Wisconsin or in Washington, DC. For example, when Congress is in session, members are in Washington; during recess, most members are in their home districts or states.

Make an Appointment

- Make sure to plan ahead, as legislators' schedules fill up weeks in advance. When attempting to meet with an elected or appointed official, begin by sending a written request via email or letter to the appointment secretary or scheduler. Because your request may go through many hands, they need something in writing; and who better to explain what you want in a meeting than you? Explain the purpose of your meeting and your connection to the elected official's district. It is easier for staff to arrange a meeting if they know what you wish to discuss and your relationship to the area or interests represented by the official.
- If you do call the office, make sure to ask for the scheduler. Introduce yourself, explain the nature of your visit (issue/bill), let the scheduler know who will be involved in the visit (provide names), how long of a visit are you requesting (15-30 min.), and when you would like to visit. You may be asked to follow up with a written request.

Understand Your Issue

- Prepare for the meeting in advance. Bring copies of any fact sheets and position papers that help explain or support your position (you may find these attached to action alerts from advocacy partners) and be prepared to leave these materials with the official and his or her staff.

Be Prompt and Patient

- When it is time to meet with an official, be punctual, patient, and flexible. Elected officials have hectic schedules, so it's common for a meeting to be interrupted, delayed, or canceled. If the official is unable to have a full discussion, continue your meeting with the staff and make sure to leave any fact sheet or handout related to the issue.
- Legislators are busy and their schedules often change at the last minute. Please do not be offended if you find you are meeting with a member of the legislator's staff. An effective meeting can be held with a legislative staff aide. These staff members are often responsible for helping to craft legislation and they will brief the legislator (or their supervisor) about your concerns.

Be Direct and Personal

- Be clear on what you are requesting and ask directly for his or her support. Describe the *personal* impact of policy issues on you, your family or loved one, community, and the state or region.

The Five-Minute Rule

- While meetings are generally scheduled for 15 – 30 minutes, you must be prepared to deliver your message powerfully and effectively in no more than five minutes. With the possible interference of votes, schedules running late, and last-minute emergencies, which may be all the time you'll have.

Summarize the Meeting

- If any commitments are made, summarize them up at the end of the meeting to ensure that everyone understands what has been decided. Keep future developments in mind by offering to provide further information. Before the meeting ends, confirm who on the official's staff will be handling these issues.

What to Leave Behind

- The key to leaving behind effective information is to make it useful, short, and easy for the staff person to keep. Consult your advocacy partners for any leave behind materials.

Townhall/Community meeting

One of the most effective ways to gain the attention of elected officials and their staff is to attend a town hall or community meeting. Members of Congress arrange these meetings to hear from people in their districts and states. State legislators also often hold these meetings in their districts. Town hall or community meetings occur whenever legislators are home, such as on weekends or during district work periods. You can learn more about the congressional schedule here: <http://www.house.gov/legislative/>. To learn more about the state legislature's schedule go here: https://docs.legis.wisconsin.gov/2021/related/session_calendar/calendar. You may find some town hall/office hours listings here: <http://townhallproject.com>. To find out about the meetings in your area, you can call your legislators' offices. Signing up for your legislators e-newsletters or following them on social media is also a great way to learn about upcoming meetings in the district.

What happens during a town hall meeting?

- Usually, the elected official makes some opening remarks and introduces his or her staff. There may be local leaders in attendance as well who wish to make remarks. Then, the floor is opened for comments from the audience – that's where you come in!

Before you attend a town hall/community meeting...

- Take a moment to learn a little about the legislator(s) hosting the event. You can learn about bills they've introduced and the specifics of their district through the U.S. Congress website at <https://www.congress.gov/>, as well as individual member sites accessible through www.house.gov and www.senate.gov. You can learn more about state legislation here: <https://legis.wisconsin.gov/> and about our state legislators here: <https://docs.legis.wisconsin.gov/2021/legislators/senate> and here: <https://docs.legis.wisconsin.gov/2021/legislators/assembly>.
- Some of the most important interactions at a townhall often occur before or after the meeting. It is always a good idea to find a few minutes before or after the event to speak directly with the legislator or staff person. This offers a wonderful opportunity to invite them to visit (with your local agency's permission of course) the local aging unit/Aging & Disability Resource Center (ADRC), senior/community center, or memory café you may be working with. If you attend more than one town hall/community meeting, they'll see you're serious about making a difference, which always makes a good impression.

Site Visit

- Work with the director/staff from the local agency you are working with to determine what you want to highlight. Be sure to consider how what you're showing a policy maker connects to the issue you want them to think about. For example, if you are trying to make the case for why you need more funding for a program, it's a good idea to show them the need, as well as how funds have been spent in the past, the number of people who received the service, and the value of the services provided (this is a great place for you to insert your family caregiver story/experience).
- Decide who to invite. There are a number of factors involved in this decision. Is this a visit for staff or officials or a combination? Be sure to invite the right elected officials who are responsible for the policies and funding of the program you are highlighting. Is the program local, state, or federally funded?
- The local director/staff should develop the invitation. The one-page letter of invitation should be directed to the official's scheduler or executive assistant, usually in the district office (for federal legislators). Call about one week after sending the first request to ensure it has been received and to answer any questions.
- For any site visit, the director/staff will need to address the coordination, including:
 - Transportation: How will the local official get to and from the event?
 - Time: How much time can the official commit to the event? Do not try to cram too much into a short visit. Make sure to hit the highlights.
 - Weather: Obviously, you can't control the weather, but you can be prepared for all possibilities. Make sure you have enough umbrellas, bug spray, or whatever you'll need to make the visit pleasant for everyone.
- Think carefully about who from the program can help to make the case. Keep the total number of people to no more than five. Following are some types to consider:
 - Staff: Officials enjoy speaking with the people who perform the day-to-day tasks of the program or service.
 - Beneficiaries: "Real people" who already benefit from your work or will in the future can speak with conviction and enthusiasm about the services (family caregivers "lived" experience).
 - Funders/Supporters: Those who have invested in your good works or who are leaders in the community can help to demonstrate support for the program/service.
- Recording the Event & When to invite the media - Some things to consider, include:
 - Photographer - Consider hiring a photographer or have someone an agency staff member designated to take pictures for use in a newsletter or on a website.
 - Note taker – Consider assigning someone the task of preparing a written report after the visit.
 - Consider inviting the media - but only after you have notified the elected official!

Other Activities

- Stay informed. There are many organizations/associations which monitor legislative activities at the state and/or federal levels. Newsletters and other publications can keep you up-to-date (see the Resource list at the end of this document).
- Contribute your ideas and energy by joining (or forming) a committee, taskforce, or campaign. Such groups may work on a single issue or a variety of issues. Even if you do not attend meetings, you can still lend your support to a letter writing campaign or telephone tree.

- Write a letter to the editor to your local newspaper stating your views. This is an effective way to help educate the public about a cause.
- Testify at a hearing. Legislative and Congressional committees often hold hearings to gather feedback on draft or recently introduced legislation. Family caregivers can provide compelling stories of their daily challenges in caring for a loved one. Be sure to contact the committee clerk prior to the hearing to find out the process for registering to speak and/or submitting written comments or to find out about any last-minute schedule changes.
- All federal bills can be searched and downloaded at: <https://www.congress.gov/>. All state bills can be searched and downloaded at: <https://docs.legis.wisconsin.gov/2021>

National & State Advocacy Resources

Track Legislation

Federal: <https://www.congress.gov/> or <https://www.govtrack.us/start>

State: Find- www.legis.wisconsin.gov, Track- <https://notify.legis.wisconsin.gov/login?ReturnUrl=%2f>

Find Your Federal Legislators

To find out who your U.S. Representative is, enter your zip code in the search function at:

<http://www.house.gov/representatives/find/>

To find out who your U.S. Senators are, go to: <https://www.senate.gov/states/WI/intro.htm>

U.S. Government Official Website - Find contact information for: federal, state, local, or tribal governments and elected officials - <https://www.usa.gov/agencies>

Find Your State Legislators

Wisconsin State Legislature - <http://legis.wisconsin.gov/> -Enter your home address in the “Who Are My Legislators?” box.

Contact Your Federal Legislators

- US Senate: <https://www.senate.gov/senators/contact>
- US House of Representatives: <https://www.house.gov/representatives>
- See [Wisconsin Members of the 117th Congress](#) for a complete list of contact information for Wisconsin’s federal legislators.

To Contact Your Federal Legislators by Phone

- Capitol Switchboard 1-202-224-3121 (ask to be connected your federal legislator’s office)
- Senate phone list - http://www.senate.gov/general/contact_information/senators_cfm.cfm
- House phone list - http://clerk.house.gov/member_info/mcapdir.aspx

Contact Your State Legislators

Wisconsin Legislative Hotline (leave a message or indicate a position on legislation): 800-362-9472 (toll-free); 608-266-9960 (in Madison); or 800-228-2115 (hearing impaired)

E-mail addresses:**Senators:** <https://docs.legis.wisconsin.gov/2021/legislators/senate>**Representatives:** <https://docs.legis.wisconsin.gov/2021/legislators/assembly>**Mailing Addresses:**

All Senators

P.O. Box 7882

Madison WI 53707-7882

Representatives whose last names begin with a letter from **A to L**: P.O. Box 8952, Madison, WI 53708**Representatives** whose last names begin with a letter from **M to Z**: P.O. Box 8953, Madison, WI 53708**Committee Members** – Assembly, Senate & Joint - <https://legis.wisconsin.gov/>**Governor Tony Evers**

115 East Capitol

Madison WI 53702

(608) 266-1212.

To Connect: <https://evers.wi.gov/Pages/connect.aspx>**OTHER RESOURCES****AARP Politics & Society** - Sign up for a free newsletter to stay up to date - <https://www.aarp.org/politics-society/> or **AARP Wisconsin** - <https://states.aarp.org/wisconsin/>**Administration for Community Living (ACL)/Administration on Aging (AoA) Programs-**
<http://aoa.acl.gov/index.aspx>**Administration for Community Living** – News & Information: <https://acl.gov/news>**Aging and Disability Resource Centers – Wisconsin** - <https://www.dhs.wisconsin.gov/adrc/index.htm>**Aging Services – Wisconsin** - <https://www.dhs.wisconsin.gov/aging/index.htm>**Alzheimer’s Association** – <https://www.alz.org/> . Also see, “Becoming an Advocate” - https://www.alz.org/get-involved-now/advocate/become_an_advocate. There are local chapters throughout the U.S. – **Wisconsin Chapter** - <https://www.alz.org/wi>**Badgeraginglist-** A listserv for the aging network. Serves as a source of advocacy material related to older adults, information on aging-related issues, a location to engage about aging matters, to exchange ideas, post aging network jobs, etc. To subscribe go to: <https://archives.simplelists.com/subscribe/badgeraginglist/>**Benefit Specialists – Disability/Elder** - help older adults and people with disabilities with questions and problems related to benefits such as Medicare, Medicaid, Social Security, FoodShare, and health insurance: <https://www.dhs.wisconsin.gov/benefit-specialists/index.htm>**Board on Aging and Long Term Care** (State of Wisconsin) - advocate for the interests of the state's long term care consumers, to inform those consumers of their rights, and to educate the public at large about health care systems and long-term care - <http://longtermcare.wi.gov/>

Caregiver Action Network - <https://www.caregiveraction.org/>

Caring Across Generations - <https://caringacross.org/>

Center on Budget and Policy Priorities - a research institute that conducts analyses on government policies and programs: <http://www.cbpp.org/>

Center for Medicare Advocacy - <http://www.medicareadvocacy.org/>

Dane County Area Agency on Aging - Legislative/Advocacy Committee:
https://danecountyhumanservices.org/aging/areaagencyonaging/aaa_legislative_committee.aspx

Disability Rights Wisconsin - <http://www.disabilityrightswi.org/>

Families USA - A leading national, non-partisan voice for health care consumers, dedicated to achieving high-quality, affordable health care and improved health for all. <https://familiesusa.org/>

Family Caregiver Alliance - <https://www.caregiver.org/>

Family Caregivers Rock – Wisconsin - <https://familycaregiversrock.org/>

Greater Wisconsin Agency on Aging Resources – General - <https://gwaar.org/>; **Advocacy and Grassroots Resources:** <https://gwaar.org/advocacy-and-grassroots-resources1>

Independent Sector- Policy & Advocacy - <https://independentsector.org/policy/>

Institute for Women’s Policy Research - <https://iwpr.org/>

Justice in Aging - <http://www.justiceinaging.org/>

Kaiser Health News- Nonprofit news service covering health policy issues at the federal and state level:
<http://khn.org/>

Kaiser Family Foundation - Health Policy Research - <http://kff.org/>

League of Women Voters of Wisconsin - Issues & Advocacy - <http://www.lwwvi.org/IssuesAdvocacy.aspx>

Meals on Wheels America (MOWA) - <http://www.mealsonwheelsamerica.org/take-action/advocate>

Medicare Rights Center - <https://www.medicarerights.org/>

My Vote Wisconsin - <https://myvote.wi.gov/en-us/>

National Alliance for Caregiving - <http://www.caregiving.org/advocacy/>

National Committee to Preserve Social Security & Medicare - <http://www.ncpssm.org/>

National Consumer Voice for Quality Long-Term Care - <https://theconsumervoice.org/>

National Council on Aging (NCOA) - Advocacy Basic - <https://www.ncoa.org/advocates/public-policy/advocacy-basics> ; **Advocates** - <https://www.ncoa.org/advocates>

OWL – The Voice of Women 40+ - <https://statusofwomendata.org/partners/owl-the-voice-of-women-40/>

Survival Coalition - <http://www.survivalcoalitionwi.org/>

United States Senate Special Committee on Aging - <http://aging.senate.gov/>

The Wheeler Report online news service that publishes articles and editorials concerning Wisconsin politics - <http://www.thewheelerreport.com/>

USAging - Advocacy in Action Center: <http://www.n4a.org/advocacyalerts>

Wisconsin Aging Advocacy Network - <http://gwaar.org/waan>

Wisconsin Board on Aging & Long Term Care – publications:
http://longtermcare.wi.gov/docs_by_cat_type.asp?doccatid=644&locid=123&linkid=1016

Wisconsin Budget Project - <http://www.wisconsinbudgetproject.org/>

Wisconsin Counties Association (WCA) - <https://www.wicounties.org/>

Wisconsin Department of Health Services – Programs and Services for Older Adults - <https://www.dhs.wisconsin.gov/aging/index.htm> ; Family Caregiver Services – <https://www.dhs.wisconsin.gov/aging/caregiver.htm>; Long-Term Care and Support - <https://www.dhs.wisconsin.gov/long-term-care-support.htm>

Wisconsin Disability Vote Coalition - <http://www.disabilityvote.org/>

Wisconsin Elections Commission (Voting/Elections) - <https://elections.wi.gov/>

Wisconsin Ethics Commission (Lobby information) - <https://ethics.wi.gov/Pages/home.aspx>

Wisconsin Family and Caregiver Support Alliance - <https://wisconsin caregiver.org/alliance>

Wisconsin’s Family Caregiver Support Programs - <http://wisconsin caregiver.org/>

Wisconsin State Legislature (legislators, committees, bills, maps, Blue Book, Session calendar & much more) - <https://legis.wisconsin.gov/>

WisPolitics - Wisconsin's Premier Political News and Information Service: <http://www.wispolitics.com>,
budget blog - <http://budget.wispolitics.com/>