



HAN

Hospice Action
Network



Advocacy 101



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When people ask me “who benefits from hospice?” I tell them about my mom. My mom, Sallie, was diagnosed with Parkinson’s disease at 65 years old. As the disease progressed, she lost her ability to work and live independently. She had to endure medication adjustments, depression and anxiety, and multiple falls—including one that resulted in a hip replacement.

After years of transitioning from different forms of care and dependence, the Parkinson’s eventually progressed to a point where Hospice Care was the best choice for my mom.

My family then experienced the promise of hospice care. We were so relieved to have our mother, our matriarch, in a safe place. In hospice care, she received personal care from her care team, joined us for family outings, and enjoyed shopping ventures. She was provided music therapy, which she loved and reminded her of her college years playing in the Penn State Blue Band.

Eventually, my mom’s hospice team alerted my brother and I that our mom was not in discomfort, but death was imminent. Our family gathered to be with her not just to witness, but also to receive care from her team.

Nurses and CNAs attended to her personal care and informed us about what was happening. The chaplain visited to provide spiritual care. The social worker attended to our family needs. Her physician came to let my mother know that she had been a wonderful patient. He told her that it was okay to let go.

Then the day came when my brother and I were called for the last time. Death was no longer coming, but here. My mom died in our arms. It was one of the greatest blessings of my life to be there. My mom was not alone when she died. She was surrounded by love. Hospice made that happen. For Mom. For me. For my family.

This story is just one of millions about how vital the Medicare Hospice Benefit is. To make a difference, you don’t need to be a policy expert. You don’t need to spend much of your already limited time. You just need to tell stories that illustrate the truth: that hospice care is unique, important, and must be protected.

If you are ready to tell your story, if you are ready to make a difference, then this toolkit is for you. It provides all the different ways you can take actions—big, small, and in between—to raise your voice in support of hospice and palliative care.

Regards,

A handwritten signature in cursive script that reads "Susan Lloyd".

Susan Lloyd

President & CEO, Delaware Hospice
Chair and Founding Member, Hospice Action Network

Hospice Action Network Advocacy 101 Toolkit

About

The **Hospice Action Network** (HAN) is the advocacy affiliate of legacy National Hospice and Palliative Care Organization (NHPCO), the nation's largest and oldest membership association for providers who care for people affected by serious and life-limiting illness.

HAN's mission is to advocate with one voice for policies that ensure the best care for hospice and palliative care patients and their families. HAN works with provider members, state organizations, other national healthcare organizations, and relevant stakeholders to advance the legacy NHPCO legislative and regulatory agenda.

HAN Board of Directors

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Words to Know

501(c)(3): Status for nonprofit organizations that focus on charitable activities like education and research. These organizations cannot support or oppose political candidates **but can engage in limited advocacy**, including lobbying, related to their cause.

Action Alerts: Pre-drafted messages on specific issues or legislation provided by advocacy organizations for advocates to send to legislators. These are designed for large numbers of advocates to rapidly respond to, and therefore to signal significant interest to legislative offices.

Advocacy: Taking action to support a cause. Methods include lobbying legislative offices, public education, and working with regulatory agencies.

- **Grassroots Advocacy:** activating a large group of people around a specific issue by raising awareness, providing education, or taking specific, easy steps to make change.
- **Grasstops Advocacy:** Engaging influential and experienced individuals with connections to legislators and/or networks of advocates to support advocacy efforts.

Coalition: An alliance of separate groups / organizations in support of common goals and causes, which may engage in joint advocacy activities.

Constituent: Community members or organization members within an elected official's district.

Lobbying: Advocating for or against a specific piece of legislation. While all lobbying is advocacy, not all advocacy involves lobbying.

Lobbyist: A regulated professional who engages in policy and legislation on behalf of a specific interest group.

Mobilize: Engaging others in an activity to achieve a goal, such as sending action alerts, reaching out to local media, or posting on social media.

Nonpartisan: Not associated with a specific political party or caucus.

Partisan: Associated with a particular political party.

Stakeholders: Individuals or groups with an interest or concern in a particular issue.

Town Hall: Meetings where policymakers meet with their constituents to discuss topics or specific upcoming legislation and regulation.



How much time do you have for advocacy?

A Minute (Or Two)

Take Action: Complete an Action Alert to tell your Members of Congress that you support policy priorities.

Sign Up for Emails: Receive monthly advocacy updates on activities, alerts, and new resources.

Learn Who Your Legislators Are: Identify your representatives in Congress, their district offices, and key staff.

Get Active on Socials: Follow legacy NHPCO and HAN's social media, boost advocacy posts, and tweet at your legislators.

An Hour (or Two)

Advocacy Basics Webinar: Watch a 46-minute training on the role of advocates, yearly activities, and resources.

Policy Priorities: Learn about HAN's stance and previous activities on key hospice and palliative care issues like program integrity, payment policy, workforce enhancement, and more.

Review our Toolkit Page: Explore advocacy resources, legislative process guides, and preparation tips for meeting legislators.

Work on Your Story: Personalize your advocacy by crafting a real-life story about a hospice and palliative care issue.

Write a Letter to the Editor (LTE): Educate the public, influence policymakers, and inspire others to act.

A Day (Or Two)

Set up a meeting: Arrange a meeting with your legislative offices to discuss the general importance of hospice and palliative care or specific policy priorities. Although the meeting may only take 15-30 minutes, take time to prepare and practice for your meeting.

Set up a tour: Invite legislative offices to tour your facility or a partner's, providing them with an informative experience to better understand hospice and palliative care operations. Tours may be combined with other events, such as a We Honor Veterans pinning ceremony.

Get on the Hill: Participate in Hill Days, joining other advocates to raise a united voice in Washington, DC and meet with members of Congress to discuss key policy priorities. At Hospice Action Week, the HAN team supports advocates who meet with their Members of Congress to discuss key policy priorities.



Your Easy Social Media Guide

Advocates and organizations are encouraged to share photos on social media to support hospice and palliative care issues.


To review our current priority bills, including lists of cosponsors, go to our [bills page](#) on the Action Center.

Sample Social Posts for Legislators:

 **Jane Doe** ✓
@loremipsum

"Thank you [\[@legislatorsaccount\]](#) for your continued commitment to improving hospice and palliative care. Let's keep pushing for better policies together! #HospiceWorks"

54 122 362

 **Jane Doe** ✓
@loremipsum

"[\[BILL TITLE\]](#) [\[BILL NO.\]](#) is essential for addressing [\[ISSUE\]](#). We urge [\[@legislatorsaccount\]](#) to support [\[BILL NO or SHORT BILL TITLE\]](#) to ensure high-quality care. #HospiceAction #HospiceWorks."

54 122 362

 **Jane Doe** ✓
@loremipsum

"#HospiceWorks! [\[@legislatorsaccount\]](#) please cosponsor [\[BILL NO\]](#) to ensure that [\[ISSUE\]](#) improves for providers and patients. We need your support!"

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General Sample Social Posts:

 **Jane Doe** ✓
@loremipsum

"Hospice and palliative care are so important in our community. [\[Example here\]](#). This is just one reason why I am advocating for better policies to support these services nationwide. #HospiceWorks #HospiceAction"

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 **Jane Doe** ✓
@loremipsum

"Did you know that hospice care helps over 1.5 million people in the United States every year? Learn more about how you can support these essential services by going to <https://hospiceactionnetwork.org/join-us/>."

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Tips:

- **Use Visual Content:** Incorporate photos, infographics, and videos to make your posts more engaging.
- **Tag Relevant Accounts:** Increase visibility by tagging legislators, and the social media for legacy NHPKO and HAN.
- **Use Key Hashtags:** #HospiceAction and #HospiceWorks.

Storytelling Practice

Storytelling is a core part of advocacy by helping legislators understand problems and their solutions. The practice structure below can help you craft a compelling and concise story that will resonate with legislative offices.

Reflection:

Before starting, reflect on your experiences in hospice and palliative care. Consider these questions and jot down story ideas:

- What has been most important to you as a provider or to the patients and families you have cared for?
- What challenges or roadblocks have impacted you or the patients and families that you care for?
- What changes would you like to see that would improve hospice and palliative care?

Hey, this template looks pretty short! You're right! In advocacy storytelling, keeping things brief is often best. Try to keep your story to 5 minutes – or about 700 words.

Introduction:

Start with the basics. Your name, where you live, your role in hospice and palliative care, how long you have worked in hospice and palliative care, etc. If advocating on behalf of your organization, include information about it, such as service area.

Paint a Picture:

Describe specific people or occurrences that have inspired you to make a difference for hospice and palliative care. This could be a personal story or examples of how your organization has positively impacted patients and families.

Issue or Problem:

Connect the picture you painted to a broader issue that needs to be addressed. Highlight the challenges or gaps in care that need legislative attention. It is okay to acknowledge challenges your organization is facing – legislators cannot fix problems that they are not made aware of.

Call to Action:

Close your story with good news: the problem has a solution. Explain how specific actions, like supporting a bill, can address the problem you described. End with a clear ask for support or action to address the issue. A link to currently supported bills can be found on in the Social Media Guide.

Letter to the Editor Guide

Why Write a Letter to the Editor?

Letters to the Editor (LTEs) are powerful advocacy tools because the opinion section is popular among readers, including legislators.

Letter Writing Tips

- **Keep it short and focused:** Address one key topic with compelling points. Do not overexplain.
- **Relevance and Timeliness:** Relate the topic to recent media coverage or prominent national issues.
- **Relatable Content:** Discuss how this issue impacts the local community, including your organization's role.
- **Plain Language:** Explain the issue in a way an average person can understand.
- **Call to Action:** End with a clear action request and its potential positive local impact.

Include Contact Information

- Provide your name, address, and contact information for verification, and potential follow up. Publications will not include your contact information in the printed letter.
- Include your title and organization, if permitted.

Submission Tips

- **Check Submission Rules:** Follow publication guidelines.
- **Word Limit:** LTES are typically limited to under 300 words.
- **Email Submission:** If submitting via email, copy + paste the letter into the email body. Do not include it as an attachment.

Op-Eds (Opinion Editorials)

- **Prominent Placement:** These are pieces prominently shown in a publication's opinion section. They are usually from higher-profile sources and have a longer length (about 750 words).
- **Contact for Assistance:** If you have a pitch for an op-ed in a prominent national publication, contact msummers@nhpco.org.

Letter to the Editor Template

Dear Editor:

Introduction

First Sentence: What are you writing about? If this letter is in response to a previous article, include the title, author, and date of publication.

Key Points: Include your main points early, as editors might cut from the bottom-up.

Case

Keep your argument simple.

Evidence: Use relevant facts and research to support your argument. Include your experience / expertise in hospice and palliative care.

Local Impact: Explain how the issue affects the community.

Conclusion

Reader Action: Encourage readers to act, such as by contacting policymakers.

Community Engagement: Encourage the community to learn more and engage with local hospice and palliative care organizations.

Sincerely,

[Name of writer]

[Writer's title]

[Writer's organization's name and address]

[Daytime contact information]

Legislative Meeting: Practice!

Preparation

■ Know the Legislator

[Use the Action Center](#) to see if the legislator is a cosponsor on any key bills or if they are on any key committees for healthcare.

■ Prepare a Fact Sheet about your Organization

If attending on behalf of your organization, use our Hospice Fact Sheet Template to break down the important information you want a legislative office to know about the role your organization serves in their district.

Roles

ROLE #1: Start the meeting/make introductions

Introduce yourself and your organization.

Example: "Hello Representative/Senator [Name]. My name is [Your Name] and I provide care in [Area] in your district. I will let everyone else introduce themselves."

ROLE #2: Name the Issue

State the issue, your position, and the action you want clearly and concisely

Example: "I am here today to talk about [Issue/Bill]. This is critical because [Reason]."

ROLE #3: Storyteller

Share a personal story or real-life example highlighting your experience with the issue. (2 people can have this role, time permitting)

Example: "[Issue] is important because [personal Story]. If [Issue/Challenge] were to improve, it would help us better meet patients' needs and impact our community positively."

ROLE #4: Make an Ask

Pose a direct yes-or-no question to the person you are meeting with.

Example: "Will you support [Bill/Policy] to improve hospice care in our community?"

■ Practice

Rehearse your story, talking points, anticipate questions. Be prepared not to know all the answers! Practice saying, "I do not have the answer to that right now, but I will follow up with more information."

■ Who will do what?

If in a group, review the below roles and decide who will have what role during the meeting.

ROLE #5: Thank the office for their time + share leave behind materials

No matter how an office responds to your ask, thank them for their time. Give the representative or staffer any handouts with relevant information and a business card to stay connected.

Additional Resources

- [Current Policy Priorities](#)
- [5 Steps to Effective Meetings with Legislative Offices](#)



Hospice Fact Sheet Template

Hospice Fact Sheet

[Open with an overview of your program’s history, and the area you serve]

Hospice Staff:

The hospice interdisciplinary team is centered around each patient and their unique needs and wishes. The members of this interdisciplinary team include a physician, nurse, hospice aide, social worker, chaplain, volunteer and bereavement specialist.

[#] employees [#] volunteers

Hospice Needs Volunteers: Trained volunteers are valued members of the hospice interdisciplinary team. Our training for hospice volunteers includes: []. Some examples of typical volunteer duties with our hospice include: [].

Current Statistics:

Service Area: [Counties, Regions, Cities, and/or States served]

Locations of care provided: [At home, hospitals, skilled nursing facilities, etc]

Average Census (number of patients being cared for on any given day): [#]

Average Length of Stay: [#] days

Median Length of Stay: [#] days

Patients served per year: [#]

Common Diagnoses served: [#]

Services provided by [Hospice Name]: [tailor to your program]

- Regular visits by interdisciplinary team, including registered nurses with advanced training in pain and symptom control, social workers, spiritual care providers
- Medical director and nurse practitioner
- Volunteer services including: 11th hour volunteers, pet therapy
- Music Therapy
- Massage Therapy
- Bereavement program for 13 months including a pediatric grief program

Additional Services provided: [tailor to your program]

- Palliative Care Program
- We Honor Veterans Program
- Programs for individuals experiencing homelessness
- Community Bereavement support services
- Advance care planning
- Specialty services (complex chronic care, transplant, cardiac, behavioral)

Other Facts if Applicable:

- Quality scores/Star Rating (consider adding as an example under “Other Facts”)
- Most hospice services are covered by [Medicare, Medicaid, other insurance]
- WHV Partner Level

For additional information: [insert hospice website] or contact [insert info for best contact person at hospice].



Advocacy Activities Calendar

Needed All Year Round

- [Subscribe](#) to Hospice Action Network emails.
- [Know your Members of Congress.](#)
- [Review the Policy Priorities.](#)
- [Visit the Action Center](#) for action alerts and endorsed bills.

JANUARY

Welcome back Congress! [Send an email to your legislators' offices.](#) Share why hospice and palliative care are important to you and your community. Include any fact sheets or policy priorities.

FEBRUARY

It is BUDGET season! Keep up with advocacy updates related to [fiscal priorities.](#) Call your Members of Congress and remind them of the importance of well-funded hospice and palliative care in their districts.

MARCH

Next month is National Healthcare Decisions Day (April 16). Begin to plan an event and invite legislative offices. Need help planning a tour? Check out this [tip sheet](#) for more.

APRIL

Host events related to National Healthcare Decisions Day. Invite the press. If you cannot hold an event, post on social media, tag your legislators, and discuss how important hospice and palliative care are in your community.

MAY

Hill Day is happening soon in DC! Encourage others to [sign up](#) for advocacy emails. Post about HAN on socials. The more advocates that join, the louder our voice will be for hospice and palliative care!

JUNE

[Hill Day](#) is happening in DC! Support our advocates gathering from across the country to lobby on the Hill. Review any new [policy one-pagers.](#) Act on any Hill Day-related [action alerts.](#)

JULY

Next month, Congress is in recess. Reach out to your Members' district offices to set up meetings or tours during the recess. Nervous about meeting with an office? [Check out this guide](#) for tips.

AUGUST

It is August Recess! Connect with your Members of Congress through meetings, events, or a tour. If you cannot hold a meeting / event, contact your district offices to inform them of why hospice and palliative care matter in their district.

SEPTEMBER

Write a Letter to the Editor to your [local media outlets.](#) Highlight the role of your organization locally and what policy priorities would help hospice and palliative care be better.

OCTOBER

November is Veterans Day and National Veterans and Military Families Month. Plan [We Honor Veterans-related events to invite legislators to.](#) Plan social media posts to highlight how your organization serves the veteran community.

NOVEMBER

It's National Hospice and Palliative Care Month! Tag your public officials in posts on social media. Let them know that hospice and palliative care need their support in Congress.

DECEMBER

Watch your inbox for any urgent end-of-year calls to action. Share resources for those experiencing [grief around the holidays](#) with your networks.

Advocacy Growth Checklist

Individual

Basics

- Sign up for advocacy emails.
- Follow HAN on LinkedIn and Twitter.
- Subscribe to your Members of Congress' email lists.
- Use the Action Center to follow your Members of Congress on social media.

Level 1

- Complete all HAN Action Alerts.
- Review current policy priorities and endorsed bills.
- Forward advocacy emails and boost social posts, especially Action Alerts, within your networks.
- Craft a personal / compelling story about a hospice and palliative care issue.

Level 2

- Watch the [Advocacy Basics webinar](#).
- Relay relevant advocacy updates to your organization.
- Send a personal email or make a phone call to your Member of Congress's in-district office.
- Write an Op Ed or Letter to the Editor and use the Action Center to connect with local media.

Level 3

- Review the HAN toolkit page, especially [Policymaking 101](#) and the Advocacy Toolkit.
- Attend local townhalls, open office hours, and events with your Members of Congress
- Invite your representatives and/or their staff to events or tours involving your program or facility.
- Meet with your legislative offices to discuss key hospice and palliative care policy priorities.

Level 4:

- Recruit 3 people / quarter to sign up to be advocates.
- Attend our annual Hill Day in DC.
- Write a blog about a hospice and palliative care issue for the [HAN blog](#).
- Apply to become a [MyHospice Ambassador](#).

Organization

Basics

- Encourage staff to work through the Individual Checklist, according to any internal government relations (GR) policies.
- Identify representatives of your covered service area.
- Review current policy priorities and endorsed bills and identify how your organization is impacted by these policies.

Level 1

- Share advocacy update emails and Action Alerts with your staff.
- Include a Policy Priorities / Advocacy section in key employee communications and all-staff meetings.
- Boost advocacy social posts and Action Alerts on your social media and newsletters.

Level 2

- Invite Members of Congress / district staff to an event or tour at your program or facility – ex. We Honor Veterans events.
- Have regular “warm touch” contact with legislative offices, through GR staff if possible.
- Aim for quarterly in-person meetings with legislative offices—and encourage non-GR staff to participate if possible.

Level 3

- Train interested staff in [Advocacy Basics](#) and policy talking points—or engage the HAN team to provide it.
- Incentivize advocacy engagement among staff by providing an annual advocacy award to a non-GR staffer.
- Identify a staff person to apply as a [MyHospice Ambassador](#).

Level 4

- Have a staff member apply to join the legacy NHPKO Legislative Affairs Committee to support crafting Alliance policy priorities.
- Arrange for 1-3 staff to attend Hill Day to advocate with Congressional offices.
- Sponsor the Hill Day, particularly scholarships for advocates who otherwise cannot attend.



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