



SEPSIS
ALLIANCE
VOICES

Sepsis Alliance Voices Advocacy Toolkit



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Dear advocate,

Thank you for your interest in advocacy work on behalf of patients with sepsis, survivors, and their loved ones. Since 2019, when Sepsis Alliance Voices was born, we have seen advocates meet with members of Congress, get Sepsis Awareness Month proclamations made at the state level, send letters, sign petitions, submit funding requests, appeal to change-making agencies, and tell their stories. We are consistently inspired by the dedication we see, and grateful for the time and expertise each of our advocates donates.

Still, these are ongoing efforts. Until no one is harmed by sepsis, there is always more we can be doing to improve sepsis awareness and care.

That's where you come in. You can help to make a direct and tangible difference for those impacted by this devastating condition. But you don't have to undertake this work alone. As the nation's first and leading sepsis organization, we are dedicated to equipping members of this extended community—including survivors, caregivers, loved ones, clinicians, researchers, and more, in all 50 states—to confidently join and contribute to our efforts. This toolkit was created for advocates like you. It is meant to support your efforts, help advocacy feel accessible and fulfilling, and ensure that every voice is heard.

We hope the information in these pages inspires and encourages you, and that you'll continue to return to Sepsis Alliance for resources and information to guide your advocacy. We are grateful for your efforts, your time, and your passion—we're glad you've joined us.

Sincerely,



Thomas Heymann
President & CEO, Sepsis Alliance

About This Toolkit

Saving lives and reducing suffering from sepsis requires us to speak out in our communities and in halls of power. You can use your voice on behalf of those impacted by sepsis. With the Sepsis Alliance Voices advocacy community, you can make an impact.

For those who have never done advocacy work before, the idea of using your voice in this new way might feel intimidating. But be assured that advocacy skills, like any other skills, can be learned even professional lobbyists were once new to this! This toolkit is meant to support you in getting started. In these pages, you will find an overview of what advocacy is, what it can look like, and how you can use the tools of advocacy to make positive changes for those impacted by sepsis.

For additional information on how to advocate, discover our introduction to advocacy webinar and other tools at SepsisVoices.org, or email info@sepsis.org with any questions.

Sponsorship Acknowledgement

Sepsis Alliance gratefully acknowledges Roche for their unrestricted grant support of the Sepsis Alliance Voices Advocacy Toolkit.



About Sepsis Alliance

Sepsis Alliance, a leading patient advocacy organization, is saving lives and reducing suffering by improving sepsis awareness and care.

Through [Sepsis.org](https://sepsis.org), [Sepsis Alliance Institute](https://sepsis.org/institute), [Sepsis Alliance Voices](https://sepsis.org/voices), [Sepsis Alliance Connect](https://sepsis.org/connect), and [Sepsis Innovation Collaborative](https://sepsis.org/collaborative), Sepsis Alliance is providing healthcare professionals, the general public, and those touched by sepsis with the education, support, and advocacy to save lives and limbs. Sepsis Alliance is enacting and influencing positive change for the 1.7 million people diagnosed with sepsis each year in the U.S. Infection prevention is sepsis prevention. For more information on Sepsis Alliance, a GuideStar Platinum Rated and Charity Navigator Four-Star rated 501(c)3 charity, visit [Sepsis.org](https://sepsis.org).

Sepsis Alliance is committed to closing inequitable gaps in sepsis awareness, incidence, treatment access, and patient outcomes. You can read Sepsis Alliance's pledge for equity, diversity, and inclusion [here](#).

Our Vision: A world in which no one is harmed by sepsis.

Our Mission: Save lives and reduce suffering by improving sepsis awareness and care.

About Sepsis

Sepsis, the body's overwhelming and life-threatening response to infection, is the leading cost of care and cause of death in U.S. hospitals. 350,000 American adults die from sepsis every year—more than from stroke, breast cancer, prostate cancer, and opioid overdose combined. Over one million Americans survive sepsis every year, many with lingering costs and complications. These can include amputations and post-sepsis syndrome. Learn more about sepsis at [Sepsis.org](https://sepsis.org).

There are many opportunities for improvement in sepsis awareness, prevention, diagnosis, treatment access, and long-term outcomes. Many of these improvements may be achievable with the help of laws, policies, and regulations at the city, state, and national levels. Big changes require the collective efforts of a dedicated sepsis advocacy community!



Carl Flatley, DDS, MSD, Sepsis Alliance founder, with daughter Erin, a victim of sepsis.

Advocacy FAQs

What is advocacy?

Advocacy: the act or process of supporting a cause or proposal.

“Advocacy” refers to a range of activities that can impact policies, laws, or regulations at local, state, or national levels. These activities may include meeting with community leaders, asking elected officials to take action on pieces of legislation, or educating the public on important issues.

Why become a sepsis advocate?

Sepsis advocates help improve care and quality of life for millions of people affected by sepsis. They support legislation, policies, and regulations that can make a difference for patients with sepsis, survivors, and their loved ones.

Who can be an advocate?

Anyone can be an advocate!

If you are willing to use your voice, you can be a part of sparking change.

How can I be an advocate?

Sepsis advocacy can take many forms. Signing petitions, sharing social media campaigns, calling or emailing decision-makers, and meeting with legislators are all examples of ways to advocate for issues of importance to

those impacted by sepsis. Advocacy can also include community work like public education campaigns, events to engage your neighbors, and relationship-building with other advocates and organizations working on related issues.

An important component of advocacy is personal storytelling. If you have a personal experience with sepsis, sharing that experience with your community or with decision-makers can help to personalize this important issue, which can motivate change.

Continue reading for more information on how to advocate for better sepsis awareness and care.



Sepsis Alliance's Advocacy Priorities

As with all our work, Sepsis Alliance's advocacy initiatives aim to improve sepsis awareness and care. Our vision is a world in which no one is harmed by sepsis. Our advocacy work focuses on five priority areas:

1. Seeking greater health equity:

Sepsis, like many medical conditions, disproportionately impacts those who have historically lacked access to quality healthcare, including some communities of color, rural communities, and individuals experiencing poverty. Through its advocacy work, Sepsis Alliance aims to help close gaps in patient outcomes and expand access to high-quality sepsis care.

2. Curbing antimicrobial resistance (AMR):

Antimicrobial resistance (AMR) occurs when specific strains of bacteria, viruses, fungi, or parasites learn to defeat the antimicrobial medications designed to kill or stop them. Because sepsis often requires effective antimicrobials to treat, AMR challenges the treatment of sepsis: some estimates indicate that AMR may contribute to 10% of sepsis deaths worldwide. Curbing the threat of AMR is one of Sepsis Alliance's top priorities.

3. Measuring sepsis to better manage it:

Clinicians, researchers, innovators, policymakers, and other experts need quality data and information to better understand sepsis. The better sepsis is understood, the more we can improve its diagnosis and treatment. One of Sepsis Alliance's top advocacy priorities is improving the collection, harmonization, and accessibility of sepsis-relevant information, so that

experts fighting sepsis on the front lines are better able to understand what they're up against.

4. Improving outcomes for pregnant people:

Infection or sepsis is the [second leading cause](#) of pregnancy-related mortality in the U.S., and the U.S. has one of the highest maternal mortality rates in the industrialized world. Through its advocacy work, Sepsis Alliance aims to help improve outcomes for people who develop sepsis during or following a pregnancy, so that more survive [pregnancy, childbirth, and the postpartum period](#).

5. Keeping the spotlight on the #1 cause of death in U.S. hospitals—sepsis:

When Carl Flatley, DDS, MSD, [founded Sepsis Alliance](#), there wasn't sufficient focus on sepsis in the general public, hospitals, or in the halls of government. In 2023, [sepsis awareness levels](#) among U.S. adults had reached 63%, up from 19% when Sepsis Alliance was first founded. Still, more than [350,000 U.S. adults](#) die every year as a result of sepsis. More awareness can mean faster recognition, diagnosis, and care, and more lives saved. As advocates, Sepsis Alliance aims to keep the national spotlight where it belongs—on sepsis.

Getting Started

Get connected.

Figuring out how to begin as a sepsis advocate can seem daunting, but visiting SepsisVoices.org will help you get started! There, you will find current actions that Sepsis Alliance is prioritizing, sepsis-relevant pieces of legislation from around the country, and more.

Do some homework.

Identify an area of sepsis advocacy that you want to focus on—for example, improving sepsis awareness, or expanding resources for sepsis survivors—and visit Sepsis.org to learn more about the scope of the problem. Reading about sepsis and sepsis-relevant issues can help to support your advocacy with facts.

Make it personal: talk from the heart.

Connect what you discover in your research to your personal experience. For example, if you are a sepsis survivor, you might share with a decision-maker that you are one in over one million people in the U.S. who survive sepsis every year—and then, tell your story. This makes sepsis feel real and urgent, which can motivate change.

Learn from other advocates.

Figure out who is already advocating on behalf of your sepsis-relevant issue so that you can learn from their resources, build on their progress, and collaborate. This might include an organization like the [Black Mamas Matter Alliance](https://BlackMamasMatterAlliance.org), which works to advance Black maternal health, or the [Infectious Disease Society of America](https://InfectiousDiseaseSociety.org), which advocates for legislation that would help to curb AMR.

Stress equity and inclusion.

Advocacy should include the perspectives of those who have historically lacked access to decision-making conversations. This might mean doing outreach and

research to incorporate a variety of perspectives. It might also mean assuming a supporting role in an advocacy campaign to uplift someone else's voice.

Identify the decision-makers.

Does the change you are looking to make need to happen at the local, state, or national level(s)? Who are the individuals or institutions with the power to enact this change? The answer might be an individual legislator, but it might be a government agency like the [Department of Health and Human Services](#), or a non-government entity like the [National Quality Forum](#). The answer might also be members of your own community—if your advocacy goal is to raise public awareness of sepsis, your neighbors are key change-makers!

Understand the decision-makers.

Do some research on the decision-makers you need to reach. Search online for their previous policy activities or statements they've made on topics related to sepsis. Try to identify what their stake might be: do they seem motivated to improve hospital performance or to protect birthing people? Do they care about cutting healthcare costs? Understanding this can help you to shape your approach.

Figure out your best approach.

Are you a strong writer? A fantastic event planner? Do you have skills in public speaking? Think about your strengths and choose an approach to advocacy based on where you shine. Examples can include emails, mailed letters, phone calls, in-person or virtual meetings, social media campaigns, educational events, rallies or marches, or other ways that utilize your strengths!

Strategize your timing.

Advocacy often involves timing constraints. If you are looking to get a bill passed, for example, there will be key dates to keep in mind, like when legislators are set to cast their votes. Make sure you know all the relevant timelines and plan accordingly.

Building Your Case

Building a strong case to present to a legislator or other decision-maker can be challenging, especially if you have limited time with them. It can be helpful to outline your points in a chronological and clear way. Use the outline provided below to help you craft a strong statement.

Who are you and how do you relate to the decision-maker?
(Do you live in their district?, etc.)

What led you to contact them?

What is sepsis? If you are discussing a specific topic (e.g. sepsis inequities, sepsis and antimicrobial resistance), what is it? Describe/define.

Why are you passionate about this issue? What are your personal experiences that relate to sepsis?

(Use this space to tell your story).

How much does sepsis impact other people in your community?
(Check statistics on your state or locality, or refer to the U.S. statistics below).

What is the specific problem you are seeking to address? (e.g. “In our state, sepsis awareness is low.”)

What concrete policy solutions or changes would help to address the problem? (e.g. “If our state observed Sepsis Awareness Month, sepsis awareness would improve.”)

What does this decision maker need to do? Be as specific as possible. (e.g. “Please issue a proclamation officially recognizing Sepsis Awareness Month in our state.”)

Key Sepsis Messaging and Statistics

When advocating, key messaging and compelling statistics can help you communicate the need for change. Find some below, and visit our page of [downloadable sepsis fact sheets](#) for even more:

- Sepsis is the body's overwhelming and life-threatening response to an infection. It can be caused by a bacterial, viral, fungal, or parasitic infection.
- Like a stroke or a heart attack, sepsis is a medical emergency that requires rapid diagnosis and treatment. It can lead to tissue damage, organ failure, amputations, and death.
- Sepsis is the leading cause of death in U.S. hospitals and the number one cost of hospitalization in the U.S. (\$62 billion annually).
- Effective sepsis care is all about time: the risk of mortality from sepsis increases by 4-9% for every hour treatment is delayed.
- More than 1.7 million people in the U.S. are diagnosed with sepsis each year, and over 350,000 of those people die – more than from stroke, prostate cancer, breast cancer, and opioid overdose combined.
- Infection or sepsis is the second-leading cause of pregnancy-related mortality in the U.S.
- There are nearly 14,000 sepsis-related amputations every year in the U.S.
- The burden of sepsis is not felt equally across race, class, and socioeconomic status: American Indians and Alaskan Natives in the Indian Health Service area are 1.6 times more likely to die from sepsis than the national average; Black individuals bear nearly twice the burden of sepsis deaths as compared to white individuals; Adults below the poverty line have over 3 to 4 times the risk of dying of sepsis, compared to adults whose family income is at least 5 times the poverty line.

You've Connected with a Decision-Maker. Now What?

You did your prep work and made a strong case. Now, you need to follow up.

Following up allows you to build on the momentum you established in your initial connection and to continue the conversation.

Say thank you.

If you connected directly with an individual or a group of individuals, send a thank you note or email soon afterwards letting them know how much you appreciated their time. Include any information guides, fact sheets, or other supporting materials to help them remember the points you made.

Keep in touch.

Continue to connect and share updates as you have them. Make yourself available, especially as deadlines near. Don't be afraid to ask a decision-maker what else you can provide that would be helpful. Remember, advocacy is an ongoing conversation.

Stay active!

Advocacy can be slow. You might be waiting to hear back from a decision-maker for a while. In the meantime, continue to educate yourself about new research, proposed legislation, and other relevant happenings. Keep reaching out to other advocates to find out how else you can get involved. Continue to build community connections.

Advocacy Quick Tips

- ▶ **Be brief:** Whether you are writing a letter or presenting in a meeting, you want to be brief and concise.
- ▶ **Be yourself:** Every person who is passionate about this issue has a unique story. Remember to bring your personal experience and insights to the conversation.
- ▶ **Always have an ask:** Always end your pitch with a specific action that you are asking the decision-maker to take.
- ▶ **Avoid acronyms or jargon:** It is important to avoid using acronyms or jargon in your conversations, especially about medical issues. Offer an explanation when you introduce a new technical term.
- ▶ **Connect the issue back to real people:** Always emphasize how sepsis affects real people—this makes it feel real and urgent. When proposing a new solution, explain how it would positively impact real people (patients, survivors, etc). Give examples wherever possible.
- ▶ **Have the possibility of a happy ending:** Everyone wants to be part of a happy ending. Highlight how the decision-maker can be part of the solution to the problem you lay out.
- ▶ **Follow up:** Making a connection is just the beginning. Be sure to follow up, share updates, and make yourself available. Advocacy is an ongoing conversation.

Thank You!

Thank you for your advocacy on behalf of patients with sepsis, survivors, and their loved ones. Please let us know how your efforts are going by emailing info@sepsis.org.

For additional information on how to advocate, visit SepsisVoices.org.

Looking for more ways to help? Please consider [a donation](#) to Sepsis Alliance. Gifts help to provide valuable sepsis awareness and education resources to healthcare providers, sepsis survivors, and the loved ones of sepsis patients. Thank you for your generosity.

