

Public Policy Advocacy Toolkit



For more than thirty years, that National Coalition for Cancer Survivorship (NCCS) has worked to improve cancer care from the moment of diagnosis through the balance of life. A critical way to help make those changes happen is through public policy advocacy. The purpose of this toolkit is to introduce you to the concept of public policy advocacy and its role in the cancer survivorship movement, share NCCS' policy priorities, and provide you with opportunities to advocate for NCCS' most pressing policy issue. The information in this toolkit is brief and focused. There are several other types of advocacy cancer survivors can engage in, many that were spearheaded by NCCS. After you make your way through this toolkit, we encourage you to read, [Self-Advocacy: A Cancer Survivor's Handbook](#).

Nothing About Us Without Us

- Improving cancer care policy and delivery must include patients' perspectives

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ABOUT NCCS

NCCS' mission is to advocate for quality cancer care for all people touched by cancer. Founded by and for cancer survivors, NCCS created the widely accepted definition of survivorship and defines someone as a cancer survivor from the time of diagnosis and for the balance of life. Advocacy has always been the cornerstone of NCCS' work. In 1992, we relocated our offices to Washington, DC to be closer to the organizations and institutions that play a role in educating government agencies and policy matters about the need for quality cancer care throughout the survivorship continuum.

NCCS has worked with legislators and policy makers to represent cancer patients and survivors in efforts to improve their quality of care and quality of life after diagnosis. Our unique niche in the cancer advocacy landscape is promoting policy change to ensure quality cancer care. Our vision is to be an advocacy organization that reflects the needs of all cancer survivors to effect policy change at the national level.

NCCS represents the millions of Americans who share a common experience – the survivorship experience – living with, through and beyond a cancer diagnosis. That experience has value and can be a transforming, positive force. NCCS also knows that cancer survivors and those who care for them face many challenges.

To help meet those challenges, NCCS:

- Advocates for changes in how the nation researches, regulates, finances and delivers quality cancer care.
- Empowers cancer survivors through its publications and programs, which provide tools for self-advocacy and public policy advocacy.
- Convenes cancer organizations to address public policy issues affecting cancer survivors.



PUBLIC POLICY ADVOCACY

What is public policy, and why is public policy advocacy important?

Public policy is government action on a public issue. Federal, state and even local governments make decisions that have an impact on cancer survivors. Public policy advocacy is an opportunity to educate others about an issue or cause that is important to you and can begin with the concept of an idea and can continue all the way through the legislative process until that idea becomes a law. Your voice and actions can shape policy and initiatives. Policy makers cannot be experts on every issue area, so they look for ways to better understand the issues that are important to their constituents. By advocating on behalf of cancer survivors, you can help policy makers, including Members of Congress and their staff, better understand issues in cancer care.

Policy Priorities

NCCS public policy focuses on three broad umbrella issues where advocacy can play an important role:

- **Improving Care:** we strive for patients to receive the highest quality of care through delivery, payment, and other policy reforms, which include cancer survivors' access to cancer care planning services, coordinated care, and adequate doctor-patient communication.
- **Ensuring Access to Care:** advocating for the Affordable Care Act, and its critical and historic patient protections, as the most effective way to ensure cancer survivors maintain access to quality and affordable health care.
- **Patient-centered Cancer Drug Review Process:** Resources to support an efficient and effective cancer drug review process at the Food and Drug Administration that takes into consideration the needs of cancer patients.

While we work on all these areas throughout the year, a specific policy priority we are leading is to enact cancer care planning legislation. Ensuring quality cancer care is complex, and there are many areas for improvement and policy action. One glaring gap is in treatment decision-making and coordination of the multiple facets of cancer care. To help address this gap, we are dedicated to ensuring that every cancer patient has access to cancer care planning and coordination services, beginning with Medicare beneficiaries, through the creation and advocacy around the **Cancer Care Planning and Communications (CCPC) Act, H.R. 5160**. Care planning services provide cancer patients information to make informed decisions about treatments; encourage collaboration among the multi-disciplinary cancer care providers; and facilitate transitions from active treatment to survivorship. Cancer care planning and coordination services are a critical first step toward reform of the cancer care delivery and payment system, and if adopted by Medicare, will hopefully be implemented across the health care delivery system eventually.



NCCS is focused on enacting the Cancer Care Planning and Communications (CCPC) Act, H.R. 5160, which will encourage the development of a personalized cancer care plan for Medicare beneficiaries. The CCPC ACT will:

- Help cancer patients through the difficult process of cancer diagnosis, treatment choices, treatment management, and survivorship care by supplying them a written plan or roadmap.
- Promote shared decision-making between patients and their cancer care teams and support informed decisions as treatment choices are becoming increasingly complex.
- Empower patients with information necessary to help manage and coordinate their care from active treatment through survivorship.

See our CCPC Act one-pager with additional information and supporting organizations. In the following sections of the advocacy toolkit we will provide information and resources on how you can help get the CCPC Act passed in Congress so that Medicare beneficiaries who are diagnosed with cancer get the care planning they need to help navigate a cancer diagnosis.

HOW A BILL BECOMES A LAW

We all remember the School House Rock song, "I'm just a bill," but the legislative process can be complicated. So how does a bill become a law? First, an organization, Member of Congress, or even constituents can develop an idea that they want to become law. Once the bill text is written and sponsored by a Member of Congress, it is introduced. A bill can start in either the House or Senate. Then, the bill goes to committee, where committee members meet in a small group to discuss the bill and make changes. The committee then votes on the bill either rejecting it, or sending it to the full House or Senate floor for a vote. When the bill is on the floor, it is debated and proposed changes or amendments are made. Both chambers have to agree on the same version of the final bill before it goes to the President. When the bill reaches the President, he or she can sign it into law or veto the bill.

ADVOCACY TOOLS

Even in the age of Twitter, Facebook and email, a phone call is often the best way to reach your representative. "It's just a matter of how people process information," says Kris Miler, researcher in politics and government at the University of Maryland. Miler's book, *Constituency Representation in Congress*, explores the ways legislators understand and respond to their constituents. In her research, she explored different options of personal contact via phone or face-to-face, or email and faxes. She concluded that, "Both have an impact, but the impact of personal and phone calls was much stronger."

Phone Calls

Calling your Member of Congress may be intimidating at first, but remember that it's the job of the staffers answering phones to hear from constituents and relay that information to their bosses. Most offices keep a spreadsheet of calls and may ask your name and your zip code. The staffer will enter this information along with your issue or request, so the more calls they get on a single issue, the more likely the Member of Congress is to act on it.

Here is a sample script to ask your Members to support the Cancer Care Planning and Communications (CCPC) Act, H.R. 5160.

Hello,

I am a survivor/caregiver/advocate from _____ . I am calling to ask that Representative/Senator _____ support the Cancer Care Planning and Communication Act, H.R. 5160. The CCPC would create a new Medicare service for cancer care planning. This care plan would help cancer patients through the difficult process of diagnosis, treatment choices and management, and survivorship care by supplying them with a written plan or roadmap. [As a survivor myself, INSERT BRIEF PERSON CONNECTION TO CANCER, IF APPLICABLE], I understand the importance of shared decision-making between patients and their cancer care teams and this bill would help empower cancer patients with information necessary to help manage and coordinate their care. I hope that your boss will support HR____, the Cancer Care Planning and Communications Act. Thank you for your time and consideration.

Members of Congress need to hear from constituents that cancer care planning is a priority. Calling your elected officials is easy and an important way to exercise your right as a citizen. Remember that it is your elected official's job—and his/her staff members—to listen to you, as a constituent!

Call Your Representative at (844) 257-6227

NCCS has a CCPC Act hotline number that will direct you to your Representative and provides some brief talking points on the CCPC Act. The hotline is great to share with friends and family so they can take action: (844) 257-6227

Tips for Calling Your Members of Congress:

- Ask for the staff member who covers health issues.
- Mention your connection to cancer, as a survivor, caregiver, provider, family member, etc.
- Stress the importance of cancer care planning and coordination:
 - Care planning encourages important doctor-patient discussions and a shared decision-making process.
 - Without a care plan, patients must navigate the complexities of a cancer diagnosis on their own.
 - H.R. 5160, The Cancer Care Planning and Communications Act, will ensure that every Medicare-eligible cancer patient has access to cancer care planning and coordination, which will improve cancer care and reduce inefficiencies in the system.
- If appropriate, share your experience with cancer care planning. If you received a care plan, how did it help you? If you did not receive a care plan, how might it have helped you?
- Ask your Representative to please co-sponsor the bipartisan H.R. 5160, the Cancer Care Planning and Communications Act.

Meeting with your Representative

If you are interested in meeting with your Representative or their staff in her/his local office, NCCS will help you schedule a meeting. Email Lindsay Houff at lhouff@canceradvocacy.org to request a meeting with your Representative to discuss the CCPC Act.

Meeting tips

- Begin by introducing yourself, where you live, and your connection to cancer.
- Briefly describe the CCPC Act and how it would benefit cancer survivors
- Ask your representative to co-sponsor the CCPC Act to promote cancer care planning and care coordination
- Print out and bring the [CCPC Act one pager](#) as a leave-behind so the staff or Member of Congress will have information on the legislation.

- If you're able, dress in business or business casual.
- Be sure to send an email to thank her/him for the meeting and to follow-up on any questions they may have asked

Writing to Members of Congress

One advocacy effort that almost anyone can do is to write to their Members of Congress. You can write to your Member of Congress through postal mail, email or fax. When writing a letter, begin by identifying yourself with your name and address, making sure to identify yourself as a constituent. In the letter, explain your connection to cancer and how the issue you are writing about affects you. Your letter should be brief and to the point. Only address one issue and identify the subject in the first paragraph. Ask your Member to stake a specific stance or action and provide a way for the Member or staffer to get in touch with you.

Visit your Member of Congress's website to find their office address or the appropriate email address to use to send the letter. If you need assistance getting the correct contact information, please contact Lindsay Houff at lhouff@canceradvocacy.org

MEDIA TOOLS

Media outlets are important avenues to tell your story to a broad audience. While the face of media has changed dramatically in the last 15 years, human interest and experience remains at the heart all types of media. However, telling your story now, or consuming media now, is very different than it was just a few years ago. The political climate is tense, news outlets are under pressure, and there is a lot of noise. Below we hope to provide you with some simple and concise information on social and traditional media, plus an outline to utilize when crafting your story.

Social Media

Advocates can use social media tools such as Facebook, Twitter, YouTube, LinkedIn, and Instagram among others to influence policy debates and impact policy decisions. These platforms are perfect ways for patient advocates to engage. Each offer their own benefits and you do not have to participate in every single one. Below we quickly highlight the benefits of the most popular social media platforms. This information comes from a presentation CPAT members AnneMarie Ciccarella and Alicia Staley shared at the 2017 CPAT Symposium.

Twitter (@canceradvocacy)

- Individual messaging
- Open, transparent conversations
- Follow Members of Congress, thought leaders, conferences, areas of interest
- Short, concise, rapid fire
- Information sharing

Facebook (facebook.com/cancersurvivorship/)

- Open and closed groups
- More in-depth conversations and discussions
- Robust information creation and sharing

- Follow Members of Congress and get information on local events, news, etc.
- Biggest area for growth

LinkedIn

- Connect with Congress
- Industry representatives
- Showcasing individual skills and involvement with key organizations

Instagram

- Secondary information creation and sharing
- Showcase images from events
- Short form video

Traditional Media

	Op-Ed	Letter to the Editor
Topic	Regarding a general issue	In response to an article or editorial
Placement	Published opposite the editorial page	Published on the editorial page
Purpose	More thorough analysis	Brief response
Length	500-800 words	200-250 words
Focus	Stay relevant and on topic	Stay relevant and on topic
Author	Someone with expertise on the subject	Anyone interested in the subject

*Source: Prevent Cancer; Advocacy Toolkit: A Guide to Grassroots Leadership

Sharing your story

People have been telling stories since human beings first sat around campfires. We are hard-wired to take in new information through stories.

Statistics reach people in the head. Stories hit people in the heart. Sharing your personal experience is a powerful way to establish a connection and drive your listener to action. Your audience (e.g., elected officials, donors, the media, other volunteers) may disagree with your facts or arguments, but they cannot argue with your unique personal experience.

The below steps are based on research in effective storytelling, but ***you should tailor them to your own circumstances.***

1. Hi I'm from [place]. *If meeting with a Congress member, identify yourself as living in their district.*
2. My life changed when [describe your diagnosis or a loved one's].
3. Fortunately, [describe the intervention you received.]
4. Where I am today.
5. I am not alone. There are millions like me.
6. Can you help by [state the call to action].

Practice. Time it and try to keep it under two minutes. Hang onto the details that are vivid and memorable. Omit the content that is unnecessary or distracting. Ask for feedback from friends and other volunteers. With practice, you will be able to shake your nervousness, but keep your energy and passion.

LEGISLATIVE ADVOCACY

NCCS serves as a voice for cancer survivors in Washington, D.C. Through lobbying efforts and grassroots activity, NCCS promotes federal policies that improve cancer care in the United States. Our public policy team serves as both a resource and as advocates for the more than 16 million cancer survivors in the United States.

The legislative process can seem overwhelming, but this step-by-step overview of the federal process will give you a basic understanding of how an idea becomes a law, and it will show you where there are opportunities to get involved.

- Legislation can be drafted and introduced in Congress by any member of the House of Representatives or the Senate.
- Members of Congress frequently get ideas for legislation from their constituents and groups that represent specific causes.
- If representatives hear about how an issue affects their constituents, they are more likely to consider legislation that addresses that problem.
- Once a bill is introduced, it is referred to one or more committees.
- These committees evaluate and amend the bill and vote on whether to move it forward in the process. If a majority of committee members agree to move a bill forward (a process that is called “reporting the bill out of committee”), it is sent to the full House of Representatives or Senate for consideration.
- The bill then goes to the Senate floor or House floor for debate and a vote.
- If a majority of the House or Senate agrees on the bill, it is referred to the other chamber, where it usually follows the same route through committee action and voting.
- After a bill has been approved by both the House and Senate in identical form, it is sent to the President for approval or rejection.

Key Congressional committees and subcommittees

Members of the House of Representatives and the Senate serve on committees that perform a range of functions, including writing and considering legislation, as well as overseeing agencies, programs, and activities.

Several key committees in the House and the Senate oversee programs related to health coverage. These committees are important because, to get legislation passed, it must be introduced and passed out of one of these committees before it is voted on by either the full Senate or the House. The CCPC Act will be considered in both the House Ways and Means and Energy and Commerce Committees, but will only be marked up in Ways and Means.

For more information on the scope of what these committees cover and updates on current legislation, visit senate.gov/committees/committees_home.htm and house.gov/committees/.

Thank you for advocating for cancer care planning so that patients have a roadmap for their cancer care. If you have any questions or would like help setting up meetings, please contact Lindsay Houff at lhouff@canceradvocacy.org