

CHRONIC DISEASE

ADVOCACY TOOLKIT

from The Chronic Disease Coalition



Chronic
Disease
Coalition

"Do what you can, where you are, with what you have,"

-THEODORE ROOSEVELT

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ADVOCACY 101

Merriam Webster defines advocacy (ad-vo-ca-cy) as:
“The act or process of supporting a cause or proposal.”

Advocacy can take several forms. Whether you're asking members of Congress to stop insurance companies from denying coverage for critical medical treatments, educating the public about a condition, or raising awareness to increase research funding, ensuring your voice is heard is a crucial part of protecting patient rights everywhere.

Sharing your story and using your voice is a key component of advocacy.

By advocating for yourself and others with chronic conditions, you can help address stigma, while creating social and political change for generations to come. Luckily, anyone can take part in building a more inclusive and equitable world, but it can be tough to know where to start and how to advocate. This toolkit is the answer to that challenge. Join us as we look at the different ways you can take a stand and create a better health care experience for all.

Five Types of Advocacy



DIGITAL ADVOCACY

Digital advocacy is also called online activism. It includes attending online classes and discussions, posting content on social media, blogging, sharing your story with local news outlets and everything in between. Digital advocacy is highly accessible and a great way to make a big impact from behind a screen!



POLICY ADVOCACY

The democratic process is nothing without the voices of the people. Meeting with legislators, writing letters and speaking publicly are effective ways for advocates to ensure that law and policy decisions are based on input from those affected most.



MEDICAL ADVOCACY

We all must be advocates both in the doctor's office and with insurance companies. Advocating for yourself is key in accessing the appropriate treatment and medical coverage needed to manage your chronic condition.



NEWS MEDIA ADVOCACY

Sharing your story can not only empower yourself and others, but also shame bad actors or highlight practices that prevent patients from accessing care. News media can also be a great way to demonstrate the importance of a topic to elected officials.



COMMUNITY ENGAGEMENT

Advocacy doesn't have to involve Facebook pages, legislators or doctors. You can network and share your story by organizing and participating in events in your own town.

Why Should You Be an Advocate?

Advocacy can sometimes be a lot of work, especially when meeting with legislators, creating a social media presence or organizing a rally. The work of an advocate is never truly done, begging the question: *Why advocate?* For the chronic disease community, there are many reasons why advocating is well worth the time and effort.

Here are just a few:

✓ **Your story matters**

As a chronic disease patient, you have a unique story to tell that can raise awareness, elicit change, educate the public and empower others to do the same.

When advocates speak out together and share their experiences, issues become real to policymakers and the broader community, helping to prompt meaningful action.

✓ **Change is possible**

Advocates are the drivers of change in our health care system. By advocating for ourselves and others, we can expand access to care, end discriminatory insurance practices and shatter chronic disease stereotypes.

✓ **Your voice grows the movement**

Participating in advocacy efforts gives you a unique opportunity to touch the lives of others. Through advocacy, you can grow your network while inspiring others to stand up and speak out about their own chronic disease journey, creating a ripple effect.

✓ **We must stand together for chronic rights**

We see the best results when we stand together in solidarity. Knowing your rights and advocating for your chronic condition can create major change in our society. As a community, we can share our experiences and fight for each other, building a better health care system for generations to come.

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How Can You Get Started?

New advocates can be left scratching their heads when starting their advocacy journey. Knowing what the issue is, who it impacts and how to effect change can be overwhelming. However, starting your advocacy journey is much easier than you may realize.

By addressing four key questions, you'll be on your way to an advocacy plan in no time.

✓ **Identify your issue**

Before you can effect change, you must identify your issue. Begin by considering what impact an issue is having on you and/or others, then determine what specifically needs to change. Knowing this will help guide the rest of your journey.

Ex: I need insurance coverage for the medication that my doctor recommends, but my insurance company is denying the drug until I try a cheaper, less effective option. My insurance company should give approval for my recommended treatment and not be permitted to supersede my doctor's advice in the future.

✓ **Identify your goal**

Once you have identified your issue, ask yourself: *What do I want to achieve?* This could be a personal goal, like getting your health plan to cover a specific treatment you need, or a community goal, such as advocating for legislation that provides everyone with access to the medications prescribed by their doctor.

Ex: My goal is to be heard by my insurer and get my treatment covered, and I want to stop insurers from practicing step therapy and other discriminatory policies to ensure future patients don't experience the challenges I have faced.

✓ **Identify your audience**

After identifying your issue and your goal, you need to determine who has the power to help make the needed change—this is your audience. Depending on your goal, you may have more than one audience. Possible audiences could be legislators, issue experts, other advocates, patients, caregivers or your family and friends.

Ex: To get coverage for my treatment, I will have to direct my message toward my health insurer and my doctor. To make lasting change, I will need to target legislators, as well as engage the people who influence legislators such as authoritative medical experts and thought leaders.

✓ **Identify the right advocacy tactic**

Knowing what you want to say, why you want to say it and who you want to say it to are just the first steps. Understanding the best way to get your message out can be another challenge entirely. Thinking about your own strengths, weaknesses and limitations will help craft your strategy and tactics.

Ex: I want to stop insurers from discriminating against chronic disease patients by talking to legislators in my state, but I cannot get around very easily because of physical limitations. Digital advocacy and interacting with legislators on social media may be a good way for me to advocate within my physical abilities.

Let's go!

Once you have a clear issue, goal, target audience and tactic you've got a plan!

This toolkit builds on this simple step-by-step approach by outlining the various types of advocacy that can help you engage with legislators, patients, doctors and more. **Read on to Take Action!**

TAKE ACTION



DIGITAL ADVOCACY

With the recent rise of technology and social media, chronic disease advocates everywhere can effectively connect and fight discrimination without leaving the living room.

Your story can educate and empower others online.



Online Opportunities

Digital advocacy is more than posting on social media. Advocates can use technology to connect with patients around the world in a variety of ways, through online forums and blogs to live social media events, online classes and webinars. Finding, attending or creating these events helps you learn more about relevant topics while building relationships with other advocates.

Here are some tips to help you engage in digital opportunities:

- ✓ **Identify and follow key groups that interact with your issue or cause.**

ALS Association

American Cancer Society
Cancer Action Network

American Diabetes Association

American Heart Association

American Kidney Fund

Arthritis Foundation

Chronic Disease Coalition

Chron's and Colitis Foundation

Epilepsy Foundation

Leukemia & Lymphoma Society

Muscular Dystrophy Association

National Alliance on
Mental Illness

National Health Council

National Hemophilia
Foundation

National Multiple Sclerosis
Society

National Organization for
Rare Disorders

National Psoriasis
Foundation

Patient Access Network

✓ **Subscribe to newsletters and alerts from key advocacy organizations.**

Stay updated on important online advocacy opportunities and current issues.

✓ **Participate in webinars and online chats.**

You can ask questions of other patients and health care leaders to raise awareness, increase your knowledge and gain exposure.

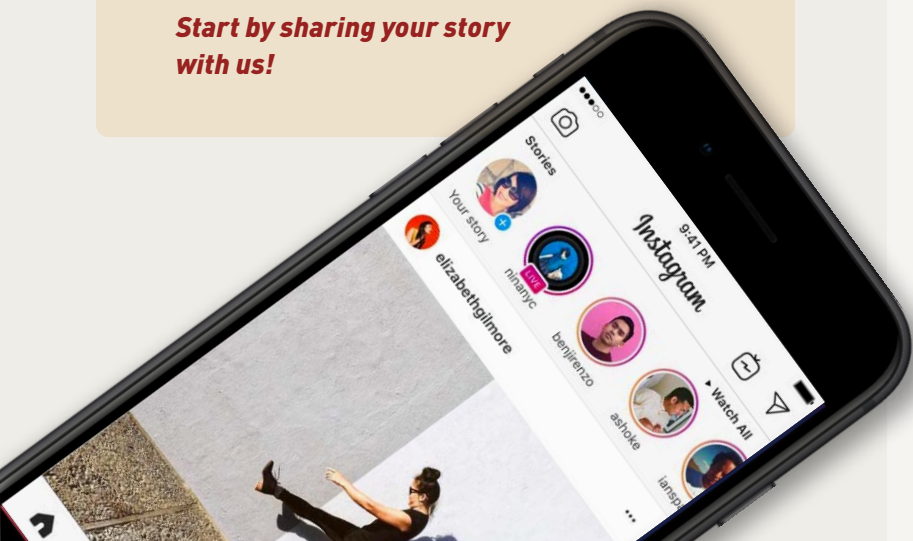
✓ **Identify and subscribe to blogs.**

Remain informed by following relevant news, blogs and organizations. You'll identify opportunities for online collaboration.

Tip:

Contact patient organizations offering support and expertise. Many advocacy organizations will work with patients to organize events, develop educational resources for their community and share advocate stories. Your story can educate, empower and provide hope for those experiencing challenges on their chronic disease journey.

Start by sharing your story with us!






Social Media

Social media is an increasingly integral part of our society, changing the way we learn, interact and connect with one another. Platforms like Instagram and Facebook are great tools to connect with people across the world and build your personal advocacy brand. Having a social media strategy and identity can help position you as a thought leader, amplify your efforts and improve your reach as an advocate.

GET SOCIAL

Between Twitter, Instagram, Facebook, LinkedIn, Pinterest, Tumblr and more, choosing the platform that is best for you can be daunting at first. Factors like your target audience, type of content you plan to share and how much time you are able to dedicate to interacting each day are helpful in determining which platform may be best for you.

	USERS — 1 billion+	RECOMMENDED LENGTH — 100 characters	FREQUENCY — Studies recommend at least 6–7 tweets a day to keep engagement up	Twitter utilizes short text posts and hashtags to have conversations in real-time. This fast-paced platform is helpful if you plan on sharing content multiple times a day and want to engage with thought leaders and decision makers.
	USERS — 1 billion+	RECOMMENDED LENGTH — 150 characters or less	FREQUENCY — Studies recommend posting at least 1–2 times a day	This platform is best for people who share visual content multiple times a week and are looking to create a consistent personal advocacy brand. Advocates can utilize Instagram to share their experience, raise awareness and inspire others more personally through images. For instance, many patients post updates about their treatment, sharing detailed accounts about living with a certain condition.
	USERS — 2.7 billion+	RECOMMENDED LENGTH — 40 characters or less	FREQUENCY — Studies recommend posting at least 5 times a week	Facebook serves as a hybrid with photo, video and text all shared often. This platform is helpful in connecting with advocates, support groups and organizations in all corners of the country. Facebook page and group functions makes meeting other advocates and building your network especially easy.

BUILD A SOCIAL MEDIA PRESENCE

Once you've determined the best social media platform and created your account, you're ready to start interacting and advocating. Maximizing the reach of your content and building a follower base can be difficult, so try these tips to increase engagement and grow your following.

✓ Use relevant #hashtags

Hashtags are keywords following the # sign that serve to group posts and spark conversations. A good rule of thumb is to hashtag two to four relevant keywords in your post. To know if a hashtag is relevant or not, search the keyword on social media. Look at top and recent posts that use the tag. A hashtag can go dormant and not be used for years, so it is important to use hashtags that are active and popular.

✓ Collaborate on social media

Social media is all about engaging with people and building connections online, which includes collaborating with other advocates. Collaborations can take many forms, from promoting an advocate or group's content to creating content or launching a project. You can find other advocates to collaborate and interact with by sending direct messages, sharing posts and commenting.

✓ **Be consistent with your brand** Once you have decided how your profile will look and feel, stick with it. A consistent image and message draws people to your page and frames you as a subject matter expert.

How to build a recognizable brand

- » Use consistent colors to develop a clear aesthetic. Start by looking at the colors that are associated with your chronic condition.
- » Determine your purpose, goal and message and stick to it. Remembering your intent is key when developing a brand and crafting each and every post.
- » Create your own hashtag to put your content in one place. A hashtag like #ChronicRights makes your content easily searchable. It can also be used to have a dialogue online.
- » Create a logo or slogan that captures your mission.

With social media, you can make a big impact even if physical barriers prevent you from leaving home.



Tip:

Free online tools like Canva allow you to easily create stunning graphics. Check out their templates for inspiration.

ENGAGE WITH YOUR AUDIENCE

Now that you have developed your advocacy account, created engaging content and expanded your follower base, you are becoming a powerful social media advocate.

Here are some great ways to advocate using social media:

- » Follow key organizations and advocates
- » Tag these organizations and advocates in your posts
- » Interact with posts related to your issue by commenting or sharing
- » Share news and opinions that position you as a thought leader
- » Track hashtags to participate in trending conversations
- » Support legislation by promoting bills and tagging legislators
- » Direct message other advocates to collaborate and amplify content
- » Join advocacy organizations that provide digital engagement opportunities

Online Etiquette

Creating content is just one of the many things that you can do to advocate online. Sometimes social media advocacy means connecting with other patients or advocates online, and knowing the dos and don'ts of online communication can be difficult.

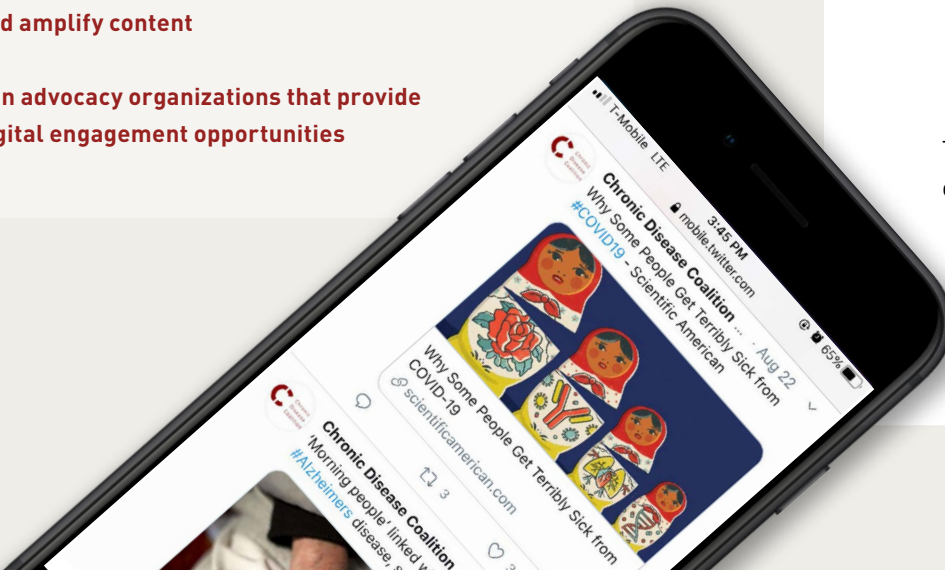
✓ Do

- » Provide supportive comments on content
- » Like and share posts that resonate with you
- » Message content creators with collaboration ideas
- » Utilize personal introductions when contacting advocates on social media
- » Thank content creators and collaborators for their time and support

✓ Don't

- » Block verified advocacy accounts that reach out to you
- » Disclose people's personal information
- » Spam inboxes when waiting for a response
- » Send threatening messages
- » Ask personal questions without an established relationship

These are just a few rules of thumb when communicating online. As you develop your social media and online presence you will find the methods of communication that work best for you, but always remember **kindness** and **patience** when communicating with others from behind a screen.



Creating Compelling Images

VISUALIZE YOUR MESSAGE

Studies show that visually compelling social media posts get more engagement than simple text posts. However, creating compelling imagery can be easier said than done. Free online tools like Canva provide a great space to practice your design skills and create professional social media content with minimal experience.

When creating visual content consider these design elements:

Color: Using consistent colors in your images can help make your social media content cohesive and easily identifiable. Try using **complementary colors** or colors that are opposite on the color wheel, like red and green. If you are having trouble deciding what colors to use, take a look at the colors associated with your condition.



Space: When designing visual content, it is important to remember how you are using space. **Don't clutter your design with unnecessary words and design elements.**

Type: Choosing the right type face can make or break an image. **A good rule of thumb is to choose fonts that fit the tone of your image.** For example, if the image is informative, a clean and legible typeface may be best. You can utilize various fonts and sizes to highlight specific messages and make certain elements stand out.

Emphasis: Determining the emphasis of your graphic can be the difference between engaging and boring content. Be sure to remember the emphasis of your message and **create your design accordingly by making the most important information stand out.**

Balance: Aside from the basics of design, considering the balance of your imagery can be a great way to elevate your content. When thinking about the balance of your graphic, consider where the majority of the color and content are in the design. **Try and balance elements in your design by remembering the rules of symmetry and considering where there is blank space!**

3 KIDNEY PATIENTS SPEAK OUT ABOUT CHARITABLE PREMIUM ASSISTANCE

CHRONICDISEASECOALITION.COM

DIGITAL HUG!

Thank you for being a part of our chronic disease community



TRAVEL TIP:

BRING HEATING AND COOLING PADS TO EASE ANY PAIN FLARE-UPS

Comfort is key on extended trips. It is smart to be prepared for any unexpected pain.



TAKE ACTION

NEWS MEDIA ADVOCACY

News media advocacy is all about using news outlets to help tell your story. In addition to connecting with organizations and patients online, technology allows you to share your story with a larger audience than ever before—even if you never step out the front door.



Storytelling Tips

IDENTIFY THE NARRATIVE

Stories are more than words on paper. They provide a crucial opportunity for the writer to connect with their readers on a deeper level that can inspire action and change. Before you can tell your story you have to learn the basics of storytelling and writing. **Try preparing an outline of your story using these four key elements.**



Character: When defining your story, it is important to ensure your character is relatable and authentic. In the case of advocacy, the character is typically based on accounts of real-life experiences, so accuracy and honesty are key. Ensuring your audience understands the character in your story and feels connected to their journey is an important part of telling your story or helping someone to tell theirs.



Conflict: Every good story has some form of conflict. Whether its dealing with insurers, coping with your condition or finding treatment options, it's important to identify the struggles and experiences that will drive your story and leave an impression on your readers.



Turning Point: This refers to the point where the character or experience changes. When telling your story, it is important to remember what moments fundamentally impacted your chronic disease journey. For example, you may be dealing with insurance discrimination, but it was not until you discovered the power of digital advocacy that you decided to act. This moment where the character decides to change is the "turning point" and a crucial part in the progression of your story.



Resolution: After taking your reader on a journey of insurance discrimination and chronic disease information, it is important to remember the resolution of your story. What was the outcome? Keep in mind, the resolution does not have to be happy or positive, but instead it should leave the reader feeling some sense of closure with a clear and powerful message.

IDENTIFY YOUR CALL TO ACTION

Once you have identified the various parts of your story, it's important to remember how this story can be used for advocacy. What is the action you want your audience to take? Not all stories have a clear call to action, and some are strictly educational, but chronic patients can utilize their story to connect with patients, legislators and community members to drive home an important call for change. The more specific you can be about what steps must be taken to address the change, the easier you make it for your audience to act. These actions could be as simple as sharing your story on social media or encouraging other advocates to join the conversation. No matter the ask, don't forget to leave your reader with a clear next step!

TAKE YOUR STORY TO THE PEOPLE

Your story can take many forms, and it may depend upon your focus, the audience or the publication you'd like to reach. First, you must decide if your story is best fit for an opinion piece, letter to the editor, or a more traditional news segment like a general print or broadcast story.

Let's review these story types.

Selecting the right type of news outlet is key to reaching your ideal audience.

✓ **Letter to the editor**

Also known as an LTE, a letter to the editor is a short piece, usually less than 250 words, typically written by a reader to a publication expressing an opinion. Subject matter can take many forms, but typically an LTE will focus on controversial and/or timely issues to connect with elected officials and community members.

Ex: My local news publication has been writing about Multiple Sclerosis, but they have overlooked the insurance hurdles that patients face.

✓ **Opinion editorial**

Commonly referred to as an op-ed, an opinion editorial is a piece where the author's opinion is clearly stated and supported by persuasive arguments. While traditional news is typically focused on facts and objectivity, op-eds use facts to argue a side of an issue and call on your community to act. Much like an LTE, op-eds are a great way to use your story to influence others to act.

Ex: My state is considering new rules requiring Medicaid enrollees to work a certain number of hours to remain eligible for coverage. This requirement would worsen my condition and isn't the right solution.

✓ **News and feature stories**

These are stories you might read in a newspaper or magazine. News stories are based on facts and the impacts of events. Feature stories are often about the human experience or culture. Both types of stories are better with first-hand accounts from real people. You can contact reporters at local and national news outlets and offer to tell your story.

Ex: My insurer isn't covering my lifesaving treatment. I can tell my story publicly and shame my insurer into providing coverage while raising awareness of injustice.

✓ **Broadcast segment**

Broadcast segments are news stories that incorporate visual elements. If you are pitching a broadcast segment, it is important to focus on a visual element that could accompany the story. This visual element could even be a personal interview on camera or photos that highlight a part of your story.

Ex: I have trouble getting into certain buildings due to ADA Accessibility, my story is largely told through visuals.

Once you have decided which news format best complements your story, it is time to decide where to pitch your piece or story. **Next step: Develop a media list!**

Reporters are always looking for first-hand accounts of how issues are affecting real people.

DEVELOP A MEDIA LIST

The best media pitches are targeted to the right reporter. To effectively pitch a story you need to identify which publications or news outlets may be interested in covering your story. Start by researching health care and related news topics in your area. Be sure to note which outlets are talking about your issue, who is writing or reporting on it and start a list.

After you have identified which outlets are talking about your interests, you need to identify a contact person. Many news stations will have a general email to submit a news tip, but based on your research, you can also pitch your story directly to a reporter or contact person who would be interested in the topic. Every individual in a newsroom serves a unique role and knowing these roles is helpful when pitching your story.

Tip:

Make a list of news outlets and contacts with specific areas of interest. You can reference this list when pitching stories or trying to contact someone at your local news outlets.

Identifying contact information for reporters you think would be interested in your story is not as hard as it may sound. Many publications share contact lists publicly, but if you can't find an email address or phone number, searching the name of the reporter or editor online might produce contact information.

Once you have an email or phone number, prepare to deliver your pitch! If you can't find contact information, **you can always call the front desk or main office of the news outlet to ask how you can reach a specific reporter.**

Remember, it's a reporter's job to find people just like you! **Don't be intimidated to call a newsroom directly.**

✓ **News assignment desk**

Sometimes outlets will provide contact information for the general news desk or main phone line. The news desk ensures stories are being assigned to reporters and produced in a timely manner. This is a good place to start when contacting a news outlet to pitch a general news or broadcast story.

✓ **Reporter**

Reporters research stories, conduct interviews and ultimately write and report on the news. Many reporters focus on specific subject areas such as health care, government, education, human interest, arts, entertainment and more. Ensuring you have targeted the right reporter for your pitch is key in capturing their interest and having your story published.

✓ **Editor**

Newsrooms are often staffed by multiple editors who oversee different areas of interest also known as beats. Editors do more than just review grammar and spelling—many also serve as an extra set of eyes for reporters, verifying information and ensuring the news being published is relevant and accurate. Editors also manage the editorial content, so if you are submitting an op-ed or LTE, you may want to follow up directly with them.



KEEP IT SHORT AND SWEET

When pitching a story to the news media it is important to provide a clear and concise summary that emphasizes your topic's relevance to the outlet's readers or viewers. Stories can be pitched via phone or email but knowing how to do both may help get your story published.

Use the storytelling tips on page 11!

✓ **Perfecting your pitch**

- » **Who are the key players in this story?** This could include you, your insurer, your doctor, a state agency, or anyone else involved in your story. These specific details matter.
- » **What is the story?** Remember to assemble a powerful narrative by thinking about character, conflict, turning point and resolution using the outline on page 11.
- » **Where is the story taking place?** If pitching at the local level, think about your story's relevance to your community, but if you are pitching to national publications like the New York Times, consider describing why your story is relevant to people everywhere.
- » **When is this story taking place?** Sometimes your story may have no set timeline, but other times your story may be built around a specific event. Typically, recent events are easier to pitch to local media.
- » **Why is your story relevant?** This is the most important element of your pitch. Most reporters are managing several stories at once, so they are always thinking about why a story is relevant to their readers. Be sure to include why your story is newsworthy at the start of your pitch. If a reporter is interested, they will often follow up with you the same day or soon after.

✓ **Types of pitches**



Email pitch

Put the most important information toward the top of your email and remember to use paragraph breaks and bullets if needed to make information easily digestible. Some important elements to include:

- » **A clear subject line**
- » **The who, what, when, where and why your story is important to the public now**
- » **What sources or information you can offer (e.g., on-camera interviews, access to supplementary sources, etc.)**
- » **Visual opportunities (e.g., interviews in-person or virtually, stock footage for video broadcasts, photos, etc.)**
- » **How to contact you to learn more**



Phone pitch

Sometimes making a direct phone call is the best way to get your story in the news, or to learn more about why your story hasn't gained traction. Before calling your local news outlet or reporter, consider preparing a short script with important points you'd like to share. Remember, keep it short and sweet, put the most important information first, emphasize your story's importance to the public and thank the reporter for their time and consideration. Be prepared with contact information.

Tip:

When pitching stories to news media, send an email first thing in the morning and follow up with a phone call to ensure the recipient has seen your message.

Preparing for an Interview

News media may want to interview you to provide a visual or narrative element to your story. Talking in front of a camera or with a reporter can be scary but these key tips can help you prepare for your interview.

✓ **Think about the details of your story.** Sometimes it can be helpful to write down the key details or “talking points” you hope to discuss in your interview. Use the Perfecting Your Pitch outline on page 14 to plan out your narrative.

✓ **Remember to remain calm and ask questions.** Most reporters understand that people aren’t always comfortable interviewing. Don’t be afraid to discuss what the interview will entail and what questions the reporter hopes to cover beforehand.

✓ **Don’t be afraid to stray from the plan.** The best interviews and stories come from advocates who are passionate and informed about their topic. Don’t hesitate to be yourself and let the conversation flow naturally. Imagine you are sharing your story with a friend or family member, but don’t forget your manners on camera!

✓ **Next question, please!** Remember, you are not required to answer any questions, if you feel the reporter is being pushy, not respecting your boundaries and straying from what was discussed beforehand, ask for the next question or end the interview.

The best interviews and stories come from advocates who are passionate and informed about their topic.



TAKE ACTION



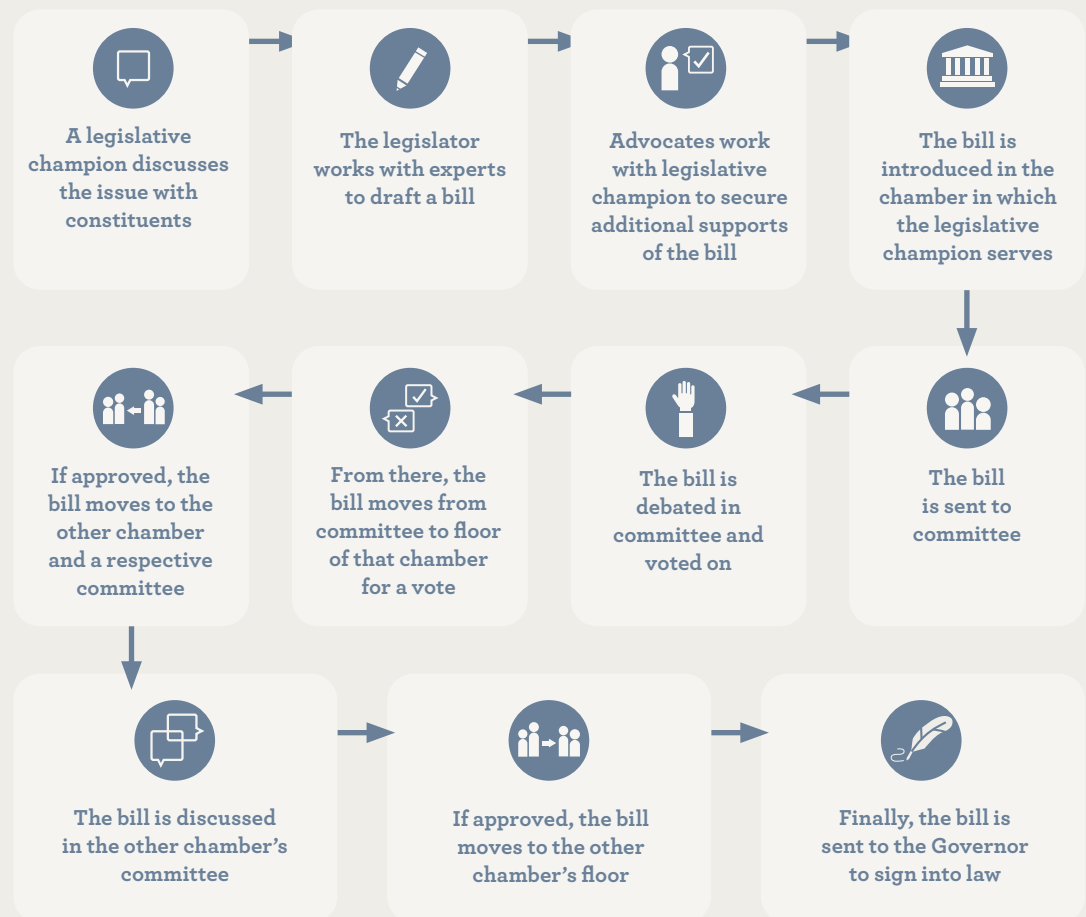
POLICY ADVOCACY

If you are able, advocating in the Capitol and working with legislators in person is a powerful way to promote your issue and make change. In this section, we will break down the legislative process and discuss ways you can advocate for your chronic condition with elected officials.

Understanding the Legislative Process

The legislative process can seem intimidating at first, but it's essential that advocates understand how policies and law are created at the state and national level. Lawmaking governs the activities of insurance companies, physicians and many other areas of focus for advocates. Taking the time to learn how laws are made will make you a much more effective advocate. Lawmaking can vary from state to state and at the national level, but there is a common process for how ideas become a written bill which can become a law.

HOW A BILL BECOMES LAW





KNOW HOW TO TRACK A BILL

It's helpful for advocates to keep an eye on legislation as it moves through the process.

Legislation may move from one committee to the next or the house floor with little warning. Amendments to bills can be changed at the last minute without explanation. Bills can be packaged together around a larger issue. This can affect a bill's success or failure.

Make sure you are aware of what's happening so you can better advocate with legislators and their support staff.

SUSTAINED, CONSISTENT ADVOCACY IS KEY TO MAKING PROGRESS

Keep this in mind: if your issue isn't an issue for the leaders of the House and Senate, then your issue isn't going anywhere.

Whether at the state or federal level, the leaders of the House and Senate bodies control every bill that moves through their chambers. The Speaker of the House and the President of the Senate will typically not bring any bill to the floor for a vote unless they know it is going to pass.

It is challenging to elevate issues above the fray of typical legislative battles, making it important that advocates remain engaged in a sustained and unified manner.

Follow these tips:

- » **Know your goal.** Try to do enough research that you are clear on the solution you wish to see.
- » **Message your goal clearly.** Be clear in your call to action. Make sure you can articulate your ask of legislators.
- » **Don't give up.** Sometimes it can take many years to elevate an issue to the point that a bill can be passed. Don't get discouraged! It's a marathon, not a sprint.

Tip

Once a federal bill gets a number, you can keep track of it at www.congress.gov.

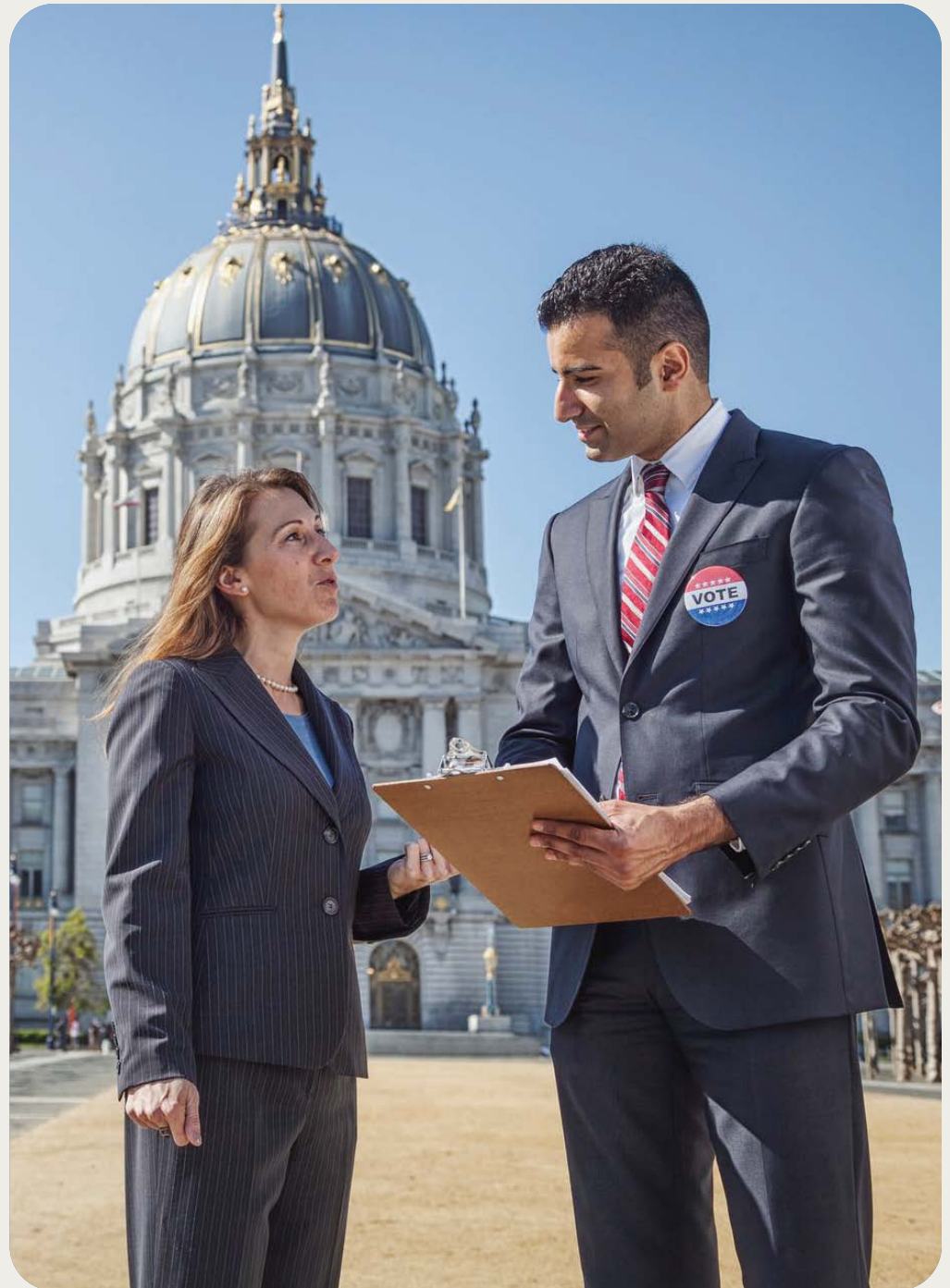
Speaking with Legislators

Meeting with legislators is a critical part of influencing how policy gets created. They need to hear from you in order to understand the importance of the law and what problems it must try to solve. Legislators want to hear from constituents. You should feel confident reaching out and asking to meet. Here are some steps to ensure you have a great connection once you've secured a meeting.

- ✓ **Plan your conversation.** When meeting with a legislator, it is especially important to show up prepared. **Become educated on your issue, prepare examples and resources and have a clear ask for your legislator.** By meeting with legislators in-person, you can have a lasting impact on the policy directives they are prioritizing and how they vote on key issues.
- ✓ **Arrive on time.** Legislators are remarkably busy. Some elected officials will meet with dozens of constituents in a single day. **Arriving to your meeting on time and ensuring you are prepared to utilize that time is key in leaving a good impression.**
- ✓ **Follow up.** After having a conversation with your state or federal representative, **it is important to follow up with a thank you email, phone call and/or social media post that reiterates your ask.** By following up, you are showing that you care about your issue and the time your legislator took to learn about it.

Follow up with a social media post and tag your legislator, thanking them for meeting with you while highlighting the issue.

Tip



Getting to Know Staffers

Having a good relationship with your legislative representatives is critical to ensuring they will be a good champion for your cause. But an invaluable and often overlooked relationship for advocates are legislative staff members. Many visitors to the capitol may feel slighted when they must meet with a staff member, instead of the member themselves but this is not an opportunity to be wasted!

- ✓ **Staffers often know more about the status of a bill or issue than the member themselves.** For this reason it is important to have a good relationship with legislative aids who deal with health care matters. They will be able to provide you the inside scoop.
- ✓ **Keep in mind that the legislative staffer is responsible for keeping an eye on ALL bills in their portfolio,** and that can cover multiple issue areas, so that your representative does not miss anything. If you are offering to help track an issue or provide solid background info when they need it, they will likely accept your offer and return the favor!
- ✓ **Remember, you are an ambassador for your patient group, dedicating your time to advocate for a cause that is important to you.** It's appropriate to reach out to staff members directly and consistently. Once a staffer knows you are legit and not a disgruntled taxpayer, they will likely share their personal email or phone number with you to share information more directly.

Other Forms of Policy Advocacy

Policy advocacy can mean more than spending all day at the Capitol. Advocates can create policy change in many ways, including getting advocacy days recognized by local government, sending letters to legislators and attending rallies in support of your issue. Follow key advocacy organizations to keep track of important events and opportunities for you to advocate. Check out the Chronic Disease Coalition website to send a letter to your legislator.



TAKE ACTION



MEDICAL ADVOCACY

Advocacy extends beyond politics to the doctor's office and, more commonly, your health insurance company. Sometimes you must advocate to get proper testing or a proper diagnosis. Other times, you may have to fight to get the treatment and insurance coverage you've paid for. Take charge by learning how to communicate with your doctor and navigate insurance denials, ensuring you get the best care possible.

Advocating for yourself and communicating with your health care provider is key to managing your chronic condition.

Communicating with Your Doctor

EXPLAIN YOUR CONDITION

Ensuring you get the coverage and treatment you need is crucial when battling chronic disease. To get adequate treatment, you need to communicate and work with your doctor effectively. Before talking with your doctor, think about how you've been feeling, your symptoms and potential issues you may have experienced from your treatment.

MAKING YOUR VOICE HEARD

- ✓ **Be prepared:** Talking with your doctor can be difficult, but being prepared to ask and answer questions can be a great way to start that conversation. **Keep a close record of your experiences with your condition so you are prepared to answer tough questions.** This includes recent medications, allergies, symptoms and more.
- ✓ **Be direct and respectful:** Don't be afraid to stand up for yourself and respectfully correct your doctor if they mishear or overlook your concerns. **Clearly explaining your experience and concerns helps provide the doctor with necessary feedback that will inform your care.**
- ✓ **Ask researched questions:** **Research your condition and utilize reliable sources** like the [Centers for Disease Control and Prevention](#) to develop and ask your own questions. By interacting with your doctor and asking good questions, you demonstrate an understanding of your condition that can open up the conversation and help build a relationship with your care provider.

Tip:

Take notes to keep track of important conversations with medical professionals.



Helpful questions to ask your doctor:

- What impact will my treatment have on my quality of life?
- What lifestyle changes can I make to improve my condition?
- Who can I contact to get more specific information on my condition?
- Can I expect my condition to worsen or improve? What is the expected progression for my condition?
- Is this treatment covered? How can I get coverage for this treatment?
- Am I eligible for any clinical or experimental trials?
- What does recent research say about my condition?
- Are there alternative treatment options I should investigate?
- Do you know of any patient support groups for my chronic illness?

When to Find a New Doctor

Talking with your doctor is an important part of advocating for yourself and your condition. If you feel your doctor does not have your health and wellness as their top priority it is important to do some research:

- ✓ **What are others saying about the doctor online?**
- ✓ **Ask your care provider if they offer a patient advocate program.**
- ✓ **Can you work with a social worker to find a better doctor?**
- ✓ **Look online to identify where other patients are having success.**

Finding a quality doctor that understands your condition and goes above and beyond to provide care can sometimes be difficult, but they will play an important role in your health and wellness, so take your time when selecting a new doctor. Ultimately, don't be afraid to switch providers if necessary.

Appealing an Insurance Denial

Imagine you need a critical treatment for a serious health condition. You talk to your doctor, have a diagnosis and a prescription, but your insurer says they won't cover it—it not unless you try and fail on another medication first, one that a doctor did not prescribe. This process is known as step therapy. Unfortunately, discriminatory insurance practices like step therapy are all too common in the chronic disease community, and sometimes you must fight your insurer to get the coverage you deserve. In this section, we will look at how to navigate insurance denials and stand up to your insurer.

Be sure to document everything!

DOCUMENT EVERYTHING

The first step to appealing an insurance denial is being prepared. Keep a clear record of everything from conversations with doctors to medication schedules and prior approvals. Be sure to remain organized so that you can provide details to your insurer when necessary.

- ✓ **Keep a record of who you have spoken with at your insurance agency and what the conversation entailed.** It's helpful to keep a call log of who you spoke with, when you talked and what they said to reference back as you move through the process.
- ✓ **Document everything so you are better prepared to walk through coverage conversations.** Share this background information with your insurer to pressure them to reverse their decision or to grant you coverage.

KNOW YOUR COVERAGE

In addition to being prepared with documents, patients should research and know the details of their health plan. CDC Ambassador and endometriosis Advocate Samantha Bowick recommends these helpful questions to better understand your insurance coverage:

- ✓ **Do I have to have a referral to see a specialist for it to be covered?** If so, is there any way I can override this if my doctor will not refer me to a specialist for my illness?
- ✓ **How long does it take for prior authorizations to be approved?**
- ✓ **Is there anything I can do if a doctor I want to see for my illness is out of network?**
- ✓ **What is involved in the appeal process?**

Tip:

Insurance companies may require prior authorizations for various types of treatment. This means your pharmacy and doctor must work together to send the insurance company paperwork regarding treatment. Approval can sometimes take days or weeks. If it is not approved, the patient is responsible for paying the entire cost—be aware!

STOP, COLLABORATE AND LISTEN!

Appealing an insurance denial requires time, patience and teamwork to ensure you have the evidence and information to get coverage for your treatment. This means communicating with your doctor's office, reviewing paperwork and clinical guidelines and having a peer-to-peer evaluation with your insurer. By being persistent and communicating through all the channels in your health care network, you will be better prepared to stand up to your insurer and get the coverage you deserve.

Tip:

If your insurer refuses to cover your doctor's recommended treatment, contact local media using tips on page 14 of this toolkit. Patients have earned coverage for treatments by bringing media attention to insurance discrimination.

EXAMPLES: Three examples of news media helping people gain coverage.

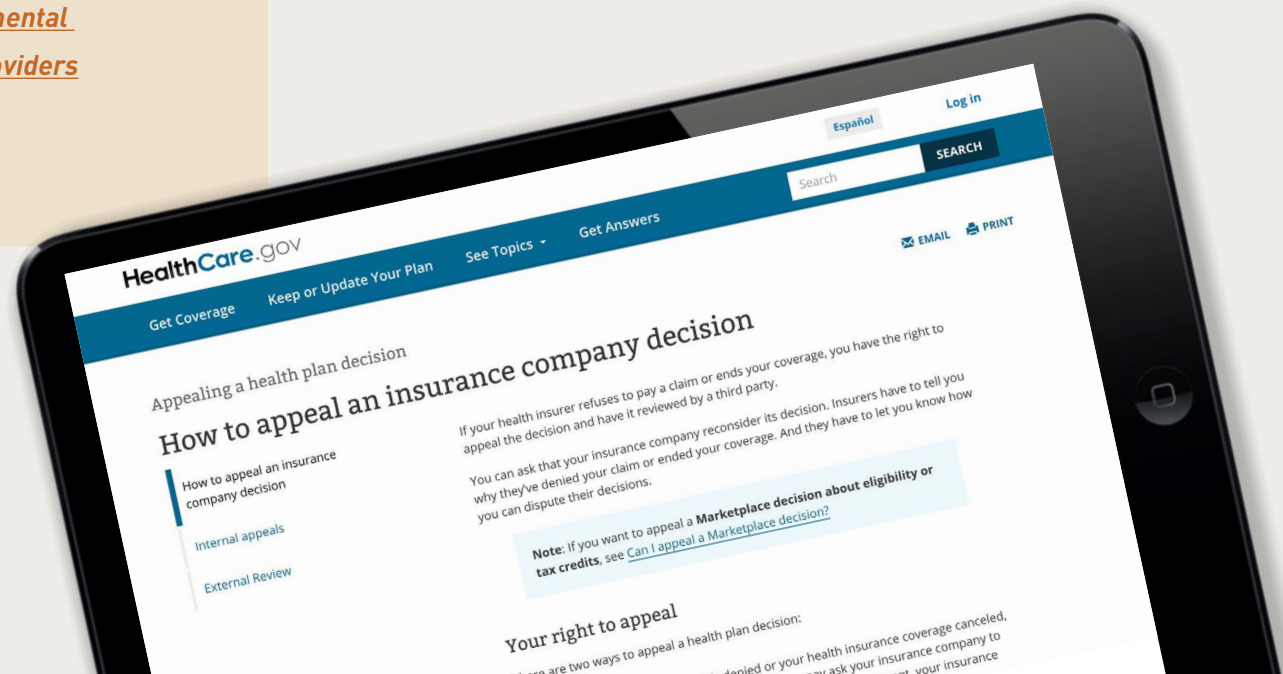
- » 'Maisie's Army' Helps 16 Other Children Get Life-Saving Medication Denied By Insurance
- » "I was being penalized for having breast cancer": Survivor fights with insurance over follow-up tests
- » 'Wrongfully denied: Minnesotans fighting mental illness denied coverage from insurance providers

Still Not Sure Where to Start?

Even after discussions with your doctor and insurer, you may still have questions. In that case, turning to online resources can help answer some basic questions.

Check out these helpful resources from the Department of Health and Human Services and the Center for Medicare and Medicaid Services to learn more about appealing an insurance denial.

- ✓ ["How to appeal an insurance company decision" by HealthCare.gov](#)
- ✓ ["Appealing Health Plan Decisions" from the Department of Health and Human Services](#)
- ✓ ["Appealing Health Plan Decisions" from the Center for Medicare and Medicaid Services](#)



TAKE ACTION



COMMUNITY ENGAGEMENT

In addition to the other forms of advocacy mentioned in this toolkit, community engagement is an excellent, local way to advocate for your chronic condition. This section discusses how to identify and create opportunities for advocacy within your community.

Community engagement is an excellent, local way to advocate for your chronic condition.

Identifying an Advocacy Opportunity

Forums, luncheons, charity auctions and awareness walks are all examples of community-based advocacy opportunities.

If you're having trouble identifying opportunities in your community try some of these helpful tips to spot important events:

- ✓ **Connect with patient advocacy organizations**
- ✓ **Connect with other advocates**
- ✓ **Attend local chronic disease support groups**
- ✓ **Research and understand the chronic disease conversation in your area**
- ✓ **Check your local state capitol's events page**
- ✓ **Ask your health care provider for recommendations**

Organizing an Advocacy Event

In some places it can be tough to find a local advocacy community, especially for rare disease patients. However, you can lead in your community by organizing an event or group of your own. By creating communities, you can spread your message and connect with new patients to ensure chronic voices are being heard across the country. These events could be advocacy walks, rallies, support groups, health fairs, official advocacy days and much more. **Before you build your local chronic community event, keep these key details in mind:**

- ✓ **Identify a date, time, location and purpose**
- ✓ **Ensure your event complies with local and state regulations**
- ✓ **Connect with local advocates to collaborate**
- ✓ **Create a clear and concise message**
- ✓ **Follow up with event notification reminders**

Still Wondering How You Can Create an Advocacy Community in Your Area?

CDC Ambassadors are showing up in all kinds of ways for their community. There's no wrong way to take the lead on building support within the chronic disease community. Here are two success stories for inspiration!



Michelle Johnson

CDC Ambassador and endometriosis advocate Michelle Johnson was looking for an opportunity to raise awareness for Endometriosis Awareness Month in her area. After contacting both her Governor and mayor, Michelle was able to get Endometriosis Awareness Month identified by both the City of Chicago and the State of Illinois sparking statewide conversations about endo and women's health!



Breanna Romaine-Guiliano

When COVID-19 hit, CDC Ambassador Breanna Romaine-Guiliano wondered what she could do to help her community. She did everything she could by bringing meals to those in need and providing various kinds of relief to at-risk patients stuck at home. Breanna expanded the reach of her own mutual aid efforts and developed an online mutual aid training program with the CDC, which was used to educate advocates about mobilizing locally to provide COVID relief.

TOOLS & TIPS

The following pages are designed to serve as handouts or cheat-sheets for training. Keep them handy at your desk for easy access!



TOOLS & TIPS CONTENTS	
Creating Powerful Stories	27
Creating Compelling Images	28
Working with Media	29

Creating Powerful Stories

IDENTIFY THE NARRATIVE

Stories are more than words on paper. They provide a crucial opportunity for the writer to connect with their readers on a deeper level that can inspire action and change. However, before you can tell your story you have to learn the basis of storytelling and writing.

Try preparing an outline of your story using these four key story elements.



IDENTIFY YOUR CALL TO ACTION

Once you have identified the various parts of your story, it's important to remember how this story can be used for advocacy. What is the action you want your audience to take? Not all stories have a clear call to action, and some are strictly educational, but chronic patients can utilize their story to connect with patients, legislators, and community members to drive home an important call for change. The more specific you can be about

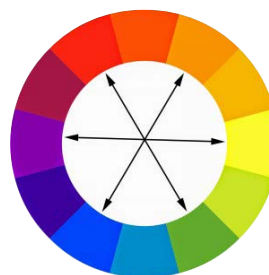
what steps must be taken to address the change, the easier you make it for your audience to act. These actions could be as simple as sharing your story on social media or encouraging other advocates to join the conversation. No matter the ask, don't forget to leave your reader with a clear next step!

Creating Compelling Images

Studies show that visually compelling social media posts get more engagement than simple text posts. However, creating compelling imagery can be easier said than done, especially when design is not your cup of tea. Free online tools like Canva provide a great space to practice your design skills and create stunning social media content with minimal experience.

When creating visual content consider these design elements:

Color Using consistent colors in your images can help make your social media content cohesive and easily identifiable. Try using **complementary colors** or colors that are opposite on the color wheel, like red and green. If you are having trouble deciding what colors to use, take a look at the colors associated with your condition.



Space When designing visual content, it is important to remember how you are using space. **Don't clutter your design with unnecessary words and design elements.**

Type Choosing the right type face can make or break an image. **A good rule of thumb is to choose fonts that fit the tone of your image.** For example, if the image is informative, a clean and legible typeface may be best. You can utilize various fonts and sizes to highlight specific messages and make certain elements stand out.

Emphasis Determining the emphasis of your graphic can be the difference between engaging and boring content. Be sure to remember the emphasis of your message and **create your design accordingly by making the most important information stand out.**

Balance Aside from the basics of design, considering the balance of your imagery can be a great way to elevate your content. When thinking about the balance of your graphic, consider where the majority of the color and content are in the design. **Try and balance elements in your design by remembering the rules of symmetry and considering where there is blank space!**

**3 KIDNEY PATIENTS SPEAK
OUT ABOUT CHARITABLE
PREMIUM ASSISTANCE**

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Disease
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TRAVEL TIP:

**BRING HEATING
AND COOLING
PADS TO EASE
ANY PAIN
FLARE-UPS**

Comfort is key on extended trips.
It is smart to be prepared for any
unexpected pain.



Working with Media



Part of advocacy involves sharing your story both online and on the news, but before you can get your story widely published, it's important to remember the basics of news media pitching. For more information on news media, check out page 12 in the CDC Advocacy Toolkit.

Identifying reporters

Before getting your story on the news, you must identify the reporters that would be interested in covering your story. When looking for reporters to target your pitch, try searching for your chronic condition or topic of interest at local news stations.

For example, searching diabetes news in Houston, Texas may yield recent publications that have talked about your issue. Identify the author of the story and find contact information for the reporter either online or on the broadcast station's website.

Pro Tip

Many reporters have an email associated with their publication. Try finding a cell phone number to follow up with as well, often times reporters may miss an email and are eager to cover a story after connecting with a quality source. Also check reporters' social media channels, many reporters will publish their emails or contact information on Twitter, Facebook and Instagram.

Pitching your story

After you have identified your reporters it's time to prepare your pitch; unfortunately, preparing an effective and informative pitch can be easier said than done. **Try answering these questions when thinking about taking your story to the news:**

- ✓ **Who are the key players in this story?** This could include you, your insurer, your doctor, a state agency, or anyone else involved in your story. These specific details matter.
- ✓ **What is the story?** Remember to assemble a powerful narrative by thinking about character, conflict, turning point and resolution using the outline on page 11 of the CDC Advocacy Toolkit.
- ✓ **Where is the story taking place?** If pitching at the local level, think about your story's relevance to your community, but if you are pitching to national publications like the New York Times, consider describing why your story is relevant to people everywhere.
- ✓ **When is this story taking place?** Sometimes your story may have no set timeline, but other times your story may be built around a specific event. Typically, recent events are easier to pitch to local media.
- ✓ **Why is your story relevant?** This is the most important element of your pitch. Most reporters are managing several stories at once, so they are always thinking about why a story is relevant to their readers. Be sure to include why your story is newsworthy at the start of your pitch. If a reporter is interested, they will often follow up with you the same day or soon after.

Preparing for an interview

Sometimes the news media will want to interview you to provide a visual or narrative element to your story. Talking in front of a camera or with a reporter can be scary but remembering **these key tips can help you prepare for your interview.**

- ✓ **Think about the details of your story.** Sometimes it can be helpful to write down the key details or "talking points" you hope to discuss in your interview. Use the Perfecting Your Pitch outline on page 14 of the CDC Advocacy Toolkit to plan out your narrative.
- ✓ **Remember to remain calm and ask questions.** Most reporters understand that people aren't always comfortable interviewing. Don't be afraid to discuss what the interview will entail and what questions the reporter hopes to cover beforehand.
- ✓ **Don't be afraid to stray from the plan.** The best interviews and stories come from advocates who are passionate and informed about their topic. Don't hesitate to be yourself and let the conversation flow naturally. Imagine you are sharing your story with a friend or family member, but don't forget your manners on camera!
- ✓ **Next question, please!** Remember, you are not required to answer any questions, if you feel the reporter is being pushy, not respecting your boundaries and straying from what was discussed beforehand, ask for the next question or end the interview.

Notes



Chronic
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Coalition

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LEARN. ENGAGE. ADVOCATE.