



Chronic Disease Advocacy Toolkit

Updated January 2026

Advocacy 101

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.



Advocating for yourself and others with chronic conditions can help address stigma while creating social and political change for generations to come. 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. Keep reading to learn about 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!



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 or affording care. News media can also be a great way to demonstrate the importance of a topic to elected officials.



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.



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 community.

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. Advocating for ourselves and others can help 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.



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's 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 it's 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's 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's 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 can 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!

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 storytelling tips on page 3 to plan out your narrative.

Remain calm and remember to ask questions.

Most reporters understand that people aren't always comfortable interviewing. Don't be afraid to discuss beforehand what the interview will entail and what questions the reporter hopes to cover.

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 or is straying from what was discussed beforehand, ask for the next question or end the interview.



TAKE ACTION



POLICY ADVOCACY

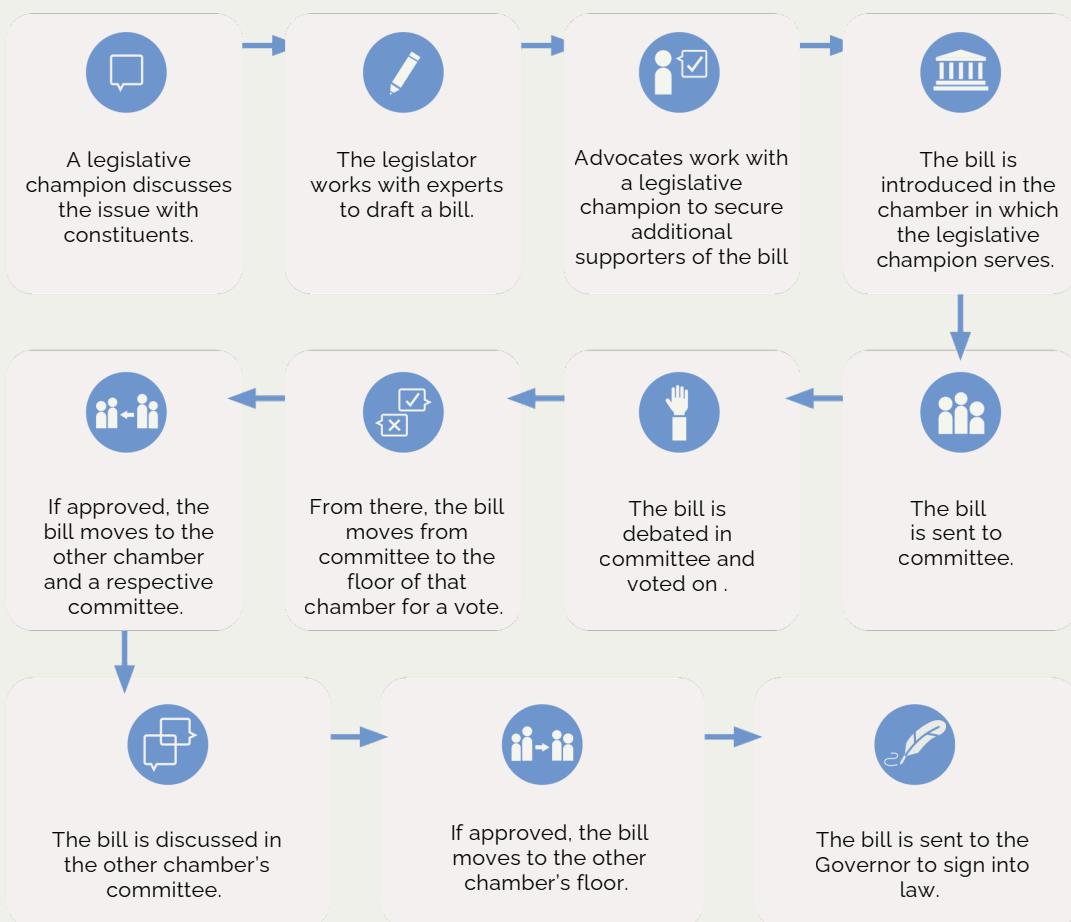
If you are able, advocating in the Capitol and working with legislators in person is a powerful way to promote your issue and make change. In this section, we break down the legislative process and discuss ways you can advocate for your chronic condition with elected officials.

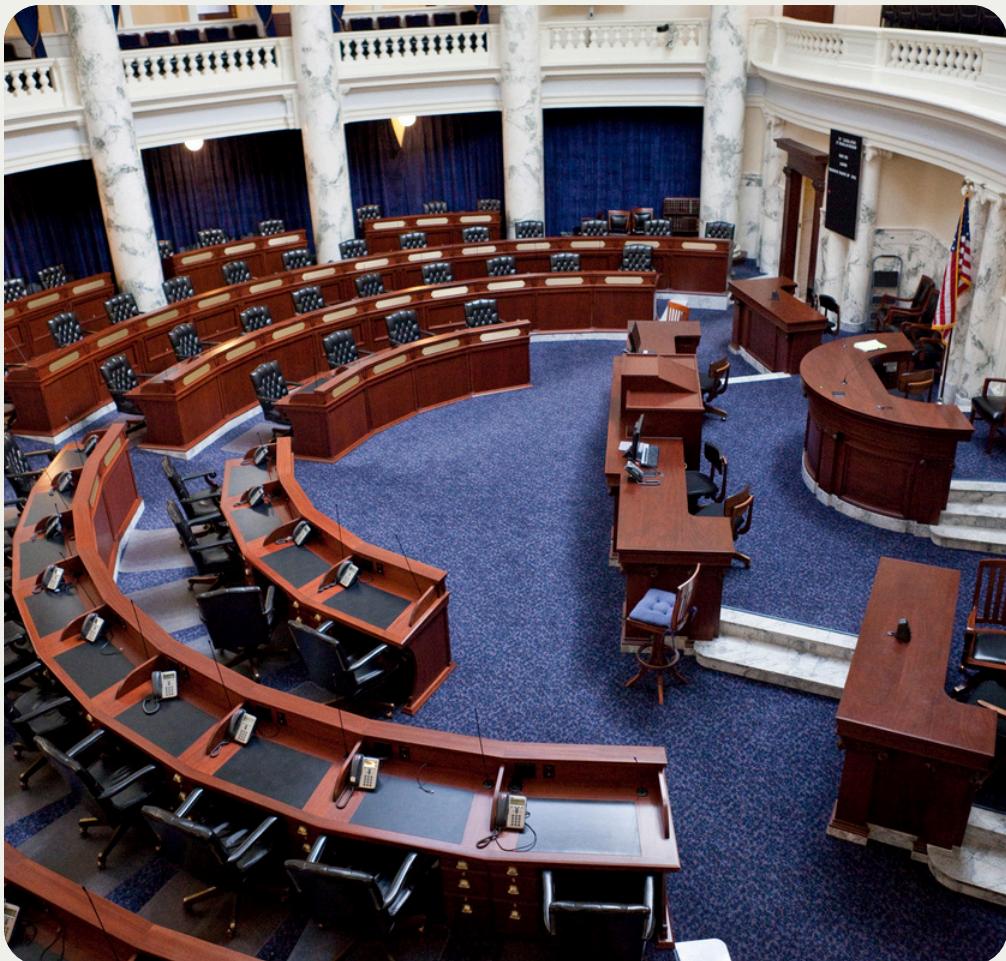


Understanding the Legislative Process

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 to 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's going to pass.

It's 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 track 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 tips to ensure you have a great connection once you've secured a meeting.

Plan your conversation.

When meeting with a legislator, it's 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.

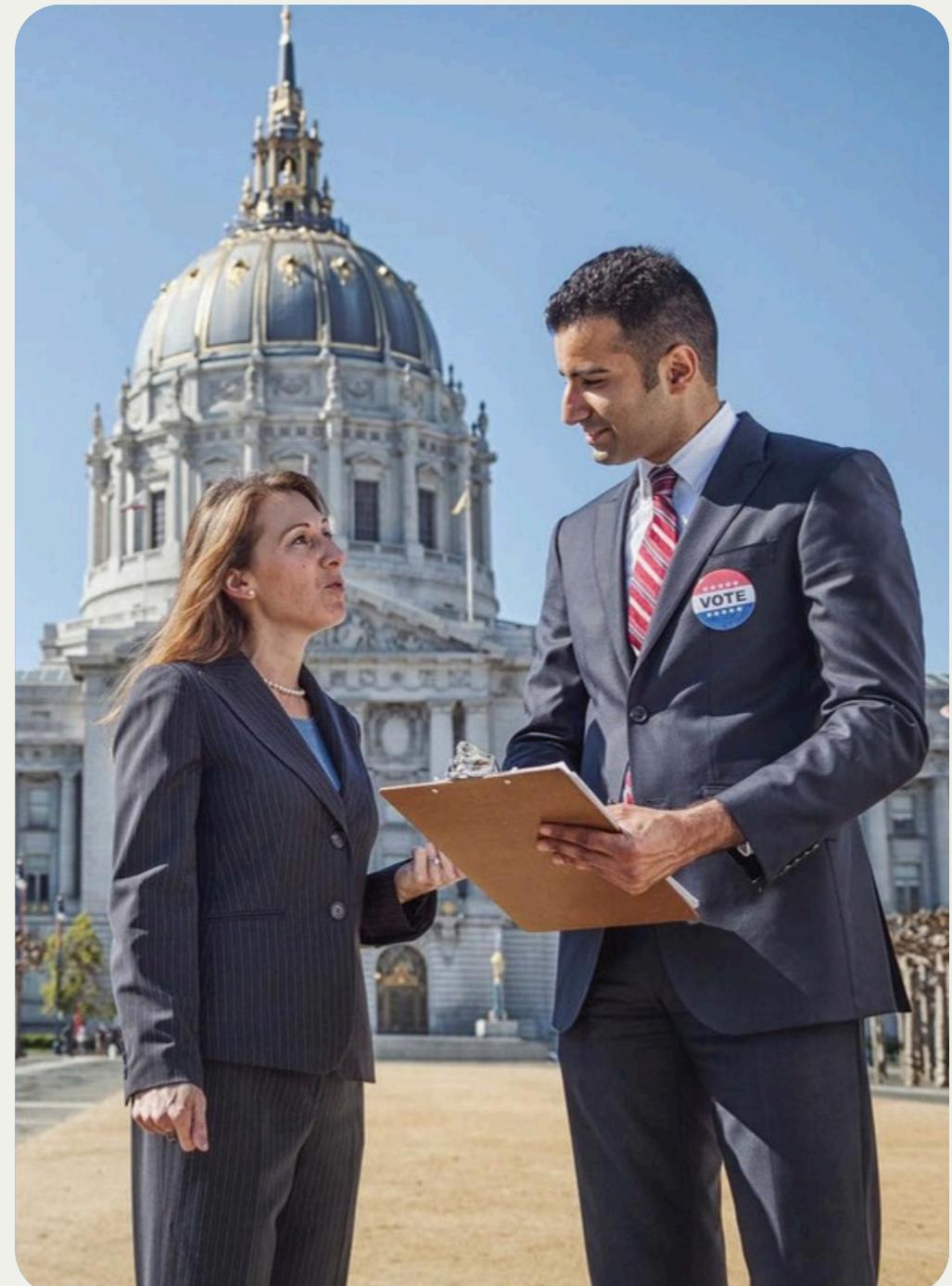
Legislators are remarkably busy. Some elected officials will meet with dozens of constituents in a single day. **Arriving to your meeting on time and ensuring you are prepared to utilize that time is key to leaving a good impression.**

Follow up.

After having a conversation with your state or federal representative, it's 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, 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.

If you are offering to help track an issue or provide solid background information 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 legitimate 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 experience 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 using reliable resources (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.



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. This health care provider will play an important role in your health and wellness, so take your time when selecting a new doctor. Don't be afraid to switch 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 don't cover it unless you try and fail on another medication first, one that your 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. Sometimes you must fight your insurer to get the coverage you deserve. In this section, we 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 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?

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:

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!

If your insurer refuses to cover your doctor's recommended treatment, contact local media using tips on page 14 of this toolkit.

Tip

Patients have earned coverage for treatments by bringing media attention to insurance discrimination. Here are 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.

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

HealthCare.gov

Get Coverage Keep or Update Your Plan See Topics ▾ Get Answers

Appealing a health plan decision

More info

- How to appeal an insurance company decision**
- Internal appeals
- External Review

How to appeal an insurance company decision

If your health insurer refuses to pay a claim or ends your coverage, you have the right to appeal the company's decision and have it reviewed by a third party.

You can ask that your insurance company reconsider its decision. Insurers are required to review claims that are denied or that end coverage. And they have to let you know the results of their decisions.

Your right to appeal

There are 2 ways to appeal a health plan decision:

- **Internal appeal:** If your claim is denied or your health insurance coverage ends, you can file an internal appeal. You may ask your insurance company to consider your appeal again. If the case is urgent, your insurance company must speed up the process.

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*

Working with Media

Part of advocacy involves sharing your story, both online and in 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 3 of the CDC's 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.

Many reporters have an email associated with their publication.

Try finding a cell phone number to follow up with as well. 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 publish their email address or contact information on Facebook, Instagram and X (formerly Twitter).

Tip

Pitching your story

After identify 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 3 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. 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 outline on page 3 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 beforehand what the interview will entail and what questions the reporter hopes to cover.

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!

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