CANCERcare®

Over 80 Years of Help and Hope

# ADVOCACY TOOLKIT

# INTRODUCTION

Navigating insurance barriers while trying to access life-saving treatment often leaves cancer patients feeling defeated. Delays, denials and high costs can disrupt treatment, distract from healing and add stress during an already challenging time.

These barriers don't have to be permanent. Every patient has a powerful story and sharing that story can help change the policies that stand between cancer patients and the care they need. This is known as policy advocacy—speaking up and impacting decisions that affect not just you, but also the many other people facing similar challenges.

This toolkit is designed to help cancer patients and caregivers harness their unique voice for policy advocacy. Use the resources available to learn about common insurance barriers and ways to use your story to advocate for access to the care that you—and all cancer patients—deserve.

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# UNDERSTANDING COMMON ACCESS BARRIERS

Many cancer patients face insurance barriers when trying to access the care their doctor recommends.

| IF YOU'VE EVER... | ...THEN YOU'VE FACED |
|---|---|
| Been told that you can't receive a test, treatment or medication that your doctor prescribed until your insurance company approves it. | Prior Authorization |
| Been prescribed a medication by your doctor, but your insurance company said you have to first try and "fail" a different medication of their choosing. | Step Therapy, or "Fail First" |
| Been told a treatment that was previously covered by insurance is no longer covered. | Coverage Stoppages |
| Been told that you can use copay assistance but it won't count toward your annual deductible, or that you can only use part of your assistance for your prescription. | Copay Accumulators & Maximizers |
| Had your employer-based insurance stop covering your medication or deny its prior authorization and instead require you to work with a third-party organization to get it. | Alternative Funding Programs |

## IMPACTS OF ACCESS BARRIERS

**Delays in care**

**Unexpected costs**

**Drain on time & energy**

**Disrupted treatment plans**

# SHARING YOUR STORY

When you share your story, you help decision makers understand the impact of these policies for people living with cancer. Shining a spotlight on harmful practices may also capture public attention and build pressure for change.

Even a short, personal example of how a barrier to treatment affected your life can help humanize these issues and push change forward.

**REMEMBER:**

Policymakers rely on stories to see how policies work in practice and vote accordingly.

**Use this simple framework and example prompts to shape your story for advocacy:**

1. **Who you are.**
   - Are you a patient or caregiver?
   - Where do you live?
2. **The barrier you faced.**
   - Prior authorization
   - Step therapy, or "fail" first
3. **Your personal experience.**
   - How did the barrier take shape?
   - Who was responsible?
4. **The impact.**
   - On your health
   - On your quality of life
   - On your emotional or financial well-being
5. **Why it matters.**
   - What do you want decisionmakers to understand?
   - What is your request or call to action?

**ADVOCACY TIP:**

You don't need to be a policy expert. Personal experiences are just as powerful as statistics.

There are different ways you can share your story with policymakers:

**Writing Letters**

**Posting on Social Media**

**Meeting with Policymakers**

# WRITING LETTERS

Policymakers or their staff often read and respond to letters they receive. Writing a letter to your representative allows you to share your story and advocate for change.

## STEP 1:

### Download & personalize the following letter

## STEP 2:

### Locate your representative

- Find your members of Congress: https://www.congress.gov/members/find-your-member
- Find your state representatives: https://openstates.org/find_your_legislator

## STEP 3:

### Send your letter

- Representatives will either have a contact form or email address listed on their website.

Dear Senator Smith,

I'm from California and I am living with stage III breast cancer. I'm sure you or someone you know has been affected by cancer. This disease has affected every aspect of my life. I'm looking for your help to ease the burden of cancer by supporting utilization management reform.

After my diagnosis, I was overwhelmed with information, appointments and decisions that needed to be made quickly. When my doctor recommended a treatment plan that would improve my health, I had hope—until insurance denied my medication, forcing me to "fail" a cheaper, less effective option first.

We are living in a time of incredible medical progress. In 2025, the FDA approved 20 new cancer treatments, building on decades of innovation and research. Yet despite this progress, 85% of patients still encounter barriers that delay or block access to potentially lifesaving treatments. For patients with cancer, time matters—and delays can have life-or-death consequences.

In my case, step therapy affected more than just my treatment timeline. The medication that insurance forced me to try actually worsened my symptoms, reversing months of progress toward remission. I missed out on work, holidays and quality time with my family because my insurance company decided they knew more than my doctor—an expert in my condition.

I appreciate your past support, and I'm grateful for your leadership on issues that affect families like mine. Please support policies that reduce utilization management barriers and relieve the emotional, physical and financial burden of these unnecessary hurdles. Cancer is already overwhelming. Insurance shouldn't be an extra layer of stress and uncertainty.

I look forward to your response and hope I can count on your leadership to help make health care more accessible for cancer patients like me.

Thank you for your time and for the work you do on behalf of constituents. I hope I can count on your support.

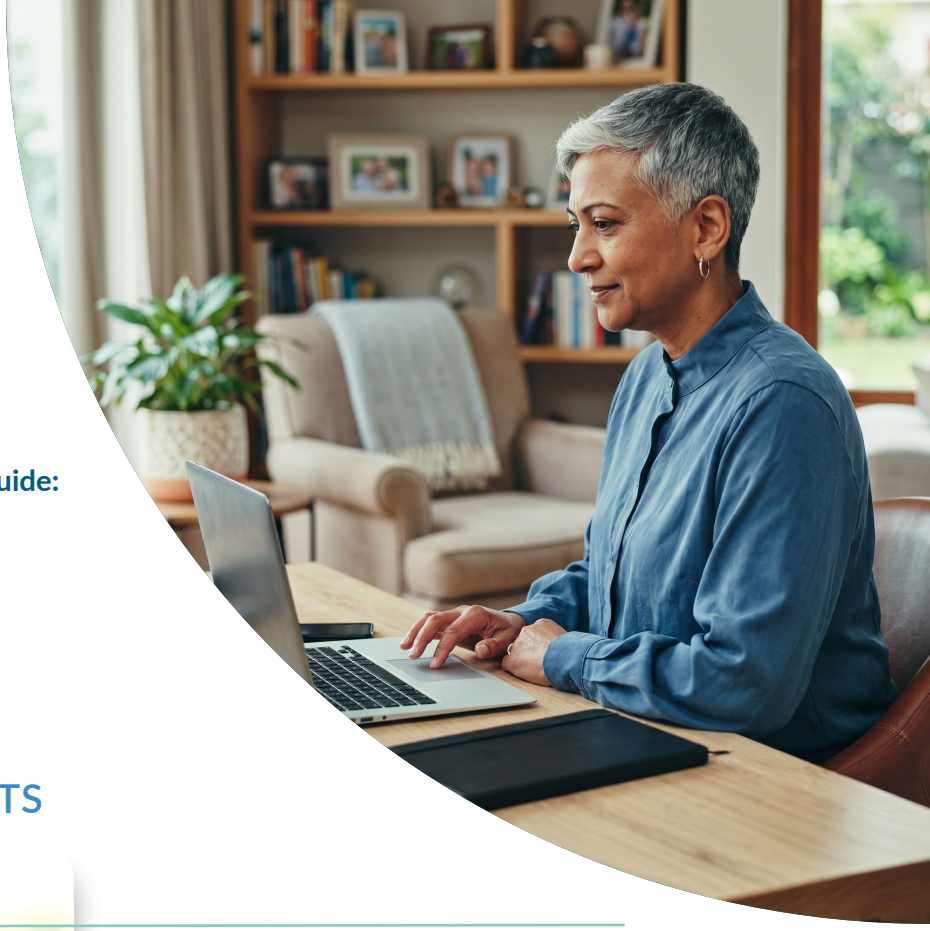
Sincerely,

Robert Garcia
123 Address Street, Sacramento, California 12345
(123) 456-7890

Download

# POSTING ON SOCIAL MEDIA

Social media is a powerful tool for sharing your story.



**Craft your own post by personalizing this guide:**

- "My name is _____."
- "I'm speaking up today because _____."
- "Patients deserve _____."
- "No one should have to experience _____."
- "I'm calling on policymakers to _____."

## SAMPLE SOCIAL MEDIA POSTS

My name is Sarah. I'm a cancer patient and I'm speaking up today because when my oncologist prescribed the treatment I needed, my insurance denied it. Patients deserve access to life-saving medication. No one should have to get worse before they get better. I'm calling on policymakers to reform prior authorization. @CancerCare

#PriorAuthorizationReform
#PatientsOverPaperwork

**Use hashtags** to join policy conversations.

**Use visuals** to increase impact and engagement.

My name is James and I'm a caregiver to my daughter, who has cancer. I'm speaking up today because my insurance company stopped covering a medication that has been improving her condition for months. Patients deserve steady access to effective treatments. I'm urging @RepJohnDavis to pass legislation that supports cancer patients. No one should have to experience the anxiety of not knowing whether their condition will improve. I'm calling on policymakers to ensure continuity of care for all cancer patients. @CancerCare

#StopInsuranceBarriers #DoctorsKnowBest

**Tag advocacy organizations or policymakers** so they will notice and engage.

# MEETING WITH POLICYMAKERS

Your representatives are available to meet with you and hear your concerns. Scheduling a face-to-face meeting is an effective way to ensure that your voice is heard.

**Tips for a successful meeting:**

## 1 BEFORE

- **Request a meeting.** Email the office of the representative you're looking to meet with and ask for time with a staff member at the office location you would like to visit.
- **Set realistic expectations.** You may be meeting with your representative's staff assistant or someone very early in their career. They're trained to listen, take detailed notes and brief the lawmaker directly.
- **Remember, you're the expert in the room.** These representatives and their staff cover many issues at once. Your lived experience is what helps them understand how policy affects real people.

## 2 DURING

- **Arrive at least 20 minutes early.** Many offices require security checks and it takes time to locate the office.
- **Introduce yourself and where you live.** Representatives and their staff meet with a lot of people. Be sure to tell them your name and where you live. All representatives seek to serve the needs and concerns of their constituents.
- **Lead with experience.** Personal stories are often the most memorable part of a meeting. Explain how insurance requirements and other barriers to care and treatment have impacted your health, finances or social life.
- **Stay focused and make a clear "ask."** Time is often limited, so aim to cover one or two key points. End by clearly stating what you want the legislator to do, whether that be broadly reducing access barriers or supporting a specific bill.
- **It's okay to say, "I don't know."** If you're asked a question you can't answer, be honest and let them know you'll follow up later. That's just another opportunity to connect.

## 3 AFTER

- **Say thank you.** Thank the representative or staff member for taking the time to meet with you and to hear your story and learn about your concerns.
- **Post your picture.** Post a picture of your meeting on social media and be sure to tag your representative and thank them for meeting with you.
- **Follow-up with an email.** Send a follow-up email thanking them for their time, with supporting materials, one-pagers and pictures. Let them know you are free to answer any questions they may have.
- **Celebrate your success.** By sharing your story, you helped represent countless other patients facing similar barriers. Take a moment to acknowledge that.

## MOVING FORWARD

Every cancer patient and caregiver has a unique and powerful story to share. The Cancer*Care* team is here to help guide you on your advocacy journey.

CANCERcare®

CancerCare is dedicated to supporting and improving the lives of people affected by cancer.

cancercare.org