

PATIENTS OVER PAPERWORK

Protecting cancer treatment decisions from insurance interference.

ADVOCACY TOOLKIT

- Learn how you can get involved.
- Now is the time to raise your voice.
- Your story matters.
- Your experience can drive change.



Together, we can forge a better path forward—one voice, one story, one policy change at a time.

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CALL TO ACTION TOOLKIT

This toolkit is part of the Cancer Support Community's Patients Over Paperwork program. Helping to protect cancer treatment decisions from insurance interference and to help you feel confident, prepared, and supported as you advocate for timely care. Cancer is hard. Fighting to get the care your doctor already recommended shouldn't be part of it.

Across the country, people with cancer are facing delays, denials, and treatment changes driven by insurance and pharmacy benefit decisions. If this has happened to you or someone you love, you are not alone and you deserve better.

Have insurance or pharmacy benefit decisions interfered with you or your loved one's cancer care?

- Has your or your loved one's cancer care been delayed by insurance?
- Did insurance require you to switch your treatment from what your doctor first prescribed?
- Did you have to "fail" another treatment before you could start the treatment your doctor first prescribed?



This information can be overwhelming.

Contact CSC's Cancer Support Helpline at 888-793-9355 or your cancer care team to help you

find a financial navigator to help understand what type of insurance you have, how to contact your insurance to report problems, and how to take action against delays, denials, and switching of your medication by insurance. <https://www.cancersupportcommunity.org/cancer-support-helpline>

WHAT'S INSIDE

You can use the resources in this guide to help you advocate for yourself and raise your voice to bring attention to these changes.

Understanding Your Insurance

A quick guide to identifying the type of insurance that you have

Taking Action When Care Is Delayed, Changed or Denied

Simple steps and real world tips for contacting your insurance and reporting these decisions to state and federal agencies.

CSC's Educational and Advocacy Resources

to Combat Insurance Obstacles

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Now is the time to raise your voice.

**Your story matters.
Your experience can
drive change.**



**The action you take
depends upon your
insurance.**

This toolkit includes a resource to help you determine your type of insurance.

REPORT INSURANCE AND PHARMACY BENEFIT PROBLEMS THAT INTERFERE WITH YOUR CARE.

See our Toolkit for step-by-step instructions on these and other actions you can take.

IF YOU HAVE MEDICARE

Call 1-800-Medicare and share how insurance and pharmacy benefit decisions or delays have interfered with your cancer care. Medicare administrators take these comments seriously. You may also contact your federal Senators and Representative by using <https://www.congress.gov/members/find-your-member> to explain the problems you ran into.

FOR ACA MARKETPLACE AND FULLY-INSURED EMPLOYER HEALTH PLANS

If you are experiencing issues with your ACA Marketplace plan or a fully-insured employer health plan, contact your state's Division of Insurance or Insurance Consumer Assistance Office to file a complaint. Each state has its own consumer support unit and complaint process.

To find the correct office in your state, visit the National Association of Insurance Commissioners (NAIC) website, <https://content.naic.org/state-insurance-departments>, which provides a directory of all state insurance departments. Simply select your state to access direct contact information and complaint instructions.

IF YOU HAVE MEDICAID

Contact your state's Medicaid Customer Service Center to share how decisions, denials, or delays have interfered with your cancer care. If you disagree with a Medicaid decision, you have the right to appeal. Information on how to file an appeal can be found on your state's Medicaid website, which is typically linked through [Medicaid.gov](https://www.Medicaid.gov) or [HealthCare.gov](https://www.HealthCare.gov).

To locate your state or local Medicaid office, you can also search for your state's Department of Social Services or Human Services office, which often manages Medicaid at the county or regional level. In some areas, dialing 311 can help connect you to local public benefits offices. You may also contact your State Senator and Representative to share the issues you encountered and seek their support.

FOR SELF-INSURED EMPLOYER HEALTH PLANS

Contact your benefits administrator or HR Department to share your insurance problems.

IF YOU HAVE TRICARE

File a written grievance with your regional contractor (such as Humana Military or TriWest) or reach out to a Patient Advocate or Beneficiary Counseling and Assistance Coordinator (BCAC) at your local military facility. You may also contact your US Senators and Representative to explain the problems you ran into.

SUBMIT YOUR STORY

Share your experience with the Cancer Support Community's Cancer Policy Institute. Upload a video or submit your written story to help shape policies that protect patient rights.

<https://www.cancersupportcommunity.org/how-has-cancer-impacted-you>

SIGN UP TO GET INVOLVED

- **Sign up** to receive updates from the Cancer Support Community's Cancer Policy Institute. <https://www.cancersupportcommunity.org/cancer-policy-institute>
- **Learn how** you can **become an advocate** and take action to influence the delivery of cancer care. <https://www.cancersupportcommunity.org/become-advocate>
- **CSC's Action Center** provides opportunities for you to add your voice, along with others in the community, and shape our advocacy. <https://www.cancersupportcommunity.org/action-center>

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PREPARING AND UNDERSTANDING YOUR INSURANCE

Before you take action, it helps to understand the basics of your insurance plan. This may make calls smoother and may help you get answers faster.

Your insurance card has the key details you need to understand your plan and ask questions. Every card looks a little different, but here's what to look for.

LOOK FOR THESE ON YOUR CARD:

- Plan name**
- Plan type** (HMO, PPO, EPO, Medicare, Medicaid)
- Member ID**
- Group number (if you have one)**
- Customer service phone number**
- Pharmacy (Rx) phone number**

TIP

If you can't find something, write down what you don't see and ask when you call. You don't need to know everything — just where to start. You don't have to memorize these terms. Having your card handy helps you ask clear questions and get answers faster.

TAKING ACTION TO ADDRESS PROBLEMS WITH YOUR INSURANCE

When your doctor prescribed cancer treatment care is delayed, changed or denied you can start by contacting your insurance company directly. Sometimes it's hard to know what to say.

Your story matters and your experience can drive change.

Before you call try to have this information available.

- Insurance card (front and back)
- Doctor's name and contact information
- Type of treatment and when prescribed
- What happened/decisions made by insurance about your treatment
- Any messages or letters you have received from insurance

TIP: *You can still call if you don't have everything.*

WHEN YOU CALL	WHAT TO SAY	WHAT TO ASK
If your doctor prescribed treatment is <u>DELAYED</u> by insurance	I'm calling about the treatment my doctor ordered to treat my cancer which has been delayed. My doctor says this is medically necessary and time-sensitive.	Can you share the status and the expected decision date? Is this being handled urgently? What else is needed to move it forward?
If your doctor prescribed treatment is <u>CHANGED</u> by insurance	I am calling about the treatment my doctor ordered for my cancer which has been changed by insurance. My doctor determined that this treatment is medically necessary for me. I am requesting a step-therapy exception and an expedited review.	Can you share the status and the expected decision date? What else is needed to move this forward?
If your doctor prescribed treatment is <u>DENIED</u> by insurance	The treatment my doctor prescribed to treat my cancer has been denied. My doctor says this treatment is medically necessary.	I would like to request an expedited appeal, please share the appeal instructions and deadline. Please send the denial letter (if you have not received it yet).

TIP: During each call – ask for this information:

Reference number for the call | Expected decision date | Where to submit doctor notes or records

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TURNING EXPERIENCE INTO ADVOCACY

Sharing your experience can help protect other patients and make sure cancer care decisions are guided by doctors and not paperwork. There are many ways to advocate for change starting by sharing your experience.

Your voice matters. When you tell your story, state and federal agencies and lawmakers learn how insurance decisions affect real people. They need to hear from you so they can understand the impact and help strengthen protections for patients.

CONSIDER SHARING YOUR STORY WITH:

- State and Federal Agencies
- Your State and Federal Elected Officials and Lawmakers



This information can be overwhelming.

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find a financial navigator to help understand what type of insurance you have, how to contact your insurance to report problems, and how to take action against delays, denials, and switching of your medication by insurance.
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USE THESE 5 STEPS TO TELL YOUR PERSONAL STORY

- | | | |
|----------|---|--|
| 1 | Who you are | My name is _____ and I was diagnosed with _____ cancer. |
| <hr/> | | |
| 2 | What treatment your doctor recommended to treat your cancer | My doctor prescribed _____ to treat my _____ cancer. |
| <hr/> | | |
| 3 | What action the insurance company took to negatively impact your care | The insurance company delayed/ changed/ denied the treatment my doctor prescribed to treat my cancer. |
| <hr/> | | |
| 4 | How this impacted you, your care and your life, be as specific as you are comfortable | This caused _____ and that has impacted my _____. |
| <hr/> | | |
| 5 | What you want | I want you to know that insurance companies/Medicare/Medicaid (depending on your insurance coverage) should respect decisions made between patients and their doctors. |

THIS GUIDE IS FOR INFORMATION ONLY AND NOT LEGAL OR MEDICAL ADVICE. YOUR CARE TEAM AND PATIENT SUPPORT SERVICES CAN HELP YOU WITH SPECIFIC QUESTIONS.

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EDUCATIONAL & ADVOCACY RESOURCES to Combat Insurance Obstacles

WHAT YOU NEED TO KNOW: INSURANCE OBSTACLES & COVERAGE COSTS

- [How to File a Health Insurance Appeal for a Denied Claim: What Patients Need to Know](#)
- [Step Therapy: What Patients Need to Know](#)
- [Help Managing Cancer Costs](#)
- [10 Tips to Understanding Your Medicare Part D Coverage](#)

GRASSROOTS ADVOCACY RESOURCES & OPPORTUNITIES

- [Share Your Story: How Has Cancer Impacted Your Life?](#)
- [How to Use Storytelling to Inspire Action & Drive Change](#)
- [Ask Ruby Video: How to Become an Advocate](#)
- [Policy Webinars & Videos | Cancer Support Community](#)
- [Grassroots Advocacy 101 Toolkit](#)

TO LEARN MORE & SHOW YOUR SUPPORT, CLICK ON THE FOLLOWING LINKS

**SAFE STEP ACT
ON THE CSC
ACTION CENTER**

**HELP ENSURE LOWER
PATIENT (HELP) COPAYS ACT
ON THE CSC ACTION CENTER**

**PHARMACY BENEFIT
MANAGER (PBM) REFORM ACT
ON THE CSC ACTION CENTER**



**Questions about insurance denials,
appeals, coverage changes, costs, etc.**

Call [Cancer Support Community's Helpline](#)
at 888-793-9355.



Scan to view &
download these resources



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