



It Starts With Us



IssueBrief

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Amplifying the client's voice: For case managers, advocacy means empowerment

What stands between individuals and the health care services they need? The long list includes poorly designed regulations, unfriendly consumer insurance practices, lack of actionable information, a sense of powerlessness that can result in inertia—and so much more. Liz Helms, president and CEO of the California Chronic Care Coalition (CCCC), understands this well.

Her life as an advocate started with a need to speak for herself. Her voice, while California-based, is relatable to consumers nationwide.

"I started as an advocate because I was partially denied access to health care, and denied access to a surgical procedure," she recounts. At first, she felt helpless. "What could I do? I didn't believe that my voice mattered. But other people brought me along and said, 'no, no, no—your voice is really important.'"

Today, she helps others find and learn to use their voices. CCCC is an alliance of more than 30 leading consumer health organizations and provider groups focused on improving the health of those with chronic conditions—in California and nationwide via MyPatientRights.org—through public policy education, legislation and advocacy.

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Case managers, in particular, need to stand up and be heard, she says. They need to speak on behalf of their profession and their clients. “Your voice as a client advocate really matters,” she says.

Case managers are accustomed to being advocates *for* their clients, says MaryBeth Kurland, CEO of the Commission for Case Manager Certification. But as important as speaking for clients is, teaching clients to speak *for themselves* is even more essential. “They have the responsibility to inform clients of their rights *and* to empower them to claim those rights and access the services they need. To do this, case managers need to encourage and *expect* active engagement from clients and their caregivers.”

Understanding advocacy

“Unfortunately, because consumers and their families are usually the least experienced participants in the health care system, their best interests can be overlooked, or even pushed aside,” Kurland says. “Most often, it happens in the name of protocols, resource constraints and impersonal system processes.”

Whatever the reason, too often patients don’t get the care they need, and many don’t know how to ask for it—or even *what* to ask for.

Client advocacy is at the heart of a case manager’s role; in fact, says Kurland, it’s an ethical obligation. Under the Code of

Professional Conduct for Case Managers, advocacy is addressed in the first principle: *CCMs will place the public interest above their own at all times.*

Advocating for clients is second nature for case managers; convincing clients to advocate for themselves can be difficult. Case managers frequently encounter clients and caregivers who, perhaps out of intimidation, lack of knowledge, fatigue or frustration, don’t want to speak on their own behalf.

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A key step is to engage the client and the caregiver, asking questions of them and finding out what their questions are, says Helms. And then help them direct the question to the right care team member. She uses medications as an example.

“We’ve been working on this for a long time, encouraging patients to work closely with their pharmacists and asking them to look at all their meds to get to medication optimization, especially on discharge from the hospital. When someone is sent home from the hospital, they should be asking questions. What medicines do I need to discontinue? What medicines do I need to change the dose for? What medicines do I need to throw away?”

Getting answers to those questions can be empowering, Helms says. The more a person understands, the better equipped they are to advocate for themselves and others.

Sometimes the client might not be able to take in all the information or even fully understand all the implications, so engaging their caregivers as advocates is crucial. Case managers are in a unique role to do this, ensuring that caregivers are also part of the team with the client, with the pharmacist, the clinician, the nutritionist—and whomever else is involved along the care continuum.

Information is power

Clients need resources to help them advocate for themselves, not just when they’re sick, but also when they’re making critical decisions about health coverage. To make those decisions, they need to understand the terminology. What’s the difference between a copayment and co-insurance? Between a deductible and an out-of-pocket maximum?

The Choose Smart form (available at ccmcertification.org/sites/default/files/open_enrollment_checklist-v5.pdf) helps with all this. It's a handy tip sheet to help consumers make wise decisions about health coverage. On one side, a glossary helps consumers speak the language of health plans. On the other, a checklist provides key questions to ask during open enrollment.

One of those questions is particularly important, she says. "Can I see a doctor outside of the plan network?"

With client relocation, provider contract disputes and shifting provider networks, this can become a critical issue for consumers almost overnight. That was the situation after the recent catastrophic fires in California, Helms says.

"In Paradise, California, the whole city pretty much went up in smoke. So did hospitals." Many individuals relocated to nearby Chico. But provider contract disputes with health plans have called into question whether insurance will cover their health care. She tells of one young Paradise resident who had a stroke after the fire. Now, he's been told he may have to pay full price for any care he receives because he is displaced and no longer has access to an in-network hospital. Helms' organization is helping him and others to make their voices heard so they can access the care they need.

Asking questions in advance of buying health plan coverage

can help clients avoid some problems—but not all. It's also important to understand how to respond once problems arise by filing an appeal or a complaint with a state health plan commission.

File a complaint

Case managers can play an important role in ensuring their clients receive the most effective therapy, Helms says. On the individual level, they may need to educate clients and engage physicians, pharmacists and other providers. But it may also mean helping clients appeal a denial to their insurers.

MyPatientRights.org is a website designed to help consumers figure out how to appeal health plan decisions. It's also a resource case managers can use to refer clients for easy-to-understand explanations of what's often a thorny process. It's at www.mypatientrights.org/file-a-complaint.

The site will walk you—or a client or caregiver—through the steps to file a complaint. It includes links to each state's major health plans and its regulatory bodies.

Helms offers a word of advice: No matter how tempting it is to go directly to the state regulator, always start with an appeal through the health plan's member services department, even if you believe it's futile. It's necessary to demonstrate you've given the health plan a chance to make things right. "Once you go to the regulator, the first thing they

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are going to ask you is, 'Did you try to work this out with your health plan?'"

Sometimes, simply being your own advocate and filing a formal complaint may be all that's required. "Once they know you are engaged, they may change their decision." If not, *then* you can turn to the regulator.

Another potential barrier that many people haven't heard about yet is the "**co-pay accumulator**" concept. It's a relatively new strategy introduced by pharmacy benefit managers—one case managers need to pay particular attention to, Helms says.

"Let's say you get a coupon to help you purchase your medicines at the pharmacy counter. Under these new accumulator programs, the money spent would not count toward your deductible or out-of-pocket maximum," she explains. That can translate to thousands of dollars patients pay directly for medications. "We will be

actively working on that this year,” Helms said.

Step therapy presents another barrier to optimal care—one CCCC has been addressing on the state and federal levels. Step therapy policies—sometimes termed “fail first”—require patients to try, and fail on, less expensive medications before the insurer will pay for the one originally prescribed. These policies often affect patients on chemotherapy for cancer; delays in getting to the optimal treatment can mean cancer advances while patients wait.

She finds the idea of denying patients the optimal medication particularly galling considering the current wasteful spending on medication that doesn’t benefit patients—and can even cause harm. A 2018 study published in the *Annals of Pharmacotherapy* estimated the annual cost of drug-related morbidity and mortality resulting from nonoptimized medication therapy was \$528.4 billion.¹ That spending, which adds up to more than the cost of the medications themselves, is from the wrong dose, skipped doses or the wrong medicine altogether—all of which can lead to additional health issues.

Helms says she’s seeing some progress: More than a dozen states have enacted step therapy reform. At the federal level, “Restoring the Patient Voice Act” was introduced during the last session to require

health plans to provide a reason—other than cost—for denying payment for a prescribed medication. It never came to a vote.

Patients need to take the right medicine, not merely the cheapest. “We’ll be working in multiple states this year on relieving the barrier of step therapy,” she says. “This is not rocket science. It is actually good care. But we have to fight for it. I can never understand why we have to fight all the time. But we have to fight all the time.”

Those fights are all about advocating for the client. Helms credits much of the success thus far on the regulatory and legislative fronts to being able to tell real stories from the point of view of real patients. To learn about one important success, see sidebar on this page.

Case manager advocacy: Think bigger

Helms wants case managers to think bigger; she encourages them

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¹ Watanabe, J. H., McInnis, T., & Hirsch, J. D. (2018). “Cost of Prescription Drug-Related Morbidity and Mortality.” *Annals of Pharmacotherapy*, 52(9), 829–837



Advocacy at work: Removing the gag

To see the power of advocacy, look no further than federal legislation enacted in 2018 that bans “gag” clauses in contracts with pharmacists.

These “gag clauses” prohibit pharmacists from telling customers they could save money by paying out of their own pockets for prescription drugs rather than using their health insurance coverage to pay for them. Pharmacists who steered patients to the cheaper out-of-pocket alternative risked being kicked out of the insurance payment network. Meanwhile, pharmacy benefit managers (who work on behalf of large employers and health plans) pocketed the difference between the contracted and the retail price.

Pharmacists, patients and advocacy groups took action. They lobbied lawmakers, coalesced support, raised awareness and generally made their voices heard. As a result—with strong bipartisan support—President Trump signed the Patient Right to Know Drug Prices Act, which prohibits gag clauses. The Know the Lowest Price Act, signed at the same time, provides the same protection for those covered by Medicare Advantage and Medicare Part D plans.

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to take on the policies that stand between patients and the health care they need.

Issues case managers and their clients have been grappling with for years have started to creep into the headlines: Patients not having access to the medication they need, exorbitant out-of-pocket costs, poorly managed medication therapy, etc. Patients often have to jump through hoops to get their necessary medications—if they get them at all.

Some regulatory issues make big headlines, while others occur with no fanfare. But either way, case managers need to stay on top of developments: The welfare of your clients is at stake, Helms says.

"Sometimes, the regulations that are developed and implemented are not always in the best interest of the patient; I think those who

make the rules may have forgotten about the patient altogether." Her advice: Monitor the news, and pay particular attention to what's happening in your state legislatures. "We would like to work more closely with case managers to understand what's happening with their clients," Helms says. "We think of advocacy as something that happens at the individual or health system level. But case managers can be powerful advocates at the community, state or national level."

Lift your voice, tell your stories

Through the MyPatientRights.org site, patients, caregivers, case managers and others can tell their stories about struggles with coverage and barriers to accessing needed care.

"We can relay that message to the legislative bodies, public-policy makers, regulators and the agencies that count on us so much to give them the voice of what's happening out in the community," she says. "The coordination of voice on top of the coordination of care—that's really vital to move advocacy forward."

Because they work so closely with clients, case managers have an on-the-ground perspective about the impact of public policy on health. Helms wants her organization and others to work more closely with case managers to understand what's happening with their clients.

"We want to hear from you. You're on the ground, you're in the

trenches seeing what is happening to people every single day."

Case managers never lose sight of this, because it's in the trenches, with clients and caregivers, where they have the most immediate impact. "We see in the headlines a push for price transparency, from both Congress and from the Department of Health and Human Services," says Kurland. "That's important, but it's essential for consumers to get the care they need, when they need it." ■

About the Experts



**Liz Helms, President and CEO
California Chronic Care Coalition**



**MaryBeth Kurland, CAE
CEO, Commission for
Case Manager Certification**

LIZ HELMS is president and CEO of the California Chronic Care Coalition, an alliance of non-profit, social, consumer and provider organizations working to improve the health of Californians with chronic conditions or diseases. On the national scene, she co-founded the Chronic Care Policy Alliance (CCPA), working across state lines to ensure access to affordable, quality health care and giving states a voice for the enforcement of anti-discrimination laws in the ACA.

Helms has been a leader within the patient's rights movement since her own recovery from temporomandibular joint disorder in the mid-1990s. She has been a catalyst for consumer advocacy and health policy reform within the chronic disease community. She serves on many state and national committees, including an advisory role with the National Quality Foundation's Measure Incubator.

MARYBETH KURLAND leads and sets the Commission's strategic mission and vision. She manages relationships with likeminded organizations and oversees business development as well as the Commission's programs, products and services. She works directly with the Board of Commissioners, building its corps of volunteer and subject-matter experts who directly support and evaluate certification and related services. Prior to becoming CEO, Kurland served as the Commission's chief operations officer, and was staff lead for the development and launch of the Commission's signature conference, the CCMC New World Symposium®.

Kurland brings extensive experience to her role, having served as executive director of organizations including the Association of Medical Media, Office Business Center Association International and the League of Professional System Administrators. She holds a bachelor's degree from the University of Delaware and is a member of the Institute for Credentialing Excellence, the American Society of Association Executives, and the Mid-Atlantic Society of Association Executives. In 2011, Kurland was recognized as Association TRENDS Young & Aspiring Association Professional.



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