



IssueBrief

June 2020

Advocacy in the age of COVID-19: The ethical principles remain constant, but how do you apply them in this strange new world?

What does advocacy look like today? What are its ethical underpinnings?

We all know that case managers who carry the CCM credential are ethically bound to advocate for their clients. 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.*

But what advocacy *actually* looks like in practice can vary with the patient's condition, competency, medical state and even culture. It requires not only knowledge but also wisdom.

Advocacy has never been a simple proposition. But now, everything has changed.

Client advocacy has taken on new dimensions in the wake of COVID-19. "As case managers we have an important role to play in assisting our clients through this difficult time, whether it's specifically related to COVID-19 or other diseases, or helping with any other concerns related to medication management or their health, both physical and mental—all with social distancing," says MaryBeth Kurland, CAE, CEO, Commission for Case Manager Certification.

"As case managers we have an important role to play in assisting our clients through this difficult time, whether it's specifically related to COVID-19 or other diseases, or helping with any other concerns related to medication management or their health, both physical and mental—all with social distancing."

— MARYBETH KURLAND, CAE, CEO,
COMMISSION FOR CASE MANAGER
CERTIFICATION

We must be advocates, but now we're looking at advocacy through a COVID lens. That may affect our response, but what remains consistent are the ethical principles undergirding advocacy, says Nancy Freeborne, DrPH, MPH, PA-C, CEO, Freeborne Health Advising.

They are

- First, do no harm, or non-maleficence:
- Autonomy
- Beneficence
- Justice
- Confidentiality

Many of these principles weave together, but Freeborne offers a basic breakdown, adding pandemic-specific insights.

Non-maleficence: Do no harm

This one is fundamental, she says. "Always, in every instance, think about doing no harm." Deciding what constitutes harm, however, requires almost-constant risk-benefit calculation. The pandemic may affect that assessment.

"Always, in every instance, think about doing no harm."

— NANCY FREEBORNE, DRPH, MPH, PA-C, CEO, FREEBORNE HEALTH ADVISING

You cannot *totally* keep your client out of harm's way. Assess the risk of harm in each particular situation, she counsels. Many decisions about the activities of daily living and independence can involve risk/benefit calculations. If you let someone walk, there's a risk they'll fall. But at the same time, you don't want to *not* have them walk. So, there's always a balance between harm and good, and these calculations come up.

During the pandemic, we need to think a little bit differently. You may be in scenarios now where you're asking, how do you coach the family if someone becomes gravely ill, and they're taken to the hospital? Should they risk placing their loved one on a ventilator?

More banal—but nevertheless important—questions arise each day. What is the risk versus the benefit of going to the grocery store? Going to church? What is the risk/benefit calculus of simply taking a walk during a pandemic?

In "normal" times *and* during a pandemic, her advice is to think of the risk/benefit analysis as a series of decision points about safety, not a once-and-done.

Autonomy

If your clients are frail, this ethical principle is quite a challenge, and it, too, requires a risk/benefit analysis. You want to give your client freedom to make decisions, but you must preserve their health and safety. Autonomy is not binary. It's a continuum, so there are no clear answers.

"So, while I would err on the side of giving the patient their freedom if they were clear-headed," delirium changes the assessment.

— NANCY FREEBORNE, DRPH, MPH, PA-C, CEO, FREEBORNE HEALTH ADVISING

Take the example of Alice, a frail client with a movement disorder. Or of Mike, who recently had a hip fracture; he's moving very slowly. How much freedom do you allow them? Do you permit them to get up and walk and to do what they want to do? Do they understand the risks?

Sometimes, you can consult with a physical therapist. But other times, *you* need to make the assessment. In some geriatric populations, you may need to consider the family's comfort with the patient's autonomy. That may differ family to family, culture to culture.

COVID-19 complicates some of these decisions. For example, it frequently leads to delirium in older patients.¹ "So, while I would err on the side of giving the patient their freedom if they were clear-headed," Freeborne says, delirium changes the assessment.

Assuming your client is clear-headed, Freeborne recommends repeating statements to the patient three

¹ <https://khn.org/news/seniors-with-covid-19-show-unusual-symptoms-doctors-say>

times—and have the patient repeat them back to you.

For example: “Mrs. Jones, I’m concerned if you go to the grocery store, you’re going to be at risk for getting the virus from a clerk. Mrs. Jones, do you understand if you go to the grocery store, you may have a risk of getting this new virus from a clerk? Mrs. Jones, if you go to Safeway this week, I’m concerned you may get the COVID virus.”

And so, you’ve said it three times; then you say to the client, “Did you understand what I said?” And Mrs. Jones will say, “Yes, I did understand. If I go to the grocery store, I may be at risk for the virus, but I’m going to do it anyway.”

Sometimes, we err on the side of safety, which is natural, Freeborne says. “But if you talk with them and if they really understand, they should have some autonomy, she counsels. “We can’t just put them in a little room and never let them out and never let them do anything.”

“But if you talk with them and if they really understand, they should have some autonomy. We can’t just put them in a little room and never let them out and never let them do anything.”

— NANCY FREEBORNE, DRPH, MPH, PA-C, CEO, FREEBORNE HEALTH ADVISING

On the other hand, there are times when safety outweighs autonomy—such as Alice, the frail client with a movement disorder wanting to forego using her walker. And you can make it about your fears. This takes the edge off any perception of nagging. “I really don’t want you walking without the walker. I know you want to walk to the bathroom without the walker, but I’m going to feel uncomfortable.”

It’s a matter of finding that middle ground.

Beneficence—promoting and achieving good

This may be as simple as asking a client—*What is the good that you want out of the day? What will give you joy?*



To be a good advocate, practice self-care

The burden of advocacy can be overwhelming. Self-care is essential, and Freeborne shares ways to make sure it happens.

She’s a fan of positive self-talk. Happiness, she says, is 45% of our own doing. Yes, some of it is genetic. External factors play a role. But you have a say, too.

Her recommendation: When you get up each and every day, if you say, “Today is going to be a good day,” that can kind of set the tone for the whole day, even if you have 12 hours on your feet, or in your case, many times in your car going to different locations. But if you kind of wake up and set the stage with that every day, it can help a little. “And I’m not saying it’s perfect because, my goodness, the exhaustion is there. But that positive self-talk is a start.”

Her other recommendations may be harder to follow, but it is, she says, essential. Carve out time each day when you are responsible for no one else, even if it’s just 30 minutes. Read. Watch TV without anyone else around. Meditate. Take a walk.

Kurland agrees with these techniques, pointing out that self-care has been a focus for the Commission for years, and it now has an array of resources for self-care, including COVID-specific information. A good place to start is our curated list of resources: ccmcertification.org/blog/understanding-enemy-curated-list-covid-19-resources-case-managers.

But self-care is about more than accessing resources. It’s about being kind to yourself. “Just make sure that you give yourself some grace,” Kurland says. In the early weeks of the pandemic, someone gave her advice that helped her tremendously. “If you step back and just kind of give yourself a moment to breathe and give yourself a little bit of grace, it’s okay.” ■

Of course, it's not at all *simple*: It takes time and energy to work through those reflective exercises that lead to an answer. One client's good may be just having a nice warm bath. For another, it could be having a brownie or a conversation with family members. What is it that they're going to get out of this day that is going to give them joy? Sometimes we get so busy with other things we don't think about the good.

The pandemic may be reshaping what clients want—especially your elderly clients. Yes, they may want that bath or that brownie. But they're probably also longing for social contact, especially with loved ones. Perhaps they need contact with their grandchildren, even if it's just waving from a window.

"When I was a hospitalist Physician Assistant, one of the patients on the cancer ward came to me and said, 'I do not want my family to know that I have breast cancer. You are to tell my family it is just a tumor.' I struggled with that, but I respected her request."

— NANCY FREEBORNE, DRPH, MPH, PA-C, CEO, FREEBORNE HEALTH ADVISING

The pandemic also intensifies the urgency of discussing death. It's important, she says, to find those reflective times to talk about death: What is the good they want for themselves? For their spouses? Their families?

It's a difficult topic, especially since many people act as if they will never die; they don't want to talk about it. "Unfortunately, with this pandemic, we're going to be talking about it a lot more, more often because there will be some unexpected deaths," Freeborne says. Case managers may need to be the ones to raise issues such as DNR, a living will, palliative care, etc.

Justice

Talking about end-of-life issues falls under justice as well as beneficence. You're giving a voice to a client before they become too incapacitated to express how they may want things to happen. Especially in a pandemic, justice could include making sure the client has the right information on which to base these decisions.

Justice also involves advocating for your client with insurance companies, hospitals, hospices, nursing homes—wherever your client's preferences need to be heeded. And that applies even if the hospital, insurance company, etc. are paying your salary, she says. As an advocate, the case manager needs to be able to say, "I disagree with what we are doing." Advocating for a client's optimal care is never optional.

Justice may demand that you speak up for those who are not your clients, she counsels. Take disparities: You may need to advocate for a particular population. COVID-19 affects some populations much more severely—including seniors—than others. "So, I would say, 'I know you guys are busy, many of us are, but if we can do something big picture to advocate for the seniors, it's important.'"

Client preferences

With these principles it's important to be sure you know your client's preferences. Some patients are open. They don't mind sharing their diseases, they don't mind sharing their medications.

Others are deeply private. "When I was a hospitalist Physician Assistant (PA), one of the patients on the cancer ward came to me and said, 'I do not want my family to know that I have breast cancer. You are to tell my family it is just a tumor.' I struggled with that, but I respected her request."

Ask clients about their preferences and respect them—*almost* all the time. Confidentiality, like autonomy, is a context-specific value, she says.

In certain rare situations, such as now, during the pandemic, other ethical considerations may outweigh confidentiality. It may become essential to share information to prevent others from becoming infected. "I would encourage you to encourage your clients that it's not the time to be

secret about this disease, because time is of essence.”

Putting it in context: Case examples

It’s easier to understand the principles of advocacy and how they interrelate by looking at examples. Freeborne offered two.

Charlie’s example involves autonomy and confidentiality. Newly diagnosed with diabetes, he has to go on insulin, but he doesn’t want his daughter to know. If you think it is best that she knows, the solution isn’t necessarily, “Okay, Charlie, I need you to tell your daughter tomorrow you have diabetes.” Maybe you bring it up again in a few weeks. Ethically, you may need to respect his autonomy and his need for confidentiality longer than makes you comfortable, Freeborne says.

Nelda and John’s situation also involves autonomy. They want to shop, but they don’t want to wear masks. They say, “Oh, I’m healthy. I’m not really worried about this. I got through the flu last year.” As discussed earlier, repeating your concern may help drive the message home. “Do you understand the grocery store is a risky place right now? Do you really understand that the grocery store is a risky place? We’re reading in the news that the grocery store is a risky place.”

If they respond, “Yes, I know the grocery store is a risky place. I’m going to take that risk,” then you may have to accept that. From

Freeborne’s perspective, the case manager’s role is to give the best information and then let the clients decide—assuming they have the capacity to do so.

Dovetailing into safety

As these examples and your own experience illustrate, advocacy and its ethical principles revolve around safety—especially when you are working with a geriatric population.

For instance, how do we coach clients to get up and move but do it carefully? How about sticking to their diets? “None of us like to be nagged and people who are 95 especially don’t like to be nagged.”

It’s important not to let your safety concerns dehumanize them; this frequently happens with dementia patients. “I know this is not news to you, but you need to think about not only what they *can’t* do safely: Find safe things they *can* do.”

Thinking about confidentiality



CCMs have the ethical responsibility to ensure none of their actions creates a breach of confidentiality. Sometimes, that’s not as obvious as it sounds, Kurland says. Here are some examples:

Keep the client apprised when information obtained through the client/case manager relationship may be disclosed to third parties (e.g., insurers, public health officials, etc.). Clients must be told before the information is released.

Avoid inadvertent disclosure: Even today, slides used at professional meetings may include patient photos and other identifying information. And we all know of examples of professionals revealing too much information about a patient online. Case managers must be cautious about what is shared, when it’s shared and how it’s shared.

Understand privacy laws: CCMC’s Code of Professional Conduct requires knowledge of and compliance with all laws dealing with patient privacy and security.

Keep track of devices: Mislaid unencrypted mobile devices, failure to destroy an abandoned computer’s hard drives and other frequent lapses can expose client data.

Nuance requires discernment

When does sharing client information—even with the care team—cross the line? The unsatisfying—but real—answer is, “It depends.” The Code gives case managers the responsibility but doesn’t specify *how* they are to fulfil it, Kurland explains. “The Code is neither a rulebook nor a playbook. It provides the broad contours of and relies on the CCM’s discretion, discernment, judgment and expertise.” ■

The Code of Professional Conduct for Case Managers

Originally adopted in 1996, the Commission developed the Code of Professional Conduct for Case Managers to assure quality and protect the public interest. It includes broad principles—advisory in nature—and prescriptive rules and standards for professional conduct.

- 1 Board-Certified Case Managers (CCMs) will place the public interest above their own at all times.
- 2 Board-Certified Case Managers (CCMs) will respect the rights and inherent dignity of all of their clients.
- 3 Board-Certified Case Managers (CCMs) will always maintain objectivity in their relationships with clients.
- 4 Board-Certified Case Managers (CCMs) will act with integrity and fidelity with clients and others.
- 5 Board-Certified Case Managers (CCMs) will maintain their competency at a level that ensures their clients will receive the highest quality of service.
- 6 Board-Certified Case Managers (CCMs) will honor the integrity of the CCM designation and adhere to the requirements for its use.
- 7 Board-Certified Case Managers (CCMs) will obey all laws and regulations.
- 8 Board-Certified Case Managers (CCMs) will help maintain the integrity of the Code, by responding to requests for public comments to review and revise the code, thus helping ensure its consistency with current practice.

Compliance with the rules and standards in the Code is an expectation for every board-certified case manager (CCM®). Accepted throughout the industry, the Code provides the framework for all case managers to follow. Case managers who carry the CCM credential commit to providing ethical advocacy for their clients, putting the client's safety, privacy and autonomy first.



And don't make it busy work. Give them a simple task they can do where they feel like they're making a difference. Consider giving them a basket of laundry. "If they fold all day long, that's okay. It's safe, and they are helping someone."

Medication safety

Ensuring medication safety can be a challenge. For example, pill boxes can be helpful, but there's no guarantee the patient is taking the right medication at the right time. Medicines used only occasionally may end up in the same box as those taken every three hours.

"Meticulously go through those pill boxes. Identify each medication and make sure it is useful," Freeborne counsels.

"You can't give a healthy 28-year-old the same dose you should give a 93-year-old with kidney issues. I'm big on trying to advocate and titer the doses if possible. Some physicians don't want to hear that, but you may need to push for that."

— NANCY FREEBORNE, DRPH, MPH, PA-C, CEO, FREEBORNE HEALTH ADVISING

"CCMs bring critical thinking, ethics, judgment and discernment. That's why they are so well suited to advocate for clients in good times and bad."

— MARYBETH KURLAND, CAE, CEO,
COMMISSION FOR CASE
MANAGER CERTIFICATION

Here again, advocacy comes into play. Sometimes, you will need to question the provider about the dose. "You can't give a healthy 28-year-old the same dose you should give a 93-year-old with kidney issues," Freeborne says. "I'm big on trying to advocate and titer the doses if possible. Some physicians don't want to hear that, but you may need to push for that."

Along these same lines, some medications are dangerous for elderly patients. At the top of the list is the antihistamine diphenhydramine, known as Benadryl. It's in Tylenol PM and many other over-the-counter sleeping pills. It has a long half-life, and it can lead to delirium in seniors. Unfortunately, many people think it's safe because it's over the counter. Always question that one, says Freeborne. Cyclobenzaprine, a muscle relaxant commonly sold as Flexeril, can be overprescribed, and it may lead to drowsiness and delirium in geriatric patients. Always question that one, too.

Herbal products raise another red flag. We often don't know where they came from, whether they've been tested and if they will interact with a patient's regular medicines.

She also shared a list of medications that need to be questioned and, often, unprescribed:

- Anti-spasmodics
- Tri-cyclic anti-depressants
- Benzodiazepines
- Muscle relaxants
- Anti-psychotics
- Alpha 1 blocker
- Oxybutynin hydrochloride
- Anti-coagulants (these may be necessary, but because of the risk, they, too, need to be questioned).

For more in-depth guidance, she recommends visiting the National Institutes of Health site, www.nia.nih.gov/health/safe-use-medicines-older-adults.

It's part of the case manager's role as advocate to understand the medications a client is taking, especially when that patient is elderly.

Constant and constantly changing

The role of client advocate, now indistinguishable from the role of case manager, has evolved

over the last few decades. Recently, Freeborne paged through an old medical ethics book—written in 1981. "There was a whole chapter dedicated to the topic of whether nurses should be subservient to doctors or should they be advocates."

The dark ages were not so long ago. But all that has changed.

Today, the case manager's role as advocate is inviolable. The ethical underpinnings are constant. But the ways in which case managers practice advocacy depend on an array of factors. Certification and ongoing training help prepare case managers for this responsibility. But that's not all that's involved.

"Yes, CCMs have the essential skills and education, but that's only one aspect," Kurland says. In times like these, the intangibles matter at least as much as the training. "CCMs bring critical thinking, ethics, judgment and discernment. That's why they are so well suited to advocate for clients in good times and bad." ■

About the Experts



Nancy Freeborne, DrPH, MPH, PA-C
Chief Executive Officer
Freeborne Health Advising

Dr. Nancy Freeborne is the chief executive officer of Freeborne Health Advising (FHA). A co-founder of FHA, Dr. Freeborne is responsible for defining the company's strategic direction as well as leading the delivery of its professional services. She is a board-certified clinical physician assistant (PA); a former community health center director of operations; an award-winning professor, career advisor and mentor at multiple universities and an experienced HRSA consultant, with experience giving technical assistance to the health centers regarding compliance with their federal grant.

Dr. Freeborne's clinical experience is in women's health, primary care/internal medicine, and geriatrics. She served as the geriatric unit director at a Veteran's Administration hospital and as the clinic manager at George Washington University Geriatrics.

Dr. Freeborne received a Bachelor of Arts in biology from Lafayette College and a Bachelor of Science in Health Sciences-PA, Master of Public Health and Doctor of Public Health degrees from George Washington University.



MaryBeth Kurland, CAE
Chief Executive Officer
Commission for Case Manager Certification

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.



Commission for Case Manager Certification

1120 Route 73, Suite 200 • Mount Laurel, NJ 08054
(856) 380-6836 • ccmchq@ccmcertification.org
www.ccmcertification.org

WRITTEN AND PRODUCED BY HEALTH2 RESOURCES
© CCMC 2020

Join our community of
professional case managers!

