



IssueBrief

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A photograph showing a woman in a white uniform, likely a caregiver, holding the hand of an elderly man. They are outdoors, and the woman is looking at the man with a gentle expression.

When everything is rarely enough: Palliative care and the power of asking the right questions

Palliative care gets a bad rap.

Palliative care is not curative; the goal is to improve quality of life. However—and this is what often gets missed—palliative care can occur alongside the most aggressive disease treatment. It provides a powerful opportunity for relief and even healing, but many clients, families and even health care professionals don't fully grasp its full meaning.

"It's critical that we have a clear understanding of what palliative care is, and what it is not," says CCMC Commissioner Michael Demoratz, LCSW, CCM. Case managers have the responsibility as advocates to inform clients about what palliative care is, and of the options they have available.

But what happens when the client asks that "everything" be done? Palliative care is certainly not the same as end-of-life care, but it surely raises that specter. In the face of that, many people want "everything."

Understanding "everything"

Answering a request for "everything" can be overwhelming for even the most insightful case manager. But here's something important: "Everything" may not mean what you think it means, says Robert Macauley,

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— MICHAEL DEMORATZ, LCSW, CCM,
CCMC COMMISSIONER; AUTHOR,
*DYING 101: A CANDID CONVERSATION
ON TERMINAL ILLNESS*

MD, Cambia Health Foundation Endowed Chair in Pediatric Palliative Care at Oregon Health and Science University.

First, nobody wants literally *everything* done: “Imagine undergoing *every single thing* modern medicine can do. Well, that’s a frightening thought,” he says.

Second, “everything” means different things to different people. The first thing to do when someone says, ‘I want everything,’ is to figure out exactly what they mean by ‘everything,’ he says. By understanding what it means for the individual client, the case manager is better able to help that client and the care team create a plan based on the *client’s* needs and desires.

Macauley, who has extensive experience with these conversations, focuses on four domains of common communication and response: affective, cognitive, spiritual and family.¹

Affective response: What do you feel?

A client might ask for “everything” because they are afraid of being abandoned and not receiving the care they need. The case manager needs to address these concerns.

Their fears aren’t unfounded. Some studies have shown that patients who are DNAR (do not attempt

resuscitation) not only receive fewer medications and fewer burdensome treatments—which would make sense—but also fewer lab tests, less documentation in the chart and fewer physician visits. “So saying ‘I want everything’ might be a way of saying, ‘don’t give up on me because I still think I have a chance.’”

It may reflect fear and anxiety, and it may reflect depression.

“So rather than saying yes or no, we might ask, ‘What are you afraid of? What worries you? What are you going through and what are you hoping for?’”

Cognitive response: What do you need to know?

It’s possible the request has more to do with reason. Maybe the client doesn’t understand how sick they are. “In that case, we might ask them what their understanding of their condition is and what their goals are in relation to it.”

Or it could be that they want to be sure everything that conceivably could be *beneficial* for them is being done. In that case, he says, the team may need to make sure it understands what the client has been told about the illness and the potential benefit of the desired treatments. Here, especially, case managers need to probe the client’s perception of “everything” as it relates to their understanding of their condition. Do they have all the facts?

Spiritual aspect: How do beliefs affect choices?

Spirituality is one of the core domains of palliative care, he says. Research shows that a very high percentage of patients make decisions based on their spiritual beliefs or their religious faith.^{2,3} The same applies to family members and other surrogate decision-makers.⁴

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Some clients embrace “vitalism.” For them, living in any form is better than not living. One way to engage them is to ask them to

1 Macauley bases these categories on Quill TE, Arnold R, Back AL. “Discussing Treatment Preferences With Patients Who Want ‘Everything’.” *Ann Intern Med.* 2009;151:345–349.

2 Givler A, Maani-Fogelman PA. *The Importance Of Cultural Competence In Pain and Palliative Care.* (Updated 2019 Feb 12). StatPearls Publishing; 2019 Jan. <https://www.ncbi.nlm.nih.gov/books/NBK493154/>

3 Puchalski CM. “The role of spirituality in health care.” *Proc (Bayl Univ Med Cent).* 2001;14(4):352–357.

4 Saneta M, Maiko, Steven Ivy, Beth Newton Watson, Kianna Montz, and Alexia M. Torke. *Journal of Palliative Medicine.* Apr 2019. ahead of print

help you understand their beliefs, he explains. “What about you or your religion or spirituality leads you to believe that? Are there other ways of interpreting that?”

Others believe that to *not* request—or demand—everything is saying they have given up hope for the miracle they believe God will provide. A care team member may help the client work through this by asking, “How will we tell when God thinks it’s time?”

The family factor: How are family members influencing decisions?

Sometimes, it’s not the client requesting “everything,” it’s the family. All sorts of issues could be in play. Perhaps the family doesn’t grasp what the client understands about the prognosis. There may be family conflict; different relatives want different things for different reasons.

“There’s an old trope in the field of clinical ethics that some people refer to as the ‘nephew from Peoria.’” That’s when a long-lost relative the client hasn’t seen in years swoops in at the 11th hour and—for whatever reason—wants the client to stay alive, no matter what the situation. His appearance shifts the focus from what the client wants to what the family member wants.

Safeguarding the patient’s autonomy and well-being is always the priority, but it makes sense to understand what the “nephew” is feeling. “I’d try to help them understand what the patient has been

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going through, as they may not have lived with that patient through their decline,” Macauley says. “Ultimately, we may need to accept that the relative’s needs will not be met.”

Perhaps the best way to address family concerns is to keep them informed. “The more a family appreciates what a patient is going through, the more they can make an informed decision.”

When the patient is a child, the situation is even more painful. “Few things in life are more instinctual and powerful than a parent’s desire to protect their child. And it is so profoundly unjust and almost unthinkable to lose one’s child.”

Ask and listen: The case manager’s gift

In each of the four domains, the key to understanding is asking the right questions of clients and family members—and listening to the answers. This allows the team to

begin developing a care plan that reflects their fears, hopes and values.

Case managers are well positioned—and professionally equipped—to take the lead here, and help clients understand palliative care in the context of their personal preferences. It’s the opportunity to ensure clients, family members—and sometimes, even physicians—truly understand that choosing palliative care isn’t about giving up, but about alleviating suffering and improving quality of life, Demoratz explains.

The treatment plan: Centering the pendulum

The next step is to propose a treatment plan based on the client’s goals, fears and concerns—the ones revealed by looking at the situation through the affective, cognitive, spiritual and family lenses.

The ultimate decision about what treatment makes sense for a

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certain condition may be up to the physician, Macauley says. "But these more profound existential questions are really the purview of the entire medical team. I think that thoughtful case managers are able to engage patients on this level in a very profound way."

They can also engage physicians to achieve the balance between radical client autonomy and old-school paternalism.

Some physicians struggle with this because the pendulum has swung pretty far over the last few decades, he says. "We went from not involving the patient or family at all in decision-making to essentially abdicating every decision to them." That places a huge burden on the client or family and asks them to make decisions without the perspective medical professionals have.

Shared decision-making is a way to move back to the middle, he says. "A recommendation is

actually part of the informed consent process, but it should be based on the patient's own values."

So where do you start? Macauley offers a model published in the *Annals of Internal Medicine*.⁵

"Given what we know about your illness and what I have learned about your priorities, it sounds like you would prefer the following balance of burdens and benefits in your treatment."

It's not the exact words that matter; it's the approach. He points to two key elements: client-centeredness and humility. "Sounds like you would prefer" is very different than saying, "I know what you think."

If the client agrees that the plan reflects her values about what "everything" means, then it's time to move forward.

The other possible response is that the client does not agree with that plan. There could be any number of reasons for this. Perhaps the team misunderstood or missed something along the way. Perhaps the client—especially from a cognitive standpoint—doesn't appreciate why certain treatments, like resuscitation, won't be a benefit. In those cases, the team needs to go back to the client and seek clarification.

Sometimes the client remains resolute. Regardless of why, the team has to address the situation.

Macauley comes down on the side of honoring the patient's request.

"There have been very few times in my 20 or so years of practice when I have said, 'I know you want this, but it's not good for you and I can't do that for you.' I think that might reflect the fact I'm sort of a perpetual optimist and hope that by preserving the relationship there may be future opportunities to intervene to minimize suffering while still recognizing and honoring the patient's goals."

Physician optimism can also have a profound impact on decision making, he adds. Case managers need to listen for what the client really wants and then advocate for the patient.

A sense of obligation

Sometimes, clients share information with a case manager that conflicts with what they told the entire team. Often, it involves a desire for less-aggressive treatment. Perhaps they changed their minds upon reflection or after a conversation with the case manager.

Or it could be because of the doctor. "One of the other reasons that may happen is that the patient may feel obligated to accept maximal treatment by virtue of the fact that physicians tend to be optimists," Macauley says. "They don't want to disappoint the physicians."

The case manager needs to bring this up to the team without

5 *Ann Intern Med.* 2009;151(5):345-349.
doi:10.7326/0003-4819-151-5-20090910-00010

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offending the physician. He recommends using “worry” and “wonder” to make the point. It could be something like this:

“I’m a little worried about this client and whether they really understand the situation. I wonder if they’re feeling a little scared. And I wonder if this treatment plan that we’ve identified is really the best way to go.”

This approach is more likely to work because it’s less confrontational. “Speaking as a physician, I know enough physicians who don’t take kindly to being second-guessed,” Macauley says.

Adjusting the focus

When clients do decide they don’t want “everything,” it’s important to focus on the positive aspects of that decision.

“Speaking as a physician, I know a lot of my colleagues who frame things in the negative.” Sometimes, in trying to make very sure that the client understands what they are *not* going to do, physicians end up disproportionately focusing on the “not.”

“It’s not uncommon for me to hear teams coming on duty and saying to a patient, ‘I just want to make sure you understand that if your heart stops, we’re not going to assist you, and if you have trouble breathing, we’re not going to intubate you.’ It makes me wonder if the patient is thinking, ‘Is there actually anything you *are* going to do for me?’ It’s very important for us to focus not only on what we’re *not* going to do but especially on what we *are* going to do.”

It’s here where case managers can be crucial, he says, by helping patients understand that “even though we may not do certain things, we’re going to do a whole

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lot of other things, and they will never be abandoned.”

Don’t wait

Palliative care discussions need to start early. Case managers can take the lead to help clients, family and caregivers have earlier *and better* conversations about it.

Ensuring that conversation takes place early requires more than good intentions, warns Macauley. “It’s not sufficient to say, ‘Hey, this is important,’ and hope everybody remembers. There needs to be a *process*.” That could be a palliative care consult, a checklist taped to the door or a multidisciplinary conversation to try to standardize understanding across the board—to say, “we know this is important.”

By making it the standard expectation, it’s hard *not* to do, Macauley says. That’s the aspiration, but in many places, it’s not yet the reality.

“We can all do better, especially when the situation lends itself to comfort and symptom management rather than cure,” Demoratz says. “Don’t wait until stress and pain have made the patient’s burden unbearable. We can help our clients live the rest of this life to the fullest. And that’s at the heart of being a case manager.” ■

About the Experts



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Dr. Macauley serves as chair of the Committee on Bioethics of the American Academy of Pediatrics, vice-chair of the American Board of Internal Medicine Hospice and Test-Writing Committee, and formerly served on the board of trustees of the American Academy of Hospice and Palliative Medicine. He has published numerous journal articles, and his comprehensive textbook *Ethics in Palliative Care: A Complete Guide* was published by Oxford University Press in 2018.

MICHAEL DEMORATZ has more than 30 years' experience working with catastrophically ill and injured clients as a licensed clinical social worker. Throughout his career, he has maintained a special interest and focus on hospice and palliative care. Nationally, he is recognized as a subject matter expert in end-of-life care. In 2001, he was awarded the Distinguished National Case Manager of the Year by the Case Management Society of America (CMSA).

He serves on the board of directors as an elected Commissioner with the Commission for Case Manager Certification and has served as a board member of the Coalition for Compassionate Care of California. His writing and presentations focus on end-of-life, bereavement, pain management and catastrophic case management. He also co-authored the book, *Dying 101: A Candid Conversation on Terminal Illness*.



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