Dear Dr. Jeff:

We occasionally have a resident in our facility whose legitimate surrogate is either unreasonable, has a personality disorder, or is frankly psychotic. What tips do you have for dealing with these situations?

Dr. Jeff responds: Your facility is no different from others in facing these problems. Indeed, a small minority of difficult families tend to consume massive amounts of time and energy, and that can leave too little for other families with legitimate concerns but a less demanding nature. While there is no perfect solution to these problems, I can offer some suggestions.

The first is to explore the notion of “legitimate surrogate.” From an ethical viewpoint, only someone who can reasonably be expected to speak with the voice of the resident should have any standing when an individual is temporarily unable to make decisions.

A surrogate designated by the resident to speak and act on his or her behalf deserves our acknowledgement, while a guardian appointed by a court has at least legal legitimacy. But the ethical concept of “substituted judgment” was developed to extend an individual’s autonomy, not restrict it.

Redirect Difficult Surrogates

Although no bank would accept a check signed by the relative of an account holder, in long-term care, we are routinely asked to consult with kin who have legal standing but no ethical standing. And frequently, individuals who are most demanding lack even legal standing. Although it is reasonable to have a designated representative for every vulnerable nursing home resident, it is an error to think that these generally well-intentioned individuals are necessarily ethically legitimate surrogates.

The importance of this distinction is huge, particularly because it reminds us to redirect the unreasonable surrogate back to what the resident would have wanted. Occasionally the family member who is demanding coffee enemas and fruit purges, asking for the person’s mercury-containing fillings to be removed, or seeking chelation therapy can be persuaded to back off when shown the lack of scientific evidence or proof of danger.

But you can calm the discussion by steering the surrogate away from weird beliefs about human physiology and back to the care that the resident would have chosen. Demands from an individual who lacks legal or moral standing should be ignored, and the individual should be referred to the genuine surrogate.

Nevertheless, it is worth exploring the motivations of a family member or other loved one who appears unreasonable. Sometimes, an angry surrogate has a legitimate concern but no idea how hostile or inappropriate it may sound to staff.

Manage Hurt and Anger

Hurtful words such as “stupid” and “incompetent” and vague threats of lawsuits or assertions of abuse come too easily to the mouths of some. These might not seem as serious to the surrogate who utters them as they do to a long-term care professional. At times, it may be helpful simply to teach a surrogate how to complain properly.

There seems to be a broad and increasing belief that there are only two ways to resolve disputes: with a lawsuit or with violence. Surrogates are often encouraged to act as “advocates” for residents against the facility. While advocacy should mean speaking for the needs of the resident, it often gradually morphs into confrontation as seen on television. Every imaginable argument is considered fair game, and every concession is basis for a new demand.

I believe that it is the role of the health care professional to be the advocate for patients. The surrogate’s role is to be our partner and to help us understand what we should be advocating.

Unreasonable surrogates can be fueled by ignorance, the influence of another clinician or lawyer, a failure to recognize reality, desire not to crush family hopes, and occasionally what must be recognized as arrogance and greed.

Can we really call someone “unreasonable” if an oncologist or vascular surgeon is offering one more hope? Or if they read a lawyer’s website saying that all pressure sores are evidence of poor care? Or if a hospital discharge planner promised that a resident was “entitled” to 100 days of Medicare nursing home coverage?

A local hyperbaric oxygen—treatment center has been running television ads suggesting its services for peripheral vascular disease and stroke. How unreasonable was the family that insisted their grandmother be sent for the treatment on her gangrenous foot? And how cruel was the vascular surgeon who told them, “It can’t hurt”?

I choose not to guess the motivation of the hyperbaric center. Rather, I ask surrogates who seem to be making decisions based on poor information to share their sources, and I offer to speak to their outside advisers directly. I provide the family with access to genuine scientific sources. This reassures the family that we are open to any reasonable solution that might help their loved one and encourages them to look to us as the experts.

The genuinely psychotic surrogate is rare. If an involved family member does go off his or her medication and presents with frank schizophrenia, our task should be to document the person’s behaviors and help them into the mental health system. Unfortunately, there is no shortage of surrogates with genuine personality disorders.

Generally, people with alcohol or drug problems and those who behave criminally can be controlled by appropriate facility security or law enforcement. Residents and staff must be protected from these individuals. When such a family member shows up for a visit, you may require that it occur in the lobby or some other observable location where the resident can have private conversation but everyone can be safe.

By the way, don’t try to use the skills of the health care professionals on your staff to treat the outsider during these visits. It is best to be compassionate but firm.

Unfortunately, this still leaves a significant number of legitimate surrogates who have what the DSM-5 would define as Cluster B personality disorders, including excessive, dramatic, attention-seeking, erratic, impulsive, and manipulative behaviors without concern for the rights of others or any sign of emotional empathy. Individuals may combine different elements of these behaviors and be characterized as anti-social, borderline, histrionic, narcissistic, or all of the above.

Take an Individualized Approach

Although there is no simple solution for these troubled and troubling family members, a few basic approaches may help.

First, and most painful, is to treat them with more respect than their endless complaints seem to deserve and to return telephone calls promptly and comparatively cheerfully. Otherwise, since they lack perspective, your failure to respond promptly is either an insult or a demonstration of your lack of concern.

At the same time, it is entirely reasonable to emphasize that you are very busy, to set strict limits on the length of meetings or telephone calls, and to enforce those limits.

You should deal with only one or two problems at each encounter, and the plan for how to proceed should be agreed upon and repeated at the end of the session.

Difficult surrogates frequently have long lists of concerns, but they should be forced to prioritize their concerns, and to allow the facility to add some of its own. With the list only partially addressed at each session, short weekly meetings are much more effective than occasional prolonged ones. And, of course, the facility must ensure that whatever is agreed to is actually done.

Since manipulative behaviors are typical, it is wise to identify one or two reasonably prominent staff members as contact persons and insist that all communication be directed through them. This saves the time of all the other staff who would be asked the same questions, demonstrates the facility’s respect by allowing access to the highest levels, and prevents the surrogate from hearing multiple different explanations—suggesting to such personalities that the facility is covering things up or has “heroes” and “villains.”

If the family talks to enough staff members, it will finally find the floor nurse or certified nurse assistant who will explain that something wasn’t done “because we don’t have enough staff,” validating that the resident isn’t receiving enough time and attention.

The suggestion that if the family isn’t unsatisfied with your care it should take a loved one elsewhere, alas, is never successful. Between narcissism preventing some family members from acknowledging that your facility might have been a poor choice and grandiosity convincing them to “fix” your operations, there is little hope in surrendering to their fantasies—or yours.

Just as difficult resident behaviors need individualized management approaches, difficult families need individualized approaches. But calm, thought-out approaches can reduce the drama and minimize the emotion drain on everyone.

By Jeffrey Nichols, MD

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Surrogate Challenges? Keep Calm and Carry On