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# Long-Term Care Survey Alert

## End-of-Life Care: Stay Out Of The Fray With A These Lessons From Survey Battle

**Case chronicles facility's struggle with a resident's end-of-life instructions - and her family's counter demands.**

Advance directives can be tough for providers to navigate in some cases, and lead to substantial deficiencies even when a facility struggles to do the right thing.

**Case in point:** One Maryland nursing facility received a state-imposed actual-harm level deficiency and a $10,000 civil monetary penalty (CMP) for allegedly failing to honor a resident's advance directive.

The facility appealed the CMP to the **Maryland Department of Health and Mental Hygiene** and lost, but the situation holds some valuable lessons for all nursing facilities grappling with end-of-life decisions.

**Here's what happened:** The administrative law judge's findings of fact after a hearing provide the following account:

Mrs. R, an 80-year-old woman with dementia, entered nursing facility XYZ in Baltimore County in 1997. She had an advance directive stipulating she did not want to receive life-sustaining artificial nutrition if she were in an end-stage condition. Mrs. R's advance directive did state she wished to receive drugs, narcotics or hydration to alleviate pain and suffering. Two witnesses, as required by Maryland state law, had signed the advance directive.

In the next few years, Mrs. R's physicians certified her as being in an end-stage condition due to her worsening dementia. She was unable to participate in healthcare decisions, and the physicians noted in writing that tube feeding and CPR would be "medically ineffective."

In 2001, Mrs. R was admitted to XXX hospital with a diagnosis of dehydration. The physician at the

hospital surgically inserted a gastrostomy tube in her stomach, and the hospital nursing staff began to give Mrs. R tube feedings through her G-tube.

When Mrs. R returned to the nursing facility, the interdisciplinary staff attempted to honor her advance directive by administering only water and medications via her G-tube. The nursing staff also attempted to feed Mrs. R orally during that time, but she was unable to take food by mouth.

Mrs. R's attending physician (who did not work for the nursing facility) and the nursing facility separately sought professional ethical consultation about the situation. Both the attending physician and facility were counseled initially to honor Mrs. R's wishes.

**Physician Documentation Tells the Story**

Mrs. R's medical record clearly showed the attending doctor's decision making about withholding the nutritive tube feedings. On April 14, 2001, Mrs. R's attending physician wrote in her progress notes: "Patient was treated for dehydration. PEG tube is placed...G tube is placed against her living will...G tube flushes until the decision made regarding nutrition. Discussion with nursing home staff."

**Another note:** "Patient had PEG placed for nutritional purposes against the wishes of the patient. I personally do not recommend a tube placement. I want to respect patient wishes and I discussed with Dr. X. Present issues are notified to

ethics committee of XXX. Continue G tube flushes no nutrition. Left message for her family."

On April 19, 2001 Mrs. R's attending physician wrote: "Tried for family. Discussed with son and daughter-in-law. Looks like they have contacted the attorney and made the decision if patient is not fed they will sue us and also they refused to give the name of attorney."

**Long story short:** Mrs. R's attending physician ordered the facility to begin feeding Mrs. R via the G tube. During this time, the facility's administrators also sought guidance from various state officials, including the Maryland Medicaid Agency, the ombudsman and the Attorney General's Office, regarding their obligations to Mrs. R.

Mrs. R. was transferred to the hospital on May 2, 2001 for medical reasons, and subsequently discharged to another nursing facility where she was also tube fed. Upon appeal, the judge agreed with the state's citation against the facility and the CMP.

**Not So Black and White**

While the state made the case sound like one where the nursing facility had egregiously violated the resident's wishes, the situation was actually colored more in ethical shades of gray.

"Although the administrative law judge's findings do not say so, the advanced directive was more ambiguous than it originally appeared to the facility," says **Stephen Sfekas, JD,** in Baltimore, MD, one of the attorneys representing the facility in the appeal.

"The attorney who drafted the advance directive had deviated from the standard regulatory language" required by Maryland law, Sfekas reports. "And we didn't know if Mrs. R had intentionally deviated from that language." Upon closer inspection, the facility found the advance directive, in fact, appeared to defer to Mrs. R's son, who had power-of-attorney for her healthcare decisions - and he was demanding she be fed via the G-tube, says Sfekas.

A Maryland state official familiar with the case tells **Eli** that the attorney general's office looked at the advance directive in the case and agrees there's "some validity to say it wasn't the best drafted instrument," but she insists Mrs. R's wishes were clear.

**2 Lessons to Consider**

The case offers a couple of key pointers for facilities caught in similar situations.

**1. Know the state statutory requirements for living wills so you can spot deviations that might come back to haunt the facility later.** "If the state has a standard form or statutory language and the nursing home resident departs from that language - which is the person's right to do - make sure to clarify the person's intent," advises Sfekas.

**Tip:** While Mrs. R entered the facility with an advance directive in place, facilities that help residents draft the durable power of attorney or living will are "playing with fire," in Sfekas' view.

"Under federal law, facilities are obligated to tell people admitted to nursing homes about such options," he says. "But if the facility's attorney or facility staff actually draft the living will, someone can always make the argument that the nursing facility coerced their grandmother, etc., into doing something she didn't want to do."

**2. Keep hospitals in the loop about a resident's advance directive.** The hospital in this case actually created the ethical dilemma by inserting the G-tube (the state also cited the hospital for failing to honor Mrs. R's advance directive)."Thus, facilities should make sure to communicate with hospitals about residents' advance directives," says Sfekas. "Hospitals tend to have a strong orientation toward curative interventions and prolonging life," he observes.

**Err on Side of the Resident**

Ethical dilemmas seldom produce any clear answers - or winners. And Sfekas believes the Maryland administrative law judge took a wrong tack in saying the facility should have withheld the nutrition and hydration before it could consult with various expert sources to know how to proceed.

"If you withhold nutrition and that turns out to be a mistake, you can't bring the resident back to life," says Sfekas, who believes the facility did the right thing for Mrs. R, given the ambiguity in the situation.

**Heads up:** Nursing facilities should consider consulting with advocacy groups for the disabled to discuss ethical issues surrounding end-of-life decision making when caring for people with mental retardation and other disabilities who have never been competent to forge advance directives, advises Sfekas. "For example, get involved with the local ARC or United Cerebral Palsy or state Developmental Disabilities' Council," he suggests.