Discontinuing Medications for a Resident with Advanced Alzheimer’s Disease

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How does one approach the family of a resident with advanced Alzheimer’s disease residing in a long-term care (LTC) facility regarding discontinuing medications that may no longer be clinically indicated, even though the family insists that “everything be done” to treat the resident?

There are no “typical” families of residents with advanced Alzheimer’s disease or dementia. Many family members will tell you that “Mom isn’t like other people with Alzheimer’s disease.” Concerned families are also quick to add “and she is our only mother.” Although discontinuation of medication is a routine part of medical care in long-term care (LTC) residents, it may not be perceived as routine, and may represent a highly emotional and sentinel symbolic transition for many families. These family decisions can be further complicated because family members rarely speak with one voice. Given this caveat regarding not generalizing, one can consider a specific clinical scenario presented here.

Mrs. A is an 84-year-old widow living in a LTC facility, with a history of a progressive 7-year downhill course with Alzheimer’s disease. During the monthly rounds, the physician documents that her ability to communicate is severely impaired, and she is immobile, bed-bound, and requires total assistance with all activities of daily living. She has been losing weight during the previous 60 days, and often refuses to open her mouth for most foods, fluids, or medications.

Mrs. A’s past medical history is significant for chronic hypertension, osteoporosis (without previous fractures), and an elevated serum cholesterol without previous significant cardiovascular complications. Although she has a Do-Not-Resuscitate order on her medical record, her son, a well known attorney living in another state, consistently insists that “everything be done” for her. She has two daughters who live locally and visit her often. One of these daughters is a nurse, who seems extremely vigilant about any perceived lapses in care. One of these daughters is a nurse, who seems extremely vigilant about any perceived lapses in care.

Mrs. A’s current medications include:

- memantine 10 mg BID
- donepezil 10 mg QD
- atorvastatin 40 mg QD
- niacin 500 mg TID
- chlorthalidone 25 mg QD
- diltiazem 120 mg QD
- enalapril 5 mg QD
- alendronate 70 mg weekly
On examination, her current blood pressure is 128/80, her cardiovascular findings are unchanged from her baseline, and her advanced Alzheimer's disease remains stable. Her cholesterol levels have been stable for years at 220 mg. Many of her medications appear no longer to be clinically indicated, including memantine, donepezil, atorvastatin, niacin, and alendronate. How should the physician best approach this family?

**RECOMMENDATIONS**

First, the attending physician should speak with the nursing staff to be sure they understand why certain of Mrs. A's medications are no longer clinically indicated and may be safely discontinued. The physician and staff must always “be on the same page” before approaching the family, because families will always re-verify what they think they heard for months after a meeting. The staff also often knows which family members to contact first, as well as the family's particular preferences for communications with the staff. It would also be useful to have the social worker call each of Mrs. A's children with the same message.

The staff and attending physician should preferably arrange a face-to-face meeting with key family members to discuss the planned discontinuation of the identified medications. Alternately, a telephone conference call could be arranged if this is more convenient for family members and staff. Most families of nursing facility residents are eager for any opportunity for direct communication with the physician, so a direct telephone conversation is often more effective in encouraging family agreement and compliance with recommendations than having the physician's recommendations transmitted “second-hand” (and open to interpretation) through the facility staff.

Set the stage at the beginning of the care meeting or conference call by stating that the meeting has been called to discuss the best available treatments for Mrs. A at this point in her illness and her life. Remind the family that progressive brain diseases are just that—they change over time and require frequent monitoring and re-evaluation of benefits, burdens, and risks. The physician should state that he/she has noted the resident's increased resistance to taking medicine, food, or fluids by mouth, her related weight loss, and the poor prognosis given the advanced stage of her dementia.

At this point, family members should be asked one at a time to talk about their expectations, what they understand to be their mother's previous values, preferences, and goals for care, and their own wishes for her care at this point. They should be specific about what is most important to her and them, as her representatives, at this time. Clarify that the focus of the meeting is to discuss medications and care for which the physician is primarily responsible, rather than leaving it open to broader issues (eg, staffing levels, food quality).

While medication use is only one aspect of the resident's care, it should be emphasized that it is an important one that should be reassessed on a regular basis. Make a point of validating the family's successes as her advocates for quality medical care over the years. Remind them that she had all the current available best treatments for dementia, osteoporosis, and prevention of cardiovascular disease at the times for which there was evidence of greatest benefit or effectiveness. Discuss which medications now may be safely discontinued in order to maximize her quality of life. Reinforce to the family that caring for someone with a progressive illness or with a number of comorbidities is often a process of continual evaluation and treatment adjustments.

Educate the family about what to expect and how medication withdrawal will be titrated to minimize adverse reactions. Prepare them for what to expect if the resident declines as she would have eventually, even if she had continued taking all of the currently prescribed medications. Always emphasize that these decisions can be reversed if they cause any unexpected burden to the resident.

This is also an ideal time to prepare the family for expected transitions in advanced dementia, such as the effects of immobility, recurrent infections, and the trade-offs with hospitalization versus active palliative care in the facility.
Explain that palliative care is an adjunct to active hospital-based treatment, not an abandonment of hope or care. Expect the family to say they aren’t ready to “go there yet.” Encourage them to discuss future treatment options, and to get back in touch with you within a reasonable time period to inform you of their decisions. Offer to refer them to other individuals who may help them through this difficult period (eg, clergy, social worker).

Working with families of residents with advanced Alzheimer’s disease is generally a back-and-forth process. While a family may take one step forward and two steps back in their decision making, most families are resilient and adapt over time, especially with repeated reassurance of access to quality health care information and guidance. Physicians are well advised to listen to families and acknowledge uncertainty, but always to offer guidance based on their clinical expertise and experience.

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**Sources**
