

HEALTH**LIFE-SUSTAINING PROCEDURES—APPLICATION OF HEALTH CARE
DECISIONS ACT TO DECISIONS ABOUT TUBE FEEDING**

November 16, 2000

The Honorable Sue Fryer Ward
Secretary of Aging

You have requested our opinion about the impact of the Health Care Decisions Act¹ on decisions about tube feeding. As you observe in your request, a prior opinion of this Office considered the question of withholding or withdrawing a feeding tube under Maryland law prior to the enactment of the Health Care Decisions Act. *See 73 Opinions of the Attorney General* 162 (1988). Given the major change in the law as a result of that 1993 legislation, you ask us to revisit the issue and address three specific questions:

1. whether tube feeding may be administered if a patient’s nutritional needs can be met through feeding by mouth;
2. whether tube feeding falls within the category of “life-sustaining procedures” that may be forgone in an advance directive or a decision by a health care agent or surrogate; and
3. whether, and under what circumstances, tube feeding meets the Health Care Decisions Act’s definition of “medically ineffective treatment,” which may be withheld or withdrawn from a patient in an end-stage condition without prior court approval.

¹ Chapter 372, Laws of Maryland 1993, *codified at* Annotated Code of Maryland, Health-General Article, §5-601 *et seq.* Unless otherwise indicated, all statutory references in the rest of this opinion are to the Health-General Article.

In addition, you ask a fourth question not directly related to tube feeding: whether, and under what circumstances, the functional impairments related to advanced dementia are consistent with an “end-stage condition,” as defined by the Health Care Decisions Act.

Our opinion is as follows:

1. If a patient’s nutritional needs can be met through reasonable efforts to feed the patient by mouth, a health care facility in Maryland may not administer tube feeding.
2. Tube feeding is a “life-sustaining procedure,” the use of which may be addressed in an advance directive or decided by a health care agent or surrogate decision maker. If a decision to withhold or withdraw a feeding tube is based on an instruction in an advance directive or the decision of a surrogate pursuant to the Health Care Decisions Act, the patient must first be certified to be in a terminal or end-stage condition or a persistent vegetative state.
3. Tube feeding meets the Act’s definition of “medically ineffective treatment” when a patient’s attending and consulting physicians have concluded that tube feeding would neither contribute to the patient’s health status nor prevent the patient’s impending death.
4. With respect to your final question, we conclude as follows: The functional impairments related to advanced dementia, to the extent that they mark a patient’s severe, generalized infirmity, are consistent with the Act’s definition of “end-stage condition.”

This opinion, we must emphasize, does not address decisions about tube feeding made outside the Health Care Decisions Act. The Act’s definitions and criteria do not apply in these other settings. That is, a patient with decision-making capacity has a common law right, unaffected by the Act, to give or withhold informed consent to medical treatment, including feeding tubes.² In addition, whatever common law decision-making authority an incapacitated patient’s

² The Act expressly preserves this common law right. Under §5-616(a), the provisions of the Act “are cumulative with existing law regarding an individual’s right to consent or refuse to consent to medical treatment” See *Wright v. Johns Hopkins Health Sys. Corp.*, 353 Md. 568, 728 A.2d 166 (1999); *Sard v. Hardy*, 281 Md. 432, 379 A.2d 1014 (1977).

next of kin or physician might have is left undisturbed by the Act.³ Finally, decisions about the use of a feeding tube for a patient under guardianship would be made pursuant to Title 13, Subtitle 7, Part III, of the Estates and Trusts Article of the Annotated Code of Maryland, not the Act.

I

Tube Feeding and Feeding by Mouth

In §5-611(d), the Health Care Decisions Act imposes an obligation to promote feeding by mouth: “A health care provider shall make reasonable efforts to provide an individual with food and water by mouth and to assist the individual as needed to eat and drink voluntarily.” A health care provider would breach this duty by inserting a feeding tube for reasons unrelated to the patient’s clinical situation – for example, to avoid the extra staff time that assisting with spoon feeding may require or to obtain higher reimbursement from an insurer.

Of course, efforts to provide food and water by mouth need only be “reasonable.” In this context, the word is used in two senses: The efforts need not be so painstaking and time-consuming as to defy common sense, and they need not be pursued when the goal of achieving adequate nutritional intake by mouth is no longer realistically achievable.⁴ A health care provider should document in the patient’s chart the clinical conditions that render spoon feeding infeasible and tube feeding medically advisable.

³ Section 5-616(a) disclaims any intent to “impair any existing rights or responsibilities which a health care provider, patient, including a minor or incompetent patient, or a patient’s family may have in regard to the provision, withholding, or withdrawal of life-sustaining procedures under the common law or statutes of the State.”

⁴ The dictionary definition of “reasonable” includes the concepts of “acceptable and according to common sense” and “not expecting or demanding more than is possible or achievable.” *Encarta World English Dictionary* 1495 (1999).

II

Tube Feeding As a Life-Sustaining Procedure

The Act explicitly includes tube feeding within its definition of “life-sustaining procedure.” Under §5-601(m)(2), this term “includes artificially administered hydration and nutrition”

In our 1988 opinion, we set forth in detail the methods for providing nutrition through artificial means. 73 *Opinions of the Attorney General* at 166-67. Suffice it to say that tube feeding involves medical procedures that, like other procedures, have potential benefits and burdens that can vary from one patient to another. The purpose of tube feeding is to maintain a patient’s nutritional status, obviously a benefit. Whether the tube is inserted through the patient’s nose or surgically inserted into the patient’s gastrointestinal tract, however, the necessary procedures, in Justice O’Connor’s phrase, “involve some degree of intrusion and restraint.” *Cruzan v. Director*, 497 U.S. 261, 288 (1990) (O’Connor, J. concurring). The weighing of these benefits and burdens, in light of a patient’s own preferences or the patient’s best interest, can result in a decision about tube feeding in an advance directive, by a health care agent, or by a surrogate decision maker.

- If an individual in an *advance directive* simply states a decision about “life-sustaining procedures,” that decision would apply to feeding tubes as well as other interventions commonly used in an effort to prolong life (*e.g.*, a ventilator). An individual is free, however, to make a decision about tube feeding that differentiates it from other life-sustaining procedures. Indeed, two of the optional advance directive forms set out in §5-603 incorporate language that invites consideration of tube feeding as a separate issue. Both the “Living Will” form and the “Part B, Advance Medical Directive” form offer individuals the opportunity to forgo “life-sustaining procedures, including the administration of nutrition and hydration artificially” or to forgo “life-sustaining procedures, except that, if I am unable to take food by mouth, I wish to receive nutrition and hydration artificially.”⁵ The withholding or withdrawal of a feeding

⁵ These forms also allow a decision in favor of receiving “all available medical treatment in accordance with accepted health care standards.” An individual who states that decision should be understood as seeking the use of tube feeding, albeit that procedure is not mentioned

(continued...)

tube on the basis of instructions in an advance directive requires prior certification that the patient is in a terminal condition, end-stage condition, or persistent vegetative state. §5-606(b).⁶

- A *health care agent* appointed under a written or oral advance directive has authority “to make health care decisions” for the individual who made the appointment. §5-602(b)(1) and (d)(1). A health care agent’s authority may be limited by an advance directive, but if it is not, the authority “to make health care decisions” includes the authority to decide whether life-sustaining procedures like tube feeding are to be used. Indeed, the statutory advance directive form for appointing a health care agent recites that the agent “has full power and authority to make health care decisions for me, including the power to ... [c]onsent to the provision, withholding, or withdrawal of health care, including, in appropriate circumstances, life-sustaining procedures.” §5-603 (Form II, Part A). Unless the advance directive states otherwise, this authority may be exercised without prior certification of the patient’s condition.

- A *surrogate decision maker* has general authority to “make decisions about health care for a person who has been certified to be incapable of making an informed decision and who has not appointed a health care agent....” §5-605(a)(2). These decisions are to be based “on the wishes of the patient and, if the wishes of the patient are unknown or unclear, on the patient’s best interest.” §5-605(c)(1).⁷ Unlike a health care agent, however, a

⁵ (...continued)
specifically.

⁶ Certification of terminal condition or end-stage condition is to be done by the patient’s attending physician and a second physician. Certification of persistent vegetative state is to be done by two physicians, “one of whom is a neurologist, neurosurgeon, or other physician who has special expertise in the evaluation of cognitive functioning” §5-606(b). These diagnostic categories are all defined in the Act. *See* §5-601(i) (end-stage condition), (o) (persistent vegetative state), and (q) (terminal condition). The definition of “end-stage condition” is discussed in Part IV below.

⁷ For a recent empirical study that illuminates the reasoning of surrogates for patients with Alzheimer’s disease, *see* Jason H. T. Karlawisch *et al.*, *Caregivers’ Preferences for the Treatment of Patients* (continued...)

surrogate's decision-making authority about life-sustaining procedures is circumscribed by the Act. That is, "a health care provider may not withhold or withdraw life-sustaining procedures ... on the basis of the authorization of a surrogate, unless [two physicians] have certified that the patient is in a terminal condition or has an end-stage condition ... [or] is in a persistent vegetative state." §5-606(b). Thus, if a feeding tube is to be withheld or withdrawn on the basis of a surrogate's decision under the Act, certification of one of these three conditions is a prerequisite.⁸

III

Tube Feeding and "Medically Ineffective Treatment"

A. *Determining "Medically Ineffective Treatment"*

Under the Health Care Decisions Act, physicians are not required "to prescribe or render medically ineffective treatment." §5-611(b)(1).⁹ The term "medically ineffective treatment" is defined in §5-601(n) as follows:

⁷ (...continued)
with Alzheimer's Disease, 55 *Neurology* 1008 (2000).

⁸ A different prerequisite applies to a surrogate who is also a guardian of the person with the power to make health care decisions for the patient. Because the withholding or withdrawing of a medically efficacious feeding tube would involve a substantial risk to the life of the patient, the guardian generally must obtain court authorization before consenting to this limitation of treatment. *Estates and Trusts Article*, §13-708(c). *See 78 Opinions of the Attorney General* 208 (1993).

⁹ Physicians are also not required to render a treatment that "the physician determines to be ethically inappropriate." §5-611(a). This statutory recognition of a physician's traditional prerogative is subject to an exception if a patient, health care agent, or surrogate has instructed that an intervention be done and "a failure to comply with the instruction would likely result in the death of the [patient]." §5-613(a)(3). In that circumstance, the intervention is to be provided pending the patient's transfer to another facility.

“Medically ineffective treatment” means that, to a reasonable degree of medical certainty, a medical procedure will not:

(1) Prevent or reduce the deterioration of the health of an individual; or

(2) Prevent the impending death of an individual.

In a prior opinion, we pointed out that this definition is properly read as if it said that a treatment is medically ineffective only if it will *neither* prevent or reduce the deterioration of an individual’s health *nor*, in the case of an individual facing impending death, prevent that death. “Conversely, if a medical procedure foreseeably would have either of the effects stated in the definition, the procedure is not medically ineffective.” 79 *Opinions of the Attorney General* 218, 234 (1994). In other words, the first part of the definition calls for an assessment of an intervention’s overall effect on the patient’s health; if the patient is also actively dying, the second part calls for an assessment of an intervention’s effect on the dying process itself.

These determinations about medical ineffectiveness are to be made “to a reasonable degree of medical certainty.” The General Assembly chose not to define this concept by reference to numerical probability, perhaps recognizing that requiring 90% probability, or any other exact number, would lend an air of false precision to what is inevitably a judgment call. Instead, the law requires that the physician’s assessment of probability be objectively based, not a mere hunch, and that the probability of the intervention’s ineffectiveness should be markedly greater than the probability of any other outcome.¹⁰

As we have already discussed, tube feeding is a medical treatment. Therefore, if in a particular case tube feeding meets the

¹⁰ This phrasing is drawn from a recent medical malpractice case in the District of Columbia and is consistent with other cases. See *Robinson v. Group Health Ass’n, Inc.*, 691 A.2d 1147, 1150 (D.C. 1997). The analysis in the text of the definition of “medically ineffective treatment” ratifies an earlier letter of advice from Assistant Attorney General Jack Schwartz to Dr. Janicemarie K. Vinicky (December 16, 1999).

Act's definition of "medically ineffective treatment," the attending physician has authority to decline to render the treatment. This authority is independently vested in the physician and requires neither consent nor (in the instance of a patient under guardianship) court approval. *See 79 Opinions of the Attorney General* at 236. Because tube feeding, is, however, a "treatment that under generally accepted medical standards is life-sustaining in nature," the attending physician may withhold or withdraw the feeding tube as medically ineffective only if a second physician concurs and only after the attending physician informs the patient or the patient's agent or surrogate of the decision. §5-611(b)(2)(i).¹¹

B. Applying the Definition to Tube Feeding

1. Overall health effects

A physician should use appropriate clinical criteria in assessing whether tube feeding is medically ineffective under the first part of the definition — whether it would "prevent or reduce the deterioration of the health of an individual." The attending physician should make this assessment based on the condition of the patient, in light of the physician's experience and pertinent information in the medical literature. The attending physician must consider, for example, whether tube feeding would make the patient more comfortable; if so, it is not medically ineffective.

This judgment, however, should be based on evidence because it cannot simply be assumed that a feeding tube helps allay health deterioration, especially in a patient with advanced dementia. A recent review article concluded that "functional status has not been improved and demented patients are not made more comfortable with tube feeding while dozens of serious adverse affects have been reported." Thomas E. Finucane, Colleen Christmas, and Kathy Travis, *Tube Feeding in Patients With Advanced Dementia: A Review of the Evidence*, 282 JAMA 1365, 1369 (1999). As another author put it, "data collected over the past decade suggest that gastrostomy tubes are not necessary to prevent suffering and may actually cause suffering." Muriel R. Gillick, *Rethinking the Role of Tube Feeding in Patients With Advanced Dementia*, 342 New Eng. J. Med. 206, 208 (2000). *See also* Christopher M. Callahan *et al.*,

¹¹ The certification of a second physician is not required if the patient is being treated in the emergency department of the hospital and only one physician is available. §5-611(b)(2)(ii).

Outcomes of Percutaneous Endoscopic Gastrostomy Among Older Adults in a Community Setting, 48 J. Amer. Geriatrics Soc. 1048, 1051 (2000) (use of this type of feeding tube “failed to achieve any clinically meaningful improvement on common measures of functional status, nutritional status, and subjective health status” among severely and chronically ill older adults in the study); Thomas E. Finucane and Colleen Christmas, *More Caution About Tube Feeding*, 48 J. Amer. Geriatrics Soc. 1167 (2000) (tube feeding characterized in this editorial as “extremely burdensome” for patients in the Callahan study, only a minority of whom “showed any measurable improvement”). In short, physicians should assess whether a feeding tube is actually contributing to the health of a patient with advanced dementia, not simply assume that it is.

2. Effect on dying process

If death is judged to be impending, the question then is whether tube feeding would “prevent” that death. We have previously explained, relying on the legislative history of this provision, that the use of the term “prevent,” coupled with a legislative decision to drop the term “postpone” from the definition, reflected the General Assembly’s decision “to allow physicians to certify as ‘medically ineffective’ interventions that might interrupt and delay, but would not really alter, the dying process.” 79 *Opinions of the Attorney General* at 235-36.

Obviously, an opinion of the Attorney General cannot provide clinically relevant criteria for determining whether tube feeding would be “medically ineffective” for an actively dying patient. We do note, however, a growing literature suggesting that tube feeding in patients with advanced dementia does not prevent death. A recent review article, for example, observes that “survival has not been shown to be prolonged by tube feeding.” Thomas E. Finucane, Colleen Christmas, and Kathy Travis, *Tube Feeding in Patients With Advanced Dementia: A Review of the Evidence*, 282 JAMA 1365, 1369 (1999). See also Muriel R. Gillick, *Rethinking the Role of Tube Feeding in Patients With Advanced Dementia*, 342 New Eng. J. Med. 206, 208, (2000) (“Gastrostomy tubes have not been shown to prolong life, ensure adequate nutrition, or prevent aspiration”); R. Sean Morrison and Albert L. Siu, *Survival in End-Stage Dementia Following Acute Illness*, 284 JAMA 47 (2000) (reporting “the high probability of death following pneumonia or hip fracture in the setting of end-stage dementia,” regardless of procedures intended to prolong life). A physician should consider this and other pertinent

literature in assessing the potential effectiveness of tube feeding for a particular patient.

IV

Advanced Dementia and End-Stage Condition

Finally, you asked us to “consider whether, and under what circumstances, the functional impairments related to advanced dementia may be consistent with an ‘end-stage condition’ as defined by the Health Care Decisions Act.” That definition, contained in §5-601(i), is as follows:

“End-stage condition” means an advanced, progressive, irreversible condition caused by injury, disease, or illness:

(1) That has caused severe and permanent deterioration indicated by incompetency and complete physical dependency; and

(2) For which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.

In an opinion issued shortly after enactment of the Health Care Decisions Act, we construed the term “end-stage condition” and sought to identify the legislative objective underlying the definition. We drew a contrast between end-stage condition and the other two conditions defined in the Act:

Unlike a patient in a terminal condition, a patient in an end-stage condition does not face “imminent” death, although the condition must be “advanced, progressive and irreversible.” And unlike a patient in a persistent vegetative state, a patient in an end-stage condition does not suffer a total loss of consciousness, although the condition must have caused “severe and permanent deterioration.”

A diagnosis of dementia, in and of itself, does not necessarily imply that the patient has an end-stage condition. As a standard reference points out, “Dementia may be progressive, static, or remitting. The reversibility of a dementia is a function of the underlying pathology and of the availability and timely application of effective treatment.” American Psychiatric Association, *Diagnostic & Statistical Manual of Mental Disorders* 137 (4th ed. 1994) (hereafter “*DMS-IV*”).

Advanced dementia, however, especially of the Alzheimer’s type, ordinarily would meet the definitional criteria of end-stage condition. The disease is “steadily progressive,” incurable, and ultimately fatal. Lawrence J. Tierney, Jr., Stephen J. McPhee, & Maxine Papadakis, *Current Medical Treatment & Diagnosis* 55 (39th ed. 2000). Moreover, “In advanced dementia, the individual may ... require constant care.” *DSM-IV* at 137-38. In the later stages of Alzheimer’s disease, patients “eventually become mute and bedridden.” *DSM-IV* at 142.

When the General Assembly included end-stage condition within the decision-making regime of the Health Care Decisions Act, it drafted the relevant definition precisely to capture the advanced phase of a progressive and incurable disease like dementia of the Alzheimer’s type. The statutory language was meant to denote the point at which patients with this kind of disease “have suffered severe and permanent generalized infirmity” 78 *Opinions of the Attorney General* at 213 (quoting Senate Floor Report on House Bill 1243 of 1993). Thus, the line of demarcation, we explained in that opinion, is linked to the impact of the disease on the patient’s functioning:

[O]n the one hand, a patient with Alzheimer’s disease who needs help with some aspects of personal care but who is able to engage in other activities independently is not in an “end-stage condition.” On the other hand, an Alzheimer’s disease patient who has deteriorated to the point where the patient needs help in *all* aspects of personal care might be determined to be in an “end-stage condition.”

Id.

V

Conclusion

In summary, it is our opinion that:

1. If a patient's nutritional needs can be met through reasonable efforts to feed the patient by mouth, a health care facility in Maryland may not administer tube feeding.
2. Tube feeding is a "life-sustaining procedure," the use of which may be addressed in an advance directive or decided by a health care agent or surrogate.
3. Tube feeding meets the Act's definition of "medically ineffective treatment" when a patient's attending and consulting physicians have concluded that tube feeding would neither contribute to the patient's health status nor prevent the patient's impending death.
4. The functional impairments related to advanced dementia, to the extent that they mark a patient's severe, generalized infirmity, are consistent with the Act's definition of end-stage condition.

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