Clinical Alert

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Maryland Department of Health and Mental Hygiene
Office of Health Care Quality
Spring Grove Center
55 Wade Avenue
Catonsville, MD 21228
410-402-8004

Parris N. Glendening,
Governor
Kathleen Kennedy Townsend,
Lt. Governor
Georges C. Benjamin, M.D.,
Secretary, DHMH
Carol Benner
Director, OHCQ

Advance Healthcare Decisions

"We have no simple problems or easy decisions after kindergarten."
-- *John Turk*

The right of a patient to accept or refuse medical intervention is a well-established principle in healthcare. In a setting that involves an alert, oriented and clearly competent individual, the process by which medical decisions are made is relatively straightforward. However, when disease or injury precludes the patient from actively participating in healthcare decisions, the situation becomes increasingly more complex. At these times, advance healthcare decisions are pivotal in preserving a patient's ability to direct his/her own care.

Advance healthcare decisions generally involve choices made by competent individuals concerning their **own** desired end of life care if they should become terminally ill, have an end-stage condition, or be in a persistent vegetative state. The individual determines, while fully able, whether he/she wishes such interventions as the insertion or continued use of a feeding tube, the initial or continued use of a ventilator, the initiation or continuation of renal dialysis and/or the administration of antibiotics. While occasionally difficult for families and even those healthcare workers caring for patients to accept, these "advance directives" should be followed in the same manner that one would in the case of a competent and communicative patient speaking directly to them.

The Office of Heath Care Quality frequently discovers situations in which healthcare providers do not honor the advance directives of patients in their care. The following deficiencies, which occurred in an area nursing home and hospital during 2001, are examples of such situations.

COMAR 10.07.02.07 A (2)
The administrator shall be responsible for the implementation and enforcement of all provisions of the Resident's Bill of Rights under COMAR 10.07.09

COMAR 10.07.09.08 C (11)
A resident has the right to consent to or refuse treatment, including the right to accept or reject artificially administered sustenance in accordance with State law.

COMAR 10.07.09.08 C (3)
'A resident has the right to a dignified existence, self-determination, and communication with and access to individuals and services inside and outside the nursing facility.

Jane Doe was an 83 year old female when she was admitted to [a local nursing home] on February 26, 1998. Almost a year prior to her admission, while still living in the community, this resident wrote certain instructions related to her healthcare. These instructions were contained in a document entitled "Advance Health Care Directive for [resident's name]". The resident signed this document on March 19, 1997, and two individuals witnessed this signing.

The creation of an advance directive is an important and proactive step in preserving one's autonomy as it relates to health care. An advance directive "speaks" for a resident at a time when she is unable, due to her medical condition, to communicate her wishes. End of life issues, such as withholding or removing life-sustaining interventions, are often the focus of advance directives. The Maryland statute governing advance directives, the Health Care Decisions Act, is found in the Code's Health General Article, §5-601 et seq.

Mrs. Doe's advance directive instructed her healthcare providers to withhold or withdraw life-sustaining procedures if she met any one of the following criteria:

1. *"If I am suffering from a terminal condition and if my death is imminent …".*
2. *"If I am in a persistent vegetative state …".*
3. *"If I have an end-stage condition …".*

Mrs. Doe, in her advance directive, specifically addressed the issue of artificial nutrition as follows:

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"I direct that no nutrition or sustenance be administered to me artificially, such as the insertion of a feeding tube; and, I direct that upon finding that I am as described [as either terminal, in a persistent vegetative state or in an end-stage condition] that any such artificial administration be terminated immediately …".

Mrs. Doe had been at [a local nursing home] for 18 months when on August 23 and September 20, 1999, two physicians certified that her medical condition was end-stage due to dementia. On July 17, 2000, two physicians again certified that her condition was end-stage secondary to dementia. At that time, the physicians also noted that tube feeding this resident, i.e. providing nutrition via a tube placed into the stomach, would be "medically ineffective".

Mrs. Doe experienced a gradual decline in her overall condition and during the first several months of 2001, it became apparent that her oral intake of food and fluids was becoming inadequate. Her capacity to make medical decisions and her ability to communicate had become severely impaired, and she was no longer able to participate in decisions related to her healthcare due to her dementia. On April 5, 2001, she was admitted to (a local hospital) for the third time in the preceding six months due to dehydration. Despite Mrs. Doe's clear advance directives to the contrary, a feeding tube was surgically placed into her stomach during this hospitalization at the insistence of her son. Fluids and tube feeding formula were then administered to her at the hospital.

She returned to [a local nursing home] on April 13, 2001. The clinical staff at the nursing center, including the attending physician, medical director, numerous members of the nursing staff, the administrator, the social worker and a corporate nurse who was a member of the facility's patient care advisory committee, all agreed that administering tube feeding to this resident would be against her wishes. Therefore, Mrs. Doe received only water and medications through the feeding tube. The facility's decision not to administer nutritional tube feeding per the resident's advance directive was communicated to the resident's family.

On April 14, 2001, the attending physician visited the resident and wrote the following progress note: *"… G tube [feeding tube] is placed against living will …"*

The attending physician next visited Mrs. Doe on April 16, 2001, and wrote: *"Pt [patient] had PEG [feeding tube] placed for nutritional purposes against the wishes of the patient. I personal [sic] do not recommend G tube [feeding tube] placement, I want to respect patient's wishes … continue G-tube [feeding tube] flushes [water only] no nutrition …"*

Three days later, on April 19, 2001, the attending physician again came to the nursing facility and wrote: *"Tried for family discussion with her 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 …"*

From the time Mrs. Doe was readmitted to the nursing facility on April 13, 2001, until the physician wrote her last note on April 19, 2001, all the resident had received was water and medications through her feeding tube. As she had on two previous occasions been declared in an end-stage condition (due to dementia) and her own physician had deemed that providing nutrition via a feeding tube would be "medically ineffective", the decision to withhold nutrition was completely in accordance with her advance directive.

However, after the resident's family made threats of legal action, the physician, on April 20, 2001, ordered the nursing staff to begin administering nutrition via Mrs. Doe's feeding tube. The nursing staff of the facility complied with this order and from April 20, 2001, through May 2, 2001, the resident was administered tube feeding formula daily. On May 2, 2001, the resident became acutely ill, was hospitalized, and did not return to the facility.

In summary, it is clear that the staff at the nursing facility was not responsible for the placement of the feeding tube. That act, in direct contrast to the expressed wishes of the resident, was performed at the hospital. The staff at the nursing facility was, however, required to honor the instructions set forth by Mrs. Doe in her advance directive. Those instructions carried the same weight as if Mrs. Doe had spoken them herself during April and May of 2001. Despite clear misgivings on the part of the nursing and clinical staff, who were personally familiar with Mrs. Doe's wishes, the facility failed to allow this resident to exercise her right to refuse treatment, specifically the right to reject the artificial administration of sustenance. Instead of honoring the very clear and concise directives of Mrs. Doe, the facility inappropriately followed the wishes of the family, which were in absolute contradiction to the expressed wishes of the resident.

Note: The nursing home appealed the above deficiency and sanction ($10,000.00 fine) to the Maryland Office of Administrative Hearings. A redacted version of the judge's decision in this case is available online at *http://www.dhmh.state.md.us/ohcq/download/alj/pdf* .

The staff of OHCQ also conducted an investigation into the care Mrs. Doe received at the hospital where the feeding tube was inserted. The hospital was seemingly unaware that a feeding tube had been placed in

this patient against her will. The Office of Health Care Quality wrote and forwarded the following deficiency to the hospital.

A76 482.13(b)(3) Exercise of Rights
The patient has the right to formulate advance directives and to have hospital staff and practitioners who provide care in the hospital comply with these directives, in accordance with 489.100 of this part (Definition), 489.102 of this part (Requirements for providers), and 489.104 of this part (Effective dates).

Based on a review of Jane Doe's medical record, the patient's advance directives and the hospital's policies and procedures, it was determined that the hospital failed to comply with the patient's advance directives that clearly indicated her desire to not be fed by artificial means.

Jane Doe was an 83 year old female who had lived at a nursing home for about 4 years. She was diagnosed with advanced dementia, with severe brain atrophy. While still capable of making her own decisions, Jane Doe had executed an advance health care directive in March of 1997. Her son was appointed her health care agent and she also spelled out detailed health care instructions.

Per the patient's instructions in her advance directives, which were to be acted upon when she was "incapable of making an informed decision," two physicians certified (July 17, 2000) that the patient had become "end-stage." The certifications specified that CPR (cardiopulmonary resuscitation) and G-tube feeding would not change patient's deteriorating health or prevent impending death. The patient's advance health care directive instructed *"that no nutrition or sustenance be administered to me artificially, such as by the insertion of a feeding tube…"* and upon finding that she has an end-stage condition *"… that any such artificial administration be terminated immediately."* Finally, she had directed, *"… that such life-sustaining procedures be withheld or withdrawn, and that I be permitted to die naturally."* The patient's son was appointed as health care agent but only to the extent the patient's wishes were unknown or unclear.

On April 4, 2001, Jane Doe was found to be unresponsive at the nursing home and intravenous fluids were started. She was sent from the nursing home to this hospital for dehydration with related abnormal laboratory findings. At the time of admission to the hospital, the patient's medical record indicated that she underwent testing and observation to rule out a heart attack. "Aggressive intravenous hydration" was started to address her dehydration. The patient did not recover sufficiently to take food or liquids by mouth. The attending physician had stated in his admitting history and physical for Jane Doe, dated April 5, 2001, that *"The patient is do not resuscitate with no ventilator or tube feedings. Orders are already in place."*

On April 7, 2001, the patient's attending physician wrote a progress note in the patient's chart saying, *"Discussed with patient's son (who had medical power of attorney) and daughter-in-law about options. They have agreed to placement of a feeding tube. Reiterated patient is DNR/DNI (do not resuscitate/ do not intubate). Will insert NG-tube and start feeds today. Cardiac arrhythmias noted, am hesitant to treat in view of hypotension (low blood pressure); will monitor. Dr. _ _ called for GI (gastroenterology) consult."*

On April 9, 2001, the GI surgeon wrote his/her signature on the patient's informed consent, for placement of the G-tube. The son's name is printed, not signed, in the space for (Patient, Nearest Relative, Legal Guardian) signature. The surgeon's signature attests that the physician has explained to the son the surgical procedure, the alternatives, and possible complications and risks.

On April 10, 2001, surgery to insert a feeding tube (G-tube) into Jane Doe's stomach was performed. Fluids and food were administered first through the NG-tube then through the G-tube for approximately a week, until her discharge on April 13, 2001, despite the patient's written directive that she should not be fed by artificial means.

The attending physician stated in Jane Doe's hospital "Transfer Summary — AMENDED REPORT" dated April 13, 2001, that *"However, after discussion with the patient's daughter-in-law, she agreed to a placement at discharge of a feeding tube."*

The patient was discharged from this hospital to her previous nursing home placement, then to another acute care hospital and finally to a new nursing home placement. About one month after discharge from this hospital, the patient died with possible aspiration pneumonia, infections in her urinary tract, several decubitus ulcers and hypotension.

The patient's attending physician and her daughter-in-law are the documented decision makers for the patient. The attending and the patient's daughter-in-law chose to institute treatments that would be medically ineffective as previously determined by the two physician certifications, i.e. treatment that would not alter the patient's deteriorating health status nor prevent her impending death.

A review of hospital policies revealed that Hospital Policy Number RI10 was enacted in order to *"foster respect for the inherent dignity of each person."* This policy defines medically ineffective treatment and end-stage condition and allows a health care provider to withhold or withdraw life-sustaining procedures provided that the patient's attending and a second

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physician have certified the patient as having a terminal condition. The certifications (noted above) predated this hospital admission by nearly one year and certified that the patient's condition was *"severe and permanent deterioration indicated by incompetence and complete physical dependency … [and] treatment of the irreversible condition would be medically ineffective."* Despite this fact, the G-tube was inserted.

A review of Hospital Policy Number RI8 revealed that this hospital policy states to *"Avoid conflicts of interest and/or the appearance of conflict."* This policy stated that the hospital *"assure that the care provided each patient is appropriate"* and *"ensure the integrity of clinical decision-making…"* This policy states that it is in place to *"promote employee and medical staff sensitivity to the full range of such needs and practices [physical, psychological, social and spiritual needs and cultural beliefs and practices]."* There was no documentation to indicate that the physician, surgeon, anesthe-siologist or other healthcare providers or administrative staff voiced the conflict between the patient's advance directive and the insertion of a feeding tube by invoking the hospital's "specific mechanisms or procedures to resolve conflicting values and ethical dilemmas among patients, their families, medical staff, employees, the institution and the community" as identified in Policy RI8.

A review of the hospital's Ethics Committee meeting minutes revealed that the hospital has a functioning system for the review of cases where there are conflicts regarding a patient's treatment, family wishes or advance directives. However, there was no documented evidence that the conflict between this family, the provider and the patient's advance directives had been referred to the hospital's Ethics Committee or for an ethics consult. Hospital staff interviewed on October 10, 2001, indicated that neither the physician nor the family referred this patient's case for an Ethics Consult.

In response, the hospital revised its policies and implemented staff training to ensure that advance directives are followed.

Discussion:
Researchers Morrison and Sin compared the treatment of patients with acute illness and end-stage dementia to another group with acute illness and without end-stage dementia. They found that patients with end-stage dementia received as many burdensome procedures as cognitively intact patients and that only 7% had a documented decision made to forego a life-sustaining treatment other than cardiopulmo-nary resuscitation. In the case of patient #1, even though she had clearly indicated her desires through advance directives to forego life-sustaining treatment, she was unable to avoid the imposition of unwanted and medically ineffective therapy.

- Does your facility have a case like Mrs. Doe's waiting to happen?
- Has it happened already? If so, what changes were made as a result?
- Does your staff understand that an advance directive is in fact the patient "speaking" to them in the only way left available?
- Will your staff honor the wishes of the demented patient who lies dying in her bed … or will unwanted care be inflicted upon her?
- Do you coordinate care when a patient is transferred between a hospital and nursing home?
- Does your facility just talk about the right of residents to direct their care, or is it part of the philosophy of your institution?

The Office of Health Care Quality considers the rights of patients to be paramount in any healthcare institution and will continue to monitor the response of facilities to this issue.

For additional information, please read:

Summary of Maryland Healthcare Decisions Act: *http://www.oag.state.md.us/Healthpol/HCDA.pdf*

Morrison, R and Sin, A. "Survival in End-Stage Dementia Following Acute Illness." JAMA. 2000; 47-52.

Administrative Law Judge's decision on the facility's appeal of this deficiency and civil money penalty: *http://www.dhmh.state.md.us/ohcq/download/alj.pdf*

Questions or comments regarding this Clinical Alert should be directed to:

Joseph I. Berman MD , Medical Director – Office of Health Care Quality
Phone: (410) 402- 8016;
E-mail: *Jberman@dhmh.state.md.us*

William M. Vaughan RN , Chief Nurse – Office of Health Care Quality
Phone: (410) 402-8140;
E-mail: *Wvaughan@dhmh.state.md.us*

Wendy A. Kronmiller,
Assistant Attorney General
Phone: (410) 767-5469;
E-mail:
wkronmiller@dhmh.state.md.us

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Office of Health Care Quality,
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For additional information contact
Joseph I. Berman MD
Medical Director,
Office of Health Care Quality
Phone: (410) 402-8016
E-mail: *Jberman@dhmh.state.md.us*