



Long-Term Links

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**ADVANCE CARE PLANNING
and GOALS OF CARE**
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The Missouri End of Life Coalition, the Department of Health and Senior Services, members of the Missouri Association of Long-Term Care Physicians, and representatives of nursing homes and hospices have developed *Guidelines for End of Life Care for Residents in Nursing Facilities*. These ideas will help lay groundwork for improving care for those dying in Missouri nursing homes. One chapter addresses advance care planning and goals of care, presenting an opportune time to review this subject in *Long-Term Links*.¹

This is an important issue for nursing homes, residents, and family members. Twenty-four percent of all Americans will die in nursing homes this year -- and 28% of Missourians. Furthermore, 30% of people admitted to the nursing home will die within one year.

A four-step process for patient-centered care includes:²

- ♦ Identifying patient preferences
- ♦ Communication about medical prognosis
- ♦ Defining goals of care
- ♦ Implementing a management plan consistent with those goals

Identifying Patient Preferences

Let's define key terms:

Advance care planning. The process of identifying the resident's personal preferences and values, which -- in conjunction with his/her current and anticipated medical status and goals -- provide the basis for making decisions about end-of-life care.

Palliative care. Medical, nursing and support services aimed at ensuring maximum comfort and dignity during the last stages of life. The emphasis is on controlling pain, relieving symptoms and preserving emotional support for resident and family.

Advance directive. This term may refer to any direction, oral or written, made by an individual before losing decisional capability, about his or her healthcare treatment wishes. Written advance care directives may include living wills, healthcare treatment directives, and durable powers of attorney for healthcare.

Durable Power of Attorney for Healthcare (DPAHC). A legal document in which a competent

**Continued:
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and Goals of Care**
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person gives another person (called an attorney-in-fact) the power to make healthcare decisions for him/her if he/she becomes unable to decide. A DPAHC can include guidelines for the attorney-in-fact to follow.

Surrogate. An agent who acts on behalf of a resident lacking decisional capability to participate in a particular decision. An appropriate surrogate may be:

- ♦ designated by the resident (e.g., in a healthcare treatment directive, living will attorney); or
- ♦ the adult most involved with the resident and most knowledgeable about his/her personal values and preferences; or
- ♦ designated by a court (e.g., a guardian).

Both federal law and Missouri law have addressed these issues. In the Cruzan case, the U.S. Supreme Court acknowledged a constitutional basis for a competent person's right to refuse medical treatment, including artificial feeding. The Patient Self-Determination Act of 1991 requires nursing facilities (and others) to inform patients of their right to make treatment decisions with advance care directives. The Missouri Durable Power of Attorney for Healthcare Law allows competent individuals to designate a surrogate to make healthcare decisions for them if they lose decisional capability as determined by two physicians (or one if so designated). Authority to with-

hold or withdraw artificially presented food or water must be designated.

The goal of advance care planning is to ensure that clinical care is in keeping with the patient's preferences when he or she has become incapable of decision-making. Expected outcomes would be to improve and share the healthcare decision-making process, allow the surrogate to speak on behalf of the patient, and respond with measured flexibility to unforeseen clinical situations. Planning should also improve the patient's outcomes and well-being by reducing over- and under-treatment, and by lessening patient concerns about possible burdens placed on family and significant others.³

We turn to a healthcare surrogate when the resident no longer retains decisional capacity, defined as the ability to make a specific decision -- the ability to understand relevant information, reflect on it, and to communicate (verbally or nonverbally) to providers. Decisional capacity may vary, based on the complexity of the decision. When we do not have a legally-defined surrogate:

"Surrogates recognized by providers/facilities and not appointed by resident's advance directive or court order should share in the decision-making process with the physician, family, and representatives of the facility."⁴

If ambiguity or conflict persists, we may turn to an ethics committee for help in resolution.

TABLE 1. Advance Directives and Healthcare Surrogates

<p><i>Advance Directive Advantages</i></p> <ul style="list-style-type: none"> ◆ Promotes physician-patient-family communication ◆ Extends patient self-determination ◆ Affords legal security for physicians ◆ Relieves patient’s anxiety about unwanted treatments ◆ Reduces potential for family strife over treatment decisions ◆ Increases physician confidence in decisions ◆ Lowers costs by withholding unwanted treatments 	<p><i>Advance Directive Disadvantages</i></p> <ul style="list-style-type: none"> ◆ Neither physician nor patient is likely to bring up the subject ◆ Terminology re: patient status and interventions vague ◆ May not be available when needed ◆ Difficult to know when to enforce ◆ May violate value of “sanctity of life” ◆ Could be used to inappropriately withdraw care ◆ May fail to express current wishes ◆ May reduce physician authority over treatment decisions
<p><i>Healthcare Surrogate Advantages</i></p> <ul style="list-style-type: none"> ◆ Serves as extension of patient’s autonomy ◆ Responds to changes and ambiguities better than a living will ◆ Formalizes common-sense approach to patient care ◆ Empowers person most knowledgeable about patient’s wishes ◆ Reduces number of interested parties to whom physician must respond 	<p><i>Healthcare Surrogate Disadvantages</i></p> <ul style="list-style-type: none"> ◆ May not have discussed with patient ◆ May not accurately anticipate or represent patient’s wishes ◆ May create an overwhelming psychological burden for the surrogate ◆ May have ulterior motives or be subject to influence of others ◆ May demand medical treatment with no hope of benefit

An advance directive goes into effect when the person’s medical condition is judged to be terminal or if the person has no reasonable chance for recovery and when he or she has lost decisional capacity.

The *Guidelines* review regulatory compliance; there is a federal requirement to “inform and provide written information ... concerning the right to accept or refuse medical or surgical treatment and ... formulate an advance directive” (F156). The surveyor guideline also delineates the elements of the Patient Self-Determination Act (42 CRR 489.102):

- ◆ Provide written information about rights under state law
- ◆ Document whether or not patient has advance directive (AD)
- ◆ Don’t discriminate based on whether he/she has one or not
- ◆ Ensure compliance with AD under state law
- ◆ Provide staff education about policies on AD
- ◆ Provide for community education

Furthermore, the regulations read that the facility is not required to provide care that conflicts with an advance directive, or implement an advance directive that the provider cannot implement as a matter of

conscience. If present, an advance directive should be reviewed annually with resident or proxy (19CSR 30-88.010 (9)).

Prognosis

In keeping with the second step of our four-step process, we should use prognosis to initiate and guide discussions. Two examples are useful. An 87-year-old woman with advanced dementia is admitted to the hospital for pneumonia. A 92-year-old bedbound man with advanced dementia falls out of bed and suffers a hip fracture in the nursing home. We now know that both residents have an average life expectancy of six

months or less.⁵

The Minimum Data Set (MDS) also holds clues for prognosis. For example, in Section J5c, the assessor can describe the resident as “end stage disease, 6 months to live,” based on observations and certification of prognosis by the attending physician.

Multiple MDS items reflect change of condition: decline in cognition, communication, mood, ADL function, urinary continence, care needs, pain, weight, pressure ulcers, hospital or ER admittance, or special procedures. Any significant clinical change in the resident’s status should merit a new MDS (significant change assessment).

Goals of Care

The third step in patient-centered care is articulating goals of care. The Residency Assessment Instrument User’s Manual Version 2.0 identifies four treatment goals: rehabilitation, maintenance, prevention, and palliative care. Care should be consistent with the resident’s goals; if the resident’s condition changes, goals must again be reviewed and changed to address the new needs.

Near time of death, the resident or surrogate should be encouraged to prioritize three main goals of treatment:

- ♦ Relative emphasis on life prolongation
- ♦ Relative emphasis on maintenance of physical and cognitive function
- ♦ Relative emphasis on comfort

To help this process, Quill⁶ recommends some representative questions:

Given the severity of your illness, what is most important for you to achieve?

How do you think about balancing quality of life with length of life in terms of your treatment?

What are your most important hopes and fears?

Management Plan

Finally, in the fourth step, it is important to implement a management plan consistent with the goals. The plan may include a range of interventions, starting with Do Not Attempt Resuscitation (DNR) orders. Since the likelihood of successful CPR is so slight in nursing home residents (less than 2%), we must expand our discussion to include other potential therapies

such as mechanical ventilation, tube feeding, antibiotics, dialysis, and even hospitalization. All such discussions should be ongoing and documented in the medical record.

This script can be used for the CPR question:

“If you were to die suddenly -- that is, if you stopped breathing, or your heart stopped -- we could try to revive you by using cardiopulmonary resuscitation (CPR). Are you familiar with CPR? Have you given thought to whether you would want it? Given the severity of your illness, CPR would likely be ineffective. I would recommend that you choose not to have it, but that we continue all potentially effective treatments. What do you think?”

Clinicians at Hebrew Rehabilitation Center for Aged in Boston⁶ have developed five pathways based on prioritizing the three major goals of care.

These are not inconsistent with the fundamental regulatory goal: “...for the resident to receive the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being in accordance with the comprehensive assessment and plan of care.” This does not mean that regardless of the resident’s condition, the facility must continue to work toward rehabilitation or restorative goals, but that there is a com-

Timothy Quill⁶ has recommended specific times when we should initiate end-of-life discussions, including both urgent and routine indications.

Urgent Indications

- ♦ Imminent death
- ♦ Talk about wanting to die
- ♦ Inquires about hospice or palliative care
- ♦ Recently hospitalized for severe progressive illness
- ♦ Severe suffering and poor prognosis

Routine Indications

- ♦ Discussing prognosis
- ♦ Discussing treatment with a low probability of success
- ♦ Discussing hopes and fears
- ♦ Physician would not be surprised if patient died in 6-12 months

Pathways for Care

- ❖ Intensive Pathway. Life prolongation is the prime goal, with maintenance of physical and cognitive function second, and maximization of comfort third. This translates into all medically indicated procedures, including cardiopulmonary resuscitation, intubation, and ICU care.
- ❖ Comprehensive Pathway. The prime goal is maintenance of physical and cognitive function, with prolongation of life second and maximization of comfort third. We would not attempt CPR or ICU care, because both of these interventions have a low probability of success and, when they do not result in death, commonly result in a functional decline.
- ❖ Basic Pathway. Maintenance of physical and cognitive function, with maximization of comfort second and life prolongation third. We would use nursing home-based care for all medical conditions and substitution of medical treatment for surgical treatment whenever possible.
- ❖ Palliative Pathway. The prime goal is comfort, with maintenance of physical and cognitive function second and life prolongation third. This means nursing home-based care exclusively, keeping diagnostic tests to a minimum.
- ❖ Comfort Only. The only goal is comfort. Treatment is exclusively to relieve symptoms, e.g., pneumonia would be treated with oxygen, acetaminophen and morphine, not antibiotics.

from Gillick⁷

prehensive assessment and plan. However, increased dependency near end of life must not result in isolation -- a predictor of abuse and neglect. In fact, dependency may result in increased staff time to care for the resident. The ongoing assessment, care plan development, care plan implementation, and revision will determine whether outcomes such as weight loss, pressure ulcers, and death are avoidable or inevitable.

In summary, the keys to end of life care are assessment, planning and implementation. Purposeful observations and conversations should be documented in the resident's record. All members

of the team should collaborate to translate the resident's wants into care goals and interventions -- a dynamic process. Symptoms should be assessed, interventions initiated, and evaluation documented. All members of the caregiving team need to be informed about changes in care. There is always something that can be done.

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Sign the Long-Term Care Physician's Pledge Online

Join more than 1000 of your long-term care colleagues who have already expressed their commitment to providing compassionate quality care, advocating for residents, and respecting patient rights. Visit www.amda.com/member/pledge.htm and sign on today! Every online signatory will receive a personalized copy of the pledge, suitable for framing.

from AMDA Reports newsletter

Feeding Assistants Regulation Released

HHS Secretary Tommy Thompson has announced new regulations that will help improve the quality of care for nursing home residents by allowing trained assistants to help residents eat and drink. "By permitting the use of trained feeding assistants, nursing homes will be able to provide their residents with better care, especially during ... breakfast, lunch and dinner," Secretary Thompson said. "[They] will now be able to free nurses and nurse aides to focus on residents' other health care needs and on residents with complex feeding problems. This means that residents will ... receive better nutrition and care."

New assistants will be required to complete a state-approved course of at least eight hours, and their use must be consistent with state law.

Protection of the Elderly Bill: Implementation Dates of Major Provisions in SBs 556 and 311.

The following sections were to be implemented on August 28, 2003:

Sections 197.500, 198.070, 660.315, and 660.320: All contain employee disqualification list provisions, applicable to home health care, long-term care, and in-home services.

Section 197.416: Allows the Department of Health and Senior Services to check the out-of-state compliance history of facilities or agencies over the past five years; applies to home health agencies.

Sections 197.478, 198.030, and 198.528: Deals with the posting of surveys, inspection reports and deficiencies in a facility.

Section 198.036: Allows the Department to immediately revoke a facility's license upon certain violations. Previously, the Department had to wait for the facility to come up for relicensure.

Section 198.066: Creates a variety of remedies that may be assigned by the Department upon a facility's violation. The severity of the remedy will depend on the seriousness of the violation.

Section 198.067: Increases the amount of civil monetary penalties assigned for Class I, II and III violations, some of which will be imposed immediately. Also provides that civil penalties will remain the sole responsibility of the operator and may not be sold, transferred, or assigned to any successor.

Section 198.071: Requires a facility to immediately notify a deceased resident's family, physician, and the local coroner prior to transferring

the deceased to a funeral home.

Section 198.105: Allows the Department to maintain a list of qualified receivers that have submitted a written request for receivership of a facility.

Sections 198.525 and 198.526: Allows the Department to reduce the frequency of inspections from two to one time per year for facilities with substantial compliance with certain requirements.

The following sections will be implemented upon available funding (not likely this fiscal year):

Sections 197.478 and 198.528: Requires the Department to post the most recent survey of every home health agency and long-term care facility on its website, unless it is in dispute.

Section 660.317: Contains significant modifications regarding criminal background checks. Checks must be performed on all full-time, part-time and temporary employees. In addition, providers must request a nationwide criminal FBI background check for out-of-state applicants who have not resided in Missouri or worked at a Missouri facility for five consecutive years.

To review the complete bill, visit www.senate.state.mo.us.

*From Missouri Association of Homes
for the Aging **Hotline** newsletter*

Best Practices Symposium
Synopsis of Meeting Minutes
Jefferson City MO ♦ Nov. 7, 2003
reported by David Cravens, M.D., MSPH

Chairing the meeting, David Morgan led a discussion of Civil Monetary Penalties (CMP). Sentate Bill #556 has allowed the use of 50% of funds collected from fined facilities for QI programs. CMP assesses \$1000/day for Class I or uncorrected Class II infractions. Class I or II violations totaled 146 in 2002; there are 96 to date in 2003.

Approximately 500 of the 1200 facilities in Missouri are certified. Forty-nine (10.6%) facilities were deficiency-free, ten fewer than the 12.5% in 2000. Nationally, there seems to be wide variability in the survey process, and possibly within the state as well. The process needs consistency.

Betty Markway informed the group that Missouri has done well in progressing toward statewide consistency. Also, we have several programs not available in other states, such as QUIPMO and the End of Life manual.

There was discussion about improving the perception of long-term care. Alexian Brothers administrator Michael Roth shared information on ways to improve perceptions, such as the "Highway to Heaven" program which aims to improve dignity in death. Also, he spoke about an annual barbecue for friends and families of residents, as

well as other programs involving community.

Tracy Cleeton led a discussion of the Life Safety Code, which prohibits facilities from storing objects in corridors, possibly interfering with egress in case of fire. Carts and lifts in hallways are acceptable if being used. However, many members expressed concern that if a lift were not nearby, aides would not retrieve it, thus risking injury. In addition, many facilities have no storage space. Tracy would be interested to know if there have been documented episodes of harm from carts being in corridors. He is considering pursuing a general waiver from CMS for established facilities without storage space.

Betty Markway reviewed information on alcohol-based gel washes. Guidelines state that it may not be stored in an egress corridor; however this restriction seems to impede infection control. She has sent a letter to CMS and is awaiting a reply.

Since the meeting, Dr. Carl Bynum has shared the following information about use of alcohol gels in long-term care:

The Executive Committee of the Hospital Fire Marshalls' Association has unanimously voted to support

the installation of alcohol-based hand-washing gels in corridors. HFMA said the committee compared the fire risk vs. the risk of infection, and concluded that the likelihood of a fire was minimal compared to the risk of spreading a life-threatening infection. The organization said it looked at the history of fires in health care facilities and did not find an incident where the corridor was the area of fire origin. It also considered studies indicating that hand gels are used more often when access to the gel is convenient to caregivers, and a study commissioned by the AHA's American Society of Healthcare Engineering that found dispensers of the gel not exceeding one liter could be safely installed in corridors as long as they were spaced intermittently and not in carpeted areas. The HFMA recommended the fire code community revisit the applicable codes and change them to clear the way for acceptance by all authorities having jurisdiction. It also recommended that facilities using the

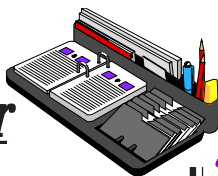
Michael Roth provided copies of an Alexian Brothers handbook, "Guide to Preventing Elder Abuse."

The next meeting of the Best Practices Symposium is scheduled for February 26, 2004.

18th Annual Symposium on Geriatrics, "Infectious Disease in the Elderly: Management and Regulatory Compliance," April 16-17, 2004, University Plaza Hotel, Springfield MO. For info call (417) 269-4747, or e-mail jill.johnson@coxhealth.com.

2004 AMDA Annual Symposium, March 4-7, 2004, Phoenix AZ. "Creating Excellence in Long-Term Care." Will feature a variety of educational sessions encompassing the scope of long-term care practice including assisted living and home care, hospice, and pediatric care.

For your Calendar



Topics include clinical practice, documentation and coding, home care, hospice and palliative care, medical direction, mental health, research, wound care, and more. For information, contact AMDA at (800) 876-2632, or register online at www.amda.com.

2004 Conference on Caring for the Frail Elderly, August 27-28, 2004, Columbia MO.

Life is mostly froth and bubble.

Two things stand like stone:

Kindness in another's trouble,

Courage in your own.

Adam Lindsay Gordon

(1833-1870)

Facts About The Missouri Senior Rx Program

- ◆ The Missouri Senior Rx Prescription Drug Program is offered as a public service to ensure that senior citizens on fixed incomes get help with the high card cost of prescription drugs.
- ◆ The program pays 60% of covered prescription drugs for eligible seniors after they pay a \$25 or \$35 enrollment fee and meet an annual deductible.
- ◆ Over 140 generic and brand-named drug companies participate.
- ◆ The 2004 application is much simpler to understand than in the past.
- ◆ Current program members will receive a 2004 application in the mail beginning in late December.
- ◆ New applicants can look for applications at participating pharmacies beginning in late December.
- ◆ Next open-enrollment period begins 1/1/ 2004 and ends 2/28/ 2004. Patients can call toll free (866) 556-9316 to request an application.
- ◆ Benefits for the 2004-05 plan year begin 7/1/ 2004.
- ◆ 1,171 pharmacies participate -- approximately 89% of all Missouri pharmacies.

Eligibility Requirements:

- ◆ Must be at least 65 years of age
- ◆ Must be a Missouri resident for the past 12 months
- ◆ Cannot receive veterans' pharmacy benefits or be enrolled in Medicaid
- ◆ Cannot have prescription insurance that is equal to or greater than the Missouri Senior Rx Program.
- ◆ Must meet income requirements as listed in the box below.

With questions, call toll free (866) 256-3937.

	Income categories	
	Individual <\$12,000 OR Married <\$17,000	Individual \$12-17,000 OR Married \$17-23,000
Enrollment fee	\$25	\$35
Deductible	\$250	\$500
State pays	60%	60%
Maximum benefit	\$5000	\$5000