



STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

201 W. Preston Street • Baltimore, Maryland 21201

Robert L. Ehrlich, Jr., Governor – Michael S. Steele, Lt. Governor – S. Anthony McCann, Secretary

MEMORANDUM

TO: All Resource Coordinators and DDA Service Providers

**FROM: Nicole Brandt, Pharm D., CGP, BCPP^{NB}
Chairman, Mortality Review Committee**

**Diane K. Coughlin, Director^{DC}
Developmental Disabilities Administration**

**Wendy A. Kronmiller, Acting Director^{AK}
Office of Health Care Quality**

SUBJECT: End-of-Life Decision Making

DATE: April 5, 2006

All citizens have the right to decide for themselves what type of medical treatment they want when they are seriously ill. People with developmental disabilities are no exception. Recent cases presented to the Mortality Review Committee highlighted the need for end-of-life decisions to be made by people with developmental disabilities in advance. All too often this vulnerable population is not given the opportunity to make critical treatment decisions in advance of crisis situations.

Resource coordinators, service providers and families need to recognize the importance of being proactive in end-of-life planning. We do a disservice to the individuals we serve if these issues are ignored until an acute situation necessitating medical decisions occurs. This is especially true for individuals who do not have participating family members, a surrogate decision maker, a guardian or other agent to make their end-of-life wishes known to the medical community.

There is a wealth of information on end-of-life planning to assist individuals and decision makers in formulating these decisions:

The Office of the Attorney General (OAG) for the state of Maryland has an Advanced Directive form that can be downloaded from their website at <http://www.oag.state.md.us/Healthpol/AdvanceDirectives.htm>.

Another resource is **The Five Wishes**, a popular document used to complete end-of-life planning. This booklet, available for a small fee, can help individuals and decision makers identify issues that, although not thought about initially, may be of concern when end-of-life planning is considered. Additional information can be obtained at <http://www.agingwithdignity.org/>.

The American Hospital Association offers multiple resources on planning for end-of-life and other important health care issues and can be reached at <http://www.putitinwriting.org/putitinwriting/index.jsp>. The National Hospital & Palliative Care Organization has excellent information on Advance Directives and Hospice Care. Their website may be accessed at www.caringinfo.org.

Apart from advance directives, the OAG recently issued a **Patient's Plan of Care: Goals & Treatment Options** (PPOC). The PPOC is an excellent document when specific issues about the use of life sustaining medical technology are presented by a patient's diagnosis and prognosis. The PPOC has been mandated for use in all of the nursing homes within the state and may also be used in other care settings.

Lastly, a collaboration between lawyers and several Maryland provider agencies resulted in a 2005 manual and DVD entitled "Informed Consent for Medical and Psychiatric Decisions: What You Need to Know." All provider agencies and DDA Regional offices were provided with one copy. Additional copies may be purchased from The Arc of Frederick County. The contact person is Ms. Kendra Sampson and she can be reached by telephone at 301 663-0909 or via the internet at ksampson@arcfc.org.

Resource coordinators, service providers, family members and team members should be aggressive and pro-active in organizing end-of-life decisions for people with developmental disabilities. Providers and others should remember that current state regulations mandate that health care for people with developmental disabilities is ". . . consistent with those of the general population." Recent high profile news reports of individuals struggling with end-of-life decisions supports the need for the community assisting people with developmental disabilities to be out front advocating for and documenting the wishes of their consumers.

Our objectives should be to determine the type of end-of-life care each person wants and needs, provide them with the level of care they have requested during a life-limiting illness, and assist them to maintain a quality of life reflective of their personal wishes.