

End of Life Care Subcommittee

Explanation of principles and objectives

January 12, 2009

Submitted by:
Philip Derrow

Destiny is not a matter of chance; it is a matter of choice. It is not a thing to be waited for; it is a thing to be achieved.

--William Jennings Bryan

The last great freedom of man is the freedom to choose his attitude under any given set of circumstances.

--Victor Frankl, noted Psychiatrist and Holocaust survivor

Our lives begin to end the day we become silent about things that matter.

--Martin Luther King Jr.

Everything should be made as simple as possible, but not simpler.

--Albert Einstein

When you were born, you cried and the world rejoiced. Live your life so that when you die, the world cries and you rejoice.

--Indian saying

When death, the great reconciler, has come, it is never our tenderness that we repent of, but our severity.

--George Eliot

These words bring to mind the wisdom that humans, unlike any other species, have the ability to choose not only the character of our lives, but, for most of us, also that of our ultimate – and certain – death. Yet most of us do not avail ourselves of that choice; and for many who do, our choices are ignored. The personal, social and financial costs resulting from failing to make our wishes known or of having others simply, even if honestly, ignoring them are astounding.

Medicaid, as the principle provider of health care services to Ohio's poor, aged and disabled citizens is uniquely positioned to both "begin the conversation" about the character of the end of life and to lead the way to assuring that the Medicaid recipients receive the services and treatments they choose.

Studies by the American Academy of Family Physicians, National Institutes of Health and American Psychological Association (among many others) have shown that fewer than 1 in 5 Americans have executed advance directives regarding the care and treatment they wish to receive at the end of their lives. Worse, studies also show that a majority of these advance directives are ignored or overruled by family and health care providers.

Cultural, social and educational factors are the most common reasons cited for the low rate of advance directive execution. Legal concerns, family disagreement, administrative

errors and medical culture are the reasons most often cited for failing to honor advance directives.

The costs to the dying, their families and those paying the bills are truly staggering. Surveys have consistently shown that when asked their fears about death and dying, most Americans are more concerned with a painful death or living on life support in a way inconsistent with the dignity of their lives. Most Americans do not want to die in a hospital setting and an overwhelming percentage of us do not want to be a burden on our families either psychologically or financially. Yet that is precisely what most of us end up doing.

Financially, studies have shown that Americans spend as much as 50% of lifetime health care expenditures in the last 6 -10 weeks of life, with little evidence that such expenditures extend or improve life. There is ample evidence that we are instead spending huge sums and getting exactly the opposite outcome most of say we want – a dignified and pain free death, in a comfortable setting, surrounded by loved ones.

As the principle payer and policy setter of health care for so many Ohioans, Medicaid can change this outcome. Since many of the impediments to honoring people's end of life choices are administrative and procedural, Medicaid can adopt policies and procedures that require the execution of end-of-life directives* for all Medicaid recipients. These policies must take into account the need for educational materials and access to appropriate counseling services to prepare and assist beneficiaries and their families with the choices available. Medicaid can also promulgate rules and procedures for health care providers which facilitate the awareness of and use of these directives. Lastly, Medicaid, as a government entity should aggressively work with elected legislative and executive officials to promote legislation to secure appropriate legal support for providers who follow advance directives.

Requiring the execution of advance directives is the single most powerful tool available to truly start the conversation among recipients, their families and their health care providers. Medicaid is uniquely positioned to help make that happen. The End-of-Life Care subcommittee will be charged with creating the process to make sure that it does. The human and financial toll makes the task worthwhile.

* Health care Advance Directives typically include a "Living Will" and a "Durable Power of Attorney for Health Care". However, the Committee recognizes that for certain segments of the population, these two advance directive documents may be insufficient to represent their life experiences and care choices or are unacceptable for religious or deeply held personal beliefs. In such cases, we propose that a "Will to Live" document be incorporated as an alternative and where the objection is for an advance directive of any sort that the recipient be permitted to sign a document attesting to their consideration of and refusal on moral or religious grounds to execute such documents.