

The Increasing Importance of Advance Care Planning

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“ I have an Advance Directive not because I have a serious illness, but because I have a family” — Ira Byock, M.D.

Advance Directives (AD) have been around for 40 years. However, they have not been very effective in directing medical care for a number of reasons.

Historically, the health care system has not been involved in the creation of most Advance Directives. Typically, an individual would complete a form with their lawyer while they were creating an estate will. Otherwise, they would complete a form on their own, and this form would end up on a shelf somewhere. Key elements were often missing from this process including: the informed communication and conversation with loved ones, the appointed Power Of Attorney (POA), and the individual's health care provider. Furthermore, the language of an AD was often overly legalistic and difficult to apply to a particular medical situation. In most cases, the document was not where it needed to be to be effective. All too often an individual's family, and even the designated POA, would not know the AD existed, nor would they understand what the document entailed. In fact, only about 20-30% of the general public even had an AD; there was fear an AD would be used to withhold or limit beneficial treatment.

Something is Changing!

The need for clear, effective ADs is increasing for a number of reasons. First, there is a greater number of people living longer, but not necessarily better.¹ Often, quality of life decreases as time goes on due to a growing burden of chronic, progressive illness. We are now facing more options, and increasingly complex choices for medical care towards the end-of-life, which sometimes turn out to be false choices. By providing a false expectation of benefits from perceived choices, additional suffering, and even harm, occurs.² As groups like the Baby Boomers age, there is more emphasis placed on a patient to participate in decisions regarding their medical treatment. However, more individuals are unable to participate due to loss of decisional capacity, as severity and burden of illness progresses.

There are good examples of how robust engagement and programming within a health care system or community can lead to effective communication and conversation that, in turn, leads to a much greater percentage of the population having a useful and effective AD.³ This improved communication and more effective ADs have been shown to lead to medical care more closely aligned to personal preferences and values.

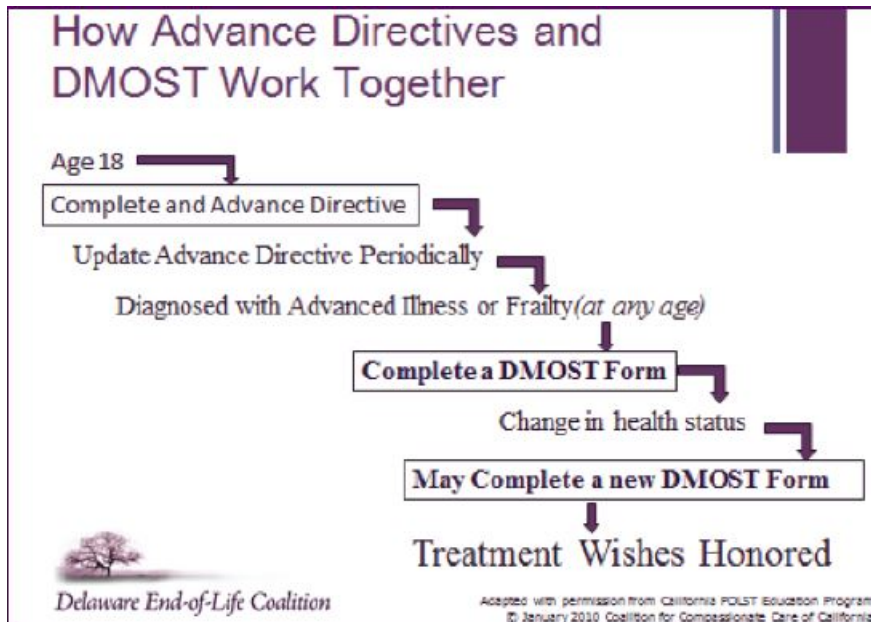
Most people do not want to die before they need to, and there is much uncertainty about when that might be for each individual. Dying in America has become an increasingly difficult and complicated affair.^{1,4}

Many of us fear the process of dying more than death itself. We all share a common humanity and mortality, but we do not all have the same ideas about what makes our lives worth living, or what we might be willing to endure to continue living.

For these reasons, in order to ensure we each get the medical treatment consistent with our own values, preferences, and goals, we must be prepared.

The process of Advance Care Planning (ACP) refers to the communication/conversation family and medical providers have about the wishes, preferences, and goals one has for medical treatment, as well as the decisions and documentation that result from that communication in the form of an Advance Directive (AD) (Living Will, Durable Power Of Attorney (DPOA)) and also a Delaware Medical Order for Scope of Treatment (DMOST) in the appropriate circumstances (see Figure 1).

Figure 1. How Advance Directives and DMOST Work Together



It is recommended that every adult person consider making an AD to help guide care decisions during a time this person may not be able to participate in such decisions. The conversation, preferences, and decisions change with circumstances so that an AD may need to be revisited regularly.

As a person enters the final phase of their life, and they can see more clearly how their life might end and which medical treatments will be helpful and which may not, the DMOST medical order form (for Delaware residents) with its clarity and specificity, has been shown to be effective in aligning a person's medical care to their preferences.⁵ A person or their surrogate decision maker (when the person no longer has decisional capacity) may complete this medical order form with their health care provider. This order can be modified or voided and should be consistent with previous AD. It is the most recent document that should be honored (see Figure 2).

Figure 2. Difference Between an Advance Directive and DMOST

Difference Between an Advance Directive and DMOST

	ADVANCE DIRECTIVE	DMOST
For whom	For all adults	For persons of any age with advanced illness whose healthcare provider would not be surprised if they died within the year
Purpose	To express values and appoint a surrogate (future wishes)	Medical orders which turn a patient's values into action (applies today)
Who can complete	Any adult with decisional capacity	Completed by individual/authorized rep and health care provider
Guide treatment decisions in the hospital	Yes	Yes



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It should be emphasized that while an AD and DMOST are both voluntary legal documents, and there is a requirement to acknowledge and honor their direction, there is often room for interpretation and application to a particular situation. These documents should be viewed in the context of ongoing-shared decision-making and medical standard of care.

There are several resources that one could use to create an effective AD.⁶⁻¹³ The steps outlined provide a general guide with an emphasis on communication and conversation with loved ones and health care providers.

Regulations for Delaware's new DMOST form have been finalized. Education for the public and training for providers on the DMOST form will be forthcoming in the next several months leading up to its availability as of April 1, 2016. This medical order form is designed for people generally in the last year of their life.

The public is demanding more accountability for their wishes. Providers are increasingly aware of the importance of ACP and goals of care conversations in driving an individual's plan of care. CMS has recently decided to reimburse providers who complete ACP with patients.¹⁴ As the health care systems find new and better ways to integrate AD/DMOST forms into the EMR and electronic registries like Delaware Health Information Network (DHIN), ACP will play a more important role in the provision of person-centered care for everyone.

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