

# POSTS MADE IN JUNE 2013

## [E-PATIENTS MUST PLAN FOR END OF LIFE DECISIONS](#)

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Decades ago, most people died at home. Today health care technology including various surgical procedures, the use of feeding tubes, ventilators, CPR, dialysis, and blood transfusions, has put patients and physicians in the precarious position of having to choose between aggressive intervention, usually requiring hospitalization in the ICU and palliative care.

Palliative care focuses on relieving and preventing the suffering of patients typically in the home environment where the patient may undergo treatment for curable illnesses receive medication for chronic conditions, and see a team of physicians, pharmacists, nurses, chaplains, social workers, psychologists, and other allied health professionals who work with the patient to formulate a plan of care. There is also Hospice, generally for individuals with a terminal prognosis, who have less than six months to live. Hospice focuses on bringing comfort, self-respect, and tranquility to people in the final stage of their life. Symptoms and pain are controlled, with medication and equipment but not with standard medical intervention. Hospice care is often provided at home but can also be provided at hospice facilities, hospitals, nursing homes, and other long-term care facilities. The **Medicare Payment Advisory Commission**(MedPAC) reports that about a quarter of the total Medicare budget, more than \$125 billion, is spent on services for beneficiaries in their last year of life. The reasons include more doctor visits, more hospitalizations that often end up in the ICU, more tests and more invasive procedures. When we look at those numbers we have to think about how much medical care \$125 billion might pay for children who have a long life ahead of them and who do not receive even basic health services. The other question is how much benefit the patient receives and

whether or not the patient is experiencing a better quality of life in those last months.

One poignant case study reveals the dilemma very well. Randi Redmond Oster, wrote in the newsletter, Case in Point, (June 2013, Vol. 11) about her 79-year-old father who she brought to the ER because it appeared that he had a stroke. In fact after appropriate testing he was diagnosed with a brain tumor called a glioblastoma. The surgeon on call that day recommended surgery but Randi's Dad wanted a minimally invasive approach. He did not want chemo, radiation or other aggressive treatment approaches. Upon questioning the doctors, Randi understood that her Dad had eight weeks to live without surgery and eight months potentially with surgery. However the side effects of the surgery included potential paralysis on one side of his body, difficulty speaking, and additional chemo therapy and radiation – all of the things that her Dad did not want. Taking her Dad home meant that he would have time to enjoy being with his family and friends and die a peaceful, relatively pain-free end of life with dignity.

Randi writes in her article, an excerpt from her upcoming memoir, *Questioning Protocol*, as I took my Dad home from the hospital a resident, pulled me aside in the hall and said, "I got to know your dad last night," he said. "He's a remarkable man and brave to make the choice he did." He hesitated and whispered, "You know, the doctors get \$15,000 for the surgery and then it's \$3,000 a day for after care. They don't tell you that."

Randi and her family took her dad home and at the very end when they were no longer able to take care of him he went to hospice where he died peacefully with no pain and with dignity. Randi learned the importance of asking the hard questions even when you don't want to hear the answers. In this case, for her dad, less care meant less time but a better quality of life.

End of life care is all about choices. These are choices that as empowered patients we should be making long before we reach that stage in our life.

## **Advance Directives**

In 1990, Congress passed the Federal Patient Self-Determination Act to encourage Americans to prepare an advance directive, a legal document that outlines the patient's wishes and directions on how to handle end of life medical care. A report in the **Archives of Internal Medicine** suggested that if even one-half of the estimated 566,000 American adult cancer patients who died in 2008 had the end-of-life discussion, the projected savings would conservatively have been \$77 million. However, fewer than 20% of Americans have an advance directive in place. Of those who do, almost 3/4ths of their physicians remain unaware of the directive because it is not included in the patient's medical record. This means that only about one in 20 Americans can feel secure that his or her wishes will be respected at a time when the ability to directly control care is in someone else's hands.

An advance directive is a legal document that contains a living will and the appointment of a healthcare proxy, a family member or close friend whom the patient trusts, and who is designated to make medical decisions for a patient who is unable to do so. The directive can be changed at any time. The best time for putting an advance directive in place is when a patient is mentally and emotionally healthy and can make well-informed, knowledgeable decisions. In the Advance Directive, patients can also document specific wishes regarding organ donation, blood transfusion, dialysis, or even more specific wishes for medical care.

Among the issues that individuals need to consider in preparation of an Advance Directive are:

1. **Aggressive Medical Measures:** decisions regarding CPR, intubation, mechanical ventilation, ICU transfer, and all other medical measures, such as antibiotics, blood transfusions, a nasogastric tube, and dialysis. Patients may decline specific treatment modalities or procedures, and such choices should be outlined.
2. **Period of treatment:** This approach employs full intervention for a limited time period, including full resuscitative and treatment

measures. If the patient's condition fails to improve after a given period of time and the prognosis or outcome is poor, less aggressive measures would be discussed with the healthcare proxy, including removal of breathing tube(if intubated), and withdrawal of treatment that would result in a transition to palliative care or hospice services.

3. Do Not Resuscitate (DNR): This provision allows the patient to be intubated and placed on a mechanical ventilator; however, no CPR, chest compressions, or cardio version are to be performed if a patient goes into cardiac arrest.

4. Do not intubate: This specifies that if a patient goes into cardiac arrest, chest compressions can be performed, and resuscitative medications can be given; however, the patient doesn't want intubation or mechanical ventilation.

5. Palliative care/comfort measures only: In cases of terminal illness or poor prognosis for recovery, a patient may choose palliative care and symptomatic management of chronic conditions only. The primary focus is making the patient comfortable and pain free; facilitating easy breathing, and providing individualized special needs, such as emotional and spiritual support.

6. Hospice care: This program provides care and support for terminally ill patients with a prognosis of six months or fewer if the disease follows its usual course. The focus is on comfort measures rather than attempting to treat incurable and terminal illnesses.

7. Do not hospitalize: Patients with advanced chronic progressive medical conditions with poor long-term prognosis may choose not to be hospitalized for treatment of any acute issues.

After a patient has documented his or her end-of-life care wishes, it is important that physicians treating that individual are aware of the document, talk with the patient and caretakers about these choices, and review the instructions annually.

Patient empowerment is about understanding the issues and planning and communicating health care choices so that everyone is on the same page. It is also about taking responsibility for the health choices

that you make. End of life choices are perhaps the most difficult decisions emotionally. Planning is key.

My own mother, who was in hospice care at the end of her life, was sent back to the hospital one last time for her congestive heart failure even after a DNR order by the family. She died that day after having an invasive procedure which drained the fluid in her lungs, a procedure that had prolonged her life for many years, but was futile, expensive and useless this last time. An Advance Directive would have prevented this procedure and saved her pain and suffering at the end.

There are several resources that can help you understand and deal with end of life decisions:

AARP Caregiving Resource Center which includes resources, videos and publications <http://www.aarp.org/relationships/caregiving-resource-center/endoflifecare.html>

Caring Connections a program of the National Hospice and Palliative Care Organization (NHPCO) can provide Advance Directive Forms by state.

Family Caregiver Alliance where you can find fact sheets, publication, newsletters that cover the issues you need to think about and the resources now available. The National Association of Hospice and Palliative Care [www.nhpco.org](http://www.nhpco.org)

The National Institute on Aging, [www.nia.nih.gov](http://www.nia.nih.gov) or 800-222-2225. PREPARE, <https://www.prepareforyourcare.org/>

A new website walks patients through the steps of making complex medical decisions and uses audio and video content to make it simple.

## [ARE PHYSICIANS TRULY ENGAGING WITH PATIENTS?](#)

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A recent report by CMS detailed statistics on how many health providers had actually received Meaningful Use (MU) incentive payments. As of March, 2013, 160,890 eligible professionals had received Medicare incentive payments and 83,765 professionals had

received Medicaid incentive payments. While these numbers seem impressive, the question we have to ask is how many of these health professionals are changing the way they deliver care to patients by engaging them in healthcare decisions, communicating health information to them and treating them as a part of the health care team.

[http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/Mar\\_EHRIncentiveProgramsPaymentsReg\\_SummaryReport.pdf](http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/Mar_EHRIncentiveProgramsPaymentsReg_SummaryReport.pdf)

The mandate for physicians to engage patients in their care is part of Meaningful Use Stage 2 which becomes law in 2014, and includes specific requirements that physicians must adhere to including:

- Provide patients with their health information (via a web portal) on 50% of occasions and have at least 5% of these patients actually download, view or transmit that data to a third party.
- Provide a summary of the care record for 50% of transitions of care during referral or transfer of patient care settings.
- Provide patient-specific education resources identified by Certified EHR technology to more than 10% of patients with an office visit.
- Engage in secure messaging to communicate with patients on relevant health information.
- Make available all imaging results through certified EHR technology.
- Provide clinical summaries to more than 50% of patients within one business day.

The question is not the existence of the regulations and their incentives but whether or not these regulations are changing physician behavior. Do a majority of physicians remain steadfast in dominating the physician/patient relationship, convinced that engaging patients in their care is a burden? Or are many of them beginning to realize that engaging the patient in their health care decisions will make health care more efficient and cost effective, and improve patient outcomes.

The Annals of Internal Medicine recently reported on a study, primarily funded by the Commonwealth Fund and the Robert Wood Johnson Foundation that evaluated physician reports of EHR adoption and ease of use and their ability to use EHRs for patient panel management. The study concluded that using the basic data input capabilities of an EHR does not translate into better management of patient populations and adherence to the Stage 2 MU criteria.

<http://annals.org/article.aspx?articleid=1692572>

Those of us who are committed to participatory medicine want to give the benefit of the doubt to our physicians who are under extreme pressure to contain costs and improve results. We know that most physicians are driven by a passion to help their patients achieve better outcomes. However, our own personal experiences and interactions tell us that many doctors have a long way to go to improve communication and patient engagement.

We know that the patient population, for the most part, is more than willing to become more participatory, although many, perhaps the majority of patients are ambivalent about access to their physician's notes in the electronic health record, and only about 40% sign up for access to patient portals for secure messaging with their health care providers – a sure way to facilitate open communication, patient access to information, and e-visits. So there is more work to be done. On the physician side, something beyond legislating these changes and dangling incentives in front of physicians has to happen in the delivery of health care. The training of new physicians and the retraining of established practitioners in communication skills and interpersonal relationships would be a good first step. We also need to get the participatory medicine message out there convincing physicians that this is the right way to practice medicine.