



## **ADVANCE CARE PLANNING AND HEALTH SYSTEM REFORM**

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The contentious debate over end-of-life planning has obscured a basic fact: life is precious, all the more so because we know that one day it must come to an end. Modern medical treatment helps us live longer than ever before. At the same time, it gives us a better chance to prepare for the day when we may want to let go of that treatment.

Fear of death is natural. However, we should not let our fears rob us of the chance to live our lives to the end as fully as possible in accord with our own values and goals.

When they are given the choice, many people decide to avoid aggressive medical treatment when there is little chance of recovery. Because this treatment is costly, and because with advance care planning people tend to make choices to reduce the amount of this treatment, programs that promote advance care planning are likely to be budget-neutral or even cost-saving. However, it is important to note that the primary intent of these programs is not to save costs, nor to shorten life. The goal is to put control back into peoples' hands over their own health care at a time when they are most vulnerable: near the end of life.

### **Critical Conversations**

Research gives us important information about the attitudes of both patients and their doctors about end-of-life care:

- People with serious illness want to make sure that if they can't speak for themselves their doctors will still know their wishes about treatment.
- Patients expect doctors to start this conversation.
- Patients are afraid that doctors won't have enough time to respond to their needs and preferences for care.
- Doctors report that they are indeed under tremendous time pressure, and that they are paid to do procedures, not to talk to patients.

Despite these challenges, conversations about the end of life are not as difficult as many people think. Studies tell us that when doctors and patients talk about the end of life, their discussions do not cause patients to lose hope or to become depressed. In fact, after these talks patients feel more confident about making decisions, and often choose to limit aggressive treatment. Their satisfaction with care also improves. On the other hand, people who do not have these discussions are forced to endure more painful tests and procedures, and tend to experience suffering instead of peace and comfort in their last days of life.

Patients who avoid these conversations are not the only ones at risk. Their families suffer as well. Many seriously ill patients lose the ability to speak for themselves as their illness worsens. When doctors are in doubt about their wishes, these patients can end up on life support with little or no chance of recovery. Without written advance directives, the burden of deciding whether or not to continue this treatment falls on the family. The responsibility can be overwhelming, and can lead to long-term guilt, complicated grief, and depression in family members.

### **Respecting Choices®**

The way to avoid these burdens is to ask patients what kind of treatment they would want, and to record their answers in the form of advanced directives. **Respecting Choices®**, a program in La Crosse, Wisconsin, has specialized since 1993 in knowing and honoring patient preferences. Its Director, Bud Hammes, PhD, reports that over 90 percent of patients state clearly that the last thing they want is to be "hooked up to machines." Their advance directives are always available to the treating physician and are honored by La Crosse doctors in over 99 percent of cases. Unlike previous efforts in other parts of the US, this systematic approach has clearly achieved the goals of advance care planning.

Some people express fear that policies supporting advance care planning will encourage rationing of medical care. In reality, there is no connection between the two. Rationing denies people medical treatment they want, treatment that would potentially prolong life. Advance care planning does not ration medical treatment. Instead, it empowers people to make informed choices about care that would not prolong life, but instead would prolong dying.

Many people believe that in serious illness, more care is better. However, research tells us that is not the case. The Dartmouth Atlas of Health Care reports that regions of the US

where larger amounts of aggressive treatment are provided near the end of life have the same, or even higher, mortality rates than areas that provide less aggressive care.

### **Aggressive Care: How Effective in End-Stage Illness?**

Medical technology has increased life expectancy, but when applied near the end of life, research shows that it provides diminishing returns. Treatment of lung cancer is a good example. Over the last decade, it has become common practice to admit terminal lung cancer patients to the intensive care unit (ICU). These patients are usually very short of breath, so many are placed on mechanical ventilators. Mortality rates in the ICU are high, and many patients, even if they survive the ICU, die before they can leave the hospital. A study of over 42,000 Medicare patients with lung cancer showed that, on average, those who received ICU care had a median survival of 33 days. However, half of these patients were readmitted to the hospital after just a short time at home, and most went on to nursing homes to die.

In order to gain an extra month of life, enduring the pain and expense of intensive care might seem worthwhile. However, it might not be necessary. Life is extended just as effectively when lung cancer patients are admitted to hospice as when they are placed in the ICU. Hospice care is usually provided in patient's homes, where nurses and social workers focus on patient comfort and family support. Lung cancer patients enrolled in hospice live, on average, 39 days longer than patients who remain under "usual care." Hospice care actually prolongs life in lung cancer, and in most other diagnostic groups, as well or better than aggressive medical treatment near the end of life.

Two conclusions, both counterintuitive, are apparent from this data. Aggressive medical treatment provided near the end of life may be less effective in prolonging life, and hospice may be more effective, than many people assume. Actually, hospice is intensive care, but it is provided in patients' homes instead of the ICU. Hospice provides intensive attention to the emotional and spiritual well-being of patients and families, beyond just their physical comfort.

### **Advanced Illness Management (AIM)®**

Advance care planning consists of more than just filling out a form. Patients' wishes can only be followed when they are available to anyone taking care of them. Advance directives don't work if they are not in the hands of the doctor when the patient arrives in the emergency room.

The current US health care "system" is really not a system at all. Communication among doctors' offices, hospitals, and home-based care is so poor that in many cases patients fall through the cracks and are lost to follow-up, or end up back in the hospital before they can even get to the doctor's office. As a result, seriously ill patients often undergo multiple hospital admissions, tests, and procedures near the end of life.

If the system performed as it should, many of these patients might never have to go to the hospital in the first place. **Advanced Illness Management (AIM)®**, a program at Sutter

Health, an integrated system in Northern California, coordinates care among medical groups, hospitals, and home-based services to provide care according to patient goals and preferences in late-stage illness. AIM® provides a customized mix of medical treatment and supportive care, so that patients don't have to choose one or the other.

Doctors don't have the time or training to provide advance care planning services all by themselves to the increasing number of seniors who need them. AIM® staff members are trained to keep the ball rolling after discussions are started in the doctor's office. Patients and families are helped to make plans and to fill out advance directives at their own pace. Patients' wishes are then made available to all clinicians to ensure that they are followed. One important advantage of AIM® is that preferences can be tracked and recorded as they change over time with increasing severity of illness.

An AIM® pilot program more than doubled hospice use among all patients studied. Moreover, hospice use was increased by almost a factor of four among African Americans, who as a group are often reluctant to accept hospice. In this way AIM® significantly reduced a widespread and longstanding racial disparity in end-of-life care.

AIM® has now become a system-wide initiative at Sutter Health. It is naturally compatible with Respecting Choices®, since both programs focus on advance care planning. In fact, a developer of the new version of the AIM® program at Sutter Health is one of only two nurses certified by the Respecting Choices® program in the state of California.

### **Financial Barriers to Innovation**

Any effort to improve end-of-life planning and the care of advanced illness must contend with the financial disincentives built into current reimbursement for doctors and hospitals, who are rewarded for providing high volumes of services regardless of their effectiveness or their desirability to seriously ill patients and families. Today, health systems that try to provide high-quality care consistent with patient preferences must not only pay the costs themselves of new care coordination programs, for which there is no current source of payment, but they must also forego revenue for avoided readmissions. This system rewards undesirable treatment and stifles innovation. New policies are needed to encourage medical treatment based on patient preference.

These policies should not be construed as primarily cost-saving. Advance care planning does not promote "government-sponsored euthanasia." It does just the opposite. Advance care planning gives seniors a voice in choosing the care they want. Many choose to reduce aggressive care, and savings for Medicare may result. Any savings, however, are incidental.

The real intent of these policies is to put control back in the hands of patients and families at the time of life when they are most vulnerable. This is when they most need the support of programs that help keep them safe and comfortable, out of the hospital, and at home with loved ones where they belong.

### **Promoting Health System Integration**

Programs like **Respecting Choices**® and **AIM**® help to knit together the broken pieces of our health care system. To be effective, advance directives must be sent to all parts of the system. At Gundersen Lutheran, 100 percent of advance directives were in the patient’s medical record at the place where their life ended. In a similar way, **AIM**® connects physicians and their medical groups with hospitals and home-based services so that patients, families and doctors can make decisions together. This is how health care should be designed to work: as a real system.

These programs have been created to work in the health system of the future, where the only certainty is that we will have to take care of more patients with fewer resources. The patients in these programs have the greatest needs, the highest risks, and the highest costs among all Medicare beneficiaries. Better care coordination will not only help them, but will also improve the operation of the system itself.

However, payment reform is needed to create the right conditions for these programs to take root and grow. Without reform, they will wither and die, as many innovative approaches have done in the past.

### **Policy Proposals**

Payment reform should incentivize all providers to make sure that patients and families get engaged in discussions about their preferences for care, that their wishes are documented in the medical record, and that specific medical orders, such as Physician Orders for Life-Sustaining Treatment (POLST), are written and signed by their physicians and followed in all care settings. Indeed, these activities must be coordinated across both place and time. They work as an ongoing process, not a single event.

Two specific policy changes would create incentives to promote advance care planning and follow-through for patients near the end of life:

- A range of billing codes should be created so that CMS can reimburse both physicians and non-physicians for their time spent discussing likely disease progression, prognosis and decisions regarding life-prolonging treatment with patients and families who are dealing with life-limiting illness. Codes should be developed for both initial and follow-up discussions, because these occur over time, not as a one-shot event.
- Home health eligibility criteria should be altered for a narrowly-focused group of seriously ill patients to provide reimbursement for the **AIM**® program. Current regulations require home health to focus on recovery, not on end-of-life planning, and they also penalize continuous care. Concerns about “gaming” a new form of home health reimbursement may be allayed in two different ways:
  - Eligibility should be defined using evidence-based clinical criteria, so that only patients with truly life-limiting illness may receive reimbursable

services. One of the authors of this paper led a project that created similar criteria for hospice eligibility for patients with non-cancer disease in the mid-1990s. These criteria were adopted by HCFA (now CMS) and used successfully on the national level to increase hospice use while controlling overutilization. A similar process could be employed to define AIM® eligibility.

- Reimbursement should be tied to the achievement of measurable outcomes, so that Medicare pays for value, not volume. Suggested metrics of process and outcome include, but are not limited to:
  - Patient quality of life
  - Patient, family and survivor satisfaction with care
  - Rates of provision of patient counseling and education
  - Advance directive completion rates
  - POLST completion rates
  - Rates of adherence to patient's desired plan of care
  - Hospital readmission rates
  - Medicare costs

Controlling costs is important, because any new revenue provided for care must be balanced by cost reductions in order to maintain budget neutrality. The Dartmouth Atlas and others have shown that decreases in hospital days, intensive care days, inpatient consultations, tests and procedures can all be achieved without any increase in mortality or other negative outcomes. Lower utilization of all these unnecessary and unwanted services can result from improvements in advance care planning leading to reduced hospital readmissions. Lower costs do not occur as a result of denying services that patients want. They result from giving patients a choice, and following their wishes.

Certain delivery-system reform initiatives already under consideration should be supported. These include Medical Home, Independence at Home, and Accountable Care Organization initiatives. For any of these initiatives, a shared savings arrangement between provider groups and CMS could help cover the costs of providing new services. Any new policy should take care not to penalize health systems that have already put innovative, cost-saving measures in place.

## **Appendix I**

### **Advanced Illness Management (AIM)® Sutter Health**

#### Outcome Measures

The following metrics will be used to evaluate program effectiveness and to guide continuous quality improvement:

1. 30-day hospital readmission rate for any cause
2. Emergency Department utilization
3. Falls at home
4. Patient and caregiver satisfaction
5. Patient quality of life
6. Hospice utilization

#### Medicare Patient Volume

Estimated number of Medicare patients to be served by the mature program system-wide equals 3500-4000 per year.

*For questions, please contact Michelle Stein, Executive Director of Long Term Living at the Center for Health Transformation ([mstein@gingrichgroup.com](mailto:mstein@gingrichgroup.com)).*