A MedSmart Members Special Report

Death-by-ICU



End-of-Life Care in America

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Death-by-ICU

End-of-Life Care in America

Introduction

End-of-life care is difficult for patients, their families and medical providers alike. There is much confusion and disagreement about the ethical dimensions of end-of-life care. Well-intentioned people on both sides of the issue often strongly disagree.

And then there are those of lesser intentions – cable TV talking heads and political grand-standers included – who exploit the universal fear of death. Long-overdue common sense measures like reimbursing doctors for time spent discussing end-of-life options with patients were torpedoed in healthcare reform for political expediency.

Allegations of euthanasia and even murder are regularly thrown at doctors, nurses and other medical providers who practice "palliative care" that's aimed at managing symptoms to preserve quality of life as much as possible – rather than trying to "cure" the underlying cause of these symptoms, an often futile effort with endstage disease.

Their detractors believe strongly that every lifeprolonging measure should be employed regardless of cost or, sometimes, even patient preference. This brief report obviously can't do justice to these ethical concerns and isn't intended to address them in any significant way. The emphasis here instead is on what many dying patients themselves seem to indicate they prefer when fully informed of what their options actually entail – and to advocate for their fuller disclosure so more patients are able to make fully informed choices.

Much of what occurs in the final weeks and months of life occurs because patients are kept in the dark about the quality of life implications of aggressive, and often

Every patient deserves to know what their final days & moments will be like futile, medical interventions in their frail conditions.

Patients' families are often not prepared for the horrible choices that need to be made, so the default practices of the local medical profession often ensue.

A recent study found these default practices can vary by 100% from one hospital to another.¹ This demonstrates the lack of consensus about what's best for patients in this situation – as well as financial incentives to use expensive interventions that may have extremely low probabilities of success for these fragile patients.

It's important to understand that even many who choose a hospice-based palliative care approach can end up with aggressive medical interventions, while those who prefer such aggressive treatments sometimes opt-out as they suffer treatment side effects and complications.



¹ End-of-Life Care For Medicare Beneficiaries With Cancer Is Highly Intensive Overall And Varies Wildly. *Health Aff* April 2012 vol. 31 no. 4 786-96.

It's not always black-and-white, like much of our medical decision-making. When it entails a loved one, however, it's further complicated by whatever emotions pertain – and they can be complex as well.

What follows isn't meant to diminish in any way the enormity of these decisions, nor advocate for one answer over another. These are highly personalized decisions that warrant different answers for different situations.

Nor will this report delve into the legal requirements, protections and authorizations that may pertain to a given situation. These will be discussed in other Medsmart Members publications (see *MedSmart Patients)*.

What this report WILL do, however, is advocate for the deciding role of the dying patient him or herself. Some will object to even this, seeing in it the seeds of assisted suicide.

The question to ask on the ethical front, however, is this: if it's not the role of government,

insurers, or other third parties to make end-of-life decisions, then how is it the role of any other third-party?

It isn't. It's the patient's role – their choice – theirs and theirs alone. That's what "patient autonomy" means – and the challenge for all wellmeaning caregivers and family members is to understand those "Patient autonomy" means it's the patient's choice as to how they wish to die

wishes and respect them as they advocate on their behalf.

If mental capacity is in decline, then their wishes obviously need to be solicited early on. If not, the burden is even greater for those left to decide on their behalf.

At some point in a patient's decline, the usual lifesaving measures may no longer be advisable (so-called "futile" care with no real hope of success). It will help to understand what's considered ethical medical practice in these extreme circumstances.

Here's what the American Medical Association's <u>Code of Medical Ethics</u> has to say about this:

"Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care. This includes providing effective palliative treatment even though it may foreseeably hasten death."

This doesn't mean the AMA's position on this is definitive. There are doctors who disagree. But these positions are arrived at through very deliberative processes involving many thought leaders devoting substantial time and effort to grapple with these thorny ethical issues.

All of which is only to suggest that it's not quite fair to demonize those who adhere to this position even when you may disagree with it.

Now let's try to tackle this sensitive subject knowing that there's no way to satisfy everyone. This is, however, one of the defining challenges confronting a nation heading for financial collapse because, in large part, of our failure to get a better grip on this tortuous subject.

End-of-Life Care

End-of-life care – generally defined as medical treatments in the last 6-12 months of life – is the 800-pound gorilla in the room when runaway medical costs are discussed.

It's a subject that evokes a lot of emotions, ranging from one's own fear of dying – the most primal of instincts – to the guilt family members often feel during the dying process to fears of turning over control of this most personal of decisions to faceless bureaucrats.

Our task as medical consumers is to overcome these natural fears and apprehensions and adopt a more rational, less emotional framework for these most difficult of decisions – no easy task.

Medical providers encounter death every day, while the families of dying patients may be confronting it for the first time. They often feel guilty and stressed by the death of a loved one and are highly vulnerable to the End-of-life care is the 800-pound gorilla in the room

institutionalized exploitation that sometimes occurs during the dying process.

This isn't the same kind of exploitation discussed in *Our Healthcare Sucks* in which individual physician greed often drives medical overutilization. It's more complicated than that.

PBS did a documentary in 2010 called "Facing Death" about end-of-life care that focused on a series of dying patients at New York City's Mt. Sinai Medical Center.

All of these patients – at least those who could communicate (95% can't) – died in the Intensive Care Unit (ICU) after heart-wrenching struggles to survive.

The ICU physicians were almost as sympathetic as their dying patients – themselves victims of technological prowess that allows us to extend the physiological signs of life indefinitely when patients' underlying pathology has ended any hope of continuing with any quality of life whatsoever.

"Broken survivors" exist in a state of suspended animation We've created a revolving door of what one of these doctors called "broken survivors" who exist in a state of suspended animation.

One of the doctors interviewed stated there were 100,000 people on ventilator support in ICUs across America at any point in time – a number

that will only grow with our technological capacity to sustain the façade of life indefinitely.

These doctors aren't villains. They're merely cogs in the wheel of medical commerce that benefits enormously from this foolhardy attempt to defy our fates. As one of them states in the documentary, "Nobody wants to die, but nobody wants to die badly".

All of the patients in this story died badly.

Enormous revenues are realized due to the guilt and grief of family members who feel obligated to grasp for every possible high-tech "life-saving" measure to prolong the dying process regardless of its cost or marginal benefit. Indeed, there's often not only *no* benefit, but actual harm and a reduced quality of life.

Our cultural infatuation with technology has led us to embrace false expectations about its ability to extend life when all it does in most cases is prolong the dying process. And it isn't pretty.

Death-by-ICU is gruesome, often bordering on cruel and unusual punishment – if not for the patients, then for their families.

As you'll see shortly, when patients see videos of what it entails, they unanimously reject it. It persists only because they *aren't* seeing those videos on a routine basis, led instead to believe there's more hope for a return to a normal life than is generally the case. When patients are shown videos of what death-by-ICU entails, they unanimously reject it

The problem is that sometimes miracles happen and a patient may actually "bounce back" and be discharged home, at least temporarily. The numbers are miniscule compared to the numbers who suffer painfully prolonged deaths, but that slight chance for survival is enough to pose ethical dilemmas for doctors charged with their care and family members alike.

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There's a case to be made that technology is the enemy in this scenario. Technology, of course, is not inherently good or bad; it's how we use it that determines its effects.

In this case, we use it to provide false hope for survival for millions of Americans.

In the absence of standards that many fear amount to "death panels" dictating who lives and who dies, individual physicians are left to their own devices.

Some are more willing to utilize every last measure possible to artificially extend patients' physiological function. Others see this as a cruel hoax and counsel families to try hospice care that will provide low-tech comfort and manage pain during the dying process.

This inconsistent and subjective approach is encouraged by a medical system that profits from medical overutilization. Cruel hoax or not, it makes many in medicine wealthy by transferring wealth from your hands to theirs.

Medical advances have turned what were once timely and expected deaths into "long goodbyes" that drag out the dying process over weeks and months at a financial cost that most families couldn't afford if they had to pay for it themselves. And to the extent it's governmentsubsidized, it hastens the financial insolvency of not just Medicare, but our entire healthcare system.

Those who consider attempts to grapple with this problem "playing God" need to ask themselves who here is "playing God".

Is it those advocating a natural and painless death or those prolonging the façade of life on life-support equipment that artificially prolongs breathing - though hardly what anyone would regard as "living" - while increasing revenues for medical institutions?

Given the pace of medical inflation in America, anyone concerned with conserving as much of their savings as possible for their family once they're gone will want to plan ahead for their final year of life.

Of course, we generally don't know we're *in* our final year of life at the time, which is why this isn't something to put off "until you get there". The odds are you won't know you're there until it's too late.

The time to make choices about what you want your final days to be like is while you're still healthy, or at least before you're terminally ill.

More Care Isn't Better Care

You can decide now whether you wish to be one of those spending the 19 days or the 13 days in the hospital - or the 52 office visits or the 24 - reflected in the table on the next page.

Or you can choose even less intensive care with hospice care - where the emphasis is on comfort and support, not technology and invasive procedures that "pad the bill" while adding nothing in terms of actual quality-of-life.



OurHealthcareSucks.com

Indeed, as the following data illustrate, more intensive care typically yields lesser quality results in our final days, as it very often does in general.

The comparative experience of three hospitals reported by the Dartmouth Atlas Project examined relative performance and spending during the final six months of life.

Here's a summary:

Comparative Performance of Select Academic Medical Centers in Last Six Months of Life (Medicare Data)

Treatment Component	UCLA Medical Center	Mass. Gen. Hosp.	Mayo Clinic
Specialists : Primary Care	2.9	1.0	1.1
Physician Visits	52.1	42.2	23.9
Hospital Days	19.2	17.7	12.9
Total Medicare Spending	\$50,522	\$40,181	\$26,330
Quality Score	81.5	85.9	90.4

Source: Variations Among Academic Medical Centers, Dartmouth Atlas Project.

This wide disparity among leading medical centers reveals several lessons for those interested in learning how to use the medical system rather than be used *by* it:

1. Not all academic medical centers rely exclusively on high-priced interventional procedures and surgeries that "pad the bill" of patients and insurers.

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All the high-spending regions across the U.S include concentrations of academic medical centers, but not all academic medical centers are big spenders.

The key is finding the 5-star quality hospital(s) with low-to-moderate spending profiles. And remember that it's *your* money – directly or indirectly – that they're spending. Make sure it's spent prudently;

2. More treatment often yields poorer quality. The highest cost of the three hospitals studied had 10% lower quality scores. This cuts against the grain of

how most Americans view their healthcare, but paying twice as much for B- care when you could get A- care for half the cost is not smart consumerism; and

3. 50-100% more days in hospitals and doctors' offices doesn't just drive up your medical bills. 50-100% more time in hospitals & doctors' offices means 50-100% more risk of medical errors

It also exposes you to 50 -100% more risk of medical errors and hospital-induced disease or even premature death.

Paying more for lesser quality results PLUS an increased risk of treatment-induced disease is *really* not smart consumerism.

So how do you get smarter about this?

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There's a useful tool at <u>dartmouthatlas.org</u> - the "Hospital Care Intensity Index" - that shows how hospitals in your state compare in terms of the intensity of care provided during the last two years of life based on Medicare payment data. It's worth checking out.

In one easy-to-understand view, you see whether the hospital(s) you're considering practices very aggressive and expensive care – including both hospital care and physician visits – or a more conservative, less aggressive approach, if that's your preference.

Clearly, spending more doesn't buy better quality of care nor better quality of life. As the physician responding to a medical blog entry about the *New Yorker* article discussed in *Our Healthcare Sucks* stated:

ICU patients are often probed by specialists "generating costs and care that won't change the outcome" "If patients and families had to bear a fraction of the costs of care, then ICU patients destined for heaven wouldn't be probed by half a dozen (specialist) consultants, each one generating costs and care that won't change the outcome."²

The emerging truth is that patients and families *will* be bearing an increasing share of this unnecessary end-of-life overspending.

And the time to curtail it is not when the patient is in the ICU, but long before the patient is even hospitalized.

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² ACP: Embracing a culture of cost-effective health care, available @ kevinmd.com/blog, 6/25/09.

Hospice is an organized program of care that can be either in a facility or home-based. Palliative care is pain relieving care that can be applied at any phase of medical treatment, not just at end-of-life.

One out of three dying patients currently chooses hospice care, which is usually in the patient's home. They are generally referred to hospice when their physician determines that life expectancy is six months or less, though this can be extended with physician certification.

Medicare will pay for hospice care under these circumstances, including 24-hour on-call support, as will most state Medicaid programs, many private insurers and Tricare for military service members and their families.

When the time is right, talk with your loved ones who may be facing terminal care in the near future and ask what kind of ending they want for their lives.

Not everyone will be receptive at first, but many people would rather die in the comfort of their own homes than be subjected to costly "heroic measures" as their final memory of life.

But if nobody asks them, they'll never get to assert their wishes.

Unintended Consequences

The assumption by most of those advocating for aggressive end-of-life treatments is that this will buy their loved one more time. They don't wish to "throw in the towel" when their loved one's life is on the line – and who can blame them? But what if their assumption is totally wrong? What if subjecting their dying loved one to highly-invasive medical interventions didn't buy them more time after all?

What if it actually shortened their lives?

A study by Massachusetts General Hospital of patients with non-small-cell lung cancer published in 2010 found just that.

Not only did the patients who chose early palliative care over aggressive medical treatments live about 33% longer, they enjoyed a better quality of life – reporting 58% less depression than those subjected to intensive medical care.³

The truth is the opposite of our assumptions: less intensive end-of-life care may help dying patients live longer They lived almost a full year compared with less than nine months for those undergoing intensive treatment regimens.

That's almost three additional months of better quality life – the exact opposite of the underlying assumption behind much of the angst generated by this end-of-life debate.

Combined with the findings below from another Harvard Medical School study – also conducted at Massachusetts General Hospital – indicating that dying patients actually reject intensive medical interventions when they see what it entails, these results suggest this debate should be turned on its head.

Maybe less really *IS* more after all.

³ Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010 Aug 9; 363(8):733-43

Embracing Death

"Cancer" is often called the scariest word in the English language despite being, in many cases, a chronic disease like diabetes or heart failure.

In reality, still relatively barbaric cancer treatments – "slash, burn, and poison" – are often scarier than the cancer itself.

But the word "cancer" is just a surrogate for death – it provokes such fear because it's still understood to mean, often erroneously, a certain death.

Today cancer is often no longer a death sentence. Many more survive it today than in generations past – only, of course, to ultimately succumb to something else.

And that's the point. Since death is unavoidable – the *only* thing we know of that's truly and unalterably unavoidable – we should be trying to anticipate it and perhaps encounter it on terms of our own making.

Our choices may be limited, but we can at least insist on terms *closer* to our own making than will occur if we remain in a fantasy world of denial.

It's easy, of course, to wax eloquent about death when it's an abstract consideration and quite another when we're "at death's door".

But the logic for doing so – for confronting our denial, our fear, and turning it to more constructive purposes – is only possible with some distance, unencumbered by the emotional trauma of the real thing.



Instead, we avoid the word "death" almost as vigorously as we avoid death itself.

Or perhaps "deny" death would be more apt, since no one's yet succeeded in "avoiding" death.

Because it *is* real but we regard it as unreal, and unthinkable, we submit ourselves and our loved ones to "treatments" that are themselves unthinkable and, very often, it's *they* that should be denied.

By contrast, hospice care is designed to comfort and support those who choose not to "fight to the death" with so-called "heroic" measures to keep them in a semivegetative state that's only technically "alive".

There's nothing the least bit "heroic" about futile end-of-life "treatments" In truth, there's nothing the least bit heroic about these end-of-life measures that inflate medical costs for payers and families alike.

The real heroism is with those who refuse to give in to their natural and understandable fear of dying.

But even this most potent of fears can be managed with the proper information.

One study of terminal cancer patients found that

- Less than 1 in 3 reported having an end-of life discussion with their physician;
- Those who did had a better quality of death; and
- At a 36% lower cost in their final week of life.⁴

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A Harvard Medical School study of cancer patients at Massachusetts General Hospital found when patients were given only a verbal description of their end-of-life options:

- About 1 in 4 (25.9%) preferred life-prolonging care, including CPR and a mechanical ventilator when they were no longer able to breathe on their own;
- More than half (51.9%) preferred basic care (hospitalization and antibiotics, but no extraordinary measures); while
- Less than 1 in 4 (22.2%) opted for "comfort care" (pain control, supplemental oxygen, other symptom relief).

The study group shown videos of what their end-oflife options actually entailed, however, made dramatically different choices:

- None were interested in lifeprolonging measures;
- Less than 1 in 20 chose the basic care; and
- More than 9 in 10 (91.3%) chose comfort care (4.4% were uncertain).⁵

NONE of the patients wanted intensive end-of-life care when shown what it entails

What does this dramatic turnaround tell us besides "A picture is worth a thousand words"?

⁵ Use of Video to Facilitate End-of-Life Discussions With Patients With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, 10.1200/JCO.2009.24.7502. **Jan 10**, **2010** vol. 28no. 2 **305-310**

More fundamentally, it reveals that patients have only vague notions of what their final days will be like if they don't opt out of death-prolonging default treatments.

When presented with visual images of what's actually entailed, they unanimously rejected it. Their justified fear of these end-of-life measures in hospital ICUs

Patients should know they can opt out of deathprolonging default treatments once they realize what they entail –
overwhelms their fear of death itself.

Death doesn't look as bad to them as the hospital "treatments" that delay death for a few days or hours. Delaying death is not always the same as prolonging life.

For this lucky minority of dying people, being able to visualize their

options for dying allowed them to choose the less intensive and more humane, dignified, and natural course of home-based hospice care.

Whether it's a greater fear of ICU-death than death at home or some nobler form of courage hardly matters.

They and their families benefit by embracing the dying process for what it's naturally meant to be – a time for shared remembrances and meaningful goodbyes, free from the hospital strangers, medical devices, and ungodly expense of death-by-ICU.

Don't we owe it to our loved ones to help them make their final decision a truly informed one?

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Ask Questions

Ask to see a video of end-of-life treatment measures if you or a loved one is in this position. If unavailable, ask for an alternative means to help visualize what the final days under death-prolonging ICU care will really be like.

If ever a situation calls for human compassion, this is it. Anything less is simply unintended cruelty, but cruelty nonetheless.

Black patients and their families need to be especially proactive about this. One study found white patients who decided against intensive end-of-life care had their wishes respected, while: If ever a situation calls for human compassion, this is it

"Similar reports were not protective for black patients...White patients with advanced cancer are more likely than black patients with advanced cancer to receive the EOL (end-of-life) care they initially prefer".⁶

Don't let the awkwardness of asking death-related questions prevent you from addressing the issue. Assuming mental competency, it's likely your loved one has been thinking about such things and may be relieved to be asked.

You can also contact a hospice in your area for advice on how best to proceed in your specific circumstances.



⁶ Racial Differences in Predictors of Intensive End-of-Life Care in Patients With Advanced Cancer. *Journal of Clinical Oncology*, vol. 27, No. 33 (Nov. 20), 2009: pp. 5559-5564.

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An informational visit from a hospice nurse can answer questions and dispel myths people may have about hospice care - like you can't remain at home (which you can) or that it means you're giving up (which it doesn't).

Online resources include the following:

- hospicefoundation.org Includes a free hospice locator:
- hospiceanalytics.com Also includes a free hospice locator;
- hospicenet.org Support for patients and families;
- hospicecare.com Support for patients and families;
- mycarecommunity.org Support for caregivers; and
- emedicinehealth.com/script/main/art.asp?articlekey=5 8715&pf+3&page=1 Explanation of Advance Directives protecting the right to die with dignity.

There are about 4,500 hospices in the U.S., so it's not exactly a new concept. But fewer people choose hospices than can likely benefit from their focus on pain management and symptom relief.

"Hospice care neither prolongs life nor hastens death", according to the Hospice Foundation of America,⁷ and is a prudent choice for those who reject the idea of enduring the pain and expense of a medically intensive end to their lives.

⁷ Choosing Hospice. Available @ hospicefoundation.org/hospiceInfo/dearabby/default.asp. © MedSmart Members LLC – All Rights Reserved OurHealthcareSucks.com

Not everyone can be expected to welcome this approach. Many Americans remain wedded to the disproven idea that "more is better", especially when it comes to medical care.

Having just reviewed some of the evidence to the contrary – and there's much more to be found in our eBook, <u>*Our Healthcare Sucks*</u> - you now know better. More is worse, not better.

And that may be most true over our last year of life when we may be deprived of a happier and peaceful death with dignity while our family members are deprived of "Hospice care neither prolongs life nor hastens death." Hospice Foundation of America

their inheritances – too often just to feed the beast of medical practices that are perpetuated largely because they maximize hospital and physician revenues.

For those interested in more on the human aspects of these wrenching decisions, there's an excellent article in *New York Magazine* by Michael Wolff entitled "<u>A Life Worth Ending</u>" that nicely encapsulates the many considerations in coping with the death of a loved one.

He aptly describes the never-ending, ever-escalating progression of medical interventions to prolong lives beyond their natural end as a "rabbit hole". His dying mother's particular rabbit hole included heart surgery that probably worsened her dementia and hastened her demise.

It's hard to believe such a dynamic woman - he describes her as having been the marketing manager for an online gaming company *in her seventies* - would have wanted such a debasing and dehumanizing ending to her accomplished life.

It doesn't have to be this way, but it will take committed and compassionate family members to make sure they and their families get the care their dying family members wants – no more and no less.

If it's a loved one in this position, ask yourself how you'd like to be treated in similar circumstances. Don't they deserve to at least know the truth about what their final days will be like?

And don't they have the right to decide for themselves with the benefit of fully knowing what each of their options actually entails?

A good advocate would demand nothing less.

Here's a link to a YouTube video of a CBS presentation on this issue: <u>http://www.youtube.com/watch?v=-pOiRb3xOKo&feature=relmfu</u>

> Dying patients presented with visual evidence of end-of-life ICU care unanimously rejected it



About The Author

John Lynch has several decades of diverse healthcare experience ranging from consumer advocacy to hospital management to regional health planning & developing innovative service delivery models:



• Founded and served as Chairman, President, and CEO of a mobile MRI company (Medical Diagnostics,

Inc., or MDI) he took public as the only profitable such company in the country; company twice named to *Business Week*'s "Best Small Companies" in America;

- Former independent consultant for hospital planning and program development projects; developed an early methodology for projecting patient need for an emerging diagnostic technology (MRI) recognized by the American Hospital Association;
- Served on the Boards of a hospital and consumer advocacy group for the medically uninsured, as well as the Hospital Trustee Committee of the state hospital association;
- Served on the Boards of community health centers, a Harvardaffiliated mental health center & statewide drug rehab program;
- Managed the emergency room, outpatient, and community-based programs of a large teaching hospital; &
- Served as Planning Director for a regional health planning agency, including review of dozens of hospital expansion plans.

This diverse range of industry experience as a hospital and regional planner, hospital manager, trustee, consultant, entrepreneur, and consumer advocate have given the author unique insights into the complex field of medical practice from various perspectives. More importantly, the research and analysis skills developed over decades of experience have served him well in researching and writing this report, as well as *Our Healthcare Sucks* and its companion volumes – *MedSmart Patients, MedSmart Living,* and *MedSmart Diet.*

Mr. Lynch's ongoing interest in the medical field – particularly in relation to consumers' unmet needs – will continue to guide his efforts with <u>OurHealthcareSucks.com</u>, where he can be reached by email and in blog post discussions.

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This report is part of a series of books and reports by MedSmart Members designed to help consumers become more aware of the threats posed by our dysfunctional healthcare system - <u>and</u> how they can best protect themselves and their families from those threats.

If you'd like to advance your understanding of these threats and commit to learning what you'll need to reduce your reliance on our fragmented, dangerous, and bloated medical system, visit <u>OurHealthcareSucks.com</u> to learn more about how we can help you help yourself.

As with end-of-life care, there are smart ways to avoid medical exploitation and endangerment - *if* you're willing to make the time to learn what you need to do so.

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Death-by-ICU: End-of-Life Care in America

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