

END-OF-LIFE CARE

Mr. WYDEN. Mr. President, late last week, the Nation witnessed the end to a saga that was heartrending not only for the medical circumstances of the young woman at its center, but for the tragic controversy that surrounded it.

The Congress has spoken once about Terri Schiavo, and in the near future the Senate's Committee on Health, Education, Labor, and Pensions is expected to hold hearings about one of the issues Ms. Schiavo's situation brought to the spotlight: the rights of the incapacitated and our society's responsibility toward that community. I hope the Congress will now begin a thoughtful examination of this and issues relating to end-of-life care. For that reason, I rise today to urge and encourage caution as the Senate moves forward.

George Washington called the Senate the saucer to cool the legislation. I would say the Senate, in fact, must cool its own passions before proceeding. The alternative is unacceptable. The Senate must not revisit the dangerous zero-sum game of 2 weeks ago, creating a false debate between those who seek protection and those who desire choices and actually sacrificing one of those rights to secure the other. This body's responsibility is to find solutions that preserve both. Protecting the vulnerable and preserving end-of-life choices are not mutually exclusive. Advocates for the disabled are right when they say that losing physical or mental capacity must not deprive anyone of their rights even if they have not had or taken the opportunity to make their treatment and wishes known.

There is legitimate cause for worry that the majority of our population might give short shrift to the real rights of a minority group. Journalist James Taranto summed it up well when he said:

It was natural for an able-bodied person to think: I wouldn't want to live like [Terri Schiavo]. But someone who is disabled and abjectly dependent on others was more apt to be chilled by the talk of her "poor quality of life" and to think: I wouldn't want to be killed like that.

Let us reject any legislative effort that springs from these false choices diminishing the rights of the incapacitated and all Americans. New Federal efforts may have the goal of protecting rights, but they may have the real effect of engineering outcomes with little regard to a patient's true interests. Instead of courting this risk, the Senate should seek to empower the disabled and all Americans.

My sense is that momentum still exists in this body to act unwisely in a way that will produce more government and fewer choices for all Americans at the end of life, so let me be clear. I intend to oppose any congressional fiat that disempowers our citizens—disabled, abled, incapacitated, or otherwise. I will oppose any such dictate that restricts the choices for our

citizens at the end of life and grows the role of government instead.

In the last 2 weeks, Americans have overwhelmingly cautioned the Congress against government mandates for the end of life. Many voices are speaking. Some have been shouting. If the Senate can't yet distinguish the country's clearly stated desire, then this body ought to fall silent and listen harder before acting.

In many ways, this is the central question of our time: whether the Federal Government will seek to expand its reach when the citizens wish for more individual empowerment. Presented with that question 2 weeks ago, the Senate got it wrong. The American people have made it clear that moving forward, there ought to be a course correction. True leaders will approach these choices dispassionately with a set of impartial principles.

I will spend a few minutes discussing what I think those principles ought to be. First, the Senate should help empower Americans to make their own choices about the end of life, whatever those choices should be. Policy ought to be grounded on the principle that Americans setting their dining room tables, in their kitchens, discussing their wishes and their fears with their loved ones, and asking in the end that government should make sure their desires are carried out. The choices they have to discuss—discuss in their homes and in their workplaces—ought to be expanded, not weakened, by Government and bureaucracy. Our policies should help their wishes to be honored by their families and their health care system—their lives sustained as they wish or unwanted treatment ended as they wish.

Second, as the Senate looks at the end of life, the Senate needs to look at the entire picture. End-of-life care is more than respirators and feeding tubes and even more than living wills. The Senate has to get beyond today's hot-button questions. The Senate ought to look at the fundamentals: conquering pain, expanding hospice care, capping the great potential of comfort care, which is known as palliative care. Supporting new ways to treat a very ill patient physically, spiritually, and emotionally, long before the last days of life, is a good use of the Senate's time.

Third, the Senate must address end-of-life issues with respect for constitutional boundaries that have been dangerously dismissed to date. For the last 2 weeks, issues of separation of powers and federalism have received virtually no attention. The Senate needs to reflect on the roots and the reason of federalism, which has given the States control over medical practice for more than 200 years. There is a line the Senate must not cross again. Beyond that line are the constitutional rights of States and, ultimately, the rights of our citizens.

Those individual rights, or citizens rights, ought to be the Senate's first

guideline in moving forward. I realize the temptation is to frame the debate entirely in terms of the heartbreaking situation of Ms. Schiavo. I believe it would be a mistake, however, to base Federal law on the basis of the tragic chaos that transpired in that woman's family. The Senate cannot jump in now and play medical czar to predetermine the outcome of every similar case. Our responsibility is to help individuals and their families to avoid the compounded tragedy that occurred in that family.

Helping Americans make their wishes clear is paramount. There are a variety of ways this can be done. The 50 States and the District of Columbia have made provisions for the declaration of individual choices, often through the creation of an advanced directive or a living will. If the Congress acts, it certainly should not thwart State laws in this area. Our goals should be to increase awareness and access and to look for ways to aid the enforcement of those wishes of families and the health care system.

Certainly, living wills should be encouraged, and thousands of Americans now are looking to fill these forms out. But in many instances, frequently that living will, a piece of paper, is not enough. Too often people will still be confused about an individual's real desires. Too often the language will not be clear or subject to misinterpretation. The bioethicist Carl Schneider of the University of Michigan said he is "appalled" at the number of people who are advising the public that a living will alone will be sufficient. He states:

Living wills often do not work.

So the national discussion about end-of-life choices should include information that will ensure that wishes be carried out, not just stated. As national leaders, those of us in the Senate can promote this discussion.

Most folks looking into advanced directives today seem to think they can just avoid a controversy through a living will. Maryland Attorney General Joe Curran recently said that 27,000 people in his State alone downloaded the forms over a period of 7 days. That is compared with 600 downloads during just 1 week in January. But, as I have indicated today—and I know it will be surprising to many Americans—the reality is the laws vary with respect to living wills and advanced directives, and often they do not ensure enforcement of a patient's wishes. Therefore, Americans need to know about vital mechanisms in addition to the living will. For example, the health care proxy, which designates one person if a person becomes incapacitated, is another approach that may be a value to our citizens because it leaves no doubt as to who speaks for those who cannot speak for themselves.

There are other options that can help ensure the effectiveness of an advanced directive. My home State uses a document called a "POLST," which stands

for "Physician Orders for Life-Sustaining Treatment," a bright-pink document that physicians place in patients' charts to help nurses and hospice workers and other providers follow the wishes of the patients for end-of-life care. Studies show these physician orders, the product of a frank discussion between patients, families, and providers, result very often in the kind of end-of-life care that patients desire.

There are various approaches being tested in other States as well, and the Senate should promote them. One of our most valuable guidelines in moving forward should be the 1990 Patient Self-Determination Act. Its spirit and letter ought to be honored for two reasons. First, the law was passed by the Congress to encourage and ease the use of States' advanced directives. It requires many Medicare and Medicaid providers to discuss advanced directives and how they will be carried out. Its requirements in that respect are as correct today as they were 15 years ago.

The second requirement of the 1990 Patient Self-Determination Act is just as important. It prohibits discrimination against those who do not have an advanced directive. Now, it is estimated that as many as 75 percent of Americans do not have an advanced directive to guide their end-of-life choices. Under the Patient Self-Determination Act, mandating different and discriminatory treatment for Medicare and Medicaid patients without advanced directives is specifically ruled out. That is the kind of protection I believe all Americans deserve: protection that ensures the preservation of all their choices.

Now, I am grateful that Senator HARKIN and others are tackling vital issues, important issues that often go ignored, such as the concerns of those who are disabled. Americans should expect the Senate, however, to do even more.

In this Congress, I will advocate vigorously for three pieces of legislation that take an appropriate Federal approach to key end-of-life issues. If the Senate has a commitment to consider the end of life seriously, I would expect those bills to come to a vote. They all involve issues I have been working on since the early 1970s when I was codirector of the Oregon Gray Panthers and taught gerontology at several Oregon universities. I have been working to improve care for older people and the dying throughout my service in the Congress and as a member of the Aging Committee in both the House and the Senate.

For more than a decade, the people of my home State of Oregon have had a passionate and thoughtful debate on end-of-life issues. Through all of this, I have found that our health care system often neglects how people die and how important it is to make dying patients and their families more comfortable.

Almost half of the dying experience moderate to severe pain in the last days of their lives. It does not have to

be that way. The distinguished Presiding Officer is one of our authorities on medical technology, and he knows medical technology and know-how exist today to reduce the suffering that I am describing. What does not exist is a medical system that supports clinicians trying to address these issues or a system to support patients and families as they try to find help for pain.

I intend to reintroduce the Conquering Pain Act, a bipartisan bill I have written that recognizes that too often at the end of life pain goes untreated for the dying patient. The Conquering Pain Act does not tell providers how to practice medicine. It certainly does not override the States' constitutional right to oversee medical practice. But it does serve to ensure that patients in every corner of our country, 24/7, 7 days a week, can get access to help as they try to deal with pain.

This legislation creates six regional Family Support Networks to assist physicians and families of patients in pain, and it ensures that in every single community in this country Americans know where to turn to get information and help when loved ones are suffering. Americans deserve to know their health care providers and their families will have resources to ease suffering. I believe the ability to see a loved one's pain properly treated can help families across this country. It certainly will add dignity and preserve choices at the end of life.

My second effort will focus on the vital work of hospice programs. More Americans are familiar with hospice today through Ms. Schiavo's case, but its true purpose may still be somewhat unclear. Hospice programs provide a range of services to control pain and other symptoms, maintain dignity, and provide comfort care, primarily to individuals in their own homes.

But the hospice benefit under Medicare needs to be improved. Today, about 20 percent of patients who die in the United States receive hospice care, and of that low number few begin their care early enough to receive the full benefit of hospice. Medicare requires patients and doctors to stop all treatment that might bring a cure before they can begin hospice treatment. I do not believe—I do not think Senators will believe—that patients should be required to abandon all hope of recovery to get the good hospice care they need, but that is what the Medicare law states today. It makes no sense, and it ought to be changed.

My Medicare Hospice Demonstration Act permits patients to seek hospice care as they seek a cure. It will not require patients and their families to abandon hope even as they move towards acceptance. For many, it will result in better care, more control, and more peaceful passage through the end of life.

Finally, the Senate ought to promote training in what is called comfort care or palliative care in our medical

schools. This is a practice that is important for the Senate to understand. Comfort care, palliative care, helps terminally ill patients live as actively as possible and helps their families cope. It neither hastens nor postpones death. It is offered in hospice programs, in the home, and in other settings. It prevents and relieves suffering by identifying, assessing, and treating pain and other problems. Those can include physical problems, emotional problems, and even spiritual concerns. Palliative care is appropriate even before hospice care. It is even compatible with aggressive efforts to prolong life, such as chemotherapy or radiation therapy.

The Palliative Care Training Act will ensure that our country has more trained professionals to offer these critical comfort care services. The legislation addresses a need that the Senate has ignored too long. Without it, our citizens will not have enough dedicated professionals to meet this enormous need.

As the distinguished Presiding Officer and I have discussed often, we are in the middle of a demographic revolution. We will have many more older people. It will not be uncommon for individuals to live beyond 100, and with Americans living so much longer than they did a century ago, it is important they have options that work for them. And demand for comfort, for palliative care, is certainly going to grow.

With all the American health care system has to offer, there has to be better care for patients and their families at the end of life. I hope these three bills I have described will get careful and thoughtful examination in the days ahead and in the hearings that apparently will begin later this week in the committee on which the distinguished Presiding Officer serves.

As I have indicated, I believe the Senate has not been appropriately careful in recent weeks. When this body first considered legislation regarding Ms. Schiavo, I made my objections known. I was compelled to block the initial version of the legislation, a bill that was put forward without hearings, without discussion, and one that threatened to turn the Congress into a convention of case-by-case medical czars. In my view, that legislation intruded dangerously on States' rights to determine medical practice.

I worked with colleagues so Congress could pass bipartisan legislation that in my view didn't set that dangerous precedent, particularly as it related to my own State's law that the people of Oregon have now approved twice. I didn't filibuster that final bill, which I had concerns about, but my concerns remain. I do not wish to see the steps of the Capitol as the new gathering place for Americans to bring their difficult family disputes at the end of life. I certainly do not want to see our Constitution trampled. Unfortunately, Congress has now opened the door to both those possibilities.

The Senate has a renewed responsibility to do better. Each State's constitutional right to determine medical practice exists whether the Congress agrees or disagrees—to put it bluntly, whether Congress likes it or not. Congress cannot only respect the principle of States rights when it thinks the State is right. In the same way, the checks and balances the Founding Fathers set among the executive, legislative, and judicial branches, those powers are not up for negotiation because they produce an outcome that is unacceptable to some Americans. Before acting, the Senate ought to consider the very nature of federalism that has brought and held our States together for more than two centuries. Then the Congress should think carefully about whether it makes sense to tear down a basic pillar of our national contract.

This body writes Federal laws. If the Senate does not like the effect of a Federal law, our prerogative is to change it. But it is not the Senate's prerogative to play constitutional chicken when matters happen outside of our jurisdiction. That is true no matter how strong our personal passions may be.

I have fought for the rights of my State and its voters to decide the issue of physician-assisted suicide at home in Oregon. As I make this point, I want to point out that I voted twice against this law as an individual citizen. On two occasions, I cast my personal ballot against legalizing assisted suicide in my State. In addition, I voted against Federal funding of assisted suicide as a Member of this body. But the people of my State have spoken on an issue they have a right to decide at home in Oregon. As I have said in this body, I intend to defend their right to make that decision in every way I can.

In the case of Ms. Schiavo, I believe that Floridians, through their representatives in the State legislature, deserve the same leeway to decide such medical matters for themselves. When Congress ignored the fact that Florida's legislature was still working on the case and ignored the right of the State courts to rule, it sought to weaken Florida's rights, Oregon's rights, and the rights of every State in our Nation. Any legislation this body passes now should not pose the same constitutional threat. The legislation I have outlined today will not, and I will oppose any legislation that does so again.

It is an imperfect process even for States to rule on medical matters. End-of-life issues are about the heart and the head, about our personal morals as well as the law. Letting States decide is the rule of the Constitution I have sworn to uphold, and I intend to stand up for that principle. It is a critically important principle that the Senate stand for. And it is a principle that ought to dictate our actions before any legislation comes to a vote on the floor. In hearings this week—and in any part of the legislative process—there are responsibilities to fulfill be-

fore the Senate acts or there is a risk of gravely irresponsible legislation.

The Senate should ask: Does any legislation on end of life meet key tests? Does it clarify and expand and ensure the choices that individuals and families can make? Does it aid in the honoring of those wishes once expressed, whether those wishes are to have life sustained or unwanted treatments withheld? Does it protect the rights of those in the disability community and those who are incapacitated, particularly when they have not had the opportunity to make their wishes known? Does it speak to more than the political debates of the moment and truly take in hand the basic issues at the end of life? Does it contribute to less pain, better care, and more peace for those at the end of life? Does it fully meet the responsibility of the Senate without usurping the constitutional role of the States and the judiciary? And finally, does it meet the obligations of the Senate to the American people without extending our reach into their personal lives?

The Senate has an obligation to learn from the events of the last 2 weeks. Before acting, let us think. The Senate has been called the world's greatest deliberative body. Let us now be more deliberative as we dare to approach issues that are more intimate and more personal than any others we could discuss.

The truth is, Americans' end-of-life choices should not be made by strangers in the Congress, pushed by the passion of one case or the political priorities that press on every side. Americans are going to continue to wrestle with end-of-life care for themselves and their loved ones for as long as breath is drawn on this soil. Americans will bring all they have to bear ethically, morally, and spiritually to make the best decisions for themselves and to honor the decisions of their loved ones. The Senate must equal their effort and do its duty with honor for those at the end of life.

I yield the floor.

The ACTING PRESIDENT pro tempore. The Senator from Florida.

Mr. NELSON of Florida. Mr. President, what is the parliamentary procedure we are in at the moment?

The ACTING PRESIDENT pro tempore. The Senator from Florida should know that we are in morning business and there is a 10-minute limit on the Senator's remarks.

USS "JOHN F. KENNEDY"

Mr. NELSON of Florida. Mr. President, I want to inform the Senate I am introducing a bill today that I will offer as an amendment to the supplemental funding bill for defense which is supposed to come out of the Appropriations Committee this week and will be coming then more than likely to the floor next week. This supplemental appropriations bill is a must-pass bill because it contains the funding for additional expenses on the war in Iraq. As

such, it becomes a vehicle through which I can try to attach an amendment that would have a significant policy effect upon our defense posture.

It is no secret that a number of us have joined in opposing the Pentagon's plans to scrap one of our 12 aircraft carriers. The aircraft carrier they have selected is the *John F. Kennedy*, which is home ported at Mayport Naval Station, which is in Jacksonville, FL. Naturally, I speak for the interests of Jacksonville and the State of Florida, but I speak with a much larger vision about the defense interests of our country.

For example, if the Pentagon, which I think has made a wrongheaded decision on budgetary reasons—they think it is going to save them a billion dollars when in fact it is not, but even so, if that were true, in the middle of a war is not the time for us to be reducing our ability to protect our forces around the world with these floating air fields that we call aircraft carriers. And we only have 12. The Pentagon is proposing to scrap one of the 12.

There is another reason. As a result of the announcement that was made by the Navy this past Friday night after business hours, the Navy is going through with the plans on the *Kennedy* by scrapping the plans for rehabbing it in dry dock. It is not a surprise, but it is a confirmation that it is the *John F. Kennedy* they are planning to axe. The significance of this from a defense posture is that it leaves all of our remaining carriers in the Atlantic fleet home ported in one port—Norfolk, VA.

The significance of that is in testimony in our Senate Armed Services Committee, over and over, four star admirals have come in front of us and said: Don't keep all of your carrier assets in one place. Spread them out.

It is no secret that when a terrorist is looking to do some damage of closing up a port, particularly a port that is upriver such as Norfolk, with some one or several carriers that could be in port, just sinking debris in the channel could close up the port. That is not the defense posture we want.

So there is no one who is in the uniformed military who thinks you should not spread your assets. As a matter of fact, on the west coast, on the Pacific fleet, we have three ports for aircraft carriers. The response is: If you are going to scrap the *Kennedy*, which is a conventional carrier, powered by oil, why not then take one of the nuclear carriers and put it down at Mayport Naval Station and you have achieved the same thing? That would be good, but it is going to take, according to testimony in the Armed Services Committee, a minimum of 5 to 7 years before that could happen because of the environmental impact statement that first has to be done and then, secondly, the reconfiguring of the docks and the other facilities to be able to handle a nuclear-powered carrier. The result of this is that for 5 to 7 years you do not have another home port for a nuclear