



Next of Kin Bill

A Guide to the Federal Patient Care Legislation

Presented by the Next of Kin Project
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Next of Kin Bill

OUR GOAL

To enact a piece of Federal legislation, much like the ones we've already enacted in California and Illinois, which will safeguard the people we love even if we're not always physically there to protect them. The legislation, nicknamed the Next of Kin Bill, will require hospitals to make every reasonable effort (via simple steps outlined in the bill) to notify the next of kin of patients who are unconscious or cannot give informed consent, within twenty-four hours of their admission.

THE STORY BEHIND THE NEXT OF KIN BILLS

Recently our family found out just how vital this simple step is in a patient's care, and how devastating it can be, when it's disregarded.

My seventy-one year old mother Elaine Sullivan, a very active woman who was living on her own in Chicago, slipped and fell in her bathroom at home. A neighbor found her and sent for the paramedics, who took her to a local hospital. Even though several doctors and nurses noted on her chart that she was unable to give them a medical history, give consent or to communicate in any way, the hospital didn't make any effort to call me (or her personal physician or HMO), for six days, despite the fact that they had my phone number right on the cover sheet of her chart. Every consent and admission form simply remained unsigned.

Several things happened during her hospitalization, but from what we and experts were able to piece together, the hospital and physicians missed an open cut on her foot which quickly led to a staph infection. They failed to take blood cultures, to give her the aggressive antibiotics she needed and neglected to feed her. By the fifth day, she was in critical condition and in intensive care.

My daughter Laura and I had no idea Mom had been hospitalized. By the time the hospital got in touch with us, it was clear that we wouldn't make it to the hospital in time to be with her. Even though we pleaded with the physicians and the nursing staff to get a phone to her, so she could at least hear our voices for what would probably be the last time, they refused.

Soon after, she passed away, alone.

When we found out how long she had been in the hospital, and received the records documenting negligence we could have prevented, had we been there, our grief turned to action. Although there's nothing we can do to bring my mother back, we want to do everything we can to keep the same thing from happening to anyone else, ever again.

So Laura and I began to research state and federal laws regulating medical care. That's when we uncovered something unbelievable. There isn't one federal law that says a hospital must make a reasonable effort to contact a patient's family, even if the patient cannot communicate or give informed consent. In fact, to date, only six states have this kind of law on their books, and two of them, recently enacted in Illinois and California, became law through our efforts. When we spoke to a local risk manager's association, we were told that the only reason hospitals notify families at all, is because it's the right thing to do. From the people we've spoken to, this seems to be the consensus. The problem is, sometimes hospitals forget to do the right thing.

Now with the backing of the California Medical Association, Illinois State Medical Society, the Association of Family Physicians, National Physician's and Dentist's Union, the California Nurses' Association, AARP, and the Alzheimer's Association, as well as other health organizations, advocacy groups and celebrities, we are working to change that.

WHAT OTHER STATES HAVE SIMILAR STATUTES?

Minnesota, Texas, Utah, Hawaii, Illinois and California. In Minnesota, the statute came about when the son of a State Representative's constituent was admitted to the hospital in a non-responsive state and remained at the hospital for several days, but no family was contacted. The young man didn't survive and the legislator was concerned that the family was not given an opportunity to be involved.

DON'T HOSPITALS USUALLY CALL A PATIENT'S FAMILY?

Remember, the only reason hospitals notify families, is because it's the right thing to do, not because they're required to. The problem is, hospitals, sometimes forget to do the right thing. Recently there was a story on the nightly news about a man who was admitted to a community hospital. He was unable to communicate and died a day or two later. His family not only wasn't notified, but was concerned when he didn't come home from work and called the police and every hospital they could think of trying to find him. Five or six days later, they found out that he'd been in that hospital's morgue the whole time. The hospital hadn't "had a chance" to notify them that he'd been admitted or that he'd died.

In a similar case a young woman was brought into an emergency room in a compromised mental state. The hospital neglected to obtain her medical history from the hospital's own records, or phone her family for information, as she requested. Despite her objections, they refused to admit her because she was uninsured. The woman committed suicide hours later. Her family won one of the largest jury verdicts ever given.

WHAT IS THE HCFA'S POSITION ON CALLING A PATIENT'S NEXT OF KIN?

In a recent update, the Code of Federal Regulations makes an effort to deal with this problem. 42 Code of Federal Regulations 482.13(b)(4), reads as follows: "The patient has the right to have a family member or representative of his or her choice and his or her own physician notified promptly of his or her admission to the hospital."

Unfortunately the regulation doesn't contain any specific requirements about timeframes, nor does it directly address the responsibility for locating that family member or representative. On the state level, the majority of Health Departments feel that health care providers can safely follow the practice validated by years of medical custom and social acceptance of turning to an incapacitated patient's spouse, parents, adult children, or other close relatives as surrogate decision makers. DHS says this practice works as long as it is followed and enforced. But that's the key. Hospitals need to follow and enforce the practice for it to work. Regulations vary considerably from hospital to hospital and even when hospitals do have well-constructed policies for notifications, they aren't always adhered to. In fact, my mother's hospital, Our Lady of the Resurrection Medical Center, had regulations regarding calling the next of kin, as did all the hospitals in the cases cited.

Without a specific, across the board statute for every hospital, there is no way that any state can guarantee that hospitals will abide by it's wishes that an incapacitated patient's family has a say in his or her care. By leaving the details of this important practice up to the individual hospital, without regulating that it be followed or enforced, the HCFA hasn't made provisions that either of these conditions will be met.

WHY IS CALLING A PATIENT'S FAMILY SO IMPORTANT?

As you can see from our examples of what can go wrong, a patient's family can be a vital link in the patient's care. In my mother's case, one simple phone call to notify us that she had been hospitalized, would have saved her life. Not only would our family have been able to be with her, we would have demanded that she be fed, that her insulin and other medications be given, and her wound and infection treated, or we would have immediately transferred her to another hospital.

A recent study was conducted to test the accuracy of surrogate decision makers in predicting their loved one's choices for medical care versus the patient's own personal physician. Dr. Peter Terry MD, Thoracic Surgeon and clinical professor at Johns Hopkins Medical School, asked three hundred patients to imagine three scenarios. "The best match-up between patient preferences and families' intuition of those preferences occurred with the first scenario, which shows a 70-80% accuracy of prediction. Physicians, not unexpectedly are... less accurate than family members at predicting what patients would want."



L to R Elaine Sullivan, Janet Greenwald & Laura Greenwald on a family heirloom bracelet

HOW MANY PEOPLE WILL BE AFFECTED BY THIS BILL?

There is no way to know precisely how many people end up each year in emergency rooms, unconscious or unable to give informed consent. According to the American Hospital Association, there are approximately 53.5 million "necessary" ER visits in America. According to the CDC about one million people end up in the emergency room each year either unconscious or physically unable to give informed consent. Senior citizens, the group most likely to end up in the hospital in an incapacitated state, are 39 million strong in this country. The U.S. Census Bureau officials estimate that by 2030, that number will nearly double to 76 million.

HOW WILL THE BILL AFFECT PHYSICIANS AND HOSPITALS?

When a patient is unconscious, the practice of turning to a surrogate decision maker can seriously reduce a doctor's and hospital's risk of professional liability. Family members can be a valuable source of information of the patient's medical history as well as his preferences for medical care. For example, had I been involved with my mother's care, physicians would have known what prescription medication she was on and wouldn't have given her another medication that interacted with it.

A recent article by Randall F. Moore, MD, JD Assistant Professor of Psychiatry, Texas A&M University, he addresses this subject. "In medical malpractice law, "informed consent" means that the physician provided sufficient information and the patient expressed a choice, either consenting to or refusing the proposed intervention. Even when the patient's understanding is of no legal significance, it is still wise, for ethical reasons and to maintain good relationships with patients, to seek consent based on understanding and adequate judgment. In some such cases, if the provider fails to adequately assess the patient's capacity and permits the patient to make an incompetent choice, the provider might be held liable, for example, for violating the patient's civil rights."

Our country already believes that the families of incapacitated patients have the right to have a say in their medical care and to be present with their loved ones during what could be the final days of their lives. By adding just a few words to that existing code in the CFR statute, we can make this practice, which is already validated by years of medical custom and social acceptance, official and enforceable.

When it comes down to it, all we have in this world is family. Even though this kind of a law is only as strong as the people who abide by it, it will serve as a reminder, that families aren't the enemy, but ready and willing participants in the care that will help bring their loved ones back where they belong -- home.

THE NEXT OF KIN EDUCATION PROJECT

After hearing that many hospitals wanted more information on ways to perform next of kin notification, we created a non-profit effort called the Next of Kin Education Project, to address those needs.

The centerpiece of the Project is the Seven Steps Information Kit. It's a full color guide, filled with articles written by top clinical experts, that give hospitals the background and materials they need to train their nurses and physicians to perform next of kin notifications and take steps to identify John Does, quickly and easily in every situation. The Information Kit is designed to make better patient care a reality for every patient, especially senior citizens and the economically disadvantaged. It was recently distributed, free of charge, to about 100,000 hospital decision-makers nationwide.

To download a copy of the NOKEP Seven Steps To Successful Notification Information Kit, go to: www.nokep.org and click on the Education Project page

TEXT OF THE FEDERAL NEXT OF KIN BILL

109TH CONGRESS

1ST SESSION H. R. 2560

To amend title XVIII of the Social Security Act to require, as a condition of participation in the Medicare Program, that hospitals make reasonable efforts to contact a family member, specified healthcare agent, or surrogate decision maker of a patient who arrives at a hospital emergency department unconscious or otherwise physically incapable of communicating with the attending health care practitioners of the hospital, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MAY 24, 2005

Mr. JACKSON of Illinois introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned.

A BILL

To amend title XVIII of the Social Security Act to require, as a condition of participation in the Medicare Program, that hospitals make reasonable efforts to contact a family member, specified healthcare agent, or surrogate decision maker of a patient who arrives at a hospital emergency department unconscious or otherwise physically incapable of communicating with the attending health care practitioners of the hospital, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Elaine Sullivan Act”.

SEC. 2. REQUIREMENT FOR EMERGENCY DEPARTMENTS TO CONTACT FAMILY MEMBERS, SPECIFIED HEALTHCARE AGENT, OR SURROGATE DECISIONMAKER OF INCAPACITATED PATIENTS WITHIN 24 HOURS OF ARRIVAL AT THE EMERGENCY DEPARTMENT.

(a) IN GENERAL.—Section 1866(a)(1) of the Social Security Act (42 U.S.C. 1395cc(a)(1)) is amended— (1) in subparagraph (U), by striking “and” at the end; (2) in subparagraph (V), by striking the period at the end and inserting “, and”; and (3) by inserting after subparagraph (V) the following new subparagraph: “(W) in the case of a hospital (as defined in section 1861(e)) with an emergency department, to adopt and enforce a policy to ensure compliance with the requirements of subsection (k) (relating to requirements to make reasonable efforts to contact certain individuals in the case of a patient who is unconscious or physically unable to communicate with staff of the hospital).”

(b) REQUIREMENT TO CONTACT FAMILY MEMBERS OR OTHER INDIVIDUALS WITH AUTHORITY TO MAKE HEALTH CARE DECISIONS.—Section 1866 of such Act (42 U.S.C. 1395cc) is amended by adding at the end the following new subsection: “(k)(1)(A) In the case of a hospital (as defined in section 1861(e)) with an emergency department, if any individual arrives at the emergency department requiring medical treatment and is unconscious or otherwise unable to communicate with a health care professional of the department, the hospital shall take reasonable measures (described in paragraph (3)) to identify and contact a person the hospital reasonably believes has the authority to make health care decisions on behalf of the individual. “(B) A person referred to in subparagraph (A) is any of the following:

“(i) An immediate family member.

“(ii) A person authorized to make health care decisions for the individual under a durable power of attorney for health care, recognized under State law (whether by statute or as recognized by the courts of the State). “(2)(A) The hospital shall take the reasonable measures as soon as practicable, but, subject to subparagraph (B), in no case later than the end of the 24-hour period that begins at the point in time that a health care professional of the emergency department of the hospital determines that the individual is unconscious or otherwise unable to communicate. “(B)(i) The 24-hour period under subparagraph (A) shall not apply during any period in which the hospital implements a disaster and mass casualty program or a fire and internal disaster program, or during a declared state of emergency (as defined in clause (ii)) or other local 7

mass casualty situation. “(ii) For purposes of clause (i), the term ‘declared state of emergency’ means an officially designated state of emergency that has been declared by the Federal Government or a State or local government official having authority to declare that the State, county, municipality, or locality is in a state of emergency.

“(3) Reasonable measures referred to in paragraph (1) include the following: “(A) Contacting the emergency contact, family

member, surrogate decision maker, or other healthcare agent identified from personal effects of the individual. “(B) Examining medical records in the hospital’s possession, including a review of any verbal or written report made by emergency medical technicians or the police with respect to the individual.

“(C) Insofar as actions under subparagraphs (A) and (B) are unsuccessful, contacting the hospital’s social service department or the appropriate local law enforcement agency. “(4) The provisions of this subsection do not preempt any State or local law requirement, except to the extent that the requirement directly conflicts with a requirement of this subsection.”. (c)

EFFECTIVE DATE.—The amendments made by this section shall apply to hospitals as of the date that is one year after the date of the enactment of this Act.

SEC. 3. GRANT PROGRAM FOR THE ESTABLISHMENT OF NEXT OF KIN REGISTRIES. (a) **IN GENERAL.**—The Secretary of Health and Human Services is authorized to make grants to qualified not-for-profit organizations for the purpose of assisting such organizations to establish and operate voluntary next of kin registries. (b) **NEXT OF KIN REGISTRY DESCRIBED.**—A next of kin registry is an electronic search service to help individuals, and family members of those individuals, who are missing, injured, or deceased. A next of kin registry is a free service to the public, health care providers and institutions, and governmental agencies using the search service. (c) **AWARDING OF GRANTS.**— (1) **APPLICATION.**—No grant may be made under this section except pursuant to a grant application that is submitted and approved in a time, manner, and form specified by the Secretary. (2) **LIMITATION ON GRANTS.**—Only 1 grant may be awarded under this section with respect to any qualified not-for-profit organizations. (d) **TERMS AND CONDITIONS.**— (1) **IN GENERAL.**—Grants under this section shall be made under such terms and conditions as the Secretary specifies consistent with this section. (2) **USE OF GRANT FUNDS.**—Funds provided under grants under this section may be used for any of the following: (A) For purchasing, leasing, and installing computer software and hardware. (B) Making upgrades and other improvements to existing computer software and hardware. (C) Providing education and training to eligible staff on the use of technology to implement next-of-kin registries. (3) **PROVISION OF INFORMATION.**—As a condition for the awarding of a grant under this section, an applicant shall provide to the Secretary such information as the Secretary may require in order to— (A) evaluate the project for which the grant is made; and (B) ensure that funding provided under the grant is expended only for the purposes for which it is made. (4) **AUDIT.**—The Secretary shall conduct appropriate audits of grants under this section. (e) **AUTHORIZATION OF APPROPRIATIONS.**—There are authorized to be appropriated to carry out this section such sums as may be necessary for each of fiscal years 2006 through 2010.



Hospitals now must contact next of kin

BY GARY WISBY STAFF REPORTER

Thanks to a bill signed into law Thursday, people like Elaine Sullivan won't have to die alone. Sullivan, 71, lay in a Chicago hospital without her family's knowledge for six days before dying because the hospital had no obligation to find her next of kin. "No one called us," said Sullivan's daughter, Janet Greenwald, outside Gov. Ryan's Thompson Center office after the governor signed the bill. Greenwald and her daughter, Laura Greenwald, thought they would find out a law had been broken because they were not notified. "We found out there was no law," she said. Sullivan fell in her apartment on Elston Avenue on April 21. Paramedics carried her to Our Lady of the Resurrection Medical Center, 5645 W. Addison.

She struck her mouth when she fell and couldn't talk. Because Sullivan had been at the hospital previously, her daughter's phone number was on her chart. But no one called it. Six days later, when the hospital finally reached Janet, it was too late. She said the hospital refused to place a phone by her mother's ear. And by the time she made it to Chicago from her Los Angeles home, her mother was dead. Sullivan's granddaughter, Laura, thinks the delay made the difference between life and death. There was no one to answer the questions noted on Sullivan's medical history. "And when a family member is there, things get done," Laura said. She and her mother are suing the hospital for malpractice and wrongful death. Hospital officials declined comment.

The Greenwalds pushed for the law that was sponsored by two Chicago Democrats, state Sen. John Cullerton and state Rep. Sara Feigenholtz. Under the measure, when a patient cannot communicate, a hospital must make every effort to reach next of kin within 24 hours.

Six states have next of kin laws, and Laura and her mother said they are working for passage of a federal law. Details of their proposals are at <http://klik.to/nok>.



Getting News of Patients to Kin

Legislation: Two women press for laws requiring notification of relatives when hospitalized people are unable to communicate.

By JULIE TAMAKI, Times Staff Writer

SACRAMENTO--For nearly a week, Studio City resident Janet Greenwald carried on her work as a screenwriter unaware that one of the most precious people in her life lay injured thousands of miles away.

It was the spring of 1995, and Greenwald's 71-year-old mother, Elaine Sullivan, had slipped and fallen in her Chicago-area apartment. Unable to speak, Sullivan was admitted to a hospital where she remained for more than five days before a social worker alerted Greenwald and her daughter, Laura.

"We asked a doctor if we could talk to her on the phone, just so that she would know that Laura and I were here," Janet Greenwald said. "He told us that phones are not allowed in [intensive care units]."

Sullivan died alone of kidney failure on her seventh day at the hospital because the Greenwalds were unable to catch a plane in time to be by her side.

The two women have since spearheaded efforts in the California and Illinois legislatures to have laws passed that would prevent their experience from being repeated.

The legislation would require that when a patient is unconscious or otherwise unable to communicate, hospitals must make a good-faith effort to notify family or another individual who can act on the patient's behalf.

The Illinois measure has won the approval of that state's Legislature and is awaiting Gov. George Ryan's signature. The California version of the bill, SB 1021 by Sen. Jackie Speier (D-Hillsborough), is scheduled to be heard next month in an Assembly committee.

"We figured out that in only four states, if someone is unconscious and unable to give consent, then next of kin must be called," Laura Greenwald said. "We found a statute in Minnesota and thought it should be a law in California."

Texas, Hawaii and Utah are the only states with laws similar to the one in Minnesota, a state Senate staff analysis shows.

The California Healthcare Assn., which represents hospitals, has declined to take a position on Speier's measure. But the legislation has won the support of AARP, formerly the American Assn. of Retired Persons.

"We are concerned that if someone is unconscious in a hospital that there is a requirement that family members be notified so they can visit and be active in their treatment," said Suzanne Miller, an AARP spokeswoman. "With 3.3 million residents over age 65, California is home to the largest elderly population in the country."

Peter Warren, a spokesman for the California Medical Assn., said his group has not taken a position on the measure, but "as individual physicians, we think it would be a good idea to solve the riddle that families are presented when their loved ones are unconscious and nobody knows where they are."

Janet Greenwald has brought a wrongful-death lawsuit against Our Lady of the Resurrection Medical Center, which is where Sullivan was taken after falling and breaking her top dental plate. A spokeswoman for the medical center said she was unaware of a lawsuit by Greenwald and could not address the allegations.

The suit accuses the hospital of failing to order and review Sullivan's chart from a prior admission.

Greenwald says her mother had previously stayed at the facility after having a stroke, so the medical center had Sullivan's records containing her daughter's phone number. She also said her mother's physician worked out of the same hospital, but was never notified that Sullivan had been admitted. The suit alleges that the facility failed to notify Sullivan's family of her admission and condition. The Greenwalds say they were told by a social worker that Sullivan had fallen and that they needed to make a decision about nursing care if it were needed once she left the hospital. The women say they tried repeatedly to get a doctor on the phone, and that when they finally succeeded, they were told that Sullivan was in a vegetative state and might not survive.

"It just makes you feel like someone else has closed a door on you that can never be opened," Janet Greenwald said. "There is no amount of money or legislation that can give us that moment back."

BILL PUSHES HOSPITALS ON NOTIFYING KIN

By Julie Deardorff
Tribune staff reporter

Six days passed before a Chicago hospital called to tell Janet Greenwald her 71-year-old mother had been hospitalized after slipping on her bathroom floor. Her mother died alone, before her family could get there from Los Angeles to say goodbye.

In most states, including Illinois, hospitals are not legally required to contact a patient's family, even if the person cannot communicate or give informed consent. They do so because it's humane, considerate and important to families.

That voluntary phone call may become mandatory in Illinois, however, as a bill spearheaded by the Greenwalds moves through the state legislature. It would force hospitals to make reasonable efforts to locate the next of kin for patients who can't represent themselves.

The "next of kin" bill, sponsored by state Sen. John Cullerton (D-Chicago) and state Rep. Sara Feigenholtz (D-Chicago), unanimously passed the Senate on Thursday and has been sent to the House. In California, a similar bill, also spearheaded by the Greenwalds, is up for its first hearing next month. "Everyone has a mother and a grandmother and everyone knows what it feels like not to be with someone when they're hurting or need help," said Janet Greenwald's daughter, Laura. She and her mother, an entertainment writing team, live in the Los Angeles area, but are from Chicago.

They believe the 1995 death of Janet Greenwald's mother could have been prevented if they had been notified earlier. "If this can prevent this from happening to just one other family, it's worth it."

The proposal will require hospitals to attempt to contact family within 24 hours of a finding that a patient lacks the ability to make a decision.

The health care provider is to make a "reasonable inquiry," which might include identifying a family member by examining the patient's personal belongings or medical records.

Though hospitals generally do notify next of kin, when they don't, it can turn tragic. The family of a Virginia man who died at Beth Israel Medical Center in 1998 filed a lawsuit claiming the hospital failed to notify them, performed an unauthorized autopsy and had him buried in a pauper's grave.

In Boston, when a man disappeared in 1994, his family spent the next 10 days frantically searching for him. He was found, complete with identification, in a hospital morgue.

In the Greenwalds' case, Janet's mother, an active and independent senior citizen, fell at home in Chicago in 1995 and was taken to a local hospital. She was conscious, but had hit her mouth and was unable to communicate, give a medical history or provide consent in any way, according to the Greenwalds, who filed a lawsuit against the hospital.

The Greenwalds allege the hospital neglected to treat her properly, and they believe they would have removed her from the hospital immediately had they known she was there.

Hospital officials and attorneys were unavailable for comment.

"We never got to tell her we loved her, to say goodbye. What you're left with are the unsaid things," said Janet Greenwald. "When you know that was the last opportunity you'll ever have, it makes you want to work so no one else has to go through this."

Greenwald and her daughter have spent the last few years researching and gathering support for their

legislation. Groups like the Illinois Hospital and Health Systems Association, the California Medical Association, the California Healthcare Association, AARP and the Alzheimer's Association have all climbed on board.

"We believe this is what hospitals are doing now, but the law would codify that," said Karen Porter, a spokeswoman for the Illinois Hospital and Health Systems Association.

If the law passes, it would amend the state's Health Care Surrogate Act, which addresses decisions concerning end-of-life care.

"We realized the Health Care Surrogate Act spoke in a tense that assumed a family member was with a loved one," said Feigenholtz. "You'd think it was a hospital rule but it's not. It falls completely silent and doesn't talk to the first step of what a provider must do or should do in a situation to reach out."

"Any step that can improve the responsiveness of hospitals towards patients is welcome," said Michael Millenson, author of "Demanding Medical Excellence, Doctors and Accountability in the Information Age." "If this is a rare case so be it, but if not, then hopefully other people won't have to go through what the Greenwalds did."



Keeping It In The Family by Natalie Dunbar

A grieving daughter tells how a new bill would have helped her to cope with her father's illness and death.

A bill co-authored by Assemblywoman Carol Liu would guarantee that medical facilities would make a reasonable effort to contact a patient's next of kin upon hospitalization.

On Memorial Day 1998, one of the last days of my father's life, I was shopping at a local discount store with a friend who was visiting from my central New Jersey hometown. "Remind me to call my dad when we get back to the house," I told her. We were expecting company that afternoon. I was concerned we'd get caught up in the festivities and it would be too late in the day to check on my dad, who'd just returned home from rehabilitation after a lengthy bout with congestive heart failure and undergoing an angioplasty.

Three years later, and I can only say that it was providence that led me to the phone after that brief shopping trip. I called and called and I called. And the phone rang, and rang. And continued to ring. I racked my brain, nervously joking that dad must have been out partying, making up for lost time after being cooped up in rehab. I knew in my heart of hearts this simply was not true. My dad, while a jazz musician of some notoriety, was rarely seen in a club or at a party. And I'd spoken with him once twice a day for at least three months -including the day before Memorial Day. He never mentioned going out.

I was scared. And I was in California some 3,000 miles away from the New Jersey home I'd grown up in, and where, after making about six more phone calls, I learned that my father lay alone on his bedroom floor suffering from what would later be diagnosed as a massive stroke. My dad eventually got to the phone that day -- I distinctly remember counting 14 rings -- and he told me in a barely audible voice that he'd fallen down in his room some 10 to 12 hours before. He was very much alone. I couldn't call 911 from Pasadena. And although dad said he did not want to go back to the hospital, my friend called her mother at her New Jersey home -- just five minutes from where my dad lay, effectively dying -- and set in motion a patchwork "continuum of care" that would at least guarantee he'd get the immediate care he needed.

Paramedics stabilized dad, and kept him comfortable. Friends came to the house to see to his needs until my son and I could get there. But by the next morning, the stroke began to ravage his body. As dad was taken to the hospital that had virtually become a second home over the last six or so months, and I made my way to LAX, I shuddered to think what would have happened if I hadn't been able to get my dad on the phone that Memorial Day. And as my son and I glided across the country in the night skies to what I knew would be our last visit, I cried conflicted tears of relief that the hospital kept in close contact with me, and allowed me the opportunity to reach my father's bedside before he succumbed to his illness.

A mother and daughter living in nearby Studio City went through this very scenario, with tragically different results. The elder woman's mother was hospitalized in an Illinois hospital where she eventually died alone -- before her daughter and granddaughter ever got a chance to see her, six days after she was admitted, mere hours after they were contacted.

Senate Bill 1041, co-authored by Assemblywoman Liu and State Senator Jackie Speier was introduced in February as a result of their grief. If passed, it will require acute care facilities to make a reasonable effort to contact a patient's agent, surrogate or family member within 24 hours to make health care decisions on the patient's behalf.

Assemblywoman Liu, whose own father died during the primaries, said the bill seemed like a reasonable thing to do. "It's common sense," Liu said, adding that like many others, she thought such requirements already existed. Currently only four states have enacted similar laws -- Hawaii, Minnesota, Texas and Utah. Liu said testimonials she heard in support of SB 1041 were remarkable. One woman said though she was clearly listed on her mother's hospital chart as the next of kin, her mother died before she was ever contacted.

People often speak of the importance of making closure when a loved one dies. I'm not so sure that you can ever close the gaping hole that's left after the death of someone you love. But if this bill is passed, at the very least, surviving family members may be able to avoid the emotional conflict and feelings of guilt for living so far away in the first place.

FOR MORE INFORMATION

For the Latest Information on the Legislation and any Breaking News go to:
www.nokep.org and click on the Legislation Page

On the web site you can also find the latest draft of the federal Next of Kin Bill, press and video clips, support letters and information about the Next of Kin Education Project, a program designed to give hospitals the tools they need to perform next of kin notifications quickly and easily.

For the latest Information on the Federal Bill go to: <http://thomas.loc.gov/cgi-bin/bdquery/z?d109:h.r.2560>:"

For questions or press inquiries, contact Janet or Laura Greenwald at:

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