

**Remarks of Attorney General Janet T. Mills
“Stroke Recovery from the Family Perspective”
7th Annual Stroke Conference
Portland, Maine, Wednesday, May 21, 2014**

I want to talk about your patients, the people in the shadows, out of the light, on the verge of darkness, those in the penumbra of life, a shadow of their former selves, even for a short time. And I want to talk about their families.

When I was a child, the father of one of my friends, a storekeeper and neighbor of my grandparents had a dropsy face. He could not walk fast. He could not smile. Or, if he did, it looked to us like a sneer, an unintentionally evil look. My grandparents spoke of it as if it were a mystery, something he couldn't help, but something that took Mr. Seeley out of the mainstream of the social life of Ashland, Maine, such as it was. Through the prejudices of an 8-year old girl, I never could warm up to Mr. Seeley, even though he was my best friend's father. He reminded me of Vincent Price. Of course, I hadn't known him before his stroke.

Fast forward 57 years.

October 1st, 2013

October 1st last year was an ordinary day. For me, a long one, but par for the course. Good weather prompted me to take a detour before leaving Augusta to go home, and to visit a friend in hospice care at Togus. I later worried that that delay could have cost my husband's life. I was an hour later than usual arriving home. So, it was not me but my brother Paul who happened to come by the house that evening and find my husband on the floor, unable to regain his balance, to speak intelligibly or to call 9-1-1.

No one could say how long he had lain there. Pangs of guilt. It should have been me. He hadn't called me in the afternoon as he so often did. He hadn't answered the phone when I called. I should have known.

At the ER, I learned, of course, that my husband had had a “Cerebrovascular accident” “Accident,” I thought, “what an interesting term. What kind of *accident* is this?” “Did he fall downstairs?” “Did a car hit his brain?”

Honestly, what other medical condition do we refer to as an “accident,” other than an unplanned pregnancy?

He had had, of course, a stroke. The fourth leading cause of death in Maine. In 2009, there were 640 deaths in Maine and 3,656 hospitalizations due to stroke. Maine has had the highest stroke death rate among all New England states. And stroke is one of the major drivers of health care costs in Maine. I can certainly see that now. Recovery is such a long, slow and unpredictable odyssey. And so many people in Maine are uninsured to boot.

My husband didn't smoke. He was not overweight. He never drank a lot of alcohol. His diet hasn't been the best, but he didn't eat a lot of fatty foods or junk food. His cholesterol was always good. But he has always been hypertensive. And he is male, he is over 70 years old and is less active than in his earlier years when he was an avid tennis player.

On the way to the ER the doctor on duty called my cell: “How many hours ago did he have his stroke?” thinking that if it were an ischemic stroke, she could administer a miracle clot-busting drug and prevent his death. Frantically I called around to people I thought may have seen him during the day, with no luck. There was no way to say he had collapsed either five hours or five minutes before he was found. That could have made all the difference in the world. But, then, a CT scan showed a hemorrhagic bleed. So the miracle drug would not have helped; in fact, just the opposite.

Stan stayed in the hospital for 5 days and they got his blood pressure under control, his hydration, his mobility. The relief was palpable. Then, suddenly, we had to make choices. Rehab -- What's best? Who do you call? Who do you ask? Is there a Consumers' Report that tells you which facilities are best? How and where could we, the family, best help him? Quiet due diligence. The decision. And the justification.

There is no book that tells you how to cope, or what to expect, with a stroke, although there are books written about the experience of a stroke—Kirk Douglas' “My Stroke of Luck” and Jill Taylor's “My Stroke of Insight,” for instance.

When dealing with stroke, there is no pill that will make it better. No cup of liquor that will comfort you. No roadmap or clock that tells you where or when things will begin to be okay again. Some days it is like a constant

purgatory. The patient is in limbo, and the family is backstage, waiting attentively with flowers and cheers or prayers and long black coats, ready to make changes, unable to know which way to turn, all life's plans on hold.

When you break a bone, you know the bone will heal. You will have some pain. But you will walk again, write again, dress again, drive again. There is an end date to your recovery.

When you have your appendix out, in a certain period of time you will recover. You will be sore. But you will heal.

When you have a stroke, you must then predict the unpredictable. Your recovery is not measured in days passed or in stitches removed or in hallways walked.

Speech may come and go. Memory may flourish or flounder. Your muscles may work, or not. You may fall without warning. You may feel funny and weak and worried. You may be depressed because you have lost control over your life. And your loved ones may become depressed because they cannot help you except, seemingly, in the most miniscule ways, partly because you are depressed. And depression, it seems, can be contagious.

Everybody asks you how he is. You cannot answer. You become the 'reassurer in chief' for the rest of the family and the treasurer in chief for the family finances. You interpret the medical information. You keep everybody informed. You give them guarded hope. Hope you do not always feel yourself. But you are the strong one. The informed one.

Privately, you try to figure out what the insurance is going to pay for and what it won't. But the papers keep piling up and they are hard to read, to sort out, even for a lawyer. You go through your husband's papers, try to figure out what he left undone, what is paid or unpaid, what matters can be put off. The disorganization of someone who you later figure has probably had TIAs in recent months is quickly demonstrated. You draft letters and answer phone calls.

This was not my first encounter with strokes.

My mother at age 90 suffered a stroke. She made a modest recovery but was never able to live independently again. She was treated at one of those nice

rehab places in central Maine where they have a kitchen set up with appliances marked “Refrigerator: Cold!” and “Stove: Hot!,” like teaching people to ride a bicycle again. One evening I called over to talk to her but she didn’t answer. I called the nurses’ station and asked where she was. “Why, she’s in the kitchen learning to make biscuits again.” “That’s funny,” I said, “she never made biscuits before! If she has another stroke, can you teach her to bake a cake?” She was a not a good cook, a woman from the County who made everything with potatoes.

My husband had had a previous stroke too. A left occipital lobe bleed twelve years ago. But, as studies have shown, the app. 29,000 adult Mainers with a history of stroke are no more likely to recognize the symptoms of stroke and the need to call 9-1-1 than those without a history of stroke. Looking back, I’m sure my husband didn’t recognize the symptoms or, if he did, that he remained in denial. Like many men of his generation, and despite having received some of the best life-saving medical treatment you could ask for, he still didn’t trust doctors. After all, “when you go to one, they just find something wrong with you!” More pangs of guilt on my part for not making him keep appointments.

My husband’s medical history is complicated. He’s been treated for various things at just about every major hospital in this state, in addition to several major surgeries at the Lahey Clinic in Massachusetts.

But when the ambulance delivered him to the city ER that evening, and the ER staff asked, “Does he have a medical history?” I wanted to say, “Really? Can’t you just punch his name up on the computer...They must have a whole book on him here!”

I was not angry with the doc for asking a logical question. But I was angry that here in the USA, in the most advanced country of the world, I couldn’t just hand her a thumb drive from my husband’s wallet, put it into the hospital computer and bring up his entire recent medical history — what meds he was taking; the fact that he had a heart attack; bladder cancer; a colectomy; a prostatectomy; chronic hypertension; and a previous occipital lobe hemorrhagic cva. Depending on the memory of a frantic family member in such a situation is *not* the best way to gather important information. And what happens when there’s nobody there but the patient who’s not competent?

Medical records in Maine, and perhaps elsewhere in this country, it seems, are in the dark ages.

The experience in one ER on October 1st was not the first, nor the last, time that I have been asked to repeat (hopefully with some degree of accuracy) my husband's medical history.

Nor is it the first time that I have felt the need to later correct that history, as reflected in the records which I insist on accessing from time to time. Because I am not a doctor, it seems, the computer won't accept my corrections; his medical records do not even reflect that I asked for corrections. Which means, that some mistakes simply repeat themselves.

As soon as my husband had his stroke, I knew he needed an advocate. Not because I mistrusted the medical staff. Rather, the family member needs to be there in order:

- 1) to provide medical history and current information, as accurately as possible;
- 2) to ask questions;
- 3) to understand the patient's medical status and his medical and personal needs;
- 4) to ask questions;
- 5) to provide emotional and personal support;
- 6) to ask questions.
- 7) To be there to check on his meds. e.g., -- "Just swallow it, *Bruce*," one CMRA said while giving the wrong pill to my husband, whose name is not Bruce but Stan. "What happens when I'm not there?" I thought.
- 8) And, again, to ask questions.

The family member, now an advocate, begins to learn the alphabet soup of stroke rehab— "CVA" "ADL's" "BID" "MRI" "OT" "ECG" "PT" "MRA" "TIA" "ABCD2 score," etc.

You learn about anomia, ataxia, neural plasticity, and aphasia — I say, if you can't pronounce it, you've probably got it. And "dysarthria"— if you can pronounce it, you probably don't have it! And why when the patient says "No" he sometimes means "Yes," and "Yes" when he means "No."

At least 25% of stroke survivors have language impairments affecting their ability to speak, write and understand spoken or written language. You learn that sometimes patients will know the right words but have problems saying them.

You quickly learn the difference between an ischemic stroke and a hemorrhagic stroke, what part of the brain is affected and what the consequences are. You are wondering, will your loved one be one of the 50% of stroke victims who are able to go home and function without help? Or will he be dependent on you and on others for months and maybe years to come, maybe for the rest of his life? Will he have another stroke, again without warning, a more serious one? Or a smaller, invisible one that disorients him and stealthily depletes his memory bank?

You are dealing with everything from paralysis and numbness to memory loss to hiccups. And eventually, you are dealing with the 'new him,' and the 'new you' and getting used to having a very different person in your life.

You want to help, you have the impulse to do things for your loved one, but you know he has to learn to do for himself once again. You look for ways for him to better communicate, to convey his needs and wants.

"Home" care issues

The decision whether to take a loved one home is an extremely difficult one. Trying to take on too much at home does not help the patient or the family. It's often a 24/7 commitment. The advantage of having the patient in a skilled rehab facility, on the other hand, is that your visits with him are quality time, not simply part of doing chores and taking care of his physical needs 24 hours a day.

Some advice to family members: It's all too easy to burn out. Focus on the important things. Engage in self-care. Celebrate small accomplishments. Keeping a bright smile is sometimes work. It doesn't come naturally in difficult circumstances. I've read that 30-50% of all stroke survivors

experience depression. And depression in turn can affect the patient's motivation in therapy. They feel frustrated. They miss the person they used to be.

Managing the emotional consequences of a stroke is the most difficult part of the job. I learned that patients do worse when caregivers are depressed, overprotective, or not knowledgeable about the stroke. Patients do best when caregivers and family are encouraging and supportive.

But depression can sneak up on family members too and zap your energy, your drive, your necessary enthusiasm for life and for your partner's life. Your heart is heavy, but you can't admit it, and it seems there's nothing you can do about it. I think this is quite normal too. And I can't stress enough the need for family members to take a break, not bring their own lives to a halt, but to exercise and to eat well (and don't feel guilty if you *don't* do these things; I mean, who needs guilt?), talk to friends, especially those friends who won't keep asking you, "How is he? Is he going to be okay?" and other simplistic questions you simply cannot answer. Let other people make meals for you. See a counselor. Get a physical, and don't ignore the normal stress the situation puts on you. Recite the Serenity Prayer if you must. But don't let the situation define who *you* are.

Insurance

What makes it harder to go through these stages with logic and resignation is the added difficulty of having to figure out who's going to pay for the medical treatment from one week, one month, to the next. There are deductibles. And copays. And terms of coverage. And there are denials.

Since my husband has been back in a skilled nursing facility in our community, after a stay in the local ICU for an illness which set him back, he has been denied coverage from his Medicare managed care company *six* times. Six times I have gotten word that his coverage will be terminated with just one or two days notice. I have had to drop everything. I consider the options. I can't take him home. Six times I have appealed on his behalf to a third party reviewer. Six times I have won the appeal and have kept him insured, kept him covered.

More recently, the same insurer denied coverage for a specific medication my husband has been getting for the past six weeks. I appealed. I was directed to a different office — their pharmacy appeals office, in a different

state. They asked me what exactly the medication did for him. Why was I appealing? Was the denial “rational?” What were the pharmacological alternatives, and why were those alternatives not used? Repeatedly I told them I was not a pharmacist, not the doctor, just the wife who got the form. I got the impression this particular drug must cost more than most. There seemed to be no real medical reason for denying coverage. Today I got word that I won that appeal too. Meanwhile, the insurance company seems to do everything in their power to discourage people from questioning them.

Just yesterday when I was jotting down notes for this part of my remarks, I got a call. The insurance company, for the *seventh* time, denied further coverage for my husband’s therapies.

Now, I am a lawyer. I am no shrinking violet. But what about other people who are faced with this paper work, these phone calls, these nuisance denials intended to wear you down at a time when you are least able to cope with a crisis. What about those families?

(There’s nothing more discouraging than when your—or your husband’s—insurance carrier gives up on you or on your loved one. You have not given up. You are there, every day. They are not. And you have to fight them to convince them that he’s either making progress or he’s not making enough progress and that he still needs the help he’s getting, and that they should pay for it.)

I was told if I take my husband out for a ride while he’s in skilled rehab, even though it’s good for him and alleviates the anxiety that prevents a speedier recovery, the insurance company will fight you and say, “if he can leave the facility to go for a ride, then he’s well enough to go home.” How ridiculous.

Stan was a widower with five daughters when I married him 29 years ago. We are family. We are friends. But gauging the needs and responses of each one of the adult children is a challenge to a parent, to a friend. Each of them has a different relationship with their father. Each of them has different needs for different information, and a different role to play in his recovery. I try to keep them all equally informed.

I asked them for advice about this talk. The youngest wrote:

“I think that although the physical side-effects from Dad's stroke are hard to handle it's the emotional and psychological changes that are the toughest to deal with, like him struggling with our names. I feel like I've had to learn who this new Dad is and while I'm incredibly thankful to still have him alive with me, I mourn for the man that he was. The guilt of whether you can provide the care the person needs is a huge weight I think a lot of people probably deal with. And, the guilt of thinking I'm not doing enough or visiting enough is debilitating to me. I could go on and on...” she wrote.

One day last fall I took my husband out of NE Rehab to go for a ride. I got coffee and muffins. We watched the boats in the bay from the Eastern Prom. We visited a friend. We had a good time. I thought he was making progress and that he enjoyed the outing. When we got back to the hospital, someone asked him where he'd gone. He said, “I'm not sure. I think I visited the Statue of Liberty.” I was devastated. I felt like I'd planned a nice afternoon for nothing.

When I explained to a physician why I was upset, he said simply, “It's not that he will remember what you do with him, where he goes, or what he sees. What he *will* remember is the kindness you showed him. And that makes all the difference.” It's all in the present. His comment reminded me of Maya Angelou's phrase, which we in politics sometimes employ: “People will not long remember what you say or what you do; but they *will* remember how you made them *feel*.”

Dealing with memory is a tricky thing. It just doesn't always come back like getting right back on that bicycle.

I know my husband doesn't remember as much as he used to. His short term memory is poor. I know he can't express himself, can't communicate about things as he used to. He doesn't recognize everybody by name. He can't name his relatives or his neighbors or his friends, though he can still recite the entire Red Sox lineup for all the years they won the World Series, including 1918!

But he knows who *I* am. He recognizes me. He knows I am someone he loves. A hug is genuinely therapeutic. And that makes all the difference to *me*.

He — my husband — and I, his wife, his advocate, his friend, greatly appreciate the care and the work of so many highly trained professionals in this state, including Dr. Kazmi and the wonderful people at New England Rehab.

Recommendations

What are some specific recommendations to the medical community?—

1. -- Medical professionals & staff should communicate by email with family members and permitted parties. Few medical personnel are available by email to facilitate communication and allow family members to phrase and jot down questions as they occur. Family members don't want to disturb a doctor's routine or bother a nurse with a question that may seem trivial in the scheme of things. At the same time, it seems that medical staff are reluctant to put something in writing to a patient's family. I'm not sure why. Carefully worded information can be invaluable. HIPAA, I think, has made us all information hypochondriacs. We are so supersensitive about talking about medical issues that we miss chances to communicate better.

2. -- Encourage referrals to lawyers. There are agencies like Legal Services for the Elderly, for instance, and the Bar Association has a list of lawyers who specialize in estate planning and elder law. Families may need a legal expert to talk about DNRs, Powers of Attorney, Family Medical Leave, long term care issues, health insurance and life insurance, wills, Medicaid and estate recovery issues, and just managing the patient's income, expenses, debts.

3. -- Improve medical records—make them easily transferable, correctable, etc. Provide records automatically to the patient or designated person, instead of waiting for a request and then asking, as some facilities do, “Why do you want them?” (“because I have a *right* to them,” I say).

The “Open Notes” concept is catching on because enabling patients to see their doctors' notes will allow patients to become true partners in discussions and decisions about their care. The yearlong Open Notes study in other states found that when patients have access to their doctors' notes, they feel more in control of their health care, they understand their medical issues better, and they are more likely to take their medications as prescribed. Virtually all participants in the study supported the idea of seeing their medical notes, and *no doctors* decided to stop sharing notes with their

patients once the study ended. Even the Department of Veterans Affairs has now adopted the Open Notes concept!

4. -- Support Prevention efforts. Eighty percent of strokes are preventable. Make sure the Fund for Healthy Maine is used for its intended purposes—Talk to legislators to make sure these funds are put towards smoking prevention, smoking cessation and promoting public health. We all know that high smoking rates in Maine have led to high cancer rates, high heart disease rates and high numbers of strokes, preventable diseases.

5. -- Advocate to reform our health insurance system – It is simply chaotic, indecipherable, irrational. And thousands of people are falling through the cracks every day just trying to navigate this system.

6. -- Improve public relations and the way we talk about stroke. This means no longer being scared of Mr. Seeley, the old man with the slur, no longer shunning the woman with the weak arm or the individual who cannot seem to form a sentence. Welcome them back into society. Bring them out of the shadows. Reward their fortitude. Give stroke victims a way to make others aware.

I recently met two people on different occasions who impressed me. One said, “Hi, Janet, I’m John. I have aphasia, so I can’t say exactly what I want to say. But may I tell you something?” Another said to me, “Hi, I’m Joan. I’ve had a stroke, so I can’t talk as quickly as I used to. But I have something I want to say.”

Make sure the public recognizes these symptoms and respects them and accommodates them. Give stroke patients the permission to introduce themselves this way, and encourage them to be up front about their symptoms in society.

I asked another friend for suggestions for family members. This woman, older than me, takes care of her husband, a stroke victim with serious physical limitations, all by herself. She brings him to the legislature where he can watch her at work.

“My experience,” she said, “has been that the only way you survive is to do what is in front of you and move on. Always know you can, because *can't* is not an option. The road is hard but progress is

possible. One of the hardest things about stroke is that recovery is glacially slow. But, always remember, it could be worse! Remember Phineas Gage!”

My friend Ann is someone for whom the glass is never half full. It is *always* full; it’s just that sometimes half the glass is full of air. May we all share her spirit of optimism.

The wonders of life are extraordinary and uncountable, as are the wonders of modern medicine. The small miracles that occur every day give us hope and gratitude.

I thank all of you who are in the business of saving lives, restoring health, peeking into the souls of patients, creating miracles and inspiring others to carry on this work, personally and professionally.

And I thank you for allowing me to share my experiences, observations and suggestions as the family member of one beloved stroke patient.

Post--

In the summer of 2014, never having fully recovered despite heroic medical efforts, Stan decided that if he could not be the person he used to be, he no longer wanted to live. He stopped eating and drinking and began to fade away. On September 24, 2014 he left us.