

How to Get Best Care – As a Hospital Patient



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Helpful advice from both her first book,
“Cautious Care: A Guide for Patients,”
and also from her new book which will be published in 2012,
“Balancing the Doctor-Patient Relationship: Getting What You Need”

Hospital Best-Care Checklist

This is a list of the topics to be covered in this chapter. You don't need to read through this list now. It is here for you to come back to review, to make sure that you're remembering everything you need to, or to see if you need to review a topic.

Hospital Best-Care Checklist

- An inpatient is in a very precarious position
- The most important safeguard for the hospitalized patient is *you*
- The bedside advocate (the "patient-sitter")
- Staying with your hospitalized loved one is *more important* than almost anything you might need to do outside the hospital
- The patient must assert his need for the bedside advocate
- General info for the bedside advocate
- Hospital journals and medical journals
- Getting the information you need for the hospital journal
- Go with the patient when he leaves the room
- Be kind to the nurses
- Hospital nurses are also patient advocates; they help prevent infections, medication errors, medical complications, and deaths
- What if the doctor asks you to leave the room?
- Some hospitalized patients are at risk for mismanaged and outdated care: example, heart attacks
- Critically important advice: Don't allow doctors or nurse to ignore your concerns
- If the patient's condition is deteriorating ...
- Other rapid respond team info
- Beware of the "one-disease-per-patient-limit"
- Don't rely on nurses for diagnoses
- Prevent hospital infections
- Specific anti-hospital-acquired-infection measures
- My own criteria for preventing an infection in my hospitalized loved one
- Every patient has the right to adequate pain control
- Protect your elderly patient with a poster board
- If you have a choice, use a hospital where visiting hours aren't limited, even in the ICU

- ___ When your back is against the wall
- ___ If you're in the hospital emergency room
- ___ Always trust your intuition

An inpatient is in a very precarious position

Remember that almost 100,000 patients die in U.S. hospitals every year due to medical errors, and that there are certain things you can *and should* do to help ensure that your loved one is not in that statistic.

The U.S. healthcare system is not a smooth-running machine—it is riddled with errors and lack of safety checks. You must step in as *the person most interested in keeping your loved one alive and in good health*, and gently and respectfully, but insistently, make certain that he gets the healthcare he needs.

“One in 10 patients admitted to the hospital will suffer an adverse event as a result of their medical treatment. A reduction in adverse events could happen if patients could be engaged successfully in monitoring their care.”*

“A true paradox exists in American hospital medicine: although we have more medical knowledge and better technology, there is evidence that inpatient medical care is becoming more disjointed and health care providers are experiencing increasing degrees of disconnection from their patients.”†

*Davis, R.E., M. Koutantji, and C.A. Vincent. “How Willing Are Patients to Question Healthcare Staff on Issues Related to the Quality and Safety of their Healthcare? An Exploratory Study.” *Quality and Safety in Healthcare* 17 (2008): 90-96.

†Phillips, Robert A., and Julia D. Andrieni. Editorial: “Translational Patient Care: A New Model for Inpatient Care in the 21st Century.” *Archives of Internal Medicine* 167(19) (2007): 2025-2026.

The most important safeguard for the hospitalized patient is *you*

Absolutely the most important thing for an inpatient: keep a close relative or a friend sitting with the patient 24/7.

When people aren't feeling well, they are not good advocates for themselves. They need someone there with them who can help.

It wasn't this way years ago, but in our modern hospital culture, doctors spend only a couple minutes a day in the room with the patient. Nurses are busy with medication-giving, IV changing, and other organizational and administrative duties. Nursing assistants are busy getting vital signs and running for supplies. The ward clerk is busy answering the phone, arranging for tests to get done and getting the patient transferred to the right place at the right time.

There is absolutely no one presently at the hospital who actually *cares* for your loved one, like nurses used to be able to do (or like we see on TV or in the movies). The loved ones of the patient *must fill in that gap*, or the patient runs the risk of being a victim of our current busy, busy, busy healthcare system. See "Medical errors" section.

You need to be there to help make sure that everything goes right. From sending the wrong patient down for a procedure, to giving the wrong medications, hospitals are fraught with errors. If the patient has someone by his side to just make sure that the only things that are happening to him are the ones that have been ordered, and to keep an eye on him in general, then that patient has a tremendous advantage of not becoming a medical error statistic.

The Joint Commission is an organization that evaluates and accredits hospitals, and holds them to certain standards. It recognizes the problems in getting safe medical care, and has launched a national campaign to urge patients to take a more pro-active role in monitoring their hospital care. Here is one of the key features of this campaign.

"Ask a trusted family member or friend to be your advocate. Ask this person to stay with you, *even overnight*, when you are hospitalized. You will be able to rest better. Your advocate can help make sure you get the right medicines and treatments."*

If you're still hesitant on this issue—as in "but I'll be in the way," or "the nurses are there to take care of him"—then don't get in the way, and realize that hospital nurses have too many demands on their time to spend any significant time at your loved one's bedside, watching over him.

Re-read the "Medical errors" section about medical errors in hospitals being the *6th leading cause of death*.

Turn back to Chapter Three and read "But I don't want to participate this much in my medical care—I just want my doctor to do it" so that you'll better understand the importance of patient and family participation.

Bottom line: Don't leave your loved one alone in the hospital *unless* he has a minor, stable condition. And even then, check on him frequently.

"There is an emerging body of opinion in the international literature that *patients and their families/nominated carers have an important role to play in monitoring and improving patient safety in health care settings*. Underpinning this view is a growing appreciation of the unique relationship that exists between patients and their families, and their collective capacity to provide continuous vigilance over both the patient's health condition and the care that is given. It is also being increasingly recognized that, unlike others who come and go, patients and their families are often situated as 'privileged witnesses of events ... who observe almost the whole process of care'. *As well as this, during the trajectory of their health care experience, patients often become 'experts' in their own illnesses and care and, as has been shown, can become very adept at recognizing and rescuing errors (e.g., wrong drug administration), near misses (e.g., tests performed on the wrong patient) and adverse events (e.g., unanticipated adverse reactions to medications; post-surgical complications) that may not otherwise be captured by a hospital's incident reporting system or patient case notes. This has led some commentators to suggest that many patients and families are well positioned (during and shortly after a hospital stay) to be a 'potentially useful source of information that could inform clinical care and guide improvement initiatives.'*"[†]

*The Joint Commission. "Speak Up™ Program." www.jointcommission.org/NR/rdonlyres/484AD48F-C464-4B5B-8D70-AA79179B3970/0/Speakup.pdf, accessed November 15, 2008, *italics added*. "These efforts to increase patient awareness and involvement are also supported by the Centers for Medicare & Medicaid Services."

†Johnstone, Megan-Jane, and Olga Kanitsaki. "Engaging Patients as Safety Partners: Some Considerations for Ensuring a Culturally and Linguistically Appropriate Approach." *Health Policy* 2008, doi:10.1016/j.healthpol..2008.08.007.

Other studies of interest on this topic

Some of you are already convinced—if you are, go ahead and go on to the next section. If you're not convinced yet, here are a few more studies and statistics that may convince you that your loved one is in a precarious position in the hospital, and you should be there to help make sure he is not the recipient of a deadly medical error. And in the next few chapters, we're going to tell you exactly how to do this.

"Errors in intensive care units (ICUs) seem to be occurring with extraordinary frequency, with reported rates as high as 1.7 per patient per day."^a

"Between 3% and 16% of patients experience one or more harmful adverse events while hospitalized and about half of these events are preventable."^b

"A major unused resource in most hospitals, clinics, and practices is the patient. Not only do patients have a right to know the medications they are receiving, the reasons for them, their expected effects and possible complications, they also should know what the pills or injections look like and how often they are to receive them."^c

"Patients in the ICU have been shown to be particularly susceptible to experiencing a medical error."^d

"Medication-related errors occur frequently in hospitals ... about two out of every 100 admissions experienced a preventable adverse drug event."^c

"Medication errors were common (nearly 1 of every 5 doses in the typical hospital and skilled nursing facility) ... Assuming 10 doses per patient day, this would mean the typical patient was subject to about two errors every day ... [These] error rates are likely to be understated... The Institute of Medicine report[s] that the medication delivery and administration systems of the nation's hospitals and skilled nursing facilities have major system problems."^e

"The Joint Commission has launched a national campaign called the Speak Up™ Initiative that is designed to help patients and their families become aware of their rights. The underlying belief is that by asking questions and knowing their rights, patients have a greater chance of receiving proper care. [Among other things], the campaign advises

patients that they have the right to ... receive treatment for pain, be informed about the care they should expect, expect that their opinion will be heard, receive an up-to-date list of their current medications, and receive treatment with respect and courtesy ... Involve family and friends in patient care by designating someone to be an advocate to obtain information and ask questions ... Because of the law requiring private patient information, a form should be signed allowing patient information to be shared with the advocate.”^f

- a. Manojlovich, Milisa, and Barry DeCicco. “Healthy Work Environments, Nurse-Physician Communication, and Patients’ Outcomes.” *American Journal of Critical Care* 16(6) (2007): 536-543.
- b. Norton, Peter G., and G. Ross Baker. “Patient Safety in Cancer Care: A Time for Action.” *Journal of the National Cancer Institute* 99(8) (April 18, 2007): 579-580. *citing* G. R. Baker, P. G. Norton, and V. Flintoft et al. “The Canadian Adverse Events Study: The Incidence of Adverse Events among Hospital Patients in Canada.” *Canadian Medical Association Journal* 170 (2004): 1678-1686.
- c. Institute of Medicine. *To Err Is Human: Building a Safer Health System*. Linda T. Kohn, Janet M. Corrigan, and Molla S. Donaldson, eds. Washington, D.C.: National Academy Press, 2000, pp. 2, 196-197, *italics added*.
- d. Reader, Tom W., Rhona Flin and Brian H. Cuthbertson. “Communication Skills and Error in the Intensive Care Unit.” *Current Opinion in Critical Care* 13 (2007): 732-736.
- e. Barker, Kenneth N., Elizabeth A. Flynn, Ginette A. Pepper, David W. Bates, and Robert L. Mikeal. “Medication Errors Observed in 36 Health Care Facilities.” *Archives of Internal Medicine* 162 (2002): 1897-1903.
- f. Sandlin, Debbie. “The Joint Commission’s Speak Up™ Initiative.” *Journal of PeriAnesthesia Nursing* 22(6) (2007): 438-439.

The bedside advocate (the “*patient-sitter*”)

When a person is so sick that he’s hospitalized, he really can’t be the best advocate for himself, and careless things can happen when he’s alone.

The person sitting with the patient can be a family member, a close friend, or even someone you hire. But this essential position—ensuring the safety of your loved one—is not for the faint of heart.

We’ll call this person the “bedside advocate” (also sometimes called the “patient advocate”), but as far as the hospital is concerned, call yourself whatever feels comfortable. (For example, “I’m just here to help” or “I’m the patient’s assistant.”) Medical personnel may still get offended if they think you doubt that everything is under control.

One day, when all hospitals, doctors, nurses and other medical personnel *get it* that family members are necessary for the good health of the patient, then the job of the bedside advocate will become easier.

For now, some doctors and nurses still haven’t accepted that the limitations placed on them by bureaucratic demands have left many patients in jeopardy, and so family members *must* step in to help.

But just ask any doctor or nurse. They know the medical system, and they wouldn’t leave their loved ones alone either!

Staying with your hospitalized loved one is *more important* than almost anything you might need to do outside the hospital

Understandably, the spouse or parent of a patient has a job, children or other responsibilities to take care of.

Nonetheless, your most *important* job at this time is to either stay at the hospital with your loved one, or find a trusted person who can.

Remember that your hospitalized loved one is at great risk because of the lack of checks and controls in the current healthcare system. *See* “The most important safeguard for your hospitalized loved one is *you*” section. Use your time where you are most needed.

Ask any of the millions of people who have lost someone to a hospital error—they would *never* again leave their loved one without someone there.

The person sitting with the patient can be a family member, a close friend, or even someone you hire.

If you don’t have a lot of people to help with the 24/7 schedule, then it would be best for the main advocate (a spouse or parent) to stay at the hospital as much as possible. At night, sleep in the room with the patient, either in the chair provided, or bring a camp chair. (Many safety-oriented and family-friendly hospitals have a chair in the room that reclines or even turns into a bed.)

Hospitals often have less staff working at night, so don’t believe for a second that when you go home your loved one will be well-taken care of.

The bedside advocate who has little or no outside support has a tough situation. He should always try to get as much sleep as possible as he stays with his loved one. He should sleep as well as he can in the chair at night and then nap in the chair during the day if he needs more sleep. Just like a new mother, the bedside advocate can get the rest he needs, and still have an “ear” to what’s happening with the patient, and awake to full alert when it’s important.

But please get some help for this important 24-hour job whenever you can. And volunteer to take an 8-hour shift to help another family in this situation.

“Patient safety problems of many kinds occur during the course of providing health care. They include transfusion errors and adverse drug events; wrong-site surgery and surgical injuries; preventable suicides; restraint-related injuries or death; hospital-acquired or other treatment-related infections; and falls, burns, pressure ulcers, and mistaken identity.”*

*Institute of Medicine. *To Err Is Human: Building a Safer Health System*. Linda T. Kohn, Janet M. Corrigan, and Molla S. Donaldson, eds. Washington, D.C.: National Academy Press, 2000, p. 35.

The patient must assert his need for the bedside advocate

Let your loved one (the patient) know that it is important that the bedside advocate be there and that the patient needs to assert his need for that person if asked by the nurses or doctors.

It is very important for the patient to follow these instructions.

For example, if the doctor or nurse asks the bedside advocate to leave the room, the patient needs to say, e.g., “I want him to stay—he promised he wouldn’t leave me.”

Have a note signed by the patient stating the patient’s desire for his own 24/7 assistant or bedside advocate. Make sure the letter says that the patient wants all of his medical information given to his bedside advocate. Tape it to the wall, so that the hospital staff can see it.

The Joint Commission (that hospitals recognize as an authority) advises you to do the following:

“Ask a family member or friend to be your advocate (advisor or supporter).

- Find out if there is a form you need to fill out to name your personal representative, also called an advocate. [Or write one yourself.]
- Your advocate can ask questions that you may not think about when you are stressed.
- Ask this person to stay with you, *even overnight*, when you are hospitalized. You will be able to rest better. Your advocate can help make sure you get the right medicines and treatments.
- Your advocate can also help remember answers to questions you have asked. He or she can speak up for you when you cannot speak up for yourself.”*

“These efforts to increase patient awareness and involvement are also supported by the Centers for Medicare & Medicaid Services.”*

On the next page is just an example of a note you might write out that would help the hospital understand that you have a personal representative.

Appointment of Personal Representative or Patient Advocate

(Activation of HIPAA Rights for Personal Representative)

Notice to All Healthcare Personnel:

I have appointed the following person as my personal representative (patient advocate) as allowed by HIPAA. Please share all of my medical information with this person(s).

“I, _____, am appointing

the following person, _____, to be my personal representative (my patient advocate), as advised by the Joint Commission, and allowed by HIPAA. I would like him to be present at all times, including at night, as he will be giving me both personal assistance and advice, and will be needed during any decision-making. Please speak freely in front of him, and give him access to all of my medical information. Even during procedures and examinations, please give him a chair in the room. He has been trained to stay out of your way and not interfere. This appointment is valid beginning the following date: _____.

Signed _____

Print name _____

Date _____

Witness (if state law requires): _____

Witness (if state law requires): _____

You will need one of these for each person who is sitting with the patient and acting as his advocate. Make sure each advocate appointed understands his responsibilities, as generalized above, and outlined in the next chapter.

*The Joint Commission. "Speak Up™ Program." www.jointcommission.org/GeneralPublic/Speak+Up/about_speakup.htm, accessed November 15, 2008, *italics added*; and www.jointcommission.org/NR/rdonlyres/58A5230D-3E58-48D8-8114-C95AF53ECA27/0/Speakup_Rights.pdf, accessed November 15, 2008.

General info for the bedside advocate

In order to “earn” your place as part of the team, the bedside advocate must be prepared to act calmly, respectfully, considerately and helpfully. Once doctors and nurses see that most advocates are acting this way, they will be welcomed.

- *Stay out of the way.* The bedside advocate should be “background”—not in the foreground.
- *Don't get into confrontations with doctors or nurses.* The bedside advocate should not get into confrontations with doctors or nurses.

If you feel that there are problems you can't surmount by talking with the medical personnel right there, then ask for the charge nurse (also sometimes called the nursing supervisor), the hospital's patient advocate, the hospital administrator, or anyone in Risk Management.

Don't get into anger or blaming—just assert what you need from whom.

- *Be helpful.* The bedside advocate should be helpful to the nurses and personnel. If you can get your loved one what he needs, then do so. Be a positive influence in the care of the patient and take over any minor tasks that you can to help out the nursing staff.

Don't take over any of the medical duties unless you've been given permission. If you and the nursing staff feel comfortable with each other, you may ask them if there's any part of the care that you could do for them.

Leave the machines and IVs completely alone so that the medical personnel feel that they can trust you not to interfere.

- *Keep the noise level and number of visitors at any one time down.* Definitely be respectful and keep the noise level and the number of visitors down if you are sharing a room with another patient. Even if you have a private room, make sure that you are not making noise and disturbances with visitors that carry into the hall and could be heard by other patients and their families. (Even if your loved one is recovering well, there might be a family next door that is facing more somber news.)
- *Clear the way for hospital personnel to work.* Train family and friends to clear out of the way as soon as any hospital personnel come into the room. (Back away from the bed and out of the way.) If the nurse or doctor asks for everyone to leave the room, the bedside advocate should help to get everyone to leave right away, and then place herself in a corner of the room, out of the way.

In this way, the hospital personnel will come to appreciate your place there, and note your helpfulness.

- *Be sensitive that the medical personnel have a lot (too much!) to do.* Don't bother them with questions you don't need answered. Let them do their jobs, and don't take up their time with “I'm just curious” questions.

Do your own research or have a friend bring you some Internet search results on the things you're “curious” about. You'll avoid taking precious time from the professionals, and you'll likely get better information, because it won't be from someone who's rushed and just anxious to get on to the next task.

- *Follow the Joint Commission’s advice for the patient to appoint an advocate(s) and for them to speak up and participate in the care the patient receives.*

The Joint Commission accredits most hospitals, and has devised the “Speak Up” program below. The Joint Commission is encouraging patient empowerment and patient and patient family involvement in the healthcare given to the patient in the hospital. It’s just going to be safer that way. The patient and his advocate(s) become an *asset*—an important part of the healthcare team that is there to help the patient. Don’t shirk your responsibility, thinking “not my job.” If you want your loved one to get safe care, it is your job. And if you get pushback from anybody at the hospital for trying to do your advocacy job, or “interfering,” just quote that “the Joint Commission has advised patients to be active in their care, and for them to have an advocate to help them.”

The Joint Commission’s Speak Up Program

Speak up if you have questions or concerns, and if you don’t understand, ask again. It’s your body and you have a right to know.

Pay attention to the care you are receiving. Make sure you’re getting the right treatments and medications by the right health care professionals. Don’t assume anything.

Educate yourself about your diagnosis, the medical tests you are undergoing, and your treatment plan.

Ask a trusted family member or friend to be your advocate.

Know what medications you take and why you take them. Medication errors are the most common health care mistakes.

Use a hospital, clinic, surgery center, or other type of health care organization that has undergone a rigorous on-site evaluation against established state-of-the-art quality and safety standards, such as that provided by The Joint Commission.

Participate in all decisions about your treatment. You are the center of the health care team.”*

*The Joint Commission. “Speak Up™ Program: Facts about Speak Up Initiatives.” www.jointcommission.org/GeneralPublic/Speak+Up/about_speakup.htm, accessed November 15, 2008.

Hospital journals and medication journals

A hospital journal is a daily log the patient advocate uses to write down *everything* that happens to the patient: what medications he is given and when (this medication journal is sometimes separate); what blood tests are drawn; what other tests/procedure are ordered and done; which doctors have been in to see the patient (and anything they may have said); vital signs; and virtually everything else that happens to the patient.

In its simplest form, it's just a spiral notebook in which the patient advocate writes down what's done with the patient, noting the date, and then the time of each entry. Circling the medications that are given can be helpful in this simple journal format (to better track the medications). The journal stays in the room with the patient, and each advocate uses the same journal.

This simplest journal can be done pretty easily—the nurses and other hospital staff are becoming incredibly helpful to patients in this regard. Most nurses are now taught to tell the patient what medication he is being given at each and every dose, and nurse's aides, as they take the patient's vital signs, will repeat them to you. And keeping a hospital journal is recommended by so many patient safety authorities, that the hospital staff has become accustomed to patients and their advocates using them, and usually won't give you a second glance.

If you feel like your patient is up to it, then give him the journal and tell him to go at it. But in my experience, most hospitalized patients are too sick to do this on their own.

Once you've decided to keep a journal, then you need to be assertive as you ask for the information you need. ("What was the result from the MRI yesterday?") Not aggressive or antagonistic, but assertive. You're doing this to be sure the patient gets the tests he needs (and *only* those), the results of those tests, and the meds he's been ordered.

A medication journal and hospital journal kept by the patient/family are also good ideas for another reason. In our big hospitals these days, consultants often come and place orders on the patient's chart, and the original doctors don't know that a new medication was started or that a procedure or test was done—so the patient advocate can use the journal to remind the doctor what procedures the patient has had and to show what medications he is on.

Hospital and medication journals can be *most* useful for making sure that the patient gets the right medications, as this continues to be a huge problem in hospitals.

The sad but true fact about hospital medications is that up to one of every five medications is given incorrectly. See "*The most important safeguard for your hospitalized loved one is you*" section.. Another fact is that although a doctor orders the medicine, he doesn't check to see how, when or even *if* it is given. (Read that last sentence one more time—it may really be important for you to remember this.)

Many times nurses still give a medicine for days after it was discontinued by the doctor. There's just no way the "system" can easily catch that error. And sometimes the patient doesn't get the medicine

that the doctor ordered, or doesn't get it for the proper length of time. And if your loved one's recovery depends on that medicine—you might be the only one to catch that error.

Read these statements from the Institute of Medicine:

“Patient partnering [having patients involved in their medicines and treatments] is not a substitute for nursing responsibility to give the proper medication properly or for physicians to inform their patients, *but because no one is perfect*, it provides an opportunity to intercept the rare but predictable error.”*

“They [patients] should be encouraged to notify their doctors or staff of discrepancies in medication administration or the occurrence of side effects. If they are encouraged to take this responsibility, *they can be a final ‘fail-safe’ step.*”*

So there's a truth that we all must face: if you don't help monitor the medications that your loved one receives, it is likely that errors will be made.

But here's a second truth that is even more depressing: it's just not that easy for you, a non-medical person, to be helpful. Medications have different names (both generic and brand names), different dosages, different ways they should be given (by mouth, by shot, or by IV), and different times to be administered. And doctors order medications one way, and nurses chart them another way.

So we know the problem, but the solution is complex.

Here's my practical advice about hospital and medication journals: as the patient's advocate, start out doing the most important thing you should—*be there*. Secondly, use the simple hospital spiral journal mentioned earlier. And then, if you can also keep a separate medication journal, then my hat's off to you.

In my experience, most people will not use a separate medication journal at the beginning—they just don't feel it's their job, and it seems like more work than they want to do.

But be prepared—if your loved one is in the hospital for a very complex reason, or not doing well, or is getting worse, then you need to get that separate medication journal started, to be sure that he's getting what he needs to recover.

A separate medication journal can be challenging for a non-medical person. But if you're going to try to make sure that there aren't medication errors, then you'll need to use it. (One can be downloaded from CautiousPatient.org.) Here's my best advice on how to use this journal:

Ask the nurses to give you a list of all the medicines the patient should be on, and what time they should be given; or ask the nurse to let you see the patient's “medication chart.” (Alternatively, ask the doctor to have the nurses let you see the patient's medication chart, because you “want to keep up on his medicines.”) If there's any hesitation, say “I'll be glad to just look at it at the nurses' station.”

When you have the medication chart in hand, use your downloaded medication journal form and fill in the information on the left side of the journal page. Then use the journal by writing in the times each of the medicines is actually given on the appropriate places on the right of the page.

When the doctor comes in, tell him you're keeping a medication journal, and ask him to look it over to see if your loved one is getting the medications he needs on the right schedule. It should only take the doctor a minute (hey, he's the one who should know all this). After he looks it over, then take it back,

and mutter (quietly, but so that the doctor can hear), “6 p.m. – Dr. Smith said accurate,” as you write that on the journal page.

At this time, it’s also appropriate to ask any questions about any discrepancies you may have noticed between how the medicine is supposed to be given, and how it is being given.

Please use really good handwriting in the journals—printing very clearly—to be the most helpful.

Some hospitals are so progressive now that they will even give you a copy of the medication chart so that you can see what *should* be given. Ask if that’s the case where you are.

In this very error-ridden part of hospital care, in order to get *best care*, family members can be the “final ‘fail-safe’ step”* in the medication process.

If you’re in a very progressive hospital, then writing in the journal will not be an extraordinary event—there’ll be lots of patients with advocates using journals. But if you’re not in one of those progressive hospitals, then you might be asked *by every person who comes in the room* what you’re doing. There might be instant suspicion (“Are they trying to sue us?”), or you may be accused of being a little OCD, or having some control issues—whatever.

Take the high road. Ignore their prejudices and just do your job. Be *nice*. Although you don’t owe an explanation to anyone, if they ask what you’re doing, they’ll feel somewhat better if you politely provide them with one. “I’m keeping a hospital journal for John” or “I’m keeping a medication journal for John” is usually a start. The next question is usually “why.” Answer whatever is easiest for you.

Say that the patient has asked you to do this for him; or that the Institute of Medicine recommends that the patient be the final checkpoint to catch any medication errors; or that the Joint Commission has asked the patient to be more involved in his care, and should have an advocate to help. Tell them that many reputable patient safety experts believe that hospital and medication journals are necessary for safe care. Or just say something that fits you and your personality and will not be threatening to them.

No need to be defensive. It’s your right (and actually, responsibility) to know what is supposed to go on, and what actually does.

(If you want to use a more formal hospital journal, a form can be downloaded from CautiousPatient.org. You simply fill out who comes in and does what, and put the time. It can be used best by 1) making sure that the patient is taken for procedures *only that have been ordered for him*; and 2) your reporting to the doctor at each visit what tests or procedures were done that day. [For example, “They took him down for his chest x-ray this morning.”] It really helps to jog their memories to get the results.)

And to get a little extra support and information on what patient safety authorities tell you to do, go to the Joint Commission’s website at www.jointcommission.org, and pay special attention to their Speak Up Initiatives. That Speak Up Program has been included in the “General info for the bedside advocate” section.

“Of all medical errors, medication errors are one of the most common ... They account for 19% to 20% of all adverse events. Of all hospitalized patients, 2.43% develop a clinically important adverse drug event during their hospitalization.”[†]

“Providing the proper drug therapy to a hospitalized patient involves several steps and multiple individuals; a mistake at any point in the process ... may lead to a significant error.”[‡]

*Institute of Medicine. *To Err Is Human: Building a Safer Health System*. Linda T. Kohn, Janet M. Corrigan, and Molla S. Donaldson, eds. Washington, D.C.: National Academy Press, 2000, p. 196, *italics added*.

†Lehmann, Christoph U., and George R. Kim. “Prevention of Medication Errors.” *Clinics in Perinatology* 32 (2005): 107-123.

‡Taylor, James A., Lori A. Loan, Judy Kamara, Susan Blackburn, and Donna Whitney. “Medication Administration Variances before and after Implementation of Computerized Physician Order Entry in a Neonatal Intensive Care Unit.” *Pediatrics* 121(1) (2008): 123-128.

Getting the information you need for the hospital journal

Now, this could be a very easy thing to do, but it also could be tough, depending on whom you're dealing with.

You'll probably have a nurse who is pleasant and just gives you the information you ask. More and more nurses are doing this, as they have been informed that it is a good idea for the patient to know about and be involved in his care.

But occasionally, nursing personnel can be curt or brusque with you for asking questions about what medicines are being given, or what the vital signs are, as if it is some sort of classified information. In the unlikely event that this happens, just be calm and say that you're just trying to keep a record, and you'd appreciate them giving you that information. Simple human courtesy should require the nurse to answer reasonable questions.

If another strategy is needed, you might need to remind the nurse (or whomever) that you know that one of the Joint Commission's patient safety goals for hospitals (Goal #13) is to "encourage patients' active involvement in their own care as a patient safety strategy,"* and that you're just helping the patient to be involved in his care. Nurses and other hospital personnel are pretty well-acquainted with rules that the Joint Commission wants them to follow, because the Joint Commission accredits the hospitals.

That should be all you need to do to get the information you need.

On very rare occasions when the nurse is not cooperative, you might have to resort to the following strategies.

Be persistent by following them out into the hall with your journal in hand if they haven't given you the information you've requested. They might get the message that you're serious about this. Then ask them to call the nursing supervisor or charge nurse to come and give you the information if they are unable to.

Speak calmly and respectfully. Stay with her until she calls the nursing supervisor or gives you the information you're seeking. Alternatively, ask the ward clerk (the non-medical person who sits at the nursing station who answers the phone) to call the charge nurse, or pick up the hospital phone yourself and ask the operator to page the charge nurse to come to your room.

If you run into a brick wall, request that they call the doctor if they think they need to get permission to give you this information. Have handy the letter that the patient has signed asking that the bedside advocate be given all of the patient's medical information.

If you need to, call the hospital's patient advocate, the hospital administrator or anyone in Risk Management. You might have to assert the patient's HIPAA rights. HIPAA (pronounced "hip'-uh") is a federal law that gives the patient a right to his medical information. You can quote the Joint Commission on your responsibility to speak up when you want answers (see Speak Up campaign in the "General info for the bedside advocate" section).

Again, most nurses today are accustomed to patients and their advocates asking a lot of questions, and you'll probably not run into a problem. But if you do, just stay calm, and be prepared.

*Joint Commission. "2008 National Patient Safety Goals: Critical Access Hospital Program." www.jointcommission.org/PatientSafety/NationalPatientSafetyGoals/08_cah_npsgs.htm, accessed November 30, 2008.

Go with the patient when he leaves his room

If your patient is sent to x-ray or another part of the hospital for a test or procedure, *go with him*. “Transportation” at the hospital typically sends an orderly to take your loved one to these places, but oftentimes your loved one is then set on the side of a hall, either coming or going, and doesn’t have anyone to help him out.

Medical personnel will assure you that you won’t be needed, *and* aren’t wanted, but just be respectful and patient, and say that you’ll just walk with them (the orderly and the bed) and wait for your loved one during the test. You’ll stay out of their way.

Be a respectful advocate for your loved one—if the wait seems long, check with someone. You will be the “legs” that go to find out what is going on for them or ask for something they need.

If they are going into a room for some tests, you may not be allowed in that room, and that is okay. Tell everyone you’ll just be waiting outside until they come out. Ask how long the test should take, and then take action (ask somebody what’s going on) if the time gets longer than expected.

Granted, if your loved one is not in pain and is in pretty good condition, this may not be necessary every time. But medical errors have been noted to be frequent when patients are in transition from one place to another.

Additionally, your loved one who is already in pain or especially immobile can suffer a lot of stress during transit to and from tests. Sometimes they are set aside in the hall and ignored for long periods of time (for many reasons—some out of the control of the personnel involved). This can obviously cause discomfort and anxiety.

Be there for your loved one.

Be kind to the nurses

There may possibly be no harder job than that of a hospital nurse.

Nurses are there to assess you and decide what your nursing needs are, and then to formulate goals and plans based on those needs; they implement those plans; and then they continually re-evaluate how those plans are working to help you get well and stay free from complications while in the hospital,

in addition to

following doctor's orders—preparing and giving regular medications, inserting IVs or NG tubes, taking vital signs, and supervising your mobility status,

as well as

watching for changes in your clinical condition, and calling for help if they believe that things are changing in your condition and you now need to be re-assessed by the doctor,

plus

documenting in charts, supervising aides, searching for supplies, and giving medications as needed to help you with pain or unpleasant symptoms.

Nurses have to keep a large amount of information about each patient they're responsible for *in their heads*, as they physically shift between different patients, while also answering questions from nursing aides or assistants about other patients.

And studies show that RNs are frequently interrupted in their duties, making everything that much harder.

One of the worst things of all is that most states don't have a legislated nurse to patient ratio. That is, each hospital on any particular day can assign whatever number of patients that they want to assign to the care of an RN. And even if the nurse knows that she doesn't have time to provide the right care for that number of patients—there's *nothing* she can do about it except do the best she can, in the face of unrealistic demands.

So, *your* very serious problem, when your loved one is in the hospital, is that you don't know whether the nurse to patient ratio that includes your loved one is adequate or not. And if it's adequate during the day, then it may not be during the night, or during another shift.

Also, some hospitals *require* nurses to take on extra shifts when they are short on personnel, even though research has adamantly shown that after twelve hours on the job, the quality of their work suffers. So you don't know if you have a tired nurse either.

Research also has shown that a higher RN to patient ratio is safer for patients. (You want a higher ratio. A higher ratio means that each nurse takes care of fewer patients.)

So, nurses have a noble calling, but in real life, they have really tough jobs. They have serious responsibilities that are often compromised by working hours and conditions where they feel they can't always do right by the patient. Sometimes the only option is to try to work faster and faster, with chronic stress and more frequent errors being the most obvious downsides of that strategy.

All this, plus they have to deal with doctors. (A survey found that over 20% of hospital nurses leave their jobs because of issues over the way doctors treat them.)

So what can you do?

Here are a few suggestions:

- 1. Be there 24/7 for your loved one, so that *your* loved one isn't the one hitting the call button for an hour before he can get a bedpan.

- 2. Be there 24/7 for your loved one so that you can personally go out and find a nurse if you see something wrong.

- 3. Be there for your elderly loved one at night so he doesn't have to be tied to the bedrails.

Elderly patients often get disoriented in the hospital at night, and the nurses have to put them into "restraints" in order to keep them from pulling out their tubes or trying to get out of bed.

Even if your loved one has to be in restraints, at least you'll be there to scratch his nose, give him a sip of water and comfort him.

- 4. Be there for the nurses. When you first see a nurse who's working with your loved one, mention that you know that nurses are overworked, and ask her how you might be of assistance to *her* in helping the patient. Watch what she's doing, and if you think it's appropriate, ask if you can take over that chore, to save her some time.

You might also ask each day when you see your assigned nurse of that day: "What can I do on *your shift today* that would give you more time and make a positive contribution to the patients on this ward?" The nurse might be able to give you some ideas, and at least she would know your heart is in the right place.

- 5. Don't complain about the little things. Take care of the little things yourself.

- 6. Be sure to give them any nice comments that are warranted. They are so overworked and under-appreciated.

- 7. If public policy is your thing, support nurses in their efforts to get state legislatures to make sure that they don't have to take care of more patients than they can safely handle.

I mean, my child's kindergarten class had a state-mandated teacher-student ratio of 1 to 22, and when 23 kids showed up to enroll, they were obligated by state law to split the class into two. So when it comes to nursing care and patient safety, why should we do less?

"Responding to research confirming the link between nurse staffing and patient outcomes, 14 states have introduced legislation to limit patient-to-nurse ratios ... Eight patients per nurse was the least expensive ratio but was associated with the highest patient mortality. Decreasing the number of patients per nurse improved mortality ... As a patient safety intervention, patient-to-nurse ratios of 4:1 are reasonably cost-effective and in the range of other commonly accepted [patient safety] interventions."^{*}

"Many RNs believe that state or federal government regulations are the only mechanism that can raise nurse staffing levels to a point where they are adequate to meet patient needs."[†]

^{*}Rothberg, Michael B., Ivo Abraham, Peter K. Lindenauer, and David N. Rose. "Improving Nurse-to-Patient Staffing Ratios As a Cost-Effective Safety Intervention." *Medical Care* 43(8) (2005): 785-791.

†Litvak, Eugene, Peter I. Buerhaus, Frank Davidoff, Michael C. Long, Michael L. McManus, and Donald M. Berwick. "Managing Unnecessary Variability in Patient Demand to Reduce Nursing Stress and Improve Patient Safety." *Joint Commission Journal on Quality and Patient Safety* 31(6) (2005): 330-338.

Hospital nurses are also patient advocates: they help prevent infections, medication errors, medical complications and deaths

Not to be taken lightly is the role that nurses play in your safe recovery while in the hospital. *See* “Nurses and good hospital care” section.

But many hospital nurses feel that they are overwhelmed by the amount of work assigned to them, and feel that they can’t keep patients safe under their present working conditions. *See* “Nurses and good hospital care” section.

That’s another reason why you have to be there to help the nurses protect your loved one.

And good nurses will understand the need for you to be there—trust me, they wouldn’t leave *their* loved ones in the hospital alone!

“The evidence indicates that inadequate nurse staffing leads to adverse patient outcomes ... The AHRQ reports that a vast amount of research has shown a relationship between lower nurse staffing and higher rates of adverse patient outcome ... Shock, cardiac arrest, UTIs [bladder infections], and pneumonia were all negative outcomes *associated with low nurse staffing levels.*”*

“*Nurses have a critical patient advocacy role: the total number of errors would be greater if nurses did not intercept 86% of all potential errors that could result in patient harm.*”†

*Garrett, Connie. “The Effect of Nurse Staffing Patterns on Medical Errors and Nurse Burnout.” *AORN Journal* 87(6) (2008): 1191-1204, *italics added*.

†Hughes, Ronda G., and Carolyn M. Clancy. “Working Conditions That Support Patient Safety.” *Journal of Nursing Care Quality* 20(4) (2005): 289-292, *italics added*.

What if the doctor asks you to leave the room?

Doctors and nurses ask you to leave the room out of habit—it's just always been done that way.

It's like thirty years ago when husbands and family members were kept out of the delivery rooms—it had just always been done that way. And we now see that as a really outdated idea.

Telling family members to wait in the waiting room or limiting the time they can watch over their critically-ill loved one is another outdated idea.

If a doctor asks you to wait outside, just say calmly yet confidently "I'm going to stay out of your way, but I need to be here." Then back away from the patient to the side of the room where you *are* out of the way.

If they ask again, just respectfully say that you promised the patient you wouldn't leave him, and you won't interfere. Stay respectful and non-threatening.

Sometimes, the patient may need to help by speaking up; for example, "I need my sister to stay." Most doctors will not oppose the patient's wishes.

But if you come across a particularly difficult doctor, you may need to talk with the hospital's patient advocate, or the hospital administrator.

Sometimes it might be a good idea to quietly sit down in the corner, and say "I'll just stay over here." This might be helpful because doctors and nurses often justify their asking you to leave by saying that you're in the way or that you are going to faint and fall down, and they don't want to have to deal with "another" patient.

Do what you need to do to stay and be an advocate for your loved one. (*Occasionally*, you'll have to give an inch to get a mile—it's a fine line, for sure. But aren't most worthwhile things in life?)

Some hospitalized patients are at risk for mismanaged and outdated care: example, heart attacks

Some hospitalized patients are being treated in an outdated fashion,* and in certain situations, that can be life-threatening. But you can intercede in some ways to ensure better care.

For example, a study by Berger et al. showed serious quality problems in patients getting the care they should when they are hospitalized with a heart attack. The researchers studied eight “quality indicators” that patients should receive, if indicated for their particular type of heart attack and other illnesses or problems. They found that the patients received the indicated, recommended best care only 41% to 87% of the time.†

Some of the treatments were *so* basic, and yet 100% of the patients did not get the treatment. For example, in the patients that *should* have gotten aspirin during their hospital treatment for a heart attack, only 87% got that treatment.†

Now that may seem like a good percentage to some people, but if my loved one was in the 13% group who *didn't* receive this simple but life-saving therapy—I mean, how hard is it to order an aspirin a day when the American Heart Association has recommended that it be given during the hospitalization, and studies have shown that “the use of aspirin resulted in a 22% lower odds of 30-day mortality rate after adjustment was done for other variables.”†

Twenty-two percent lower risk of dying in the first 30 days after your heart attack if you receive aspirin during your hospital stay, and yet 13% did not get that protection!†

So, although you're not a doctor, here's what you can do in this situation to help your loved one if he is hospitalized with a heart attack:

- *The very first day*, go on the Internet and search for “heart attack quality indicators” (*without* the quotation marks). What you'll find are organizations that have listed the medications and/or procedures that are *proven to be beneficial, and should be given* when your loved one has a heart attack. This is not a list of *everything* that should be done, but these things are absolutely proven to be beneficial for recovery and should not be forgotten. My current favorite sites for these indicators are listed on CautiousPatient.org. (Today, when I typed in that search, I found good information at these websites: bloomingtonhospital.org, ecommunity.com, carechex.com, and methodisthealthsystem.org.)

- Print out those pages and take them to your loved one's doctor, and say “if John is a candidate for any of these medications/treatments, then I want to make sure he gets them.”

- Go down the list with the doctor and ask specific questions. For instance, “Is John a candidate to take aspirin in the hospital?” If yes, then “is he on it?” If the doctor says “yes” to the candidate question, but “no” to the “is he on it” question, then say, “Would you make sure he gets that?” Go on down the list.

- You can ask that the doctor make your request part of the patient's chart.

▪ Don't be obnoxious, but don't be shy either—you could save your loved one's life. Just let the doctor know that you want to make sure that *your* loved one gets 100% of the best care that he could.

(Although I gave you the example that 13% of heart attack patients didn't get aspirin when they should have, in 5 of the 8 quality indicators in the study, greater than 30% of patients did not receive the treatment or medication that they should have!†) (Aspirin was just easiest to explain here.)

(In addition, although all 4300 patients in this study were eligible for at least one of the quality indicator treatments, 12% of the patients received *none* of the quality recommendations!†)

Yes, you're not a doctor, and it would just be so nice to be able to leave it up to the doctor. I mean, he's the one with all the training, and who are you to say what should happen?

But at these rates of non-compliance in ordering recommended medications or treatments that save the lives of patients with heart attacks, do you want to rely just on faith that your doctor is doing all that he can?

He may need a little help from you.

(There are also quality indicators for heart failure, pneumonia, and surgical care. See a listing at CautiousPatient.org.)

“The failure to use effective therapies for [heart attack] may lead to as many as *18,000 preventable deaths each year.*”†

*Bodenheimer, Thomas. “The American Health Care System: The Movement for Improved Quality in Health Care.” *New England Journal of Medicine* 340(6) (1999): 488-492.

†Berger, Alan K., Daniel W. Edris, Jeffrey A. Breall, William J. Oetgen, Thomas A. Marciniak, and Gaetano F. Molinari. “Resource Use and Quality of Care for Medicare Patients with Acute Myocardial Infarction in Maryland and the District of Columbia: Analysis of Data from the Cooperative Cardiovascular Project.” *American Heart Journal* 135(2) (1998): 349-356, *italics added*.

Critically important advice: Don't allow doctors or nurses to ignore your concerns

Always trust your intuition and make sure your health providers are listening. You know your loved one better than anyone else.

If you can't get your doctor or nurse to listen and act on your concerns, then contact the hospital's patient advocate. Many hospitals now have them, and they are vital to patient safety. If one isn't handy, ask for the charge nurse, the hospital administrator, or anyone in Risk Management.

Over and over again, loved ones who have lost someone to medical error relate that they knew something was wrong, but they weren't listened to or taken seriously.

Don't let this happen to you.

But if you can't get your doctor's or nurse's attention ...

If the patient's condition is deteriorating . . .

If your loved one is in the hospital, he's getting worse, you're very worried that adequate attention is not being paid to it, and you believe it to be critical, then call for a "rapid response team." These teams have been developed for those situations where a patient's condition is deteriorating, the reason is unknown, and steps are not being taken to correct the problem.

Rapid response teams have been put into play to come at a moment's notice and completely re-assess a patient who is getting worse without apparent reason. They bring immediate attention and a fresh perspective as they completely re-assess the patient.

They can literally be lifesaving.

If there is no rapid response team at your hospital, then call your doctor and insist that a physician come right away to re-assess the patient. If the doctor doesn't do so, then call the charge nurse, the hospital's patient advocate, the hospital administrator, or anyone in Risk Management.

You can also keep an eye on your loved one following some of the same criteria that are used to identify patients who have become unstable and need to be rapidly re-evaluated.

Watch for these warning signs in your loved one:

- ***Pulse*** less than 40 or greater than 130 beats per minute*;
- ***Systolic blood pressure (BP)*** less than 90 (systolic BP is the first and higher of the two numbers—e.g., if BP is 120/80, then 120 is the systolic blood pressure)*;
- ***Breaths*** (respirations) less than 8 or more than 24 per minute*;
- ***Seizure*** (convulsion) activity of any kind*;
- ***Acute change in mental status*** (e.g., a person who is normally conscious and aware becoming delirious, confused, or "out-of-it").*

If these signs come and persist, then let the nurse know and get medical attention for your loved one immediately.

The following describes the implementation of some rapid response teams in the last several years:

"Community Health Network in Indianapolis has launched a new patient safety initiative, Call FIRST (Family-Initiated Rapid Screening Team), in all five of its hospitals. As part of the program, patients and their families are encouraged to make a phone call when there is a change in the patient's condition and they feel their concerns are not being addressed. A designated internal phone line has been established for the program at each facility. When the number is called, a nursing supervisor or consult nurse will provide help within 15 minutes at the bedside to evaluate and stabilize the situation ... The program is based on the 'Condition H' program started by the University of Pittsburgh Medical Center in 2005 ... 'There are a number of situations in which the program can prove beneficial,' says Wilson [vice president of nursing at Community Hospital North]. 'For example, there could be a case of a woman who has been with her husband for 20 years and knows he is not acting normal,' she says. 'The family members might recognize something that we don't.' Because of this added level of communication, she adds, 'We feel family involvement will increase patient safety.'"[†]

*Offner, Patrick J., Joseph Heit, and Robin Roberts. "Implementation of a Rapid Response Team Decreases Cardiac Arrest Outside of the Intensive Care Unit." *Journal of Trauma* 62(5) (2007): 1223-1228.

†Healthcare Benchmarks and Quality Improvement. "Program Increases Patient, Family Involvement: Patient Safety Initiative Honors NSPG [National Patient Safety Goals, recommended by Joint Commission]." *Healthcare Benchmarks and Quality Improvement* 14(12) (2007): 139-141.

See also Joint Commission's 2009 National Patient Safety Goals at www.jointcommission.org/patientsafety/nationalpatientsafetygoals.

Other Information on Rapid Response Teams

For those who want to read a little more about these teams:

"The rapid response team is designed to bring critical care to the floor patient's bedside with rapid evaluation and resuscitation. Several studies document reduced rates of cardiac arrest, unanticipated ICU admission, and mortality."^a

"One contributing factor to the failure to rescue these patients is the failure to recognize a patient's deteriorating clinical condition."^a

"The rapid response team concept has evolved as a means of extending critical care outside of the intensive care unit to intervene early and prevent deterioration to cardiac arrest."^a

"Rapid response teams (RRTs) have become one of the most widely implemented patient safety interventions in American hospitals, with nearly 3,000 hospitals committing to the implementation of an RRT."^b

"There are a sufficient number of reports of benefit to support a recommendation that hospitals implement and locally assess an RRS [rapid response system]."^c

a. Offner, Patrick J., Joseph Heit, and Robin Roberts. "Implementation of a Rapid Response Team Decreases Cardiac Arrest Outside of the Intensive Care Unit." *Journal of Trauma* 62(5) (2007): 1223-1228.

b. Ranji, Sumant R., and Kaveh G. Shojania. "Implementing Patient Safety Interventions in Your Hospital: What to Try and What to Avoid." *Medical Clinics of North America* 92 (2008): 275-293.

c. DeVita, Michael A., Rinaldo Bellomo, and Kenneth Hillman et al. "Findings of the First Consensus Conference on Medical Emergency Teams." *Critical Care Medicine* 34(9) (2006): 2463-2478.

Beware of the “one-disease-per-patient-limit”

This concept is a little difficult to explain, but it occurs frequently, and you must understand it to get the care that you need and avoid some disastrous consequences.

Many doctors engage in a form of “tunnel-vision” when they see you as a patient. They focus on what you’ve told them to start with, they make an assessment, and then they don’t re-assess you when further symptoms develop. They just assign those additional symptoms to the diagnosis that they decided on in the first place.

And if your new symptoms are the result of a new disease, and it’s a life-threatening one, then you’re in trouble if it goes undiagnosed.⁴

For example, if you’re in the hospital after surgery, then the doctor’s perception of you is that you’re in the “post-surgical recovery stage.” Then, when you report any symptoms, he tends to automatically assign them to the “post-surgical recovery process.”

This “tunnel vision” diagnosis gets you into trouble when your new symptom is actually the presentation of a new and serious illness, but your doctor isn’t even considering an alternate problem. And if your new problem is serious, undiagnosed and untreated, the consequences can be deadly.

Imagine you entered the hospital with a certain condition like a kidney stone, and then find yourself with chest pain. If that had been your presenting symptom, your doctor would have done everything necessary to rule out a heart attack—but since you’re in the hospital with a kidney stone, your doctor hears “pain” and everything else just isn’t clicking because you’ve been assigned “kidney stone” in his mind, and he’s not thinking that something *else* might be going on.

Here’s where you have to listen to your body, your doctor *and* trust your intuition. If everything just doesn’t seem to make sense, and if things aren’t getting better, then do what you have to do to get your doctor to re-assess you.

You might say this to your doctor: “I know you’re saying that [*this new symptom*] is a result of [*your already diagnosed illness*], but something just doesn’t feel right to me, and I want you to re-assess me, just focusing on what else this new symptom could be.”

If your doctor isn’t willing to do that, then insist that he call in a consultant who will.

And if you think the situation is urgent, then call for a rapid response team.

“Once a diagnosis has been established, it is often used to explain all newly occurring symptoms *without necessarily considering that another underlying disease might be present.*”*

*Kirch, Wilhelm, and Christine Schafii. “Misdiagnosis at a University Hospital in 4 Medical Eras: Report on 400 Cases.” *Medicine* 75(1) (1996): 29-40, *italics added*.

Don't rely on nurses for diagnoses

Sometimes you might experience a frightening, new, and disturbing symptom while you're in the hospital, and you'll call the nurse in to tell her about it. She should take your information, check your vital signs, and then call your doctor about the new development.

But sometimes a nurse will listen to you and then come up with her own diagnosis of what's wrong, and give you a version of what she thinks, and then go about her way.

If it's something minor that's not causing you much discomfort, then you're probably okay, and you can wait until the doctor is making rounds.

But if your new symptom remains disturbing or painful, then you might be in danger from a complication or new illness. And then the nurse's failure to notify the doctor about the problem could be dangerous.

Nurses usually know when they can comment confidently and when they should call the doctor. But occasionally, several things can get in the way of the nurse's best judgment: too much to do/too many patients to care for; double-shifts or tiredness; inexperience; or dreading to call the doctor (more on this later).

So if a new symptom develops while you're in the hospital, and it's troubling and you feel it could be important, be respectfully insistent that a doctor be called to examine you.

If you can't get the nurse to call the doctor, then call for the charge nurse, the hospital's patient safety advocate, the hospital administrator, or anyone in the Risk Management Department.

And you can call for a rapid response team if it appears particularly urgent.

One note: specialty nurses, who have had special training on patients with a certain condition, are incredibly valuable to your safe care. These nurses have been trained to handle some analysis and decision-making on their own in their specialty areas, so you can usually rely on their advice in the areas they're trained in.

You're usually in the best hospital situation possible when you have a nurse attending to you who has been specially trained about patients with your particular condition, *and* who has a good teamwork relationship with your doctor. (More about this later.)

Even so, if you feel uncomfortable with a nurse's handling of a new symptom, go ahead and listen to your intuition and ask for a doctor to re-assess your situation. As with any other healthcare worker, there may be times that fatigue, too many patients, or some other factor may be interfering with her best judgment. Follow your instinct.

Prevent hospital infections

Hospital-acquired infections are deadly. Hospital-acquired infections in U.S. hospitals occur 1.7 million times a year, and 99,000 patients *die* each year from those infections.*

I personally think that that statistic makes it imperative for any of you who have a loved one in the hospital to read these next three sections *every day*, and require anyone else “sitting” with you patient to read them as well.

“Optimal hand hygiene behavior is considered the cornerstone of healthcare-associated infection prevention.”[†]

The bedside advocate is the patient’s best shield against acquiring an infection.

Keep a bottle of gel hand sanitizer (like Purell) in the hospital room near you. When any nurses, doctors, other hospital staff or visitors come into the room, the bedside advocate should walk or lean toward them and help them take some into their palm (if they do not observe the healthcare worker using some at the door or washing his hands).

Say “we’re asking everyone who comes in to use this hand sanitizer.” You could also tape a sign on the wall behind the patient’s bed that says “Please use hand sanitizer when you come into the room,” and you could point to that as you’re offering the gel.

(This is not necessary if you see the medical personnel use a hand sanitizer as they come into the room—just make sure that you *see* them use the sanitizer.)

Here’s an interesting suggestion given to me: Ask the doctor if it would be a good idea if all people washed their hands or used the gel when they come in the room. If he says “yes,” then put up a sign that says “Always wash your hands or use gel—doctor’s orders,” and point to that sign when people come in the door. (And if he doesn’t say “yes”—ask another doctor.)

If hospital personnel come into the room and then don a pair of gloves from a box at the door, then that’s good enough in some cases (but not all, and medical personnel *are* supposed to have washed their hands in addition to using gloves).

Be sure that the bedside advocate also uses the hand sanitizer, or washes his hands, *each time* he enters the room.

Here’s a sobering thought: Recent studies have shown that a majority of patients (76-77%) would not feel comfortable asking a nurse or doctor to clean their hands if they noticed they had not done so.[‡] Please help us get this number lower. I know it’s hard to be assertive towards your doctors and nurses, but realize that your intervention is truly wanted by those we are trying to control infection, and that your loved one’s health may be at risk if you don’t.

And never, *ever* pick up anything off the floor and continue to use it for the patient. Anything that hits the floor has to be sanitized immediately or trashed.

Most importantly, remember that the risky and potentially deadly infections that patients get while in the hospital *usually* start in a surgical wound, or where the patient has a break in his skin or a tube into his body, like where he has an IV catheter, or where he has a urine catheter. In fact, 32% of hospital-acquired infections are urinary tract infections; 22% are surgical wound infections; 15% are lung infections (pneumonia) (especially if your loved one is on a ventilator); and 14% are bloodstream infections (often from a contaminated IV site).*

So, be *especially vigilant* when anyone is about to touch a surgical wound, any open skin surface, or an IV site. *The people who touch those sites absolutely need to have freshly cleansed hands.*

Studies have shown that patients can often have their urine catheter taken out earlier than a doctor will remember to discontinue it (and when the urine catheter comes out, so does the chance of an infection to start that way).

Believe it or not, it's easy for a doctor to forget the urine catheter's there, because it's under the covers, and usually he's not focused on it. You can do the patient and his doctor a favor by reminding the doctor about it every day.

And the surgical wound—sometimes doctors actually forget to look at it! Keep your eye out, and make sure that a doctor looks at it at least once a day. And while he's looking at it, get a glimpse of it yourself, so you know what it looks like. Ask “is there any sign of infection?” while the doctor's looking at the wound, and you'll learn something about what wounds look like when they're healing fine and when they're infected.

Also look at the wound when the nurse uncovers it to put a new dressing on it.

Keep remembering the 99,000 people who die in the U.S. each year from hospital-acquired infections, and be vigilant about observing and protecting each place that your loved one might be vulnerable.*

And when your loved one leaves the hospital without having acquired one of these infections—celebrate! And congratulate all the nurses and the bedside advocates.

See the “Specific anti-hospital-acquired infection measures” (next section) for specific handwashing recommendations.

*CDC. <http://www.cdc.gov/ncidod/dhqp/hai.html>, accessed July 26, 2008.

†Allegranzi, B., and D. Pittet. “Role of Hand Hygiene in Healthcare-Associated Infection Prevention.” *Journal of Hospital Infection* 73 (2009): 305-315.

Specific anti-hospital-acquired infection measures

In this section (and the next), I have described very specifically *how* hospital-acquired infections (HAIs) are acquired; *and* I give very specific ways that you can thwart that happening in your loved one. For now, feel free to skip over these sections to continue your reading, and come back to these section when you're ready to take some *action to prevent infections* when a loved one is in the hospital.

And I would recommend that you have each person who “sits with” your loved one read the following as well.

Below, I have outlined proper interventions and procedures that *you* can do to help your loved one to not acquire an infection in the hospital.

See the “Hand Hygiene Saves Lives” video by the CDC noting that for hospital patients “it is appropriate to ask or remind their healthcare providers to practice hand hygiene.”* (Providers should either wash their hands or use an alcohol-based hand sanitizer.)

“WHO [the World Health Organization] estimates that at any point in time more than 1.4 million people around the world have a hospital acquired infection and says that many of these infections can be prevented by good hand hygiene.”[†]

“Healthcare-associated infections (HAIs) represent a major risk to patient safety and contribute towards suffering, prolongation of hospital stay, cost and mortality. Hand hygiene is the core element to protect patients against HAIs and colonization with multi-resistant microorganisms. Cleansing hands with alcohol-based hand rub is a simple and undemanding procedure that requires only a few seconds. If hand rub is easily available at each point of care, hand hygiene can also easily be integrated in the natural workflow—even in high-density care settings [like ICUs]. However, most healthcare workers practice hand hygiene less than half as often as they should.”[‡]

The authors of the above offer a simple, easy-to-remember concept for healthcare workers—what they call “My Five Moments for Hand Hygiene.”[‡]

- 1. Before patient contact [when they come into the room, *after* touching the door, and *before* touching the patient][‡]
- 2. Before aseptic task [*before* working with a surgical wound or an IV site on the patient][‡]
- 3. After body fluid exposure [*after* handling a urine bag, e.g.][‡]
- 4. After patient contact [*after* last physical contact with the patient or his surroundings at that visit][‡]
- 5. After contact with patient surroundings [*after* touching anything else in the patient’s room and before touching patient again or leaving room][‡]

How to best protect your loved one considering all these rules? Although medical personnel are supposed to follow all of the above, *you* can do a lot of good by being mindful of these two special moments when it’s most important that hands are cleansed:

- 1. When medical personnel or visitors come into the room,**
and
- 2. Before they touch a surgical site or an IV site, *if* they have touched anything else in the room after the first cleansing.**

And “medical personnel” includes doctors.

If you’re in an intensive care unit where patients don’t have individual rooms, then the above rules apply whenever the nurse returns to *your* loved one after attending to any other patient or being anywhere else in the ward.

Additional Specific Handwashing Recommendations[§]

Healthcare personnel (nurses, doctors, aides, etc.) are supposed to “perform hand hygiene” in these circumstances[§]:

- “Before and after having direct contact with patients;
- after removing gloves;
- before handling an invasive device for patient care, regardless of whether or not gloves are used;
- after contact with body fluids or excretions, mucous membranes, non-intact skin, or wound dressings;
- if moving from a contaminated body site to a clean body site during patient care;
- after contact with inanimate objects (including medical equipment) in the immediate vicinity of the patient;
- and whenever hands look soiled or have potentially been contaminated, and after using the bathroom.”[§]

Hand hygiene should be performed as follows[§]:

- “Alcohol handrub: apply a palmful of product and cover all surfaces of the hand; rub together until the hands are dry.
- Soap and water: wet the hands first and apply enough soap to cover all surfaces of the hands.
- Make sure the hands are dry and towels are not used repeatedly or by multiple people.
- Water: health settings are encouraged to ensure that water is available for hand hygiene, but in settings without easy access to water, efforts should be made to make available alcohol-based handrubs as a priority.”[§]

Gloves should be used as follows[§]:

- “Gloves do not replace the need for hand cleansing with rubs or soap and water.
- Gloves protect staff from blood and body fluids, non-intact skin and mucous membranes.
- Remove gloves after caring for a patient. Do not use the same pair of gloves for more than one patient.
- Change or remove gloves if moving from a contaminated body site to a clean site on the same patient.
- Avoid reuse of gloves.”[§]

“Enforcement remains lax, even for willful violations of reasonable safety standards such hand hygiene.” **

“Although hand hygiene is considered one of the most important measures for preventing transmission of pathogens in health care facilities, compliance with hand hygiene recommendations remains suboptimal in many facilities.”^{††}

* http://www.cdc.gov/handhygiene/Patient_Admission_Video.html, accessed July 26, 2008.

†Pandey, Kaushal. News: “WHO Launches List of Nine Solutions to Improve Patients’ Safety.” *British Medical Journal* 334 (2007):974.

‡Sax, H., B. Allegranzi, I. Uckay, E. Larson, J. Boyce, and D. Pittet. "My Five Moments for Hand Hygiene": A User-Centered Design Approach to Understand, Train, Monitor and Report Hand Hygiene." *Journal of Hospital Infection* 67 (2007): 9-21.

§Allegranzi, Benedetta, Julie Storr, Gerald Dziekan, Agnes Leotsakos, Liam Donaldson, and Didier Pittet. "The First Global Patient Safety Challenge 'Clean Care is Safer Care': From Launch to Current Progress and Achievements." *Journal of Hospital Infection* 65(S2) (2007): 115-123.

**Wachter, Robert M. "Patient Safety At Ten: Unmistakable Progress, Troubling Gaps." *Health Affairs* 29(1) (2010): 165-173.

†† Lent, Victoria, Elizabeth C. Eckstein, Alan S. Cameron, Rachel Budavich, Brittany C. Eckstein, and Curtis J. Donskey. "Evaluation of Patient Participation in a Patient Empowerment Initiative to Improve Hand Hygiene Practices in a Veterans Affairs Medical Center." *American Journal of Infection Control* 37 (2009): 117-120.

My own criteria for preventing an infection in my hospitalized loved one

I'm a nice guy, so I don't like to aggravate people incessantly over small points of protocol. So here's where *I* draw the lines. I'm not saying my way is better—just that I've found it comfortable for me, and safe for the patient. (What you will *never* see me do is “ask” if they've washed their hands. I just don't think that's a safe option.)

I have used most of the following advice myself, because when I'm advocating for a friend in a hospital that doesn't know I'm a doctor, I don't tell them. I handle things like I've outlined below, and still get what I (and my loved one) needs; but this way I also get information to help *you*—I get the same pushback and “whatevers” as you do, so I figure out a way to move forward in spite of the fact that the staff thinks I'm an idiot.) (Oops, didn't quite mean to go there.) Here's the advice:

- IF there is an antiseptic dispenser on the wall inside my loved one's room, and I don't see the person who entered use it, I will say quickly, “Oh! The hand sanitizer is at the door!” (*Pointing*). And then almost all will go back. If they proceed further into the room, I would feel comfortable saying, “Please use the hand sanitizer. (*Pointing*) I appreciate it so much.” And on, and on, until they use it.

- If there isn't a place where I can see them use the sanitizer, then by the time they get close to the bed, I lean forward with a bottle in my hand—get very close to their hand—and say, “We're asking everyone to use a sanitizer,” as I squeeze a pumpful into their palm.” (You wouldn't believe how easy it is to get something into people's hands this way—they just automatically open, so there's no discussion.)

- If someone comes into the room, but doesn't approach my loved one, I don't say anything unless he gets close to the bedside.

- If someone uses the sanitizer (and then maybe examines the patient), then touches something else in the room, and *then* approaches my loved one, I lean forward just like in the first tip, and say, “Here. Let's re-sanitize if you're going to touch [*patient's name*] again.” (Or, maybe he used the sanitizer, and then right off touched the sink, or wall or whatever, then approaches the patient. Use the same drill.)

Basically, here's what I'm going to assume, and how I'm going to handle the situation:

- The patient's *wound* (surgical site) is covered, and everything underneath it *has to stay sterile*. If *anyone* is uncovering the surgical wound bandaging, *always say*, “You'll re-sanitize your hands before you touch anything on or around the wound, right?” Then help them do that. (Think: the outside of the bandage is *not* sterile, so you *can't* undo the bandage and then use that same hand to touch the wound or any of the sterile skin around the wound without re-sanitizing your hands or donning a sterile glove.)

This includes aides, nurses, doctors, brain doctors, rocket-science doctors, Chiefs of-Staff—*everybody*.

I'm going over this again—just to be sure you've got it. Think, and help everyone else think: “The outside of the bandage is *not* sterile, so as I'm peeling it back, if I'm going to touch *any* area inside, I will need to re-sanitize or don sterile gloves.”

This would also be a good sign to place over the patient's bed, on the patient's bedside—anywhere and everywhere in the room:

“The patient’s wound (surgical site) (and the skin around it under the bandage) is sterile, but the bandage covering it is not. If you plan to touch any part of the skin under the bandage, you absolutely must re-sterilize your hands or don sterile gloves *after* uncovering—but before touching—the wound or the skin surrounding the wound.”

Now! If you keep the surgical site from getting infected, that's a big deal.

Once you've kept the surgical site from getting infected, a very close second site where deadly infections start are in any catheters going into blood vessels. This includes the IV, and any “central lines.” Use absolutely the same protocol as above—the “bandaging” over the IV or central line is not sterile on the outside, but on the underneath side, everything is supposed to be sterile. So you can use the same protocol as described for a surgical wound.

It's “possible” that under the outside dressing, there is a “sterile” dressing underneath before you can see the catheter going into the skin. If that's the case, then the healthcare worker may re-sanitize before touching the interior dressing, and that's okay. What's *not* okay is for them to go directly from touching the outer dressing to touching the catheter underneath, or any of the surrounding skin.

A third infection site that you can prevent is where the urinary catheter is. The catheter on the outside of the body is not sterile, so it's treated like the outside of a bandage. But if they are changing the catheter, they need to use sterile technique. (Making sure they use sterile technique when changing the catheter is beyond your grade level, so I really don't think this part should be of high importance to you—but you can just watch it. Once they swab your loved one's private parts with antiseptic, then they lay down a sterile field [a sterile drape, usually paper, which they handle by the edges]. Then they don sterile gloves and everything they touch from then until the catheter is inserted should be a *sterile* surface). But really, since you're out-of-your-element here, you don't need to intervene unless you see something really stupid like they dropped something onto a sheet or floor and then picked it up and seemed like they were going to keep going. Then it would be, “No! The sterile field is compromised! Start over!” (Or just, “No! Stop!” is sufficient, until you've gotten their attention and explained what you just saw.)

Also, in preventing urinary tract infections (above) (also called UTIs or bladder infections), you can watch to make sure everything around that “private parts” area is kept as clean as possible—especially not contaminated with bowel movement (BM) activity. (As your Mom always told you—wipe from the front to the back, not the other way around.) The urinary tract is sterile—it only becomes non-sterile where the urine meets the air. The gastrointestinal (GI) system (which produces the BM) has *lots* of bacteria—so it's important to keep the back from contaminating the front. (Am I trying to be too subtle here as I'm trying not to say BM or feces or stool or whatever too many times?)

Another proven way to prevent a UTI is for you to *remind* the doctor that there's a catheter. It's true! Many, many times the catheter can come out, but the doctor actually forgets to order it taken out! It's under the covers, often, so he just doesn't think about it. So, when the doctor comes around, and make

sure all advocates of your loved ones who take shifts know, *always* mention “he still has a urinary catheter—does he still need that?” Or, even a bit more subtly, “He still have a urinary catheter—he still needs that?”

Now, another infection I want you to try to prevent is pneumonia. This is *really important*. You can do this by making sure that your loved one is doing his respiratory exercises frequently after surgery (that “inhale deeply and steadily and see the ball hover in this chamber” exercise). And if he feels like coughing, encourage him to get it going, even though the surgical wound hurts. Don’t let the pain stop the coughing. (Although check with your surgeon on this, and don’t go to the “overdoing it” part. Although most surgeons have sewn up their patients quite well enough to encourage them to cough, yours might be a different situation—just check.)

Also, to prevent pneumonia, make sure that anything that goes into the back of the patient’s throat or lungs is clean. If your patient has a suction, make sure it stays away from “dirty” surfaces. And don’t drop anything and then use it inside your patient’s mouth or nose.

If your patient is on a ventilator, a well-known medical fact is that the head of his bed should be raised 45 degrees in order to help him not get pneumonia. Most hospitals are right on top of this now, because Medicare stopped paying for pneumonias acquired while patients are on ventilators. (All are thought to be because of lack of proper technique and care.) BUT, you will find someone who rolls your patient back into the room and lowers his head, and walks away—an orderly just hired yesterday. So keep an eye on it, and get it raised right away—go ahead and call the nurse, just to be sure.

And the last infection I want you to try to prevent is *an infection in any other area of non-intact skin*. That might be the “previous” IV site—keep a bandage over it so it heals without coming in contact with a bad bacteria. Or a scratch, or a scab, or a sore. Keep *all* of those covered in the hospital, so one of those deadly hospital bacteria don’t get in. You have to treat those small wounds differently in the hospital than you would at home, where there aren’t usually deadly and resistant bacteria lurking.

Wow, you’re saying, this is all too hard. Yeah—that’s why 99,000 people die each year in U.S. hospitals due to hospital-acquired infections (HAIs). But that doesn’t have to be *your* loved one, if you care enough to do the work.

Every patient has the right to adequate pain control

Pain that doesn't go away with routine pain medication is a warning sign. If the pain is a new symptom for your hospitalized loved one, or the pain has significantly increased, insist that a doctor come to re-assess the patient.

If your loved one is in pain, the hospital *must* respond. The Joint Commission, the organization that accredits hospitals, has mandated that hospital personnel *must* ask a patient about his level of pain, and if it is moderate or greater, *must* do something about it.

The bedside advocate needs to remind the patient that when the nurse comes in and asks “how are you today?”—that is not a social question. It's actually the pain assessment question. The patient must speak up and tell the nurse about his pain. Don't let the patient say “fine,” which is a reflexive act when someone asks “how are you?”

The nurse will then write “no complaints” in her chart, because that is what she heard. Remind the patient to tell the nurse what is hurting or actually how he is physically feeling every time a nurse asks that question.

If the doctor says there's nothing more that can be done for the pain, then ask for a pain doctor to consult.

In an acute situation, if you're having no luck with getting the nurse to listen, then call for the charge nurse, the hospital's patient advocate, the hospital administrator, or anyone in Risk Management.

“In July 2000, the Joint Commission introduced a new objective to improve the quality of health care in the United States. Effective January 1, 2001, institutions [hospitals] wishing to be compliant became responsible for ensuring that pain would be assessed and managed in all patients. The Commission concluded that acute and chronic pain were major causes of patient dissatisfaction in our health care system, leading to slower recovery times, creating a burden for patients and their families, and increasing the costs to the health care system.”*

Be sure to stay with your loved one on pain medication. With the mandated increased use of pain medicines, hospitals have had more patients with “opioid over sedation adverse drug reactions,” which means that some patients received *too much* narcotic (more or less narcotic overdoses, which can be very dangerous).

It was also found that over 90% of the narcotic overdose patients *were noted by nurses to have decreased consciousness* during the 12 hours *prior to* the narcotic overdose emergency.* Thus, if the nurses had acted to have the narcotic dose decreased when they noted the decreased level of consciousness in the patients, it is probable that many of these narcotic emergencies could have been averted. (If *anyone* notes the patient's decreased consciousness level, and makes sure action is taken, then many of these narcotic overdose emergencies can be avoided.)

SO, if you have a loved one in pain, make sure he gets what he needs as far as pain medication is concerned, but be there to make sure that he is either awake and alert, or sleeping but easily aroused by voice. If he becomes confused or cannot be aroused by voice, then alert the nurses right away.

That's just another reason why you need to be there. If the hospitalized patient is not complaining, the nurses really don't get to his side very often to assess him. You be there for him instead.

*Vila, Hector, Jr., Robert A. Smith, and Michael J. Augustyniak et al. "The Efficacy and Safety of Pain Management Before and After Implementation of Hospital-Wide Pain Management Standards: Is Patient Safety Compromised by Treatment Based Solely on Numerical Pain Ratings? *Anesthesia and Analgesia* 101 (2005): 474-480.

Protect your elderly patient with a poster board

Older patients who have had a sudden major illness onset often look very different than they were immediately before the illness; this can result in really inadequate treatment in the hospital.

That's because many doctors and nurses see the older, wrinkled patient who is now incoherent, comatose or just "out-of-it" from an acute illness, and may not realize that this person was very active until this illness event.

Since doctors and nurses see many patients who are really ill and unresponsive from Alzheimer's or people from nursing homes who are not "with it," they often assume that the elderly patient they're seeing now (*your* loved one) has been in that condition for some time, and they don't understand that this *particular* older patient was very active until this hospitalization.

So it's terribly important to let the staff know that your older loved one was really active before this present illness (if that was the case).

Get a poster board, or some sheets of paper, and write with a thick marker something like this: "This patient (my mother or Jane Doe) was playing bridge last week!" or "This patient (my dad or John Doe) was playing tennis last week!" or whatever the truth might be, and tape it to the wall and make sure the healthcare personnel see it.

If you have the opportunity, you can put up a good recent photo of the patient, and make sure you put the date of the photo in large, bold print so they're able to see that it was a recent one! Patients can look very different when they're seriously ill, and it will give the medical personnel a good perspective on your loved one that will translate to more appropriate medical care.

If you have a choice, use a hospital where visiting hours aren't limited, even in the ICU

Try to keep your loved one from being admitted to a hospital where visiting hours are limited.

That can be particularly difficult for you if your loved one is in the intensive care unit (ICU); but many hospitals now allow a family member to stay overnight even in ICU rooms. Use these hospitals whenever possible.

Even in ICUs, some hospitals may reduce the nurse to patient ratio at night, and if your loved one's nurse gets tied up with another patient who is critically ill or crashing, then *your* loved one may not be able to get someone's attention—even in the ICU. Be there for him.

In addition, although one might think that the ICU is the best place for your loved one to get careful medical care, studies show that many errors occur there as well.

And the ICU is a very scary place for a critically ill patient. Be there to hold his hand. Just that one connection could be critical to his well-being.

“The complexity of intensive care and the medical conditions of patients admitted to intensive care units increases the likelihood of medical errors ... Medical errors appear to be common among patients requiring intensive care. Medical events resulting in an error can result in the need for additional life-sustaining treatments and, in some circumstances, can contribute to patient death.”*

“One study found that the average ICU patient experiences 1.7 errors per day, nearly one-third of which are potentially life-threatening. Most involve communication problems.”†

“Adverse events and serious errors involving critically ill patients were common and often potentially life-threatening. Although many types of errors were identified, failure to carry out intended treatment correctly was the leading category ... In general, medicine [the medical system] has focused more on determining what to do than on ensuring that plans are effectively executed.”‡

“[In the ICU], sleep cycles of patients are disrupted by alarms or other disruptive sounds, by care providers taking vital signs or administering medications, and by the high and prolonged levels of lighting. It is estimated that between 12.5% and 38% of patients who arrive at the ICU alert and oriented show signs of dementia after extended stays.”§

*Osmon, Stephen, Carolyn B. Harris, W. Claiborne Dunagan, Donna Prentice, Victoria J. Fraser, and Marin H. Kollef. “Reporting of Medical Errors: An Intensive Care Unit Experience.” *Critical Care Medicine* 32(3) (2004): 727-733.

†Wachter, Robert M. “The End of the Beginning: Patient Safety Five Years After ‘To Err Is Human.’” *Health Affairs* 2004 (July-December) (Suppl. Web Exclusives): W4-534 – W4-545, citing Donchin, Y., D. Gopher, and M. Olin et al. “A Look into the Nature and Causes of Human Errors in the Intensive Care Unit.” *Critical Care Medicine* 23(2) (1995): 294-300.

‡Rothschild, Jeffrey M., Christopher P. Landrigan, and John W. Cronin et al. “The Critical Care Safety Study: The Incidence and Nature of Adverse Events and Serious Medical Errors in Intensive Care.” *Critical Care Medicine* 33(8) (2005): 1694-1700.

§Donchin, Yoel, and F. Jacob Seagull. “The Hostile Environment of the Intensive Care Unit.” *Current Opinion in Critical Care* 8 (2002): 316-320.

When your back is against the wall ...

If there are limited visiting hours where you are, and you don't have a choice about hospitals, you still must do whatever you need to do to stay with your hospitalized loved one.

Many detrimental things have happened to patients when they didn't have family members with them—ask the thousands of family members who have left the hospital thinking their loved one was in good hands, and then returned to find their loved one in serious danger or suffering unnecessarily.

Start with this: many times the posted visiting hours aren't strictly enforced, so just quietly and unobtrusively stay where you are when visiting hours are over. If someone comes in and says anything to you, just say that you're just going to stay and help a while longer.

If hospital personnel finally feel it necessary to “lay down the law,” tell them about your promise to your loved one to stay with him. Show them the document that says your loved one wants a 24/7 bedside advocate when hospitalized. Tell them that you know the Joint Commission has advised patients to have a loved one stay with them 24 hours a day.

If they persist, respectfully ask that they contact the hospital's patient advocate for you to talk with before you leave, because you believe it would be a mistake to leave your loved one, since you'd promised you'd stay with him, and you just don't think it would be right to break that promise.

If told that the hospital's patient advocate is not available right then, ask for an emergency meeting with the hospital administrator, as this is a significant issue and a patient safety issue for your loved one. Make certain that you state your intention of just quietly watching over and being an extra hand to the patient if he needs it.

Make sure that the patient also stresses to the hospital personnel that they need the family member to stay.

Hospitals listen to patients a lot better than they listen to the families of patients. So if your loved one is conscious, make sure he stresses over and over again to the hospital personnel that he needs you to stay with him.

If needed, the patient could say “I can't sleep if he's not here,” or “I get too scared and have to call the nurses too much.”

Do what you need to, but do it quietly and respectfully. There are many power struggles in hospitals, and when there's a rule on the wall, and they don't like you, you won't win.

If you're in the hospital emergency room . . .

When you're a patient in the emergency room, you're neither an outpatient nor an inpatient, and in this "in-between" zone it is sometimes harder to get the help you might need. You're probably thinking I'm kidding, but many tragic situations have happened as a result of inattentive emergency room care.

Here's the most common problem: when you go to the emergency room, you might start out with some symptoms that would indicate a minor illness. Then, during the time that you're being "worked-up" and you're there waiting for lab or x-ray results, the symptoms get worse or you start to feel new symptoms that would now point to a much more serious illness.

It often takes a patient advocate (your friend or loved one) to get adequate attention for this new development. Although it's hard to believe, emergency room personnel may not re-assess your situation unless *absolutely pressed to do so*; and that inattention to new or worsening symptoms has caused devastating results for many patients.

This sounds unbelievable, but consider this true case: a patient went into the emergency room with a kidney stone, and *while there* had the onset of crushing chest pain (that would have caused him to call an ambulance if he were at home), but because he was in the emergency room with a different presenting symptom *the staff didn't feel like they needed to complete an additional work-up for the new symptom*. He ended up with major damage to his heart from an unrecognized heart attack, and his health was compromised for the rest of his life.

So, when you're in the emergency room, it's *very important* that you have someone stay with you at all times, just as if you were an inpatient.

Also, re-read the "Don't allow doctors or nurses to ignore your concerns" section, and follow those instructions in the emergency room as well.

If you're in the emergency room and you don't feel your concerns are being taken seriously, then respectfully ask the doctor to write your concerns into the chart, and ask the nurse to enter your concerns into the nurse's notes.

If you're getting pushback from both doctors and nurses, mention that you believe this is a *patient safety issue*, and you need to talk with the hospital's patient advocate or the hospital administrator immediately.

Also be aware that studies have found errors in diagnosis as being a problem in emergency rooms.

In a 2005 study, Daudelin et al. found that about 26,000 patients are sent home annually from U.S. emergency rooms with a missed diagnosis of heart attack/unstable heart condition, which *nearly doubled the death rate for those patients*.*

"Diagnostic errors in the emergency department (ED) are an important patient safety concern A total of 79 claims (65%) involved missed ED diagnoses that harmed patients. Forty-eight percent of these missed diagnoses were associated with serious harm, and 39% *resulted in death*."¹

“The specialties with the largest proportion of highly preventable adverse events are general medicine ... and emergency medicine. Negligent errors in emergency and urgent care are usually due to delayed or incorrect diagnoses.”‡

“By directly involving patients in their own care, and encouraging them to inform their providers of any signs of errors, the level of safety can be elevated for all emergency department patients,’ ... [said] Thomas E. Burroughs, Ph.D., associate professor at St. Louis University Center for Outcomes Research.”§

“Many studies have confirmed that the major cause of malpractice claims in EDs [emergency departments] is a failure to diagnose ... As a specialty, EPs [emergency physicians] have developed skills that open them to potential errors in cognition [reasoning] such as confirmation bias ... Put simply, this means that ... [a doctor] may have an initial or a preconceived idea about something and interpret subsequent information or data so as to confirm that idea.”**

Just recognize that emergency room doctors, just like others, can make mistakes; and if you’ve been given a diagnosis, but it doesn’t seem right, or you’re getting worse, then get another opinion.

*Daudelin, Denise H., and Harry P. Selker. “Medical Error Prevention in ED Triage for ACS: Use of Cardiac Care Decision Support and Quality Improvement Feedback.” *Cardiology Clinics* 23 (2005): 601-614, *italics added*.

†Kachalia, Allen, Tejal K. Gandhi, and Ann Louise Puopolo et al. “Missed and Delayed Diagnoses in the Emergency Department: A Study of Closed Malpractice Claims from 4 Liability Insurers.” *Annals of Emergency Medicine* 49(2) (2007): 196-205, *italics added*.

‡Holohan, Thomas V., Janice Colestro, John Grippi, Jane Converse, and Michael Hughes. “Analysis of Diagnostic Error in Paid Malpractice Claims with Substandard Care in a Large Healthcare System.” *Southern Medical Journal* 98(11) (2005): 1083-1087.

§ED Management. “Most ED Patients Feel Safe, But Many Fear Errors.” *ED Management* 17(3) (2005): 33-34.

**Pines, Jesse M. “Profiles in Patient Safety: Confirmation Bias in Emergency Medicine.” *Academic Emergency Medicine* 13 (2006): 90-94.

Always trust your intuition

You care the most and know your loved ones the best. Listen to your intuition and follow it. Don't be talked out of it—it could save your loved one's life someday.

