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**Elder Care Featured Article:
Being a “Patient Advocate” When a Loved One is Hospitalized**

By Myra Gerson Gilfix



FEATURE: ELDER CARE

By **Myra Gerson Gilfix**

Advising Clients About Hospitalization And Operations

Add patient advocacy to your arsenal

As attorneys working with the older population and with individuals with disabilities, we frequently encounter clients and client family members who face hospitalization and operations. Because this isn't a "legal environment," we're typically not involved beyond the preparation of an advance directive or other document appointing health care surrogates.

Patient advocacy is nevertheless a growing need. We're particularly well positioned to develop guidelines, at minimum, for our clients who face medical challenges.

I'm not suggesting that this type of support and advice is in fact or should be deemed legal advice. It isn't. Rather, it's vitally important information that we're well-equipped to offer in light of our experience dealing with health care systems and the vagaries of aging.

Patient Advocate's Role

The hardest among us find it difficult to be assertive and independent or to gather facts when we're ill. The stress and anxiety of being ill are enough to keep us from functioning optimally at best. In addition, the hospital environment itself, perhaps unintentionally, strips us of our normal life role. We wear hospital gowns that are uncomfortable and too revealing. The most sophisticated and erudite among us are suddenly called by our first names, infantilized. A Nobel Prize winning client of my office, revered in the scientific community and always referred to as "Professor," was suddenly called "Jim" by nurses, certified nursing assistants and other well-meaning hospital staff members.

So, it's a multi-faceted challenge to ask the right questions and to protect ourselves.

While there are professional patient advocates who work in myriad settings, my focus is on helping families and friends with some tips about how to "be there" for their loved one when he's facing hospitalization. To understand how important this is, one unfortunately has to understand that hospitals aren't always safe havens. Far from it.

Clients Facing Hospitalization

Our clients are of all ages and health statuses—healthy, ill, injured, chronically ill, dealing with disabilities and/or providing care for others.

We counsel all of them about end-of-life decisions. We help them express how they want to be treated when they can no longer make decisions. We encourage them to think about whether they want to be home or in a hospital when end of life is near; whether they want to be kept on life support and under what circumstances. We bring up many other issues that arise when someone has permanently lost capacity.

We push them to communicate to those closest to them, as well as to their medical professionals, their assumptions, thoughts, values and feelings.

The Basics

We often know whether a client has a chronic or life-threatening illness, is about to undergo surgery and/or is facing an imminent hospitalization. These experiences are in the medical realm, and we may not be involved unless a specific legal problem arises or long-term care (LTC) costs are on the horizon. However, we're in a position to offer help. Knowing at least some of the basics about patient safety allows the opportunity to provide practical, possibly life-saving advice at a time when it can accomplish the most.



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Medical error. The unintended down side of medicine is the very real risk of being harmed by errors and certain practices that may occur in medical care and the institutions that provide it.

The estimated number of deaths in the United States resulting from preventable medical error differs. But, whether we accept the Johns Hopkins patient safety experts' number of 250,000 (or 700 deaths per day)¹ or the *Journal of Patient Safety* estimate of 440,000,² either number is too high.

Preventable medical error may now be the third leading cause of death in the United States—more than respiratory disease, accidents, stroke and Alzheimer's.³

Countless others suffer illness or injury as a result of medical errors.⁴

Dr. Martin Makary, professor of surgery at Johns Hopkins University School of Medicine in Baltimore and leader of the Johns Hopkins research,⁵ explained that the category of "medical error"⁶ includes a wide variety of ills, both systemic (such as failures in communication during patient transfers to another staff) and individual (such as individual doctors' mistakes). "It boils down to people dying from the care that they receive rather than the disease for which they are seeking care," he said.⁷

The Leapfrog Group⁸ underscored the need for hospitals to make patient safety a priority. However, more importantly from our perspective, the authors indicated that it's in our sphere as patients, family members and friends to "...protect [our]selves and [our] families from harm..."⁹

As a practical matter, family members and friends are well positioned to serve as patient advocates. They may be named in advance directives or other documents appointing surrogates in the context of medical care decision making. However, if they are, the directive can indicate the desire for help with the medical world even when capacity isn't impaired or absent. Perhaps you can suggest a document that allows Health Insurance Portability and Accountability Act (HIPAA) authorization for those whom the client/patient trusts the most.

Prominent geriatrician Dr. Mark Lachs asserts, "As perilous as hospitalization can be ... I firmly believe that there is no health-care venue where laypeople—patients, families, concerned friends and neighbors—can have a greater impact on improving outcomes of care."¹⁰

That's because many of the dangers of hospital care aren't a result of technical procedures and tests. Most of the time those are done well. The devil, as they say, is in the details—those that occur before, after or in between the procedures or surgeries. Errors, as noted above, aren't the only way that harm can be done.

The effects of hospitalization itself. Patients often suffer from being kept in bed too long, from confusion, even from malnutrition—all of which impair recovery. Concerned lay people can, among many other things, help to ensure that the patient is as mobile as soon as and as often as possible; they can facilitate communi-

Attorneys can alert clients to their own and their family's ability to facilitate recovery and avoid harm.

cation and help to coordinate multiple medical professionals. Even a reminder to a staff person or a visitor to wash hands can be lifesaving. This simple measure can prevent a virulent hospital-acquired infection.

When family members or other caring individuals take such steps, they're acting as patient advocates.

The Attorney's Role

The sheer number of clients we see who are facing medical issues, together with our awareness of the avoidable dangers of dealing with medical care, puts us in an opportune position to give practical tips and information that—while not legal advice—are uniquely valuable.

We can be proactive when a client or client family member faces hospitalization. We can encourage him to identify the best individual(s) who can help him survive a hospitalization and enjoy an effective rehabilitation experience. We can alert clients to their own and their family's ability to facilitate recovery and avoid harm.

Sometimes it takes a village. A client may not have the perfect individual to advocate and otherwise watch



out for her. Or, she may have one ideal advocate, but one individual alone can't be there 24/7. Friends and family, as well as church and synagogue groups may be called into play to help. A professional patient advocate may be needed if no other resources present themselves.

Elder law and estate-planning attorneys routinely counsel clients and family members about health insurance, Medicare, Medicaid, HIPAA, medical malpractice, asset preservation in the context of LTC and other matters. Attorneys tend to become involved in the health care setting only when problems arise. They become involved reactively.

I suggest that attorneys become much more proactive, offering clients practical, fact and research-based advice and information to equip them to serve as advocates for their family members. Give this advice and information, in particular, to individuals named in advance directives. Family members who'll be present in the hospital room or at doctor visits should be similarly educated and empowered.

In addition, you should add "patient advocacy" to your arsenal. Nothing prevents you from including it in your consultations, your correspondence or even your document preparation. It will expand your practice. It will add to the quality of health care for your client community as well.

Sample Documents

With this in mind, I share a typical handout for you, the practitioner, to expand, edit, adapt and distribute to appropriate clients and family members. (See "Sample Handout," this page and "Sample Pre-hospitalization Letter," pp. 45-46.) 

Endnotes

1. "Medical error—the third leading cause of death in the US," *BMJ* 2016; 353:i2139 (May 3, 2016), <http://dx.doi.org/10.1136/bmj.i2139>. Analyzing medical death rate data over an 8-year period, Johns Hopkins patient safety experts calculated that over 250,000 people die each year due to medical errors in the United States.
2. http://journals.lww.com/journalpatientsafety/Fulltext/2013/09000/A_New_Evidence_based_Estimate_of_Patient_Harms.2.aspx.
3. *Supra* note 1; www.hospitalandsafety.org/newsroom/display/hospital-errors-third-leading-cause-of-death-in-us-improvement-too-slow. Some argue that this estimate is too high, but that the real problem is a failure of the medical system to handle complex care. See <http://blogs.scientificamerican.com/guest-blog/the-real-cause-of-deadly-medical-errors/>.

Sample Handout

Give to clients facing impending hospitalization

We understand that [you are] or [a loved one is] facing hospitalization and perhaps an operation. This is a challenging and perhaps scary time for you.

We believe that the following information can help make this encounter with the medical world safer and more productive for your health.

THE BEST OVERALL, GENERAL ADVICE in the medical care realm IS TO TRUST, BUT VERIFY.

DON'T ASSUME:

- That you will reliably hear about test results. Establish a time by which you will be notified. Do follow up if you haven't heard.
- That medical professionals will communicate with each other about you. Don't be afraid to remind about tests done, information given.
- That all tests ordered or proposed are necessary.
- That your diagnosis is correct (40 percent are wrong). Get a second—and possibly a third opinion.
- That every doctor will actually read your chart. You may have to repeat your story many times. Keep track of your symptoms as well as so that you are able to accurately share what may be critical information.
- That the doctor will listen carefully and actually hear what you say.
- That everyone in the hospital practices good hand hygiene. Critically important to remind EVERYONE who comes into your room or in contact with you to wash or gel hands thoroughly.
- That surfaces are sterile. Use wipes to wipe down bedrails, the call button, etc.

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[com/guest-blog/the-real-cause-of-deadly-medical-errors/](http://blogs.scientificamerican.com/guest-blog/the-real-cause-of-deadly-medical-errors/).

4. www.washingtonpost.com/news/to-your-health/wp/2016/05/03/researchers-medical-errors-now-third-leading-cause-of-death-in-united-states/?utm_term=.a84018518677.
5. Dr. Martin Makary's research involves a more comprehensive analysis of four large studies, including ones by the Health and Human Services Department's Office of the Inspector General and the Agency for Healthcare Research and Quality that took place between 2000 and 2008.
6. "Medical error" has been defined as an unintended act (either of omission or commission) or one that doesn't achieve its intended outcome, the failure of a planned action to be completed as intended (an error of execution), the use of a wrong plan to achieve an aim (an error of planning) or a deviation from the process of care that may or may not cause harm to the patient. Patient harm from medical error can



Sample Pre-hospitalization Letter *

Send after speaking with a specific client

Dear [Client],

It was good to meet you and to talk with you today. First, I want to wish you the best possible outcome on your upcoming procedure/hospital stay. I wish you a speedy and complete recovery. Here's a brief summary of what we spoke about.

We understand that [you are] or [a loved one is] facing hospitalization and perhaps an operation. This is a challenging and perhaps scary time for you.

Below are some of the things we talked about as well as other tips to make your experience as health-restoring and safe as possible.

Pre-op Appointment [if it's a surgery]

To the appointment, bring a complete list of all of the medications (both prescription and over-the-counter) and supplements that you're currently taking. Any drug allergies?

Make sure you know which to stop taking, if any, before surgery, and how long before surgery to stop taking them.

Ask the surgeon how you can be as prepared as possible for surgery. For example, you'll want to make sure your blood pressure and blood sugar are well-controlled.

You'll want to be as healthy as you can be.

Ask how soon you can be moving and how to keep breathing as deeply as you can. Often, someone at the hospital can teach you appropriate breathing exercises.

At your pre-op appointment, ask as much as you can about what to expect of the procedure. Ask what you can anticipate in terms of recovery.

Ask about each possibility—both the possibility that the lymph nodes will be clear and the tumor removed, or what happens if the tumor isn't removed in terms of immediate recovery.

What are the plans for pain relief? Will there be any tubes involved post-surgery? Can they be safely avoided?

Many hospitals now employ a surgical checklist. This has reduced complications for patients dramatically. Ask if such a checklist will be used.

Preventing Harmful Bacteria

Find out about whether the hospital does a nose swab to test for MRSA prior to your procedure.

Also, follow instructions for cleaning your body prior to surgery.

Ask whether antibiotics will be given within an hour of your surgery and, in most cases, stopped 24 hours later.

Ask that you be kept warm during surgery; that helps you heal.

Prehab

Ask your surgeon about prehab programs. If it's safe to exercise before surgery, ask what you can and should be doing to be in good shape. For more information about prehab and its importance, see the article, "Prehab Improves Outcomes for Oncology Patients," www.accc-cancer.org/oncology_issues/articles/JA16/JA16-Prehab-Improves-Outcomes-for-Oncology-Patients.pdf. For strategies to improve physical and emotional health before cancer treatments and surgeries, see <http://awomanshealth.com/cancer-prehabilitation/>.

Participants learn exercises to build strength and endurance and receive nutrition counseling.

Reduce Stress

A study in the journal *Brain, Behavior and Immunity* found that relaxation exercises and guided imagery for three days before and seven days after surgery helped people heal faster. Try taking slow, deep breaths, or do meditation. The UCLA Mindful Awareness Research Center provides some ideas, at <http://marc.ucla.edu/body.cfm?id=22>.

Eat Well

Eat a well-balanced diet. Get healthy protein from foods like fish and beans—not protein drinks—for example.

The Role of Your Advocate

For your well-being while in the hospital, or during and right after the procedure, make sure you have someone with you.

Appoint an advocate or a team of advocates (to take shifts). A friend or family member can be invaluable to help monitor your care, asserting your needs, asking questions and keeping notes.

Ask your companion to help you during check-in and discharge as well.

This person can help you mitigate the risks of medical errors and infections by asking questions and monitoring hand-cleansing, medication administration, keeping IV lines and catheters clean (and making sure they're removed when no longer needed) and just speaking up in general if something doesn't seem right.

Shift Transitions

Another important time to ensure that information about you and your care is accurately communicated is during shift transitions. Meet the new staff on each shift. Hospital protocols vary in how effectively these important transitions are handled.

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Sample Pre-hospitalization Letter (continued)

Hand Hygiene Essential

You and your companion/advocate should absolutely (but nicely, of course) insist on clean hands for every single person who comes into your room. That includes nurses, doctors, other staff, friends, family, etc. Good hand hygiene is the single best way to avoid getting an infection while being in the hospital—or in any health care setting. Ask that anyone visiting you also clean hands on exiting your room.

Keep Other Surfaces Clean, Too

Don't be afraid to ask to wipe surfaces in the room, bedrails, call buttons, television controls, etc. with an antiseptic wipe.

Minimize Tubes

Ask if catheterization can be safely avoided. But, if the use of tubes, such as a catheter or a breathing tube, is unavoidable, ask every day whether they can be removed. The longer they stay in, the greater the risk of infection.

Medications

Track medications while in the hospital. Find out what these are and when they should be taken. Ask questions about why you're taking them. Make sure that medical staff is aware of what you're taking and that it's properly charted.

Ask specifically what you're to continue (and discontinue) to take after you're discharged, and for how long.

Get Moving If It's Safe

If your doctor says it's safe, make sure you get help to get out of bed and move. Don't hesitate to ask for help to get to the bathroom. Staying in bed longer than necessary is counterproductive to healing and recovery.

Minimize Sleep Disturbances

Some hospitals are implementing plans to reduce noise and disruptions so that patients have a better chance to sleep. Even if there's no such protocol, ask that disruptions be kept to true need and for help to keep it quieter.

Discharge Plan

Make sure you find out everything you need to know upon discharge. Will

you need care at home? Equipment? Physical therapy? Breathing exercises?

Know how to take care of any incisions—in detail, including what to use, how often to do it and what to look out for to report to the surgeon.

Common errors with incision care include touching it with unwashed hands or applying peroxide, lotion or antibiotic ointment to it. Don't do any of those.

Ask specifically how to keep the incision safely clean. Check it several times a day. If it's hot or red or seems to be pulling apart, call the surgeon right away.

Keep a Notebook

You can keep the notebook with you, and your advocate can use it to keep an eye on things, record what meds you're given, what tests are ordered or carried out, etc. You can use your notes to help avoid duplicate tests as well as unhelpful ones. Ask when tests and treatments are to be carried out.

Make sure you and your advocate know whom to call if there are any problems. Who's the charge nurse? Who's the attending physician (if other than the surgeon)? Ask who'll be in charge of your case when your attending physician isn't available, and get his phone number.

This is necessarily an incomplete list of things that you or your friend/family advocate can do. However, it should give you a sense of how much is possible to facilitate your recovery. Being "engaged" in your care boosts your well-being. Know that it's not only "okay" to ask questions or give reminders, it's affirmatively helpful to your care!

Again, I wish you all the best for a full healing and great recovery.

Warmly,
Myra Gerson Gilfix

* This sample letter is based on a specific client consultation. It's to a particular client who was about to undergo surgery to remove a tumor, written after a talk with her.

— Gilfix & La Poll Associates LLC

occur at the individual or system level. The taxonomy of errors is expanding to better categorize preventable factors and events. I focus on preventable lethal events to highlight the scale of potential for improvement. See *supra* note 1.

7. *Ibid.*

8. www.leapfroggroup.org/.

9. www.hospitalsafetyscore.org/newsroom/display/hospitalerrors-thirdleading-causeofdeathinus-improvementsstooslow.

10. Mark Lachs, M.D., *What Your Doctor Won't Tell You About Getting Older: An Insider's Survival Manual for Outsmarting the Health-Care System* (2011).