

Empowered Patient®

Hospital Guide

For

Patients and Families



Updated by Dr. Julia A. Hallisy
An Empowered Patient® Publication

Empowered Patient®

The Empowered Patient®

Hospital Guide For Patients and Families

An updated version of
The Empowered Patient®
Guide to Hospital Care for Patients and Families
©2009 Dr. Julia A. Hallisy and Helen W. Haskell
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and Strategies You Need to Know
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To Kate

And to my patient and understanding family, who sacrifices so much for this work and yet never loses sight of the larger goal. Above all, for Kate and all the others lost to medical error.

DISCLAIMER

This guide was written to educate and inform readers about the specific information and skills they need to be active participants in their medical care. It is intended to be a catalyst for patients and their advocates to cultivate mutually respectful relationships with healthcare providers, to learn to ask the right questions, and to communicate effectively about treatment options.

It is informational in nature and is not intended as a substitute for the professional advice of a physician, attorney or other advisor.

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Legend

The following icons are used in the guide to draw attention to action steps and safety strategies that are especially important.



Please Note



Very Important



Safety Item

PREFACE

My daughter, Katherine Eileen Hallisy, fought cancer five times before the age of ten. Kate was diagnosed when she was five months old with an aggressive eye cancer called bilateral retinoblastoma. Kate's decade-long plan of treatment included experiences with radiation, chemotherapy, reconstructive surgeries, the removal of her right eye, a hospital-acquired infection that led to toxic shock syndrome, and an above-the-knee amputation. During all those years of interacting with physicians and hospitals, we encountered virtually every challenge a patient and their loved ones can face.

My husband and I spent years of our lives in hospital hallways, waiting rooms, and emergency rooms. We became savvier and more educated the longer my daughter's illness went on. We had come across everything we knew the hard way – by watching our daughter suffer through medical errors, misdiagnoses, and communication glitches. These difficult experiences made us vow to find answers so that if we ever had to face a health crisis again, we would be prepared.

The information presented in this guide draws on the experience of my own family and of many other patients and advocates. It is backed up by over a decade of research into patient safety and health care quality. This information has come at a high price physically, economically and emotionally. But it has also taught us that tragedy does not have to define us. The quest for healthcare safety and quality has become a vehicle to help many advocates channel the pain of loss into actions that honor the memory of Kate and the many thousands of others harmed by adverse events. We all want this journey to be easier for those coming behind us.

- Julia Hallisy, January, 2012

Chapter One

WHERE TO START:

ADVOCATES AND IMPORTANT DOCUMENTS

Some of the most important choices you need to make about your medical treatment need to be made in advance, while you have time to review your options and make thoughtful, planned decisions.

The three main decisions include:

1. Choosing an **advocate**.
2. Naming a legal **health care proxy or agent** using a **health care power of attorney** document.
3. Detailing your **wishes** about your medical care in writing (an **advance directive or living will** document) and sharing them with your agent.

AN ADVOCATE

What is it?

Simply put, an advocate is someone who assists a patient while they receive medical care. Advocates provide encouragement and support and may help the patient with basic needs such as bathing, eating or walking. Advocates may also assume a more involved role by talking to providers, listening to treatment options, or keeping track of information in a patient journal.

You may choose the same person to be both your informal advocate and your legal health care agent, or have different people for each role. There are also professional advocates across the country that you can hire for a fee.

What I need to know:

- Plan ahead for the unexpected and give some thought to the person or persons you would want as your advocate.

- The person should not have any conflicts that will prevent him or her from acting as an advocate. The advocate must have the time to spend with the patient in the hospital (or can take the time off of work) and have a reliable means of transportation.
- The advocate should be comfortable asking questions, speaking to doctors about the patient and working as part of a team. *Remember, not all people are capable of being assertive – no matter how much they care about you.*
- The advocate is willing to support the patient's decisions even if he or she disagrees with any of the choices.
- The advocate **should know who is named as the Medical Power of Attorney** (if another person has been chosen) and should know where the patient keeps his or her copies of signed power of attorney documents.
- If you want your advocate to be able to do more than offer moral and physical support and have **the legal right to make medical decisions for you**, he or she must be named as your agent in a medical power of attorney (POA) document. (See next page).

IMPORTANT DOCUMENTS

It is difficult to overemphasize the importance of having the proper paperwork about your healthcare wishes and agents. If you do not state your wishes in writing, your doctor and your advocates may have to make decisions for you without knowing your personal choices. *Especially in an emergency, treatments may be used that are not what you would want.* There is no way around the fact that the best way to be certain that your wishes will be carried out is to sign legal documents. Documents you may encounter include:

GENERAL MEDICAL RELEASE FORM

What is it?

This form is a request from a patient or his or her legal representative to release medical records.

What I need to know:

- Signing a form to release records is standard operating procedure and it protects your privacy. No one is trying to create a roadblock for you – a request has to be signed to release the records.
- Hospitals will have medical record release documents for you to sign and will likely require you to use their form.

- If you are asking for your advocate to be able to access your medical records you will need to also sign a HIPAA (privacy) release form.

HIPAA AUTHORIZATION OR HIPAA RELEASE FORM (CONSENT TO DISCLOSE PROTECTED HEALTH INFORMATION)

What is it?

A HIPAA form gives permission for a doctor or hospital to use or disclose “protected health information.” Examples of protected information include the patient’s name, address, social security number, and the medical record itself. The HIPAA form confirms that patients have certain rights of privacy for the sharing of their health information.

What I need to know:



- The Healthcare Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law that grants specific rights to patients. (There are exceptions in mental health situations). One of the rights HIPAA gives you is **the ability to read and copy your medical records**.
- The HIPAA release form must list the specific health information that will be used, the name of the individual doctor or group you are authorizing to use the information, and the name of the person giving consent. Physicians and hospitals will have their own HIPAA forms for you to sign.
- Under the HIPAA Privacy Rule, healthcare providers are *allowed* but not *required* to discuss your condition or treatment with friends or family members.

MEDICAL DURABLE POWER OF ATTORNEY

What is it?

This form is a legal document that confirms your choice of a person (who may also be called a **healthcare agent, attorney-in-fact, or proxy**) to make medical decisions for you *if you become unable to make decisions for yourself*. A medical power of attorney document (also referred to as a **POA, healthcare power of attorney, or healthcare proxy**) is the *single most important form* to have in place before a hospitalization.

What I need to know:



People are often afraid to sign a medical POA form because they fear it may give their agent too much power. If you are able to make your own decisions, you will be able to do just that. **Your healthcare agent cannot overrule your choices** as long as you are able to make your own decisions. This is not a scary document – it is designed to protect you!

- A POA can be revoked at any time. If you change your mind about any details in your POA, including the person you have chosen as your legal agent, ***you can change your mind and update the document*** by adding or removing people.
- If you become unable to make your own decisions and you do not have a signed power of attorney form, **your doctors may make decisions for you**. The doctors will likely not know you personally and they may not make the decisions you would want.
- **The medical power of attorney works best when used with an advance directive.** Your healthcare agent needs to know your wishes as you have detailed them in your advance directive. The power of attorney form only names the person in charge - the advance directive *tells them what you want them to do*.
- Most states have a standard medical power of attorney form that can be downloaded from the Internet and signed in the presence of a witness or witnesses. It may need to be notarized, so check. Go to <http://www.caringinfo.org/stateaddownload> to find your state's form.
- It is important to **have your adult children sign healthcare powers of attorney as soon as they turn eighteen**. Without a medical POA, parents have no legal right to be given information about their adult children, even in an emergency. If your child attends college out of state, be sure you sign the power of attorney form for that state as well as one for your home state.
- Your healthcare proxy should keep a copy of the signed POA form in a safe, and readily accessible, place. In general, a safe deposit box is NOT a good choice as it may not be easy to access. **Never give a healthcare provider your original copy of a legal document.**

ADVANCE DIRECTIVE (LIVING WILL)

What is it?

An advance directive or living will is a legal document that allows patients to state their decisions about their medical treatment and end-of-life care in writing. An advance directive is a way for you to *communicate your personal health care wishes* to family members and doctors if you become too ill to make your own decisions.

What I need to know:

- It is very important to have someone speaking for you who knows your wishes concerning end-of-life care.
- Most states have their own versions of advance directives, often as part the healthcare power of attorney document. **Some states require advance directives to be notarized**, so be sure to check. In general, advance directives are easy to obtain and simple to fill out.

- Some state advance directives are very general, while others address specific issues such as breathing machines (ventilator use), kidney dialysis, and feeding tubes. Visit <http://www.caringinfo.org/stateaddownload> for an advance directive for your state.
- The information provided here is not a substitute for professional legal advice. **You may want to use the services of an attorney** to ensure that the documents are complete.

PHYSICIAN'S ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

What is it?

A personal wishes form that is a cross between an Advance Directive and a Do Not Resuscitate order. The POLST form details your decisions about specific medical treatments including comfort measures, antibiotics, nutrition and feeding tubes, and IV fluids (hydration).

What I need to know:

POLST is a medical order signed by a physician and used by people who are seriously ill or elderly to state their wishes about their care. The POLST form can be transferred between facilities – it is part of the medical record and it follows the patient wherever they are receiving care. Patients can decide between full treatment, limited additional interventions, comfort care measures only, and allowing a “natural death” (the Do-Not-Resuscitate option) for the medical treatments listed above. A POLST form can be changed, but a doctor’s signature is needed.

DO-NOT-RESUSCITATE ORDER

What is it?

A do-not-resuscitate order, or DNR, is a form stating that the patient does not wish to have their heart function or breathing restarted once it has stopped.

What do I need to know?

- **A DNR must be obtained from and signed by a doctor** – this is not a form you can download on the Internet and sign on your own. Because it is a doctor’s order, **only a physician can revoke a DNR**.
- A DNR is supposed to go into effect when heart function or breathing has stopped. **Patients with do-not-resuscitate orders are still entitled to “comfort care”** such as having medications for pain and receiving oxygen to breathe easier.
- **DNR’s are not in effect during surgery**, when patients routinely have their breathing managed by machines.
- A properly signed DNR form must be readily available to paramedics or other emergency personnel, **or they will be required to start heroic life-saving measures**. Emergency responders cannot take anyone’s word that the patient does not want to be resuscitated – they must see a signed DNR document with their own eyes.

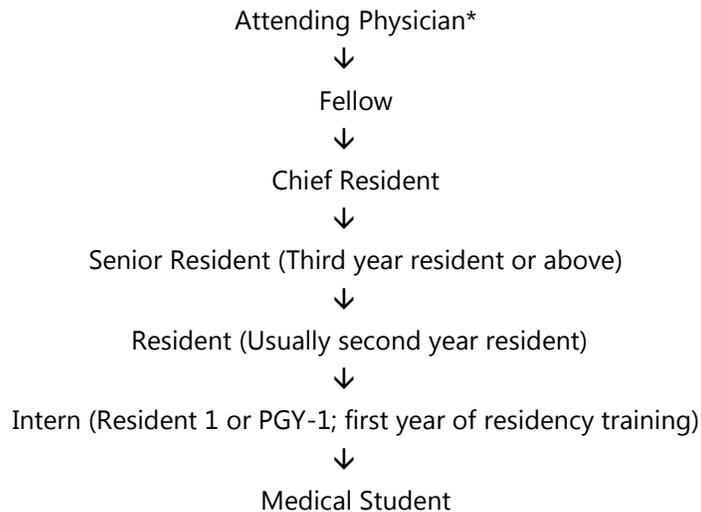


Chapter Two

YOUR HEALTHCARE TEAM

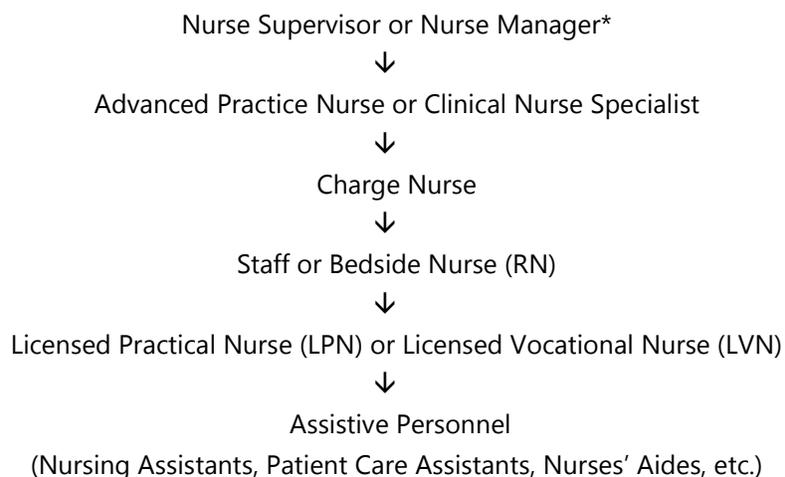
A modern healthcare team necessitates the collaboration and communication of a number of professionals, each of whom possesses knowledge, ideas and experience that is geared to the specific needs of patients. The following charts and corresponding definitions will help you understand the levels of authority and the unique skills of the members of the hospital hierarchy.

Physician Hierarchy



* If your Attending Physician cannot address your serious concerns, contact the Department Head or the Medical Director

Nursing Hierarchy



*If the Nurse Manager cannot address your serious concerns, ask for the Director of Nursing or Chief Nursing Officer (CNO).

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ATTENDING PHYSICIANS are the most senior doctors directly responsible for your care. Simply stated, they are the bosses of the house staff. They are responsible for the quality of care delivered to each patient under their watch and they may also train and supervise residents (doctors-in-training). If you encounter a problem that your attending physician cannot resolve, ask for the **Department Head** or the **Medical Director**. Department heads are doctors who manage specific areas in the hospital (such as orthopedics or pediatrics). Medical directors oversee all of the staff doctors.

HOSPITALISTS are doctors who specialize in caring for hospitalized patients. They are often employed by the hospital to focus only on the specific needs of hospital patients.

HOUSE STAFF is a term that includes all doctors-in-training: interns, residents, and fellows. In teaching hospitals, the house staff provides a great deal of your medical care and is supervised by more senior medical staff. (See definitions of doctors-in-training below).

FELLOWS are doctors at a level of responsibility right below attending physicians. Fellows have completed their residency training and are obtaining advanced training in a particular specialty. Fellows often work as a back-up to attending physicians.

RESIDENTS are classified by their level of training. Depending on the year of the resident, there are many levels of skill. All doctors complete at least a 3 year residency and may study from 4 to 7 years for extra training in a specialty such as surgery. Titles can vary from hospital to hospital and a new doctor can be called an intern, an R-1 for residency year one or PGY-1 for the first "post-graduate year." (See levels of residents below, starting at the highest level).

Fifth and Sixth Year Residents are often training to become surgeons and spend extra years learning surgical techniques. They may have limited direct contact with patients.

Resident -4 or PGY-4 is a doctor who is training for an extra year or completing research projects.

Chief Resident is doctor who has been chosen by the program director to be the supervisor of the other residents. The "chief" has duties including scheduling and supervising the residents, caring for patients, arranging for speakers for the residency program, and evaluating the performance of the residents he or she oversees.

Resident -3 or PGY -3 is a doctor in her third (and possibly last) year of training who is usually much more confident and knowledgeable. Third year residents are making decisions about where they will practice, what medical group they might join, or whether they should obtain more training.

Resident -2 or PGY-2 refers to the second year of residency training. These doctors assume more responsibility when working with patients and they help train and supervise first-year residents. Their experience, ability, and confidence level is increased but they now have the additional duty of supervising other doctors.

Intern, Resident -1 or PGY-1 refers to doctors in their first year of the residency program. First year residents are the new kids on the block and they may seem nervous or unsure of themselves. They are constantly being evaluated by their bosses and their place in the residency program depends on their performance. Do not expect first year residents to have the same level of skill as more experienced doctors.

MEDICAL STUDENTS are not yet doctors but they may be part of your care team. Medical students do clerkships, or rotations, which allow them to work in the residency program to gain hands-on experience with patients. Medical students may be writing orders in your chart, which need to be reviewed by a licensed doctor. Find out if medical students will be writing orders for you and ask which physician will review and sign these orders.

NURSES comprise the largest segment of healthcare workers and because they are the most hands-on of all hospital caregivers, nurses may be an important advocate for you. Registered nurses attend a state-approved school of nursing and may obtain a two-year associate degree (ADN), a three-year hospital program (ASN) or a baccalaureate degree (BSN) after the completion of a four-year university program. A nurse is continuously observing, monitoring, and assessing your progress, which often allows him or her to detect the first signs of a complication.

NURSE SUPERVISORS and **NURSE MANAGERS** are part of the leadership team and are considered “nursing executives.” There is usually a nurse manager or nurse supervisor available 24 hours a day who is the direct supervisor of the charge nurses. With few exceptions, a nurse manager or supervisor will be available to patients. Nursing supervisors and nurse managers are overseen by a **Director of Nursing** or a **Chief Nursing Officer (CNO)**.

ADVANCE PRACTICE NURSES are registered nurses who have completed advanced training beyond the basic criteria that all RNs must fulfill. They meet higher educational and clinical requirements than other nursing groups. Within this category, there are two groups and both require masters or doctorate degrees in nursing:

- **Nurse practitioners (NP)** work closely with physicians and are qualified to diagnose and treat common illnesses and injuries. A NP can actually function as a patient’s main healthcare provider.
- **Clinical nurse specialists (CNS)** function as experts whose focus is on a specific area of nursing practice. For example, a CNS may specialize in treating surgical, diabetic, geriatric, cardiovascular, psychiatric, or pediatric patients.

CHARGE NURSES are responsible for scheduling and directing the nursing care in a specific ward or unit during each assigned shift. The charge nurse is the first person to contact if there is a problem with your bedside nurse. If you are not satisfied with her response, ask to speak to the nurse manager.

STAFF NURSES are registered nurses who provide direct patient care at the bedside. Your staff nurse will be up-to-date on your vital signs, medications, and overall treatment plan. Your bedside nurse is the first nurse to consult if you have a question or a concern.

LICENSED VOCATIONAL NURSES OR LICENSED PRACTICAL NURSES (LVN or LPN)

completes 1500 hours or approximately one year of training and is licensed by the state in which he or she works. In general, LVNs perform basic patient duties such as taking vital signs, monitoring IV's and other catheters, administering oral medications, and writing notes in the patient's chart. LVNs collect patient information but they do not evaluate or interpret it, since this requires the clinical skills of a registered nurse.

ASSISTIVE PERSONNEL work in a supportive role to a licensed nurse. Assistants have duties such as helping patients with their basic needs, answering call lights and helping patients bathe or eat. Some assistive personnel, including nurses' aides (NAs) and nursing assistants may be licensed by their states. Other types of workers such as patient care assistants (PCAs) may have brief training courses that do not require passing a state licensing exam.

OTHER IMPORTANT TEAM MEMBERS

CASE MANAGERS are registered nurses or social workers who coordinate the care of patients with complex treatment plans or chronic diseases. The case manager evaluates your unique needs, provides an assessment, and helps direct your care plan in the hospital. If you have a complex or chronic health issue, ask if you can work with a case manager.

PALLIATIVE CARE team members work to control side effects, minimize pain, and ensure that the individual needs of patients and families are part of the care plan. The team often includes doctors, nurses, social workers, and chaplains who spend time answering the patient's questions, assisting the patient in making decisions about their care, and dealing with the side effects of treatment.

Palliative care is often misunderstood by patients, who think that it is only for those who are terminally ill and not expected to recover. While hospice, or end-of-life care, is one of the many options available to palliative care patients, it is not the only outcome. Patients who work with palliative care specialists tend to spend less time in the hospital, feel more comfortable and in control during their care, and experience less pain.

DISCHARGE PLANNERS are social workers or registered nurses who coordinate the plan for your care after you leave the hospital. The discharge planning process often begins as soon as you are admitted, so ask to speak to a discharge planner at the beginning of a hospitalization if you have any special needs.

Discharge planners arrange for a variety of services, ranging from rides home and picking up medications to assistance with insurance and hiring home care employees. Discharge planners help ensure a successful transition from the hospital, whether it is home, to a rehabilitation facility, or to long-term care.

WORKING WITH YOUR HOSPITAL TEAM

- When you are admitted, tell your bedside nurse that you are interested in **“patient-centered care”** and **that you would like to meet with the team during daily rounds**. Have your questions ready: What is the care plan for the day? Are doctors ordering any new medications or tests? How can the patient or advocate help?
- **Have an advocate** at the hospital who can speak to the doctors during daily “rounds” if you are unable to do so.
- Remember that **staffing may be lower on weekends and holidays**, so schedule elective procedures at other times. These are especially important times to have an advocate with you.
- **Write things down in a patient journal** (a free patient journal can be downloaded at www.EmpoweredPatientCoalition.org/publications) to help you or your advocate stay up-to-date on the most recent plan for care. Ask to be notified if there are any changes in the plan.
- Always have a way to **contact your surgeon**, or their answering service, in case of an emergency. Ask your surgeon if he will be staying in town for the first few days after your procedure and how he can be contacted in an emergency. If another doctor will be on call for him, be sure you have his or her full name and direct contact number.
- Know that you can always **request a consultation with a more experienced physician** either in person or by phone. Ask specifically for the attending physician if you have serious questions about the decisions made by residents. Be sure that the person who is contacted is an attending physician and write down her name in your patient journal. If your hospital has an intensive care unit you may be able to consult with an **intensive care specialist, or intensivist**, for serious situations.
- If the **staff does not agree with you about the need to contact the attending physician**, and *you believe that you or a loved one is being placed in jeopardy*, write a note explaining that you requested, but did not see, the attending. Sign and date your note, ask for a copy, and request that it be added to your medical record.
- **Ask if your hospital utilizes Rapid Response Teams (RRT)**. A RRT is a group of highly-trained hospital staff members who respond to a sudden decline in a patient’s health. Usually, the nurse calls the team but in some hospitals, patients and their advocates can call the team directly (This type of program may be called “Condition H” for “Help.”) Ask if patients can call the team and, if so, be sure the number is posted by your phone.



Chapter Three

INFORMED CONSENT

Hospitalization requires that patients give their consent to be treated by the hospital staff. Additional consent is necessary for invasive procedures and surgeries. It is important to realize that the consent process is much more than a form with a signature. Aside from representing a moral, ethical, and legal requirement for providers, it recognizes and protects a patient's right to know what is being done to their body. Informed consent allows for patients to ask questions, to understand the answers they are given, and to know who will be performing their procedure.

TRUE INFORMED CONSENT includes the following:

- **Consent should be obtained by the doctor who will be performing the procedure** as recommended by the American Medical Association (AMA). The informed consent process should not be delegated to other staff members who may not be able to answer all your questions.
- **The doctor should have a thorough discussion with the patient** on the details of the treatment or procedure, why it is needed, any reasonable alternatives, the risks and benefits, side-effects and what will happen if the patient does not have any treatment at all.

UNDERSTANDING YOUR ADMISSION FORM can be a challenge but knowing what to look for will make the process much easier.

- 
- If you are in a **teaching hospital**, it is likely that your admission form will state you will be cared for by medical students, interns, residents, and fellows who are supervised by an attending physician. If you have any reservations about being seen by students, you may want to consider using a private hospital.
 - The form may state that the interns, residents, or fellows will be under the **“direction” or “supervision” of an attending physician**. You need to ask the attending physician personally how involved he plans to be in your care and how he can be reached if there is a problem.
 - If wording on the admission form makes you uncomfortable, **ask if you can make changes** or draw a line through the parts that are troubling you. Be sure to initial any changes. Some institutions will not allow this, so ask about the policy. The admitting office should be able to find the answers to any questions you may have.

UNDERSTANDING YOUR SURGICAL CONSENT FORM will be much easier if you meet in advance with the surgeon who will be performing the procedure before you are expected to sign the form. Here are questions to ask and what you need to know:

- Ask about the **identities and experience level of all people who will participate in your surgery**. You should know if any residents or students will be directly involved in the operating room. How many procedures like yours have they completed? How much supervision will the lead surgeon **provide**?
- Be specific about the **amount of direct supervision** provided by your surgeon. Will she be present for the entire surgery from start to finish? Or, will she supervise indirectly or for only part of the procedure?
- Time should be set aside for you to meet with your **anesthesiologist**. Ask if the anesthesiologist is board-certified and if he will be physically present and responsible for your entire case. (Please see Chapter 6 for a detailed discussion on anesthesia).
- **Ask if your surgeon will be using the services of an assistant surgeon**. Which parts of the procedure will be handled by the assistant surgeon?
- Will there be any **non-medical personnel in the operating room** such as sales representatives? Their presence could be a source of infection, a distraction, or it could mean that the surgeon is using a new piece of equipment or an unfamiliar technique.
- **Plan to request a copy of your operative report** from the hospital and confirm with your surgeon when you sign the consent form that he will be listed as the “responsible surgeon” in the report. The lead surgeon is generally listed as the responsible surgeon. An assistant surgeon or surgical resident is usually listed on the operative report as the “assistant surgeon.”

THE COEXISTENCE OF MEDICAL EDUCATION AND PATIENT CARE

Does this mean that patients should never agree to allow a resident to use their surgery as a teaching opportunity? If this were to happen, doctors would never acquire the hands-on experience they need to become skilled at performing surgery. If physicians are forthcoming and transparent about the members of the surgical team, an overwhelming majority of patients would willingly agree to participation by residents. Here is what patient’s need:

- ✓ To be informed in advance about all the members of the surgical team.
- ✓ To clearly understand who is the lead surgeon.
- ✓ To know the names, titles, and experience levels of the residents involved in their treatment and surgery.
- ✓ To know how much responsibility will be delegated to residents and assistants.
- ✓ To know how much direct supervision will be provided by attending physicians or lead surgeons.
- ✓ Continued involvement by surgical residents during the recovery period, which inspires confidence in the teaching system.

Chapter Four

YOUR MEDICAL RECORD

THE PLAYBOOK OF YOUR LIFE

Even with the recent health care reform mandate for doctors and hospitals to implement electronic medical records (EMR), the recommendation that patients begin using personal health records (PHR), and the ultimate goals of integrating all of our health information into an accessible electronic health record (EHR) and then sharing that record through a health information exchange (HIE), few patients give much thought to the written records that chronicle their health care experiences. Most patients don't realize that the record is the point of convergence of every single piece of crucial data relating to their health.

Many people assume that their medical record is inaccessible to them, but today's patients have unprecedented legal access to their medical records. You should read through your medical record as it may give you a completely new perspective on your treatment.

It is important for patients to take the time to maintain a complete and accurate personal medical history. A medical history should be a living document that patients manage themselves and keep accessible and updated. Just as hospitals keep a medical chart when you are an inpatient, patients need to keep their own records as well. A complete personal history is the foundation of your medical record and a form is included in the free Empowered Patient Journal available at www.EmpoweredPatientCoalition.org/publications to use as a starting point. Keep the completed form handy as you will likely be asked about your history many times during a hospital stay.

Important considerations about your medical records:

HIPAA PRIVACY RULE AND MEDICAL RECORDS

In most situations, you are guaranteed access to your medical records under the federal Healthcare Insurance Portability and Accountability Act, or HIPAA, for short. (Remember, there may be exceptions for mental health records).

What I need to know:

- One of the rights HIPAA gives you is **the ability to *inspect, review, and receive copies of your medical records***. If you are denied access to your records, it may be a violation of federal law.
- **If you find an error in your medical record**, contact the hospital or provider. If they agree that there is missing or erroneous information, they are supposed to make corrections. If they do not agree with your request to make changes, you have the right



to submit a brief statement of disagreement to be added to your record. Be sure to date the letter and keep a copy.

- A provider may **share medical information** with a relative, friend, or other person of the patient's choosing. If the patient becomes unable to make their own decisions, these oral agreements to share information may not be continued. This is why you need signed documents naming a legal agent.

VIEWING MEDICAL RECORDS WHILE IN THE HOSPITAL is both possible and appropriate.

Here is what you should know:



- Federal law allows for patients or their agents to view the medical record during a hospitalization. A HIPAA privacy release needs to be signed. Remember, if you want your advocate to have guaranteed access to your record, be sure he or she is named as your legal agent.
- Speak to your nurse, the charge nurse, or the nurse manager to work out a "**plan for access**" to view the record on a regular basis. Be respectful of the work flow of the unit and ask for the most convenient time and location.

WHAT TO LOOK FOR IN YOUR MEDICAL RECORD

- Are the notes legible?** Is any information missing or incorrect? If you find an error or omission, ask for the hospital's policy on adding your own brief note to the record to clarify.
- Do the notes **provide enough detail?** Be sure the language is not too vague to accurately document the situation.
- Are the providers providing the **rationale for their professional judgment?** If they note that a patient is "now responding" or "clinically improved" they should include the facts that back up their opinions.
- Are the doctors communicating with each other?** Notes should mention the opinions and recommendations of other providers and clearly indicate that they have consulted with each other – either verbally or in writing.
- Do any of the doctors disagree with the treatment plan?** Reading the notes will tell you which doctors have reservations and allow you to consult with them directly.
- Is the "**differential diagnosis**" listed? A differential diagnosis contains all of the possible conditions, with the most likely ones at the top of the list and helps the staff keep a broad focus. Be sure potential diagnoses are eliminated once testing rules them out.

- Is every possible treatment option being explored?** An order may have been overlooked or an important test not scheduled.
- Does the level of uncertainty or disagreement lead you to believe you need a **second opinion**? You may want to choose a doctor who does not work at the hospital you are using.

OTHER THINGS YOU NEED TO KNOW

- ✓ **Request copies of your medical record** and keep them in a safe place. Be sure to have copies of operative reports, discharge summaries, any dictated notes from doctors in specialized units such as the ICU, and MRI, CT, x-ray and pathology reports. Expect to pay a fee when requesting records.
- ✓ Ask for MRI scans, CT scans, sonograms and x-rays to be **saved on a CD or flash drive in DICOM format** to take with you before you leave the imaging department. There is usually no charge for burning a CD but you may want to bring your own storage device to be sure. Keep the CD with the copy of the written report.
- ✓ **Bring a laptop or a medical dictionary** to the hospital to help you understand medical terms. Many hospitals have free wireless access for patients and visitors.
- ✓ **Keep your own notes in a patient journal.** Download a free Empowered Patient Journal at www.EmpoweredPatientCoalition.org/publications.

Chapter Five

THE DIAGNOSTIC PROCESS

An accurate diagnosis is the first step in deciding on a plan and moving forward with treatment. Patients can assist in this process by keeping track of their symptoms, questions and concerns, and sharing them with their providers each step of the way. Patients should be prepared to research their diagnosis, follow up on test results, and obtain second -and even third - opinions, if needed.

ENSURING AN ACCURATE DIAGNOSIS

- **Research your condition** to be sure the description matches your symptoms. Be sure you have the complete medical name of your diagnosis to make it easier to search for information. Research can be done while in the hospital using a laptop.
- Set up a **Google alert** with the name of your diagnosis to find doctors who specialize in your condition, recent news articles, and any new research or clinical trials being conducted.
- If you have any nagging doubts about your diagnosis, arrange for a **second opinion**. This is a time to *trust your intuition*. Always ask, "What else could this be?"
- Provide an accurate and **updated medical history** to your providers. Include any information about conditions that may run in your family.
- **If your symptoms change or get worse**, alert your physician and immediately report anything new.
- For a diagnosis of cancer, ask if the patient's case can be presented to a **tumor board** to obtain the input and experience of many specialists.
- **Understand your care plan** and write down information in your patient journal to know which tests, treatments, and consultations are pending.
- For complex treatment plans for diseases such as cancer, **ask for a copy of the written protocol** listing chemotherapy drugs and dosing schedules.



TESTS

- Tell your providers that you are interested in understanding **why each test is being ordered and what information it will provide**. Ask, "How will this information affect my treatment plan?"



- **Research which tests are appropriate for your condition.** If your research leads you to a commonly used test that is not being ordered, ask if it would be helpful.
- **Do not assume that “No news is good news!”** If you don’t hear about test results, be sure to follow up. This will be much easier if you track your pending test results in your patient journal. Your nurse may be able to call the lab directly if results are delayed.
- Take the time to ask that your **test results be confirmed by a second radiologist or pathologist**, especially for x-rays, CT and MRI scans and pathology specimens.
- It is often standard operating procedure for **all tissue biopsies to be verified by a second pathologist**, but you cannot just assume this is the policy at your hospital, so you need to ask that it be done. This is especially important if the biopsy reveals a tumor, or malignancy.
- Be sure the staff **checks your ID band** before a test or procedure. Confirm that **your name and medical record number is listed** on all written requests for tests and be sure your **specimen containers** have your name on them.
- If you are having x-rays or scans, you should know how many **“views”** are needed and if your scan requires the injection of any **contrast mediums, or dyes**. Forgetting to add the dye could lead to repeating the test and being exposed to more radiation.



A SECOND OPINION ABOUT YOUR DIAGNOSIS is appropriate if your physician is unsure of the diagnosis, if there are questions about your disease, or if your own intuition is causing you doubt. Remember, you may want to consult a doctor who is not associated with your current doctor or hospital. Hospitals will usually allow outside opinions of their patients if the appropriate liability forms are filled out. The question to ask is *“What do I have to do to have an outside doctor provide a second opinion?”* A second opinion may be needed if:

- The **diagnosis is uncertain** or unconfirmed. An accurate diagnosis is vital to the formation of a successful treatment plan.
- The diagnosis is a **serious, rare, or life-threatening illness**. These types of illnesses warrant a consultation with a recognized specialist.
- Your **biopsy results are inconclusive or tests you have already completed need to be repeated** in order to firm up a diagnosis. You can obtain **second opinions from independent pathology labs** on your slides. Google “second opinions on pathology results.” Johns Hopkins and MD Anderson Medical Centers are good places to start.
- There are **questions about the “staging” of a malignancy or disease**. It is not unusual at the time of a cancer diagnosis for tumors to be present in two or more organs, which may make it hard to tell which one is the “primary,” or original tumor. Treatment is often based on knowing the site of the primary tumor, so you need to be as sure as possible.

A SECOND OPINION ABOUT YOUR TREATMENT PLAN may be needed if:



- The **treatment plan is unacceptable to you** because it is either too aggressive or not aggressive enough. Treatment plans can often be changed or customized to meet a patient's needs.
- The **treatment is simply not working**. If you don't respond to the treatment plan as expected, it could mean that the initial diagnosis isn't correct. It may be time to **re-evaluate the original diagnosis and explore other treatment options**.
- The patient is told that there is **no hope** or is only offered pain relief as treatment.
- There is a difference in philosophy about when to **continue treatment or to end it**. Doctors may decide that further treatment is "futile" and recommend stopping treatment when you want to move forward. Be sure you have talked to your doctor in advance about your treatment goals.

OTHER REASONS FOR SEEKING A SECOND OPINION

- ✓ **You aren't feeling like part of the team.** The amount and the quality of the communication and interaction between you and your doctors is the foundation of care that is "patient-centered."
- ✓ **Your doctor is not communicating effectively.** You should assume responsibility for keeping the lines of communication open, take part in decisions about your care, and remind the team that you want to be included.
- ✓ **Your side effects are not being managed properly.** Problems with nausea, immune function, and pain management may need the expertise of a specialist.
- ✓ **You aren't comfortable with the doctor's level of experience, decision-making ability, or personality.** The doctor should have an approach and a demeanor that allow you to work together toward a common goal.
- ✓ **Your intuition is telling you that something just isn't right.** Sometimes, your common sense or a gut feeling can rival years of formal medical training.

Chapter Six

SURGERY, ANESTHESIA AND PAIN CONTROL

A modern healthcare team involves the skills and expertise of many people and nowhere is this put to the test more than during surgery. The patient and their advocate are part of this team and have important roles to play both before and after surgery. The following headings discuss the specific areas in which patients and their advocates can make a big difference.

SHOULD I HAVE SURGERY? Most patients have time to carefully weigh their choices before deciding on surgery. The following may help you decide:

- I know **why the surgery is needed**, what condition it may help improve, any and all alternatives, including doing nothing.
- I know **how successful this surgery is** at correcting my problem. I know if this is a new or experimental procedure.
- I know the **short and long-term risks** associated with this procedure and I am aware of all the potential **side-effects and serious complications**. I know what to expect during my **recovery**.
- Is there a **minimally invasive technique** such as laparoscopy that can be used for my surgery?

CHOOSING A SURGEON is a critical part of your decision-making process. Ask people you trust for a referral and research the surgeon yourself. In addition, you need to:



- **Ask how many times the surgeon has done this exact surgery.** Has he or she had good outcomes? What is his or her rate of complications, including infection? Expect specific numbers and not vague generalizations like “not many.”
- Ask if the surgeon is **board-certified in the specialty you require.** Check to see if she is a member of the American College of Surgeons (www.facs.org) and the American Board of Medical Specialties (www.abms.org). Check medical board disciplinary actions at www.patientsrighttoknow.org.
- **Know if the surgeon is part of your insurance plan.** Just because you were referred to him doesn't mean that he accepts your insurance. This also true for anesthesiologists, hospitalists, radiologists, and pathologists.
- **Feel comfortable with the surgeon** and have all your questions answered without feeling rushed or intimidated.

QUESTIONS TO ASK YOUR SURGEON

- Will you be performing my entire surgery?** Will you be assisted by any other surgeons, residents, or students? How much supervision will you be providing to residents? If being assisted by others, will you be present in the operating room for my entire surgery? Who will talk to my loved ones in the waiting area after surgery?
- Should I make any lifestyle changes** such as losing weight or not smoking?
- Will I need to **stop taking any of my regular medications** such as blood thinners? Should I take my **usual medications the morning of surgery**?
- Will I need **antibiotics** one hour before surgery? (Called antibiotic prophylaxis or premedication). Does my surgery carry a higher risk of infection? Some surgeries, such as those on the bowels or intestines, carry a greater risk of infection.
- Is there a possibility that I could need a **blood transfusion**? Should I bank my own blood ahead of time? Why or why not?
- Will I need any **implanted medical devices** such as screws, plates, rods or pins? Do I need any tissue grafts from animals or human cadavers? Will I need to take antibiotics to prevent bacterial endocarditis (heart infection) after having this implant? For how long?



WHERE TO HAVE SURGERY is yet another part of your pre-surgical preparation. Surgery may be scheduled in a hospital, a surgery center, or the doctor's office. It is important that you understand why the surgeon is recommending a certain setting. Here is what you need to consider:

- **Research your hospital online.** Check if the hospital is accredited by The Joint Commission at www.Qualitycheck.org. Explore hospital quality ratings at www.hospitalcompare.hhs.gov to check infection rates and surgical outcomes.
- Find out if the hospital is a **teaching institution**. In a teaching hospital, much of your care will be provided by residents.
- Ask if the hospital has an **ICU** staffed with specially trained physicians called **"intensivists."** Also ask if the hospital has a **rapid response team (RRT)** and if patients and their advocates can call the team directly.
- If your surgery is scheduled for a **private office or surgery center**, ask if a board-certified anesthesiologist will be providing your sedation and inquire how **emergencies** are handled. There should be staff members with training in advanced life support protocols. The surgeon should have privileges at a local hospital, just in case you need to be admitted.

SCHEDULING SURGERY is usually done around the doctor's availability or the patient's needs. There are other considerations as well:

- Schedule surgery **early in the day on a week day**, if possible. There is often less staff available on nights and weekends.
- Try to **avoid having surgery around major holidays** when regular staff may be on vacation.
- New medical school graduates start their residency programs on July 1st each year. Expect to see residents who are new to their assignments at this time.

QUESTIONS TO ASK ABOUT YOUR RECOVERY

- How can surgeon be reached for serious complications?**
- How will post-operative issues such as nausea, vomiting, or severe headache be managed?** Which staff member will be making decisions and writing orders for the above conditions?
- What is the plan for **pain control**? Will the patient need to use pills, IV medications or a PCA (patient controlled analgesia) pump? Which staff member will write the orders for pain medications and how can he or she be contacted?
- Will stool softeners be needed to **prevent constipation** from narcotic pain medications?
- Will the patient have any **drains, catheters, tubes, or other machines** attached to him during recovery?
- Do you expect the patient to spend any time in a specialized unit like the **intensive care unit (ICU)**?
- What will **the wound** look like? Will dressings need to be changed in the hospital or at home? Will the wound be left open or closed with stitches, metal staples, or glue?
- Does the patient need **blood-thinning medications** after surgery to prevent blood clots? Should the patient use compression leg wraps after surgery to prevent clots?



ANESTHESIA

- **Ask to meet with your anesthesiologist prior to surgery** to review your health history, allergies, medications and any other important information.
- Ask the surgeon in advance if the person putting you under anesthesia is a **board-certified anesthesiologist or certified nurse anesthetist** and confirm with the anesthesia provider.

- **Will any residents or students be participating in my anesthesia?** What will be their role and will a board-certified anesthesiologist be in the room supervising for the entire procedure?
- What **type of anesthesia** will I have? (Local, epidural, general, or conscious sedation?) Are pre-operative sedation medications available if I need them?
- Will I have a mask placed over my face before I fall asleep? Will I have a **breathing tube** inserted?
- Take out your **dentures** and any other removable appliance in your mouth. Tell the anesthesiologist about any loose teeth, crowns, caps, bridges, and veneers – especially those on front teeth.
- Report any **previous problems with anesthesia** (including nausea, head ache and vomiting). Tell the doctor if you have **sleep apnea** or a restricted airway.



PREPARING FOR SURGERY

- **Be sure all pre-operative tests are completed** or surgery could be delayed. This includes physical exam, blood tests and typing, x-rays or scans.
- **Do not shave your surgical site within 24 hours of surgery.** If hair removal is necessary, the hospital staff will use clippers. **Delay having a manicure or pedicure** – especially before hand or foot surgery. Shaving and nail care may allow bacteria to enter your bloodstream through small cuts in the skin or cuticles.
- Ask if you should shower with an **antibacterial body wash** containing chlorhexidine gluconate the night before, and/or the morning of, surgery. An inexpensive, over-the-counter brand is Hibiclens. Follow the doctor’s instructions for use.
- **Do not eat or drink** for six to eight hours before surgery –even if you are brought a meal tray. Ask if you can take your usual medications with a small amount of water.
- Bring copies of your signed **Medical Power of Attorney** document and your completed **Advance Directive** to the hospital. Bring this guide and download your free patient journal at www.EmpoweredPatientCoalition.org/publications.



SURGICAL COMPLICATIONS – See Chapter 8, Preventing Medical Errors

THE DAY OF SURGERY

- **The surgeon needs to sign the patient’s surgical site in pen.** The patient should confirm the location and sign the site as well, if possible.
- **Advocates and family members should confirm where they should wait** to receive information and updates.



- **Check the information on the patient’s wristband** for accuracy and be sure he wears the wristband at all times.
- **Does the patient have a preferred IV site?** Tell the staff if you have had a hard time using a certain vein in the past.
- Are all **pre-operative medications** ready? Is the patient having sedative drugs before going into surgery? Are anti-nausea drugs or antibiotics needed? *Note: Antibiotics are usually given within one hour of the start of surgery.*
- The patient needs his or her **glasses** available to read forms and sign the surgical site. Make sure the patient reads all documents and signs consent forms *before she receives any type of sedation.*
- Remind team members to take a **“time-out”** before the start of surgery. It is the last opportunity to confirm the right patient, the surgical site, and the correct procedure. Mention the “time out” in the pre-op area and again as you are wheeled into surgery.
- Ask if the team will be using a **“surgical checklist.”** Checklists are successful in ensuring that the staff follows important protocols before, during, and at the end of surgery.



ONCE SURGERY IS OVER

- **Have an advocate present at all times in the surgical waiting room** to speak to the surgeon to discuss the details of the procedure while they are fresh in the doctor’s mind. Even a quick trip to the cafeteria may mean missing the opportunity to speak to the surgeon.
- **When speaking to the surgeon after surgery ask focused questions** such as “Were there any complications, unexpected situations, or additional procedures needed?” and “Was there any excessive blood loss?”
- Ask the surgeon when the patient can get out of bed, walk, have their catheter removed, and begin to drink fluids or eat solid food.
- If the patient experiences problems during recovery ask the doctor if there were any surgical mishaps or complications that could be slowing the patient’s progress.
- **Keeping the patient warm** and not shivering, **controlling blood sugar levels** in diabetics and the **use of oxygen** after surgery may all be associated with a lower number of infections.
- Be sure that **pain and nausea are being controlled.** Alert the staff if the patient seems to be in distress.
- If the patient is receiving **narcotic pain medications**, be sure that his vital signs are being watched closely. Some patients have bad reactions to pain medications that cause them to hallucinate, become ill, or experience labored breathing.



PAIN CONTROL

- **Have an advocate present to help assess the patient's pain level.** Patients are entitled to effective pain management but should not be over-medicated.
- **Patient controlled analgesia (PCA) pumps can malfunction** and deliver a dose that is too high or too low. Be sure the machine is plugged in and that the numbers change when medication is given. If the patient seems overly sleepy or confused, or is in a great deal of pain, alert the staff.
- **Do not push the PCA button without the patient asking.** Do not push the button just to help the patient sleep.
- **Do not bring medications from home**, including Tylenol or anti-inflammatory drugs such as Advil or Motrin. The drugs you are given in the hospital may already contain these medications and too much acetaminophen (Tylenol) or non-steroidal anti-inflammatory drugs (NSAIDS) can cause serious, even life- threatening side effects.
- Pain medications can cause **severe constipation** and even lead to a serious blockage in the bowel. Ask if stool softeners are needed and be sure they are given.
- If the patient's pain seems excessive or hard to control, a consultation with a **pain management specialist** may be needed. Ask if the hospital has a pain management team to evaluate the patient.



Chapter Seven

INFECTION CONTROL AND PREVENTION

Infections that occur as a result of hospitalization are called *nosocomial* (*know-so-ko-me-ul*) *infections*. We pay a staggering price for these infections – almost one hundred thousand deaths a year and billions of dollars that could be spent on prevention and wellness programs. The following categories explain the specific strategies patients can utilize during their hospital stay to reduce their chances of developing an infection.

HAND WASHING is a vital first-line defense against hospital infections.

- Newer guidelines allow providers to use **fast drying alcohol gels** to clean their hands. Providers should **still wash with soap and water if hands are visibly soiled, or if the patient has a C-diff infection**.
- **Communicate your hand washing expectations** as soon as staff enters the room. Simply say “I am asking all my providers to wash their hands before they touch me to keep me safe from infection.” Hang a sign on your door and over your bed, if needed.
- **Patients need to wash their hands *before* eating**. Ingesting the spores of bacteria such as C-diff can lead to serious infections.
- Be sure the **soap dispensers and paper towel holders** in your room are filled because gels are not useful in every situation. **Bring hand gel to the hospital** with you and keep it by your bed – for you and for visitors to use.



GLOVES should be worn when there is the potential for coming into contact with blood or other bodily fluids, mucous membranes, non-intact skin, or items that are soiled with blood or other bodily fluids.

- **Gloves should be worn when drawing blood, starting an IV or changing surgical bandages.**
- Providers should wear gloves when there is any risk to a patient, but determining which situations warrant glove use can be a gray area. **You can ask providers to wear gloves when you feel it is necessary.**
- Healthcare workers need to **wash their hands both *before and after* using gloves.** **Wearing gloves is never a substitute for hand washing!**



SURFACE DISINFECTION is an important step in the infection control process, but one that is often overlooked. Cleaning and disinfecting are not interchangeable terms. “Cleaning” refers to the physical removal of organic materials (dirt and debris) and “Disinfection” refers to the use of

a product to kill or inactivate disease-causing pathogens (germs) on surfaces that have *already been cleaned*. Basic cleaning should be done first and then followed by surface disinfection.



- **Be prepared to clean and disinfect your own room.** Visit a home health store or order “hospital-level disinfectant” products online. Ask your nurse to provide you with disinfecting wipes, and show you how to use them. You should wear gloves and a mask when using these products.
- **The surfaces to be disinfected include:** Door handles, sink and toilet handles, IV pumps, phones, bed controls, bed rails, TV remote, and computer keyboards.
- **Wear slippers over your socks and remove them before getting into bed.** This prevents germs from the floor being transferred to your bedding.
- Make sure doctors and nurses **wipe the round end of the stethoscope** with an alcohol wipe. The stethoscope touches dozens of bodies a day and has been shown to be a potential source of shared germs.
- Ask if a **plastic blood pressure cuff** can be left at your bedside, to be used exclusively for you. Be sure that it is wiped down with disinfectant before and after use.

A ROOMMATE can be another source of communicable diseases. Most people prefer a single room for privacy considerations, but it also offers protection against infection.

- Patients who must share a room can ask discreetly if their roommate’s condition poses any risk of infection, especially if you observe coughing, fever or diarrhea.
- You may be exposed to germs from your roommate’s family members and visitors.

VISITORS can be a welcome diversion but are also a potential source of infection.

- **All visitors need to wash their hands** before entering and leaving the room, **postpone visits if they feel ill**, and **avoid using the patient’s bathroom**.
- Visitors should not **touch or sit on the patient’s bed** and should not lay their purses or other items on the bed. Doing so can bring germs from outside the hospital to the patient.

INTRAVENOUS LINES that deliver life-saving medications can also be a source of life-threatening infections. To reduce your odds of infection from an IV line, be aware of the following:

- There are several types of IV lines, including a regular or “**peripheral**” line that enters your body via a superficial vein in your arm or hand. A **PICC line** (peripheral intravenous central catheter) is a line placed into a vein in the arm and then advanced to a large vein near the heart. A **central venous line or catheter** is inserted into a large vein in the chest, neck, or groin and is used to deliver fluids and medications and measure oxygen

levels or blood pressure. All carry a risk of infection, so care is needed when they are used. Consider the following:

- The first step in IV insertion is for staff to **wash their hands and wear gloves** before puncturing the skin.
- The patient's **skin should be cleaned** with alcohol, betadine, or other appropriate skin prep.
- **Ideally, only gloved fingers should touch your skin to feel for your veins.** Staff may remove their glove to feel for a vein with their ungloved finger for greater tactile sensation. Bare fingers can contaminate the clean IV site and lead to infection. If a staff member removes their glove to feel for a vein, they must take the time to prep their hands again and put on a new pair of gloves.
- Patients and advocates should be familiar with the five components of the "**Central Line Bundle.**" The following five steps have been shown to significantly reduce the odds of infection from a central line:

1. Careful hand washing
2. Barrier precautions used during line insertion (including hair covers, masks, sterile gloves, sterile gown, eye protection)
3. Cleaning the skin with chlorhexidine gluconate skin prep
4. Avoiding the femoral vein (upper leg near the groin), if possible, and using the subclavian vein (upper chest area)
5. Daily review of the need for the line and prompt removal of unnecessary lines.

URINARY CATHETERS, also referred to as Foley catheters, are devices used to drain the bladder of urine when the patient is not mobile. Too often, a catheter is looked upon as a routine procedure, yet it should be seen as a last resort since each day of catheterization places the patient at greater risk of infection.

- If the use of a catheter is unavoidable, **it should be used for the shortest time possible.**
- **Catheter insertion must be done under sterile conditions.** The skin needs to be prepped several times with an antiseptic such as betadine; staff needs to wear sterile gloves (they come sealed in their own package); a sterile, single-use package of lubricant is needed; and a sterile paper drape is needed under the catheter insertion site.
- If the patient comes out of surgery with a catheter, **ask every day if it can be removed.** In general, urinary catheters should be removed one or two days after surgery.
- To help prevent infection, keep the catheter bag below the level of the bladder to keep urine **flowing downward** and not backing up in the tube. The bag and the draining spigot should never touch the floor. The bag **should be emptied regularly and not allowed to remain full.**

SURGICAL SITE INFECTIONS (SSI) pose a potentially serious risk for every one of the millions of people who have surgery each year. There are many simple strategies that patients can use to reduce the odds of developing a surgical site infection:



- Know which **factors increase the risk** of developing a surgical site infection, including diabetes, nicotine use, malnutrition, obesity, chronic steroid use, and prolonged pre-operative hospitalization.
- If your surgeon determines that antibiotics are needed before an operation, there are three crucial factors to consider. One, **you must receive the correct antibiotic**. Two, the antibiotic should generally be given intravenously **approximately 60 minutes before the initial incision**. Three, if antibiotics are to be continued after the surgery they should generally be **stopped within 24 hours**, so be sure to ask.
- Inquire about using a **pre-surgical body wash** containing chlorhexidine gluconate. Many surgeons are now having their patients bathe before their surgery with an anti-microbial soap to lower the bacterial count on their skin. Be sure to follow the directions when using the wash.
- If you are a diabetic, realize that there is a causal **relationship between high glucose levels and increased SSIs**, especially during the first 48 hours after surgery.
- **Hair should be clipped, not shaved**. If the area to be operated on requires hair removal, you need to know that shaving the operative site within 24 hours of the surgery with a razor is associated with significantly higher infection rate. A razor can cause small cuts in the skin that provide bacteria a perfect environment to multiply.
- Remember, ask if you should **receive oxygen** after surgery, and be sure that you **stay warm and are not shivering** after procedures. Extra oxygen, keeping patients warm, and **controlling blood sugar in diabetics** has been shown to lower the chance of infection.
- **Try not to touch or scratch your surgical site** and keep your hands clean.
- Know that the Centers for Disease Control and Prevention (CDC) recommend that **sterile gloves** and sterile technique be used when changing the dressings on *all* surgical incisions.

VENTILATOR-ASSOCIATED PNEUMONIA (VAP) may develop from using a ventilator to assist breathing. As many as 15 percent of patients on ventilators develop pneumonia and approximately 50 percent of these cases result in death.

- **Know the risk factors** for pneumonia that occur during ventilator use, including being in a continuous supine position (lying flat); having breathing tubes in the nasal cavity instead of the throat; being re-intubated; undergoing frequent ventilator tubing changes; going through a long duration of ventilation; the development of gastrointestinal bleeding from stress ulcers; the use of paralyzing medications; the development of blood clots; and the lack of routine cleaning of the oral cavity.



- If a patient is on a ventilator, **elevating the head of the bed to 30 to 45 degrees** (as opposed to lying in a flat position) is thought to decrease the chance of aspiration, a risk factor for pneumonia. This may not be appropriate for patients with Acute Respiratory Distress Syndrome (ARDS) who may need to lie flat to increase their oxygen levels.
- **“Sedation breaks”** in which the patient is brought to a higher level of consciousness to see if they can breathe on their own are important, so bring it up to the staff. Some studies recommend a “daily trial of weaning” to identify the earliest opportunity to remove the patient from the ventilator.
- Ask if **medications** are needed to reduce stomach acid and to prevent bleeding from ulcers. Medications to prevent blood clots may also be necessary.
- **Care of the mouth, nasal passages, and lips** is part of the strategy for preventing VAP. The teeth, tongue, and tissues (even areas where teeth are missing) should be brushed with a soft toothbrush twice a day. The mouth should be swabbed with a rinse of .12 percent chlorhexidine gluconate, which can be applied and then removed by suction. The chlorhexidine gluconate kills bacteria in the mouth *but it is not a substitute for brushing*. Keep nasal passages clean and clear and lips moisturized.

METHICILLIN -RESISTANT STAPHYLOCOCCUS AUREUS (MRSA - pronounced MER-SUH) is a potentially dangerous type of staph bacterium that is difficult and even sometimes impossible to treat with our current antibiotics. People who carry staph but do not become ill from it are said to be “colonized” with staph. MRSA is spread through direct contact with infected or colonized individuals or contaminated surfaces.

- Look for the signs of MRSA - **a skin lesion that is warm, red, swollen, and quickly worsening**. MRSA lesions can look like a blister or insect bite and fever and chills may also be present. Do not hesitate to call the doctor if you suspect a MRSA infection as early detection and treatment is important.
- Prevent MRSA by keeping your skin moist and healthy and **wash your hands regularly** or use a hand sanitizer, especially in crowded places such as gyms.
- The **visitors** of patients with an active MRSA infection may be at an increased risk of infection. Do not touch the bandages, clothing, or bedding of a MRSA patient.
- Place a towel over **equipment you are using at the gym** and wipe down machines before using them. Wash and dry gym clothes between uses.
- Do not share any **personal items** such as razors, towels, bars of soap or wash cloths.
- **Keep any wounds covered** with a clean, dry bandage; wash hands after touching a wound.
- If you are diagnosed with MRSA, **finish all prescribed antibiotics** to help prevent a recurrence.
- If you become infected with MRSA, ask your doctor if you need to use any special ointments or **anti-bacterial body washes** to keep the infection from returning.



- **Once you have been infected with MRSA you will always be at a greater risk for developing other MRSA infections.** Ask your physician for appropriate precautions.

CLOSTRIDIUM DIFFICILE (C. diff) is an extremely hardy spore-forming bacterium that is a common cause of diarrhea associated with antibiotic usage in healthcare settings and is now being seen in community settings and long-term care facilities as well. The C. diff bacteria can produce toxins that cause *severe diarrhea, stomach pain, fever, and nausea* in patients whose normal intestinal bacteria has been disrupted by the use of antibiotics. In severe cases, a fecal transplant or surgery to remove part of the intestines may be the only ways to stop this potentially life-threatening infection.

C. diff bacteria originate in the feces of infected patients and are spread by touch. Without proper hand washing, trace amounts of feces are transferred to skin, clothing, and other surfaces in the hospital. Without proper cleaning, the bacterial spores can remain on contaminated surfaces for weeks. The C. diff spores are often transferred to patients by the hands of healthcare workers or by direct contact with contaminated surfaces. Considerations for patients include:

- Major **risk factors** are the use of antibiotics, a recent hospitalization, and advanced age. Many new cases originate in nursing homes or outpatient office and clinic settings. If a patient on antibiotics develops **watery diarrhea**, ask if he or she should be tested for C. diff.
- Patients, caregivers, and health care providers should **wash their hands with soap and water** as *alcohol hand sanitizers are not as effective against the C. diff bacteria*. **Wash hands before eating** to avoid ingesting C. diff spores that may have been transferred to hands after touching contaminated surfaces. Patient's using antibiotics may want to wash their hands with soap and water *after using the restroom* and **before eating meals** to be extra cautious.
- **Probiotics** (cultures of living organisms) may be useful in preventing a recurrence of C. diff by restoring normal bacteria in the intestines. Ask if it could be helpful.
- **If a patient is waiting for test results to see if they have C. diff, they may need contact precautions.** Patients should be given their own room, if possible, and caregivers need to **wash their hands and wear gloves and gowns** as appropriate.
- Regular cleaning and disinfecting methods may not be effective against C. diff spores. If a case of C. diff is confirmed, surfaces should be cleaned with a **diluted bleach (hypochlorite) solution** or bleach wipes (be certain they actually contain bleach - not all of them do. Read the label carefully). The bleach should be used at a 1:10 dilution and *left on surfaces for 10 minutes* to be completely effective.
- The **surfaces that need to be disinfected** with the bleach solution include: thermometers, blood pressure cuffs, stethoscopes, over-bed tables, sinks, floors, commodes, toilets, walkers, and canes –*all surfaces that caregivers or patients touch*.



- **Visitors also need to use contact precautions if C. diff is diagnosed** - wash hands, wear a mask, and avoid touching the patient or their bedding.
- **There is a new antibiotic, Difid (fidaxomicin), to treat C. diff infections.** Fidaxomicin may be just as effective as vancomycin (the usual antibiotic used) in treating C. diff but it seems to be better at preventing recurrences.

ANTIBIOTICS have proven so useful at treating illnesses that we have come to rely on them as “magic bullets” for the prevention and treatment of infections. The success of antibiotic therapy has led to widespread over usage and the phenomenon of antibiotic resistance – in which bacteria change and mutate in response to constant exposure to antibiotics and then become “superbugs” that may be impossible to treat. Here is what you need to know:

- Change your mind set about antibiotics. They are **serious medications** to be used only when medically necessary.
- When patients are told that they do not need antibiotics and that resistance is a problem they often say “That doesn’t apply to me because I hardly ever use antibiotics.” What they don’t realize is that ***the bacteria become resistant, not the person.*** Resistant bacteria will not selectively infect only those individuals who have overused antibiotics! Everyone is at risk for acquiring a resistant infection.



- **Antibiotics have no effect on viruses – they only work on bacterial infections.** Studies have shown that as many as 90 percent of infections are viral or low-grade bacterial infections that do not need antibiotic therapy. Realize that a majority of sore throats and coughs do not require the use of an antibiotic.
- **Finish the entire dose of prescribed antibiotics.** Stopping the drugs when you start to feel better may only wound the bacteria and encourage them to mutate and become resistant to commonly used antibiotics.
- **Do not self-medicate with leftover antibiotics.** You may not have an infection at all or the antibiotic on hand is not the right one for your illness.
- **Other resistant bacteria include:** Vancomycin- Resistant Enterococcus (VRE), Klebsiella, Acinetobacter, Pseudomonas and Enterobacter.
- **If you are diagnosed with an infection of any kind, ask the name of the exact bacteria causing your illness.** Write down the name and research online to learn about your infection and to see if any special precautions are needed.

Chapter Eight

PREVENTING MEDICAL ERRORS

Patients and advocates can learn skills to help them assess and identify particular risks, evaluate their vulnerabilities, and employ effective safety strategies. The following boldface headings define separate areas in which medical errors often occur, and the bullet points represent actions patients and advocates can take to ensure their hospital stay is as safe as possible.

LACK OF COMMUNICATION / MISCOMMUNICATION. Communication failures are involved in a large percentage of medical errors. Communication breakdowns often occur during *telephone or verbal orders*, when *caregivers fail to communicate with each other*, and when *patients talk to their providers*.

- **Try to see that telephone orders are avoided.** If a phone order is necessary, ask the nurse to take the time to read all orders back to the doctor.
- Ask that your providers read each other's entries in the medical record and have reviewed all recent test results. **Check your medical record** yourself to be sure nothing is overlooked
- **Verify that the doctors and others involved in your care have consulted with each other** and that everyone's input has been considered when implementing the treatment plan.

PATIENT TRANSFERS OR "HAND-OFFS." One point at which errors are particularly likely to occur is when responsibility for the patient is transferred or "handed off" to a new provider. This can happen during a shift change, when a patient is moved to another floor or unit in the hospital, when the patient is taken out of their room briefly for a test, or even when the patient is discharged to their home or a rehab unit. Patient transfers depend on a great deal of information being condensed and then presented accurately to another provider. Any time that patient information is incomplete, missing, or inaccurate it increases the odds of adverse events.



- Recognize that any transfer or hand-off places the patient at an additional risk of errors. **Be extra careful every time a patient is moved or sent home.**
- The patient or advocate should **communicate any important information to new staff members** as soon as the patient reaches another floor or unit.
- Pay close attention to **be sure medication dosages are not missed or given more than once** after a patient is moved.
- Be sure that all **machines and oxygen sources are plugged into the wall and restarted.**



STAFF ISSUES. Human error can arise from a variety of sources. Among other things, staff can be *overworked, inexperienced, or relying too heavily on their memories.*

- Notify the charge nurse, the chief resident, the attending physician, and the hospital administrator **if staffing levels seem inadequate.**
- It is always appropriate to **ask a staff member about their title and level of training or experience.**
- Your providers should be **up-to-date on your treatment plan and view all recent computer entries.** Many hospitals have computers right at the bedside for staff to use.

SURGICAL MISHAPS. Even routine surgery carries risks. Among the risks are *lacerations, perforations, instruments left in patients and complications of anesthesia. Surgery on the wrong part of the body and surgical fires* are an ever-present risk on operating rooms.

- Remember, **have an advocate who will be present** immediately following your surgery to talk to your surgeon and ask if there were any complications.
- **Have your surgeon sign the surgical site in pen.** Let the staff know that you would like to be involved in signing the surgical site.
- Asking about **protocols to prevent leaving supplies in patient's bodies** will at least guarantee that the subject is on the minds of the surgical team.
- Be aware that **obese patients have a higher incidence of surgical tools being left in their bodies.** Taking an x-ray before the wound is closed may be useful in double-checking that all instruments are accounted for.
- Ask the surgeon if a **cautery unit** will be used in your surgery, and verify that precautions are in place to prevent a fire on the patient's body. Ask your surgeon if he and his staff know how to put out a **surgical fire.**
- **Be aware that a slow recovery may be a sign of infection or bleeding** related to surgery. Do not hesitate to ask the doctor if any surgical mishaps, lacerations, or perforations occurred during your surgery.
- Be sure that your surgeon is aware of any **blood-thinning medications you're taking** and ask how far in advance of the surgery you should stop using them. Be sure that blood-thinning medications are not given before a surgical procedure.



INTRAVENOUS LINES. Intravenous lines can be the cause of injuries that range from mild to severe, including bloodstream infections and blood clots. Careful insertion technique (good hand washing and the use of gloves) and vigilant monitoring of IV lines by both healthcare workers, patients, and their advocates is essential.

- You or your advocate must alert your caregiver if you notice any **pain, swelling, moistness, redness, itching, or bruising** at your IV site.

- **Ring for the nurse if the IV pump alarm goes off**, so the line does not remain static (not flowing) for any length of time.
- As annoying as the sound of the alarm might be, **resist the temptation to push the button to silence the alarm on your pump**. The alarm is signaling for a reason and once it is quiet it is easy to forget that you pushed the button. Do not tamper in any way with your infusion pump.
- **Report blood backing up into the tubing**, since this can indicate that a clamp needs to be opened or it can be a signal of an inadequate infusion rate.
- **IV lines may need to be injected with saline solution (flushed) before, after and between doses of medications**. Flushing with a blood thinning medication such as heparin is usually not needed except in special circumstances, and is now thought to pose a risk to the patient. Ask if your IV line can be flushed with saline (salt water solution) instead of heparin.
- IV lines that are still in place but not being used will still need to be flushed with saline; ask your nurse or doctor. **IV catheters that remain static (not running or flowing) too long may form blood clots** and otherwise endanger your health.
- **IVs should be removed when they are no longer needed**. Ask regularly if it's time to take out your line.



PATIENT INJURIES. *Every* person who enters the hospital is at risk for being injured in an accident. Patient injuries from *falls, hospital beds, and MRI scans* are an ongoing problem in our hospitals and many are considered to be completely preventable.

- Be aware of **spills, unlocked wheelchairs, and patients left alone on gurneys**.
- To **avoid falls from reaching**, keep the patient's eyeglasses, the TV remote, the telephone, and the call button close by.
- **The mattress should fit the bed frame snugly** and not slide easily so patients cannot become trapped between the mattress and the rails.
- **If all bed rails are left up, they are considered a "restraint system"** unless the patient is receiving sedation or waking up from anesthesia. Patients can become agitated when the bed rails are up and fall while trying to climb out of bed in a panic.
- Patients can receive **burns and other injuries during MRI scans**. Patients have been burned by looped ECG leads or pulse oximeter cables touching the skin. Patients can be injured by the strong magnet of the MRI machine if they have any **metal objects** in, on, or around their body.



PRESSURE SORES or pressure ulcers (also called bed sores or decubitus ulcers) are areas of skin that have been damaged from a lack of blood flow caused by pressure to a specific area. Bed sores are categorized from Stage I to IV, depending on the degree of damage to the tissues.

Stage III and IV sores have deep open wounds that can be difficult to treat, *and may even lead to sepsis, or infection.*

- Sores often occur in **bony areas where pressure is concentrated**, including lower back, tailbone, buttocks, spine, elbows, ankles, knees, heels, shoulders, and hips.
- **Risk factors:** being elderly, bedridden, paralyzed, poor circulation, using a wheelchair, agitation or muscle spasms, poor nutrition, and inability to hold urine.
- Prevention involves daily inspection of the skin, **turning immobile patients every two hours**, using pads instead of diapers to keep skin drier, monitoring food and fluid intake, and tracking body weight.
- Poor nutrition, dehydration and the loss of muscle mass all increase the odds of developing pressure sores.
- Using air mattresses or soft padding is **not a substitute for physically turning the patient every two hours.**



MEDICATION ERRORS. The average hospital patient can experience one or more medication errors every day. Errors can occur during *prescribing, administering, or monitoring* medications.

To help avoid inaccurate prescribing you can . . .

- **Bring a prescription drug manual to the hospital**, or check for drug interactions at reference.medscape.com/drug-interactionchecker or at <http://healthtools.aarp.org/drug-interactions>. Or, look for a good smartphone app.
- **Ask for a pharmacist to be directly involved in your treatment planning**, especially if you have a complex drug regimen. Pharmacists can consult right at the bedside and their input is often vital to finding a successful drug combination and managing side-effects.
- **Keep a list of any previous allergic reactions** to medications in your patient journal. Include the full name of the medication and the specific reaction.
- Pay close attention to the **placement of decimal points. A medication dose that is .1% is ten times the strength of one that is .01%!** *Know your dosages.*



To help avoid errors in administering medications, you can . . .

- **Know the drugs most often associated with medication errors:** Hydromorphone (opioid pain medication), Warfarin (blood thinner also known as Coumadin), Morphine Sulfate (opioid pain reliever), Insulin (both human and synthetic –Glargine), Vancomycin (antibiotic), Enoxaparin (blood thinner also called Lovenox), Potassium Chloride (used to treat low potassium levels), Fentanyl (narcotic pain reliever) and Midazolam (benzodiazepine used for sedation).
- Be aware that many medications, including aspirin, Coumadin (warfarin), Plavix, and Lovenox, can cause blood-thinning. **Taking multiple blood thinners can cause stroke and bleeding.**



- Request a copy of the physician’s orders or a copy of the **Medication Administration Record (MAR)** and place it in the binder with your journal. Confirm that all medications given to the patient are correct and delivered at the right time.
- **If you are given a pill that looks different from the pill you’re used to taking**, don’t be afraid to ask why.
- **Ask if any of your IV drugs are incompatible with each other.** A saline flush may be needed before infusing the second drug to ensure that the medications do not come into contact with each other. Some medications are incompatible and cannot be mixed together in IV tubing.
- Realize that **transdermal patches, commonly used to administer hormones, nicotine for smoking cessation programs, and narcotics for pain relief**, are another potential source of medication errors. The most common problem is an overdose of medication from forgetting that a patch has been previously applied and then using another one. If you are hospitalized, be sure the date, time, and location of patches on the body are recorded in your chart and in your Patient Journal.

To ensure that medications are monitored and side effects are reported, you can ...

- Be certain that your response to a drug is regularly evaluated and recorded in the medical record. **Any adverse reactions should be noted** in your chart, and you should document the fact in your patient journal.
- **Report any reaction, no matter how minor**, including itching, rash, hives, breathing difficulties, nausea or vomiting. Patients can have allergic reactions to food, dyes used in diagnostic tests, adhesive tape, and the latex gloves worn by staff members.
- Be aware that patients who are given a narcotic reversal agent such as **Narcan or Naloxone** may have received an overdose. The use of narcotic reversal agents should lead to the initiation of a review by the hospital.
- Be sure your nurse **immediately reports confirmed medication errors** to the nursing supervisor and attending physician and notes the error in your medical record. You should also ask the nurse to fill out an Occurrence Report or Adverse Drug Event Reporting Form. Hospitals may have different names for these forms, but when you use this terminology they will know to what you are referring.
- **Patients can report medication errors and near misses** to the Institute for Safe Medication Practices Medication Errors Reporting Program (MERP) at 1-215-947-7797 or <https://www.consumermedsafety.org/merp.aspx> . All communications are confidential and information is entered into a nationwide database to track errors. You can report serious reactions with drugs or medical devices to the Food and Drug Administration MedWatch program by telephone at 1-800-FDA-1088 or online at <http://www.fda.gov/Safety/MedWatch/HowToReport/ucm053074.htm>



THE DETERIORATING PATIENT

It is often a bedside advocate who recognizes subtle changes in the patient's condition hours before the patient takes a turn for the worse. Advocates who listen carefully to the patient's own assessments and then add this information to their own careful observations can be proactive instead of reactive when a patient seems to be struggling. Advocates now function as safety partners by using their unique knowledge of the patient to recognize when the patient needs additional assessment or help.

Advocates at the patient's bedside are in a perfect position to function as safety partners by paying close attention to the patient indicators listed below and then sharing their crucial observations and instincts with the staff.

WARNING SIGNS OF A RAPIDLY DECLINING PATIENT

- High or low **BODY TEMPERATURE**
- Changes in **HEART RATE** (pulse) or **RESPIRATORY RATE** (breathing)
- A drop in the patient's **BLOOD PRESSURE** (it becomes much lower)
- MENTAL CONFUSION** or other change in mental state
- Decrease in **AMOUNT OF URINE**/urine dark in color, looks "concentrated"
- THE PATIENT STATES THAT SOMETHING IS WRONG** with them
- The advocate observes that **THE PATIENT DOESN'T LOOK RIGHT**
- The patient is **SHORT OF BREATH** or having chest tightness or discomfort
- ACUTE PAIN**, especially in the abdomen
- The patient is **VERY PALE** or breaking out in cold sweats

Chapter Nine

DISCHARGE AND HOME CARE

Discharge is considered a “hand-off” and carries additional risks and responsibilities for patients and advocates. Leaving the hospital is often the beginning of new and challenging duties such as caring for a wound or managing a more complicated medication schedule. The following bullet point lists will help you stay on track.

DISCHARGE INSTRUCTIONS

- Does the patient need help at home** or will he be able to care for himself? If help is needed, can a **discharge planner** help with the process?
- The patient should have a clear, readable copy of the **discharge instructions and the Discharge Summary**. It should be clear when bandages should be changed or removed and when the patient can walk, bathe, drive, or return to work.
- Be sure you **have the names and dosages of discharge medications in writing**, especially if new medications have been added to the care plan.
- Be sure the discharge documents contain **the phone number of the doctor** to call if there are questions.
- Has the **hospital communicated with the patient’s regular medical doctor** about the details of the stay?
- Is the patient being discharged home or to a **skilled nursing facility**? If discharged to a facility, how long is he or she authorized to stay?
- Does the patient need to perform **wound care** or deal with surgical drains?

FOLLOW UP CARE

- When is the patient to return for follow-up?** Which doctor is she supposed to see?
- Will a visiting nurse be needed?** If so, have orders been written and authorization obtained?
- Does the patient need physical and/or occupational therapy?** When should therapy start and who will schedule it?
- Will the patient need any medical equipment** such as oxygen, wheelchair, hospital bed, commode, or walker? Has the order been placed? When should it arrive? Is it covered by insurance?

- Does the patient need to monitor any vital signs** at home such as blood pressure or temperature? Should these numbers be written down to share with the doctor?
- Does the patient have **dietary restrictions** or need **nutritional supplements**?

HOME MEDICATIONS

- Will medications be provided by the hospital or will they **need to be picked up from an outside pharmacy**? Will the medications be picked up and started right away? In many situations, it is important to start home medications immediately. Let the staff know if you expect any delays in obtaining medications to use at home.
- Have new medications been **evaluated for drug interactions** with the patient's regular medications?
- Will the patient be using narcotic pain medications?** Be aware that narcotics can cause dizziness, loss of appetite, constipation, and hallucinations. Are stool softeners needed to prevent constipation?
- Ask if any pain medications contain **acetaminophen or ibuprofen**, which are the ingredient in Tylenol and Advil. If so, be sure the patient **does not take additional Tylenol or Advil** at home – it can cause liver damage and bleeding. Check all over-the-counter medications for acetaminophen or ibuprofen – it can be present in cold or sinus medications and sleep aids.
- Do not drink alcohol** while taking pain medications. Not even a small amount.

The following are symptoms that can be signs of serious complications. Always know who to call to report any of the following complications:

- ✓ Know the **signs of clots: swelling, redness or breathing difficulties**. Should the patient be up and walking to prevent blood clots? Does the patient need blood-thinning medications? Realize that clots can occur weeks after leaving the hospital.
- ✓ Know the basic signs of **wound, blood, or urinary tract infection**: fever, redness, rashes, swelling around incision, pain, drainage from incision, and painful urination.
- ✓ Know the signs of **internal bleeding and shock** including shortness of breath, pale skin, or feeling cold, low urine output, mental confusion or rapid breathing.
- ✓ Know whom to call if advocate notices **loss of appetite, weight loss, depression, anxiety, or insomnia**.

Chapter Ten

COMMUNICATING CONCERNS IN THE HOSPITAL

Most hospital stays are brief and uneventful; medical treatment proceeds as planned, outcomes are successful, and patients leave the hospital healthier than when they came in. But, for some patients, hospitalization creates problems, ranging from minor to severe.

There are many paths of assistance in place for patients, both inside and outside the hospital. The logical starting point for communicating concerns is your bedside nurse and treating physician. If problems arise that are not resolved by dealing directly with your doctor or nurse, you need to be aware of other staff members who can intervene on your behalf.

BEDSIDE NURSES

What do they do?

Bedside nurses are registered nurses who provide direct patient care. Your staff nurse will be up-to-date on your vital signs, medications, and overall treatment plan and help manage and coordinate your care.

How can they help me?

Your bedside nurse is the first nurse to consult if you have a problem and she can help identify and contact the appropriate staff members to assist you, including patient relations, social workers, and nursing supervisors.

CHARGE NURSES

What do they do?

Charge nurses are responsible for scheduling and directing the nursing care in a specific ward or unit during each assigned shift. They function as immediate supervisors for bedside nurses.

How can they help me?

The charge nurse is the first person to contact if there is a problem with your bedside nurse. If the charge nurse cannot resolve your issue ask her to contact the nurse manager or a nursing supervisor to assist you.

DEPARTMENT HEADS

What do they do?

Heads of departments are physicians who oversee all the doctors working in a specific area of the hospital such as Pediatrics, Surgery, or Orthopedics.

How can they help me?

Patients can ask to speak to a department head if they have a disagreement with a physician or the treatment plan she is recommending, if communication between patient and doctor is poor, or if any situation arises that makes a patient or advocate feel that they need input from a doctor with authority over their physician.

SOCIAL SERVICES

What do they do?

Social services staff members function as coordinators between you, the healthcare team, and any available community resources. Social services staff is available to assist patients before, during, and after a hospital visit.

How can they help me?

You can turn to social services personnel to help open the lines of communication between you and your caregivers, to help you express questions and concerns, and to schedule family meetings with your providers. Social workers can help you identify appropriate community resources such as home care or meal delivery.

PATIENT RELATIONS/ PATIENT ADVOCATE

What do they do?

Patient relations specialists or representatives (also known as patient advocates or ombudsmen) function as liaisons between patients and the hospital.

How can they help me?

Patient relations staff can explain hospital policies and procedures, help mediate disputes, and generally help you and your loved ones work through any bumps in the road during hospitalization. Look for information about the patient relations department in your admission materials and contact them using the phone at your bedside if you need their assistance.

INFECTION CONTROL PROFESSIONALS

What do they do?

Infection control professionals manage the hospital's infection control program and implement the policies that minimize the risk of infection for patients, visitors, and staff members.

How can they help me?

Infection control professionals (ICP) evaluate and improve infection control policies and procedures and are involved whenever there is an outbreak of infection. If you develop a hospital infection, ask to speak to the ICP and have her look into the root cause of your infection and suggest ways you can protect yourself and recover sooner.

HOSPITAL ADMINISTRATION

What do they do?

Administrators manage the day-to-day operations of hospitals and direct hospital policy, oversee budgets, and ensure quality. Administrators often have titles such as President, Chief Executive Officer (CEO) or Chief Administrative Officer (CAO) and larger hospitals may have several administrators. *Administrators are ultimately responsible for the safety of the care provided in their hospitals.*

How can they help me?

While it is often most effective to handle questions or problems by consulting those closest to the situation (nurses, physicians, patient relations and social services), some circumstances or emergency situations may require decisions from the administration. The hospital administrator may be able to bend hospital policy and bring immediate improvement in your situation. Your bedside nurse, a nursing supervisor, or the patient relations department can help you contact the administration. Even after hours and on weekends, there is an administrator on call. Patients can ask to speak to a representative from the hospital administration while they are hospitalized and can also contact the administrator's office once they are home to provide feedback or suggestions.

CHIEF OPERATING OFFICER (COO)

What do they do?

The Chief Operating Officer represents a level of authority directly above the hospital administration. The COO works closely with administrators by establishing hospital policies, ensuring strong communication between the administration and the medical staff, addressing the diverse health needs of the community, and evaluating and improving safety and quality in the medical center.

How can they help me?

If you encounter a serious safety or quality issue that warrants contacting the hospital administration, you should also share your experience with the COO. It is unlikely that the COO will respond directly to the patient's bedside so it is more efficient contact the COO in writing. You can obtain the correct address from the patient relations department, the hospital administrator's office or the hospital website. Clearly state the nature of your problem and include your name, date of hospitalization, medical record number, physician's name, and the unit you were in and keep a copy of your letter. It is especially important to discuss the issues that impacted your hospital stay and any ideas or suggestions you can offer for improvement. Expect a response and follow up if you don't receive a reply.

RISK MANAGEMENT

What do they do?

The risk management department helps the hospital minimize their liability and reduce the risk of lawsuits. Hospital staff contact risk management when situations occur that concern them and the risk manager (often a lawyer) responds and offers advice.

How can they help me?

The risk manager is not a staff member that patients will usually want to contact but you should be aware that their presence in your room or having them look at your medical record could be an indication of a problem with your care. This is another reason why you need to know the name and title of any staff member you interact with during a hospital stay.

WHY IT IS IMPORTANT TO REPORT NEAR-MISSES

Were you handed the wrong medication, given the wrong dose of a medication, or was the wrong bag hung on your IV pole? Was the mistake somehow caught before the medication or fluid was administered? **Reporting near misses is important** because even though you were not injured, there is still **a serious flaw in the system that needs to be evaluated and corrected; the next patient may not be so lucky.** Your nurse should fill out a medication incident form so that quality control personnel can evaluate what allowed the wrong medication to reach your bedside in the first place. When there are problems or dangers of a caliber that represents a “systems failure” – meaning that the current procedures are flawed and the same problems will occur over and over again until the procedures are modified – the hospital administration should be notified.

COMMUNICATING WITH PROFESSIONALS

Many adverse events during hospitalization are directly related to a breakdown in the communication process. The SBAR (Situation-Background-Assessment-Recommendation) is a Navy communication aid that was adapted by the Kaiser Permanente Health Plan to assist in communication among health care workers. The SBAR form on the next page (using the headings Situation- Background-Assessment-*Request*) has been specifically designed for patients to use when communicating with health care professionals.

Make copies of the form or download at www.EmpoweredPatientCoalition.org/publications and fill in the blanks to use as a script when speaking to nurses and doctors. The form is easy to use and it allows you to present vital information clearly and efficiently using a format that is familiar to your health care providers.



SBAR COMMUNICATION TECHNIQUE FOR PATIENTS & ADVOCATES

Situation

I AM _____ (state your name).

I AM THE _____ (relative, advocate, friend, Medical Power of Attorney) for
_____ (state patient's name).

I AM CONCERNED ABOUT _____.

Background

THE PATIENT CAME TO THE HOSPITAL BECAUSE _____.

THE PATIENT'S DIAGNOSIS IS _____ or is unknown at this time.

THE PATIENT'S PHYSICAL OR MENTAL LIMITATIONS ARE _____.

(**Examples:** dementia, hearing loss, difficulty walking, unable to communicate,
language barriers)

THE PATIENT IS _____.

(**Examples:** on oxygen, receiving new medications, having procedures or surgery,
awaiting test results)

Assessment

NEW SYMPTOMS I have noticed are _____.

WHAT HAS CHANGED in the patient's condition is _____.

(**Examples:** pain level, vital signs (blood pressure, temperature, pulse),
breathing, mental status, color of skin, sweating, agitation, dizziness, lack of
energy)

THE PATIENT SEEMS TO BE _____.

(**Examples:** stable, unstable, declining or deteriorating, in serious trouble)

Request

I WOULD LIKE TO DISCUSS THE FOLLOWING POSSIBLE ACTIONS: _____.

(**Examples:** consultation/evaluation, a second opinion, calling the Attending
Physician, scheduling a family meeting, additional tests or monitoring, transfer
to another unit or facility)

IF A CHANGE IS ORDERED, how and when should I contact you if there is no
improvement? _____.

Chapter Eleven

COMMUNICATING CONCERNS OUTSIDE THE HOSPITAL

If you experience problems with your medical care, it is best to enlist the appropriate staff member at the hospital to help you right as the situation is happening. For serious situations involving systems errors or life-threatening medical events, there are groups and agencies outside the hospital where you can file a complaint. Reporting to the entities listed below is far from a perfect solution since they all have limited power and authority, but it is important for patients to have their voices heard and their experiences counted.

HOSPITAL LICENSING AND CERTIFICATION agencies seek to improve the quality of care by ensuring that state health and safety laws are being implemented. Licensing and certification agencies are administered under state health departments or departments of health services and are in charge of the front line oversight of health care institutions.

Licensing and certification agencies have investigators on staff to investigate consumer complaints. To make a complaint, call your state department of health or your state capitol and ask for the division that inspects hospitals. Follow their guidelines for making a complaint and keep copies of all documents. Investigators will conduct an investigation, write a report, and may issue “deficiencies” for care that does not meet minimum standards and require the hospital to submit a plan of correction. The agency’s findings are often confidential but the Code of Regulations in your state may grant access to these reports, so check.

PUBLIC HEALTH DEPARTMENTS may be able to accept reports about healthcare infections and adverse events directly from patients. A number of states have implemented mandatory infection and/or medical error reporting laws and are beginning to make the data available to the public. Contact your local and state Public Health Departments to see if they allow patient reporting.

STATE MEDICAL BOARDS oversee the licensing of physicians, regulate the practice of medicine, and discipline those who violate the Medical Practice Act. Patients, family members, and hospital personnel can all file medical board complaints. Find your state medical board at www.patientsrighttoknow.org or by calling the state capitol for a contact number. Once a complaint is made, a preliminary assessment is done and an investigator uses his judgment about whether to proceed with an inquiry.

Once an investigation is complete, several outcomes are possible. A case can be closed without further action, there can be administrative actions such as the suspension of a license, or the case can be referred to the attorney general or local district attorney for legal action (this rarely happens). Many states make it more difficult to prove a medical board violation than to prevail

in a malpractice case, and unless your case involves “gross negligence” it will likely be closed. As frustrating as it may be, there is value in reporting to medical boards. Even if a complaint does not result in the disciplinary action you hope for, the numbers and the data are being collected and they are increasingly available to the public and to the legislature.

FEDERAL HIPAA (PRIVACY) COMPLAINTS can be filed if the privacy of your health information is compromised. Complaints against healthcare providers, hospitals, pharmacies, and insurance companies are filed with the Office for Civil Rights (OCR). Complaints must be filed within 180 days of the privacy violation. For more information on filing a complaint, visit the Department of Health & Human Services website at <http://www.hhs.gov/ocr/privacy/hipaa/complaints/index.html>.

CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS) is the federal agency that administers Medicare, Medicaid, and the Children’s Health Insurance Programs (CHIP). If you are a Medicare patient and are denied a medical service, or feel you are being released from the hospital too soon, you can appeal at <http://www.medicare.gov/navigation/medicare-basics/understanding-claims/medicare-appeals-and-grievances.aspx>.

If you experience a medical error or a quality issue with your hospital care, Medicare allows you to file a complaint with your local QIO –a Quality Improvement Organization. To locate your local QIO go to http://www.ahqa.org/pub/connections/162_694_2450.CFM

For more information and resources, visit the CMS Beneficiary Ombudsman website at <https://www.cms.gov/center/ombudsman.asp> or call 1- 800-MEDICARE.

THE JOINT COMMISSION is a private, non-profit group that accredits healthcare organizations, including hospitals. The Joint Commission seeks to improve the quality of care in accredited hospitals by making recommendations for improvements. Literally, the Joint Commission knocks on the hospital door, conducts an unannounced evaluation, and issues a report on how they are doing compared with other institutions.

Participation by hospitals is voluntary, it is funded almost entirely by fees from the very hospitals it evaluates, and some of its board members are hospital executives. The commission makes safety and quality recommendations to hospitals but it does not have the authority to enforce regulations or impose any real sanctions. The commission maintains a “sentinel event” database to track serious problems in hospital care but the small number of reports it contains does not begin to capture the scope of the problem. Hospitals should voluntarily report safety issues and patients can report medical events as well. Download a Quality Incident Report form at www.jointcommission.org or call 1-800-994-6610.

The Joint Commission will review your report and they will inform you of any action they are taking but they do not share the specific details of the investigation. You will not be able to confirm that your medical event, no matter how serious, is included in their sentinel event database. For these reasons, many patients find the Joint Commission experience frustrating.

THE MEDIA offers the power of the written word and is often used as a last resort when all other attempts at dealing with a hospital over a serious problem have failed. Involving the media can be a powerful means to an end. The information you provide may result in important media coverage to help alert the public to ways they can keep themselves safe. And since media stories that appear in smaller publications could be picked up by larger ones, you don't have to start with the *New York Times*.

You can begin by contacting a health reporter at a local paper, writing a blog post, or sharing your story on a social media outlet. There is no doubt that our current information age has been a great asset in bringing all kinds of social problems to the public's attention, and healthcare safety has certainly benefitted from this phenomenon.

HOSPITAL DISCLOSURE is an approach taken by progressive healthcare institutions across the country. This practice is dependent on hospitals being open and honest when an error happens, informing the patient of the situation, and conducting an immediate investigation into the "root causes" of the event. Truly transparent hospitals will interview the patient and family and allow them to share their observations and opinions with the investigation team.

If the hospital finds that they are at fault, they will often make an offer of financial compensation to the patient. This is intended to avoid traumatic and costly legal action. Other non-monetary concessions may also be made including assurances that new safety measures will be put in place to spare others from being harmed by the same error. If the patient is not happy with the offer they can still proceed with a lawsuit. Patients may want to have the offer reviewed by an experienced malpractice attorney. In general, reaching a mutually acceptable agreement with the hospital is a better solution than a lawsuit.

THE LEGAL SYSTEM may be the only way for some people to obtain information or to receive enough compensation to meet their lifelong medical needs. Patients need to be aware of several realities about lawsuits.

It may be very difficult to find an experienced malpractice attorney willing to take your case, even if you have been seriously injured. Be sure to consult with an attorney who handles medical malpractice cases on a regular basis. Call your state bar association for names of reputable malpractice attorneys. If more than one attorney declines to take your case, it could be an indication that the case is not likely to be successful.

There are strict statutes of limitations on malpractice cases, so be certain about dates when speaking to an attorney. Realize that many states have "caps" (limits) on awards for pain and suffering. A pain and suffering case could cost more in legal fees than the final award. For this reason, an attorney may not want to pursue a case unless the victim has a significant loss of current or future income to include in the lawsuit.

THE NEXT STEPS

Congratulations! You have taken an important first step in patient empowerment – seeking information and resources to educate yourself about the safety and quality of your medical care.

Because the material in this guide is presented in a logical and highly organized sequence, it does not have to be read in any particular order, including cover-to-cover, to be useful to you. Each chapter is an independent and condensed guide to the subject at hand. Is a loved one having surgery next week? Start with the Surgery and Anesthesia chapter and read the others when you have time.

Please visit our website at www.EmpoweredPatientCoalition.org/publications to download an additional section of this guide – the *Patient Journal*. The *Patient Journal* is meant to be used as a hospital diary. The forms have been customized to meet the unique needs of patients and their advocates and will allow them to understand their care and stay focused and organized.

You can print The Patient Journal section and place it in a binder with the rest of this guide for easy use while you are in the hospital. Or, view and download the forms on your computer or mobile device.

Please remember that this guide was written to educate and inform readers about the specific information and skills they need to be active participants in their medical care. It is informational in nature and is not intended as a substitute for the professional advice of a physician, attorney, or other advisor.

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