

Family Centered Patient Advocacy

A Training Manual

Written and Edited by

Ilene Corina and Eve Shapiro

Published by PULSE of NY

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Printed in the United States of America.

Published by:
PULSE of New York

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Acknowledgements

PULSE wishes to acknowledge the following people for helping to make this training manual possible:

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Acknowledgements

Special thanks to: South Nassau Unitarian Universalist Congregation, Freeport, Long Island, and the members who so graciously host meetings of PULSE and share their health care experience.

With funding from: Gilead Sciences Inc., Long Island Unitarian Universalist Fund, National Patient Safety Foundation, North Shore-Long Island Jewish Health System, and N.Y. State Senator Kemp Hannon.

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Preface

Patient safety experts and organizations encourage patients to participate actively in their care to help reduce the rate of injuries from medical errors. Written material, often distributed upon admission to the hospital, tells patients what they can do to guard their safety. One action every patient and prospective patient should take is to appoint a patient advocate before one is actually needed. Choosing an advocate before you are sick is an important part of safeguarding your care. Selecting an advocate before you become ill or need hospitalization will offer you the greatest protection and peace of mind.

A patient who is injured, sick, in need of surgery or a medical procedure, or just elderly with an ailing body may not be in a position to be actively involved in their care. They may just want to focus on getting well. For this reason a family member or friend, chosen in advance to be an advocate, is crucial to guarding the patient's safe care. But what exactly does an advocate do? And who would make a good advocate?

I would like to think I know who would be my best advocate. But the person who loves me most may be too emotional to form an objective partnership with health care providers and help me get the best care. I, too, may not be a good advocate for the person I love most if my emotions get in the way of good communication.

What does the doctor want from me if I am acting as an advocate? How can I help nurses do their job safely and effectively without getting in the way? How can I make the patient feel comfortable while keeping him or her safe? These are some of the questions we answer in this manual.

PULSE spent a year interviewing and surveying more than 300 people who have used the health care system or who work in health care. Their stories and experiences have taught us some of the behaviors that work to make a good advocate and some that do not work. In developing this manual, *Family Centered Patient Advocacy*, we asked experts in their fields to share what they

want you to know so you can be an effective advocate for someone you care about.

You will learn about preparing for a trip to the emergency room and about helping a patient to prepare for a doctor visit, for surgery, and more. You will learn about policies and standards used in the hospital to keep patients safe and about how you can help to ensure standards are met. You will also learn that a pen and notebook are your most important tools, since the patient advocate is responsible for writing down all medical information and keeping accurate records for the patient.

The information in *Family Centered Patient Advocacy* should not take the place of a reliable relationship between the patient and their health care provider. But it should work as a tool to answer some basic questions about how to advocate effectively for your friend or family when they need you most.

Good Luck and be well.

Ilene Corina

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Introduction

“Dr. Donald Berwick, president of the Institute for Healthcare Improvement, tells the story of his wife Ann’s experience when she developed symptoms of a rare spinal-cord problem at a leading hospital. His concern was not just how she was treated; it was that so little of what happened to her was unusual. Despite his best efforts, tests were repeated unnecessarily, data were misread, information was misplaced. Things weren’t just slipping through the cracks; the cracks were so big, there was no solid ground.

“An attending neurologist said one drug should be started immediately, that ‘time is of the essence....The first dose was given 60 hours later...Nothing I could do, nothing I did, nothing I could think of made any difference,’ Berwick said in a speech to colleagues. ‘It nearly drove me mad. One medication was discontinued by a physician’s order on the first day of admission and yet was brought by a nurse every single evening for 14 days straight. No day passed—not one—without a medication error,’ Berwick remembers. ‘Most weren’t serious, but they scared us....If that could happen to a doctor’s wife in a top hospital,’ he says, ‘I wonder more than ever what the average must be like. The errors were not rare. They were the norm.’”—Time Magazine, April 23, 2006.

Between 44,000 and 98,000 people die each year in hospitals in the United States as a result of preventable medical errors, according to the Institute of Medicine (IOM) in its 1999 report, *To Err is Human*. In its 2006 report, *Preventing Medication Errors*, the IOM targets the most common medical errors—medication errors—estimating that hospitalized patients are subject to an average of at least one medication error each day and that “at least a quarter of all medication-related injuries are preventable.”

The errors referred to by the IOM are limited to those occurring in hospitals. They do not include errors made each year in doctors’ offices, clinics, outpatient surgical treatment centers, pharmacies, nursing homes, or other settings. If one were to add to the IOM statistics the number of medical errors made in

these facilities, the number of errors made each year would reach 180,000, according to the Veterans Administration.

Although the IOM statistics are the subject of continued debate, leaders in the medical community such as Donald Berwick, M.D., Lucian Leape, M.D., and many others agree that something must be done to prevent and reduce medical errors. That ‘something’ includes involving patients, family members, and patient advocates as partners in patient care.

There are many good reasons to be involved. Doctors, nurses, and other health care professionals, according to The Joint Commission—the leading organization in the United States that grants hospitals accreditation—are strongly encouraged to make patients and families partners in their care.

Patients, whether inside or outside of the hospital, cannot always be expected to ask questions, to remember the answers, or to be vigilant about all aspects of their care. The anxiety and fear that commonly accompany pain or a serious illness, the nature of the illness itself, and the side effects of medication often make it impossible for patients to be alert enough to ask questions that would promote their own safety. That is why patient advocates are so important.

Although all of us are potential patients and potential patient advocates for others, few of us would know what to do if we were called upon to become so intimately involved in someone’s care. What, exactly, would be expected of us?

This practical handbook answers such questions. It focuses on the role of the patient advocate in a range of health care settings, from the doctor’s office to the operating room and beyond. It explains information we should have at our fingertips at all times, such as complete and accurate information about all medications we take. It includes examples of questions we should not be afraid to ask doctors, nurses, surgeons, anesthesiologists, and others. As patient advocates, we must feel empowered to ask questions such as, “Have you washed your hands?” and “Are you sure this is the right medication, in the right dose,

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that it matches exactly what the doctor prescribed...and that it is meant for this patient?”

The idea of asking such questions may still make many of us uncomfortable, despite the encouragement of hospitals, The Joint Commission, and many other organizations. But remember that patient safety is at stake, and that the patient advocate plays an essential role in ensuring it.

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CHAPTER 1

The Patient Advocate

Not every patient feels comfortable questioning their doctors or nurses about medications, procedures, or other care they are about to receive. Sometimes, even when patients ask, the answers to their questions may not be conveyed in terms they can easily understand or in ways that ease their anxiety about asking questions in the first place. Even when patients are highly educated, anxiety about their illness, the illness itself, or the effect of medication can make it difficult to know which questions to ask and to remember the answers.

For these reasons and more, it is important for everyone to have a patient advocate—to designate someone who will accompany them to the doctor's office, for medical tests, and to the hospital for the duration of their stay. A patient advocate can be a family member or a friend, but it must be someone whom the patient trusts and someone who is reliable, assertive, diplomatic, persistent, and well organized. Sometimes more than one person may feel entitled to speak on behalf of the patient. To avoid confusion and hurt feelings, the patient should, whenever possible, clearly tell clinicians and family members who the patient advocate will be.

The importance of having a patient advocate is recognized by organizations such as The Joint Commission, the Agency for Healthcare Research and Quality, the National Patient Safety Foundation, and others.

A patient advocate, as defined by the PULSE Patient Safety Network Council, defines a patient advocate as a trained individual, such as the patient or someone specifically designated by the patient or family, to help oversee the patient's needs, care, and safety while creating an objective partnership between patient, family, and health care provider.

“A trained individual” is more than a friend who is coming along to help the patient carry an overnight bag. There is a place for friends and family in the partnerships to be developed, but a patient advocate is more. “An objective partnership” means that the advocate should be free of bias or preconceived

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notions when acting as a liaison between the patient and health care professionals, and should always have the patient’s safety and best interests in mind.

The patient and advocate must decide, in advance, what the advocate’s responsibilities will be. The sample checklist, below, gives examples of common roles the patient advocate can play.

The Health Insurance Portability and Accountability Act of 1996 limits the ability of health care workers to discuss patient information with anyone other than the patient. Whenever possible, the patient should give written permission for their health information to be shared with the patient advocate.

Sample Patient Advocate Checklist

My patient advocates are (list those who are expected to advocate for the patient):

My patient advocate’s duties will include (check all that apply):

- Check medication.
- Verify procedure is being done to correct body part.
- Help me organize and understand lists of instructions.
- May make decisions for me (health care proxy is on file)
- May not make decisions for me (health care proxy is _____)
- Choose appropriate food/menu items.
- Assist with bathroom use.
- Assist with bath.
- May be present when the doctor speaks with me.

Other _____

Tips for the Advocate:

Learning Confidential Information

You may hear information about the patient's health care that is highly confidential. Information about past illnesses, present illnesses, or diseases may be discussed in your presence by the patient and health care provider. Other information that may be discussed include height, weight, medications, and allergies. As an advocate, you must remember to keep all information completely confidential. Unless you are the health care proxy, too, you will not be making decisions for the patient but will be making sure the patient is capable of making his or her own decisions, or making sure the appropriate family member or health care proxy has the information needed to make decisions.

Do not discuss at a later time what you heard about the patient. Be considerate and don't ask them about their drug addiction, alcohol addiction, or tubal ligation if you hear these are parts of their medical history.

Advocates do not have access to the patient's chart unless the patient requests this. Your role in helping to make decisions is strictly based on the information the patient shares with you. Doctors or nurses should not be expected to share information with you unless the patient has given prior permission for them to do so.

A patient advocate should have a notebook to begin keeping records for the patient.

The notebook should list:

- Doctors' names, addresses, telephone numbers, and e-mail addresses.
- Medications the patient takes, including over-the-counter medicines and herbal supplements.
- The pharmacist's name, address, telephone number, and e-mail address.
- Addresses of hospitals and other health care facilities.

The notebook should also contain:

- Questions to ask the doctor.
- Doctors' answers to all questions.
- Instructions about follow-up appointments.

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- Information from follow-up phone calls about test results.
- A list of family members and friends who are helping the patient, including their contact information.

This notebook will become a history of the patient's care, making it easy for the patient and the patient advocate to retrieve and share information with designated health care professionals and family members.

CHAPTER 2

Helping the Patient Prepare for the Doctor

It is important to prepare for doctor visits as far in advance as possible. Such preparation includes keeping track of all medication the patient currently takes, getting any required forms in advance for the patient to fill out at home, ensuring the patient will have enough time with the doctor, and helping the patient to see the doctor in a group practice or clinic with whom he or she is most comfortable. If the patient is and remains uncomfortable speaking with the doctor, encourage the patient to change doctors. Ask for recommendations from trusted friends or other doctors.

Following these tips will help the patient and the patient advocate prepare for the doctor visit:

If you take a list of medications: List prescription medicines, vitamins, herbal supplements, and any over-the-counter medicines, such as cold medicines or stomach antacids, the patient currently takes. Include:

- The patient's name.
- All of the patient's allergies, including any medication allergies or bad reactions the patient has had in the past.
- Dosage of each medication.
- Number of times each day the patient takes the medication.
- Actual times the patient takes the medication.
- When the medication was started.
- When the medication was or will be stopped.
- Name of the doctor who ordered the medication.
- Reason the medication was started.
- Reason the medication was or will be stopped.

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If you “brown-bag” it: Instead of listing all the medications the patient currently takes, you may prefer to put all the prescription and over-the-counter medicines, vitamins, and herbal supplements in a bag to take to the doctor’s office. Be sure all medications are closed tightly before putting them into the bag and that the original labels are in place. Also, look inside each bottle to be sure the patient did not combine medications. Sometimes patients remove medications from their original containers and put them into containers that are easier to handle. If you see they have done this try to discourage it in the future.

The advocate can call ahead to find out how long the patient will have to wait to see the doctor. Long waits may make patients’ blood pressure rise or may cause them to want to rush through the visit. It may be up to you, as the patient advocate, to ask those who schedule the appointments for enough time—from the patient’s point of view—to talk with the doctor.

Try to call the doctor’s office at least one week before the appointment and ask them to send you a copy of any questionnaires and forms that need to be completed before the patient sees the doctor. This way, the forms can be completed and questions answered at home, in private and without rushing. Most doctors’ offices will be happy to mail this information in advance and have you return the completed forms at the time of the appointment.

Bring your notebook with a list of questions for the doctor. Include the patient’s symptoms and concerns, and any research you have done on the symptoms.

If you are not sure which doctor the patient will be seeing in a large clinic or group, ask. If the patient is more comfortable with one doctor than another, tell the office staff in advance. If it isn’t possible for the patient to see the doctor of his or her choice, prepare the patient accordingly.

Ask the patient whether he or she would like you to be in the exam room. Don’t be offended if the patient does not want you there. It will be up to you and the patient to remind the doctor that you need to be present after the exam to help ask questions and note the answers. It is best for the patient and patient advocate to make these arrangements before the doctor visit.

CHAPTER 2 Helping the Patient Prepare for the Doctor

If the patient is not physically able to dress or care for him- or herself, you may need to discuss the patient's concerns with the nurse and be available to help. Respecting the patient's privacy is the best way to convey respect and sensitivity and get the relationship off to a good start.

Prepare the patient appropriately for the doctor visit, allowing plenty of time for waiting, the exam, any required testing, and filling prescriptions.

Tips for Choosing a Doctor

- Research physician profiles by state. Some states maintain lists that include doctors' background information, but beware: the information is not always objective because it is reported by the doctors themselves. It also may not be current.
- Ask doctors you respect whom they would see if they or a family member were the patient.
- Ask friends and family members whom they have used and would recommend. Some prefer a good bedside manner and some prefer a doctor who has been around for 40 years. What matters most to the patient is what's important.
- If you know someone who works in the hospital with which a doctor is associated, ask his or her opinion.

CHAPTER 3

In the Doctor's Office

When arriving at the doctor's office, be prepared to wait. The patient will have to read and sign forms (if the patient has not done this in advance), be examined, listen to what the doctor says, ask questions, note the answers, and get information about any necessary follow-up care. It is best for the patient to decide before the appointment whether the advocate will accompany the patient into the exam room. The advice in the following sections will help to make the doctor visit as informative and relaxed as possible.

In the Waiting Room

The advocate should be patient while waiting for the doctor. Read, chat with the patient, or bring a crossword puzzle book to occupy your time. Do not discuss confidential information that may make the patient feel uncomfortable in the waiting room. This can be a stressful time for the patient. Do what you can to relax, and to help the patient relax, before going in to see the doctor.

Be sure the patient reads and understands all the forms before signing. If the patient doesn't understand the information in the required forms, either read and explain it, or ask the doctor or nurse for clarification or more information (see the box, Informed Consent, on p. 34 for an explanation of this process and what the patient is entitled to know and understand before signing anything). If you will be helping to fill out forms for the patient, ask for a room where you and the patient can talk privately and where the patient will feel comfortable answering questions honestly. The doctor's office may not have a private place where others can't hear you, so consider how to handle this situation in advance. Are you capable of answering the questions for the patient? Can you get the information the forms require while waiting in the exam room for the doctor? The lack of privacy may jeopardize honest answers.

In the Doctor's Office and Exam Room

Ideally, the patient will introduce the advocate as a family member or a friend

who is there to help, not necessarily as the patient advocate. The patient may or may not want the advocate in the room during the exam. This should have been decided earlier.

If the patient advocate will not be in the room during the exam, either the patient or the advocate should tell the doctor that the advocate will be present following the exam to write down instructions. That way, the doctor will have the advocate return immediately after the exam. If the patient does not want the advocate to write down any information, the patient should ask the doctor to do this. The patient needs to tell the doctor and the patient advocate, clearly, what he or she wants.

If the patient advocate will be in the exam room to help the patient get onto the table, get undressed, get dressed, or translate information, allow for privacy during the exam. The patient should feel comfortable with anyone who is in the room.

Do not ask questions during the exam. Patients should ask their own questions if they are able to. This is a time for the doctor to discuss pain, look for symptoms, and talk to the patient, if possible.

A Doctor's Clear Handwriting is Essential

If the provider plans on writing down any information for the patient to take home, be sure to review it with the doctor and make sure you understand it before you leave the office. Can you read the doctor's handwriting on all prescriptions? If you or the patient has any doubts, ask the doctor to print the prescription so you can read it.

Make sure the doctor includes the name of the medication, its generic name, the dosage, the time of day to take the medication, and how long the patient will need to take the medication. Ask whether the patient should avoid any other medications, foods, or alcohol while taking this medication. Ask what the side effects of the medication might be. You or the patient should verify all of this information when picking the medication up at the pharmacy.

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Conversation after the Exam

Although it is best for the patient advocate to remain quiet while the doctor examines the patient, it is appropriate for the patient advocate to ask questions afterward. It may help to follow these tips:

- Make a list of your own questions, whether you are in the exam room or the waiting room.
- If the patient is alert and able to understand the doctor's explanation of a procedure, symptoms, or other concerns, do not interrupt with questions. Write them down instead.
- Write down as much of the conversation as possible so the patient can go back and review it later.
- Never discuss or ask questions about your own experience, your own health, or your or your family members' problems.

When the doctor and patient finish their conversation, the patient advocate can ask the patient for permission to ask the doctor a few questions. Getting the patient's permission lets the health care provider know you are there in the patient's best interests.

This may be the time to suggest research on the symptoms or the subject and to ask the doctor for the most reliable sources of information. If you've brought some information with you, the doctor may ask to see it to be sure it comes from a reliable source. This is an important concern because commercial Web sites often have products they are trying to sell, making it difficult to know whether the information is objective, research-based, and can be trusted.

Write down the date and time for the next appointment and the telephone number to call for any test results. **You or the patient should call for test results, even if the office says they will call you. Never assume that no news is good news.**

If the patient sees different health care providers for different medical problems, ask each of them to forward their reports on any tests, findings, or recommended treatments to the patient's primary care doctor. Call to ask the primary care doctor if he or she has received a report, read it, and has an opinion about it.

CHAPTER 4

Medication Safety

Taking medication carries risks and benefits. The benefits can be treating infection, pain, disease, chronic conditions such as depression, and many more. The risks include allergic reactions to the medication itself, the negative effects of one medication combined with others the patient is taking, and the negative interactions with certain foods or alcohol. And there are other risks: the risk that a prescription will not be written clearly and may be misread by the pharmacist, that a decimal point will be misplaced, or that the name of the patient will not be the name written on the pharmacy's medication label.

The patient advocate plays a vital role in helping to prevent medication errors. The following tips will help the patient advocate ensure the patient's safety when medication is needed.

Always carry an updated list of the medications the patient takes.

The list should include:

- Any allergies, including medication allergies and any bad reactions the patient has had to medications in the past.
- All prescription medications.
- Over-the-counter medications—including cold or allergy medications, antacids, pain relievers, and so on.
- Vitamins and herbal supplements.

The list should include the name of the doctor who prescribed the medication, the dosage, and when during the day it is to be taken. It should also include the date the patient begins taking the medication and the date it is or will be discontinued.

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Remind the patient it is important to tell the doctor about any use of “street drugs” or alcohol, or the misuse of prescription medications. This information, like all other information in the patient’s medical record, is confidential.

Be sure you can read and understand the doctor’s written prescription. Before leaving the doctor’s office, look carefully at the prescription. Ask how to spell the medication and what the dosage is. If it is hard to read or understand, ask the doctor to print it. Also, be sure you understand why each medication is being prescribed and how often, and for how long, it should be taken.

While at the pharmacy, carefully check the patient’s name, medication name, dosage, and directions on all medication labels. It is important to check the spelling of the medication because there are many medications whose names are spelled alike. Make sure the dosage is exactly what the doctor prescribed. Check the patient’s name to be sure this medication is intended for the right patient.

Make sure everything matches exactly what the doctor ordered. Tell the pharmacist immediately if:

- The patient’s name on the medication label is not the patient’s name.
- The dosage is different from what the doctor ordered.
- The directions about when and how often to take the medication written on the label are different from what the doctor told the patient.
- The medication looks different from past orders.
- You have any questions or if something does not seem right.

Ask the pharmacist if he or she is aware of the patient’s allergies and of other medications the patient is taking. If not, consult your medication list and let the pharmacist know. The patient may not have given the pharmacist this information.

HIPAA regulations prevent the pharmacist from sharing health information with anyone other than the patient. If the patient can confirm, by telephone, that the patient advocate has permission to intervene, the pharmacist should be able to discuss the patient's medications.

Speak to the pharmacist whenever picking up a prescription from the pharmacy. By law, pharmacists must offer counseling when dispensing prescription medication. Ask the pharmacist about the medication's side effects. Sudden stomach cramps, a chronic cough, dizziness, or other side effects may be due to a new medication. Be aware of potential side effects and call the doctor or pharmacist if they occur.

When using asthma inhalers, be sure they are marked appropriately. Inhalers often look similar but function differently and may contain different treatments. The proper treatment can be written with a marker right on the case. Ask your pharmacist about the best way to mark the inhaler, especially if you didn't save the outer box with the instructions or name.

If the doctor prescribes antibiotics, make sure the patient follows the directions carefully. If the patient and patient advocate do not understand the directions, ask the doctor or pharmacist questions until the directions are clear. The patient should take the entire amount prescribed. If the patient has any negative reactions or unusual symptoms, call the doctor immediately.

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CHAPTER 5

In the Hospital

The need for hospitalization can be stressful for many, if not most, of us. We are concerned about our illness and about the hospital stay itself. Knowing what to expect upon admission and while hospitalized may help to make this a less stressful experience for everyone. It is important to stay calm and try to reduce anxiety as much as possible. Advance preparation is key.

If it is not an emergency and the advocate is driving the patient to the hospital, leave plenty of time for parking. Find out in advance where to report and whom to see when you arrive.

Before leaving for the hospital prepare the following items to take along:

- Checklist of medications.
- Telephone numbers of family members and doctors.
- Overnight bag with appropriate changes of clothing, rubber-soled shoes, and any comfort items.
- A newspaper or book to read.
- Disinfectant wipes or alcohol sanitizer to use on the hospital telephone, television remote control, call buttons, arms of chairs, bed rails, and toilet flush handles.
- Notebook and pen to write down information and instructions.

Patients should do as much for themselves as they can or want to do, including talking to the nurses and doctors.

Follow these important tips when the patient is admitted to the hospital or other health care facility and throughout their stay:

- Find out the names of the people in charge and caring for the patient.
- Ask whom to call or see if a problem arises or if you have a concern about the safety of the patient's care. The hospital should give the patient this information upon admission, but if they don't, ask. Don't wait until a problem arises to get this information.
- Hospital bed-rest increases the risks of blood clots in the legs. Patients should get out of bed and take frequent walks, if they can, to minimize these risks. If they are unable to walk, ask the patient's health care providers what can be done to minimize the risk of blood clots.
- Ask whether the hospital has a rapid response team on call 24 hours a day, 7 days a week. If there is a rapid response team, ask how to access it and keep this information handy.
- Anyone who comes into the patient's room must introduce themselves. If they don't, ask their names.
- Write in the notebook the names of all physicians and consultants who come in to see the patient and the name of the charge nurse.
- The patient should be comfortable and have as much privacy as possible. The patient shouldn't feel the need to move things around the room.
- Ask the staff whether they will be able to meet the patient's needs if you to have to leave. You may find out that it would be better not to leave.
- Is the current list of the patient's medications and allergies in the patient's chart? Ask the doctors and nurses to double-check this list before they administer any medication.

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- Keep a list of medications the patient is taking, including the name, dosage, and time of day it should be administered, at the bedside. The hospital should label all medications given to the patient, including IV bags. This allows any visitor to check to see if a medication being administered is correct, is being given at the right time, and is being given to the right patient. If there is any question, ask the nurse about it right away. Anyone who knows the patient well enough to visit should be encouraged to advocate on his or her behalf.
- Be sure the patient takes the right medications at the right time, as directed by the doctor. A nurse may give the patient a medication to take at a time not prescribed by the doctor. If the time a nurse dispenses a particular medication is different from the time the doctor ordered the patient to take it, ask to speak to the charge nurse, a patient relations representative, or to the doctor. Do not let the patient take any medication about which you have any doubt. Do not let yourself be intimidated by a nurse who insists the patient take any medication about which you have questions.
- If you do not understand why the patient is receiving a medication, speak to the doctor or nurse immediately. Do not allow any medication, including IV solutions, to be administered if you or the patient does not know why the patient is receiving it. Do not allow the patient to take any medication if you think it is not what the doctor prescribed. Ask questions!
- Anyone who comes into the patient's room—whether it is a doctor, nurse, physician assistant, technician, dietician, or someone who will transport the patient for tests or to another unit, including surgery—must check for at least two patient identifiers. This ensures that the service or treatment to be provided is matched to the right patient. The provider may ask for the patient's name and date of birth, or for other identifiers of the hospital's choosing. Or a provider may check the patient's wrist band, where both identifiers may appear. In addition to the name or date of birth, identifiers may

be a patient identification number or a telephone number. But one of the identifiers cannot be the patient's room number.

- Ask anyone who comes into the patient's room to deliver care or services whether they have washed their hands, because hand washing prevents infections from spreading from patient to patient in the hospital. The health care provider may use an alcohol-based hand rub to cleanse their hands.
- When speaking to health care providers, ask their names and titles. Do not assume that someone is a doctor or a nurse. Look at their identification tags. Health care providers are required to wear identification tags so they are visible to everyone. If you cannot see it, ask them to show it to you.
- Speak up as soon as you notice a change in the patient's condition:
 - Symptoms are vital pieces of information. Do not assume what the patient is experiencing is normal.
 - The patient has the right to pain management. If the patient is in pain, report it.
 - If you see redness or swelling, such as at the site of an IV, tell the health care provider immediately. This could be a sign of infection.
 - If a wound is oozing or has an odor, tell the health care provider immediately. This could be a sign of infection.
 - Report any other symptoms or changes in the patient's condition right away.
- If your concerns or those of the patient are not acted on promptly and you are worried about a patient's worsening symptoms or deteriorating condition, ask to speak with the physician provider or the charge nurse on the unit. If this does not resolve the problem, access the hospital's rapid response team if there is one. If there is not, call for senior staff or ask where you can immediately reach senior staff.

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- Report any concerns about the quality of care or treatment to the individual identified by the hospital upon admission. This person may be the hospital's patient safety officer. The hospital's patient safety officer is there to help health care providers and patients better understand each other's concerns. If the hospital staff does not respond to the reported concerns, check with your state Department of Health or contact The Joint Commission (<http://www.jointcommission.org>) if the facility is accredited by The Joint Commission.
- If you or the patient is concerned about the appropriateness of the patient's care, ask to talk to a member of the hospital ethics committee.
- Report any adverse effects or suspected bad reactions to medications to the physician and nursing staff immediately. You can also report this information to the Institute of Safe Medication Practices (<http://www.ISMP.org>).

Rapid Response Teams

Find out whether the hospital has a rapid response team. Hospitals increasingly have teams of health care professionals on call 24 hours a day, 7 days a week. The purpose of the rapid response team is to come to the immediate aid of a patient in distress if prior requests for help have not been taken as seriously as the patient or patient advocate thinks they should be. Look for information about how to contact the hospital's rapid response team in the patient's admission packet and in signs posted throughout the hospital. If this information isn't there, ask about it and keep the rapid response team telephone number handy.

Pressure Sores

Developing pressure sores, or decubitus ulcers, is a common risk of being hospitalized. The National Institutes of Health defines pressure sores as an area of skin that breaks down when patients stay in one position for too long without shifting their weight, which often happens when a patient uses a wheelchair or is bedridden. The constant pressure against the skin reduces the blood supply to that area and the affected tissue dies. (<http://www.nlm.nih.gov>)

There are four stages of pressure sores, classified according to severity, as follows:

- Stage 1—a pressure sore starts as reddened skin that does not turn white when pressed.
- Stage 2—the skin blisters or becomes an open sore. The area around the blister may be red and irritated.
- Stage 3—the skin breakdown looks like a crater where there is damage to tissue below the skin.
- Stage 4—the pressure sore becomes so deep that the muscle and bone are damaged, and sometimes there is also damage to tendons and joints.

There are many causes of or contributing factors to pressure sores. Some of these include the following:

- Chronic conditions, such as vascular problems or diabetes, which prevent blood from flowing to some areas of the body.
- Being confined to bed or to a wheelchair without frequent changes of position.
- Problems controlling the bladder or bowels, causing moisture to remain next to the skin for long periods of time.
- Being elderly.
- Being malnourished.
- Wearing clothing, including underwear, diapers, and shoes, that fit too tightly.
- Continually rubbing parts of patients' bodies while moving them, which causes friction.

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Pressure Sores *(continued)*

- Leaning a body part against an object, such as the foot pedal of a wheelchair, which causes pressure.

The keys to preventing pressure sores are keeping the skin clean and lubricated, making sure the patient does not stay in one position for too long, and using pressure-relieving mattresses and chair cushions.

It is appropriate for the patient advocate to ask the patient's doctors, nurses, and dieticians what, if anything, can be done to help prevent pressure sores, and what role the advocate can play in their prevention.

The Health Care Proxy

- A 'health care proxy' is a person legally selected and appointed by the patient to make decisions about their health care treatment when the patient is unable to make them.
- The patient advocate should encourage patients to appoint a health care proxy to make treatment decisions if the patient is unable to do so, according to the patient's wishes. This includes decisions about life support or artificial nutrition and hydration if these are ever presented as options.
- Before the patient appoints a health care proxy, the patient should ask that person if he or she is willing to make such decisions on the patient's behalf.
- Patients receive information on appointing a health care proxy whenever they are admitted to the hospital.
- To appoint a health care proxy, the patient must complete a health care proxy form and two people other than the appointed proxy must witness it.
- A health care proxy cannot make financial decisions.
- A person named in a 'General Power of Attorney' can make financial decisions but cannot make health care decisions if the patient is unable to do so.

Discharge Instructions

When the patient is discharged, he or she must receive clear, understandable discharge instructions. If such instructions are not included in the patient's discharge packet, ask for them. These instructions should explain:

- The treatment the patient received.
- Medications the patient should take at home, for how long, and on what schedule.
- When to follow up with the doctor.
- Other care needed after discharge.

If the patient cannot read the discharge instructions or does not understand them, the patient and the patient advocate should ask questions until you both understand. Share these instructions with the patient's primary care doctor at the patient's next appointment.

The riskiest time for a hospitalized patient is when he or she is moved from one area of the hospital to another, from the hospital to home, or from the hospital to another facility. During such transfers, poor communication can lead to a mix-up of medications or procedures. Ask:

- Is all the necessary information going with the patient?
- Do the patient and family thoroughly understand this information?
- What about medications--are there new ones to obtain at the pharmacy before discharge?
- How do any new medications interact with the medications the patient was taking before entering the hospital?

Remind the patient to ask for the results of any tests, such as a blood tests, x-rays, or sonograms, that he or she had while in the hospital. All patients have a right to and should know their test results. Keep records of all tests and results in the notebook.

Encourage patients to request and keep a copy of their discharge summary.

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Striking the Right Balance

Sometimes hospital staff may convey the sense that they think the patient or patient advocate is too intrusive, too nosy, or meddling. Don't unnecessarily pester the nurses. It is important to realize that they are often stressed, busy, or tired. Still, to protect the patient's safety, you must be aware of what is happening and why. Why is the patient's diet changing? What is this new pill? When can the patient take a walk, take a shower, take a nap, go outside, go for a test, or have his or her operation or procedure? Ask questions until you are satisfied with the answers. If the nurse's responses do not answer your questions, ask the head nurse on the unit.

Learning the Hard Way

At the age of 75, Susan R. had a total right hip replacement in a Maryland hospital. She was admitted to a nursing home/rehabilitation facility affiliated with the hospital three days later. "The rehabilitation facility left much to be desired," she confides. "The equipment was old and difficult to manipulate, and there was little room to maneuver the wheelchair and walker in and around the bed and the room. Even more troubling was that the facility was dirty," she says.

All this came as a shock to Susan and her husband, Ned, who had made an assumption before her surgery that proved to be incorrect: they assumed that when she was ready, she'd be able to go to the rehabilitation facility of her choice.

The problem was, Susan was ineligible to go to the facility of her choice but she didn't learn this until just before she was discharged from the hospital. Because she had chosen the rehabilitation facility based on the recommendation of a trusted friend, she and her husband looked no further. When she was discharged from the hospital and learned she was ineligible for the one she wanted, Susan found herself in a facility she and Ned knew nothing about, and one not of her own choosing.

"Prior to surgery it is essential to check out three rehabilitation/nursing facilities," Susan cautions. "In the haste of discharge we agreed to go to this place,

Learning the Hard Way *(continued)*

which is part of the same hospital complex as our chosen facility. In retrospect, we should have asked a lot of questions and done some research in advance. If we had, I would have been able to make an informed decision about a second choice," she says.

Medication Mismanagement

"At 6:00 a.m. of my first day in the nursing facility," 70-year-old Leah recounts, "a nurse came in with two of my medications: one that I'm supposed to take an hour before breakfast and the other that I'm supposed to take half an hour before breakfast. I told her I could take the first medication now but would have to wait another half hour before I could take the second.

"When I asked the nurse to leave the second medication in my room so I could take it at the right time, she told me she wasn't allowed to do that. And she said she couldn't come back in 30 minutes to give it to me. Instead, she said it was alright for me to take them both at the same time. I refused and called my doctor. My doctor confirmed that I could not take the two medications at the same time and told me I did the right thing in refusing. Taking the two together, he told me, could be dangerous.

"When they brought my breakfast, the nurse did not bring a third medication I'm supposed to take with my meals. Instead, she brought it to me an hour or two after I'd eaten. At the same time, they brought a valium, which I am only supposed to take at night if I have difficulty sleeping. Again, I refused to take them.

"My solution? Since the medications help me digest my food, my solution was to stop eating. Clearly not the ideal solution, but it was easier than fighting with the nurses."

Leah's advice is, "When medications are brought to you, ask what each one is because they often substitute a generic that you may not recognize. Ask about it if you have any doubts. And be sure you are given the medication at the time prescribed by your doctor. If this doesn't happen, don't take them until you talk to the doctor. You have the right to refuse. Don't let the nurses intimidate you."

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Preventing Falls in Health Care Facilities

Hospitals and other health care facilities cannot prevent all falls, especially if a person has a history of falling. But the patient advocate can help to prevent patient falls by taking the following steps:

- Tell the nurses about the patient's history of falling, including times the patient has fallen and the patient's sleeping and bathroom habits.
- Make sure the patient has non-slip, closed-back, properly fitting rubber-soled slippers, sneakers, or shoes.
- Patients who are at risk for falls should not try to get up by themselves—they should always call for help instead, even if they are feeling better and think they can get out of bed on their own.
- Encourage patients to become familiar with their surroundings. Patients can forget where they are.
- Encourage patients to ask their doctors about the side effects of medication. Sometimes, adjusting to a new medication can increase one's risk of falling.
- Ask the nurses about the need for side rails, since they can actually increase a patient's risk of falling.

Although side rails are a safety device that can prevent a patient from falling, they can also pose a danger to patients. Disoriented patients may try to climb over side rails to get out of bed and fall from a greater height as a result. Patients can become trapped between the rails. Side rails should be used with discretion. Discuss any concerns about side rails with the patient's nurse.

CHAPTER 6

Surgery

What can be more anxiety-provoking than to hear the words “You’re very sick and need an operation?” On one hand, surgery can offer a cure from cancer, relief from intractable pain, drainage of a life-threatening infection, salvage of a limb, the control of serious bleeding, restoration of eyesight, and other benefits. On the other hand, surgery also carries with it the risk of complications, even death, whether or not a medical error occurs.

The patient advocate can play a vital role in keeping patients safe while they are in the hospital preparing for and recovering from surgery. A list of steps the patient advocate can follow in a variety of situations is presented below.

Before Entering the Hospital

- Encourage the patient to meet the surgeon in advance and ask about his or her experience dealing with similar problems.
- Encourage the patient to get a second opinion when confronted with a difficult decision. The more information and alternatives the patient has, the easier it will be to make informed decisions.
- Ask the patient whether he or she has told the anesthesiologist or nurse anesthetist about anything that could influence the patient’s care during any operative procedure. These professionals often practice independently of the hospital. The patient should talk to them ahead of time to find out what will happen and what to expect during and after the operation.
- Check to be sure the surgeon knows about the patient’s medical history, relevant family illnesses, all medications they are taking—including non-prescription, over-the-counter drugs and nutritional supplements—and about the patient’s eating, drinking, smoking, and exercise habits.

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- Ask the patient if he or she knows what the laboratory tests indicate.
- Talk to the patient about possible complications of the surgery and whether something can be done to prevent them. (For example, encourage the patient to ask whether the surgeon recommends antibiotics before the surgery to prevent infection, and whether the temperature in the operating room can be adjusted to minimize the chances of post-operative problems.)
- Be sure the patient completes a living will or advance medical directive before entering the hospital, even if the patient is young and healthy. It is also vital that the patient advocate, family, and closest friends know the patient's wishes. If the patient is unable to speak for him- or herself at any time during an illness, a health care proxy appointed by the patient may need to convey the patient's wishes.

Before Surgery

- Encourage the patient to ask any doctor or nurse who walks into the hospital room to deliver care, "Have you washed your hands?" If the patient is unable to ask for any reason, the patient advocate should ask on their behalf. Hand washing is the best way to prevent infection.
- Check to be sure the surgeon has marked the site where surgery will be performed while the patient is still awake and alert, before being taken to the operating room. Failure to mark the correct surgical site is the reason for too many wrong-site surgeries.
- Encourage the patient to ask how his or her skin will be protected from excessive pressure.
- Remind patients who have chronic medical problems, such as heart or lung disease, diabetes, cancer, or other problems, to ask their surgeons how these conditions will affect their care after surgery.
- Encourage patients to ask the anesthesiologist how the responsibility

for their care and safety will be shared among various health care professionals during surgery.

- Be sure the patient asks about the ways in which he or she will be monitored in the operating room and in the post-anesthesia care unit.
- Encourage patients to tell the doctors and nurses right away if they have a cold or a fever or are otherwise not feeling well.
- Be sure a 'time out' will be called immediately before any surgery or invasive procedure. The time out allows time for the health care team to be sure they have the right patient and that the surgery about to be performed is correct.
- Encourage the patient to ask how to take care of him- or herself after surgery. If the patient can't ask the following questions and write down the answers, the patient advocate should do it:
 - Will I need special therapy, such as respiratory, physical, speech, occupational, or other?
 - How will my usual medications interact with any new medicines prescribed?
 - Will there be any special dietary restrictions?
 - Will there be an exercise program to follow?
 - Can I climb stairs?
 - Will I need any special help getting my bowels back to normal?
 - Will I need help at home?
 - Should my family be coached about how to provide care?
 - Should I consider home nursing care?
 - How should I take care of wounds?
 - Will I need a prosthesis? And, if so, when should I get it?
 - Are there community resources or support groups I should contact?

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Checklist: Before Surgery

Before the patient undergoes any surgery or procedure, the answer to all of the questions below should be "yes":

- Tell the nurses about the patient's history of falling, including times the patient has fallen and the patient's sleeping and bathroom habits.
- Unless the surgery or procedure is an emergency, has the patient spoken to the doctor who will perform the surgery or procedure and know where and why the surgery will be performed?
- Does the patient understand what the normal course of recovery will be?
- Does the patient know about the possible complications and side effects of the procedure, anesthesia, or medications?
- Does the patient know which other doctors will be involved in the patient's care?
- Does the patient know which health care providers will be with the patient during the recovery period?
- Do the patient and patient advocate know how to contact the primary care doctor if necessary?
- Does the patient know whether he or she will need to take any antibiotics before surgery?
- Does the patient or advocate know how to contact the surgeon? Will the surgeon be available in the days immediately following surgery?
- Do the patient and advocate know when to continue regular medications at home?

After Surgery

The patient advocate can promote the patient's safety after the operation by ensuring the patient knows what to expect in the post-anesthesia care unit.

Ask:

- What tests will be performed?
- Who are the people responsible for the patient's care?
- How will the patient be treated for pain?
- When will the patient be discharged?
- Where will the patient go next?
- Can the patient see his or her family?
- Who will talk to the family immediately after the operation?
- How will the surgeon and the anesthesiologist or other specialists communicate about the patient's care?

Advise the patient to tell the surgeon and others about his or her wishes about resuscitation and end of life care as expressed in the living will or advance medical directive.

Encourage the patient to ask about the possibility of falling when trying to walk to the bathroom and to ask about any precautions he or she can take. During a hospital stay, patients are in an unfamiliar environment and may be taking medications that lead to disorientation or imbalance. There are special devices that can protect the patient from injury if he or she falls. Encourage the patient to ask about their availability.

Advise the patient to ask about common post-operative complications, such as pneumonia and blood clots. Ask about what help will be available and how the patient's family or close friends can help the patient exercise.

Be sure patients who cannot move around on their own ask nurses about the need for frequent turning, changing of bed linen, pillow placement under bony body parts such as the sacrum, ankles, knees, and elbows, as well as fre-

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quent examination to detect the early signs of skin breakdown. If the patient cannot ask these questions, the patient advocate should ask them.

It is important for patients and their advocates to know what to expect after surgery. Ask the doctor what to expect during recovery, what additional treatments may be needed, and when the patient can be expected to walk, eat, and go home.

Informed Consent

A doctor and hospital must receive a patient's informed consent before any surgery or procedure can be performed. *Informed consent is a process* requiring health care providers to ensure the patient understands and agrees to the procedure or the surgery before it is performed. Informed consent does not mean the patient simply signs a form allowing a procedure or surgery to take place. To obtain informed consent, health care providers must follow these steps:

- Explain the recommended procedure and the reasons for it.
- Explain the risks and benefits of the recommended procedure.
- Explain any alternatives to the recommended procedure.
- Explain the risks and benefits of any alternatives to the recommended procedure.
- Ask the patient to explain in his or her own words what they've been told about the recommended procedure and any alternatives to it.
- If the patient does not understand, the health care provider must find alternate ways of explaining until the patient does understand. If there is a language barrier, the hospital is required to have someone available to translate as an aid to patient understanding.

“An Experience from Hell”

Sixty-year-old Rachel N. had knee replacement surgery in a hospital outside of Washington, D.C. She recounts what happened: “The surgeon ordered that my dressing be removed or changed, depending on whether there was any leakage from the wound, when I was discharged and transferred to another facility,” she says. “When I got to this facility, I was told the dressing would be taken care of after lunch. When I asked the nurse about it, she said she would do it later. Of course, I kept asking and continued to get the same answer. It was not until after dinner that she arrived.

“When the nurse finally removed the dressing she saw that there was still some oozing. She left the wound open while she went to get clean dressing equipment. In the half hour it took her to return with the clean dressing, the patient in the next bed began vomiting while a horsefly buzzed overhead. I was lying there with an open wound, a woman was throwing up in the next bed, and a fly was buzzing around the room. I was terrified of getting an infection! When the nurse finally came with the clean dressing equipment, she forgot to bring the tape. I had to wait another ten minutes until she returned. When I told her it wasn’t good to leave a wound open in these circumstances, she actually shrugged it off!

“When the physical therapist came for my session the following morning, I told her about what happened and how distressed I was. She informed an administrator who came in to hear my complaint. She told me she was truly sorry and that if there was anything she could do for me, to please call her from now on. When my husband came at noon, we told them I wanted to be discharged to go home. The resident doctor and nurse filled out all the proper papers (while we waited for two hours) and home I went. This was an experience from hell.”

CHAPTER 7

Anesthesiology

Traditionally, patients and their families have been frightened by the prospect of anesthesia for surgery or a diagnostic procedure (usually, but not always, general anesthesia during which the patient is rendered unconscious by anesthetic medications). Older people may remember a time when most patients had nausea and vomiting after general anesthesia—which is much less common today—or when people feared they would reveal secrets under the influence of drugs, which simply never happens. There are news stories about patients who said they were paralyzed, accidentally awoke in the middle of surgery, and were in pain. There are now monitors intended to prevent even a chance of this. Of course, the big fear is not waking up from general anesthesia.

There has been a revolution in the safety of anesthesia care over the last 20 years, making anesthesia much safer than it was. Today, with the many improvements in anesthesia care involving personnel, their training, technology, medications, and “systems,” the risk of an otherwise relatively healthy person suffering a catastrophe from the anesthesia alone (death, cardiac arrest, or permanent brain damage) is vanishingly small—probably 50 times less than the risk of riding in a car for a year.

Some patients have serious surgical problems, such as a leaking artery in the abdomen or brain, or an underlying medical condition, such as heart disease or severe asthma, which pose major challenges to providers of anesthesia care. Sometimes these problems or conditions lead to unintended outcomes and have nothing to do with the anesthesia itself.

The Role of the Patient Advocate

There are many things patient advocates can do in preparation to help make the patient’s anesthesia care as easy, comfortable, and safe as possible. If the surgery is elective, encourage the patient to ask the surgeon or procedure-ist the following questions in advance:

- Who will administer the anesthetic?
- Would you be confident having your own mother, spouse, or child receive the same anesthesia care from the same person under the same conditions?

While it is fine and appropriate for patient advocates to ask anesthesia providers about their education, training, certification, and experience, it is reasonable to expect the surgeon to be comfortable with the quality of anesthesia care at that facility and for patients to use that as their benchmark.

- If the procedure will be done in a doctor's office or a clinic, encourage the patient to ask the doctor:
 - Do you have the same capabilities as a hospital operating room has, particularly regarding oxygen, suction, resuscitation equipment, and so on?
 - Do you have an equivalent recovery area, with the same patient monitoring equipment that would be found in a hospital surgical recovery room?
 - Who in the office is certified to provide advanced cardiac life support? It is critical to have qualified staff whose only job is to "recover" a patient immediately after an anesthetic.
 - With what hospital do you have an acute care arrangement? If there is a complication, there must be a routine way to provide help and get the patient to the hospital immediately.

Patient Evaluation

A patient who will receive anesthesia in any setting must be evaluated thoroughly in advance. This involves taking a complete medical history and giving a physical examination. Anesthesia personnel ask the patient or the patient advocate about the patient's medical history and will discuss relevant parts of the "history and physical" prior to the actual anesthetic.

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As the patient advocate, you should know that it is critical for the patient to fully disclose all medical and surgical conditions. It is essential to reveal any of the following conditions because they may require that changes be made to the planned anesthesia care:

- Heart disease of any kind.
- Previous stroke.
- Obstructive lung disease (including asthma).
- Smoking.
- Acid reflux of stomach contents.
- Obstructive sleep apnea (severe snoring to the point where breathing stops).

Remember, anesthesia personnel are not the police. They are simply trying as hard as possible to keep the patient safe. Complete and honest disclosure of consumption of alcohol and "street" drugs (including steroids, "power" drinks, and supplements) is critical because of potential interactions with the anesthetic medications.

Prior experience with anesthesia, particularly if there were any problems, is very important, as is any family history of difficulties with anesthesia.

Remind the patient to tell the anesthesia staff about:

- Loose, missing, or broken teeth.
- Dentures.
- Trouble with the jaw or with opening the mouth.

This is important because anesthesia care often involves manipulating the airway to facilitate breathing during the anesthesia.

About Medications

On the pre-operative anesthesia visit, bring all medications and preparations in a bag so the staff can examine them. We advise patients to carry an updatable printed card that lists every prescribed and over-the-counter medication,

vitamin (including mega-vitamin), herbal supplement, and any other preparation they are using. Herbal preparations and mega-vitamins may contain substances that influence organ systems in the body that will require changes in the way anesthesia drugs are administered.

For patients who will come into the facility from home on the day of a procedure and who take medications regularly, be aware that the staff needs to develop a plan to tell patients which medications to take, and when, on that day. A small sip of clear water to get the pills down should be fine, but nothing more.

No Eating or Drinking Before Surgery

The direction “nothing by mouth,” or “NPO,” is important to follow. Patients scheduled for elective procedures must have empty stomachs so that the risk of vomiting and then breathing in or choking on the vomit is minimized. If a patient is having surgery or a procedure that is not elective, the patient advocate must be sure the anesthesia staff are given a complete and honest report, to the greatest extent possible, about what and when the patient has eaten or drank. Anesthesia personnel can give medications and perform procedures that will help minimize the risks of vomiting and its consequences.

Guidelines regarding time periods and exactly what must be avoided, including chewing gum, before anesthesia may vary somewhat from place to place and should be given by the facility where the anesthetic will be administered.

Immediately before the surgery or procedure and before the patient receives any sedating medication, the patient advocate should make sure the patient clearly tells clinicians exactly what operation or procedure is about to be done and on what part of the body. Be sure the facility personnel mark, in ink, the correct surgical site on the patient’s body. If a patient is not asked what operation or procedure they’re about to undergo—and where it will be done, with the site being marked by the staff—the patient advocate should bring this up and voice concern.

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Patient advocates should encourage patients to speak openly and completely with their anesthesia providers about the plan for the anesthetic, including their concerns or fears. Patients should never worry that they will be seen as silly or neurotic. It is much healthier to share and deal with any concerns than to suppress them.

Anesthesia Options

There are some options regarding anesthesia. The patient advocate and the anesthesia personnel should know the patient's preferences for anesthesia in advance, to the extent possible. For example, some patients would like to avoid general anesthesia, if possible, and would prefer a regional anesthetic that numbs the nerves to the part of the body being operated on. This can involve a nerve block injection to an arm or leg, or a spinal or epidural anesthetic (administered by an injection between bones of the lower back that numbs the body below the chest). Often in such cases the patient would get some light IV sedation at the same time. Other patients facing operations that could be done with a regional block injection anesthetic may nevertheless prefer to be unconscious, under general anesthesia. The patient advocate should encourage the patient to discuss this preference with the anesthesia personnel. Whether the patient's preferences can be followed depends on the particular operation.

Pain

Patients may be concerned about how much pain they might experience when they emerge from anesthesia. Make sure the anesthesia personnel discuss pain with the patient. The patient must be assured that pain-control measures will be used, possibly even including some pre-operative interventions intended to afford pain relief later.

It is virtually impossible to have too much communication with the anesthesia personnel and it is potentially harmful, even dangerous, to have too little. Never hesitate to speak up!

CHAPTER 8

Staying Safe in the Emergency Department

Emergency rooms (ERs), now more commonly called emergency departments (EDs), are well known to Americans through television and personal experience. Hospital EDs are where the real-life dramas of life unfold, including the crises of illness, injury, and death, and the feelings of sadness and grief that ensue.

Patients and families expect to find an environment focused on professionalism, caring, and safety in the ED. Modern American EDs provide among the best emergency care in the world to critically ill patients. They are well equipped, staffed with professionals, and are generally safe places to receive care. But EDs are complex, often stressed with large volumes of patients—more than 114 million patient visits each year—and patients, advocates, and family members are often frustrated when their visit to the ED does not meet their expectations.

A visit to an ED can be a confusing experience. The experience can be made less stressful and safer if patients, advocates, and family members understand how EDs function and keep in mind certain tips about how to improve a visit to the ED. This chapter provides:

- Basic information about EDs.
- How to plan before an emergency occurs.
- How to best access an ED.
- What to expect when arriving in an ED.
- How to make an ED visit a safer and more positive experience.

What is an Emergency Department?

Emergency departments provide care to patients with any emergency medical condition 24 hours a day, 7 days a week. The ED, like fire and police servic-

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es, is always there for patients and their families. Such continuous availability requires great commitment and expense in equipment and personnel.

The ED is always staffed with at least one doctor who is trained to provide emergency care and who is often certified as an emergency medicine specialist. Such doctors, along with nurses certified to provide emergency care, provide care for problems on a scale ranging from those that are relatively minor to those that are life-threatening. This team of specialists can assist in any emergency or can make arrangements for other specialists to assist in care, if needed, in any given case.

Nevertheless, using an emergency department often provokes anxiety because of the illness or injury that brings one to the ED in the first place. In addition, EDs can be confusing places and the waits for treatment can be long. But there are ways to make a trip to the ED a little less stressful.

Plan Ahead

The nature of emergencies is that they occur without warning. Still, it is possible to plan ahead to some degree before an emergency arises. One of the ways to plan ahead is to understand what constitutes an emergency; another is to decide where to seek emergency care when the need arises.

A medical emergency is any health problem that creates significant concern or anxiety on the part of the patient, patient advocate, or family member that cannot be explained logically and that does not seem to improve despite home treatment and time allowed.

Some emergencies are obvious, such as:

- Severe pain.
- Loss of consciousness.
- Severe bleeding.
- Problems breathing.
- Inability to think, move, or feel.
- Suicidal thoughts.
- Significant trauma, such as injury due to a car accident.

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Patients and patient advocates should also consider situations in which the problem is less obvious, such as unexplained stomach pain, which could be a symptom of appendicitis. A visit to the ED may be appropriate.

It is important to know how to get to the closest ED before an emergency occurs. Practice driving to the closest ED when there is no emergency. Patients should not usually drive themselves to an ED; therefore, it is important that the patient advocate and all members of the family know how to get to the closest ED.

Develop a Pre-emergency Information Packet

The patient advocate should keep a list handy of the patient's medical problems, all medications the patient takes—including over-the-counter medications, vitamins, and herbal supplements—and medication and food allergies. This list should be accessible to patients and family members if a trip to the ED is ever necessary. The patient advocate should encourage any patient with complex medical problems who is taking multiple medications to have the patient's doctors prepare lists of them all. The master list should include home and work telephone numbers of family members, telephone numbers of all doctors, and copies of insurance cards that will be needed in an emergency.

It is a good idea to keep files containing medical and emergency information in a special place that all family members know about. Some families keep health information packets in their refrigerator/freezer (if you use the refrigerator or freezer as a place to store information, put all documents in a well-sealed plastic bag so water won't damage them). Often, the refrigerator is marked with a sign indicating the health information is in that appliance. As an alternative to storing information on paper, some choose to store medical information on a CD or a flash drive.

Since wallets and purses are rarely forgotten even when something unexpected occurs, these are good places to keep a summary of medical information and medications. For critical medical information, medical alert bracelets are important for patients to wear; but because they have limited information they should not replace the sources of medical information just mentioned.

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In an Emergency

It is especially important for the patient advocate to stay calm and to help the patient stay calm. In an emergency requiring transportation to an ED, patient advocates or family members are reasonable sources of transportation. Of course, no one should drive a loved one if they cannot focus on driving safely. No one should transport a sick patient if they don't know how to get to the closest ED. Patients should NOT drive themselves to an ED when they are ill or impaired, since they may be a danger to themselves or others.

In most locations an ambulance can be called by dialing 911. This registers the emergency and location with sophisticated systems that allow trained medical professionals to reach the patient. These professionals can appropriately transport ill patients to the closest ED while providing excellent care.

Whoever calls 911 should identify the patient's location and explain the nature of the emergency. In an obvious emergency, the ambulance should transport the patient to the closest ED rather than to an ED the patient may prefer, which could be farther away or may not have the right resources. Patients may want to be transported to a hospital that takes their insurance. In true emergencies, most insurance companies will pay for care in the ED no matter where it is located. It is usually best for the patient to be taken to the closest ED as safely and quickly as possible.

Arriving at the Emergency Department

There are typically two entrances to the ED. One is the ambulance entrance, where most ambulances drop off and pick up patients. Patients transported by ambulance usually enter the ED and are handled according to the seriousness of their condition. Patient advocates and family members, regardless of how patients arrive, usually enter the ED through doors that should be clearly marked, "emergency entrance." If a patient advocate or family member drives the patient to the ED and the patient is worried about having a serious problem such as a heart attack, stroke, serious bleeding, or is about to deliver a baby, drive directly to the ambulance entrance. That is where most very ill patients go to get the quickest care.

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If the patient advocate accompanies the patient to the walk-in entrance believing there is a serious emergency, let a hospital staff member know immediately. Do not wait in line. Others may have been waiting, but if the patient feels very ill, let the ED staff know. Once they are initially evaluated patients may have to wait for further care if they are not as ill as others; but it is imperative that hospital staff know what the patients' problems are and how they have changed if they've gotten worse.

Whether the emergency condition is critical or not immediately life threatening, information is required about a patient before safe care can be provided. Many of the same questions are asked by different medical personnel. This is often distressing to patients, their advocates, and families because they see this as delaying care. Nevertheless, all medical staff must have complete and accurate information to provide the safest care. This is precisely why having this information written in advance is so important.

Triaging Care in the Emergency Department

Triaging care means the ED staff takes care of the sickest patients first. After the sickest patients are provided care, the less ill are cared for. Patients arriving by ambulance often are sicker and therefore are evaluated before patients who have not arrived by ambulance and who are usually not as ill.

Part of the triage process includes taking each patient's blood pressure, pulse, respiratory rate, temperature and, at times, additional tests. This allows the ED staff to assess the priority order in which the patient will receive care. In EDs there often are unavoidable delays because many patients must use limited resources. When waits seem long it is appropriate to ask about delays.

Staff collects information so each patient can be identified accurately, their care and progress can be tracked, and their insurance and contact information can be filed. While this processing is taking place, the patient advocate—unless the patient can speak for him- or herself—should tell the ED staff the following information about the patient:

- The patient's symptoms.
- When the problem started.

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- Whether the patient has any specific concerns or worries.
- Whether there are underlying medical conditions.
- What medications the patient takes, including over-the-counter medicines, vitamins, and herbal supplements.
- What drug allergies the patient has.

Whoever talks to the ED staff must be direct and honest. Being direct and honest helps the ED staff evaluate patients rapidly so all patients can receive care as quickly as possible. Not communicating concerns and important information will slow evaluation and could prevent the patient from receiving the best care. If the patient starts to feel worse while waiting for care, let the nurses and doctors know about the change in symptoms even if someone has already evaluated them. Not communicating changes can be dangerous to the patient's health. **Do not assume the ED staff knows about changing symptoms.** No one knows the patient as well as the patient and the patient advocate.

Communicating Effectively with Doctors and Nurses

Effective communication is essential in emergency care and ensures that staff on one hand, and patients and their advocates on the other, understand patients' needs and know what to expect from treatment in the ED.

Time with the doctor will be limited. Writing down questions in advance will help make the best use of the doctor's time. It is appropriate for the patient to ask for pain medication and to ask why the pain is occurring. There is often little privacy in a busy ED, but even in busy EDs there should always be as much respect for the patient's comfort, dignity, and privacy as possible. A patient or patient advocate should not hesitate to ask for more privacy, or for special consideration for any anxiety-producing or embarrassing situation.

If doctors or nurses do not introduce themselves, ask them who they are and what their role is in the patient's care. Ask doctors or nurses whether they have washed their hands before examining the patient or providing treatment because hand washing prevents infections.

Examples of questions patients or patient advocates commonly ask the ED

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doctor include the following:

- What is the diagnosis, in lay terms? Medical terminology is hard to understand.
- What medications and treatments are needed?
- How and when should this medication be taken, and for how long? (Remind the ED staff about any medication allergies or negative reactions the patient has had to medications in the past.)
- Are you sure this medication is for me? I am Jane/John Jones.
- What can the patient do and not do until health returns to normal?
- When and how should the patient get follow-up care?

No questions are too minor or insignificant. But because the time with the doctor will be limited, it is essential to organize your thoughts and ask the most important questions first.

Bringing a patient to the ED can be a stressful experience. Such stress sometimes leads a patient or a patient advocate to express anger or cynicism toward the staff. It is important to be aware of this and to guard against it. The patient and the patient advocate have a role to play in making this a collaborative and respectful relationship.

Additional Safety Tips While in the Emergency Department

While in the ED, the patient or patient advocate should do everything necessary to help prevent medical errors. These steps include:

- Making certain the information on the patient's identifying arm band is correct. Arm bands should have the patient's correct name and, often, include the date of birth.
- Asking the ED staff to check the patient's arm band, and tell the doctor or nurse the patient's name and date of birth.
- Helping the physicians and nurses to properly identify the patient before medications are administered or procedures are performed.

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- Repeating your understanding of what medications and tests are for. Your understanding should be the same as the doctor's or nurse's.
- Letting the doctors and nurses know about the patient's concerns or frustrations. It may not be possible to speed up the evaluation or provide certain items of comfort, but is best to let the ED staff know what the patient needs. Be sure to ask for the following on behalf of the patient if these items are not provided:
 - Pain medication.
 - Food or drink.
 - A warm blanket.
 - Bathroom or bedpan assistance.
 - An explanation of waiting times at any stage.
 - Information about care after leaving the ED.
 - Items for religious or personal needs.
 - Help making telephone calls or arranging transportation home.
 - Whether the person about to touch the patient has washed his or her hands.
 - Help in getting the right medicine or medical equipment at home.

Leaving the Emergency Department

When the ED visit is complete, the patient will either be admitted to the hospital or discharged. Patients and patient advocates should ask the reason for either decision if there is uncertainty. If the patient feels too ill to be discharged, let the medical staff know why being discharged should be reconsidered. If the diagnosis and treatment seems incorrect, request a more detailed explanation.

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Get written instructions about care after discharge, including how additional follow-up care can best be obtained. If medications are ordered, ask if you don't understand:

- What the medications are for.
- How to take them.
- Precautions about using them.
- What to expect in terms of benefits and risks.

Also, let the ED staff know if the patient will be unable to get the medication the doctor has ordered because of transportation problems or lack of money to buy them.

Ask for help in getting the patient home, if needed. It is important for patients to know whether it is safe for them to drive themselves home. If the patient is not feeling well enough to drive, the patient advocate should discourage them from driving because of the risk to themselves and others.

EDs are vital health care resources. Like all emergency social support systems, we never want to have to use them, but we appreciate their being there if we need them. Because it is likely that we will all have to use the ED at one time or another, we must be prepared for medical emergencies and we must know how to respond if one occurs.

CHAPTER 9

Steering Clear of Diagnostic Errors

Doctors need the help of the patient and patient advocate to reach the correct medical diagnosis. There are approximately 10,000 known medical conditions. Many diseases have similar signs and symptoms, and there may be no way to easily distinguish one disease from another. Even a single disease may have different signs and symptoms, depending on the person affected and the stage of the disease. A diagnostic error can be serious and even fatal.

An accurate and timely diagnosis is essential so the correct treatment can begin as soon as possible. The following eight tips can help reduce the risk of making diagnostic errors:

1. Help patients tell their stories well. Patients should try to present their symptoms and problems as clearly, completely, and accurately as possible. They should pay attention to what makes their symptoms better or worse. For example, they should look for patterns in their symptoms: are their symptoms related to meals, activities, locations, times of day, or times they take medications?

As a patient advocate, you can ask the patient these and other questions, and write their answers in your notebook before the doctor visit. Thinking about the patient's symptoms in advance increases the likelihood that you will give the doctor a complete and accurate report. In some health care settings, a nurse or health technician may first interview the patient before the patient sees the doctor. Don't assume the patient's symptoms will be transmitted accurately by someone else--make sure the physician hears the information directly from the patient or from you.

2. Help patients to be good historians. Before going to the doctor, ask the patient questions such as, what treatments have been tried in the past, and what was your response? How has the illness evolved? Write down the questions and answers in your notebook and take it with you to the doctor.

3. Help patients keep good records. Make sure patients keep their own records of test results, consultations, and summaries of hospital admissions. If necessary, help them to keep an accurate list of all the medications they take, whether prescribed, over-the-counter, vitamins, or herbal supplements. Take these items to the doctor visit.

4. Be an informed consumer. Ask the doctor to recommend reputable on-line sources of information or reliable and up-to-date printed information. Educate yourself about the patient's condition and the tests the patient will undergo. The patient or you should ask the doctor: What are the benefits and risks of these tests? What are the benefits and risks of not having these tests? What are the alternatives to having these tests, and what are the risks and benefits of those? How accurate and reliable are these tests? Write the questions and answers in your notebook.

5. Facilitate communication and coordination. If the patient has other doctors or consultants, make sure that everyone involved in the patient's care knows what the others are thinking and planning. Don't assume the patient's care is being coordinated by someone behind the scenes. The patient and patient advocate are the most reliable people to coordinate care.

6. Ensure that test results are known. Don't assume that no news is good news. Make sure that both the patient and the doctor receive the results of any diagnostic tests.

7. Ensure follow-up. If the patient is diagnosed with a disease or condition, ask the doctor:

- How do you prefer we let you know if new symptoms develop?
- Are the results of treatment different from what you expected?

You and the patient should know when the doctor will follow up, and when and how you or the patient should contact the doctor if the need arises.

8. Encourage doctors to think broadly. If the physician offers an initial diagnosis, don't be afraid to ask, "What else could this be?"

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Second Opinions and Specialists

For simple medical problems and for many complex ones, generalists such as internists, pediatricians, geriatricians, and some gynecologists are perfectly capable of making accurate and timely diagnoses. That being said, specialists have advanced knowledge and more experience diagnosing conditions in their area of expertise.

In general, specialists will be:

- Better able to differentiate similar diseases from one another.
- More knowledgeable about choosing tests and interpreting test results.
- Better able than generalists to detect significant variations in the patient's response to treatment.

Encourage patients who are considering seeing a specialist to discuss this with their primary care physician. Their primary care doctor can advise patients about seeking a second opinion from a specialist and can provide the patient with the names of specialists they trust.

Diagnostic errors are often detected by a fresh set of eyes. Second opinions offer a way to substantially decrease the risk of diagnostic error. But here are a few things to consider if the patient is considering getting a second opinion:

- Financial costs are involved in obtaining a second opinion.
- There is the possibility of extra testing and extra stress if opinions differ about the patient's condition.
- A second opinion may not be necessary for non-critical conditions, but should be considered if a patient is faced with a major illness or a critical decision.

Radiology: Incidental Findings

A common problem with radiology imaging procedures is that tests may show abnormalities that were unexpected and that are irrelevant to the original problem being investigated. Examples include the findings of cysts of the kid-

neys or liver, small tumors in the adrenal glands, anatomic variants of all sorts, or findings that are not clearly defined by the study that was done.

Radiologists often suggest that additional testing be performed to clarify these conditions. The physician may feel the need to practice defensive medicine and advise the patient to proceed with these studies. If such studies are suggested, the patient advocate can encourage the patient to have an honest discussion with the doctor to evaluate the benefits and risks of investigating these incidental findings. Ask the doctor to present the risks and benefits clearly in simple terms so the patient can make an informed decision.

Screening Tests

Screening tests are powerful tools that can detect diseases or conditions early, when they are easiest to treat. Examples of common screening tests are mammograms, Pap smears, cholesterol tests, and blood pressure checks. But screening tests can also have drawbacks. Some screening tests have a high rate of false positive results, which can lead to unnecessary anxiety, unnecessary further testing, and additional expense for the patient.

If a patient thinks he or she needs a particular screening test, the patient or patient advocate should ask the doctor about the test's risks and benefits. Write down the doctor's recommendations in your notebook so the patient can review the information and think about it carefully before deciding what to do.

The U.S. Preventive Services Task Force is regarded as the authority on screening tests. Members of this group continually and thoroughly review the latest evidence on these tests and make recommendations based on the balance between a screening test's benefits and potential harms.

Patient advocates should be aware of the Task Force's latest recommendations on a wide variety of screening tests. Encourage the patient to review the recommendations for their particular disease or condition. The Task Force's recommendations are updated regularly and can be found on the Agency for Healthcare Research and Quality Web site: <http://www.ahrq/clinic/uspstfix.htm>

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Anyone who is ill has an urgent need to know what is wrong and what can be done to treat them. But making the right diagnosis may take time and depends on the active involvement of the patient and the patient advocate. It is important to work with the doctor and follow the tips presented to help the doctor make the correct diagnosis as quickly as possible.

Do's and Don'ts for Patients and Patient Advocates

Here is what Charles Bruzzone, M.D., advises patients and patient advocates about the essential role of open, honest, and complete communication with the doctor at each and every visit:

“I have found that in all my years in private practice, a large percentage of patients do not prepare themselves for their doctor visit. Many people will leave my office having forgotten to ask me certain questions. Also, patients rarely write things down. I will give instructions or advice that goes in one ear and out the other. The most important thing patients can do to help themselves is to provide accurate and detailed information to their doctor. The most important thing a patient advocate can do is to help the patient do this.

“Never hide any information or bend the truth because you are too embarrassed. It is a fact that half of all diagnoses are made by the doctor based on the history alone. Being completely honest with the doctor is the only way to make the best outcome possible. Most doctors who have been in practice for a number of years can tell when the patient is lying. Teenagers often lie in response to doctors' questions about sex, drugs, or smoking.

“The doctor should always ask the patient if they are taking any medications. The term ‘medication’ refers not only to those prescribed by a doctor, but includes over-the-counter medicines such as cough syrup, vitamins, herbal supplements, and antacids. Any of these can react negatively with a new medicine the doctor prescribes. The patient or patient advocate should tell the doctor everything the patient is taking before leaving the office with a prescription. It is also essential to tell the doctor if the patient is allergic to any medications. The doctor does not make any judgments. Do not withhold any information.

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“It is sometimes difficult for doctors to understand why some people refuse immunizations, blood transfusions, or other medical care that could save their lives. Their cultural or religious beliefs may be the reason for such refusal. It would be helpful for the patient or the patient advocate to discuss these concerns with the doctor before an emergency arises.

“When a child is the patient, the adult taking the child to a new doctor or to the emergency room should always have the child’s immunization booklet with them. Many times a grandparent, babysitter, or other well-meaning adult brings the child to the doctor or emergency room because both parents are at work. They may not know all the facts about the child’s health or immunization history. If the parents are unable to take the child to the doctor, the parent should call the doctor to explain all the details of the child’s health, medication, and immunization history.

“A parent must get a privacy statement from the doctor’s office, fill it out in advance of a child’s needed medical visit, and make sure that whoever will bring the child to the doctor has this important form. The privacy form allows the physician to discuss medical information about a child with someone other than the parents.”

CHAPTER 10

Health Insurance Advice for Everyone

Discussing health insurance is like trying to hit a moving target. Before 1989, no one had ever heard of managed care; five years later it was running the whole show. Convincing your health insurance company to pay for needed health care has become harder, more complex, and more expensive than ever before.

The most important thing to know in dealing with your insurance company is that every dollar not spent on health care goes into the company as profit.

The 21st century health insurance business model includes making it difficult and confusing to access care. The newest insurance products on the market give you financial incentives to limit your own care.

Most people think if you have health insurance, you will get good medical care. This is simply not true. Doctors, hospitals, and other providers have contracts with insurance carriers that the public is not allowed to see. These contracts give health care providers and facilities incentives to practice medicine in a manner designed to benefit the insurance company. Managed care is structured around the concept that the amount of money spent on health care can be reduced by controlling what the doctor does in the office, whether or not this is in the patient's best interests. This creates a conflict of interest for health care providers who then must choose between their own financial well-being and the well-being of their patients.

Insurance companies require doctors to spend no more than a prescribed amount of time with patients, require them to see a certain number of patients per hour, stipulate the number of tests doctors can give, and tell doctors which treatments benefit the majority of patients. If doctors don't comply with insurance company rules, the companies will drop the doctors from their plans. In this way insurance companies pit the doctors' interests against the patients.'

Ask yourself the following questions before leaving the doctor's office:

- Has everything you need been discussed and checked?
- Does the doctor want a follow-up visit?
- Are you satisfied, or do you feel something has been left unsaid or unexamined? If so, ask your doctor to spend a little extra time and make sure you get what you need.
- Is anything bothering you about the way you are receiving care? If so, it is important to speak up. Ask for more time if you think you need it.

How to Lower Costs When You Have Been Denied Coverage

If your health care needs do not conform to health care protocols as defined by your health insurer, you may be denied payment for the care received.

Don't let the threat of a denial of coverage prevent you from seeing a doctor. Instead, get the care you need and remember that there are several ways to lower the costs of care to a more manageable level:

- Ask doctors if they will reduce their fees.
- Ask the hospital to allow you to pay the Medicare rate, which can be ten times less than a hospital's "sticker price."
- Hire a billing advocate if things get scary.
- Write to the CEO and the CFO of the hospital and your Congressperson if necessary.

Always state you want to pay a fair price for the services rendered. It is well known in the health care industry that the costs listed on an itemized bill have little or no relation to the actual costs of providing that care. Many people are surprised at the amount a bill can be reduced by a provider.

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If you need care, get it first and fight with the insurance company later. The breast cancer the mammogram would have found might kill you. The surgery you put off because it didn't pass the insurance company's "medical necessity" test could have crippling consequences.

Insurance Paperwork

The insurance company will do everything in its power to state why a claim should be denied. When they do, they are obligated by law to tell you why. The paper they send you stating their reason is called an Explanation of Benefits, or EOB. If you are insured, you should get one every time you access care. The EOB is required by law to state why the claim was paid or not paid. Their justification is usually provided by a code that is explained on a key at the bottom of the page.

If payment for service is denied, find out exactly why. Call your insurance company's customer service department and ask what the EOB means; if you are dissatisfied, or if they are unable to explain it clearly, talk to a supervisor. Go up the chain of command until you reach someone who will explain your denial so you can understand it. The phrase "not a covered service" could mean your benefits were "exhausted," or the insurance company thinks another insurer should pay, or any number of other things, including a processing error.

Timeliness is Important

If you are denied payment, don't wait before you act. Your insurance company has set the rules so you may have as few as 30 days to appeal their denial. Your benefits book will explain how to launch and complete an appeal. Insurance companies know only a small percentage of people will appeal, and that an even smaller percentage will appeal properly, with all the documentation needed and a logical argument as to why this care should be paid for.

After filing an appeal, you may be denied for "lack of timely filing." Check your benefits book to find out exactly the number of days you have to file an appeal. Sometimes even insurance companies make mistakes about their guidelines.

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Don't rely on your doctor to file an appeal for you. The office staff has many things to do, and advocating for you is not their top priority. If you think they will fight for payment for your care, you are only partly right. They will—up to a point. The bottom line in the doctor's office is that if they are denied payment you, the patient, become liable for the cost of care. Your doctor might now decide to bill you for the full price of care, which is much more than what your insurer would have paid through their contracted discount.

Things to Keep in Mind

- Insurers routinely pre-certify procedures and deny them later for lack of medical necessity.
- There are cases in which the doctor is granted insurance approval for a procedure but the facility in which the procedure was performed was disallowed, and vice versa.
- Orthopedic procedures may be approved, but patients and providers have to fight for every rehabilitation visit.
- The contract may appear to provide for a generous supply of physical therapy—for example, 60 visits—until you read the fine print and notice they provide for 60 consecutive days of therapy, which is very different. Physical therapy is often given only two or three days each week to allow for recovery. In this case, inserting the word “consecutive” effectively cuts down the number of visits you'll get by two-thirds.

Going Out of Network

If the doctor does not participate in your health plan, ask for a discount; that is, ask if he or she will accept your health plan's reimbursement as payment in full. Then ask your insurance company if it will pay him. A tightly managed health maintenance organization (HMO) will not pay anyone out of network unless it is an emergency.

Controlling your choices is one way insurance companies control the costs of your care. Whether it is for a specific procedure, doctor, medication, or hospital, every limit in your health insurance contract is meant to exert control

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over your choice of medical care. Insurance actuaries have decided in advance what is appropriate based on how much money it will save them.

Cost Shifting

Insurance companies are now selling more Preferred Provider Organization (PPO) contracts, which means that if you stay within their roster of “preferred” providers you will pay less out of pocket. But having a PPO encourages people to see any provider—and if that doctor has not directly contracted with your insurance company, your insurer will pay them a smaller portion of their fee.

Any extra costs, such as additional deductibles, larger co-payments, and a higher total fee are shifted to you. If you are seeing out-of-network providers, your overall expenditure will be higher. You may be able to negotiate with these providers to accept less than their full fees.

50 percent of American bankruptcies are associated with a health care crisis for people who had insurance at the time of their illness. So many people are living within a tight budget that when that \$2,500 deductible and the 20 percent co-payment are due, they can't afford the costs of their health care.

Don't Ignore the Paperwork

This is a final word about opening your mail. You may think your insurance plan has paid or ought to pay your bill, but you keep getting statements from your provider. Don't throw them in the trash thinking your insurance plan will pay them! Getting statements month after month is a clear sign that something has gone wrong!

Don't let those bills pile up. Whatever the problem is, hospital and doctor bills don't magically disappear. Call your health plan and your doctor or hospital to find out what the problem is. Sometimes the problem is minor and can be easily fixed, such as providing documentation that you have no other insurance plan. Other times the problem can be major, requiring hours on the phone, correspondence, and getting other people to help in the process.

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With luck and diligence, you may never have your care compromised. Remember that the health care you get involves 100 percent of your attention. Don't let it control 100 percent of your life.

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Conclusion

We hope this book has helped you understand more about the health care system and the important role you can play in ensuring the best outcome possible for yourself and your family.

PULSE prides itself on collaborating with others to make health care safer. The idea for this manual began when a group of us reflected on the importance of patient advocacy but realized there was no clear definition of what a patient advocate was or what a patient advocate's role should be.

Clearly, a manual for patient advocates is needed. Health care organizations tend to target patient safety information toward the patient, who is often too sick or impaired to follow such advice. Well-meaning family members or friends may want to help but don't know what to do, how to recognize problems, or how to prevent them.

There is so much to know about patient safety and so many people involved in the health care system that it is impossible to cover all the information in such a brief space. But we hope the information presented in this manual will help you understand the vital role the patient advocate can play in helping to ensure patient safety. We hope you will use this manual to navigate safely through the health care system.

Good luck and be safe,

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Resources

The following organizations' Web sites provide helpful information for patients and their advocates.

Health Plan Navigator

<http://www.healthplannavigator.com/>

Health Plan Navigator LLC is an organization of health care advocates who understand the nuances of the modern health insurance landscape. It doesn't matter if you are a provider, a patient, or a corporation, if you are on this Web site, chances are you have experienced the confusion and headaches that come with every hospital bill and insurance claims form.

Institute for Healthcare Improvement

<http://www.ihl.org/ihl>

The Institute for Healthcare Improvement (IHI) is a not-for-profit organization leading the improvement of health care throughout the world. IHI was founded in 1991 and is based in Cambridge, Massachusetts. IHI's work is funded primarily through fee-based program offerings and services, and also through the generous support of a distinguished group of foundations, companies, and individuals.

Institute for Safe Medication Practices

<http://www.ismp.org/>

The Institute for Safe Medication Practices (ISMP), based in suburban Philadelphia, is the nation's only 501c (3) nonprofit organization devoted entirely to medication error prevention and safe medication use. ISMP represents more than 30 years of experience in helping health care practitioners keep patients safe, and continues to lead efforts to improve the medication use process. The organization is known and respected worldwide as the premier resource for impartial, timely, and accurate medication safety information.

Family Centered Patient Advocacy - A Training Manual**National Patient Safety Foundation****<http://www.npsf.org>**

The National Patient Safety Foundation is an independent not-for-profit 501(c)(3) organization that has been diligently pursuing one mission since its founding in 1997—to improve the safety of patients.

The Joint Commission**<http://www.jointcommission.org/>**

The Joint Commission is dedicated to continuously improve the safety and quality of care provided to the public through the provision of health care accreditation and related services that support performance improvement in health care organizations. The Joint Commission evaluates and accredits nearly 15,000 health care organizations and programs in the United States. An independent, not-for-profit organization since 1951, The Joint Commission is the nation's predominant standards-setting and accrediting body in health care.

PULSE**<http://www.pulseamerica.org/>****<http://www.pulseofny.org>**

PULSE is a nonprofit, 501(c) (3) organization working to improve patient safety and reduce the rate of medical errors using real life stories and experiences. Survivors of medical errors are encouraged to use their experience to educate the community and advocate for a safer health care system.

Sorry Works!**<http://www.sorryworks.net/>**

Doctors, insurers, lawyers, hospital administrators, patients, and researchers join together to provide a “middle ground” solution to the medical malpractice crisis.