Everyone has a role in making health care safe. That includes doctors, health care executives, nurses and many health care technicians. Health care organizations all across the country are working to make health care safe. As a patient, you can make your care safer by being an active, involved and informed member of your health care team.

An Institute of Medicine report says that medical mistakes are a serious problem in the health care system. The IOM says that public awareness of the problem is an important step in making things better.

The “Speak Up™” program is sponsored by The Joint Commission. They agree that patients should be involved in their own health care. These efforts to increase patient awareness and involvement are also supported by the Centers for Medicare & Medicaid Services.

This program gives simple advice on how you can help make health care a good experience. Research shows that patients who take part in decisions about their own health care are more likely to get better faster. To help prevent health care mistakes, patients are urged to “Speak Up.”
Speak up if you have questions or concerns. If you still don’t understand, ask again. It’s your body and you have a right to know.

- Your health is very important. Do not worry about being embarrassed if you don’t understand something that your doctor, nurse or other health care professional tells you. If you don’t understand because you speak another language, ask for someone who speaks your language. You have the right to get free help from someone who speaks your language.
- Don’t be afraid to ask about safety. If you’re having surgery, ask the doctor to mark the area that is to be operated on.
- Don’t be afraid to tell the nurse or the doctor if you think you are about to get the wrong medicine.
- Don’t be afraid to tell a health care professional if you think he or she has confused you with another patient.

Pay attention to the care you get. Always make sure you’re getting the right treatments and medicines by the right health care professionals. Don’t assume anything.

- Tell your nurse or doctor if something doesn’t seem right.
- Expect health care workers to introduce themselves.
- Look for their identification (ID) badges. A new mother should know the person who she hands her baby to. If you don’t know who the person is, ask for their ID.
- Notice whether your caregivers have washed their hands. Hand washing is the most important way to prevent infections. Don’t be afraid to remind a doctor or nurse to do this.
- Know what time of the day you normally get medicine. If you don’t get it, tell your nurse or doctor.
- Make sure your nurse or doctor checks your ID. Make sure he or she checks your wristband and asks your name before he or she gives you your medicine or treatment.

Educate yourself about your illness. Learn about the medical tests you get, and your treatment plan.

- Ask your doctor about the special training and experience that qualifies him or her to treat your illness.
- Look for information about your condition. Good places to get that information are from your doctor, your library, respected websites and support groups.
- Write down important facts your doctor tells you. Ask your doctor if he or she has any written information you can keep.
- Read all medical forms and make sure you understand them before you sign anything. If you don’t understand, ask your doctor or nurse to explain them.
- Make sure you know how to work any equipment that is being used in your care. If you use oxygen at home, do not smoke or let anyone smoke near you.

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

- Your advocate can ask questions that you may not think about when you are stressed.
- Ask this person to stay with you, even overnight, when you are hospitalized. You will be able to rest better. Your advocate can help make sure you get the right medicines and treatments.
- Your advocate can also help remember answers to questions you have asked. He or she can speak up for you when you cannot speak up for yourself.
- Make sure this person understands the kind of care you want. Make sure he or she knows what you want done about life support and other life-saving efforts if you are unconscious and not likely to get better.
- Go over the consents for treatment with your advocate before you sign them. Make sure you both understand exactly what you are about to agree to.
- Make sure your advocate understands the type of care you will need when you get home. Your advocate should know what to look for if your condition is getting worse. He or she should also know who to call for help.

See a hospital, clinic, surgery center, or other type of health care organization that has been carefully checked out. For example, The Joint Commission visits hospitals to see if they are meeting The Joint Commission’s quality standards.

- Ask about the health care organization’s experience in taking care of people with your type of illness. How often do they perform the procedure you need? What special care do they provide to help patients get well?
- If you have more than one hospital to choose from, ask your doctor which one has the best care for your condition.

The goal of the Speak Up™ program is to help patients become more informed and involved in their health care.
Medicine mistakes happen every day—at the doctor’s office or hospital, even at home. You can get the wrong medicine. Or, you can be given the wrong amount of medicine. This brochure has questions and answers to help prevent mistakes with your medicines.
Who is responsible for your medicines?
A lot of people—including you!
• Doctors check all of your medicines to make sure they are OK to take together. They will also check your vitamins, herbs, diet supplements or natural remedies.
• Pharmacists will check your new medicines to see if there are other medicines, foods or drinks you should not take with your new medicines. This helps to avoid a bad reaction.
• Nurses and other caregivers may prepare medicines or give them to you.
• You need to give your doctors, pharmacists and other caregivers a list of your medicines. This list should have your prescription medicines over-the-counter medicines (for example, aspirin) vitamins herbs diet supplements natural remedies amount of alcohol you drink each day or week recreational drugs

What if you forget the instructions for taking a medicine or are not sure about taking it?
Call your doctor or pharmacist. Don’t be afraid to ask questions about any of your medicines.

What can you do at the hospital or clinic to help avoid mistakes with your medicines?
• Make sure your doctors, nurses and other caregivers check your wristband and ask your name before giving you medicine. Some patients get a medicine that was supposed to go to another patient.
• Don’t be afraid to tell a caregiver if you think you are about to get the wrong medicine.
• Know what time you should get a medicine. If you don’t get it then, speak up.
• Tell your caregiver if you don’t feel well after taking a medicine. Ask for help immediately if you think you are having a side effect or reaction.
• You may be given IV (intravenous) fluids. Read the bag to find out what is in it. Ask the caregiver how long it should take for the liquid to run out. Tell the caregiver if it is dripping too fast or too slow.
• Get a list of your medicines—including your new ones. Read the list carefully. Make sure it lists everything you are taking. If you’re not well enough to do this, ask a friend or relative to help.
• You may be given IV (intravenous) fluids. Read the bag to find out what is in it. Ask the caregiver how long it should take for the liquid to run out. Tell the caregiver if it is dripping too fast or too slow.

Questions to ask your doctor or pharmacist
• How will this new medicine help you?
• Are there other names for this medicine? For example, does it have a brand or generic name?
• Is there any written information about the medicine?
• Can you take this medicine with your allergy? Remind your doctor about your allergies and reactions you have had to medicines.
• Is it safe to take this medicine with your other medicines? Is it safe to take it with your vitamins, herbs and supplements?
• Are there any side effects of the medicine? For example, upset stomach. Who can you call if you have side effects or a bad reaction? Can they be reached 24 hours a day, seven days a week?
• Are there specific instructions for your medicines? For example, are there any foods or drinks you should avoid while taking it?
• Can you stop taking the medicine as soon as you feel better? Or do you need to take it until it’s gone?
• Do you need to swallow or chew the medicine?
• Can you cut or crush it if you need to?
• Is it safe to drink alcohol with the medicine?

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Five Things You Can Do
To Prevent Infection is supported by

American Hospital Association
www.hospitalconnect.com

Association for Professionals in Infection Control and Epidemiology, Inc.
www.apic.org

Centers for Disease Control and Prevention
www.cdc.gov

Infectious Diseases Society of America
www.idsociety.org

The Joint Commission
www.jointcommission.org

Society for Healthcare Epidemiology of America
www.shea-online.org
Avoiding contagious diseases like the common cold, strep throat, and the flu is important to everyone. Here are five easy things you can do to fight the spread of infection.

1. Clean your hands.
   - Use soap and warm water. Rub your hands really well for at least 15 seconds. Rub your palms, fingernails, in between your fingers, and the backs of your hands.
   - Or, if your hands do not look dirty, clean them with alcohol-based hand sanitizers. Rub the sanitizer all over your hands, especially under your nails and between your fingers, until your hands are dry.
   - Clean your hands before touching or eating food. Clean them after you use the bathroom, take out the trash, change a diaper, visit someone who is ill, or play with a pet.

2. Make sure health care providers clean their hands or wear gloves.
   - Doctors, nurses, dentists and other health care providers come into contact with lots of bacteria and viruses. So before they treat you, ask them if they’ve cleaned their hands.
   - Health care providers should wear clean gloves when they perform tasks such as taking throat cultures, pulling teeth, taking blood, touching wounds or body fluids, and examining your mouth or private parts. Don’t be afraid to ask them if they should wear gloves.

3. Cover your mouth and nose.
   Many diseases are spread through sneezes and coughs. When you sneeze or cough, the germs can travel 3 feet or more! Cover your mouth and nose to prevent the spread of infection to others.
   - Use a tissue! Keep tissues handy at home, at work and in your pocket. Be sure to throw away used tissues and clean your hands after coughing or sneezing.
   - If you don’t have a tissue, cover your mouth and nose with the bend of your elbow or hands. If you use your hands, clean them right away.

4. If you are sick, avoid close contact with others.
   - If you are sick, stay away from other people or stay home. Don’t shake hands or touch others.
   - When you go for medical treatment, call ahead and ask if there’s anything you can do to avoid infecting people in the waiting room.

5. Get shots to avoid disease and fight the spread of infection.
   Make sure that your vaccinations are current—even for adults. Check with your doctor about shots you may need. Vaccinations are available to prevent these diseases:
   - Chicken pox
   - Measles
   - Tetanus
   - Shingles
   - Flu (also known as influenza)
   - Whooping cough (also known as Pertussis)
   - German measles (also known as Rubella)
   - Pneumonia (Streptococcus pneumoniae)
   - Human papillomavirus (HPV)
   - Mumps
   - Diphtheria
   - Hepatitis
   - Meningitis

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There are many different causes and kinds of pain. Pain can be caused by injury, illness, sickness, disease or surgery. Treating pain is the responsibility of your doctor, nurse and other caregivers. You can help them by asking questions and finding out more about how to relieve your pain. This brochure has some questions and answers to help you do that.

Questions To Ask Your Caregivers

- What pain medicine is being ordered or given to you?
- Can you explain the doses and times that the medicine needs to be taken?
- How often should you take the medicine?
- How long will you need to take the pain medicine?
- Can you take the pain medicine with food?
- Can you take the pain medicine with your other medicines?
- Should you avoid drinking alcohol while taking the pain medicine?
- What are the side effects of the pain medicine?
- What should you do if the medicine makes you sick to your stomach?
- What can you do if the pain medicine is not working?
- What else can you do to help treat your pain?
Talking About Your Pain

Is it important for doctors and nurses to constantly ask about your pain?

Yes. This is because pain changes over time or your pain medicine may not be working. Doctors and nurses should ask about your pain regularly.

What do you need to tell your doctor and nurse about your pain?

First, tell them that you have pain, even if they don’t ask. Your doctor or nurse may ask you to describe how bad your pain is on a scale of 0 (zero) to 10 with 10 being the worst pain. They may use other pain scales that use words, colors, faces or pictures. Tell them where and when it hurts. Tell them if you can’t sleep or do things like dressing or climbing stairs because of pain. The more they know about your pain the better they can treat it. The following words can be used to describe your pain:

- aching
- dull
- sharp
- bloating
- numbing
- shooting
- burning
- pressing
- soreness
- cramping
- pressure
- stabbing
- comes and goes
- pulling
- throbbing
- constant
- radiating
- tightness
- cutting
- searing

What can you do when your pain gets worse?

Tell your doctor or nurse. Tell them how bad your pain is or if you’re in pain most of the time. Tell the doctor if the pain medicine you’re taking is not helping.

Should you include pain medicine on your list of medicines or medication card?

Yes! Even pain medicine that you will take for a short time should be listed with all of your other medicines. List all of your pain medicines—those prescribed by your doctor and those you buy over-the-counter.

Managing Your Pain

What can be done to treat pain?

There are many ways to manage your pain. There are medicines that can be used to relieve pain. There are also other ways to treat pain without taking medicine. Your doctor will work with you to find out what works best for you.

What are some of the medicines used to treat pain?

Some pain medicines are acetaminophen, aspirin, ibuprofen, naproxen and opioids. Opioids include morphine, oxycodone and hydromorphone. Many of these medicines come in pills, liquids, suppositories and skin patches. Some pain may be treated with medicines that are not usually thought of as pain relievers. For example, antidepressants.

Are there other ways to relieve pain?

That will depend on your illness or condition and how much pain you have. Sometimes pain can be relieved in other ways. Some other treatments for pain are listed here:

- Acupuncture, which uses small needles to block pain
- Taking your mind off the pain with movies, games and conversation
- Electrical nerve stimulation, which uses small jolts of electricity to block pain
- Physical therapy
- Hypnosis
- Massage
- Exercise
- Heat or cold
- Relaxation

What are the side effects of pain medicines?

It depends on the medicine. Side effects can include constipation, nausea, vomiting, itching and sleepiness.

What can you do if you have side effects or a bad reaction?

Call your doctor or nurse as soon as possible. Find out what can be done to treat the side effect. Ask if there is another pain medicine that may work better for you.

Are you afraid to take a pain medicine?

You may have had a bad experience taking pain medicine in the past, such as a side effect or bad reaction. Or you may be taking a lot of other medicines. Your doctor or nurse should be able to ease your fears. It’s important that you take your medicine.

Are you afraid that you’ll become addicted to pain medicine?

This is a common concern of patients. Studies show that addiction is unlikely. This is especially true if the patient has never had an addiction. Talk to your doctor or nurse about your fears.

Are you afraid that your pain medicine won’t work if you take it for a long time?

This is called “tolerance.” It means that after awhile your body gets used to the medicine and you need to make a change to get pain relief. It’s also possible that the condition causing your pain is getting worse or you have a new type of pain. You may need more medicine or a different kind of medicine to control your pain. Talk to your doctor or nurse.

Can you crush pills if you can’t swallow them?

Check with your doctor, nurse or pharmacist. Some medicines can be crushed and some cannot. For example, time-release medicines should not be crushed. Ask your doctor or nurse if the medicine comes in a liquid or can be given another way.

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Medical tests and laboratory tests are important aids for doctors. However, sometimes the wrong test is ordered. Or the test results can be misunderstood. Or your doctor gets the results too late to give you the best treatment. Some tests can have side effects that can hurt you. This brochure includes questions and answers to help you prepare for your test.

For more information
Speak Up: Help Prevent Errors in Your Care—Laboratory Services,
http://www.jointcommission.org/PatientSafety/speakup_bro.htm
Joint Commission Journal on Quality and Patient Safety, Volume 31, Number 2, February 2005
www.radiologyinfo.org
What if you don’t understand the medical forms you’re asked to sign?

Ask staff to explain the forms. Don’t sign anything until you understand what you are signing. Also, keep your eyeglasses with you so you can read forms, labels and other information.

How do you know that the test results are yours?

Staff should ask for your full name and another piece of information, such as your birth date. If they don’t, speak up. Ask to see the labels on the containers that your samples are put in. The label should have your full name and another piece of personal information. Also, make sure that the containers are immediately sealed to prevent mislabeling and contamination.

What if you don’t understand what is being done and why?

Ask the health care worker to stop the test and explain what he or she is doing.

How can you be sure that the test you get is the one ordered by your doctor?

Get a copy of the test order from your doctor and take it to the test. Also, if you think you are about to get the wrong test, don’t be afraid to tell staff.

You’re supposed to get a “contrast agent.” What is this?

A “contrast agent” is a liquid that makes organs and blood vessels more visible on X-rays and other tests. If you get a contrast agent and begin itching or have trouble breathing, tell the health care worker. If you are pregnant or nursing, ask your doctor and the health care worker if there is anything that should be done before or after the test to protect you and your baby.

What is a “MRI” and how do you prepare for it?

MRI stands for magnetic resonance imaging. The MRI machine has magnets inside it that are used to take a picture of your body. These strong magnets can quickly pull metal objects into the MRI machine, which can cause injuries. The machine also can heat up metal objects causing burns. If you get a MRI, be sure to remove all metal from your body—such as hairpins—and tell the health care worker if you have any implants in your body.

Your test results show something is wrong. What should you do?

Talk with your doctor and with one or more specialists to decide what the best treatment is for you. You’ll be able to make the best decision when you have more information.

What should you do if you have a bad experience at the laboratory or test facility?

If the lab or facility is part of a hospital, call them so that they can correct the problem. You can also file a complaint with the accrediting organization (like the Joint Commission) or licensing authority. The Joint Commission provides a complaint form on its website at www.jointcommission.org.

Don’t assume that no news is good news.

Always ask how and when you should get your test results. Follow-up with the doctor who ordered the test. Talking with your doctor and other health care workers can be important in getting the treatment you need as soon as possible.

Questions to ask your doctor

• Why is this test being done? What should it tell you about my health?
• Can I get a copy of my test order to take to the place where the test is being done?
• Are there any foods or drinks I should avoid before or after the test? For how long before or after the test should I avoid the food or drink?
• Should I take my medicine before the test?
• Is there anything else I need to do to prepare for the test?

• Are there any side effects of the test? Will it be painful or uncomfortable? Is it unusual to have pain or discomfort?
• Can I call or visit the laboratory or test facility before I go to take the test?

Questions to ask the health care workers who give the test or take your blood

• Is this facility accredited? Is it inspected by a government agency? When was the last inspection? What was the result?
• Have you washed your hands?
• Do you need to wear gloves while you take my blood or sample?
• When will the results be ready? How will my doctor and I be informed of the results?
• Will you quickly notify me if the test shows a problem that needs immediate action? Will you notify my doctor, too?
• Can you give me a telephone number to call if I have questions?

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Mistakes can happen during surgery. Surgeons can do the wrong surgery. They can operate on the wrong part of your body. Or they can operate on the wrong person. Hospitals and other medical facilities that are accredited by The Joint Commission must follow a procedure that helps surgeons avoid these mistakes. (Facilities that are accredited by The Joint Commission are listed on The Joint Commission’s Quality Check website: www.qualitycheck.org.)

Mistakes can also happen before or after surgery. A patient can take the wrong medicine. Or they don’t understand the instructions about how to take care of themselves. As a patient, you can make your care safer by being an active, involved and informed member of your health care team.
Preparing for your surgery

Ask your doctor

☐ Are there any prescription or over-the-counter medicines that you should not take before your surgery?
☐ Can you eat or drink before your surgery?
☐ Should you trim your nails and remove any nail polish?
☐ If you have other questions, write them down. Take your list of questions with you when you see your doctor.

Ask someone you trust to

☐ Take you to and from the surgery facility.
☐ Be with you at the hospital or surgery facility. This person can make sure you get the care you need to feel comfortable and safe.

Before you leave home

☐ Shower and wash your hair. Do not wear make-up. Your caregivers need to see your skin to check your blood circulation.
☐ Leave your jewelry, money and other valuables at home.

At the surgery facility

The staff will ask you to sign an Informed Consent form. Read it carefully. It lists:
☐ Your name
☐ The kind of surgery you will have
☐ The risks of your surgery
☐ That you talked to your doctor about the surgery and asked questions
☐ Your agreement to have the surgery

Make sure everything on the form is correct. Make sure all of your questions have been answered. If you do not understand something on the form—speak up.

For your safety, the staff may ask you the same question many times. They will ask:

☐ Who you are
☐ What kind of surgery you are having
☐ The part of your body to be operated on

They will also double-check the records from your doctor’s office.

Before your surgery

☐ A health care professional will mark the spot on your body to be operated on. Make sure they mark only the correct part and nowhere else. This helps avoid mistakes.
☐ Marking usually happens when you are awake. Sometimes you cannot be awake for the marking. If this happens, a family member or friend or another health care worker can watch the marking. They can make sure that your correct body part is marked.
☐ Your neck, upper back or lower back will be marked if you are having spine surgery. The surgeon will check the exact place on your spine in the operating room after you are asleep.
☐ Ask your surgeon if they will take a “time out” just before your surgery. This is done to make sure they are doing the right surgery on the right body part on the right person.

After your surgery

☐ Tell your doctor or nurse about your pain. Hospitals and other surgical facilities that are accredited by The Joint Commission must help relieve your pain.
☐ Ask questions about medicines that are given to you, especially new medicines. What is it? What is it for? Are there any side effects? Tell your caregivers about any allergies you have to medicines. If you have more questions about a medicine, talk to your doctor or nurse before taking it.
☐ Find out about any IV (intravenous) fluids that you are given. These are liquids that drip from a bag into your vein. Ask how long the liquid should take to “run out.” Tell the nurse if it seems to be dripping too fast or too slow.
☐ Ask your doctor if you will need therapy or medicines after you leave the hospital.
☐ Ask when you can resume activities like work, exercise and travel.

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For more information
National Alliance for Caregiving
www.caregiving.org
(301) 718-8444
Centers for Medicare & Medicaid
Services Care Planner
www.careplanner.org
(877) 267-2323
Before leaving the hospital, you should be given written instructions about your follow-up care. This brochure provides questions to help you get the information you need for the best follow-up care.

What should you do before leaving the hospital?
- Find out if the hospital has a discharge planner, social worker or nurse who can help you plan your follow-up care.
- Ask a family member or friend to help plan your follow-up care.
- Take a notepad to the hospital that you can write questions, answers and reminders on.

What if you have trouble understanding the language used in the instructions?
Ask for a translation or an interpreter.

You feel overwhelmed by the follow-up care you need. What can you do?
Ask about referrals for home care services or a skilled nursing facility. Find out about payment options, including whether financial assistance is available. Find out if the service or organization is licensed or accredited. Organizations accredited by The Joint Commission are listed on Quality Check at www.qualitycheck.org.

Questions to ask about your condition
- How soon should you feel better after leaving the hospital?
- Will you be able to walk, climb stairs, go to the bathroom, prepare meals and drive?
- Are there any special instructions for daily activities? For example, should you take a shower instead of a bath?
- How much help will you need after you leave the hospital? Should someone be with you 24 hours a day?
- What signs and symptoms should you watch for? If you have them, what should you do?
- Will you need any special equipment at home? Where can you get the equipment? Is it covered by your insurance, Medicare, or other health plan?
- Will you need physical therapy? Are there any physical exercises you need to do? If so, get written instructions.
- If you have wounds, how do you take care of them? How long should it take them to heal?
- Will you need to have any follow-up tests? Who should you follow up with to get the test results?
- Will you need to schedule any follow-up visits with your doctor?
- When can you expect to go back to work?
- Who can you call if you have any problems after leaving the hospital?

What signs and symptoms should you watch for? If you have them, what should you do?

Questions to ask about your medicines
- What medicines will you need to take at home? Get a written list that includes all of your medicines—new and old. Take this list with you when you go for follow-up care.
- Can you get written instructions about your medicines? Make sure you understand the instructions. Ask any questions before you leave the hospital.
- Are there any medicines, vitamins or herbs that you should not take with your medicines?
- Are there any foods and drinks—including alcohol—that you should avoid while you’re taking your medicines?
- Are there any side effects of your medicines? What should you do if you have side effects?

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Understanding your doctors and other caregivers

It can be difficult to understand what your doctors and other caregivers are telling you about your care and treatment. This brochure has questions and answers to help you understand caregivers.

Questions to ask your caregivers

- Is there someone who can help you understand your doctor, nurse, and other caregivers?
- Is there someone who can help you understand how to take your medicine?
- Is there any written information in your language?
- Is there any written information in your language that is easy to read?
- Is there someone who speaks your language who can help you talk to caregivers?
- Is there a support group for people like you? For people with your illness or condition?
- Are there other resources for you?
What can you do if you don’t understand what your caregiver is saying?

Tell them you don’t understand. Use body language. If you don’t understand shake your head to show that “No, I don’t understand.” Ask lots of questions. By asking questions you’re helping them understand what you need.

What can you do if they explain and you still don’t understand?

Tell them you still don’t understand. Try to be as clear as possible about what you do not understand. Caregivers have a duty to help you understand. You should not leave until you understand what to do and what is happening to you.

What if the caregiver is rushed and doesn’t have time to answer your questions?

Ask them if you need to schedule another appointment when they can answer your questions.

What can you do if you speak another language?

Ask for someone who speaks your language. This person can help you talk to caregivers. This person should work for the hospital or health center. Their job is to help people who speak other languages. This person may not be in the office. He or she may be on the telephone. You have the right to get free help from someone who speaks your language. Ask if there is paper work in your language.

What can you do if you have trouble reading? Or if you cannot read?

Don’t be embarrassed. Tell your caregivers. They can help you. They can explain paper work to you. They may even have paper work that is easy to read and understand.

Your doctor’s instructions are not clear. Should you try to figure it out yourself?

No. Instructions from your doctor or others are important. Tell them what you think the instructions are. Tell them if they need to write down the instructions. Tell them if you have a family member or friend who helps you take your medicine. Ask the doctor to have someone talk to your family member or friend, too.

What if you don’t understand written instructions?

Tell your caregivers. Tell them that you need to have the instructions read to you. Tell them you need instructions that are easy to read. Or that you need instructions in your language.

What can you do if you don’t understand the instructions for your medicine?

Tell your doctor if you need help. Tell them what you think the instructions are. Tell them if you don’t understand how to take your medicine. Tell them if you don’t understand when to take your medicine. Some patients don’t understand and take too much or too little of the medicine. That can be dangerous.

How can you remember all of your medicines?

Ask for a card for your medicines. Ask your caregiver to help you write down the medicines and the amount you take. Bring the card with you every time you go to the doctor.

The doctor says I need to have a “procedure.” What does that mean?

A procedure can be an operation or a treatment. A procedure can be a test with special equipment. You might be put to sleep or a part of your body might be numbed. Ask questions about what will be done to you. If you speak another language ask for someone who speaks your language. Even if you’re in the emergency room you need to understand what will happen to you.

What is informed consent?

Informed consent means that you know how your illness or condition will be treated. It means that you agree to the operation or treatment. It means that you understand the risks. That you know about other treatments available to you. And that you know what can happen if you aren’t treated. You will be asked to sign paper work after you agree to the treatment. You need to decide if you will sign or not sign the paper work only after you understand all that was explained to you.

You don’t understand the paper work you’re given to fill out. What can you do?

Ask caregivers to explain the paper work. Ask them if they can help you fill it out.

Your caregiver asked you to do something that is against your culture or religion. What can you do?

Tell your caregiver about your culture. Or tell them about your religious beliefs. Explain to them what you need to do. When they know what is important to you, they can understand better how to take care of you. There may be a way to meet your caregiver’s needs and your needs.

Where can you find more information about your illness or condition?


www.jointcommission.org

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Questions to ask your doctor

- How often will your doctor see you during your stay?
- Who is responsible for your care when the doctor is not available? For example, on weekends and at night?
- What happens to you if life-saving actions are taken?
- If your test or procedure shows that you need another procedure right away, can you get it done here? Or will you need to go to a different facility?

Resources
The goal of the Speak Up™ program is to help patients become more informed and involved in their health care.

You have rights and a role regarding your treatment and care. This brochure has questions and answers to help you find out about your rights and role as a patient. Knowing your rights and role can help you make better decisions about your care.

What are your rights?
- You have the right to be informed about the care you will receive.
- You have the right to get information about your care in your language.
- You have the right to make decisions about your care, including refusing care.
- You have the right to know the names of the caregivers who treat you.
- You have the right to safe care.
- You have the right to have your pain treated.
- You have the right to know when something goes wrong with your care.
- You have the right to get an up-to-date list of all of your current medicines.
- You have the right to be listened to.
- You have the right to be treated with courtesy and respect.

Ask for written information about all of your rights as a patient.

What is your role in your health care?
- You should be active in your health care.
- You should ask questions.
- You should pay attention to the instructions given to you by your caregivers. Follow the instructions.
- You should share as much information as possible about your health with your caregivers. For example, give them an up-to-date list of your medicines. And remind them about your allergies.

Can your family or friends help with your care?
- Find out if there is a form you need to fill out to name your personal representative, also called an advocate. Ask about your state’s laws regarding advocates.
- They can get information and ask questions for you when you can't. They can remind you about instructions and help you make decisions. They can find out who to go to if you are not getting the care you need.
- No, not unless they are your legal guardian or you have given them that responsibility by signing a legal document, such as a health care power of attorney.
- The law requires health care providers to keep information about your health private. You may need to sign a form if you want your health care providers to share information with your advocate or others.

What is "informed consent"?
- This means that your health care providers have talked to you about your treatment and its risks. They have also talked to you about options to treatment and what can happen if you aren't treated.

Can your advocate make decisions for you?
- If something goes wrong, you have the right to an honest explanation and an apology. The explanation and apology should be made in a reasonable amount of time.

How do you file a complaint?
- First, call the hospital or health system so that they can correct the problem. Next, if you still have concerns, complaints can be sent to the licensing authority or The Joint Commission. The Joint Commission provides a complaint form on its website at www.jointcommission.org.

Questions to ask before you enter the health care facility
- Can you have an advocate? Do you need to sign a document so your advocate can get important information about your care?
- What will be done to make sure I don't get an infection?
- Is there a form you need to sign about life-saving actions, like resuscitation?
- Is there a form you need to sign about life support?
- Does the organization allow members of your religion to visit and pray with you?
- What kind of security does the facility have?
- Is there a 24-hour guard or alarm system?
- Whom do you speak to if a problem arises?
- How does the organization handle complaints?
- Are there any procedures that cannot be done at this facility for religious reasons?
- Can you get a copy of your medical record and test results?
For more information
Gift of Life Donation Initiative
www.organdonor.gov
United Network For Organ Sharing
www.unos.org
Association of Organ Procurement Organizations
www.aopo.org
University Renal Research and Education Association
www.ustransplant.org
National Kidney Foundation
www.livingdonors.org
Help Avoid Mistakes in Your Surgery
www.jointcommission.org/PatientSafety/SpeakUP/
Health Care at the Crossroads:
Strategies for Narrowing the Organ Donation Gap and Protecting Patients
www.jointcommission.org/PublicPolicy/organ_donation.htm
Joint Commission Transplant Center Certification Program
www.jointcommission.org/CertificationPrograms/TransplantCenterCertification/
Every year nearly 6,000 Americans become living organ donors. Usually, they donate a kidney. But donors can also give a part of their liver, lung or pancreas. If you are thinking about becoming a living organ donor, this brochure gives you important questions to ask your health care team.

Can anyone be a donor?
No. Living organ donors must be healthy. They cannot have diseases like diabetes, cancer, and kidney, heart and blood disease. Also, the donor’s blood type must match the recipient’s. And, donors must be able to handle the stress of surgery and recovery.

Will you have medical tests?
Yes. Your health care team will do tests to see if you are healthy enough to be a donor. Tell them about your health history and any concerns you have.

Are there risks?
All surgeries have risks, including the risk of death. You could get an infection or another complication. Ask about the risks of your surgery.

Will you get the same kind of health care as the organ recipient?
Both you and the organ recipient should expect safe, quality care.

Is living organ donation always successful?
No. Sometimes, the recipient’s body rejects the new organ. Or, the recipient may have complications. You can ask about the expected result of the surgery for the recipient, and the risks to him or her.

Can you change your mind?
Yes. You can change your mind at any time for any reason. Organ donation is a personal decision. No one can make the decision for you. You should not feel pressured to donate.

How do you get ready for the surgery?
- Ask your health insurance company if it will cover your care and any complications from the surgery. Ask if your premium or coverage will change as a result of your donation.
- Ask your life insurance company if your premium or coverage will change.
- Find out about the medical leave policy where you work. If you take time off with less or no pay, you will need to budget carefully.
- Ask the hospital to help connect you with someone who has donated an organ. This person will give you a better idea of what to expect.
- Ask someone you trust to be with you at the hospital. This person can make sure you get the care you need to feel comfortable and safe.

What happens after the surgery?
- If the surgery is out of town, make plans to get back home after you leave the hospital. Or, ask the hospital to help you find a place to recover until you can travel.
- If you live alone, have children or live with the organ recipient, find someone you trust who can care for you while you recover. You may be in pain or feel weak or tired. And pain pills can make you groggy.

What should you ask the doctor?
- Is organ donation the only solution for the recipient?
- What tests will be done to make sure you are healthy enough to be a donor?
- Does the hospital have a special unit and specially trained nurses to care for living organ donors?
- Has my surgeon done this operation before? How many times?
- What are the risks of the surgery?
- What medicines will you need to take? Are there side effects? Will you need to take medicines for a long time?
- What kind of follow-up care will you need? Who will oversee your follow-up care?
- How long will recovery take? Will it be difficult?
- Will you need physical therapy or any other kind of therapy?
- How will the organ donation affect your health in the future? What is your risk to develop organ failure after donation?
- When can you exercise? When can you get back to your regular routine? Are there any sports or other activities that you won't be able to do after donation? Will it affect your ability to do your job?
- Does the surgeon use the Joint Commission's Universal Protocol to Prevent Wrong Site, Wrong Procedure and Wrong Person Surgery™?
What you should know about research studies

For more information
Citizens For Responsible Care and Research
www.circare.org
United States Food and Drug Administration
www.fda.gov/cigcp
United States Department of Health & Human Services
Office for Human Research Protections
www.hhs.gov/ohrp
United States Department of Veterans Affairs
Research & Development
www.research.va.gov/programs/pride/veterans/default.cfm
The Center for Information & Study on Clinical Research Participation
http://ciscrp.org
Medical research helps improve the quality of life for people around the world. Research studies test new medicines, treatments, devices and equipment. This brochure has questions and answers about research studies.

Research studies are also called
- clinical experiments
- clinical research trials
- clinical studies
- clinical tests
- experimental studies
- experimental trials

Will your doctor be doing the research study?
The study may be done by your doctor, another doctor, or a researcher.

Will your health insurance pay for the cost of the research study?
Not always. Ask the doctor or researcher and your insurance company if you will need to pay for any of the research study costs.

What happens during research studies of new medicines?
First, a few volunteers test the safety of the medicine and how much should be taken. Then, larger groups of people test the long term safety of the medicine and how well it works. Find out which group you will be in.

Are you guaranteed to get the new medicine or treatment?
You could get a “placebo” in some studies. A placebo is a medicine or treatment that won’t affect your health. Or, you could get a substitute medicine or treatment. The substitute is compared to the new medicine or treatment.

Will the study help you if you get a placebo or substitute?
Probably not, but your participation can result in information that will help others.

Can the research study make your condition worse?
Ask the doctor or researcher what could happen to you during the study. Ask for a copy of the study “protocol” or plan. Ask about side effects of the medicine, treatment, device or equipment. Look for side effects while you are in the study.

What is “informed consent”?
This means that the doctor or researcher told you about the research study and its risks. It also means that you understand what you were told. You will be asked to sign an informed consent form. Take the form home and read it with your family before you decide if you want to sign it.

What should you do if you don’t understand the informed consent form or study protocol?
Ask your doctor or the researcher to explain them. You can also ask your doctor or the researcher to recommend a patient “advocate.” This person helps patients understand their treatment and their choices in treatment.

Who can you call if you have concerns about the research study?
- Your doctor or researcher
- An Institutional Review Board
- The Office of Human Research Protections

Questions to ask the doctor or researcher
- Why is the research study being done?
- Who is doing the study?
- How long will the study last?
- Will you be able to continue seeing your own doctor?
- Is there any cost to you? Will you be paid to participate in the study?
- Does anyone receive money for your participation in the study?
- What tests or treatments will be used in the study?
- What are your other choices if you decide not to take part in the study?
- Will the new treatment help you more than the regular treatment?
- Could you get a “placebo” or a substitute?
- What could happen to you if you take part in the study? Has anyone reported any bad effects? How serious were they?
- Could your condition get worse during the study? What happens if it does? If your condition worsens, will you be told? How?
- Who pays for your care if you’re injured during the study?
- Can you stop participating in the study if you change your mind? Is there any danger to you if you stop participating?
- What will happen to you after the study?
- Will you be told the results of the study?
- Who do you contact for information about the study?
- Are there any patient advocates you can talk to? The advocate should not be employed by the clinic or laboratory that is doing the research study.
- Who could benefit financially from the results of the study?
- Does the doctor or researcher personally benefit if you participate?

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