



A HIGHER LEVEL OF CARE

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Navigating Health Care.

Finding your way through today's system.



A HIGHER LEVEL OF CARE

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This guide is meant to help caregivers understand how to prepare themselves or loved ones who may need medical attention now or in the future.

The information contained in this handbook is based on sources believed to be reliable and accurate. It was compiled from a collection of personal narratives and correspondence, books and online resources. To the best knowledge of all parties involved in the information gathering, all content was accurate at the time of press. The parties do not accept liability for any new information contrary to that contained in this publication.

This handbook is intended to provide helpful and informative material. The information in this handbook should not be used as a substitute for advice from a medical professional or legal counsel. The parties involved expressly disclaim responsibility for any adverse effects arising from the use or application of the information contained in this handbook.

Internet Warning: Not all information on the Internet is credible. Web sites sponsored by government agencies, medical foundations, health associations, and medical colleges are typically the most trusted sources of health care information. Remember to compare information with other resources.

In general, sites ending in .gov (government), .edu (education) and .org (organization) are more reliable than commercial sites ending in .com. The sponsors of this guide do not advocate or take responsibility for the information on these Web sites. Always check the credentials of the host.

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Getting Started.

Create Medical Folders for Yourself and Loved Ones. (See Appendix)

Since you never know when you or a loved one might need to see a doctor or go to the hospital, it's important to have your medical records all in one place. Begin by gathering the following information for yourself or a loved one. For easy access, put it in a folder or on a CD and indicate when the folder was updated. Always keep the original records.

- Patient's legal name
- Date of birth
- Social Security Number
- Health insurance policies including Medicare, Medicaid and long-term care plans
- Health care providers
- Emergency contact information
- Plan for family & friends — who will go with you, what will they bring, who will they notify
- List of medications and dosages including injections, drugs as needed (such as inhalers), and over-the-counter medication including herbal supplements. *See Appendix A for a sample form.*
- Pharmacy information
- Health history — immunization record, allergies, conditions, illnesses, chronic diseases, hospitalizations, surgeries
- Dates and results of recent tests
- Family health history
- Lifestyle profile — household members, exposure to second-hand smoke, pets, diet, typical sleep pattern, alcohol and drug intake, exercise routine, and a list of languages spoken so an interpreter can be provided as needed
- Advance Directives, Health Care Proxy, Power of Attorney, Living Will, Do Not Resuscitate form (DNR), Medical Orders for Life-Sustaining Treatment (MOLST), wishes, statements, values

Do Your Homework.

Become an advocate for yourself and others by finding out as much as you can. There are many sources of information available regarding conditions, diagnoses, treatments and options.

- **Talk with health care professionals, such as a primary care doctor or the Onondaga County Medical Society.**
Ask your doctor what your main problem is, what you can do to improve the situation and why that is the best treatment. Ask for referrals, advice, and where you can get more information. Don't be shy!
- **Search the Internet.**
There are numerous health care Web sites that can provide background information on just about every medical situation. Here are a few sites that may help you.

HealthGrades

Ratings and profiles of hospitals, nursing homes and physicians to consumers, corporations, health plans and hospitals.
www.healthgrades.com

Joint Commission

Information on the safety and quality of care provided to the public. Click on "quality check" to search for accredited health care organizations in an area.
www.jointcommission.org

The Leapfrog Group

Compare health care quality at hospitals. Reduce preventable medical mistakes, improve care, encourage public reporting, and reward quality care.
www.leapfroggroup.org

Medicare

Official U.S. government site for people with Medicare. Information on enrollment, plan choices, billing, appeals, long-term care, prescription drug plans, providers, preventive services, and a Medicare glossary.
www.medicare.gov

Medline Plus

Current health news, drug information, medical encyclopedia, and resources for finding doctors, dentists, and hospitals.
www.medlineplus.gov

National Institutes of Health (NIH) Health Information

Health and medical information in publications and fact sheets, databases, and other resources.

www.health.nih.gov

National Library of Medicine

The "Guide to Finding Health Information" includes links to consumer health information, health-related organizations, as well as information about conducting research at a public library or a medical library.

www.nlm.nih.gov/services/guide.html

New York Online Access to Health (NOAH)

Consumer health information, in both English and Spanish, that is compiled by librarians and health professionals.

www.noah-health.org

New York State Department of Health

Information on state records, programs, statistics, laws, regulations, insurance programs, diseases, health care providers, health care settings, and more.

www.health.state.ny.us

St. Joseph's Hospital Health Center

St. Joseph's Web site contains a section entitled "Health Information," which includes a health encyclopedia, an animation player, care guidelines, health calculators, health exam guidelines and more. A comprehensive, interactive medical reference includes more than 50,000 pages of medically-reviewed health content written in easy-to-understand language, along with medical illustrations, videos/animation and other presentations to help you understand important health issues.

www.sjhsyr.org

■ **Conduct research at a public library or at consumer health medical libraries.**

Public libraries are a great source for research. When you go, you can expect:

- Individual assistance from a librarian who can point you toward local or regional resources.
- Free Internet access to health resources.
- Medical references including medical or nursing textbooks, dictionaries or encyclopedias, drug information handbooks, and therapy books.
- Medical and health directories listing doctors and medical specialists in your area, consumer health resources, support groups, and organizations.

- Databases that index magazines, newspapers, and medical journals, which include current journal articles written by and for health professionals. If your library does not own the magazine or journal you are looking for, ask about Interlibrary Loan.

Medical libraries are often located at medical, nursing, and dental schools; large medical centers; and community hospitals.

- Medical libraries carry medical, dental, nursing and specialty textbooks, as well as health-related journals.
- To find the closest public medical library, call 1-800-338-7657 or visit www.nlm.nih.gov/network.html

■ **Find related organizations and associations for information, brochures, newsletters, and more.**

You can use the National Library of Medicine Directory of Health Organizations to search for associations and voluntary organizations by name, keyword or acronym by visiting dirline.nlm.nih.gov

Understand Health Care Provider Options.

There are many types of professionals who can assist with health care. Below, you'll find more information about the differences among these providers.

Primary Care Provider: Physician, chosen by or assigned to a patient, who provides a broad spectrum of preventive and curative care, and coordinates the patient's care among the various doctors the patient may see. Family physicians, most pediatricians and internists are primary care providers.

Family Physician: Physician who is trained in family medicine and specializes in continuing and comprehensive health care for the family and the individual.

Pediatrician: Physician who specializes in pediatrics, or the care of babies and children.

Internist: Medical doctor who specializes in certain diseases or conditions and care of adults. Patients may choose an internist as their primary doctor or to specifically treat an illness.

Hospitalist: Physician who treats or consults patients in the hospital. They are assigned by the hospital and not chosen by the patient. Hospitalists can assume care for the patient immediately, while it is often difficult for private physicians to travel to the hospital when a patient arrives or needs treatment. They are trained in either internal, emergency or family medicine. When discharged, patients return to their primary physician, or a referral is made.

Specialist: Doctor who treats certain parts of the body, certain health problems, or certain age groups. Cardiologists, orthopedists and gynecologists are examples of specialists.

Intensivist: Physician who specializes in critical care medicine for critically ill or injured patients.

Case Manager: Nurse or social worker who collaborates with the physician and the health care team to facilitate the patient's inpatient stay and coordinates services for the next level of care.

Examples:

- **Insurance Case Manager:** Assists patient with obtaining services during or after hospitalization based on his or her insurance policy. May also direct patients toward health wellness programs.
- **Hospital Case Manager:** Manages the patient's stay and coordinates services for the next level of care.
- **Residential Care Facilities Case Manager:** Collaborates with the patient and family regarding services needed during a stay in the rehabilitation center and makes arrangements for patients when they no longer need that level of care.

Social Worker: Professional who offers support to patients and their families, including information about home care, social services, and support groups.

Understand the Abbreviation After a Name.

The letters MD, DO, DC, PA, NP, RN, LPN, CNA look like alphabet soup! Here is a quick guide to what those letters mean.

MD = Doctor of Medicine: Licensed to diagnose and treat patients using drugs, surgery, or other medical resources.

DO = Doctor of Osteopathic Medicine: Uses a holistic approach to health and emphasizes preventive care. Licensed by the state and often completes MD residency programs.

DC = Doctor of Chiropractic Medicine: Diagnoses and treats back and neck pain. Often considered a primary care physician. Deals with spines and the body's muscular, nervous and skeletal systems.

PA = Physician Assistant: Conducts physical exams, diagnoses and treats illnesses, orders and interprets tests, counsels on preventive health care and assists in surgery.

NP = Nurse Practitioner: An RN with an advanced degree, typically a master's degree, who has clinical experience in the diagnosis and management of common medical conditions. NPs write prescriptions.

RN = Registered Nurse: Professional nurse who is an advocate and health educator for patients, families and communities. Earned an associate's degree, bachelor's in nursing or completed a hospital diploma program. Monitors symptoms, reactions and patient progress; assists during surgery, treatments, and examinations; administers medications; and assists in recovery and rehabilitation. RNs supervise LPNs and often CNAs.

LPN = Licensed Practical Nurse: Provides basic bedside care under the direction of physicians and RNs. Often takes vital signs, applies dressings, assists with bathing and hygiene, and administers medicines.

CNA = Certified Nurse Assistant: Provides bedside care and assists with daily activities. Helps monitor patients for nurses. Supervised by an RN or LPN. Also referred to as home health aides, personal care assistants, nurse's aides, and patient care technicians.

Select the Right Doctor.

Make a list of current providers and compare it to a list of your needs or the needs of a loved one. If the doctors listed cannot meet those needs, you may need to search for a new one by asking for referrals from other medical professionals. Ask them who they see or who they would recommend for their own family members.

Look for a doctor who:

- Accepts your insurance
- Sees patients with health situations similar to yours
- Is taking new patients, but regularly sees other patients
- Studied at accredited medical and residency schools
- Has hospital privileges at quality hospitals
- Is in a practice with other physicians
- Has been certified for more than three years

Here are a few Web sites that may also help with your search:

American Board of Medical Specialties

Find board-certified physicians in the specialty you need.

www.abms.org

American College of Surgeons

Choose a qualified surgeon and read FAQs about operations, second opinions, and giving your informed consent.

www.facs.org

American Medical Association

Search “group practice locator” by state.

www.ama-assn.org

Best Doctors®

An independent paid service that includes a database of 50,000 of the best doctors worldwide and explanations of why other physicians consider them “the best” and would refer a friend.

www.bestdoctors.com

Family Doctor

Search for family physicians and read clinically reviewed articles on health topics for men, women, and children.

www.familydoctor.org

healthfinder.gov

A health-library search engine for information on health topics, drugs, and health organizations. Includes a directory of doctors, dentists, and hospitals.

www.healthfinder.gov

MedlinePlus

Provides links to directories of health professionals, services and facilities.

www.medlineplus.gov

Onondaga County Medical Society

Online database of member physicians in Onondaga County.

www.oncms.org

Hospital Web Sites

Check the Web sites of hospitals in your area for physician directories and 800 referral numbers. For example, St. Joseph’s Physician Finder lists more than 800 physicians who practice within the hospital’s network.

www.sjhsyr.org

Get a Second Opinion.

Patients should seek a second opinion in some situations. In fact, research has shown getting a second opinion changes treatment substantially in nearly one-third of all cases.

Doctors should not be upset if you want a second opinion. It’s your life or the life of a loved one, so don’t be afraid to make sure you get the correct diagnosis. It is usually helpful to give the second doctor access to medical records, test results and the first physician’s opinion in order to make a comparison possible.

Think about getting a second opinion if you are:

- Thinking about major surgery
- Not sure if surgery is the only option
- Not able to get a diagnosis from your regular doctor
- Seeing a doctor who is not a specialist in the disease or condition you have
- Having difficulty communicating with your doctor
- Not getting better or your condition doesn’t improve
- Diagnosed with a life-threatening disease or condition
- Told you may need a second surgery
- Having several medical problems

How to ask for a second opinion:

- Ask your family doctor to refer you to a specialist who is an expert in the area of the diagnosis.
- Consider finding a board-certified specialist on your own because doctors who are friends may not want to contradict each other.
- Don’t limit yourself to doctors who are nearby because specialists can often consult from across the country.
- Find the best specialist for your condition.
- Some health care organizations offer second opinions online.
- Check with your hospital.

Before you go for a second opinion:

- Research your condition.
- Remember not everything you find on the Internet is reliable.
- Find a study with a large sample that was conducted by a big clinic or a university hospital and was paid for by an organization that did not have a stake in the results. Make sure there were controls on the subjects to ensure the integrity of the findings.

What to ask the second doctor:

- What will happen if I don't do anything at all?
- Is there a chance the problem could have a different diagnosis?
- What are the side effects of the treatments?
- Are there other forms of treatment available?
- What risks are associated with the treatment options?
- How will the treatment improve my health?
- How long will it take to recover?
- If there is a difference between the two opinions, what is different and why?

After you get a second opinion:

- Do not assume the opinion you would rather have is right.
- Do not base judgment on which doctor you like better.
- If there is a difference between the opinions, you may need a third.

Understand Health Care Setting Options.

Hospitals, urgent care, and emergency departments are just a few of the health care setting terms you should be familiar with.

Hospital: Licensed facility where physicians and nurses provide diagnostic and therapeutic services for surgical and non-surgical medical conditions. Inpatient accommodations must be available.

Ask the following questions to help choose a hospital that's right for you:¹

- Does your doctor treat patients at the hospital?
- Does the hospital accept your insurance?
- Does the hospital specialize in your condition?
- Would your own doctor choose this hospital for his or her own treatment or that of his family's?
- Is the hospital clean?
- Is it a "Magnet" hospital for high quality nurses, such as St. Joseph's Hospital Health Center in Syracuse? The Magnet Recognition Program[®] was developed by the American Nurses Credentialing Center to recognize health care organizations that provide the very best in nursing care. Check www.nursecredentialing.org
- Is it accredited by the Joint Commission?
- Does the hospital employ hospitalists or full-time doctors who treat critically-ill patients?
- Does the hospital use an electronic system for patient orders and prescriptions? (reduces handwritten errors)
- Is it a teaching hospital affiliated with a medical university?
- Do attending physicians adequately supervise the residents?

Tips about staying at the hospital:

- *What to bring:* Night clothes, bathrobe, and sturdy slippers, clothes to wear home, toothbrush, toothpaste, shampoo, comb, brush, deodorant, razor, and up to \$10 for newspapers or magazines.
- *What to leave home:* Cash, jewelry, credit cards, checkbooks, electric razors, hair dryers, and curling irons. If you must bring valuables, ask to keep them in the hospital safe.

Inpatient: Formally admitted to stay overnight at the hospital for observation, care, diagnosis, or treatment. The average length of stay is 4.8 days, according to the National Center for Health Statistics.

Outpatient: Comes to the hospital for a clinic visit, referred visit, observation service, surgery, and emergency department visits, but does not stay overnight.

Short-Stay Patient: Outpatient who is not admitted, but occupies a hospital bed for an overnight stay.

Same-Day-Admission Patient: Admitted to the hospital on the morning of surgery.

Patient Education: Most hospitals offer health and wellness information in electronic, video, or print forms. Hospitals may sponsor both inpatient and outpatient education programs to teach you to manage chronic diseases. You can attend both private and/or group sessions if needed. Ask your doctor to refer you to these services.

Emergency Department (ED): A 24-hour hospital facility that provides unscheduled outpatient services to patients whose conditions require immediate care. Off-site EDs open less than 24 hours are included if staffed by the hospital's ED.

Characteristics of an excellent ED:¹

- Specialty doctors are available for the treatment you need. If you have children, you should look for an ED that specializes in pediatrics.
- It's designated a Level 3, which is considered the best, and it's a trauma center, which is specially equipped to treat injuries from accidents.
- Testing is available 24-hours a day, seven days a week.
- The "door to wire" time, the time it takes to get patients with heart emergencies through the ED and into the cardiac catheterization laboratory, is 30 minutes or less, and the hospital has a cardiac surgery team to perform open heart surgery, if it's needed.
- The average wait time to be seen by a doctor is reasonable.
- Doctors are certified in emergency medicine.
- Plastic surgeons are available, if such treatment is needed.
- The ED looks and feels comfortable at its most chaotic times, which often are late in the evening or early in the morning.

After calling 911:

- Mention all symptoms. Don't leave anything out.
- Call your primary-care doctor. Ask the doctor to call the ED and meet you there.
- Call the ED yourself if you can't reach your doctor. You'll be better off if they know you're coming.
- Bring your medications. Hand them to the EMTs to bring to the hospital with you.
- Bring your medical folder.
- Have someone call your insurance company. It may save you time and effort later.

Tip: Put a note in your wallet next to your insurance card that says, "In an emergency, please take me to (specific hospital) at (address) if it is practical."

Urgent Care: Ambulatory medical care outside of a hospital ED on a walk-in basis without a scheduled appointment. X-ray facilities and minor trauma rooms are typically available. Visits are usually less expensive than at hospital EDs and quicker than waiting for an appointment at a physician's office. Patients often receive care in less than an hour, while ED visits average 3.2 hours, according to the Center for Disease Control (CDC). Many ED visits are non-urgent or semi-urgent and are more appropriate for urgent care.

Communicate With Your Health Care Provider.¹

Your safety depends on your involvement with your care or the care of your loved one.

- Be proactive.
- Speak up if you think you are about to receive the wrong medication, if you think the physician has you confused with someone else, or if something doesn't seem quite right — don't be embarrassed.
- Bring an updated medical folder to all appointments and hospital stays.
- Keep good notes.
- Keep a list of questions.
- Maintain good communication between health care professionals by asking questions until you understand the answers.
- Know what time you are supposed to take your medicine and make sure you receive it.
- Ask providers to coordinate care with your primary care physician and other doctors.
- Bring a health care advocate to all appointments to ask questions, prevent mistakes, and help you understand and remember instructions given by the provider. An advocate can be a family member or be a supportive and reliable friend, but does not have to be a medical expert.
- Identify one person who will be responsible for talking to the doctors.
- Keep hand sanitizer on the nightstand and ask visitors to wash their hands each time they enter the room.

Questions to ask if you're having a test:

- What does the test measure?
- Why do I need the test?
- What alternatives are there?
- What might happen if I do not take the test?
- How much does it cost?
- How much will my insurance cover?
- How accurate is the test?
- When will I get the results and an explanation? Do not assume no news is good news.
- After the test, what's next?

Questions to ask if you're considering surgery:

- Why do I need this surgery?
- What alternatives are there?
- What might happen if I do not have it?
- How much of the surgery will my insurance cover?
- How many of these surgeries does the hospital do each year?
- How many times have you performed this procedure?
- How do I prepare for the surgery?
- What risks are involved?
- How much pain will I be in afterward?
- How long is the recovery?
- When will I be able to drive again?
- Will I have a scar?
- How much time off will I need?
- Will I need physical therapy?
- Who should I call if I have questions after the surgery?

Before you have surgery:

- Ask how long before surgery, or another procedure, you will need to stop having food or fluids.
- Ask which medications you should stop and when.
- Ask if you should take antibiotics to prevent infection.
- To help prevent infection, let the medical team shave the surgery area. Don't do it yourself.
- No jewelry, makeup, or nail polish. Besides getting lost, they can trap bacteria or get in the way during surgery.
- Ask for a supplemental oxygen supply during and after the operation.
- Request a blanket and ask the anesthesiologist to make sure you stay warm during and after surgery.
- Ask when you can restart medications after surgery.

Avoid Prescription Mistakes.

Show the doctor your complete medicine list, including over-the-counter drugs, vitamins, and herbal supplements.

When the doctor prescribes medicine, ask:

- Are preprinted medication information sheets available so I can circle the important points as you review it?
- Can you spell the name of the drug for me? (Regardless of your doctor's penmanship, write it down for yourself and make sure that's what you are given at the pharmacy.)
- Why is it the best drug for my situation?
- What form does the drug come in?
- Is there a generic version available?
- How much should I take and how often should I take it?
- For how long?

- Should I take it with food?
- Are there any foods, beverages, or activities I should avoid while I am on the medication?
- What are the side effects associated with this drug?

Generics vs. Prescription Drugs

When you need a prescription, you may be able to cut down on your health care costs by asking your doctor if there is a generic instead of a brand-name medication that will treat your condition. Most generic medications are one-quarter the cost of their brand-name counterparts without sacrificing quality. Today, approximately one-half of all prescriptions in the U.S. are filled with safe, effective, FDA-approved generic drugs.

Identify When You Need Outside Help.

If you are experiencing any of the following, you may need to see a medical professional:

Physical Illness:

- Decline in health
- Inability to carry out daily activities
- Bleeding uncontrollably
- Physical pain
- Loss of balance
- Involved in a driving accident
- Alcohol or substance abuse problems

Mental:

- Increased loss of memory
- Confusion
- Dementia
- Hallucinations
- Delusional thoughts
- Insomnia
- Thinking about hurting yourself
- Exhaustion to the point you cannot get out of bed

Emotional:

- Inappropriate behavior
- Uncontrollable anger
- Excessive crying
- Frequent mood swings

Spiritual:

- Depression
- Isolation

Health Insurance.

Understand the Health Care Insurance Plan.

Insurance can be overwhelming. Here are a few types and definitions that should help simplify the situation.

Choosing the right plan:

- Find the right doctor for you.
- Find out which plans your doctor accepts.
- If you regularly see a specialist, consider a plan that allows you to do so without a referral.
- Decide which hospitals and health centers you prefer. Find out which plans they accept.
- Request an insurance brochure for plans you are interested in.

Four basic types of health care plans:

Indemnity Insurance or Fee-For-Service: Expensive but least restrictive type of insurance plan. Traditional insurance coverage that typically pays for most health problems, but not preventive care. Coverage is usually limited to a percentage of the billed amount. Subscribers often pay a higher monthly premium than for other plans, but can choose any doctor or hospital. About 10% of employer-paid insurance plans.

Health Maintenance Organization (HMO): Least expensive and generally the most restrictive. Covers most health care services, including check-ups, immunizations and hospitalizations, for a small co-payment typically between \$5 and \$40. There are no claim forms, but subscribers must choose from doctors and hospitals affiliated with their plan or they risk having to pay 100%. HMOs make up about one-third of employer-paid insurance plans.¹ An EPO, or Exclusive Provider Organization, is a similar type of plan.

Preferred Provider Organization (PPO): Economical yet less restrictive than HMOs. Covers many health care needs for a small per-visit fee if subscribers choose from the list of “preferred providers.” If a doctor is chosen who is not on the list, the subscriber usually has to pay more and may have to pay a deductible. Some PPOs require claim forms. PPOs are the most popular plan in the United States and make up nearly 40% of employer-paid insurance plans.¹

Point of Service (POS): Less expensive than indemnity plans, but more restrictive. Each time subscribers use health care services, they can choose to use the plan like an HMO or an indemnity plan.

- **HMO:** Must pay a nominal co-payment for choosing physicians who are on the list and for obtaining authorizations for certain services and referrals to specialists.
- **Indemnity plan:** Choose the provider you want, but if you choose a non-participating provider, without coordinating care through your primary care physician or health plan, you will pay more. Subscribers are generally responsible for a deductible and a percentage of the bill.

Insurance terms:

Managed Care: Attempts to lower the price of health care by managing the patient’s access to care. With managed care, the health plan has specific requirements, like pre-authorization or second opinions, which enable the primary care physician to coordinate or manage all aspects of your medical care within a network of providers. Typically refers to an HMO, Point of Service, EPO, or PPO plan.

Medicare: Federal health insurance program for people age 65 and older or disabled. Individuals pay premiums, deductibles, and co-pays. Made up of four parts:

Part A: Hospital Insurance

Part B: Medical Insurance

Part C: Medicare Advantage Plan (private health insurance)

Part D: Prescription Drug Plan

Medicaid: Joint federal and state program that helps with medical costs for some people with low incomes and limited resources. Medicaid programs vary from state to state, but most health care costs are covered if you qualify for both Medicare and Medicaid. It provides supplemental insurance for people with little to no income. It is often used to pay for nursing home costs.

More information is available through America’s Health Insurance Plans, the voice of America’s health insurers, by visiting www.ahip.org

Understand Billing Issues.

If you have questions about your hospital bills:

- Call the hospital insurance office.
- Call the hospital business office. Most hospitals have patient account representatives who can help patients understand their billing charges.
- Call your insurance company.
- Check with your hospital to see if charity care is available for those who cannot afford to pay. They may require that you fill out a Medicare application.

Financial Resources: Most hospitals have a financial counseling unit with trained financial counselors who can help patients understand their financial responsibility and payment options. St. Joseph's leads the way in financial counseling; the hospital was the only one in Syracuse to be named an "A" rated health facility for its financial aid practices, according to a report by Citizen Action of New York.

A few options:

- Enroll in Medicaid, Child Health Plus, or Family Health Plus.
- Set up an interest-free payment plan if you have insurance but have excess out-of-pocket expenses or deductibles.
- Apply for full or partial financial aid.

Not everyone has insurance

According to the U.S. Census Bureau, about 41 million (17%) of those under age 65 years do not have health insurance coverage. The most common reasons cited are cost and a change in employment.

According to the Institute of Medicine of the National Academies, almost 18,000 Americans between the ages of 25 and 64 die each year as a result of being uninsured. Don't be one of them. If you don't have insurance, you may want to check out:

- www.hrsa.gov/help/default.htm
- www.insurekidsnow.gov
- www.covertheuninsuredweek.org
- www.patientadvocate.org

Making Decisions for the Future.

Understand Adult Care Options.

How to find the right adult care facility:

- Determine what the individual needs the most such as social activities, mental stimulation, exercise, or help walking.
- Ask for recommendations from your family doctor, local social services or health department, mental health centers, or local senior centers.
- Call the Area Agency on Aging at 1-800-677-1116 for the AAA in your area.

Onondaga County Department of Aging & Youth

John H. Mulroy Civic Center, 421 Montgomery St., 13th Floor,
Syracuse, NY 13202
(315) 435-2362
www.ongov.net

New York State Office for the Aging

2 Empire State Plaza, 5th Floor, Albany, NY 12223
(518) 474-4425 or 1-800-342-9871
www.aging.state.ny.us

- Look in the Yellow Pages under adult care or senior citizens' services.
- Spend a day at a center to get to know the people and the environment.

Questions to ask:

- Who owns or sponsors the agency?
- How long has it been operating?
- Is it licensed or certified? (if required in your state)
- What are the days and hours of operation?
- Is transportation to and from the center provided?
- Which conditions are accepted (e.g., memory loss, limited mobility, incontinence)?
- What are the staff's credentials, and what is the ratio of staff to participants?
- What activities are offered? Are there a variety of individual and group programs?
- Are meals and snacks included? Are special diets accommodated?

Home Care: Nurses and other professional staff (physical therapists, occupational therapists and speech therapists) come to the home to assist patients and families in managing illness, assess patient status and perform and teach patients/caregivers to perform care tasks, such as dressing changes and medication management. Home health aides may also come to the home to assist patients with bathing, light housekeeping and/or meal preparation. The goal of home care is to assist patients in recovering from illness and to manage chronic illness, enabling them to be at home.

Safety tips:²

The following steps help reduce the risk of serious injuries from falling:

- Keep hallways and stairways well-lit and place light switches at both ends of the stairs
- Use nightlights
- Install handrails, grab bars and non-skid mats
- Wear shoes with non-skid soles
- Keep exits, hallways and stairwells clear
- Avoid throw rugs and use carpet that is tacked to the floor
- Arrange furniture so that there is a clear path
- Maintain outdoor steps and walkways
- Spread sand or salt on icy walkways
- Take your time and don't rush

General safety:²

The following steps help reduce the risk of serious injuries from falling:

- Keep emergency phone numbers by the telephone
- Keep a telephone close to the bed
- Keep the stove, sink and countertop work areas well lit
- Keep kitchen appliances away from water
- Unplug extension cords when not in use
- Do not run extension cords under a rug
- Store medicines in their original containers

Adult care facilities:

There are many options for adult care. Here is a guide to help choose what's best for you or your loved one.

Adult Day Care: Provides planned social activities that promote well-being through social and health-related services. Medical services, such as help taking medication and checking blood pressure, are sometimes available. Facilities are typically open weekdays during business hours to provide mental and social stimulation outside of the house and to give caregivers a break from their responsibilities. Nutritious meals and snacks are often included. Participants usually have some mobility, but are

physically or cognitively challenged. It is ideal for someone who desires companionship, cannot be left at home, or is cared for by someone who is frequently away from the home. Medicare does not cover it, but private insurance may cover some costs if licensed medical professionals provide the care.

In Central New York, Franciscan Health Support, Inc. is a Joint Commission-accredited, licensed homecare services agency and durable medical equipment supplier specializing in respiratory therapy and skilled nursing among other services. St. Francis Adult Day Service desires to provide personalized loving support and care to the elderly.

St. Francis Adult Day Service

7246 Janus Park Drive, Liverpool, NY 13088

(315) 458-3600

www.franciscan-services.com

Adult Day Health Center: Provides physical, occupational, and speech therapy, and is usually staffed with RNs and other health professionals. Medicaid will cover most costs.

Independent Living: Senior housing or retirement housing is for people who can no longer live in their houses, but do not need continuous long-term care. These rental apartments have often been adapted for seniors by installing railings in the bathrooms and placing power outlets higher on the walls. Other services include meals, transportation, housekeeping and daily activities.

Assisted Living Program: For those who need a little more help than senior housing can offer. It combines residential and home care services. It is designed as an alternative to nursing home placement for individuals who historically have been admitted to facilities for reasons that are primarily social, rather than medical. The assisted living program is responsible for providing or arranging for resident services that include room, board, housekeeping, supervision, personal care, case management and home health services.

Enriched Housing Program: Provides long-term residential care to five or more adults, primarily persons 65 years of age or older, in community-integrated settings resembling independent housing units. The program provides or arranges for the provision of room, board, housekeeping, personal care and supervision.

Adult Home: Provides long-term residential care, room, board, housekeeping, personal care and supervision to five or more adults unrelated to the operator. It may be operated by an individual, a partnership, a not-for-profit corporation, a public corporation, a non-publicly traded business corporation or a limited liability company.

Nursing Homes: Provide 24-hour nursing care for those who are recovering from an illness or injury. Sometimes they provide end-of-life care, as well. Nursing homes are mostly for people who need more specialized medical care that is not available at other long-term care facilities, including wound care, rehabilitation and respiratory therapy. Nursing home staff members also assist patient with daily activities, including bathing, dressing and going to the bathroom.

For more information on long-term care options or to select a facility, visit Carelink at www.carelinkusa.com

PACE CNY: Located in Central New York, PACE is a Program of All-Inclusive Care for the Elderly. It is a collaborative effort between Loretto and St. Joseph's Hospital Health Center that serves nearly 350 older adults by helping frail seniors remain independent and living in the community for as long as possible. Participants must be at least 55 years of age and eligible for nursing home-level of care. They must also live in Onondaga County, be able to live safely in the community with PACE support, qualify for Medicaid and/or Medicare or agree to pay privately, and need the services of the plan for more than 120 days. The Onondaga County Long-Term Care Resource Center also verifies participant eligibility. For more information call (315) 458-8173 ext. 356.

For more information on adult care facilities in New York State, visit www.health.state.ny.us/facilities/adult_care

Types of Long-Term Care.

Long-term care services assist people with health or personal needs and activities of daily living over a period of time. They can be provided at home, in the community, or in various types of facilities, including nursing homes and assisted living facilities. Most long-term care is custodial care. Medicare doesn't pay for this type of care if this is the only kind of care you need.

According to the U.S. Department of Health and Human Services, by the year 2020, 12 million older Americans will need long-term care. People over the age of 65 have at least a 40 percent lifetime risk of entering a nursing home.

Hospice: Focuses on caring for terminally ill patients, not curing, so they can die pain-free with dignity. Care is usually provided in the patient's home. It is also available in hospice centers, hospitals, nursing homes, and long-term care facilities. Support is given to loved ones as well.

It is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

The hospice team is on call at all times and regularly visits to:

- Manage the patient's pain and symptoms.
- Assist the patient with the emotional, psychosocial and spiritual aspects of dying.
- Provide needed drugs, medical supplies, and equipment.
- Coach the family on how to care for the patient.
- Deliver special services like speech and physical therapy when needed.
- Make short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time.
- Provide bereavement care and counseling to surviving family and friends.

Hospice of Central New York

990 Seventh North St., Liverpool, NY 13088
(315) 634-1100
www.hospicecny.org

In Central New York, Francis House provides a home and a supportive extended family to people with terminal illnesses with a prognosis of six months or less to live.

Francis House

108 Michaels Avenue, Syracuse, NY 13208
(315) 475-5422
www.francishouseny.org

Palliative Care: A specialty designed to care for those who are facing a terminal illness or disease. Provided by a team of physicians, nurses and social workers, palliative care's goal is to relieve the pain, symptoms and stress that accompany progressive, life-threatening illnesses.

St. Joseph's Hospital Health Center is home to a palliative care unit for patients with life-threatening illnesses. The focus is on the patient's quality of life rather than curative treatment. These rooms include special furniture that creates a home-like environment for the patient and fold-out beds for family members. The nurses and volunteers are trained in end-of-life care and symptom management, and provide social work, spiritual care and volunteer support.

For more information on palliative care, visit:

Caring Connections
www.caringinfo.org

National Hospice and Palliative Care Organization
1-800-658-8898
www.nhpco.org

Talk to Loved Ones About End-of-Life Issues.

It's never easy to discuss end-of-life care and life-saving treatments, but it's essential that you choose a spokesperson and make your wishes known. **Before you become sick or injured, you should think about what you want and discuss it with your friends and family.** People of all ages should complete the forms described below, review and update their wishes periodically, and provide copies to loved ones and medical providers.

End-of-life decisions are yours to make. Talking about these important issues while you still can may limit stressful situations down the road because your loved ones won't have to make unaided decisions on your behalf.

Tips on how to begin the conversation:

- Reference a news story that provides a good opening.
- Mention a friend who had a problem when a parent died because an advanced directive was not established.
- Tell them your attorney suggested it.
- Suggest that you do this just in case anything was to happen.
- Acknowledge it is a difficult topic to discuss.

Determining end-of-life wishes:

- Who do I want to be around?
- Do I want to be at home?
- Do I want to be alert, even if it means I'm in pain?
- Do I want to avoid life-sustaining treatments at the risk of shortening my life?
- Do I want to have time to reconcile the past or say goodbye?
- Do I want to live long enough for my family to see me, even if I'm unconscious?
- What are my biggest hopes and fears about the end of my life?

Advance Directives.

These documents enable individuals to make their health care wishes known in the event that they are unable to communicate. Examples include a health care proxy and a living will. They become legal as soon as they are signed in front of the required witnesses.

Ask your doctor or lawyer about state laws to determine which best suits your needs. Advance directives help answer questions such as:

- Would you want to donate your organs and/or tissues?
- Would you want your doctor to withhold or withdraw medical treatment, if it will only delay the fact that you will eventually die?
- Would you want maximum pain relief even if it means you will die more quickly?
- Would you want cardiopulmonary resuscitation (CPR) to restore stopped breathing and/or heartbeat?
- Would you want to continue the use of machines to facilitate breathing?
- Would you want a tube or intravenous feeding and water?

Do Not Resuscitate (DNR): DNR forms indicate individuals' requests not to receive cardiopulmonary resuscitation (CPR) if their hearts stop or they stop breathing. These orders are accepted by doctors and hospitals in all states. DNR orders and non-hospital DNR forms (for home and nursing home care) are issued by doctors with consent from the patient or health care agent.

Health Care Proxy: The New York Health Care Proxy Law allows you to appoint a trusted spokesperson and an alternate to decide upon treatments not only at the end of life, but if you lose the ability to decide for yourself as well. The spokesperson, known as a health care agent, will decide how your wishes apply as your medical condition changes. You can give your health care agent as little or as much authority as you desire when it comes to making decisions about your health care and specific treatments. The form to appoint a health care agent is available at: www.health.state.ny.us/nysdoh/hospital/healthcareproxy/intro.htm

Living Will: This written document describes the types of medical treatments or life-sustaining treatments individuals 17 years of age and older would want if they became terminally ill or faced an irreversible condition that prevented them from making their own medical decisions. You cannot use a Living Will to name a health care agent; you must use a Health Care Proxy. In New York State, a Living Will is not a legal document, but it further establishes wishes and supports the Health Care Proxy form.

Medical Orders for Life Sustaining Treatment (MOLST): The MOLST form is a single document that acts as an actionable medical order and can transition with a patient through all health care settings. The approved physician order form is used statewide by health care providers and facilities as the legal equivalent of an inpatient DNR form. In contrast to a Health Care Proxy, the MOLST applies immediately and is not conditional on losing decision-making capacity. It is available at: www.health.state.ny.us/professionals/patients/patient_rights/molst/index.htm

Power of Attorney: A durable medical power of attorney (DPA) does not apply in New York State, but in other states the designated individual can make health care decisions on your behalf if you are unconscious or otherwise unable to. If you trust someone to make decisions for you, a DPA is generally more useful than a Living Will. This is separate from a durable financial power of attorney, which allows your agent to carry out financial tasks for you when you are unable to do so. Those tasks may include paying bills, managing property, and handling money matters.

The American Bar Association has prepared a kit on advanced planning at: www.abanet.org/elderly/toolkit/home.html

Getting Support for the Caregiver.

Besides assisting a loved one with transportation, supervision, financial management, feeding, bathing, lifting, and toileting, many caregivers are married or living with a partner, have a paid job, and care for a child or another elder.

Tips for Caregivers:³ It's important for caregivers to also take care of themselves, while helping a loved one. It's best to take one day at a time.

- Learn about available resources.
 - Join a support group. Internet-based support groups are available if you don't have time to leave home.
- Develop contingency plans and accept help.
 - Make a list of jobs you need help with such as household chores, home repair or maintenance, driving, paying bills, or finding information on services. Then, ask for the help.
 - Arrange for adult day care for your loved one so you will have time to run errands.
 - Hire a temporary caregiver from a respite care program.
- Make YOUR health a priority.
 - Make time for daily exercise.
 - Eat nutritious meals. Don't give into stress-driven urges for sweets or too much alcohol.
 - Get enough sleep at night and consider taking a nap during the day.
- Be good to yourself and make time for leisure.
 - Get out of the house. Schedule regular afternoons or evenings out.
 - Invite a friend over.
 - Take time to relax and pamper yourself by taking a warm bath, lighting a candle, or reading a book.
 - Plan a weekend getaway or a vacation.
 - Draw strength from your faith.
- Share your feelings with others.
 - Call a friend or family member. Even a brief chat can help lift your spirits.

Respite Care: Provides caregivers with temporarily relief from their caregiving responsibilities. It can take place in an adult day center, in the home, or in a residential setting such as an assisted living facility or nursing home. All caregivers need planned temporary, intermittent, substitute care.

Typically, someone comes to the home to sit or care for a loved one. Nursing homes or assisted living facilities may care for a family member for a day, weekend or during a caregiver's vacation. Adult day care centers provide respite care as well.

As a caregiver, if you are experiencing any of the following, you should consider respite care:

- Depression
- Anxiety, irritability, or anger
- Burnout
- Feelings of detachment, numbness, or exhaustion
- Constant self-criticism
- Withdrawal from daily activities
- Negligence or hatred toward caregiving responsibilities
- Trouble at work or in relationships

Support Groups: Allow you to meet other caregivers. You can discuss and exchange concerns, advice and ideas with people who understand and can identify with your situation.

- Community support groups: Face-to-face meetings with people from your area who are familiar with local resources and challenges. Typically meet on a weekly or monthly basis.
- Internet support groups: Online meetings with people from all over the world who share similar interests or problems through e-mail lists, Web sites, message boards, and chat rooms.

To find a support group, check the yellow pages or call a local organization that deals with the kind of problem you would like to address in a support group.

More information is available through Johnson & Johnson Consumer Products' "The Caregiver Initiative." The site provides tips, a message board and a newsletter for caregivers. There is also information on the signs, symptoms, and basic facts about the most common health conditions caregivers care for as well as advice about daily care.
www.strengthforcaring.com

Other Resources.

Counselor: A health professional who helps clients and families evaluate their patterns of problem solving and develop more effective ones.

Occupational Therapist: The therapeutic use of self-care, work/productive activities, and play/leisure activities to increase independent function, enhance development, and prevent disability.

Parish Nurse: A specialized practice of professional nursing that is based on spirituality. They focus on the promotion of health within the context of the values, beliefs and practices of a faith community. Parish nurses provide support, encouragement and companionship to members of the congregation.

Pastoral Counselor: Certified mental health professional with in-depth religious and/or theological training. Pastoral counselors combine spiritual resources and a psychological understanding for healing and growth.

Physical Therapist: Uses exercises and physical activities to help condition muscles and restore strength and movement.

Rehabilitation: An organized program to enable individuals to regain their physical, intellectual, psychological and social abilities. It may include physical, occupational or speech therapy.

Spiritual Care: Many hospitals offer spiritual care to help comfort and support patients within their own faith traditions.

Wellness Programs: Focus on promoting or maintaining good health rather than correcting poor health.

- For example, St. Joseph's Wellness Place provides proactive health care education. It was Syracuse's first health screening, disease prevention and general information center. It provides free blood pressure screening and general health information. St. Joseph's Wellness Place is located in Liverpool. Call for programs and other information at (315) 458-3600.
- The Agency for Healthcare Research and Quality provides pocket guides to good health for adults, children, and staying healthy at 50+ that are available under "prevention & wellness" at www.ahrq.gov.

Conclusion.

If you are making medical decisions for yourself or others, be sure to investigate the health care system. The more you can learn, the more prepared you will be to care for yourself and your loved ones.

Web Links.

Additional Web Links.

Center for Health Care Strategies

A national non-profit organization devoted to improving the quality of health services for beneficiaries served by publicly financed care, especially those with chronic illnesses and disabilities.

www.chcs.org

Excellus BlueCross BlueShield

A health insurance provider.

www.excellusbcb.com

Families USA

The voice for health care consumers.

www.familiesusa.org

Health Assistance Partnership

The partnership works with State Health Insurance Assistance Programs (SHIP) to enhance their capacity to better serve Medicare beneficiaries through high-quality education and personalized counseling.

www.healthassistancepartnership.org

Navigating the Health Care System

Lists sources for more information.

library.uchc.edu/departm/hnet/hcbib.html

WebMD

Online health information, tools for managing your health, and support.

www.webmd.com

Index of Web Links.

Adult Care Facilities (New York State)

www.health.state.ny.us/facilities/adult_care

Agency for Healthcare Research and Quality

www.ahrq.gov

America's Health Insurance Plans

www.ahip.org

American Bar Association (advanced planning)

www.abanet.org/elderly/toolkit/home.html

American Board of Medical Specialties

www.abms.org

American College of Surgeons

www.facs.org

American Medical Association

www.ama-assn.org

American Nurses Credentialing Center

www.nursecredentialing.org

Best Doctors®

www.bestdoctors.com

Carelink

www.carelinkusa.com

Caring Connections

www.caringinfo.org

Center for Health Care Strategies

www.chcs.org

Directory of Health Organizations (National Library of Medicine)

dirline.nlm.nih.gov

Excellus BlueCross BlueShield

www.excellusbcb.com

Families USA

www.familiesusa.org

Family Doctor
www.familydoctor.org

Francis House
www.francishouseny.org

Health Assistance Partnership
www.healthassistancepartnership.org

Health Care Proxy (New York State)
www.health.state.ny.us/nysdoh/hospital/healthcareproxy/intro.htm

healthfinder.gov
www.healthfinder.gov

HealthGrades
www.healthgrades.com

Hospice of Central New York
www.hospicecny.org

Insurance
www.hrsa.gov/help/default.htm
www.covertheuninsuredweek.org
www.insurekidsnow.gov
www.patientadvocate.org

Johnson & Johnson — “The Caregiver Initiative”
www.strengthforcaring.com

Joint Commission
www.jointcommission.org

The Leapfrog Group
www.leapfroggroup.org

Medical Orders for Life Sustaining Treatment (MOLST) (New York State)
www.health.state.ny.us/professionals/patients/patient_rights/molst/index.htm

Medicare
www.medicare.gov

MedlinePlus
www.medlineplus.gov

My Family Health Portrait
www.familyhistory.hhs.gov

National Hospice and Palliative Care Organization
www.nhpco.org

National Institutes of Health (NIH) Health Information
www.health.nih.gov

National Library of Medicine Guide to Finding Health Information
www.nlm.nih.gov/services/guide.html

Navigating the Health Care System
library.uchc.edu/departm/hnet/hcbib.html

Network of Medical Libraries
www.nlm.nih.gov/network.html

New York Online Access to Health (NOAH)
www.noah-health.org

New York State Department of Health
www.health.state.ny.us

New York State Office for the Aging
www.aging.state.ny.us

Onondaga County Department of Aging & Youth
www.ongov.net

Onondaga County Medical Society
www.oncms.org

St. Francis Adult Day Services
www.franciscan-services.com

St. Joseph’s Hospital Health Center
www.sjhsyr.org

WebMD
www.webmd.com

Resources

¹ Roizen, M.F., & Oz, M.C. (2006). *You the Smart Patient: An Insider’s Handbook for Getting the Best Treatment*. New York: Free Press.

² *In Home Safety*. (n.d.). HCR Manor Care. Available at: www.hcr-manorcare.com/care/education_in_home_safety.asp.

³ *Help and Resources for Caregivers: Tips for Preventing Caregiver Burnout*. (n.d.) HelpGuide.org. Available at: www.helpguide.org/elder/caring_for_caregivers.htm.

Appendix:

Medical Information.

Patient's legal name _____

Preferred name _____

Sex _____ Age _____ Date of birth _____

Address _____

Phone number _____

E-mail _____

Social Security number _____

Health Insurance: (including Medicare, Medicaid and long-term care plans)

Insurance Co. _____

Policy # _____ Group # _____

Phone number _____

Insurance Co. _____

Policy # _____ Group # _____

Phone number _____

Insurance Co. _____

Policy # _____ Group # _____

Phone number _____

(Attach photocopy of both sides of insurance cards.)

Health Care Providers:

Provider _____

Specialty _____

Address _____

Phone number _____

Provider _____

Specialty _____

Address _____

Phone number _____

Provider _____

Specialty _____

Address _____

Phone number _____

Emergency Contact Information:

Name _____

Relationship _____

Address _____

Phone _____ Cell _____

Name _____

Relationship _____

Address _____

Phone _____ Cell _____

Plan for Family and Friends:

who will go with you, what will they bring, who will they notify

Personal Medication Record.

Date Last Updated: _____

Name of Medication	Dose	Time(s)
_____	_____	_____
_____	_____	_____
_____	_____	_____

List all prescription and over-the-counter (non-prescription including herbal supplements) medications (Example: aspirin, St. John's wort, vitamins). Please include prescription medications taken as needed (Example: nitroglycerin, pain medication, inhalers, aspirin, eye drops).

Pharmacy:

Name _____

Address _____

Phone number _____

Immunization Record:

Date Given

Flu Shot _____

Pneumonia Vaccine _____

Hepatitis _____

Tetanus _____

Other _____

Allergies: (also describe your reaction)

Conditions _____

Illnesses and Chronic Diseases:

Hospitalizations and Surgeries:

Recent Tests:

Test _____

Date _____

Result _____

Test _____

Date _____

Result _____

Test _____

Date _____

Result _____

Family Physical and Mental Health History:

List all conditions including breast cancer, colon cancer, diabetes, heart disease, ovarian cancer, stroke, etc. If the family member is deceased, please indicate the cause of death.

Mother's name: _____

Date of birth: _____

Conditions: _____

Father's name: _____

Date of birth: _____

Conditions: _____

Sibling's name: _____ M / F _____

Date of birth: _____

Conditions: _____

Sibling's name: _____ M / F _____

Date of birth: _____

Conditions: _____

Sibling's name: _____ M / F _____

Date of birth: _____

Conditions: _____

Maternal grandmother's name: _____

Date of birth: _____

Conditions: _____

Maternal grandfather's name: _____

Date of birth: _____

Conditions: _____

Paternal grandmother's name: _____

Date of birth: _____

Conditions: _____

Paternal grandfather's name: _____

Date of birth: _____

Conditions: _____

A free family health history form is available at:

www.familyhistory.hhs.gov.

Lifestyle Profile.

Household members:

Name _____

M / F _____ Age _____ Relationship _____

Name _____

M / F _____ Age _____ Relationship _____

Name _____

M / F _____ Age _____ Relationship _____

Name _____

M / F _____ Age _____ Relationship _____

Name _____

M / F _____ Age _____ Relationship _____

Name _____

M / F _____ Age _____ Relationship _____

Second-Hand Smoke:

How often are you exposed? _____

Where? _____

Pets:

Diet:

Typical sleep pattern:

Average alcohol intake per week:

Average drug intake per week:

Exercise routine:

Languages:

Primary language _____

Secondary language _____

Other _____

Advance Directives:

Please attach all advance directives such as a Do Not Resuscitate (DNR), Health Care Proxy, Living Will, Medical Orders for Life Sustaining Treatment (MOLST), Power of Attorney, or wishes, statements and values.

Keep this information with you:

- Bring this list to your doctor visits, the hospital and all medical tests.
- Update this form when medications change.

