

January 10, 2000

Dear State Medicaid Director:

I enclose a copy of *Your Guide to Choosing Quality Health Care*, which was developed by the Agency for Health Care Policy and Research (AHCPR). The guide is directed to consumers of health care. It is intended to help consumers in choosing health plans, doctors, treatments, hospitals and long-term care providers. While AHCPR developed the guide for a general audience, you may also find it useful as you develop materials for Medicaid beneficiaries.

Sincerely,

Timothy M. Westmoreland
Director

Enclosure

cc:

All HCFA Administrators

All HCFA Associate Regional Administrators for
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QUALITY
CHOICES

Your Guide to
Choosing
Quality
Health Care

Health Plans 

Doctors 

Treatments 

Hospitals 

Long-Term Care 



Agency for Healthcare Research and Quality

On December 6, 1999, under Public Law 106-129, the Agency for Health Care Policy and Research (AHCPR) was reauthorized and renamed the Agency for Healthcare Research and Quality (AHRQ). The law authorizes AHRQ to continue its research on the cost, quality, and outcomes of health care, and expands its role to address patient safety and medical errors. Visit our Web site at www.ahrq.gov for more information about AHRQ.

This guide was developed by the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Health Care Policy and Research (AHCPR), in cooperation with other agencies of the U.S. Department of Health and Human Services, and other public- and private-sector health organizations. AHRQ is the lead Federal agency charged with sponsoring and conducting research on the quality and outcomes of health care services, as well as the cost, use, and access to those services. For more information on AHRQ-sponsored research and products, call 1-800-358-9295, or visit AHRQ's Web site at <http://www.ahrq.gov/>. For information on resources available from the U.S. Department of Health and Human Services, visit the Department's gateway Web site, <http://www.healthfinder.gov/>.

A Message from the Director of AHRQ

Health care quality varies in this country—a lot. For example, some health plans and doctors simply do a better job than others of helping you stay healthy and getting you better if you are ill.

Research shows that Americans want and value quality health care. And that's a good thing. Because when you make health care choices that offer the best possible care, you are most likely to get the best possible results.

So when it comes to making major health care decisions—about health plans, doctors, treatments, hospitals, and long-term care—how can you tell which choices offer quality health care, and which do not?

Fortunately, more and more public and private groups are working on ways to measure and report on the quality of health care. This means there is more and more information to help you make choices that improve the quality of your own care.

The goal of this guide is to help you find and use such information to choose quality health care. It can also help you measure quality for yourself according to what is most important to you. You can trust the information in this guide because it is based on research about what people want and need in order to make quality health care choices.

Here are some important things to remember as you make such choices:

Quality matters. It can be measured, and it can be improved.

Take part in every decision about your health.

See yourself and your doctor as a team. You need to work together to get the best care.

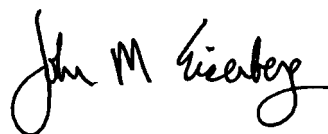
Ask questions, and make sure you understand the answers. The only “bad” question is the one you **wish** you had asked.

Remember that “more” is not always “better.” It is always a good idea to find out why a test or treatment is needed and how it can help you.

Find and use reliable health care information. Ask your doctor or nurse, use your library, explore the Internet.... This guide has many resources for you to try.

I urge you to keep and use this guide. It can help you and your family answer many of the health care questions you will have.

Make quality health care choices. Your good health, and your family's, depends on it.



John M. Eisenberg M.D.

High-quality health care is something we all want. But research shows that many people do not have the information they need to make informed health care choices. The first step is to understand what quality means and how it is measured. To find out, read:

A Quick Look At Quality 1

This guide can help you find and use information about quality that is based on research. You can use this information as you make five important health care decisions:

1 Choosing a Health Plan	3
2 Choosing a Doctor	13
3 Choosing Treatments	23
4 Choosing a Hospital	33
5 Choosing Long-Term Care	37

It also tells how you can:

• Improve communication with your doctor	17
• Keep track of your personal health history	20
• Get only the tests you need, and the most accurate results	24
• Find self-help groups for the support you need	26
• Make informed decisions about elective (non-emergency) surgery	28
• Find reliable health information on the Internet	46

Each section also has a “Quick-Check for Quality” checklist, which summarizes the major ways you can check for quality health care. If you want more detailed information, refer to the resources at the end of each section. A convenient tear-out page of all five “Quick-Check for Quality” checklists is on page 47.

Please note that this guide is not meant to be read cover-to-cover, all at once. Save it, and use it as a reference when you need it.

Also, it isn’t necessary or practical for any one person to do everything this guide suggests. Pick and choose what you need and what feels comfortable for you to try.

Quality health care means doing the right thing, at the right time, in the right way, for the right person—and having the best possible results.

Although we would like to think that every health plan, doctor, hospital, and other provider gives high-quality care, this is not always so. Quality varies, for many reasons.

Fortunately, there are scientific ways to measure health care quality. These tools, called measures, have mostly been used by health professionals. They use measures to check up on and improve the quality of care they provide.

But there is some quality information you can use right now to help you compare your health care choices. And more and more is becoming available all the time. Many public and private groups are working to improve and expand health care quality measures. The goal is to make these measures more reliable, uniform, and helpful to consumers in making health care choices.

What is Measured?

There are two main types of quality measures that can help you choose quality health care: **consumer ratings** and **clinical performance measures**. Both types are based on “outcomes research.”

Outcomes research measures the end results of health care practices and treatments. For example, after treatment, is the pain gone? Can the patient carry out his or her daily activities? Is he/she satisfied with his or her care?

1. Consumer ratings (or “consumer satisfaction” information). These look at health care from the consumer’s point of view. For example, do doctors in the plan communicate well? Do members get the health services they need?

Many consumer ratings of health plans are based on a survey called the Consumer Assessment of Health Plans (CAHPS) and on the HEDIS member satisfaction survey, which includes CAHPS questions (read on for more about HEDIS). For more information on CAHPS, see pages 4-5 in the “Choosing a Health Plan” section.

2. Clinical performance measures (also sometimes called “technical quality” measures). An example of some widely used clinical performance measures is the Health Plan Employer Data and Information Set (HEDIS). These measures look at how well a health care organization prevents and treats illness. For example, one HEDIS clinical performance measure looks at whether children get the immunizations (shots) they need when they need them.

See pages 5-6 in the “Choosing a Health Plan” section for more information on HEDIS.

What Should I Look For?

Quality Reports. You may be able to find consumer ratings, clinical performance measures, or both in quality reports. Quality reports go by different names, including performance reports and report cards. Quality reports don’t tell you which health care choices are the best. But they can help you decide which are best for you, based on the things that are most important to you.

See pages 5-7 in “Choosing a Health Plan” and pages 34-35 in “Choosing a Hospital” for more information about quality reports.

Accreditation Reports. Another way to compare quality is to use information about accreditation. Accreditation is a “seal of approval.” It is mainly used for health care organizations such as health plans, hospitals, and nursing homes.

To earn accreditation, organizations must meet national standards, often including clinical performance measures. Organizations choose whether to participate in accreditation programs. Therefore, you will not find accreditation information on every nursing home, for example.

For more information on accreditation, see pages 7-8 in “Choosing a Health Plan,” page 25 in “Choosing Treatments,” page 33 in “Choosing a Hospital,” and pages 42-44 in “Choosing Long-Term Care.”

Today there are more health plans to choose from than ever before. Not everyone has a choice. But if you do, this section can help you choose the plan that offers the best quality for you and your family.

Quick-Check for Quality ✓

Look for a plan that:

- Has been rated highly by its members on the things that are important to you.
- Does a good job of helping people stay well and get better.
- Is accredited, if that is important to you.
- Has the doctors and hospitals you want or need.
- Provides the benefits you need.
- Provides services where and when you need them.
- Meets your budget.

The quality of health plans varies widely. In 1997, a study published by the National Committee for Quality Assurance (NCQA) showed differences in the ways managed care organizations provide access to care, keep people healthy, treat illness, deliver high-quality service, and satisfy patients. For example, studies show that treating heart attack patients with beta blocker drugs saves lives. The NCQA found that in some health plans, most heart attack patients got beta blockers. In other health plans, only one in three did.

Research shows that Americans say that quality is the most important thing they think about when choosing a health plan. But research also shows that few people understand their options well enough to make an informed choice.

Your Health Plan Affects Many Things:

- **Who** will care for you (doctors and other health care providers), and how much choice you will have.
- **What** kind of care you will receive (for example, which preventive services are covered?).
- **Where** you will receive your care (which hospitals, for example).
- **When** you will receive your care (will you receive it when you need it?).
- **How** you will be cared for (the quality of care you receive).
- **How much** you will pay.

What Are Your Choices?

The two major types of health plans are “fee-for-service” and “managed care.” Managed care plans can go by many names: Health Maintenance Organization (HMO); Preferred Provider Organization (PPO); Individual Practice Association (IPA); and Point of Service (POS) plan, to name a few. But different groups do not always define these names the same way.

Do not be confused by whether the plan is a “fee-for-service” plan, or whether the plan is one of the many kinds of managed care plans. What you need to understand is not the plan’s label, but the characteristics of the plan. Research shows that it is important to understand your options and how they affect your choice of providers and services, costs, and quality of care.

How to Make Decisions Based on Quality.

The next section lists several questions you may want to consider when choosing a health plan. These questions are based on research about what consumers want to know when choosing health plans. Under each question you will find more information to help you choose the plan that is right for you. You also will find a way to compare the health plans you are looking at. Here’s how:

- Read the questions. Which are most important to you in choosing a health plan?
- Under each question you have chosen, write the names of the plans. Space is provided for comparing three plans.
- Read and think about the information under each question. Then ask yourself the question. If the answer is “yes” for a plan, check the box under its name.

Of course, the answers to these questions may not be as simple as “yes” or “no.” Still, these questions should help you to think about and compare your health plan choices.

- Do this for all the questions you have chosen. Which plan or plans have the most check marks?

Rate Your Health Plan Choices.

1. Do members rate the plan highly on things that are important to me?

Plan: _____ Plan: _____ Plan: _____
Yes Yes Yes

Before you join a plan, it is hard to know what kind of care you will get. One way to find out is to learn what members of the plan say about it. This kind of information is called consumer ratings or consumer satisfaction information.

More and more States, businesses, health plans, Medicare, and even the Federal Government’s personnel office are starting to use a survey called Consumer

Assessment of Health Plans (CAHPS). It tells them what members think of the plans they are in. CAHPS was designed by national experts in health care quality, under a project funded by the Agency for Healthcare Research and Quality.

Also, NCQA has added CAHPS survey questions to its own member satisfaction survey. The NCQA survey is part of its performance measurement program, called HEDIS (see page 6 for more information).

The information from the CAHPS surveys is summarized in reports to help you compare health plans and decide which one is best for you. Here are examples of the kind of information you will find in a report that is based on CAHPS survey questions:

- Do members get the health services they need? Without long waits?
- How easy is it for members to get a doctor they are happy with?
- How easy is it to see a specialist?
- Do doctors in the plan listen carefully?
- Do they explain things well?
- Are office staff polite and helpful?
- Is the health plan's customer service good at giving information and helping with problems?
- Do members have too many forms to fill out?
- How do members rate the care from the doctors and other health care providers in the plan? How do they rate their plan overall?

Find out where the survey information came from. Is it CAHPS, HEDIS, or another source? Are you satisfied that it is a reliable source? Who collected the data?

How can you find consumer ratings? Ask your employer, Medicare or Medicaid office, or the health plan if a CAHPS or HEDIS survey report is available. If not, ask if there are other consumer ratings.

You also may want to check your phone book for your State's department of health, or the insurance commissioner's office. For more help in finding your State health insurance contact, write or call the National Association of Insurance Commissioners, Executive Headquarters, 2301 McGee, Suite 800, Kansas City, MO 64108-2604; telephone 816-842-3600 or, if busy 816-374-7175. The information also is available at its Web site: <http://www.naic.org>.

2a. Does the plan provide preventive services to help keep people well?

Plan: _____ Plan: _____ Plan: _____
Yes Yes Yes

2b. Does it do a good job of helping them get better when they are sick?

Plan: _____ Plan: _____ Plan: _____
Yes Yes Yes

The Health Plan Employer Data and Information Set (HEDIS) uses various types of quality measures. The HEDIS clinical performance measures are based on information such as members' medical records. These measures help to compare how well plans prevent and treat illness. For example, one HEDIS measure looks at how many adult smokers or recent quitters were advised to quit by a health professional in the plan. Another looks at whether two-year-olds are up to date on recommended shots. Some other HEDIS measures look at breast cancer screening, prenatal care, and at eye exams to prevent blindness in people with diabetes.

States, employers, health plans, and groups like the California-based Pacific Business Group on Health use HEDIS performance measures to prepare reports for consumers. These reports are known as performance reports, report cards, or various other names. They also may include HEDIS member satisfaction ratings or other consumer ratings.

To find out if there is performance measure information available on the plans you are looking at, ask your employer, Medicare or Medicaid office, or the health plan. Or, call your State department of health or the insurance commissioner's office.

When you read the report, check to see where the measures came from. Are you satisfied that it is a reliable source?

3. Is the plan accredited?

Plan: _____ Plan: _____ Plan: _____
Yes Yes Yes

Many health plans choose to be reviewed and accredited (given a "seal of approval"). Contact the following organizations to find out if the plans you are looking at are accredited, or find out from the plans.

- The National Committee for Quality Assurance (NCQA) evaluates and rates managed care plans using more than 50 standards. The standards focus on efforts to continuously improve quality of care; doctors' credentials (training, licensing, and other background information); members' rights and responsibilities; preventive health services; and whether appropriate health care services are provided.

Visit NCQA's Web site <http://www.ncqa.org> to generate a report card on one of hundreds of health plans. You can also call 1-888-275-7585 or 1-800-839-6487 to ask for the following information:

An Accreditation Status List, which lists all the health plans NCQA has reviewed. (No charge)

A copy of a 2-page Accreditation Summary Report for any health plan reviewed since July 1995. (\$3 per report by mail; free on the Web)

- The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) evaluates and accredits all types of health care organizations. JCAHO standards focus on patient-related areas it views as most closely related to improving health outcomes. The standards cover: rights, responsibilities, and ethics; continuity of care; education and communication; health promotion and disease prevention; leadership; management of personnel and health information; and continuous quality improvement.
Call 630-792-5800 to ask for information on specific accredited managed care or other organizations. Or visit the JCAHO Web site:
<http://www.jcaho.org>. Information on accredited organizations is free of charge.

- The American Accreditation HealthCare Commission/URAC develops accreditation standards and programs for managed care. Its Network Standards address five general areas: network management, utilization management (checking to see that health care resources are used appropriately), quality management, credentialing, and member participation and protection.
Call 202-216-9010 for information on accredited organizations. Or, for a free list of accredited organizations, visit the Commission/URAC's Web site at <http://www.urac.org/directory/default.htm>.

4. Does the plan have the doctors and hospitals I want or need?

Plan: _____ Plan: _____ Plan: _____
Yes Yes Yes

Here are some questions to think about:

Are you happy with your current doctors?

Call their offices to find out which plans they are in. You may be able to choose a plan that will allow you to keep seeing those doctors without paying extra.

Do you want to make sure the plan includes the kinds of doctors you will want to see?

Call the plans you are looking at to get a list of their doctors and other providers. Or, ask your employer's benefits manager.

And remember, the hospital you go to often depends on the plan you are in and where your doctor has privileges. If going to a certain hospital is very important to you, keep that in mind when choosing a plan.

5. Does the plan provide the benefits I need?

Plan: _____ Plan: _____ Plan: _____
Yes Yes Yes

Which health care services are most important to you and your family? On the next page, mark the boxes next to those services that you want or need. There are extra spaces in which to write other services. Then, check the health plan materials from your employer or the plans. Or, ask your employer's benefits manager or the plan's customer service office. Do the plans provide the services that you checked?

ARE THESE SERVICES COVERED?	PLAN A	PLAN B	PLAN C
Cancer screening (colorectal cancer tests, mammograms, Pap smears, etc.)			
Cholesterol screening			
Immunizations (shots)			
Prenatal care			
Well-baby care			
Care for a pre-existing condition (one you have before joining the plan)			
Diabetes supplies			
Dental exams/treatments			
Eye exams/glasses/contact lenses			
Hearing exams/hearing aids			
Outpatient prescription medicines			
Medical equipment for use at home			
Mental health services			
Physical therapy			
Hospice care			
Counseling to stop smoking			
Drug and alcohol counseling			
Alternative treatments (such as acupuncture or chiropractic services)			
Home health care			
Adult day care			
Nursing home care			

6. Do the doctors, pharmacies, and other services in the plan have convenient times and locations?

Plan: _____ Plan: _____ Plan: _____
 Yes Yes Yes

Here are some questions you may want to call the plan to find out:

Are the services close enough to home or work?

Are they on convenient routes for public transportation?

Is parking available?

Are offices open in the evenings and on weekends?

7. Does the plan meet my budget?

Plan: _____ Plan: _____ Plan: _____
 Yes Yes Yes

Use the health plan materials from your employer or the plans to answer these questions:

	PLAN A	PLAN B	PLAN C
How much will the premium cost me each month?			
If there is a deductible , how much will I have to pay before the plan starts to pay for medical care?			
For prescription medicines?			
How much will I have to pay (co-payment) each time I use a service?			
Doctor visit			
Hospital visit			
Prescription			
How much more will I need to pay if I go outside the health plan's network of doctors, hospitals, and other providers to get services?			

SOURCES OF ADDITIONAL INFORMATION

Choosing and Using a Health Plan.

Details health plan choices, benefits, costs, and suggestions for getting the most from your plan. 29 pages. Free.

Agency for Healthcare Research and Quality

Publications Clearinghouse

P.O. Box 8547

Silver Spring, MD 20907

1-800-358-9295

Web site: <http://www.ahrq.gov/consumer/>

Medicare Compare.

<http://www.medicare.gov/MPHCompare/Home.asp> is an interactive database with detailed information on Medicare's health plan options. Medicare offers a variety of free guides on its Web site,

<http://www.medicare.gov>

or call the Medicare Hotline: 1-800-633-4227

How to Choose a Health Plan and Straight Talk About Health Plans. Free.

American Association of Health Plans.

202-778-3200

Web site: <http://www.aahp.org> (click "For Consumers")

Guide to Health Insurance. Covers different kinds of plans and coverage, changing jobs, and answers frequently asked health insurance questions. 15 pages. Free.

Health Insurance Association of America

1201 F Street, N.W., Suite 500

Washington, DC 20004-1204

202-824-1600

Web site: <http://www.hiaa.org>

Putting Patients First. Contains a guide to patients' rights and responsibilities, lists resources for 170 conditions and diseases, and has a consumer's checklist for evaluating health plans. 24 pages. Free.

National Health Council

1730 M St., N.W., Suite 500

Washington, DC 20036-4505

202-785-3910

Web site: <http://www.nationalhealthcouncil.org>

Choosing Quality: Finding the Health Plan That's Right For You.

Helps consumers evaluate health plans. Covers what to look for, plan accreditation, report cards, and ways to evaluate quality. Glossary. 4 pages. Free.

National Committee for Quality

Assurance, Publications Center

1-888-275-7585

Web site: <http://www.ncqa.org>

Nine Ways to Get the Most from Your Managed Health Care Program.

Topics include referrals, prescription drug coverage, getting care when you are seriously ill, legal rights and protections, and grievances. 40 pages. Free.

American Association

of Retired Persons (AARP)

601 E. St., N.W.

Washington, DC 20049

1-800-424-3410

Web site: <http://www.aarp.org>

Pacific Business Group on Health Web Site.

Offers helpful information about choosing a health plan and evaluating HMOs. Includes consumer and physician ratings of California HMOs.

Web site: <http://www.healthscope.org>

Your Guide to Managed Care. A 15-page on-line guide to choosing health care coverage. Part of an on-line series published by Health Pages.

Web site: <http://www.thehealthpages.com>

Families USA. Offers an in-depth resource list and information clearinghouse on managed care.

Web site: <http://www.familiesusa.org>

Healthfinder—

<http://www.healthfinder.gov>—provides links to reliable health information from the Federal Government and its many partners.

It is important to choose your doctor with care, because quality varies. For example, the Pacific Business Group on Health asked patients of California doctors' groups how they rated their care. The results? More than 80 percent of the patients said they were satisfied with their care.

But fewer than two-thirds were happy with the ease of getting that care.

Quick-Check for Quality ✓

Look for a doctor who:

- Is rated to give quality care.
- Has the training and background that meet your needs.
- Takes steps to prevent illness—for example, talks to you about quitting smoking.
- Has privileges at the hospital of your choice.
- Is part of your health plan, unless you can afford to pay extra.
- Encourages you to ask questions.
- Listens to you.
- Explains things clearly.
- Treats you with respect.

This chapter can help you choose a primary care doctor who will meet your needs and give you quality care. The information also may be useful in choosing any specialists you might need.

Primary care doctors are specially trained to serve as your main doctor over the long term.

They provide your medical and health care, help you stay healthy, and help to manage your care.

Your primary care doctor can refer you to specialists (doctors who treat only certain parts of the body, conditions, or age groups) if you need them.

Internists and family physicians are the two largest groups of primary care doctors for adults. Many women see obstetricians/gynecologists for some or all of their primary care needs. Pediatricians and family practitioners are primary care doctors for many children.

Physician assistants, nurse practitioners, and certified nurse midwives are trained to deliver many aspects of primary care. Physician assistants must practice in partnership with doctors. Nurse practitioners and certified nurse midwives can work independently in some States, but not others.

Doctors and Health Plans

If you already are in a health plan, your choices may be limited to doctors who participate in the plan. But if you have a choice of plans, you may want to first think about which doctor(s) you would like to use. Then, you may be able to choose a plan that has your choice of doctor(s).

Decide What You Want and Need in a Doctor.

What is most important to you in a doctor? A few ideas are listed below. Add your own to create a list that will help you choose a doctor who is right for you.

- My doctor must be highly rated by a consumer or other group. (You will want to find out who did the ratings. Is the information reliable? Who collected it? Does the group have something to gain from the ratings?)
-

- My doctor needs to have experience with my condition(s): (Research shows that doctors who have a lot of experience with a condition tend to have better success with it.) _____

- I want a doctor who has privileges (is permitted to practice) at the hospital of my choice: _____
-

- My doctor must be part of my health plan. _____
-

Make a List of Doctors.

- If you are in a managed care plan, check the plan's list of doctors first.
- Ask doctors or other health professionals who work with doctors, such as hospital nurses.
- Check the "Physician Select" service of the Web site of the American Medical Association. This can give you lists of doctors, by specialty, who practice near you. You can also check on training and board certification:
<http://www.ama-assn.org>.
- Call a doctor referral service at a hospital. But keep in mind that these services usually refer you to any of the doctors on the staff of that hospital. The services do not have information on the quality of care these doctors provide.
- Some local medical societies offer lists of doctors who are members. Again, these lists do not have information on the quality of care these doctors provide.
- Ask family, friends, neighbors, and co-workers.

Write your list here.

NAME	PHONE #

Check on Quality.

Once you have a list of doctors, there are several ways to check on their skills and knowledge, and the quality of care they provide:

- Find out if a consumer or other group has rated doctors in the area where you live. (Again you will want to find out how reliable the ratings are.)
- Information on doctors in some States is available on the Internet at <http://www.docboard.org>. This Web site is run by Administrators in Medicine—a group of State medical board directors.
- The American Board of Medical Specialties (800-733-2267) can tell you if the doctor is board certified. “Certified” means that the doctor has completed a training program in a specialty and has passed an exam (board) to assess his or her knowledge, skills, and experience to provide quality patient care in that specialty. Primary care doctors also may be certified as specialists. You can also check the Web site at <http://www.certifacts.org>. (Note: While board certification is a good measure of a doctor’s knowledge, it is possible to receive quality care from doctors who are not board certified.)
- Call the American Medical Association (AMA) at 312-464-5000 for information on training, specialties, and board certification about many licensed doctors in the United States. This information also can be found in “Physician Select” at AMA’s Web site: <http://www.ama-assn.org>.

Contact the Doctors’ Offices.

When you have found a few names of doctors you might want to try, call their offices. The first thing to find out is whether the doctor is covered by your health plan and is taking new patients. If the doctor is not covered by your plan, are you prepared to pay the extra costs?

Below are some questions you might want to ask the office manager or other staff. You may have some additional questions. Note that some of these items might have more to do with the health plan than with the doctor’s office.

Choosing a Doctor

Things to find out from office staff:	Doctor A	Doctor B	Doctor C
Which hospitals does the doctor use?			
What are the office hours (when is the doctor available and when can I speak to office staff)?			
Does the doctor or someone else in the office speak the language that I am most comfortable speaking?			
How many other doctors “cover” for the doctor when he or she is not available? Who are they?			
How long does it usually take to get a routine appointment?			
How long might I need to wait in the office before seeing the doctor?			
What happens if I need to cancel an appointment? Will I have to pay for it anyway?			
Does the office send reminders about prevention tests—for example, Pap smears?			
What do I do if I need urgent care or have an emergency?			
Does the doctor (or a nurse or physician assistant) give advice over the phone for common medical problems?			

You may also want to talk briefly with the doctor by phone or in person. Ask if you are able to do this and if there is a charge.

The next step is to schedule a visit with your top choice. During that first visit you will learn a lot about just how easy it is to talk with the doctor. You will also find out how well the doctor might meet your medical needs. Ask yourself: Did the doctor...

1. Give me a chance to ask questions? YES NO
2. Really listen to my questions? YES NO
3. Answer in terms I understood? YES NO
4. Show respect for me? YES NO
5. Ask me questions? YES NO
6. Make me feel comfortable? YES NO
7. Address the health problem(s) I came with? YES NO
8. Ask me my preferences about different kinds of treatments? YES NO
9. Spend enough time with me? YES NO

Trust your own reactions when deciding whether this doctor is the right one for you. But you also may want to give the relationship some time to develop. It takes more than one visit for you and your doctor to get to know each other.

Talking with your Doctor

Research has shown that patients who have a good relationship with their doctors tend to be more satisfied with their care—and to have better results. Here are some tips to help you and your doctor become partners.

Give information. Don't wait to be asked!

- You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know.
- It is important to tell your doctor personal information—even if it makes you feel embarrassed or uncomfortable.
- Bring a “health history” list with you (and keep it up to date). You can use the form on page 20 of this guide. You might want to make a copy of the form for each member of your family.
- Always bring any medicines you are taking, or a list of those medicines (include when and how often you take them). Talk about any allergies or reactions you have had to your medicines.

- Tell your doctor about any natural or alternative medicines or treatments.
- Bring other medical information, such as x-ray films, test results, and medical records.

Get information.

- Ask questions. If you don't, your doctor may think you understand everything that was said.
- Write down your questions before your visit. List the most important ones first to make sure they get asked and answered.
- You might want to bring someone along to help you ask questions. This person can also help you understand and/or remember the answers.
- Ask your doctor to draw pictures if that might help to explain something.
- Take notes.
- Some doctors do not mind if you bring a tape recorder to help you remember things. But always ask first.
- Let your doctor know if you need more time. If there is not time that day, perhaps you can speak to a nurse or physician assistant on staff. Or, ask if you can call later to speak with someone.

Take information home.

- Ask for written instructions.
- Your doctor also may have brochures and audio and videotapes that can help you. If not, ask how you can get such materials.

Once you leave the doctor's office, follow up.

- If you have questions, call.
- If your symptoms get worse, or if you have problems with your medicine, call.
- If you had tests and do not hear from your doctor, call for your test results.
- If your doctor said you need to have certain tests, make appointments at the lab or other offices to get them done.
- If your doctor said you should see a specialist, make an appointment.

Urgent or Emergency Care Centers

What if you get sick at night, on a holiday, or over the weekend?—You can't get to your doctor, but you're not sick enough to go to the emergency room. There may be an "urgent" or "emergency" care center near you. These centers are open long hours every day to handle problems that are not life threatening. But they are no substitute for a regular primary care doctor.

To make sure an urgent or emergency care center provides quality care, call your health plan or visit the center to find out:

- If your health plan will cover your care there.
- If it is licensed. Then check to see if it is accredited by a group such as the Joint Commission on Accreditation of Healthcare Organizations (telephone 630-792-5800; Web site <http://www.jcaho.org>) or the Accreditation Association for Ambulatory Healthcare (telephone 847-676-9610, Web site <http://www.aaahc.org>). The accreditation certificate should be posted in the facility.
- How well trained and experienced the center's health care professionals are.
- If the center is affiliated with a hospital. If it is not, find out how the center will handle any emergency that could happen during your visit.

SOURCES OF ADDITIONAL INFORMATION

Talking With Your Doctor: A Guide for Older People. Suggests ways to discuss health concerns, medicines, and issues important to older people. 29 pages. Free. *National Institute on Aging Information Center*

Building 31, Room 5C27
31 Center Drive MSC 2292
Bethesda, MD 20892-2292
301-496-1752; TTY 1-800-222-4225
Web site: <http://www.nih.gov/nia>

Talking With Your Doctor. Focuses on a healthy doctor-patient relationship and suggests questions for patients to ask their doctor. Written for cancer patients but also helpful to others. 6 pages. Free.

American Cancer Society
1-800-ACS-2345

Web site: <http://www.cancer.org>

Health Care's Front Line: Primary Care Physicians. Discusses choosing a primary care doctor and making the most of the first visit. Part of a series published by the Health Pages' on-line magazine.

Web site: <http://www.thehealthpages.com>

Personal Health Guide and Child Health Guide. Put Prevention Into Practice (PPIP) encourages Americans to get the preventive care they need. Two patient booklets help you keep track of preventive services: Free.

Agency for Health Care Policy and Research Publications Clearinghouse
P.O. Box 8547
1-800-358-9295

Web site: <http://www.ahcpr.gov/consumer>

Publications Clearinghouse
P.O. Box 8547

1-800-358-9295

Web site: <http://www.ahcpr.gov/consumer>

Personal Health History. A confidential form that you can fill out and use to track your health and medicine history is on the American Medical Association Web site.

Web site: <http://www.ama-assn.org>

(Click on Search, and enter "personal health history.")

Healthfinder—

<http://www.healthfinder.gov>—provides links to reliable health information from the Federal Government and its many partners.

Your Personal Health History

Use this form to keep track of your health history. Take it with you to your doctor appointments to help keep your doctor up-to-date.

1. I WAS IN THE HOSPITAL FOR (List conditions):

Date

2. I HAVE HAD THESE SURGERIES:

Date

3. I HAVE HAD THESE INJURIES/CONDITIONS/ILLNESSES:

Date

4. I HAVE THESE ALLERGIES (List type of allergy—food, medicine, etc.—and reaction):

Your Personal Health History

5. I HAVE HAD THESE IMMUNIZATIONS (SHOTS):

(Note: In the list below, the names of the shots follow the names of the diseases they prevent.)

For children:	Suggested age	Date(s) received
Hepatitis B (HBV)	Dose 1: Birth to 2 months	
	Dose 2: 2 months to 4 months	
	Dose 3: 6 months to 18 months	
	Dose 1 or 3: 11 years to 12 years	
Polio (IPV)	Dose 1: 2 months	
	Dose 2: 4 months	
	Dose 3: 6 months to 18 months	
	Dose 4: 4 years to 6 years	
Haemophilus Influenzae type B (Hib)	Dose 1: 2 months	
	Dose 2: 4 months	
	Dose 3: 6 months	
	Dose 4: 12 months to 15 months	
Diphtheria, Tetanus, and Pertussis (DTaP, Td)	Dose 1: 2 months	
	Dose 2: 4 months	
	Dose 3: 6 months	
	Dose 4: 15 months to 18 months	
	Dose 5: 4 years to 6 years	
	Td Once: 11 years to 16 years	
Measles, Mumps, Rubella (MMR)	Dose 1: 12 months to 15 months	
	Dose 2: 4 years to 6 years	
	or Dose 2: 11 years to 12 years	
Chickenpox (Varicella) (VZV)	Once: 12 months to 18 months or once: 11 years to 12 years	

Your Personal Health History

Pneumococcal Disease (Prevnar™)	Dose 1: 2 months	
	Dose 2: 4 months	
	Dose 3: 6 months	
	Dose 4: 12 months to 15 months	
Hepatitis A	Once: 2 years to 12 years in selected areas	
For adults:	Suggested age	Date(s) received
Influenza	Every year starting at age 65	
Pneumococcal	Once at age 65	
Tetanus (Td)	Every 10 years	

6. I TAKE THESE MEDICINES/SUPPLEMENTS (Bring with you, if possible):

7. MY FAMILY MEMBERS (PARENTS, BROTHERS, SISTERS, GRANDPARENTS) HAVE/HAD THESE MAJOR CONDITIONS:

8. I SEE THESE OTHER HEALTH CARE PROVIDERS:

Name	Why I see them

Research shows that millions of Americans receive treatments that are unnecessary, costly, and even harmful to their health. On the other hand, millions of Americans do not get the treatments they need.

Quick-Check for Quality ✓

When choosing a treatment, make sure you understand:

- What your diagnosis is.
- Whether treatment is really needed at this time.
- What your treatment options are.
- Whether the treatment options are based on the latest scientific evidence.
- The benefits and risks of each treatment.
- The cost of each treatment.

Study after study has found that the use of certain treatments varies widely—from region to region, State to State, and city to city.

But there are even large differences in the use of treatments within a single health plan or hospital, or by a single doctor.

That is why it is very important to work closely with your doctor when treatment decisions need to be made. Make sure your doctor knows your questions, concerns, and preferences. Ask your doctor if the treatments he or she recommends are based on the latest scientific evidence.

If you understand and feel comfortable with your treatment plan, you are more likely to do your part to make it work. And, research shows that people who are actively involved in their own health care tend to get better results.

Learning About the Problem.

The first step in getting the right treatment is to tell your doctor what's going on. This information might include:

- Your symptoms: _____

- When they first started: _____

- When they occur: _____

- Are they getting better? Worse? _____
- What makes them better? Worse? _____

- Are they affecting eating, sleeping, or other activities? How? _____

- Medicines you take: _____

Before a treatment decision is made, your doctor needs to make a diagnosis. Medical tests are an important way to help your doctor learn about the problem. It is important to make sure that any tests your doctor suggests are appropriate for you.

Medical Tests

Doctors order blood tests, x-rays, and other tests to help diagnose medical problems. Perhaps you do not know why you need a particular test or you don't understand how it will help you. Here are some questions to ask:

- How is the test done? _____

- What kind of information will the test provide? _____

- Is this test the only way to find out that information? _____

- What are the benefits and risks of having this test? _____

- How accurate is the test? _____

- What do I need to do to prepare for the test? (What you do or don't do may affect the accuracy of the test results.) _____

- Will the test be uncomfortable? _____

- How long will it take to get the results, and how will I get them? _____

Medical Tests (continued)

- What's the next step after the test? _____

One study found that anywhere from 10 percent to 30 percent of Pap smear test results that were called “normal” were not. Errors such as this can lead to a wrong or delayed diagnosis.

You want your tests to be done the right way, and you want accurate results.

What can you do?

- For tests your doctor sends to a lab, ask which lab he or she uses, and why. You may want to know that the doctor chooses a certain lab because he or she has business ties to it. Or, the health plan may require that the tests go there.
- Check to see that the lab is accredited by a group such as the College of American Pathologists (800-323-4040) or the Joint Commission on Accreditation of Healthcare Organizations (telephone 630-792-5000; Web site <http://www.jcaho.org>).
- If you need a mammogram, make sure the facility is approved by the Food and Drug Administration. You can find out by checking the certificate in the facility. Or, call 800-4-CANCER 9:00 a.m.-4:30 p.m. EST to find out the names and locations of certified facilities near you.

What about the test results?

- Do **not** assume that no news is good news. If you do not hear from your doctor, call to get your test results.
- If you and your doctor think the test results may not be right, have the test done again.

Getting the Diagnosis.

When your doctor has decided what your problem is, he or she will give you a diagnosis. But you should know that reaching a diagnosis can be hard. Sometimes it can take a long time. And sometimes it is hard to find out exactly what is wrong.

Ask your doctor to explain what you have and how it might affect you and your family.

- What is the diagnosis? _____

- What is my prognosis (outlook for the future)? _____

- What changes, if any, will I need to make in my daily life? _____

- Is there a chance that someone else in my family might get the same condition?

- Will I need special help at home for my condition? If so, what type of help?

Ask for materials you can take home. You also might want to find out if there are any support groups for people with your condition.

Looking at the Options.

The next step is for you and your doctor to look at your treatment options. Your doctor may recommend one or more of the following:

- Behavior change (for example: eating a healthier diet, getting more exercise, quitting smoking).
- Prescription medicine.
- Non-prescription (“over-the-counter”) medicines.
- Surgery.
- Rehabilitation (such as physical therapy).

Support

“Self-help” groups offer support to people with disabilities, cancer, and many other health problems. The groups are made up of people who have “been there” and who share experiences and information.

Call the American Self-Help Clearinghouse for information on national groups. It also can refer you to any State or local self-help clearinghouses in your area. If you want to start your own self-help group, the Clearinghouse has information to help you.

To contact the American Self-Help Clearinghouse:

Call: 973-625-3037
or, if calling from New Jersey only, 1-800-367-6274

Write: American Self-Help Clearinghouse
St. Clare’s Health Services
25 Pocono Road, Denville, NJ 07834-2995

Visit Web site: <http://www.mentalhelp.net/selfhelp/>

- Other treatments (for example, chiropractic services, massage, or acupuncture).
- “Watchful waiting.” (You and your doctor keep track of your symptoms and watch for any changes. If there are changes, then treatment might be the next step.)

Not all treatments have been proven by research studies to work—or to be the best treatment for what you have. “Clinical practice guidelines” can help doctors and patients make the right treatment choices for some conditions. Some of these guidelines are based on scientific evidence about which treatments work for certain conditions and which do not. Ask your doctor if there are evidence-based guidelines on treatments for your condition.

Ask about any books or special materials that can help you decide which treatment is best for you. For example, “shared decisionmaking programs” use video, audio, and computer graphics to help patients make decisions based on science and on their own values and preferences. Self-help groups, patient organizations (such as the American Cancer Society and the American Diabetes Association), the Internet, and your library are other sources of information.

All treatments have benefits and risks. To learn more about them you may want to ask your doctor:

- What is the recommended treatment? Are there other choices? _____

- What are the chances the treatment will work? _____

- What are the expected results? When will I see them? _____

- What are the risks? _____

- What are the benefits? _____

- Are there any side effects? (Most treatments have them.) What can be done about them? _____

- Is the treatment painful? How can the pain be controlled? _____

Choosing Treatments

- What happens if I choose to have no treatment at all? _____

- How much does the treatment cost? Will my health plan pay? _____

Once you have the answers to these questions, you might want to make a chart of “Benefits and Risks” or “Pros and Cons” to help you decide if the treatment is right for you. Here is a sample chart:

BENEFITS (PROS)	RISKS (CONS)
Treatment has worked well for others with my condition.	Some minor side effects (rash, stomach upset) could be troubling.
The medicine only needs to be taken once a day.	The medicine is costly.
No major side effects are expected.	

What Can You Do to Help the Treatment Work?

- Ask about anything you do not understand.
- Follow the doctor’s directions. If you have a problem with the directions, tell the doctor—the sooner, the better.
- If you have made any changes in the treatment plan, tell the doctor.
- If you feel worse, have new symptoms, or have side effects from the treatment, call your doctor.

Making Decisions About Surgery

Some surgery has to be done right away. But most surgery is not an emergency. That means you have time to talk with your doctor and decide what is best for you.

No surgery, not even minor surgery, is risk-free. To decide if a procedure is right for you, learn about it and its possible benefits and risks. Research shows that patients who know the facts about surgery and other treatments can better work with their doctors to make decisions based on science and on what the patient prefers. The result? A more satisfied patient.

Here are some questions you may want to ask your doctor or surgeon:

- Do I really need this surgery? Is there some other way to treat my condition?

- What will happen if I wait until later to have surgery? Or never have it at all?

- How often does this type of surgery help my kind of problem? How much does it help? _____
- Where will the surgery be performed? _____
- Does the surgeon, hospital, or surgery center have a lot of experience with this kind of procedure? _____
- Is the surgeon experienced and qualified to perform the surgery? _____
- What complications or side effects might I have? _____
- What kind of pain might I have? How will it be treated? _____
- How long will it take me to recover? Will I need help at home? What kind of help? _____
- How much does the surgery cost? _____
- Will my health plan pay? _____

Getting a Second Opinion

A “second opinion” is when another doctor gives his or her views about what you have and how it should be treated. A second opinion can help you decide whether the surgery is right for you at this time. Your doctor and surgeon should welcome your request for a second opinion. Your health plan may even require one for some types of surgery.

You can ask your doctor, health plan, a local medical school, or local medical society for help in finding someone to give you a second opinion. But first check to see if your health plan covers second opinions.

Ambulatory Surgery Centers

Today more and more surgeries are done in places other than hospitals. These are “in and out” (ambulatory) surgery centers, where you may stay for a few hours or up to one night. If you plan to have surgery at such a center, call your health plan or visit the center to find out:

- If your health plan will cover your care there.
- If it is licensed. Then check to see if it is accredited by a group such as the Joint Commission on Accreditation of Healthcare Organizations (telephone 630-792-5800; Web site <http://www.jcaho.org>) or the Accreditation Association for Ambulatory Healthcare (847-676-9610). The accreditation certificate should be posted in the facility.
- How well trained and experienced the center’s health care professionals are.
- If the center is affiliated with a hospital. If it is not, find out how the center will handle any emergency that could happen during your visit.

SOURCES OF ADDITIONAL INFORMATION

Be Informed: Questions to Ask Your Doctor Before You Have Surgery. A list and in-depth discussion. 12 pages. Free.

Prescription Medicines and You. Prepared by the Agency for Healthcare Research and Quality and the National Council on Patient Information and Education. Includes tips for getting involved in your treatment, asking the right questions about your prescriptions, and keeping track of your medicines. 17 pages. Free.

The National Guideline Clearinghouse will make clinical practice guidelines available to the public via the World Wide Web. The Clearinghouse was developed by AHCPR, the American Medical Association, and the American Association of Health Plans.
Web site: <http://www.guideline.gov>.

FDA Guide to Choosing Medical Treatments. Designed to help consumers avoid fraud and deception when choosing medical treatment. Use publication number (Reprint 95-1223) when ordering. 6 pages. Free.
*Food and Drug Administration
Office of Consumer Inquiries: HFE-88
5600 Fishers Lane
Rockville, MD 20857
301-443-3170
Web site:* <http://www.fda.gov>

Taking Part in Clinical Trials: What Cancer Patients Need to Know. This booklet by the National Cancer Institute describes how clinical trials work, and their possible benefits and drawbacks. 18 pages. Free.
*Cancer Information Service:
1-800-4-CANCER (1-800-422-6237)
9:00 a.m.-4:30p.m. EST. Also available on
the new Clinical Trials Web site:
<http://cancertrials.nci.nih.gov>*

When You Need an Operation. This brochure by the American College of Surgeons covers how to assess a surgeon's qualifications, whether to seek a second opinion, and informed consent and cost issues. It and 12 other informational brochures are available free from:

*The American College of Surgeons
Office of Public Information
633 N. Saint Clair Street
Chicago, IL 60611-3211
312-202-5391
Web site: <http://www.facs.org>*

The Web site of the American Medical Association offers a helpful on-line guide to common radiology tests. Included are descriptions and actual images of a CT scan, fetal ultrasound, MRI, mammography, and x-ray.

Web site: http://www.ama-assn.org/insight/gen_hlth/rad/rad.htm

Information about women's health, men's health, and treatments for arthritis, diabetes, and other conditions is available from the Health Pages' on-line magazine. *Web site: <http://www.thehealthpages.com/article5.htm>*

Healthfinder—

<http://www.healthfinder.gov>—provides links to reliable health information from the Federal Government and its many partners.

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Choosing Treatments

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How can you choose the best quality hospital for the care you need? It is important to consider quality, because research shows that some hospitals simply do a better job than others. For example, we know that hospitals that do a greater number of the same surgeries have better outcomes for their patients. The following questions can help you make the best choices.

NOTE: You may not have a choice right now because of your health plan or doctor. But keep these questions in mind for when you might make a change.

Quick-Check for Quality ✓

Look for a hospital that:

- Is accredited by the Joint Commission on Accreditation of Healthcare Organizations.
- Is rated highly by State or consumer or other groups.
- Is one where your doctor has privileges, if that is important to you.
- Is covered by your health plan.
- Has experience with your condition.
- Has had success with your condition.
- Checks and works to improve its own quality of care.

1. Does the hospital meet national quality standards? YES NO

Hospitals can choose to be surveyed by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) to make sure they meet certain quality standards. The standards address the quality of staff and equipment, and—most recently—the hospital’s success in treating and curing patients. If a hospital meets those standards, it becomes accredited (gets a “seal of approval”). Reviews are done at least every 3 years. Most hospitals participate in this program.

The JCAHO prepares a performance report on each hospital that it surveys. The report lists:

- Accreditation status (six levels—from the lowest, “Not Accredited,” to the highest, “Accredited with Commendation”).
- Date of the survey.
- Evaluation of the key areas reviewed during the survey.
- Results of any followup activity.
- Areas needing improvement.
- Comparison with national results.

You can order JCAHO’s performance reports free of charge by calling 630-792-5800. Or, check the JCAHO’s Web site at <http://www.jcaho.org> for a hospital’s performance report or for its accreditation status.

2. How does the hospital compare with others in my area?

One important way to learn about hospital quality is to look at hospital report cards developed by States and consumer groups. A recent study about such reports found that besides helping consumers make informed choices, they also encourage hospitals to improve their quality of care. This is a very good reason to look for and use consumer information about hospitals. Here are some ways to find such information:

- Some States—for example, Pennsylvania, California, and Ohio—have laws that require hospitals to report data on the quality of their care. The information is then given to the public so consumers can compare hospitals.
- Some groups gather information on how well hospitals perform and how satisfied their patients are. An example is the Cleveland Health Quality Choice Program, which is made up of businesses, doctors, and hospitals.
- Consumer groups publish guides to hospitals and other health care choices in various cities.

Find out what kind of information is available where you live by calling your State department of health, health care council, or hospital association. Also, ask your doctor what he or she thinks about the hospital.

3. Does my doctor have privileges (is permitted to admit patients) at the hospital? YES NO

If not, you would need to be under the care of another doctor while at the hospital.

4. Does my health plan cover care at the hospital? YES NO

If not, do you have another way to pay for your care?

If going to a certain hospital is important to you, keep that in mind when choosing a doctor and/or health plan. In general, you will go to the hospital where your doctor has “privileges.”

5. Does the hospital have experience with my condition? YES NO

For example, “general” hospitals handle a wide range of routine conditions, such as hernias and pneumonia. “Specialty” hospitals have a lot of experience with certain conditions (such as cancer) or certain groups (such as children). You may be able to choose General Hospital “X” for gallbladder surgery, Specialty Hospital “Y” if you need care for a heart condition, and Specialty Hospital “Z” for your children.

You also may want to find out if the hospital has a special team of health professionals that works with people with your condition or treatment.

6. Has the hospital had success with my condition? YES NO

Research shows that hospitals that do many of the same types of procedures tend to have better success with them. In other words, “practice makes perfect.” Ask your doctor or the hospital if there is information on:

- How often the procedure is done there.
- How often the doctor does the procedure.
- The patient outcomes (how well the patients do).

Also, some health departments and others publish reports on “outcomes studies” about certain procedures. These studies show, for example, how well patients do after having heart bypass surgery. Such studies can help you compare which hospitals and surgeons have had the most success with a procedure.

7. How well does the hospital check and improve on its own quality of care?

More and more hospitals are trying to improve the quality of their care. One way is to keep track of patient outcomes for certain procedures. Another way is to keep track of patient injuries and infections that occur in the hospital. By finding out what works and what doesn’t, the hospital can improve the way it treats patients.

Ask the hospital quality management (or assurance) department how it monitors and improves the hospital’s quality of care. Also, ask for any patient satisfaction surveys the hospital has done. These will tell you how other patients have rated the quality of their care.

SOURCES OF ADDITIONAL INFORMATION

Hospital Select. An on-line hospital locator that has basic information on all U.S. hospitals: size, capabilities, accreditation. The site also has links to the American Medical Association home page that lists physicians and specialists.
Web site: <http://www.hospitalselect.com>

A Patient's Bill of Rights. Available from the American Hospital Association. Free.
Telephone: 312-422-3000
Web site: <http://www.aha.org> (Click on Resource Center; go to Search at bottom of page; type in Patient's Bill of Rights.) Also available from Fax on Demand, at 312-422-2020; document number 471124.

All Hospitals Are Not Created Equal. Information and questions to ask to help you choose the hospital that best suits your needs. Part of a series published by Health Pages' on-line magazine.
Web site: <http://www.thehealthpages.com/articles/ar-hosps.html>

Choosing a Hospital and Hospital Quality Checklist. On-line Web site offered by the Pacific Business Group on Health .
Web site: <http://www.healthscope.org/hospital/quality.asp>

Healthfinder—
<http://www.healthfinder.gov>—provides links to reliable health information from the Federal Government and its many partners.

NOTES

“Long-term care” means helping people of any age with their medical needs or daily activities over a long period of time. Long-term care can be provided at home, in the community, or in various types of facilities. This section deals

mainly with older people who need long-term care. However, the information also may be useful for younger people with disabilities or illnesses that require long-term care.

Quick-Check for Quality ✓

Look for long-term care that:

- Has been found by State agencies, accreditors, or others to provide quality care.
- Has the services you need.
- Has staff that meet your needs.
- Meets your budget.

When you look for long-term care, it is important to remember that quality varies from one place or caregiver to another.

It is also important to think about long-term care before a crisis occurs. Making long-term care decisions can be hard even when planned well in advance.

Research shows that to make the best choices, you need to think about:

- What your options are.
- Whether they meet your or your family member’s needs (physical, medical, emotional, financial, etc.).
- How to find the highest quality care.

Types of Long-Term Care

Research shows that many people do not know about or understand long-term care options. Following are brief descriptions of the major types of long-term care:

Home care can be given in your own home by family members, friends, volunteers, and/or paid professionals. This type of care can range from help with shopping to nursing care. Some short-term, skilled home care (provided by a nurse or therapist) is covered by Medicare and is called “home health care.” Another type of care that can be given at home is hospice care for terminally ill people.

Community services are support services that can include adult day care, meal programs, senior centers, transportation, and other services. These can help people who are cared for at home—and their families. For example, adult day care services provide a variety of health, social, and related support services in a protective setting during the day. This can help adults with impairments—such as Alzheimer’s disease—continue to live in the community. And it can give family or friend caregivers a needed “break.”

Supportive housing programs offer low-cost housing to older people with low to moderate incomes. The Federal Department of Housing and Urban Development (HUD) and State or local governments often develop such housing programs. A number of these facilities offer help with meals and tasks such as housekeeping, shopping, and laundry. Residents generally live in their own apartments.

Assisted living provides 24-hour supervision, assistance, meals, and health care services in a home-like setting. Services include help with eating, bathing, dressing, toileting, taking medicine, transportation, laundry, and housekeeping. Social and recreational activities also are provided.

Continuing care retirement communities (CCRCs) provide a full range of services and care based on what each resident needs over time. Care usually is provided in one of three main stages: independent living, assisted living, and skilled nursing.

Nursing homes offer care to people who cannot be cared for at home or in the community. They provide skilled nursing care, rehabilitation services, meals, activities, help with daily living, and supervision. Many nursing homes also offer temporary or periodic care. This can be instead of hospital care, after hospital care, or to give family or friend caregivers some time off (“respite care”).

Another type of long-term care takes place in home-like settings called Intermediate Care Facilities for the Mentally Retarded. They provide a wide variety of services to mentally retarded and developmentally disabled people from youth to old age. Services include treatment to help residents become as independent as possible, as well as health care services.

You can learn about long-term care options in your area by contacting:

- The Eldercare Locator (1-800-677-1116, weekdays, 9.00 a.m. to 8.00 p.m., EST). This service can refer you to your Area Agency on Aging.
- Area Agencies on Aging provide information on a wide variety of community-based services. Examples are meals, home care, adult day care, transportation, housing, home repair, and legal services.
- Your State or local Long-Term Care Ombudsman (call the Eldercare Locator for the number). Ombudsmen visit nursing homes and other long-term care facilities to check on and resolve complaints, protect residents’ rights, and give emotional support to lonely older people. A call to your area Ombudsman can give you information on:

- The most recent State survey (inspection) report of the facility.
 - The number of outstanding complaints.
 - The number and nature of complaints lodged in the last year.
 - The results of recent complaint investigations.
- “Nursing Home Compare”
<http://www.medicare.gov/nhcompare/home.asp>—a Web site created by the Health Care Financing Administration, which runs Medicare and Medicaid. This site helps you locate nursing homes in your area. It also has inspection records for nursing homes that receive Medicare or Medicaid funds.
 - Hospital discharge planners.
 - Social workers (some can be “case managers” or “care managers,” who can help you coordinate long-term care services).
 - Doctors and other health care professionals.
 - Local nursing facilities.
 - Volunteer groups that work with older people.
 - Clergy or religious groups.
 - Family and friends.

There are three important questions to ask yourself when deciding about long-term care for yourself or a loved one:

1. What kind of services do I need?
2. How will I pay for these services?
3. How can I choose the best quality services?

What kind of services do I need?

Think of long-term care as a menu of services. A person may need only one or a few kinds of services. Or, several kinds may be needed over the course of a person’s older years.

To help find out what kind of services you or a loved one need, check the items below that apply. Keep in mind that these needs may change over time.

Do you or your loved one need help with daily activities? Health care needs? Both? You can use the chart on page 40 to help you identify the type(s) of long-term care that meet your needs.

This chart shows which types of long-term care services offer which kinds of help. The “Relative Costs” information shows how costly the settings can be when compared with each other.

Choosing Long-Term Care

Help With Daily Activities

- | | |
|---|--|
| <input type="checkbox"/> Shopping | <input type="checkbox"/> Dressing |
| <input type="checkbox"/> Preparing meals | <input type="checkbox"/> Grooming |
| <input type="checkbox"/> Eating | <input type="checkbox"/> Going to the bathroom |
| <input type="checkbox"/> Laundry and other housework | <input type="checkbox"/> Remembering to take medicines |
| <input type="checkbox"/> Home maintenance | <input type="checkbox"/> Walking |
| <input type="checkbox"/> Paying bills and other money matters | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Bathing | <input type="checkbox"/> _____ |
| | <input type="checkbox"/> _____ |

Health Care Needs (as recommended by a doctor or other health care provider)

- | | |
|---|---|
| <input type="checkbox"/> Physical therapy | <input type="checkbox"/> Alzheimer's disease care |
| <input type="checkbox"/> Speech therapy | <input type="checkbox"/> Health monitoring (for diabetes, for example) |
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Pain management |
| <input type="checkbox"/> Rehabilitation | <input type="checkbox"/> Nursing care services |
| <input type="checkbox"/> Medical nutritional therapy | <input type="checkbox"/> Other medical services provided by a doctor or other clinician |
| <input type="checkbox"/> Oxygen | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Care for pressure ulcers or other wounds | |

	Home Care	Community Services	Supportive Housing Programs	Assisted Living	*CCRC	Nursing Homes
Help with daily activities	✓	✓	✓	✓	✓	✓
Help with health care needs	✓				✓	✓
Relative Costs	Low to High	Low to Medium	Low to Medium	Medium to High	High	High

*Continuing Care Retirement Communities

How will I pay for these services?

Long-term care can be very expensive. In general, health plans and programs do not routinely cover long-term care at home or in nursing homes. Here is some general information about long-term care coverage:

- **Medicare** is the Federal health insurance program for people age 65 and older and for some disabled younger people. Medicare generally does not pay for long-term help with daily activities. Medicare pays for very limited skilled nursing home care after a hospital stay. If you need skilled care in your home for the treatment of an illness or injury, and you meet certain conditions, Medicare will pay for some of the costs of nursing care, home health aide services, and different types of therapy.
- **Medicaid** is a Federal-State program that pays for health services and long-term care for low- income people of any age. The exact rules for who is covered vary by State. Medicaid covers nursing home care for people who are eligible. In some States, Medicaid also pays for some home and community services.
- **Private Insurance.** Medicare beneficiaries may supplement their policy with insurance purchased from private organizations. Most of these policies—often called Medigap insurance or by a similar name— will help pay for some skilled care, but only when that care is covered by Medicare. Medigap is not long-term care insurance.

Commercial insurers offer private policies called long-term care insurance. These policies may cover services such as care at home, in adult day care, in assisted living facilities, and in nursing homes. But plans vary widely. If you have such a policy, ask your insurer what it covers. If you think you may need long-term care insurance, start shopping while you are relatively young and healthy, and shop carefully.

- **Personal Resources.** You may need to use resources such as savings or life insurance to pay for long-term care. Most people who enter nursing homes begin by paying out of their own pockets. As their personal resources are spent, many people who stay in nursing homes for a long time eventually become eligible for Medicaid.

Choosing Long-Term Care

Your State Health Insurance Program (SHIP) can give you general information about Medicare, Medicaid, managed care plans, and the types of health insurance that can supplement Medicare, including Medigap and long-term care insurance. Counselors also can help you with questions about your medical bills, insurance claims, and related matters. These services are free. To find the phone number of the SHIP office in your State, call the Medicare Hotline at 1-800-633-4227. Or, look at the consumer Web site for MPedicare services, <http://www.medicare.gov>.

How can I choose the best quality services?

Here are some tips for choosing the kinds of long-term care people most often use: home care (including home health care) and nursing homes.

Home Care

- In many States, home care agencies must be licensed. Check with your State health department to see if your State requires it. If so, be wary if an agency is not licensed.
- Ask if the agency is certified by Medicare. Medicare inspects home health care agencies to assure they meet certain Federal health and safety requirements. Medicare will pay for services only if the agency is Medicare-approved and if the services are covered by Medicare.
- If the home health care agency is certified by Medicare, you can review its survey report. Call the Medicare Hotline at 1-800-633-4227 and ask to be referred to the Home Health Hotline for your State. You can request a copy of the report from that hotline.
- Find out if the agency has been accredited (awarded a “seal of approval”) by a group such as the Joint Commission on Accreditation of Healthcare Organizations (630-792-5800); <http://www.jcaho.org>) or the Community Health Accreditation Program (1-800-669-1656; <http://www.chapinc.org>).
- Contact your State or local consumer affairs office to see if any complaints have been filed against a home care agency. Also ask about the outcome of any complaint investigations.
- Whether you work with an agency or hire someone yourself, carefully check the backgrounds of the people who will be coming into your home. Ask for references who have worked with the agency or person. Call them, and ask about their experiences. Would they use the agency or person again?

- Does the home care worker have the necessary skills and training for your needs? Ask to see training certificates. Make sure the worker knows how to safely assist and care for patients.
- Does the agency have supervisors who check on the quality of care its workers provide?
- How does the agency follow up on and resolve complaints?

Nursing Home Care

- All nursing homes that participate in Medicare or Medicaid are visited about once a year by a team of trained inspectors. They check the home and the care provided and prepare a survey report. You have a right to review the report, which must be posted in the nursing home. Speak to the nursing home administrator to learn more about any problems that appear on the report. Ask if the problems have been corrected.
- Call your State or local Long-Term Care Ombudsman. Ombudsmen visit nursing homes on a regular basis and know about each nursing home in their area. You can ask about the latest survey report and about complaints that have been filed. You can also ask what to look for when visiting local nursing homes.
- Compare the inspection records of your top choices by visiting the “Nursing Home Compare” Web site:
<http://www.medicare.gov/nhcompare/home.asp>.
- Some nursing homes have been accredited by a national group such as the Joint Commission on Accreditation of Healthcare Organizations (630-792-5800). It may be helpful to find out if the home participates in this voluntary process and to learn the results.
- Location is very important. Is the nursing home close enough so that family and friends can visit? Close enough for the resident’s personal doctor to visit?
- The most important step is to visit—more than once—and look around. Go at different times of the day—for example, first thing in the morning and at mealtimes.
- Do residents seem to enjoy meals? Is there help for those who cannot eat on their own? If possible, eat a meal at the facility.
- Is the home clean and free of odors? Is it pleasant?

SOURCES OF ADDITIONAL INFORMATION

A Guide to Choosing a Nursing Home. Has sections on gathering information, visiting nursing homes, and residents' rights and quality of life. Includes phone lists for State ombudsmen, State survey agencies, and insurance counseling. 47 pages. Free. *Medicare: 1-800-633-4227*

Web site:

<http://medicare.gov/Publications/Search/View/ViewPubList.asp?Language=English>

Resource Directory for Older People.

The Administration on Aging and National Institute on Aging offers lists of hundreds of organizations, names, and phone numbers, including State agencies on aging and State long-term care ombudsmen programs. Not available in print. *Web site:*

<http://www.aoa.gov/default.htm>

American Association of Homes and Services for the Aging. Offers a series of pamphlets on nursing homes, assisted living, continuing care retirement communities, community services, housing options for older people, and understanding Medicare managed care. Free.

1-800-675-9253

Web site: <http://www.aahsa.org>

How to Choose a Home Care Provider.

Explains who provides what kind of care, the various services offered, who pays for services. Has billing and payment information. Lists patients' rights, accrediting agencies, and State resources and information. Free.

National Association for Home Care

202-547-7424

Web site: <http://www.nahc.org>

Myths and Realities of Living in a Nursing Home, How to Pay for Nursing Home Care, What Consumers Need to Know About Private Long-Term Care, and Circle of Care.

A series of six pamphlets on selecting and paying for long-term care. Free. For more than one copy: 1-800-663-7387 (packets of 25).

*The American Health Care Association
1201 L St., NW*

*Washington, DC 20005-4014
202-842-4444*

Web site: <http://www.ahca.org>

(Click on Consumer Information)

Nursing Home Life: A Guide for Residents and Families.

Includes first-hand accounts from residents and family members. Topics include adjusting to nursing home life; services and staff; getting what you need; and dealing with poor care. Has useful appendices and resource lists. 44 pages. Free.

*The American Association of Retired Persons
601 E. St., N.W.*

Washington, DC 20049

1-800-424-3410

Web site: <http://www.arp.org>

Choosing a Nursing Home and All About Home Health are available on-line from Health Pages. *Web sites:*

<http://www.thehealthpages.com/articles/ar-nrshm.html>

<http://www.thehealthpages.com/articles/ar-homeh.html>

Healthfinder—

<http://www.healthfinder.gov>—provides links to reliable health information from the Federal Government and its many partners.

Quick-Check for Quality ✓

Look for a plan that:

- Has been rated highly by its members on the things that are important to you.
- Does a good job of helping people stay well and get better.
- Is accredited, if that is important to you.
- Has the doctors and hospitals you want or need.
- Provides the benefits you need.
- Provides services where and when you need them.
- Meets your budget.

Quick-Check for Quality ✓

When choosing a treatment, make sure you understand:

- What your diagnosis is.
- Whether treatment is really needed at this time.
- What your treatment options are.
- Whether the treatment options are based on the latest scientific evidence.
- The benefits and risks of each treatment.
- The cost of each treatment.

Quick-Check for Quality ✓

Look for a hospital that:

- Is accredited by the Joint Commission on Accreditation of Healthcare Organizations.
- Is rated highly by State or consumer or other groups.
- Is one where your doctor has privileges, if that is important to you.
- Is covered by your health plan.
- Has experience with your condition.
- Has had success with your condition.
- Checks and works to improve its own quality of care.

Quick-Check for Quality ✓

Look for a doctor who:

- Is rated to give quality care.
- Has the training and background that meet your needs.
- Takes steps to prevent illness— for example, talks to you about quitting smoking.
- Has privileges at the hospital of your choice.
- Is part of your health plan, unless you can afford to pay extra.
- Encourages you to ask questions.
- Listens to you.
- Explains things clearly.
- Treats you with respect.

Quick-Check for Quality ✓

Look for long-term care that:

- Has been found by State agencies, accreditors, or others to provide quality care.
- Has the services you need.
- Has staff that meet your needs.
- Meets your budget.





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