

NOW YOU HAVE A DIAGNOSIS: WHAT'S NEXT?

USING HEALTH CARE
INFORMATION TO HELP MAKE
TREATMENT DECISIONS



Agency for Healthcare Research and Quality

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This booklet was created through a partnership between the Agency for Healthcare Research and Quality (AHRQ) and the Kanter Family Foundation.

In the future, you and your doctor or other health care provider may be able to tap into a nationwide database containing the results of treatments for thousands of individuals like yourself with the same condition. This database could help you make good decisions about the right treatments—based on the evidence of what works and doesn't work for people just like you in similar circumstances.

The Kanter Family Foundation and AHRQ are supporting the initial efforts underway to develop this national database. The goal of their partnership is to:

- **Improve health care decisionmaking by giving people information—including print and Internet resources—based on scientific research.**
- **Support the development of a national outcomes database that will be used by doctors and patients to determine which treatments work best for specific diseases and conditions.**
- **Encourage the standardization of health outcomes data throughout the health care system so that a national outcomes database can be developed and used.**

Good information is essential to good decisions

It may have taken you only a visit or two to your doctor or other health care provider to find out what's causing your health problem. It may have taken longer. But now you have a diagnosis. It's time to make some decisions about your treatment.

For many conditions, there is no one “right” treatment. You may have several options—each with its upsides and downsides. Some of your options may have been proven by health care research to be effective, while others may not. The quality of your health care can vary too, depending on your doctor or other health care provider, your health plan, your hospital, and where you live. So, how do you make sure that you make the right decision to get the best treatment?

Finding out more about your condition is a good place to start. This booklet will help you find places to look for information. By contacting groups that support your condition, visiting your local library, and searching on the Internet, you can find good information to help guide your treatment decisions. Some information may be hard to find—especially if you don't know where to look. This booklet has been created to point you in the right direction.

Finding reliable information

Where Can You Find Good Information?

Books, newspapers, magazines, television and radio programs, and the Internet offer access to a lot of health-related information. However, not all information is good information.

How do you start your search? And how do you figure out what's good information and what's not?

Contact a Group That Advocates for Your Condition

Groups such as the American Heart Association, the American Cancer Society, and the American Diabetes Association will probably have a local chapter in your community. These organizations can be a valuable source of information and support.

If you can't find organizations that advocate for your condition in the phone book, most libraries have directories that provide phone numbers and Internet addresses for their national headquarters.

The National Health Information Center (NHIC) offers a toll-free telephone referral service to help people get in touch with organizations and resources that can provide information about specific conditions and illnesses. You can talk to an information specialist by calling 800-336-4797.

Visit Your Local Library

At the library you can find:

- Medical textbooks and reference books.
- Consumer health books.
- Newspapers and magazines.
- Medical and health care journals.

You can ask reference librarians for help with your search. They may know about resources that would be unfamiliar to you.

Get on the Internet

Another way is to search for information on the Internet. If you don't have your own computer, many libraries provide access to the Internet through their computers. Ask your librarian if this is available to you and don't hesitate to ask for help if how to get "online" isn't clear.

Here are some ways to get good information on the Internet:

- **Start at a site that focuses on health.** There are many sites that focus on health information on the Internet. Some are commercial sites; others are sponsored by universities or the Federal Government. Using these sites to launch your search is an easy way to get going. The healthfinder[®] site (www.healthfinder.gov) is a good place to start.

- **Look for a name you can trust.** Besides Government-sponsored sites, many medical schools and university medical centers have consumer health education sites that contain a wide range of information. The information in these sites is most likely to be science-based and reputable.
- **Look at the latest and best studies.** You might find clues or pieces of information in articles from medical journals. Although these articles are written in medical language, sites that direct you to summaries of the articles can be helpful. A good place to begin is with the National Library of Medicine’s free online catalog of medical journal articles and article abstracts (www.nlm.nih.gov/medlineplus).
- **Exercise caution.** Genuine medical miracles are few and far between. Beware of any drug or treatment that makes “big” claims. Not all information is objective and honest. The Federal Trade Commission (FTC) offers this list of words and key phrases to look for. These could indicate phony, exaggerated, or unproven claims on Internet health sites. The list could also apply to any other source of information.
 - Phrases such as “scientific breakthrough,” “miraculous cure,” “exclusive product,” “secret formula,” and “ancient ingredient.”

- Use of “medicalese”—impressive terminology to disguise a lack of good science.
- Case histories from “cured” consumers claiming amazing results.
- A laundry list of symptoms the product cures or treats.
- The latest trendy ingredient making headlines.
- A claim that the product is available from only one source, for a limited time.
- Testimonials from “famous” medical experts.
- A claim that the Government, the medical profession, or research scientists have conspired to suppress the product.

Understanding different types of health care research

What Can Health Care Research Tell You?

Health care research plays a critical role in providing up-to-date information on what works and doesn't work in treating many different kinds of diseases and conditions. This information helps improve health care quality by making sure that:

- You receive the right treatment, at the right time, in the right way, and with the best possible results.
- You don't receive treatments that are unnecessary, cost too much, or may be harmful to your health.

You may hear about the results of health care research—perhaps even studies about your condition—on the news or read about them in a newspaper or magazine. That's because scientists are constantly involved in a variety of research projects supported by the Federal Government, charitable foundations, and other public- and private-sector groups.

Main Types of Research Studies

There are four main types of studies researchers conduct about health conditions:

- **Laboratory experiments.** These studies are done to find out the cause of a disease, or how a drug or treatment works. They are usually carried out on cells or tissue or in laboratory animals.

- **Clinical trials.** Clinical trials use different study methods to make sure the results they get are true and not due to outside influences. People are randomly assigned to different treatment groups—some get the research treatment, others get a standard treatment or may be given a “placebo” or no treatment. The groups are monitored, and results are compared to evaluate whether or not the treatment works.
- **Epidemiological research.** These studies look at the natural course of diseases in a particular group of people; relationships between people and their health habits, life styles, and environment; and the risk factors for certain diseases. For example, this kind of research has shown that people who smoke have a higher risk of developing lung cancer.
- **Outcomes research.** Outcomes research uses a wide variety of information about how well treatments actually work. Outcomes research can tell whether treatments work better for certain types of patients or in specific situations. Then, recommendations can be made about treatments based on whether they work or not, and which ones are most likely to give the best results with the fewest risks. This is known as “evidence-based medicine.” Sometimes these recommendations are gathered together in clinical practice guidelines. Doctors and other health care providers can use this kind of information to help you weigh the risks and benefits of your treatment options.

Making your decision

How Do You Make Your Decision?

Once you have found out as much as you can about your diagnosis—and perhaps sought out a second opinion—it's time to talk to your doctor about the information you've gathered. You might want to create a list of questions to ask. If you have trouble getting started, *Your Guide to Choosing Quality Health Care* (a free publication from AHRQ—see page 14 of this booklet) offers some sample questions to get you going.

Now is the time to start making decisions with your doctor about how to treat or manage your condition.

Check Out Your Options

Evidence-based medicine, in the form of clinical practice guidelines, can help you and your doctor or other health care provider decide what would be the best treatment for you. Selecting the best treatment is a decision that depends on the following:

- What research shows has worked or hasn't worked for your particular condition.
- How you feel about the different treatments.

The National Guideline Clearinghouse™, sponsored by the Agency for Healthcare Research and Quality, the American Medical Association, and the American Association of Health Plans Foundation, is an Internet resource that offers hundreds of evidence-based clinical practice

guidelines for treating the most common medical conditions. You can visit the site at:
www.guideline.gov

Look at the Benefits and Risks of Each Treatment

Every treatment has benefits and risks. There are trade-offs to be made—and they will depend on what you determine is best for you, both medically and psychologically. How do you decide which treatment is best for you? What matters is what matters most to you.

For example, if you're an older man with a prostate problem that makes it hard to urinate, there are a number of treatments a doctor or other health care provider can recommend. Surgery is one option; medicine is another.

Develop a Treatment Plan With Your Doctor or Other Health Care Provider

Once you and your doctor or other health care provider have decided on a treatment, you can work together to develop a treatment plan—one you know you can stick to. Studies show that people who take an active role in developing their treatment plan have a better chance of staying on course and feel more satisfied with their care.

One way to do this is to prepare a list of questions before your visit, and then write down the doctor's answers. Or you might consider bringing along a friend or family member to the doctor's office. That way, if you have difficulty remembering everything that your doctor or other health care provider tells you, you can refer to your notes or ask your companion. If you have information that you have found on the Internet, bring it with you and ask your doctor or other health care provider to discuss it.

Getting support

Why Should You Get Support?

Sometimes the emotional side of illness is just as hard to deal with as the physical side. You may have fears and concerns or feel overwhelmed by your situation. Everyone has different ways of dealing with these feelings. Your attitude about your condition, your expectations, and how well you cope with your condition can play a big part in the success of your treatment. Depending upon your situation, here are some resources you may want to consider to get support.

Ask Family and Friends for Help

In general, having close and supportive ties with friends and family seems to have a positive impact on health. The people you're closest to are the most likely to give you the support you need. Even so, you may have trouble asking for help.

If you do have trouble asking for help, think about specific ways in which people can help, and start by asking one person to assist you with the easiest thing on the list. You may be surprised at how willing people are to help.

Talk to a Counselor

A good counselor can help you cope with sadness, depression, and feelings of being overwhelmed. If you think counseling might be right for you, ask your doctor or other health care provider to recommend someone in your area.

Join a Support Group

Health care research has shown that support groups—groups of people with the same condition who get together on a regular basis to discuss their illness—often help people cope better with their condition.

For example, a study looking at breast cancer survivors revealed that the women who participated in a support group lived longer and had a better quality of life than similar women who did not participate in the group. The women in the support group learned coping skills and they shared their feelings with other women who were in the same situation.

If you are interested in a support group, ask your doctor or other health care provider about available groups for your condition. If there is a fee for your group, you might want to check with your health plan to see if the cost will be covered.

Churches, synagogues, and other houses of worship, as well as senior centers, might also have groups that could offer you the social support you need. Ask your friends or family members if they know of any.

Use Online Support Groups

Commercial Internet service providers offer forums and chat rooms for people with different illnesses and conditions. Other Internet sites may also offer similar types of online groups. These online self-help communities can help you connect with a network of people whose concerns are similar to yours. But be careful. Online support groups are places where people talk informally. All the treatments or discoveries you hear about may not be scientifically proven to be safe and effective. If you read about something interesting and new, check it out with your doctor or other health care provider. The more you know, the better you will be able to cope with your condition on a day-to-day basis.

Resources

Free Booklets

Your Guide to Choosing Quality Health Care is a 47-page workbook that describes what quality health care is and how to get it. This workbook leads the reader through the decisionmaking process for choosing a health plan, doctor, treatment, hospital, and long-term care: www.ahrq.gov/consumer/qntool.htm

Be Informed: Questions To Ask Your Doctor Before You Have Surgery is an easy-to-read pamphlet that outlines important questions for patients to ask their doctor when a surgical procedure has been recommended:

www.ahrq.gov/consumer/surgery.htm

Copies of both of these booklets are available by writing to the Agency for Healthcare Research and Quality at: AHRQ Publications Clearinghouse, P.O. Box 8547, Silver Spring, MD 20907; by calling toll-free 800-358-9295; or by visiting the AHRQ Web site: www.ahrq.gov

Telephone Referrals

The National Health Information Center (NHIC) offers a toll-free telephone referral service to help people get in touch with organizations and resources that can provide reliable information about specific conditions and illnesses. Information specialists are available to help you at 800-336-4797.

Internet Resources

[Health Care Quality](http://www.healthcarequality.gov) is an Internet site sponsored by the Federal Government's Quality Interagency

Coordination Task Force. This site explains what quality health care is, why it matters, and how you can get it. Go to: www.consumer.gov/qualityhealth

The healthfinder[®] Web site, sponsored by the U. S. Department of Health and Human Services, offers links to hundreds of sites on the Internet that contain reliable health care information. Go to: www.healthfinder.gov and click on “Choosing Quality Care” for more information about specific diseases and illnesses.

The National Guideline Clearinghouse[™] is an online resource for hundreds of clinical practice guidelines on common medical conditions and treatments. This site is sponsored by the Agency for Healthcare Research and Quality, American Medical Association, and American Association of Health Plans Foundation. Go to: www.guideline.gov

The National Institutes of Health offers online access to several databases of public and privately sponsored clinical trials being conducted in various locations within the United States. This is the place to start if you are looking for opportunities to participate in clinical trials. Go to: www.nih.gov/health/trials/index.htm

Virtual Treatments Can Be Real-World Deceptions, on the FTC Web site, offers a list of words and key phrases to be on the lookout for that could indicate phony, exaggerated, or unproven claims on Internet health sites. Go to: www.ftc.gov/bcp/online/pubs/alerts/mrclalrt.htm

The National Health Council offers a list of Internet links to patient-based groups and voluntary agencies for more than 40 different chronic diseases and/or disabilities. Go to: www.nhcouncil.org/members.htm



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