

Next Steps After Your Diagnosis:

Finding Information and Support



AHRQ
Agency for Healthcare
Research and Quality
Advancing Excellence
in Health Care

The mission of the Agency for Healthcare Research and Quality (AHRQ) is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. The Agency works to ensure that its research findings are put into practice—that is, that doctors and other clinicians use the scientific evidence to make health care the best it can be.

AHRQ also helps consumers to become better informed and participate as partners in their own health care—and get safer, higher quality care. See inside back cover for a list of AHRQ's consumer publications.

Take charge: Be an active health care consumer.

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Where to find more information

For easy access to the Web sites and links referenced in this document, refer to the on-line version at www.ahrq.gov/consumer/diaginfo.htm

This booklet includes selected organizations and other resources that provide information and support to people with a wide range of diseases and disorders. The listings are not intended to be comprehensive. Nor does inclusion of any particular resource, outside of those sponsored by the Federal Government, imply endorsement by AHRQ or the Department of Health and Human Services. AHRQ advises that no information from any resource in this booklet should take the place of medical advice from your doctor.

Introduction

Your doctor* gave you a diagnosis that could change your life. This booklet can help you take the next steps.

Every person is different, of course, and every person's disease or condition will affect them differently. But research shows that after getting a diagnosis, many people have some of the same reactions and needs.

About this Booklet

Next Steps After Your Diagnosis offers general advice for people with almost any disease or condition. And it has tips to help you learn more about your specific problem and how it can be treated.

The information in this booklet is presented in a simple way to help you scan the material and read only what you need right now. Organizations, publications, and other resources are included if you would like to know more. The on-line version www.ahrq.gov/consumer/diaginfo.htm has many additional resources and their Internet links.

Five Basic Steps

This booklet describes five basic steps to help you cope with your diagnosis, make decisions, and get on with your life.

Step 1: Take the time you need.

Do not rush important decisions about your health. In most cases, you will have time to carefully examine your options and decide what is best for you.

Step 2: Get the support you need.

Look for support from family and friends, people who are going through the same thing you are, and those who have "been there." They can help you cope with your situation and make informed decisions.

* Your medical care might come from a doctor, nurse, physician assistant, or another kind of clinician or health care practitioner. To keep it simple, in this booklet we use the term "doctor" to refer to any of these professionals with whom you might interact.

Step 3: Talk with your doctor.

Good communication with your doctor can help you feel more satisfied with the care you receive. Research shows it can even have a positive effect on things such as symptoms and pain. Getting a “second opinion” may help you feel more confident about your care.

Step 4: Seek out information.

When learning about your health problem and its treatment, look for information that is based on a careful review of the latest scientific findings published in medical journals.

Step 5: Decide on a treatment plan.

Work with your doctor to decide on a treatment plan that best meets your needs.

As you take each step, remember this: Research shows that patients who are more involved in their health care tend to get better results and be more satisfied.

Although most of the published research referred to in this publication focuses on cancer, it likely is relevant to people with other diseases and conditions as well.

Step 1:

Take the time you need.



*Take time to breathe.
Don't panic, and don't
feel pressured into making
a rush decision.*

Alexis, cancer survivor

A diagnosis can change your life in an instant.

Like so many other people in your situation, you might be feeling one or more of the following emotions after getting your diagnosis:

- Afraid
- Alone
- Angry
- Anxious
- Ashamed
- Confused
- Depressed
- Helpless
- In denial
- Numb
- Overwhelmed
- Panicky
- Powerless
- Relieved (that you finally know what's wrong)
- Sad
- Shocked
- Stressed

It is perfectly normal to have these feelings. It is also normal, and very common, to have trouble taking in and understanding information after you receive the news – especially if the diagnosis was a surprise. And it can be even harder to make decisions about treating or managing your disease or condition.

Take time to make your decisions.

No matter how the news of your diagnosis has affected you, do not rush into a decision. In most cases, you do not need to take action right away. Ask your doctor how much time you can safely take.

Taking the time you need to make decisions can help you:

- Feel less anxious and stressed.
- Avoid depression.
- Cope with your condition.
- Feel more in control of your situation.
- Play a key role in decisions about your treatment.

Step 2:

Get the support you need.



I was shocked when I was diagnosed with diabetes. The extra support I got from my friends and support group really helped me adjust to the new lifestyle I had to adopt.

Richard, person with diabetes

You do not have to go through it alone.

Sometimes the emotional side of illness can be just as hard to deal with as the physical side. You may have fears or concerns. You may feel overwhelmed. No matter what your situation, having other people to turn to will help you know you are not alone.

Here are the kinds of support you might want to seek:

■ Family and friends.

Talking to family and friends you feel close to can help you cope with your illness or condition. Just knowing that someone is there can be a comfort.

Sometimes it is hard to ask for help. And sometimes your family and friends want to help, but they do not want to intrude, or they do not know how to ask or what to offer. Think about specific ways people can help you. One idea is to ask someone to come with you to a doctor's appointment to help ask questions, take notes, and talk with you afterward.

If you do not have family or friends who can provide support, other people or groups can.

■ Support or self-help groups.

Support groups are made up of people with the same disease or condition who get together to share information and concerns and to help one another. Support groups may or may not be led by experts. Self-help groups are similar to support groups but usually are led by the participants. The names “support group” and “self-help group” sometimes are used to refer to either kind.

Research on support groups shows that participants feel less anxious, experience less depression, have a better quality of life, and have more success coping with their disease or condition. Similar findings have been reported for self-help groups.

■ On-line support or self-help groups.

The Internet has support or self-help groups for people whose concerns and situations may be similar to yours. You can also find “message boards,” where you can post questions and get answers. These on-line communities can help you connect with people who can give you support and provide information.

But be careful. Not every idea or treatment you come across in these groups will be scientifically proven to be safe and effective. If you read about something interesting and new, check it out with your doctor.

■ Counselor or therapist.

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

■ People like you.

You might want to meet and talk with someone in your own situation. Someone who has “been there” can talk about the real-life outcomes of their treatment choices as well as how they have learned to live with their disease or condition. Some advocacy or support groups can help you make this kind of contact.



If only I had known what it would be like to live with the after-effects of this type of surgery, I might have chosen a different kind.

Susan, who underwent surgery for a digestive disease

Help is available.

Take advantage of the support that is available to you. See “Where to Find More Information” on page 20 for specific places to find support. An expanded list appears in the on-line version of this booklet at www.ahrq.gov/consumer/diaginfo.htm.

Step 3:

Talk with your doctor.



I had trouble understanding what my doctor was telling me. The words were too technical, and there was too much to absorb. I finally asked her to slow down and keep it simple. That helped a lot.

Dana, person with heart disease

Your doctor is your partner in health care.

You probably have many questions about your disease or condition. The first person to ask is your doctor.

It is fine to seek more information from other sources; in fact, it is important to do so. But consider your doctor your partner in health care—someone who can discuss your situation with you, explain your options, and help you make decisions that are right for you.

It is not always easy to feel comfortable around doctors. But research has shown that good communication with your doctor can actually be good for your health. It can help you to:

- Feel more satisfied with the care you receive.
- Have better outcomes (end results), such as reduced pain and better recovery from symptoms.

Being an active member of your health care team also helps to reduce your chances of medical mistakes, and it helps you get high-quality care.

Of course, good communication is a two-way street. Here are some ways to help make the most of the time you spend with your doctor.

Prepare for your visit.

- Think about what you want to get out of your appointment. Write down all your questions and concerns. Some suggested questions are listed on page 12.
- Prepare and bring to your doctor visit a list of all the medicines you take.
- Consider bringing along a trusted relative or friend. This person can help ask questions, take notes, and help you remember and understand everything once you leave the doctor's office.

Give information to your doctor.

- Do not wait to be asked.
- Tell your doctor everything he or she needs to know about your health—even the things that might make you feel embarrassed or uncomfortable.
- Tell your doctor how you are feeling—both physically and emotionally.
- Tell your doctor if you are feeling depressed or overwhelmed.

Get information from your doctor.

- Ask questions about anything that concerns you. Keep asking until you understand the answers. If you do not, your doctor may think you understand everything that is said.
- Ask your doctor to draw pictures if that will help you understand something.
- Take notes.
- Tape record your doctor visit, if that will be helpful to you. But first ask your doctor if this is okay.
- Ask your doctor to recommend resources such as Web sites, booklets, or tapes with more information about your disease or condition.

Also see “Ten Important Questions to Ask Your Doctor After a Diagnosis,” on page 12.

Do not hesitate to seek a second opinion.

A second opinion is when another doctor examines your medical records and gives his or her views about your condition and how it should be treated. You might want a second opinion to:

- Be clear about what you have.
- Know all of your treatment choices.
- Have another doctor look at your choices with you.

It is not pushy or rude to want a second opinion. Most doctors will understand that you need more information before making important decisions about your health.

Check to see whether your health plan covers a second opinion. In some cases, health plans require second opinions.

Here are some ways to find a doctor for a second opinion:

- Ask your doctor. Request someone who does not work in the same office, because doctors who work together tend to share similar views.
- Contact your health plan or your local hospital, medical society, or medical school.
- Use the Doctor Finder on-line service of the American Medical Association at www.ama-assn.org.

Get information about next steps.

- Get the results of any tests or procedures. Discuss the meaning of these results with your doctor.
- Make sure you understand what will happen if you need surgery.
- Talk with your doctor about which hospital is best for your health care needs.

Finally, if you are not satisfied with your doctor, you can do two things: (1) talk with your doctor and try to work things out, and/or (2) switch doctors, if you are able to. It is very important to feel confident about your care.

To learn more, see “Where to Find More Information” on page 20. The on-line version of this booklet includes additional resources.

Ten Important Questions to Ask Your Doctor After a Diagnosis

These 10 basic questions can help you understand your disease or condition, how it might be treated, and what you need to know and do before making treatment decisions.

1. What is the technical name of my disease or condition, and what does it mean in plain English?

2. What is my prognosis (outlook for the future)?

3. How soon do I need to make a decision about treatment?

4. Will I need any additional tests, and if so what kind and when?

5. What are my treatment options?

6. What are the pros and cons of my treatment options?

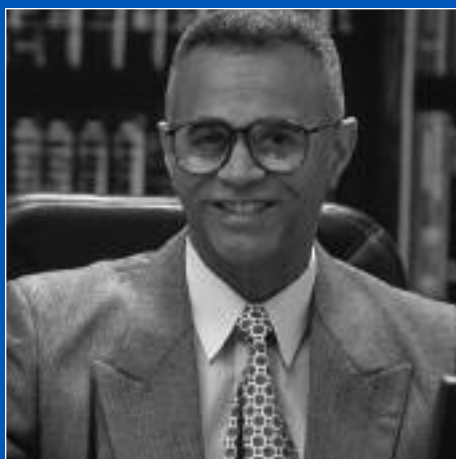
7. Is there a clinical trial (research study) that is right for me?
(See page 13.)

8. Now that I have this diagnosis, what changes will I need to make in my daily life?

9. What organizations do you recommend for support and information?

10. What resources (booklets, Web sites, audiotapes, videos, DVDs, etc.) do you recommend for further information?

Step 4: Seek out information.



I'm really glad I took the time to research my options. It stopped me from jumping into a treatment that would have been completely wrong for me.

Seth, prostate cancer survivor

Now that you know your treatment options, you can learn which ones are backed up by the best scientific evidence. “Evidence-based” information—that is, information that is based on a careful review of the latest scientific findings in medical journals—can help you make decisions about the best possible treatments for you.

Evidence-based information comes from research on people like you.

Evidence-based information about treatments generally comes from two major types of scientific studies:

- **Clinical trials** are research studies on human volunteers to test new drugs or other treatments. Participants are randomly assigned to different treatment groups. Some get the research treatment, and others get a standard treatment or may be given a placebo (a medicine that has no effect), or no treatment. The results are compared to learn whether the new treatment is safe and effective.
- **Outcomes research** looks at the impact of treatments and other health care on health outcomes (end results) for patients and populations. End results include effects that people care about, such as changes in their quality of life.

Take advantage of the evidence-based information that is available.

Health information is everywhere—in books, newspapers, and magazines, and on the Internet, television, and radio. However, not all information is good information. Your best bets for sources of evidence-based information include the Federal Government, national nonprofit organizations, medical specialty groups, medical schools, and university medical centers.

Some resources are listed below, grouped by type of information. See “Where to Find More Information” on page 20 for additional ideas. The on-line version of *Next Steps After Your Diagnosis* lists many more, and includes links to Internet sites.

Information.

Information about your disease or condition and its treatment is available from many sources. Here are some of the most reliable:

- **healthfinder®:** www.healthfinder.gov/organizations/OrgListing.asp
The healthfinder® site—sponsored by the U.S. Department of Health and Human Services—offers carefully selected health information Web sites from government agencies, clearinghouses, nonprofit groups, and universities.
- **Health Information Resource Database:**
www.health.gov/nhic/#Referrals
Sponsored by the National Health Information Center, this database includes 1,400 organizations and government offices that provide health information upon request. Information is also available over the telephone at 800-336-4797.
- **MEDLINEplus®:** www.nlm.nih.gov/medlineplus
MedlinePlus® has extensive information from the National Institutes of Health and other trusted sources on over 650 diseases and conditions. The site includes many additional features.
- **National nonprofit groups** such as the American Heart Association, American Cancer Society, and American Diabetes Association can be valuable sources of reliable information. Many have chapters nationwide. Check your phone book for a local chapter in your community. The Health Information Resource Database (www.health.gov/nhic/#Referrals) can help you find national offices of nonprofit groups.

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- **Health or medical libraries** run by government, hospitals, professional groups, and other reliable organizations often welcome consumers. For a list of libraries in your area, go to the MedlinePlus® “Find a Library” page at <http://www.nlm.nih.gov/medlineplus/libraries.html>.

■ Current medical research.

You can find the latest medical research in medical journals at your local health or medical library, and in some cases, on the Internet. Here are two major online sources of medical articles:

- **MEDLINE/PubMed®:** <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>
PubMed® is the National Library of Medicine's database of references to more than 14 million articles published in 4,800 medical and scientific journals. All of the listings have information to help you find the articles at a health or medical library. Many listings also have short summaries of the article (abstracts), and some have links to the full article. The article might be free, or it might require a fee charged by the publisher.
- **PubMed Central:** <http://www.pubmedcentral.nih.gov/>
PubMed Central is the National Library of Medicine's database of journal articles that are available free of charge to users.

■ Clinical trials.

Perhaps you wonder whether there is a clinical trial that is right for you. Or you may want to learn about results from previous clinical trials that might be relevant to your situation. Here are two reliable resources:

- **ClinicalTrials.gov:** <http://clinicaltrials.gov/ct/g>
ClinicalTrials.gov provides regularly updated information about federally and privately supported clinical research on people who volunteer to participate. The site has information about a trial's purpose, who may participate, locations, and phone numbers for more details. The site also describes the clinical trial process and includes news about recent clinical trial results.
- **Cochrane Collaboration:** www.cochrane.org
The Cochrane Collaboration writes summaries (“reviews”) about evidence from clinical trials to help people make informed decisions. You can search and read the review abstracts free of charge at <http://www.cochrane.org/>

reviews/index.htm. Or you can read plain-English consumer summaries of the reviews at www.informedhealthonline.org.

The full Cochrane reviews are available only by subscription. Check with your local medical or health library (see page 22) [link back to library section in on-line version] to see whether you can access the full reviews there.

Outcomes research.

Outcomes research provides research about benefits, risks, and outcomes (end results) of treatments so that patients and their doctors can make better informed decisions. The U.S. Agency for Healthcare Research and Quality (AHRQ) supports improvements in health outcomes through research, and sponsors products that result from research such as:

- **National Guideline Clearinghouse™:** www.guideline.gov
The National Guideline Clearinghouse™ is a database of evidence-based clinical practice guidelines and related documents. Clinical practice guidelines are documents designed to help doctors and patients make decisions about appropriate health care for specific diseases or conditions. The clearinghouse was originally created by AHRQ in partnership with the American Medical Association and America's Health Insurance Plans.

Steer clear of deceptive ads and information.

While searching for information either on or off the Internet, beware of “miracle” treatments and cures. They can cost you money and your health, especially if you delay or refuse proper treatment. Here are some tip-offs that a product truly is too good to be true:

- Phrases such as “scientific breakthrough,” “miraculous cure,” “exclusive product,” “secret formula,” or “ancient ingredient.”
- Claims that the product treats a wide range of ailments.
- Use of impressive-sounding medical terms. These often cover up a lack of good science behind the product.
- Case histories from consumers claiming “amazing” results.
- Claims that the product is available from only one source, and for a limited time only.

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- Claims of a “money-back guarantee.”
 - Claims that others are trying to keep the product off the market.
 - Ads that fail to list the company’s name, address, or other contact information.

To learn more about finding evidence-based information, see “Where to Find More Information,” page 20. The on-line edition of this booklet has many additional resources.

Step 5:

Decide on a treatment plan.



My doctor told me I had done one of the hardest but most important things a patient has to do: Face up to the diagnosis and make decisions. It feels good to be where I am now.

Bob, person with a neurological disorder

At this point, you have learned about your disease or condition and how it can be treated or managed. Your information may have come from the following sources:

- Your doctor.
- Second opinions from one or more other doctors.
- Other people who are or were in the same situation as you.
- Information sources such as Web sites, health or medical libraries, and nonprofit groups.

Work with your doctor to make decisions.

When you are ready to make treatment decisions, you and your doctor can discuss:

- Which treatments have been found to work well, or not work well, for your particular condition.
- The pros and cons of each treatment option.

Make sure that your doctor knows your preferences and feelings about the different treatments – for example, whether you prefer medicine over surgery.

Once you and your doctor decide on one or more treatments that are right for you, you can work together to develop a treatment plan. This plan will include everything that will be done to treat or manage your disease or condition—including what you need to do to make the plan work.

Remember, being an active member of your health care team helps to reduce your chances of medical mistakes, and it helps you get high-quality care.

Take another deep breath.

You have taken important steps to cope with your diagnosis, make decisions, and get on with your life. Remember two things:

- Call on others for support as you need it.
- Make use of evidence-based information for any future health decisions.

Where to Find More Information

Get the support you need.

American Self-Help Group Clearinghouse

<http://mentalhelp.net/selfhelp/>

National Board for Certified Counselors (NBCC)

3 Terrace Way, Suite D

Greensboro, NC 27403-3660

336-547-0607.

www.nbcc.org

National Institute of Mental Health

Public Information and Communications Branch

6001 Executive Boulevard, Room 8184, MSC 9663

Bethesda, MD 20892-9663

Phone: 866-615-6464 (toll-free)

TTY: 301-443-8431

<http://www.nimh.nih.gov/HealthInformation/GettingHelp.cfm>

Talk to your doctor.

Be an Active Member of Your Health Care Team. Food and Drug Administration. 2004. http://www.fda.gov/cder/consumerinfo/active_member.htm. Phone: 888-INFO-FDA (888-463-6332).

Be Informed: Questions to Ask Your Doctor Before You Have Surgery. Agency for Healthcare Quality and Research. 1995. <http://www.ahrq.gov/consumer/surgery.htm>. Phone: 800-358-9295.

Five Steps to Safer Health Care. Agency for Healthcare Research and Quality. 2003. <http://www.ahrq.gov/consumer/5steps.htm>. Phone: 800-358-9295.

Getting a Second Opinion Before Surgery. Centers for Medicare & Medicaid Services. 2004. www.medicare.gov/Publications/Pubs/pdf/02173.pdf. Phone: 800-MEDICARE (800-633-4227).

How to Get a Second Opinion. National Women's Health Information Center. 2003. <http://www.4woman.gov/pub/secondopinion.htm>. Phone: 1-800-994-WOMAN.

Quick Tips – When Planning for Surgery. Agency for Healthcare Research and Quality. 2002. <http://www.ahrq.gov/consumer/quicktips/tipsurgery.htm>. Phone: 800-358-9295.

Quick Tips – When Talking with Your Doctor. Agency for Healthcare Research and Quality. 2002. <http://www.ahrq.gov/consumer/quicktips/doctalk.htm>. Phone: 800-358-9295.

Talking with Your Doctor: A Guide for Older People. National Institute on Aging. 2002. www.niapublications.org/pubs/talking/index.asp. Phone: 800-222-2225. |

Seek out information.

2005 Toll-Free Numbers for Health Information. National Health Information Center. www.health.gov/nhic/pubs/tollfree.htm. Phone: 800-336-4797.

AARP Health Guide. AARP. 2004. www.aarp.org/health/healthguide. Phone: 888-OUR-AARP (888-687-2277).

HON Code of Conduct (HONcode) for Medical and Health Web Sites Health on the Net Foundation. <http://www.hon.ch/HONcode/>

How to Evaluate Health Information on the Internet: Questions and Answers. National Cancer Institute. 2003. http://cis.nci.nih.gov/fact/2_10.htm. Phone: 800-4-CANCER (800-422-6237).

How to Find Medical Information. National Institute of Arthritis and Musculoskeletal and Skin Diseases. 2001. <http://www.niams.nih.gov/hi/topics/howto/howto.htm>. Phone: 877-22-NIAMS (877-226-4267) (toll-free).

JAMA Patient Page: Health Information on the Internet. The Medem Network. http://www.medem.com/medlb/article_detailb.cfm?article_ID=ZZZLJLLTMC&sub_cat=603

National Guideline Clearinghouse™. Agency for Healthcare Research and Quality. <http://www.guideline.gov/>

NOAH: New York Online Access to Health. <http://www.noah-health.org/>

A User's Guide to Finding and Evaluating Health Information on the Web. Medical Library Association. 2003. <http://www.mlanet.org/resources/userguide.html#1>

Virtual Treatments Can Be Real-World Deceptions. Federal Trade Commission. 2001. <http://www.ftc.gov/bcp/online/pubs/alerts/mrclart.htm>

Your Guide to Choosing Quality Health Care. Agency for Healthcare Research and Quality. 2002. <http://www.ahrq.gov/consumer/qntool.htm>. Phone: 800-358-9295.

AHRQ consumer publications:

20 Tips to Help Prevent Medical Errors—Practical tips and questions to ask. (AHRQ 00-P038)

20 Tips to Help Prevent Medical Errors in Children (AHRQ 02-P034)

Five Steps to Safer Health Care—Shorter version of 20 Tips. (AHRQ 03-M007)

Ways You Can Help Your Family Prevent Medical Errors!—Easy-to-read version, with drawings. (AHRQ 01-0017)

Your Guide to Choosing Quality Health Care—Based on research about the information people want and need when choosing health plans, doctors, treatments, hospitals, and long-term care. (AHRQ 99-012)

Improving Health Care Quality: A Guide for Patients and Their Families—Short version of *Your Guide to Choosing Quality Health Care*. (AHRQ 01-0004)

Quick Checks for Quality—Checklist to use when choosing health plans, doctors, treatments, hospitals, and long-term care. (AHRQ 99-R027)

Quick Tips:

When Getting Medical Tests (AHRQ 01-0040b)

When Getting a Prescription (AHRQ 01-0040c)

When Planning for Surgery (AHRQ 01-0040d)

When Talking with Your Doctor (AHRQ 01-0040a)

To order AHRQ publications:

For electronic copies of these publications, go to the AHRQ Web site at www.ahrq.gov/consumer

For print copies, contact the AHRQ Publications Clearinghouse at 800-358-9295.

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