

Next Steps After Your Diagnosis:

# Finding Information and Support



.....  
health care quality

## Introduction

Your health care provider 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 online version [www.ahrq.gov](http://www.ahrq.gov) has many additional resources and their Internet links.



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## **Five Basic Steps**

This booklet describes 5 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.

### **Step 3: Talk with your health care provider**

Good communication with your health care provider 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 health care provider 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.



# Step 1: Take the time you need

## A diagnosis can change your life in an instant

Like so many other people in your situation, you might be upset after getting your diagnosis. You might feel:

- 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 feel any of these. 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 breathe.  
Don't panic, and don't  
feel pressured into making  
a rush decision.**

*Alexis, cancer survivor*



### **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 health care provider 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

### **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.

### **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.**

**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*



### **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 participants. The terms “support group” and “self-help group” are sometimes 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.

## **Online 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 where you can post questions and get answers. These online 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 online will be scientifically proven to be safe and effective. If you read about something interesting and new, check it out with your health care provider.

## **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 health care provider 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.



## Step 3: Talk with your health care provider

### **Your health care provider is your partner in health care**


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

It is fine to seek more information from other sources; in fact, it is important to do so. But consider your health care provider 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 health care providers. But research has shown that good communication with your health care provider 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 2-way street. Here are some ways to help make the most of the time you spend with your health care provider.

### **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 pages 15-16.
- Prepare and bring 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 office.

### **Give information to your health care provider**

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

I had trouble understanding what my health care provider was telling me. The words were too technical. I finally asked her to slow down and keep it simple.

*Dana, person with heart disease*



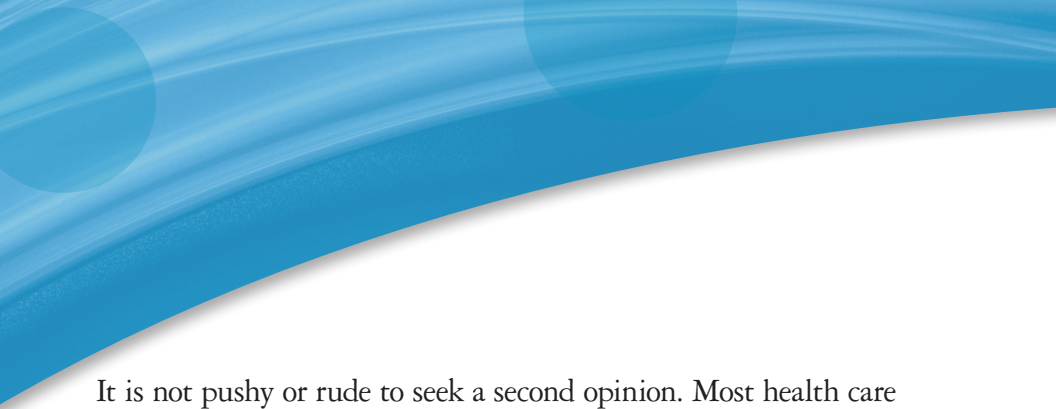
### **Get information from your health care provider**

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

### **Do not hesitate to seek a second opinion**

A second opinion is when another health care provider 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 health care provider look at your choices with you.



It is not pushy or rude to seek a second opinion. Most health care providers 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. Some health plans require second opinions in certain types of cases.

Here are some ways to find a health care provider for a second opinion:

- Ask your health care provider. Request someone who does not work in the same office, because health care providers 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 at [www.ama-assn.org](http://www.ama-assn.org), an online service of the American Medical Association.

### **Get information about next steps**

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

Finally, if you are not satisfied with your health care provider, you can either try to work things out or switch doctors. It is very important that *you* feel confident about your care.

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.

## Ten Important Questions to Ask After a Diagnosis

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

**What is my prognosis (outlook for the future)?**

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

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

**What are my treatment options?**

**What are the pros and cons of my treatment options?**

**Is there a clinical trial (research study) that might be right for me?**

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

**What organizations do you recommend for support and information?**

**What resources (booklets, Web sites, audiotapes, videos, DVDs, etc) do you recommend for further 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*



## **Step 4:** Seek information

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 about treatments generally comes from 2 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**

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 26 for additional ideas.

## 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/findservices](http://www.healthfinder.gov/findservices)  
The healthfinder® site—sponsored by the US 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](http://www.health.gov/nhic/#Referrals) Sponsored by the National Health Information Center, this database includes 1400 organizations and government offices that provide health information upon request.
- **MEDLINEplus®:** [www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus)  
MedlinePlus® has extensive information from the National Institutes of Health and other trusted sources on over 800 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.

- **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 [www.nlm.nih.gov/medlineplus/libraries.html](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 2 major online sources of medical articles:

- **MEDLINE/PubMed®:** [www.ncbi.nlm.nih.gov/entrez/query.fcgi](http://www.ncbi.nlm.nih.gov/entrez/query.fcgi) PubMed® is the National Library of Medicine’s database of references to more than 18 million articles published in 5516 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:** [www.pubmedcentral.nih.gov](http://www.pubmedcentral.nih.gov) PubMed Central is the National Library of Medicine’s database of journal articles that are available free of charge.

## 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 2 reliable resources:

- **ClinicalTrials.gov:** [clinicaltrials.gov/ct2/](https://clinicaltrials.gov/ct2/)

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](https://www.cochrane.org)

The Cochrane Collaboration writes summaries (reviews) about evidence from clinical trials to help people make informed decisions. You can also read plain-English consumer summaries of the reviews at [www.informedhealthonline.org](https://www.informedhealthonline.org).

The full Cochrane reviews are available only by subscription. Check with your local medical or health library 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 health care providers can make better informed decisions. The US 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](http://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 health care providers 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 they cause you to postpone or decline proper treatment. Here are some tips to spot deceptions:

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

To learn more about finding evidence-based information, see “Where to Find More Information,” page 26. The online edition of this booklet has many additional resources.

**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*



## **Step 5: Decide on a treatment plan**

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 health care provider
- Second opinions from one or more other health care providers
- Other people who are or were in the same situation as yours now
- Information sources such as Web sites, health or medical libraries, and nonprofit groups

## Work with your health care provider to make decisions

When you are ready to make treatment decisions, you and your health care provider 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 health care provider knows your preferences and feelings about the different treatments—for example, whether you prefer medicine over surgery.

Once you and your health care provider 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 help 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 2 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

[www.mentalhelp.net/selfhelp](http://www.mentalhelp.net/selfhelp)

National Board for Certified Counselors (NBCC)

3 Terrace Way

Greensboro, NC 27403-3660

[www.nbcc.org](http://www.nbcc.org)

National Institute of Mental Health

Science Writing, Press, and Dissemination Branch

6001 Executive Boulevard, Room 6200, MSC 9663

Bethesda, MD 20892-9663

[www.nimh.nih.gov/index.shtml](http://www.nimh.nih.gov/index.shtml)

### Talk to your health care provider

Be an Active Member of Your Health Care Team. Food and Drug Administration. 2012. [www.fda.gov/Drugs/ResourcesForYou/ucm079480.htm](http://www.fda.gov/Drugs/ResourcesForYou/ucm079480.htm)

Having Surgery? What You Need To Know. Questions to Ask Your Doctor and Your Surgeon. 2005. [www.ahrq.gov/consumer/surgery/surgery.htm](http://www.ahrq.gov/consumer/surgery/surgery.htm)

Getting a Second Opinion Before Surgery. Centers for Medicare & Medicaid Services. 2010. [www.medicare.gov/Publications/Pubs/pdf/02173.pdf](http://www.medicare.gov/Publications/Pubs/pdf/02173.pdf)

Talking With Your Doctor: A Guide for Older People. National Institute on Aging. 2010. [www.niapublications.org/pubs/talking/index.asp](http://www.niapublications.org/pubs/talking/index.asp)

## Seek out information

AARP Health Guide. AARP. [healthtools.aarp.org/health-encyclopedia](http://healthtools.aarp.org/health-encyclopedia)

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

Evaluating Health Information on the Internet: National Cancer Institute. 2011. [www.cancer.gov/cancertopics/cancerlibrary/health-info-online](http://www.cancer.gov/cancertopics/cancerlibrary/health-info-online)

National Guideline Clearinghouse. Agency for Healthcare Research and Quality. [www.guideline.gov](http://www.guideline.gov)

A User's Guide to Finding and Evaluating Health Information on the Web. Medical Library Association. 2013. [www.mlanet.org/resources/userguide.html#1](http://www.mlanet.org/resources/userguide.html#1)



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.

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 health care provider.

**sanofi aventis**



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