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## HEF481 Maintaining A Treasure Chest: Your Health Record (Participant Manual)

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# Maintaining A Treasure Chest: Your Health Record



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- [Why Know about Your Health Record?](#)
- [What Is in a Medical Record?](#)
- [Who Reads My Medical Record?](#)
- [How Do I Protect My Privacy?](#)
- [How Do I Get My Medical Records?](#)
- [How Do I Keep My Medical Records Current?](#)
- [What about Health Expense Records?](#)
- [What's Lurking in Your Family Health Tree?](#)
- [What about My Extended Family?](#)
- [What about the Records for Adopted Persons?](#)
- [Where Do I Get Information to Build "The Tree"?](#)
- [What Details Are Useful?](#)
- [What's the Bottom Line?](#)
- [Health Record Dilemma: Genetic Testing](#)
- [References](#)

Also see the companion  
publication,  
Leader Guide HE Form 482,  
*Maintaining A Treasure Chest:*  
*Your Health Record*

The health care system in the United States is changing in ways that require consumers to take more responsibility for their health. The preventive philosophy of health care demands that we move from passive recipients to active consumers of health care. A very important part of health care is maintaining accurate medical records for yourself and members of your family.

You may say, "My physician keeps that record." Have you ever seen a copy of that file? Do you have just one health care provider responsible for your care? Does your medical provider pay your bills? How private is your record? Is your record easily accessible for emergencies? The answers to these questions should underscore the importance of maintaining your own record.

When treatment *is* required in today's changing health care climate, knowing your rights and having an accurate medical record can help you secure more efficient and effective care with less confusion or duplication of services.

Several studies have found that lifestyle choices affect our health history. However, we also are learning that a predisposition to some health concerns may be a part of our family heritage. Knowing about your family's medical "pedigree" not only can have lifesaving implications for *you*, but it may turn out to be one of the most important legacies you leave your children! By identifying potential health concerns, you and your family can adopt healthy lifestyle behaviors to reduce your risks. You also can work with your health care provider to use screening techniques that detect and treat illnesses early. New medications and procedures then can be used to delay the onset or progression of potentially life threatening diseases.

In this lesson you will learn how to:

- understand your rights to information as a health care consumer;
- keep track of health care expenses and reimbursements;
- obtain information about your family's health history; and
- preserve your family's medical information for use in the future.

## **Why Know about Your Health Record?**

Health care is a shared responsibility between you and your health care provider. In order to receive the best possible care, you must be able to communicate your past medical experiences with each of your providers. With our complex lives, today's mobile society, and the movement to managed care, you are the best one to manage your health information. Experts offer even more reasons to be familiar with your medical records. Among them:

- To be a more informed participant in your own health care. Knowing as much as possible about your condition can help you make a better decision for a proposed treatment that requires informed consent.
- To preserve records that may be routinely destroyed after a period of time, lost when a physician's office is closed, or shared among health care providers.
- To correct errors in the record. Is your name similar to someone else's so records could be confused easily? Do you have different providers for your health care?
- To keep from overpaying or double-paying medical bills as well as staying on top of insurance payments or transactions.

## **What Is in a Medical Record?**

You may be surprised to know that your medical record includes more than information about your physical health. The most intimate aspects of your life may be recorded in your health file. It may contain records and remarks about your history of disease and treatments, sexual practices, character and mental state.

## **Who Reads My Medical Record?**

It used to be that no one saw or had a reason to see your medical record other than your physician. As

the U.S. health-care system has become more complex, many groups have staked a claim to the information in your medical file. Here are just a few:

- Health insurance companies
- Government benefit programs
- Medical researchers
- Employers

Medical information is valuable. There are no uniform legal constraints on the uses of medical records except for those placed on researchers. At this writing, no federal law protects the confidentiality of medical records, although Congress and the Nebraska Legislature are exploring related issues. (**Note:** The federal regulations related to the 1998 changes in Medicare, however, **do require** medical plans to protect the confidentiality of Medicare patient records AND *not* sell their members' names and addresses for any purpose.)

Records in physicians' offices and hospitals have never been totally secure. With computer networks, protecting records has become more difficult. Your physician's records may be in a computer file that is accessible to people outside the office. The Physician Computer Network has access to the patient records of 41,000 physicians, about one of every 10 office-based physicians in the U.S. With health care reform and the continuing computerization of medical records, confidentiality is becoming an even greater concern.

## **How Do I Protect My Privacy?**

Since no laws exist to protect medical record privacy, it is up to you. This applies to medical records that exist at your physician's office, hospital, employer, insurer, or free clinic (includes wherever health screenings are offered). Even transactions involving the purchase of medical products from commercial concerns need to be handled cautiously. For more information, refer to the [NebGuide G98-1368, \*Medical Record Privacy\*](#).

## **How Do I Get Medical Records?**

Procedures vary from state to state and from one institution to another. Nebraska law says that the record itself belongs to your provider. You may ask to review the information; however, you may be asked to pay a fee to receive a copy.

Make your request for records at the medical records department of your provider in person or in writing. If your request is denied, ask for an explanation in writing.

Sometimes asking for specific parts of your medical records is easier. Instead of asking for a copy of the entire record, you might want to request one of the following:

- Most recent history or physical
- Medication record
- Allergies list, including allergies to prescriptions
- Immunization record
- Lab or X-ray reports
- Problems list, including illnesses or surgeries.

A national source that may or may not have a copy of your medical records is the Medical Information

Bureau. To see if the bureau has a report on you and to get a copy, write to:

Medical Information Bureau  
P.O. Box 105, Essex Station  
Boston, MA 02112  
Phone: (617) 426-3660

Reports are free if you have been rejected or "rated" as a result of your report. Otherwise the fee is \$8 (as of this writing).

It's likely you will not understand everything in your records since many reports are written in a kind of medical shorthand. This is one reason physicians and hospitals are cautious about sharing records. Make a note of information you do not understand, and on your next visit to the doctor take your notes and ask questions to clarify the information.

Keep in mind that you are not a physician. The American Medical Association recommends against anyone trying to make a self-diagnosis and attempting self-treatment after looking at their medical records.

### **How Do I Keep Medical Records Current?**

If a medical record requires a correction, bring the proper information to your physician's attention. Find out if the record has been sent elsewhere and make sure a correction is sent to each location. Your physician will need to verify any changes in your medical information.

If a record needs to be transferred, you may need to sign a "release of medical records form." Prompt transfer of a medical record is important because your record helps your new doctor understand your medical history. You may be able to avoid repeating tests that you have already had.

Keep track of your records on an ongoing basis. Don't wait until you're sick.
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### **What about Health Expense Records?**

Another important part of your health record "treasure chest" is your record-keeping system for tracking health expenses and reimbursements. *Activity 1* (in the Leader Guide, HEF 482) is a sample medical expense record chart, including a sample entry. Adapt your form to you and your situation. Use the example only as a guide. Use a separate entry form for each *person* in your household AND for each *episode* of care.

Any medical condition or expense encountered by you or a family member must be recorded on a similar form. Be sure to record special and unique information that may prove vital at a later time, such as date and time of telephone conversations with providers or your insurance company; name of person (s) with whom you spoke; answers to questions you have about charges and other issues. Timely records on a similar form will enable you to chart the flow of medical billing and insurance claims. Keep those forms in an easily accessible place like an accordion file folder that is organized alphabetically or by date and stored in a file or desk drawer.

Financial or medical expenses are a very important part of your health care record. By keeping track, charting the ebb and flow of procedures, appointments, insurance payments and all other matters related to your health care, you have further documentation of your health care record.

## **What's Lurking in Your Family Health Tree?**

Some research shows that family medical patterns may influence physical and mental health. You can obtain health history information from a variety of sources. Examples of general health histories include the information requested of new patients in physicians' offices.

In order to safeguard your present health and the health of future generations, it is important to take one additional step. Begin *now* to keep medical records up-to-date for yourself and the family members for whom you care. Compile a general health history, including information about lifestyle behaviors. (See *Activity 2*, in the Leader Guide, HEF 482.) Put copies of the following information with each person's health history form:

- Vaccination records
- Records of illnesses
- Results of physical examinations
- Results of medical tests
- Records of hospitalizations and surgeries, including information about hospital admission and discharge
- Dental records

Record a physical description of each family member. Then, include information about lifestyle behaviors. This information can help your physician sort truly genetic conditions from those that have developed due to personal habits. For instance, the risk of heart attack would be greater in a person who has a history of obesity; certain cancers might be expected in lifelong smokers or heavy drinkers.

Record as much information as you can get about health: illnesses experienced, age at first occurrence, treatment, progression of the disease, surgeries, etc. In the case of cancer, find out where the cancer started. Many times cancers metastasize to other areas of the body, but the origin is the most important factor to record.

A complete child-bearing history, including miscarriages, still births, birth defects, mental retardation, etc., should be obtained as part of a complete health history. For future reference, also note physicians and/or hospitals that provided treatment.

The information you gather not only will help assure a high, consistent quality of care for you now, but it also will have an impact on generations to come. Some authorities suggest attaching a photograph to each health history form since photographs can reveal interesting or prevalent familial traits that are not evident on the health history forms.

You may want to have two copies for each person in your family; one for active use and one for historical purposes. Both should be kept up-to-date for family members' future use. As you change or are referred to new providers, furnish a copy of your personal record for the provider's information.

Safeguard the historical document by keeping your health care records in a safe, secure place — just as you would care for any of your important legal documents. You may even want to keep the historical document in a location away from your home such as your safe deposit box.

## What about My Extended Family?

To gather information about your medical family tree, it is most important to obtain health information about "first-degree" relatives, those most closely related to you (your parents, your brothers and sisters, and your children). You also should gather information through four generations of extended family — your grandparents, aunts and uncles, nieces and nephews, and even cousins. Information about these relatives will have a less direct impact on your health risks; however, finding out about their health can give you a more complete picture of patterns of disease that might be present in your genetic background.

You will want to complete a health history form for each relative and attach supporting information such as death certificates. An easy way to get a picture of your family's health at a glance is to develop a pedigree chart and mark it using a code to represent the different illnesses that have occurred.

Developing a pedigree chart may seem confusing at first. It may take you several tries to arrange all of your relatives so that they fit on the paper! If you use these simple rules, your chart will be easily understood by your physician or genetics specialist. (See Pedigree Chart, *Activity 3* (in the Leader Guide, HEF 482.)

Determining a genetic link to a certain illness undoubtedly will take more extensive investigation by certified genetic counselors. The information gathered in your search can give your physician important insight into what special medical concerns may exist. Together you can plan a personalized health care strategy to reduce your risks and improve the quality of your life.

### What about the Records of Adopted Persons?

Creating a health history is a difficult and almost impossible task for adopted persons. The process is very much like searching for birth parents. The International Soundex Reunion Register (ISRR) has a medical alert and genetic outreach program that allows birth parents to provide updated health information if they choose to do so. The address is: ISRR, P.O. Box 2315, Carson City, NV 89702-2312.

If you are contemplating adoption, you should consider requesting the child's medical history at the time of adopting and in the future through a third party, if necessary.

## Where Do I Get Information to Build "The Tree"?

You can get medical information about your relatives from a variety of sources:

**Talk to relatives.** Start by asking each living relative to complete a health history form. (See *Activity 2*.) They may be reluctant to share personal information but may be more willing once you explain that you will keep the information confidential. (This will vary depending on family circumstances.) Explain that developing a medical family tree could benefit their family as well as yours.

Also, you may wish to ask living relatives to recall information about those who are deceased. While this can yield a wealth of information, remember that some information may be incomplete, incorrect or misleading.

**Death certificates.** You might be able to obtain death certificates from the state Bureau of Vital Statistics. This can be costly and may require that you document your relationship before obtaining the record. Before ordering certified copies, check with family members to see if you can make a photocopy of death certificates they already possess.

**Newspaper obituaries.** While the cause of death is no longer typically included in obituaries, this information frequently was listed in death notices in the past.

**Medical records.** Medical records may have been kept by physicians, hospitals and/or insurance companies. When seeking information, state your relationship to the person and indicate that you are inquiring because you want to develop a medical family tree. Because laws vary from state to state, this information may be difficult to access. If so, visit with your physician. If the information has an important bearing on your health, a physician may be able to request the information on your behalf.

**Military records.** Military records can contain a wealth of information about your relative — everything from physical description to medical conditions. To secure information on veterans who served since World War I, write the National Personnel Records Center, 9700 Page Boulevard, Saint Louis, MO 63123.

## What Details Are Useful?

In addition to the usual information such as name, date and place of birth, parents' names, etc., you should record the following details about each family member:

**Their relationship to you.** While you will be primarily interested in blood relatives, you also may include those who are related by marriage or adoption and note special circumstances such as half-siblings.

**Nationality.** Although not fully understood, some genetic conditions are more common in certain ethnic groups so it is important to know about your family background. For instance, cystic fibrosis is known to affect whites of northern and western European descent far more than other groups, while sickle cell anemia is more commonly diagnosed in persons of African background.

**Occupation.** It is important to obtain vocational information so that your physician can tell whether illnesses in your family are truly genetic or can be attributed to occupational hazards. For instance, farmers and construction workers may be at an increased risk for developing skin cancer due to exposure to ultraviolet radiation. Knowing this can help your physician determine if an occurrence of basal, squamous or melanoma cancer is genetic or related to other risk factors.

**General health history including information about lifestyle behaviors.** This is the same information needed for your immediate family. It includes a physical description of each relative; information about lifestyle behaviors; illnesses experienced, age at first occurrence, treatment, progression of the disease, surgeries; a complete child-bearing history; and physicians and/or hospitals providing treatment.

**Date, age and cause of death.** Of course, these details will be among the most important information you can gather, but you must be sure it is complete. For instance, word-of-mouth from relatives may not be totally accurate, and even medical terminology on death certificates may not be as precise as a medical diagnosis. Your physician may be able to help you interpret information from older death certificates into terms commonly used today.



In addition, an apparent cause of death such as "heart attack" may have been a secondary cause of death. Perhaps a fatal heart attack was actually a complication of some other condition such as diabetes mellitus. Suicide may have resulted after a diagnosis of a life-threatening disease. Getting complete details is important if you are to have an accurate picture of your medical family tree.

## What's the Bottom Line?

Health care systems are complex. The recent changes in health care systems require that consumers take more responsibility for their health care. We (consumers) need to be the ones responsible for managing our own treasure chest of health-related information. We must be timely and not wait until we're sick. Our family's health history, as well as medical expenses/reimbursements, is key in this process.

### **Health Record Dilemma: Genetic Testing**

Genetic testing is a relatively new procedure that has evolved from research focused on mapping human genes. Society is becoming more familiar with genes, DNA, gene therapy, gene splicing and genetic testing. The related ethical, moral and environmental issues are tremendous. Who will be able to have a genetic test? Who will get the information? What will they do with it? How will knowing test results affect a person socially and psychologically? How will this change marriage, partner selection and child-bearing decisions? How will results affect a person's insurance? How will this influence a person's career? Dr. Norman Fost, M.D., University of Wisconsin medical ethicist, says, "Most agree that genetic testing should be done only where the persons have education, information and counseling available; where they will be able to make an informed choice; [and where they will] be able to have post-test counseling to deal with decisions made."

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