A Guide to Family Health History

Does it Run in the Family?

SIOUXLAND COMMUNITY HEALTH CENTER
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This toolkit will help you collect, organize, and understand your family health history. In “Book 1: A Guide to Family Health History”, each section includes choices of activities. Choose the activity that works best for you.

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Read “Book 2: A Guide to Genetics and Health” to learn more:
1. Why is genetics important to my family and me?
2. Which diseases might run in my family?
What is family health history?

Family health history is information about diseases that run in your family, as well as the eating habits, activities, and environments that your family shares. Knowing about the diseases that run in your family can help you make healthy choices.

Your family's health is one part of the history of your family. While collecting your family health history, pay attention to events, stories, and experiences as well. Gathering your family history helps you share your family stories and health information with your family members and children.

Family stories are powerful. They have the power to connect us to our past and history. They also have the power to warn us about healthcare risks that we may face in our future.

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How can family health history affect my health?

You inherit many things from your parents and grandparents. They pass on culture and values through photos, recipes, stories, spiritual practices, and music. You also inherit how you look—for example, how tall you are and the color of your eyes. Small structures in cells called genes carry information for these characteristics and how your body works. Your genes were passed on to you from your parents.

My family tree

Last summer, a classmate from medical school showed me her family tree. As she told me the story of her ancestors, I started to wonder about my family's history.

As I put together my family tree, I realized that many people on my father's side who had died all had cancer. This family history of cancer inspired me to investigate all the health issues in my family.
Some genes can make it more likely that you will get certain diseases. When members of your family share health problems, you might be at risk for getting the same health problems in the future. This is because family members can have genes, lifestyle, and environment in common. However, you may be able to **prevent illness by knowing your family health history** and by making healthy choices.

I decided to include a family health history in my family tree so that my family members can share it with their physicians. I will be a doctor soon, and I will tell all my patients how important it is to know their family health history.
How can my choices affect my health?

Many things shape your health. Some things—such as your genes—are outside of your control. Other things—such as what you eat, if you smoke or exercise, and what you do for a living—can be influenced by the choices you make. To make healthy choices, you need to understand your current health, your risk for getting certain diseases, and your environment.

Inevitability of disease

I told a friend of mine about the family health history information that I was gathering and she said: "If it happened in my family, it is going to happen to me. Why get into it? It is going to happen anyway."

I told her this isn't true! There are so many little things a person can do to help prevent the onset of certain genetic diseases. For example, my mother, aunt and sister all have diabetes, but I do not.
Family health history is the first step on the road to better health.

I make sure to walk a little bit everyday - even if it is just a block or so. I take the stairs instead of the elevator, and I bake my food instead of frying. I think positively; those things might make all the difference.
What information should I collect?

Who to collect information on:

- Yourself
- Your parents
- Your brothers and sisters
- Your children
- Extended family

Basic information to collect:

- Name and how you are related (myself, parent, child, etc.)
- Ethnicity, race, and/or origins of family
- Date of birth (or your best guess—for example “1940s”)
- Place of birth
- If deceased, age and cause of death

Collect stories about your ancestry and culture. This is a great chance to preserve your family’s memories.

You don’t have to collect everything!
Be sure to record age at onset of symptoms (when the disease started)

Health history:
- Alzheimer’s disease
- Asthma and allergies
- Birth defects (such as cleft lip, heart defects, spina bifida)
- Blindness/vision loss
- Cancer (such as breast, ovarian, colon, prostate)
- Current and past medications
- Deafness/hearing loss at a young age
- Developmental delay/learning disorders
- Diabetes/sugar disease
- Heart disease
- High blood pressure
- High cholesterol
- History of surgeries
- Immunizations
- Mental health disorders (such as depression, schizophrenia)
- Obesity
- Pregnancy (such as number of children, miscarriages, complications)
- Stroke
- Substance abuse (such as alcohol, drugs)

Lifestyle:
- Exercise
- Habits (such as smoking, drinking, regular doctor/dentist checkup)
- Hobbies and activities
- Nutrition and diet
- Occupation

It is important to learn what you can.
How do I collect family health history?

**Talk to your family**

Your relatives are the best source of information about your family. Family history is often shared while talking at family events like birthday parties, weddings, reunions, religious gatherings, holiday dinners, and funerals. These events provide a chance to ask family members about their lives.
Use what you have

Check first to see if your family has family trees, charts, or listings of family members. This information may be written in baby books, photo albums, birthday date books, a family bible or other religious records. Review your own medical history with your doctor to make sure you are not forgetting anything.

Plan an individual conversation

After you have brought up the idea of collecting your family health history, you may want to talk with certain family members to get a more complete record of what they know. If possible, record these talks so you can go over them later. This guide includes questions to ask.

Send a questionnaire

You may wish to send out a questionnaire or survey asking for health information from relatives. Paired with a holiday newsletter, this may be a quick and easy way to collect information. Remember that not everyone will feel comfortable sharing their information in this way, and be sure to explain exactly why you are asking questions.
Tips for collecting family health history

• Start with your parents if they are still living. Often, older relatives are good sources of information and can be the “family historian.”

• If you are adopted, you may be able to learn some of your family history through your adoptive parents. You may also ask to see the adoption agency records.

• It is important to respect others. Some relatives may not want to share their medical histories. Some may not know their family history.

Importance of recording

My family has always talked about health. We pass down our family history in stories. When my father had a stroke, we talked about it, but no one ever wrote it down. It seemed so real and so recent. How could I forget that my own father had a stroke? One day, my doctor began asking me about my family's health history. I told him about my father's stroke, my grandfather's heart problems, and my uncle's heart disease. But then I suddenly drew a blank! I couldn’t remember how my great-grandfather passed away.
• It can be scary to find out about a health concern in your family. **Sharing family history with your healthcare provider can help** you understand if you are at risk.

• Family members may not clearly identify all diseases. For example, someone who suffered from “the blues” may have had depression. Ask family members to talk about how relatives acted.

I realized that pivotal points in my life would have the same impact on generations to come. My doctor stressed how important it is to record my family health history and share it with other family members. That evening, I started drafting a family health history tree. I want my children and grandchildren to be well informed.
How do I ask my family members about family history?

On the next page is a list of questions that will help you talk with your family members. These questions will help you learn about your family stories, as well as health patterns and any impact environment, lifestyle, and family history may have on family health. Add your own questions that relate to your family.

Prepare ahead of time

• Write down what you know—such as family members’ names, where they were born, or how many children they have.

• Pick the questions you will ask ahead of time.

• Record the interviews on a tape recorder or video camera.

Family health discussion

I thought I knew about my family history because I am an elder, but I actually don’t know much. My grandmother had 20 children, and my mother was the twentieth. My father was an orphan, and I don’t know anything about his parents. As a child, we were not allowed to ask questions when someone was ill. I thought discussing my history of illness would make my children worry.
During the conversation

- Write down health-related information given by your relative.
- Try to keep the questions short. Avoid questions that can be answered with a simple “yes” or “no.”
- Use follow-up questions such as “why,” “how,” and “can you give me an example.”
- Do not expect people to know the answers to all of your questions.
- Respect a person’s wishes not to talk about certain topics.
- Ask your family member to show you pictures, recipes, letters, and other family keepsakes. These can help people remember details and lead to more family stories.

Try not to interrupt—let your family member tell his or her story!

Even though my son knows that I have health problems, I never explained the medications I take to him. Now I will talk to my son and my grandchildren, ages 25 and 18, so they will have accurate information to share with their doctors.
Sample questions

These questions are examples. You should change them to fit your conversation.

**Questions about childhood**

- Where were you born?
- Where did you grow up?
- Did you experience any health problems (for example, allergies) as a child?
- Do you have any brothers or sisters? Are they living? How old are they?

**Questions about adulthood**

- What jobs have you had? Can you tell me about a normal day?
- What was your work environment like?
- Do you have children? What are their names? When were they born? Did they have any health problems?
- What habits (sun exposure, physical activity, smoking, etc.) have you had that could have affected your health?
- Did you have any health problems as an adult? At what age? How was this treated (e.g. medicine, surgery)?
Questions about parents and grandparents

• When and where were your parents born? What do you know about them (for example, their jobs and hobbies)?

• When and where were your grandparents born? What do you remember about them?

• Did your parents or grandparents have any health problems?

• Do you know if your parents or grandparents took medicine on a regular basis? If so, for what? Did they use home remedies? What kinds and for what?

Questions about family life

• Has your family lived anywhere that caused them health problems (e.g. disaster areas, waste sites)?

• What foods does your family usually eat? Describe a typical family breakfast or dinner. Do you eat special foods for special occasions?

• Does anyone smoke? Drink a lot of alcohol? Is anyone overweight?

• Has anyone had problems in pregnancy or childbirth? What kinds of problems?

• Are there any diseases that you think might run in our family?

• Is there anything else you would like to tell me about your life or health concerns in our family?
How can I organize my family health history?

The family health history information you collect can be written down or typed into the computer. It is important to write down all of the information so it makes sense to you, your family, and your healthcare provider. We have included some ideas below to help you organize your information.

**Family health portrait**
A family health portrait is like a family tree showing family members and their health. Because it is a simple picture of your family health history, it can be easily shared with your healthcare provider. Turn to page 18 for more information.

**Keep an up-to-date record**
As a young person, I never paid too much attention to my family health history. I just got an annual check up. As I have gotten older and learned more as a major in health care administration, my eyes have opened to things like nutrition, environment, and the impact of different medications used to treat illnesses. It is important to tell your doctor what is going on in order to get the right medication, but it is also important to eat a healthy diet and exercise.
Healthcare Provider Card
Online (www.geneticalliance.org/ccfhh), you will find a card to fill out and bring to your provider. The card focuses on concerns you have about your family health history. It also gives your provider more information on how to best use your family health history to figure out your risk for getting a disease.

By keeping accurate records of your health it is possible to take health care prevention measures. Health history can help you pass information along to other family members so that they can get themselves checked for anything that may have been genetically passed down.
How can I draw a family health portrait?

If you have access to the Internet, you can use the U.S. Surgeon General’s *My Family Health Portrait* to create a family health history tree on your computer.


You can also draw your own family health portrait. Use the example on the next page to help guide you.

**Instructions for drawing a family health portrait**

- Write your name and the date at the top of a large piece of paper.
- Draw yourself at the center using a square if you are a man or a circle if you are a woman.
- Draw your parents above you and label each symbol with his or her name and birth date (or approximate age).
- Draw a line between them and then draw a line down to you.
- When possible, draw your brothers and sisters and your parents’ brothers and sisters from oldest to youngest, going from left to right across the paper.
- Add the health information you collected for each individual.
- Add the ancestry and any other information you have collected.

**Family Health Portrait Legend**

- □ male
- ○ female
- ✓ deceased

**Does it run in the family?**
**Kim's story**

1. To start my family health portrait, I added myself. Any women on the portrait are drawn with a circle. Under my name, I wrote my birth date.

2. Next, I drew in my mother and father. Any men in the portrait are drawn as squares. I connected my parents to each other using one line and drew another line that connected to me.

3. Next, I added my brother and sister and their birthdates. I connected each of them to the line that connects my parents.

4. For my father’s parents, I put their names above his and drew one line connecting them to each other and another line connected to my father. I also added my family’s ancestry. Finally, I drew a line diagonally through my grandmother’s circle to show that she died at age 42.
What now?

• Save your family health history and update it with new information you learn about your family.

• Find out more about the diseases that run in your family and how to stay healthy.

• Share information with your family.

• Take your family health history to your healthcare provider.

• Read “Book 2: A Guide to Genetics and Health.”
Resources

Genetic Alliance Family Health History Resources
www.geneticalliance.org/familyhealthhistory

Surgeon General's Family Health History Initiative
www.hhs.gov/familyhistory

The American Society of Human Genetics
http://www.ashg.org/education/family_history.shtml
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To be a patient-centered medical home that improves the physical, dental, and behavioral health of the Siouxland community while eliminating access barriers.