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DOES IT RUN IN THE FAMILY?

A Guide to Family Health History
Contents

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 Understanding Genetics and Health” to learn more about:
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 a collection of information about diseases that run in your family, as well as the eating habits, activities, and environments that your family shares. Knowing about diseases in your family can help you make healthy choices.

Your family's health is one part of the entire 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 heritage and culture with your relatives and future generations.

“Family health history is the simplest, most powerful means of open communication about where you came from. Your family can share wonderful stories about grandparents and great-grandparents and others that teach lessons that apply to our lives today. Hear. The messages are life messages. Get to know the characters in the family play. Share.”

– Caroline Lieber  
Director, Joan H. Marks Graduate Program in Human Genetics, Sarah Lawrence College
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—or example, your height 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.

Victor’s story

All my male relatives died at an early age, and heart disease is to blame. I had high cholesterol all my life, but because I exercised regularly and did not drink or smoke like my father and uncle, who died of heart attacks at age 53 and 63, respectively, I believed my risks were low. At age 49, I had a heart attack. This experience made me look at how much I know about nutrition, including the latest scientific information regarding nutrition, environment, genetics, and
Some genes can increase your chance of developing certain diseases. When members of your family share health problems, you might be at risk for developing 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 being aware of your family health history and by making healthy choices.

Eight years later, I am healthier and fitter than I have ever been and am careful to maintain a healthy lifestyle.

For heart help, visit www.wcmc.com and click “Heart Center” or call 914.493.7000.
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, whether you smoke, whether you 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 developing certain diseases, and your environment.

Sophie’s story

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 at Iona College, 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. By keeping accurate records of your health it is possible
The lessons learned from family health history can arm you and allow you to take control of your health.

– Caroline Lieber
Joan H. Marks Graduate Program in Human Genetics, Sarah Lawrence College

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.
What information should I collect?

Who to collect information on:

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

Then move on to your extended family.

Basic information to collect:

- Name and relationship to you (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 heritage and culture. This is an excellent opportunity to preserve your family’s memories.

You don’t have to collect everything!
Who to collect info from

Collect the medical and health information on:
- yourself
- your brothers and sisters
- your children
- your parents
- then go back a generation at a time and include:
- grandparents
- aunts and uncles
- Cousins
- nieces and nephews

Basic info to collect
- name and relationship to you (myself, parent, child, etc.)
- Race, ethnicity and/or origins of family
- Date of birth (or if the information is unavailable, write your best guess—for example “1940’s”)
- Place of birth
- If deceased, age and cause of death

- 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

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 differences
- 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)

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 during conversations at family events like birthday parties, weddings, reunions, religious gatherings, holiday dinners, and funerals. These events provide an opportunity to ask family members about their lives.
Use what you have
Check first to see if your family has existing family trees, charts, or listings of family members. This information may be recorded 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’re not forgetting anything.

Plan an individual conversation
After you’ve introduced the idea of family health history, you may want to talk with certain family members to get a more complete record of what they know. If possible, it is a good idea to record these interviews so you can go back later and review them. This guide includes sample 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. They may refer you to the “family historian.” Often, older relatives are good sources of information.

• 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.

Jan & Seth’s story

Most first-time parents experience a wide range of emotions: joy and excitement, anxiety and fear.

We were no different. We knew that cystic fibrosis (CF) had been diagnosed on Jan’s side of the family, so we talked with our obstetrician about risk. We could not definitely determine a family history of CF for Seth because he had no “family historian” with knowledge about his family.
• It can be alarming 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. Ask questions that invite family members to describe behaviors that might suggest health issues. For example, someone who suffered from “the blues” may have had depression.

health history. Yet, his parents had no memory of any childhood diagnoses of a chronic condition in our generation or previous ones.

Together with our physician, we explored and learned more about our child’s risk for CF. These discussions made us less worried as we came to understand that the genetic factor needed to be present in both parents.

Today, our child is active and healthy and has been joined by two equally active and healthy siblings. Knowledge of our family health history helped to inform our decision-making and assuage some of our expectant parent anxiety.

For information on CF, visit www.cff.org or call 914.993.1460.
How do I ask my family members questions about family history?

On the next page is a list of sample 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. Be sure to add your own questions that relate more specifically to your family.

Prepare ahead of time

- Write down what you already know—such as relatives’ names, where they were born, or how many children they have.
- Pick the questions you will ask beforehand.
- Try to record the interviews on a tape or digital recorder or video camera.

Bella’s story

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.
During the conversation

- Write down health-related information provided by your relative.
- Try to keep the questions short and 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.”
- Don’t expect people to know the answers to all of your questions.
- Be sensitive to a person's desire not to talk about certain topics.
- Consider asking your relative to show you photographs, recipes, personal letters, and other family memorabilia. These help people remember more details and can lead to more family stories.

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

I thought discussing my history of illness would make my children worry. 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 conditions (for example, allergies) as a child?
- Do you have any brothers or sisters? Did any of them pass away during childhood?

**Questions about adulthood**

- What jobs have you had? Can you tell me about a typical day?
- What was your work environment like?
- Do you have children? What are their names and when were they born?
- What habits (sun exposure, physical activity, smoking, etc.) have you had that could have affected your health?
- What are your favorite foods?
- Did you develop any health conditions or illnesses as an adult? At what age? Did any of these conditions require medical treatment or surgery?
Questions about parents and grandparents

- When and where were your parents born? What do you know about them (for example, their occupations and pastimes)?
- What do you remember about your grandparents? Where and when were they born?
- Do you recall any health conditions or physical ailments that affected your parents and/or your grandparents?
- Do you recall if they took any over-the-counter or prescription medications 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 near any sites that may have been hazardous or lived through any major disasters that may have affected their health?
- What foods does your family usually eat? Describe a typical family breakfast or dinner. Do you eat special foods for special occasions?
- Do you know of family members who experienced difficulties in pregnancy or childbirth? What kinds of difficulties?
- Are there any conditions or illnesses 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 summarize all of the information so it makes sense to you, your family, and your healthcare provider. We have included some useful and creative ideas below for organizing your information.

**Family health portrait**

A family health portrait is a special version of a family tree showing relatives 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.

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**Kara’s story**

My mother was 37 years old when she died from colon cancer, and I was eighteen. We never discussed her disease. Why? I’m not sure. At that time cancer was the dreaded “C” word, even though my mother, father, grandmother, and aunt all died of colon cancer.

I have always made sure that my children and I receive regular physical examinations, but one day I realized I was following the
Healthcare Provider Card

In your toolkit, 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 determine your risk for getting a disease.

same path of silence as my mother by not discussing our family's health history with them. I want to leave the best legacy possible for my children, so I decided to break the code of silence that runs in my family. I gathered information about colon cancer from the American Cancer Society and set up a formal meeting with my children to have our first conversation about the family's health history. Many conversations have followed. Our knowledge about colon cancer and other health issues in our family has grown. Now I really feel I am leaving a good legacy for the people I love.

To learn more about colon cancer, visit www.mskcc.org or call 212.639.2000.
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.

Visit www.familyhistory.hhs.gov.

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 starting with the oldest to the youngest, going from left to right across the paper.

• Add the health information you collected for each individual.

• Add the country of origin and any other information you have collected.
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. I connected them 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. Any men in the portrait are drawn as squares.

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 where each side of the family was originally from. 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 diseases that run in your family and learn how to stay healthy.
- Share information with your family.
- Take a clear summary of your family health history to your healthcare provider.
- Read the next booklet, “Does It Run In the Family? A Guide for Understanding Genetics and Health.”
Resources

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

The Smithsonian Folklife and Oral History Interviewing Guide
www.familyoralhistory.us/news/view/the_smithsonian_folklife_and_oral_history_interviewing_guide/
and visit the American Folklife Center website:
www.loc.gov/folklife/fieldwork

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National Society of Genetic Counselors (NSGC)
www.nsgc.org
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