A Guide to Family Health History

Does it Run in the Family?

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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 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 faces are magic mirrors. Looking at people who belong to us, we see the past, present and future. We make discoveries about ourselves."

Gail Lumet Buckley, writer
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.

Melvin's story

I learned that my grandfather and father suffer from diabetes and high blood pressure along with high cholesterol. My grandmother and mother both died from brain aneurysms due to high cholesterol levels. I also suffer from high blood pressure and high cholesterol. Sometimes I see small white spots and have throbbing inside my head.
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 talked to my doctor about these concerns. I am now controlling my blood pressure and cholesterol level by taking medicine and changing my diet. Knowing that I have so many family members who have died at an early age has motivated me to take better care of myself.
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.

"Cowboy" Mark's story

My immediate family has many serious health issues. My father has diabetes, high blood pressure, kidney cancer, and shakes. One of my brothers has Celiac disease and frequent, non-epileptic seizures. My other brother has high blood pressure. Both this brother and my mother have had to have their gall bladders removed. My mother also has a rare, painful neurological condition called dermatomyositis.
Family health history is the first step on the road to better health.

The cause of my father’s shakes, my brother’s seizures, and my mother’s dermatomyositis are unknown. My mother suffered for months before doctors discovered her inflamed gall bladder. Now I pay close attention to how I feel and look for early signs of all these health issues so I can get help quickly.
What information should I collect?

Who to collect information on:
- Yourself
- Your parents
- Your brothers and sisters
- Your children
- Your grandparents
- Grandparents
- Aunts and Uncles
- Cousins
- Nieces and nephews

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
• Sickle Cell Anemia
• Clotting/Bleeding Disorders
• 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.

Reach out to Family
Take small steps. Even if you have lost contact. Call a family member and ask how they are doing. Find out more about why a relative past away or why someone is sick. Pay more attention to the cause of death on death certificates. Share your health information with relatives, so that they will feel more comfortable sharing theirs.
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.

Henry's story

I always knew my mother suffers from diabetes, but when I asked about my family health history I discovered that my grandmother was also diabetic, and she developed glaucoma from it. Watching my mother suffer from diabetes was hard, and I started going with her to her doctor appointment to learn more about diabetes. I learned how to draw insulin and give the injection. I also learned the importance of how to manage your diet.
• 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.

Since my diagnosis in 2002 I have been managing my diabetes with insulin, diet changes, and daily blood glucose level monitoring. I never knew that helping my mother with her diabetes would someday help me with mine. The difference between my healthcare and what my mother gets is like night and day.
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.

Curtis’s story
My great-grandparents on both sides of my family were slaves brought from Africa to a plantation in South Carolina. Their diet consisted entirely of pork and fried food. This diet was passed down through my family, but I know the importance of eating healthy regardless of what your parents or family eats. I walk regularly and I realize the importance of exercise for my current and future health.
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!

I learned a lot about my family at a recent family reunion. One of my family members hired a genealogist to trace our family tree. From this I learned about the history of my family and about the medical conditions they had.
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?
• Who were the other relatives or extended family members that help raise me?

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)?
• What has been your biggest challenge as an adult?
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?
- Do you think your parents lived a healthy life? What could they have done different?

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?
- Do you think there are needed life style changes that could make a difference in your health today?
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.

*Cassie's story*
My mother, father, paternal grandfather, and both grandmothers all died from heart attacks. High blood pressure and diabetes also run rampant in my family. Despite their heart troubles, all of my grandparents lived very long lives. On my father’s side, my grandfather lived to be 102 years old, and my grandmother lived to be 115 years old. On my mother’s side, my grandparents lived to be 99 years old and 95 years old.
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.

Knowing my family’s health history has made me aware of my increased risk of these problems. Now I am taking extra steps to prevent developing these problems myself. I check my blood pressure daily and always take my medicine. I am meeting with the dietician at the Daily Planet to improve my diet, I exercise regularly, and I am working to quit smoking.
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 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
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.

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
The Daily Planet Healthcare for the Homeless Center
www.dailyplanetva.org

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