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Health is relative - How to shake your family tree for medical information

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As a specialist in genetics, Allan Fisher routinely compiles information about his patients' family medical histories.

But sometimes, there's a hitch.

"You'd be surprised how much people really don't know about their family, healthwise," says Fisher, director of maternal-fetal medicine at Morristown Memorial Hospital. "I'll have patients calling their parents from my office and saying, 'What did Uncle Joe have?'"

Knowing what diseases and other medical conditions run in your family is pretty critical stuff, Fisher says. "Every one of us is carrying around six to 10 genes that are lethal, not only to ourselves, but to our progeny."

There has been a national movement within the health community over the past several years to encourage people to compile their family medical histories, also called "family health histories" or "medical family trees," and share that information with their doctors.

The idea is, tracking your family medical history can help you determine what risks you may have for developing certain diseases or conditions in the future. Then, you take your history to your healthcare provider with the goal of establishing a strategy, such as undergoing more frequent health screenings, making lifestyle changes through diet and exercise or getting a referral for genetic testing, to lower your risk or at least delay onset.

The U.S. surgeon general launched the "Family History Initiative: How to Create My Family Health Portrait" in 2004 in partnership with the National Human Genome Research Institute, which is part of the U.S. Department of Health and Human Services. Others that have taken up the call, and provide how-to instructions online for developing a family medical history, include the National Centers for Disease Control and Prevention, the Health Resources and Services Administration, the Mayo Clinic and the American Society of Human Genetics.

In New Jersey, Maria Young, a Family and Community Health Sciences educator for Rutgers Cooperative Research and Extension of Passaic County, has devoted more than a year to developing a family health history program that includes making how-to presentations to senior citizens groups, historical commissions and other organizations about assembling family medical histories.

"If you know more about your health history, wouldn't that motivate you to try to stay well?" reasons Young, who says she has reached about 800 people with her presentations. "You want your quality of life to be as good as possible. I don't want to be 85, sitting in a wheelchair. I want to be on a cruise."

"You wouldn't go to a financial planner without your financial records any more than you shouldn't go for a health-risk assessment without your family history records," says Judith Benkendorf, a board certified genetic counselor and project manager for the American College of Medical Genetics. "But we also know people are much better about keeping their financial information than they are about their family medical history information."

Part of this is due to reluctance, often on the part of older relatives raised in an era when one didn't openly discuss such delicate topics as Grandpa's colon cancer, Aunt Betty's heavy drinking or Uncle Dan's disturbingly erratic behavior. "People never talked about it," says Young. "People were sick and in bed, but you never knew."

"Family history can be very important in knowing individual risk for specific diseases and being able to change your health behavior," says Alan Guttmacher, a geneticist and pediatrician, who is deputy director of the National Human Genome Research Institute. But, he adds, family health history remains a medical tool that's often "under utilized," not only by the general public, but by healthcare providers. He and other health experts explain that, while many doctors routinely request a patient's family medical history, it's often not pursued in depth.

"That's more of a time and recall thing," says Ashish Parikh, an internist at Saint Barnabas Medical Center in Livingston. He explains that physicians usually don't have a lot of time during office visits to devote to recording a thorough medical history. Their patients, in turn, wouldn't know or remember off the top of their heads what diseases or conditions run in their families, especially if they're preoccupied with undergoing a physical exam.

If a person puts together his own family health history in the comfort of his own home, Guttmacher maintains, "we'll get a better history, and they can do it at their own pace and on their down time and do it in a way to share it with other family members."

But compiling a family health history shouldn't be looked at as a panacea for protecting your health, according to Charles Kilo, an Oregon physician and a fellow of the Institute for HealthCare Improvement, in Cambridge, Mass. "Obviously, it's absolutely fine for people to be aware of their family health history. For them to keep some sort of record of what Grandma had and what Mom and Dad had is fine," stresses Kilo.

But, he says, "here we are, telling the most obese country on the face of the earth, by far, that an important thing for their health care is family history. It's almost ludicrous.

"We can't get people to get off their duffs and get out and exercise and eat right. It's typical for the American health care industry to focus on these kinds of initiatives when what is so glaringly obvious about good health goes largely neglected - that is, eat right, exercise, control your weight and make sure the basic, preventive things have been done," Kilo says. "We should focus on getting these basics right before we spend too much time and energy on a more detailed family history."

A family health history can also take some time to assemble. "Gathering your family history is not an event, it's a process," says **Joann Boughman**, a geneticist who has been involved in a family health history project of the American Society of Human Genetics, which she serves as vice president. "You may want to sit down with your grandmother and get as much as you can but, next time, you might just ask a few questions."

You don't have to go back numerous generations to compile your health history, since medical diagnosis wasn't as accurate for those generations as it has become for more recent ones, Boughman says. Geneticists recommend you try to get information, ideally, for at least three generations before your own: parents, grandparents, great-grandparents. Then, include your own medical history and, if you have them, information about your siblings, your spouse and your children. You can also include your aunts and uncles, if you're able to do so.

If your family is small, Young advises, "at least do yourself and your siblings so you can look at what's going on in the immediate family."

Record the family history in any way that works best for you, she says. You can develop your own system for listing your findings. Or you can download the "My Family Health Portrait" form supplied by the Surgeon General's office. The form contains a chart, also known as a "pedigree" - with a format similar to the one used for tracking a family genealogical history - where you fill in the names of relatives and their various health conditions. The form is available online at www.hhs.gov/familyhistory/ - click on "My Family Health Portrait, Paper Version."

Young recommends you start by compiling your own health history before you move on to the next step, which is speaking with family members, especially elderly relatives, who would remember which relative had which medical condition. "You will be asking people for personal information. So, if you're open with your situation, they're more likely to participate," says Young.

When it comes time to talking with family members, you might want to follow what Parikh, the Saint Barnabas internist, does when he takes a patient's family health history. "What's important to me is common disorders - heart disease, diabetes and cancer. Those are the things I want to ask about specifically (because) they're a common cause of illness and death in our society."

Other common diseases to ask about are osteoporosis, hypertension, stroke and obesity, according to Young. You'll also want to find out if relatives developed conditions, or died from them, at a relatively early age because that could mean you, too, could develop the condition sooner rather than later, Parikh says.

Don't be surprised if you run into resistance from relatives at first. And don't get too pushy if your dear Aunt Tess isn't eager to divulge why her oldest brother died at 50. Just try to appeal to their essential goodness, says Rovenia Brock, author of "Dr. Ro's Ten Secrets to Livin' Healthy" (Bantam Dell, \$14).

"I would say nine times out of 10, these are the people who most want you to fare well. You could say to them, 'I have a chance to live a healthier, better quality of life because of the information you share with me. You have information that can help not only me but the generations that are going to follow,'" Brock says.

"Most people will want to be a part of that because they love you. It's their family."

1. LIST: Where to get health info Aside from talking with relatives, you can gather information about your family health history from other resources such as: Birth and death certificates, which are available through your state health department. Obituaries. Photographs, which can provide visual clues of family health problems such as obesity or osteoporosis. Marriage licenses. Immigration records. Old passports. Military records. Childbearing history. Family Bibles and baby books. 2. LIST: What to look for As you gather information for your family medical history, here are some red flags that could signal you may have an increased risk for certain health problems: Any disease occurring before age 50. Any disease occurring in more than one close relative. Disease that doesn't usually affect a certain gender, for example, breast cancer occurring in a male relative. Sudden death of a family member who seemed healthy. Certain combinations of diseases within a family, for example, breast and ovarian cancer, or heart disease and diabetes. 3. INFO GRAPHIC: Family health tree template

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