

Globe Life

Know your medical pedigree

Sharing information on family illnesses is key to knowing what your genes have in store for you

Helen Branswell

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A decade after scientists completed the once unthinkable task of charting the genetic codes of humans, a simple low-tech tool may be more, not less, important for staying healthy.

Gathering a detailed family medical history is still crucial to a range of medical decisions, whether it's having another child, diagnosing a tricky ailment or making key choices about how to treat certain types of cancer, experts say.

"Your family (medical) history holds key information about your past and clues to your future health. That's kind of the bottom line," says Karin Dent, a genetic counsellor from Salt Lake City who is president-elect of the U.S. National Society of Genetic Counsellors.

As a tool, medical histories have been around for eons. Sign up with a new doctor and he or she will ask you a range of questions designed to reveal which chronic diseases run in your family so the physician can get a sense of what your genes may have in store for you.

But increasingly, experts are suggesting that information shouldn't just be sitting in the files of your family physician. People should draw up and maintain their own medical equivalent of a family tree, called a pedigree, they say.

In fact, a former U.S. surgeon-general, Richard Carmona, made promoting the gathering of family medical histories a signature campaign.

Since Dr. Carmona launched the effort in 2004, U.S. officials have urged Americans to use their annual Thanksgiving gatherings as a way to piece together information such as what kind of cancer killed Aunt Sally and how old Grandpa was when he had his first heart attack.

Ms. Dent uses a fact from her family history to illustrate how this type of information can guide medical decision-making and better one's chances of finding some forms of cancer early, when they may be treated more successfully.

"My father's dad died of colon cancer. And it was important for us to know at what age he died, because I wouldn't know that. I was very young," she explains.

"That was information my father collected because [her grandfather] did die at a young age of that condition. Therefore my father started screening for colon cancer at a younger age than would be (normally) recommended."

A page on the National Society of Genetic Counsellors website explains what kind of information you need to gather and how to lay it out.

On the website of the U.S. Department of Health and Human Services, there's even a program into which you can plug all your family's particulars. Once you're done, it generates a pedigree for you that you can print or download.

These tools make the actual laying out of the information easy. But getting the pertinent facts to plug into the pedigree –that can be the toughest part of the job.

Even though society is far past the days when the word “cancer” was whispered – or not spoken at all – many people still don't like to talk about issues as private as the illnesses they've suffered, says Cheryl Shuman, director of genetic counselling at Toronto's Hospital for Sick Children.

“People have to be sensitive to that,” Ms. Shuman says. “Some families are very private about their genetic information or the health issues that they've encountered.”

Baby boomers who are hitting the years when heart disease and cancers are no longer theoretical risks may want to gather information while they still can – if they still can. As parents die or their memories start to fail, key pieces of a pedigree can be lost.

“If you think your grandmother had cervical cancer but it really was ovarian (cancer), it makes a huge difference,” says Rochelle Demsky, a genetic counsellor in the familial breast and ovarian cancer clinic at Toronto's Princess Margaret Hospital.

“(But) we're not going to find out because it happened 50 years ago in Italy. ... And there's always going to be some uncertainty when we're talking about people and talking about relationships.”

How much information do you need? Experts say you should concentrate on three generations worth – siblings and first cousins; parents; aunts and uncles, and grandparents.

“We don't need to know about third cousins. That's not going to affect things so much. The more immediate family is more of the concern,” Ms. Demsky says.

Look to both sides of the family. “I still very often hear from patients, ‘My doctor told me I don't have to worry because it's from my dad's side,’ ” she says with evident frustration.

Patients who see Ms. Demsky may be deciding whether to have a single or double mastectomy to lower their risk of breast cancer, or whether to undergo a hysterectomy because of familial patterns of ovarian cancer.

There are genetic tests that can tell women if they carry the BRCA1 or BRCA2 gene mutations known to convey a high risk of these cancers.

But these mutations aren't found in all families with strong patterns of these cancers – underscoring the importance of a family medical history, Ms. Demsky suggests. “If five women in the family got breast cancer at 30, there's something going on that didn't just happen by chance.”

Knowing your family's cancer profile is important, but that's not the only time a family medical history comes into play. Ms. Shuman uses them as she works with parents whose children develop medical problems, be they physical deformities or developmental issues.

Pedigrees can help doctors hone in on a diagnosis. They can also help medical staff predict for parents what that child's future health picture may look like and what kind of help might be useful for the child.

For some people, though, there's no way to plumb the past. People whose families were wiped out in the Holocaust or other genocides, for instance, or children of closed or foreign adoptions may have little or no insight into their family medical history.

"If somebody just comes in and says 'Well, I'm adopted' but without anything, we can't really do anything," Ms. Demsky says.

"I find that that can be frustrating for families," adds Ms. Dent. "And yet in some ways what it does for them is they make sure that their offspring, that they share as much health information about themselves as they can, because they want to help others."

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