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Doctor conducts the test and the study of DNA molecules .

Can Genetic Testing Make You Uninsurable?

By Matt Alderton | Monday, November 20, 2023

5 SECOND SUMMARY

Read on to learn about the implications of genetic testing on insurance, laws to protect you against genetic discrimination, and why it's still a good idea to get genetic testing.

Many people worry that if a genetic test reveals they have amyotrophic lateral sclerosis (ALS), muscular dystrophy, or another genetic disease in their DNA, they could be subject to discrimination. While our country has medical privacy and antidiscrimination laws to prevent that, some types of insurance are not covered by those laws.

Here's what you need to know about insurance when considering genetic testing.

Protections against genetic discrimination

There are at least three federal healthcare laws that protect individuals who receive genetic testing. The first is the Health Insurance Portability and Accountability Act (HIPAA), which safeguards the privacy of individuals' medical records and forbids unauthorized use or disclosure of the information they contain. Initially passed in 1996, it was amended in 2013 to include protections for genetic information. It's important to note, however, that HIPAA applies only to "covered entities" like health insurers and healthcare providers. Its privacy protections do not extend to commercial providers of genetic testing like 23andMe or Ancestry.com.

Jennifer Leib is a genetic counselor.

Then there's the Genetic Information Nondiscrimination Act (GINA). "GINA prevents employers and health insurers from using your predictive genetic information against you in their practices," explains Jennifer Leib, a genetic counselor and founder of Innovation Policy Solutions, a government affairs consulting firm specializing in genomics and precision medicine. Jennifer emphasizes the word "predictive." "If you are currently manifesting or have a genetic disease, GINA does not provide any protections for that specific condition," she says.

Finally, there's the Affordable Care Act (ACA). "The ACA puts protections in place for preexisting conditions," explains Tiffany Grider, MS, LGC, a genetic counselor at the University of Iowa. That means health insurers can't deny you health insurance or charge you more for it because you have a medical condition, including a genetic disease. Although it doesn't apply to small employers — businesses with fewer than 50 full-time employees are not required to offer healthcare coverage to their employees — it gives consumers the opportunity to shop for individual coverage via the ACA Health Insurance Marketplace.

Tiffany Grider is a genetic counselor.

Despite their limitations, HIPAA, GINA, and the ACA are lifelines for those with neuromuscular conditions. "Because most of these conditions are fairly complex and require quite a bit of medical care, access to quality insurance is a big deal for the neuromuscular disease community," says MDA Director of Access Policy Joel Cartner. "If there weren't protections in place, it would make it so much harder for people in the neuromuscular disease community to get an accurate diagnosis and the insurance they need to be able to afford treatment."

Joel Cartner is MDA's Director of Access Policy.

What about life and disability insurance?

Unfortunately, the protections that exist regarding health insurance don't extend to other types of insurance.

"It's not just genetic diseases," says bioethicist Melissa Goldstein, an associate professor in the Department of Health Policy and Management at the Milken Institute School of Public Health at George Washington University. "For any of us that have chronic conditions, there is no legal requirement that life insurance has to cover you. There is no legal requirement that disability insurance has to cover you. And there is no legal requirement that long-term care insurance has to cover you. They can deny you, or they can decide that they'll cover you, but you have to pay $15,000 a year or much more."

Melissa Goldstein is a bioethicist.

Melissa likens life, disability, and long-term care insurance to flood insurance: In areas that are prone to flooding, flood insurance can be difficult and expensive to obtain because providing universal and affordable coverage would result in a rash of claims that insurance companies wouldn't be able to pay. "It's not about justice or equity among people," Melissa says. "It's about the business model."

In the case of floods, the Federal Emergency Management Agency (FEMA) is there to provide public-sector relief in the absence of a private-sector business case. Medicare and Medicaid serve the same function for health insurance. When it comes to life, disability, and long-term care insurance, however, lawmakers so far have been unwilling to fund that kind of support — or require it from private insurers.

"There's been discussion in recent years to try to expand GINA to other types of insurance, but there just isn't a lot of appetite in Congress to do that right now," Jennifer says.

Reasons to choose genetic testing

Even with the risk of being excluded from certain types of insurance, there are many reasons to seek genetic testing.

If you have a family history of neuromuscular disease, for example, genetic testing might be able to tell you whether you've inherited disease-causing genes. This information may help you plan for the future or make decisions about having children if you're thinking about starting a family.

If you have symptoms of a neuromuscular condition, a genetic test might be necessary to confirm your diagnosis and qualify you for lifesaving therapies and clinical trials.

So, if you need genetic testing, you should get it, advises Jennifer. "Genetic information, in my opinion, is one of the most protected types of healthcare information out there," she says. "I always encourage people: If you can benefit from having a genetic test, you should feel assured about getting one. Don't let the fear of your genetic information being used against you cause you to unnecessarily suffer health issues."

Consider your options

If you are interested in life, disability, or long-term care insurance, it might be best to secure your policy before you undergo genetic testing.

"It's important to ensure your financial matters are in order well before you are genetically tested because your results will become part of your medical records," advises Nathan Peck, CEO of Cure VCP Disease, a patient advocacy group whose mission is discovering a cure for neuromuscular and neurodegenerative diseases like myopathies, dementia, ALS, Parkinson's, and Charcot-Marie-Tooth disease (CMT), all of which can be caused by a mutation of the valosin-containing protein (VCP) gene.

Nathan Peck leads a patient advocacy group.

Nathan, who lives with VCP-associated multisystem proteinopathy (MSP), obtained disability insurance before he was diagnosed. "I purchased a long-term disability insurance policy years before I knew I had the disease or was feeling symptoms," he explains.

If you're working, find out if your employer provides disability or other types of insurance among its benefits. "Employer-provided coverage is relatively inexpensive and oftentimes there aren't any additional requirements, like physicals," Nathan says. "You just deduct the premium from your paycheck, and you're good to go."

But the easiest option might not be the best option, according to Nathan, who notes that employer-provided plans aren't portable — if you leave your job, you lose your coverage — and, in the case of disability coverage, they typically pay only a fraction of your monthly salary when you file a claim. If you receive Social Security, the policy will usually pay even less.

Commercial policies are not tied to a job and typically offer better benefits. Because they have stricter underwriting guidelines, however, they usually require a physical exam and are only available to individuals who do not have symptoms of or a diagnosis of a genetic disease.

Individuals who have already gotten a genetic test, or even a genetic diagnosis, can still apply for coverage. "You might have to pay more or settle for a less reputable insurance company, but it's still possible," Nathan says.

Your genetic counselor may be able to help you navigate your options. In addition, the MDA Resource Center can provide resources related to genetic testing, healthcare, and insurance. (Call **833-ASK-MDA1** or email ResourceCenter@mdausa.org.)

When it comes down to it, your decision to get genetic testing should be based on what is best for you and your family's health. By understanding the rights that you do and do not have regarding your genetic status, you can plan your healthcare and your finances in ways that safeguard both.

Matt Alderton is a Chicago-based freelance writer who frequently covers health and transportation.

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