

INSURANCE AND GENETIC CONDITIONS

Source: Genetic Alliance UK

<https://geneticalliance.org.uk/information/living-with-a-genetic-condition/insurance-and-genetic-conditions/?sfw=pass1659520036>

Accessing appropriate insurance is a significant problem for many people affected by genetic conditions. We regularly receive helpline calls and emails from people affected by genetic conditions who are finding it difficult or impossible to access appropriate or affordable insurance cover.

On this page we talk about taking out insurance when you have been diagnosed with a genetic condition.

GETTING INSURANCE WHEN YOU HAVE A GENETIC CONDITION

What information am I expected to disclose to insurance companies about my condition?

You will normally be asked about your current health, previous health problems and any major health problems in your family.

What if the insurance company has not heard of my condition?

Insurance companies need to understand your condition so they can assess your application. If your condition is not common, the insurance underwriter may want to find out more information from you or your doctors. An insurance company may also consult with their Chief Medical Officer (a qualified medical professional) or other qualified experts. Information from your GP or hospital doctor may also be requested to better understand the risk. The insurance company will always ask for your permission to contact your GP or hospital doctor.

What if I don't know a lot about my condition?

You will need to disclose that you have a condition and may be asked about treatment, consultations and any associated issues. The insurance company may request a report from your GP or hospital doctor to find out a bit more about your condition. Insurance

companies employ medical doctors to help them with unusual and difficult cases, sometimes they investigate the condition and may ask medical experts for input.

RISK OF FUTURE MEDICAL CONDITIONS

You only have to answer what is asked for by the insurance company, or requested on the application form. Answering all questions truthfully will prevent any chances of your policy becoming void.

You must be honest about your diagnosis and the likely progression of your condition.

What if I have not taken a predictive genetic test and am not showing symptoms?

If other members of your family have been diagnosed with a disease but you have not experienced any signs or symptoms, you must disclose any medical history about yourself and family members if asked by an insurance company.

What if I have taken a predictive genetic test and am not showing symptoms?

If you have taken a predictive genetic test and the test result is 'positive', but you are asymptomatic and all other tests are normal, then you do not currently have the disease. You do not need to disclose the result of this predictive genetic test to the insurance company, with the exception of a predictive genetic test for Huntington's disease for life insurance cover over £500,000.

What if I am an unaffected carrier of a genetic condition?

Being a carrier of a genetic condition but showing no symptoms does not need to be disclosed to the insurance company. However you must disclose all relevant medical history.

TREATMENT

Should I tell the insurance company if I am receiving treatment for a condition?

Explaining current treatment is essential, it shows that the condition is treatable; it may alter your prognosis and maintain your health. The insurance company may ask for a letter from your GP or a hospital doctor for further information of the treatment and its effectiveness.

Should I tell the insurance company if I start receiving treatment after the insurance cover starts?

Unless your insurance company specifically requests that you advise them about treatment, after you have taken insurance cover, you do not have to tell the insurance company about any treatment you are taking. However, if you later start a new policy, you will have to disclose the treatment you have had to the insurance company.

Receiving treatment may affect the price of the premium in a positive way; remember if treatment is effective, insurance companies may take this into account when calculating your premium.

REQUESTING INFORMATION FROM YOUR GP OR DOCTOR

Why do insurance companies need medical information from my GP or hospital doctor?

Insurance companies may request medical information from your GP or hospital doctor to better understand your condition in order to accurately price the additional risk from any health problems you disclose.

What questions will the insurance company ask my GP or hospital doctor?

With your fully informed consent, insurance companies will usually send your GP or hospital doctor a 'General Practitioners Report' (GPR) which they will be required to complete. General questions typically involve:

Current health – are you receiving any medical care, medication, treatments.

Sickness record – have you taken days off work due to ill health.

Past health – have you had any hospital admissions, treatments, illnesses.

Predictive genetic test results – must be disclosed only in the case of Huntington's disease cases for life insurance policies over £500,000.

Can I ask my medical geneticist to explain my rare disease or condition, or does the insurance company only ask my GP or hospital doctor?

There is nothing to stop you from sending information to the insurance company from your medical geneticist. This may be helpful if you have a rare disease or condition which you feel the insurance company may not be familiar with.

What are my rights when an insurer is requesting information from my GP or hospital doctor?

If a GP or hospital doctor report is requested, you will be asked for your fully informed consent, and there may be a question asking if you want to see a copy of the report before

the GP sends it to the insurance company. The insurance company will tell the GP or hospital doctor if you do want to see a copy of the report first.

You are entitled to talk with your GP or hospital doctor before medical reports are sent to the insurance company.

You are entitled to know what information your GP or hospital doctor has provided to the insurance company.

Can insurance companies really interpret my genetic test results?

Yes. The interpretation will be carried out by a nominated senior insurance company staff member. They will refer to qualified medical experts for guidance whenever it is needed.