Frequently Asked Questions: Life Insurance and Long-Term Care

What are life insurance and long-term care (LTC) insurance plans, and what benefits do they offer planholders?

Life insurance is an agreement between an individual and an insurer. The individual pays premiums to the insurer in exchange for an agreement that if they should pass away during a defined period of time, the insurer will pay a lump sum of money to the individual's beneficiary.

Long-term care (LTC) insurance is a type of policy that reimburses an individual for money spent on home or facility health care services to help assist with daily activities. Most commonly, you must have a loss of two or more activities of daily living to receive benefits/reimbursement under an LTC policy.

What are the differences between the accessibility of these plans when provided through your employer versus public plans? Are there other benefits/drawbacks of either type?

If you can, always try to secure policies through your employer. Nearly every time, the policies will offer more "guaranteed issue" amounts, which do not require a medical questionnaire, plus premiums are generally cheaper. This is possible because when an insurance company looks at the risk pool over an entire company versus one individual, there is always less risk over time when providing coverage to a large group of individuals.

For life insurance, this means that the insurer will offer a set amount of guaranteed life insurance, most commonly on a term life insurance policy. To secure this guaranteed amount, you may need to enroll at your first opportunity when hired or during a special enrollment period (for example, if your employer switches insurance carriers during a benefits renewal). Even if you apply for amounts over the guaranteed issue and are rejected, you are still guaranteed coverage up to the guaranteed amount. Term insurance is a great way to secure a large death benefit for relatively inexpensive premiums and can generally be thought to cover you during your working years. If your employer offers whole life (not term) policies, they will most often require a medical questionnaire or lab work.

LTC insurance guaranteed issue amounts are harder to secure. If your employer offers an LTC policy, be sure to read the plan overview documents during onboarding or open enrollment to see if the plan offers guaranteed amounts.

Portability, or the ability to take a policy with you on an individual basis should you leave your employer for another job, differs from plan to plan. It's always best to read the plan overview document to find the details specific to your plan before you enroll.

If you are struggling to find coverage through your employer or if your employer does not offer these benefits, you can always reach out to a local insurance agent to shop around for policies.

What is the earliest age you can obtain a life/LTC insurance policy?

Adults may purchase life insurance policies for their minor children at any age. Most LTC policies can be purchased at any time as well. However, if you buy young, you may need to pay premiums for a long time before being eligible to file a claim, which may be a turnoff for some. If you have Alport syndrome, it is advisable to try to obtain coverage earlier in life while your overall health picture is better. This is especially the case if you need to complete a physical or blood work as part of your policy.

Why might people with a confirmed diagnosis of Alport syndrome be denied one of the policies or forced to pay a higher premium for these services?

Ultimately, insurance companies are for-profit organizations with shareholders. Their goal is to maximize profits and minimize losses. Insurance companies and actuaries must weigh the risks associated with the individuals they insure, similar to car insurance or any other type of insurance. Because of this, any health issue that may negatively impact your life expectancy or reliance on home health care services will cause you to pay more for coverage or be denied coverage altogether.

Should I delay or avoid confirming an official Alport diagnosis in order to obtain an insurance plan?

This question comes up a lot, both related to life insurance and previously due to concerns about exclusions for pre-existing conditions for health insurance. However, the choice to pursue genetic testing (or any other diagnostic testing) is up to the patient.

That said, obtaining diagnosis through genetic testing has many important benefits to be aware of when making this decision:

- Life insurance companies were the first to figure out that albuminuria was a risk factor for mortality – if one applied for life insurance with any significant proteinuria, one would be excluded by most companies anyway. So from a practical standpoint, the knowledge of a COL4A variant is unlikely to make a difference.
- For males with potential X-linked Alport syndrome and males and females with potential autosomal recessive Alport syndrome, delaying onset of proteinuria and protecting your native kidneys with appropriate treatment can improve life expectancy and quality of life. Learn more about Alport syndrome genetics on the ASF website.
- Knowledge is power! Knowing one's precise condition/mutation offers connection with others like you and the potential to participate in registry studies and clinical trials that may benefit you, your family, and other families in the future.

What are the best strategies or tips for getting life/LTC insurance if you have Alport syndrome and are pre-kidney failure?

Without a doubt, the most important thing you can do to secure coverage if you have Alport syndrome is to maintain good health outside of your kidneys, plus improve your kidney numbers if you can. Insurance companies look at "the whole picture" when it comes to your health. Keeping things like your A1C (blood sugar), cholesterol, weight, and blood pressure in good standing will all go a long way toward insurability. In terms of actually finding a policy, reaching out to a local insurance agent may help in shopping around different carriers for policy eligibility.

Can someone who is on Medicare due to end-stage renal disease (kidney failure) obtain life/LTC insurance? What are potential alternative options to consider?

Obtaining any policy while in a late-stage disease is no easy task, especially policies with large payouts such as life and LTC. Insurers are going to be strict. There are ways to prepare yourself for the cost of care later in life and it is advisable to begin as soon as possible.

Starting a health savings account (HSA) instead of contributing high premiums to a LTC policy is a good alternative for a few reasons:

- The contributions are made with pre-tax dollars, or if made post-tax, dollars are tax deductible.
- Money can be used for anything health related and the funds rollover 100% from year to year.
- The account balance can grow over time if treated like a long-term investment account (HSAs have different investment options, so talk to the issuing bank for more details).
- Once you turn 65, the money can be used for anything, penalty-free.

You must be on an HSA-qualified health plan to be able to contribute to an HSA. HSA-qualified plans are common today and in some cases may be the only plan option available to some employees. Much like a 401(k), the key is to start contributing early to these accounts so that they can grow over time and so that when you need to pay for care, you have a large sum to pull from.

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