GLAD ANSWERS
for the LGBTQ Community

Private Disability Benefits

What People with HIV & Their Doctors Should Know About Getting Coverage & Taking the Right Steps to Keep it

November 2014

ABOUT GLAD'S AIDS LAW PROJECT

Through strategic litigation, public policy advocacy, and education, GLBTQ Legal Advocates & Defenders works in New England and nationally to create a just society free of discrimination based on gender identity, HIV status, and sexual orientation.

GLAD's AIDS Law Project was founded in 1984 to protect the rights of *all* people with HIV.
Fighting discrimination and establishing strong privacy protections have been important for people with HIV since the beginning of the epidemic. We outline here the basic state and federal laws of particular importance to people with HIV. The more information you have about existing laws, the more prepared you will be to stand up for your legal rights.

If you have questions about any of these laws, or believe that your legal rights have been violated, contact GLAD Answers by phone at 800-455-GLAD (4523) or by live chat or email at www.GLADAnswers.org.

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INTRODUCTION

Private benefits from a long-term disability insurer can make a huge difference in the lives of people who are unable to work due to HIV or AIDS.

Recent treatment advances have allowed many people with HIV or AIDS to experience a significant improvement in health. With increasing publicity about new medications, it is a good bet that long-term disability insurers will be reviewing benefits applications and claims files more closely.

While many people who have received disability benefits have been able to return to work, this is unfortunately not true for everyone. Insurers may nonetheless attempt to terminate benefits for people with HIV who, while significantly improved, continue to be unable to work due to severe fatigue, side effects from medications, deficits resulting from past opportunistic infections, or other debilitating effects of advanced HIV disease.

Whether a person with HIV or AIDS is eligible for disability income benefits must, of course, be determined case-by-case through an individualized assessment of a person's medical condition and functional limitations. No two cases are identical.

If you are currently receiving disability benefits, there is no need to panic. But now, more than ever, you and your doctor must understand how disability benefits work and what to do *today* to be in the strongest possible position if an insurer attempts to terminate your benefits in the future.

We set out here some common questions and answers that we hope will help you and your doctor work together to protect your benefits. This publication does not address public benefits, such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), which are administered under different systems. However, the guidance laid out here about how to ensure proper medical documentation of your disability will be helpful in those arenas as well.

LONG-TERM DISABILITY BENEFITS OVERVIEW

What is Long Term Disability Income Insurance?

Long-term disability (LTD) insurance provides you with a percentage of your lost income (usually 60%) if you are unable to work due to illness or injury.

Some people buy an individual LTD policy directly from an insurance company. Most people, however, obtain LTD insurance as an employment benefit. Benefits such as employer-based group or disability insurance are known as "employee welfare benefit plans" and are governed by a federal law known as ERISA (Employee Retirement Income Security Act). As you will see later in these Questions and Answers, ERISA creates specific procedures and standards that will apply in the event that an insurer denies or terminates your benefits from a group LTD plan. These procedures do not apply for individually purchased LTD plans.

How "disabled" do I have to be in order to be eligible for private LTD income benefits?

An insurance policy is a contract or agreement. As the insured, you must meet the definition of "disability" in the policy in order to be eligible for benefits. If you obtained your LTD as an employment benefit, the definition of a disability will be in a document known as the Summary Plan Description. Ask your employer for a copy of it. While you must check your policy's specific definition of "disability," there are two common ways disability is defined in LTD plans.

The first definition requires that you are unable to perform each of the material duties of your regular or usual job. This typically refers to your job or occupation at the time of or immediately preceding your application for benefits.

The second definition of disability requires that you be unable to perform any type of full-time work. This definition is typically stated as being "unable to perform each of the material duties of any gainful work or service for which you are reasonably qualified taking into consideration your training, education, experience and past earnings."

Under most plans, the "regular job" standard applies for an initial period of disability (commonly two or three years) and then the definition changes so that you must satisfy the more difficult "any job" standard in order to continue to receive benefits.

Under these definitions of disability, you do not have to be unable to participate in basic life activities, bedridden, or appear ill to others. The definition focuses on occupational limitations. You must therefore be able to demonstrate that HIV substantially impairs your functioning and restricts your ability to work as defined by your policy.

And remember, check the precise definition of disability in your plan. That is the standard you must meet.

I have been receiving LTD benefits for five years without a problem. Does the insurer have the right to reassess my eligibility for benefits at any time?

Yes. An insurer can always require you to demonstrate that you are currently disabled. An insurer may request updated medical records and statements from your doctor about your medical condition, limitations, and restrictions. In addition, an insurer can send a nurse or representative to visit you and ask you for a detailed description of your daily activities.

Do not ignore requests for information from insurers. Be complete and accurate in your response. Do not exaggerate your limitations. It will not help you in the long run.

If you are unclear about how to handle certain questions, consult a lawyer or advocate.

I have been approved for disability benefits by the Social Security Administration. Can a private long-term disability insurer come to an opposite conclusion?

Yes. Under the law governing private disability insurance, the determination of the Social Security Administration (SSA) that you are unable to work is not conclusive or binding on a private insurer. The SSA's determination is one piece of strong evidence that you are unable to work. You must, however, provide a private insurer with independent proof that you meet your policy's definition of "disability."

Proving You Meet the Definition of Disability in Your Policy

What is the most important thing I can do today to be in the strongest possible position to prove disability if an insurer attempts to terminate my benefits in the future?

The key to protecting disability benefits is the ongoing, consistent, and detailed documentation of your limitations in your medical record.

At every visit, report to your doctor problems such as fatigue, low energy or stamina, sleeplessness or insomnia, sleeping long hours, the need to sleep and nap during the day, night sweats, neuropathy, any difficulty with concentration or memory, diarrhea, nausea, side effects from medication, or any other effects of your HIV.

Do not stop reporting symptoms such as fatigue or diarrhea simply because they may have become the norm of your life and therefore no longer seem remarkable or noteworthy to you. Remember, even if you have become used to a certain level of fatigue, the relevant factor for determining disability is your current level of fatigue as compared to your level of functioning prior to your disability. If limitations are not noted in the medical record, an insurer will question whether they really exist.

In addition, be sure that your doctor provides a detailed explanation of your limitations and the basis for them in any communications with insurers. Do not assume that it is sufficient simply to state, without elaboration, that you have HIV or AIDS.

I am unable to work because of severe and limiting fatigue. Can I establish disability based on a subjective symptom like fatigue?

Severe fatigue is a common reason why a person with advanced HIV disease may be unable to work. While subjective symptoms such as pain and fatigue are arguably less dependable than objective medical evidence, most courts in disability cases have rejected the principle that a symptom or deficit must be susceptible to precise measurement in order to be the basis for disability.

A recent case in federal court in Massachusetts provides an example. An employee filed a LTD claim based on severe pain he was experiencing from back spasms. The insurer ultimately terminated benefits because no objective information had been provided to support the subjective complaints of low back, shoulder, neck and wrist pain. The United States District Court Judge ruled that the "[r]ejection of the claim solely on the basis of a purported lack of objective evidence is troubling and questionable." In crediting the non-objective evidence, the court ruled that a doctor's assessment of pain is significant medical testimony. See *Pollini and Pollini v. Raytheon Disability Employee Trust et al*., United States District Court for the District of Massachusetts (1999).

In evaluating disability claims based on subjective evidence, courts will likely take into account: (1) the professional opinion of the treating and examining doctor; (2) whether there is evidence of underlying impairment that potentially could reduce the symptoms; (3) the claimant's medical history and credibility; and (4) the congruity (or lack) between the reported symptoms and the person's activities and claimed limitations.

What are the important considerations in proving disability based on HIV-related fatigue?

First, as noted above, consistently report to your physician fatigue, low stamina and any related symptoms.

Second, in response to inquiries from insurers, it is important for your doctor to buttress your self-reports of fatigue with all objective medical evidence that is consistent with or contributes to fatigue.

The specifics of your medical history will dictate what is relevant, but here are some common points for you and your doctor to keep in mind.

a) Based on your history of CD4 and viral load counts, as well as your history of opportunistic infections, your stage of HIV disease is frequently characterized by severe and limiting fatigue which is incompatible with work. It is important to put this information in context by explaining to the insurer the nature and course of HIV disease generally.

b) Tell the insurer if you have already had an AIDS-defining illness. That type of breakthrough in your immune system is relevant to your current health, even if your measures of immune system functioning have risen since that time.

c) The progressive nature of HIV means that the longer one has an AIDS diagnosis, relatively low CD4 counts and, if applicable, viral replication, the greater the likelihood of significant and debilitating fatigue.

d) If you have relatively low CD4 counts, and either ongoing or intermittent viral replication, it is important to point out that your body is constantly fighting viral replication with a depleted, weakened immune system, which contributes to the likelihood of severe fatigue.

e) Point out that while new medications have stabilized the pace of disease progression, you have not necessarily experienced a significant recovery in your immune system.

f) Identify any other intermittent or chronic conditions which worsen or contribute to fatigue, either by themselves or by further taxing the immune system. Examples include anemia, B-cell deficiency, encephalopathy, or frequent diarrhea.

g) Identify side effects and toxicities from medications.

h) Although not specific to fatigue, point out, if applicable, that due to drug resistant virus, a narrowing of treatment options has reduced the likelihood of significant immune system recovery.

Can I establish that I meet the definition of disability because it is difficult for me to take a burdensome and complex medication regimen while working full-time?

In many cases, it will be difficult to establish that adhering to a medication regimen by itself makes you unable to work. This is because employers are obligated to provide you with a reasonable accommodation if necessary to take your medications. Side effects from medication, however, can help establish disability if they are sufficiently debilitating. Make sure that you point out how the medications actually affect you, not simply the general or potential side effects that can result.

Although I have many limitations that result from advanced HIV disease, my T-cells have increased and my viral load is down (or non-detectable). I noticed in my medical records numerous references to "clinically stable," "asymptomatic," and "doing well." Will these notations be problematic if an insurer reviews my medical records?

An insurer may take phrases like "clinically stable" or "asymptomatic" out of context to assert that you are not experiencing any negative effects of HIV disease. In communications between your doctor and your insurer, it is important to put any such language in the medical record in the context of your overall medical history and condition. While antiretroviral therapy may have slowed the pace of disease progression, such notations do not necessarily mean that you are without significant deficits and debilitation from HIV disease. Rather, terms like "clinically stable," "doing well," and "asymptomatic" are used in relation to the patient's baseline medical condition of advanced AIDS. Such terminology indicates that at a given time, the patient did not have a specific or manifest HIV-opportunistic infection. Similarly, language such as "feeling well," or "feeling great" for a patient with advanced AIDS does not mean that the patient feels "well" in the way that a person without advanced AIDS might feel "well."

Challenging a Denial or Termination of Benefits

My insurer has terminated my benefits, claiming that I no longer meet the policy's definition of disability. What is the process for challenging the insurer's decision?

If your benefits are through an employee benefit LTD plan, it is subject to the requirements of ERISA. Under ERISA, an insurer (who usually acts as the administrator of the plan) is permitted to require that you first file an internal appeal of the termination or denial of your benefits before you are permitted to bring a lawsuit in court. The insurer must specify the reasons the claim was denied. You usually have 60 days from the date of the termination or denial of benefits to file your internal appeal with the insurer.

The most important consideration to keep in mind during the internal appeal is that you must present to the insurer at this stage of the process *all* of the medical and other evidence that establishes that you are disabled. If an insurer denies your appeal and you file a lawsuit, you will most likely not be permitted to present any evidence that you had not previously submitted to the insurer. The focus of the lawsuit will be to determine whether the insurer made an erroneous determination of your eligibility for benefits based on the information it had during the internal appeals process.

As part of your internal appeal, you should submit: (1) all medical records which support your claim that you are unable to work (do not assume that the insurer has these); and (2) statements from doctors giving a detailed explanation of your medical history, current condition, and the doctor's assessment of and the medical basis for limitations and restrictions on your ability to work. Keep in mind the points made in the section above: **PROVING YOU MEET THE DEFINITION OF DISABILITY IN YOUR POLICY**.

It may also be helpful for you to submit your own statement describing your limitations. Let the insurer know if you need ten hours of sleep each day, if you need significant rest even after a short period of

light activity, or any other ways in which your capacity for activity is incompatible with full-time work.

Do not fail to appreciate the importance of providing detailed and comprehensive medical records, physician statements, and statements about your fatigue and limitations during the appeal. Do not rely on conclusory statements or think that only stating that you have HIV or AIDS will be sufficient.

Prior to preparing the internal appeal, you should obtain a copy of your claims file from the insurer. Under ERISA, the insurer is obligated to provide it to you. It will give you an idea of what evidence the insurer relied upon to make its determination that you are not eligible for benefits.

While it is preferable to retain a lawyer at this stage of the proceedings, you can submit your own materials in support of your appeal.

The insurer must either uphold or reverse its denial of benefits within 60 days. Unfortunately, ERISA regulations make it easy for the insurer to assert its right to an extra 60 days to make the determination.

Note that if your LTD insurance is an individual rather than employment benefit plan, the plan is not subject to ERISA and you do not have to file an internal appeal prior to filing a lawsuit.

If I sue my insurer to reinstate my benefits, what is the standard that a court will apply in determining whether I am entitled to benefits?

Reversing a denial or termination of benefits for a plan subject to ERISA is a challenging task. This is because under ERISA the legal standard of review that a court will use is weighted heavily in favor of the insurer. Consistent documentation of your limitations in the medical records and the submission of a comprehensive, detailed record in your appeal will, however, give you the best shot at this stage.

There are two possible standards of review a court will use under ERISA. The first standard is known as "abuse of discretion," A court will employ this standard of review if the plan documents give the insurer (or plan administrator) discretionary authority to determine your eligibility for benefits. Under an "abuse of discretion" standard, the judge will determine whether the insurer had substantial evidentiary grounds for its decision, even if the judge would have come to a different conclusion if making the decision in the first instance. In other words, the insurer's basis for denying the appeal is given some added weight.

The second standard is known as "de novo" review. A court will apply this standard if the plan documents do not give the insurer (or plan administrator) discretionary authority to determine your eligibility for benefits. Under this standard, the insurer's prior decision during the appeal is not given any extra weight. Rather, the judge will review all of the evidence submitted during the appeal and will make a new evaluation of whether you meet the plan's definition of disability.

If your plan is not subject to ERISA because it was individually purchased (i.e., not an employee benefit plan), then the abuse of discretion standard is also irrelevant and the court will make an independent evaluation of whether you meet the plan's definition of disability.

What damages can I recover in a lawsuit against an insurer for wrongfully terminating my benefits?

If your plan is an employee benefit plan, ERISA is your only remedy. That is because ERISA, a federal law, has a specific provision prohibiting you from asserting claims under state law. Under ERISA, you can only recover past benefits owed to you and enforce your rights to future benefits. You cannot recover emotional distress or punitive damages. In addition, you cannot assert a state law claim for bad faith insurance practices or unfair or deceptive trade practices.

If your plan is not subject to ERISA, you have a greater range of remedies. In addition to recovering for past benefits and enforcing your rights to future benefits under state law, you can assert any other available state law claims for bad faith insurance practices or unfair or deceptive trade practices.

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GLAD Answers and publications are provided *free of charge* to all who need them. We hope that those who are able will make a contribution to ensure that GLAD can continue the fight for equal justice under the law.

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Thank You!

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