What Is HIPAA?

Disclaimer: The American Cancer Society does not offer legal advice. This information is intended to provide general background in this area of the law.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a law that was created to protect millions of working Americans and their family members with medical problems. These people often had trouble getting health insurance because of a medical problem they had before they tried to buy health insurance (called a *pre-existing condition*). In fact, before the important protections of the health care law known as the Affordable Care Act took effect, many people with serious health problems couldn't get health insurance.

Now, many of the provisions of HIPAA are no longer needed because of the stronger protections of the newer health care law. But people who have older health plans – known as grandfathered plans – can still benefit from HIPAA protections. These protections are discussed in more detail here.

Does the Affordable Care Act affect HIPAA?

The Affordable Care Act (ACA) passed in 2010 has changed the way health insurance companies manage coverage for pre-existing conditions.

- Before ACA became law, HIPAA helped protect people with pre-existing conditions like cancer. Now, most people with pre-existing conditions will be able to get coverage more easily. That's because group plans, including employer-based plans and new individual health plans are no longer allowed to deny coverage to people with pre-existing conditions.

- People under individual health plans that existed before September 23, 2010 – known as grandfathered plans, will still be allowed to use pre-existing condition exclusions. Plans issued or renewed on or after September 23, 2010 must follow the ACA rules.

This document will discuss HIPAA's effects on the older "grandfathered" plans and point out the changes that will happen later due to newer health care laws.

How does HIPAA help people with cancer?

The following information applies to grandfathered plans, those that existed before September 23, 2010. Check with your employer to find out your health care plan's start date, to learn if it's grandfathered. If it isn't, this section does not apply to you.

HIPAA includes several parts that may help people with cancer who are under older grandfathered individual health plans.

- It limits what's considered a pre-existing condition. An employer health plan can exclude a medical condition from coverage only if the person had a gap in coverage longer than 63 days, and also had or was recommended to have treatment or medical advice in the 6 months before enrolling in the plan.
- It limits the time a new employer plan can exclude the pre-existing condition from being covered. An employer health plan can avoid covering costs of medical care for a pre-existing condition for no more than 12 months after the person is accepted into the plan.
- It gives certain people the right to buy individual health insurance if no group health plan coverage is available, and the person has exhausted COBRA or other continuation coverage. (For more information on COBRA, see our document *What is COBRA?*) Certain conditions and time limits must be met.
- It does not allow employers or their health insurers to discriminate or act unfairly against employees and their dependents based on their health status or genetic information.
- It guarantees certain people the ability to get or renew individual health insurance coverage.

HIPAA also protects privacy and gives you more access to your medical records.

In 2002, the HIPAA laws were expanded to give patients greater access to their own medical records. The expanded law also gave patients more control over how their personally identifiable health information is used. In general, health information may not be shared without written permission of the patient. The law requires health care providers and health insurance plans to protect the privacy of patient health information, too. Medical records must be kept under lock and key and are available only on a need-to-know basis.

What doesn’t HIPAA do?

Even though HIPAA offers protections and makes it easier to switch jobs without fear of losing health coverage for a pre-existing condition, the law has limits. For instance, HIPAA:

- Does not require employers to offer health coverage, though the new health care law will require some to offer it
- Does not require employers that offer coverage for employees to also cover their families or dependents
- Does not guarantee that you can afford the health coverage your employer offers
- Does not keep an employer from imposing a pre-existing condition exclusion period if you have been treated for a condition during the past 6 months and have had an interruption in your coverage (group plans can’t do this after January 1, 2014)
- Does not replace your state as the main regulator of insurance where you live

Even so, HIPAA has generally made it much easier to switch health plans or change jobs without losing coverage if you have a health problem.

HIPAA, pre-existing condition exclusions, and creditable coverage

The following questions and answers apply to grandfathered plans, those that existed before September 23, 2010. Check with your employer to find out your health care plan’s start date, to learn if it’s grandfathered. If it isn’t, this section does not apply to you.

How does HIPAA limit the pre-existing condition exclusion of group or employer health insurance coverage?

It counts “creditable” health coverage against the pre-existing condition time.

Under HIPAA, a group health plan may not impose a pre-existing condition exclusion if the person has had *creditable medical coverage* for at least 12 months as long as the person had no more than 63 days with no coverage. (Creditable coverage refers to health insurance, and includes most health coverage, such as a group health plan, HMO, individual health insurance policy, Medicaid, or Medicare.) If the coverage was for less than 12 months, the pre-existing exclusion period may be reduced by the number of months of prior creditable coverage.

Example: Maria completed her cancer treatment 2 months ago. She had health coverage for the 14 months before she left her job 6 weeks ago, which means she would have 14 months of creditable coverage. The 42 days she went without insurance doesn't qualify as a "significant break" in coverage. She would have no pre-existing condition exclusion at her new job if she signs up for insurance there, but she must sign up before she has had 63 days without insurance.

It only allows exclusion of pre-existing conditions for which you were seen or treated in the past 6 months.

A group health plan may only impose a pre-existing condition exclusion on new enrollees for conditions for which medical advice, diagnosis, care, or treatment was received or recommended within the 6-month period before their enrollment date (called the 6-month "look-back" period). A person's enrollment date is the earlier of either the first day of coverage or the first day of any waiting period for coverage.

If you had a medical condition in the past, but have not received any medical advice, diagnosis, care, or treatment for it within the 6 months before your enrollment date in the plan, that condition cannot be considered a pre-existing condition. (Check with your state's Insurance Commissioner's Office to see if a shorter look-back period might apply to you.)

Example: Alana was diagnosed with lobular breast carcinoma in situ 4 years ago. She didn't need treatment, but she was told to follow up every year with her oncologist. She saw her doctor a year ago. Then 10 months later, she found a job and signed up for their group insurance. Her breast carcinoma would not be considered a pre-existing condition because she has had no treatment nor was treatment recommended for her in the 6 months before she enrolled. Her break in coverage does not come into play because she is not considered to have a pre-existing condition.

It sets a maximum length of 12 months on pre-existing condition exclusions if you don't enroll late into the new plan.

HIPAA also sets a maximum of 12 months which a group health plan may impose as a pre-existing condition exclusion period – even if the person has been uninsured up to this point. This means people will not be punished for getting care for chronic and life-long illnesses in the past.

Example: Joseph has been out of work for 5 months, and has been uninsured during that time. Last month, he learned he had prostate cancer. Joseph's prior coverage is not creditable because his break in coverage was more than 63 days. And, since he was given a diagnosis and/or medical advice about it during the past 6 months, his pre-existing cancer can be excluded for up to 12 months. But if he signs up for the health plan, any cancer treatment he gets after the year has passed would be covered**.**

Are there “pre-existing conditions” that cannot be excluded from coverage under HIPAA?

Yes. As of January 1, 2014, the ACA prohibits pre-existing condition exclusions in new plans.. Older individual plans (called grandfathered plans) may still use the old rules and exclude pre-existing conditions. However, pregnancy cannot be considered a pre-existing condition. Further, genetic information may not be considered a pre-existing condition if no related diagnosis has been made, regardless of whether the plan is new or grandfathered.

Since I’ve had cancer I want to focus on a new career path. How do I know if my cancer is subject to a pre-existing condition exclusion period in the plans offered at my new job?

Many plans cover pre-existing conditions right away. A plan must tell you if it has a pre-existing condition exclusion period. It can exclude coverage for a pre-existing condition only after you have been notified. The plan must also tell you about your right to show that you had prior health insurance coverage (creditable coverage) to shorten the pre-existing condition exclusion period.

If the plan does have a pre-existing condition exclusion period, the plan must decide about your insurance coverage and the length of any pre-existing condition exclusion period that applies to you. In general, a plan must make this decision within a reasonable time after you provide a certificate or other information that shows you had prior insurance coverage.

You must be notified of this decision if, after looking at all the evidence of creditable coverage you’ve had recently, the plan decides to impose an exclusion period for your pre-existing condition. (Creditable coverage includes most health coverage, such as a group health plan, HMO, COBRA, an individual health insurance policy, Medicaid, Medicare, TRICARE, CHAMPUS, Veteran’s Health Coverage from the VA, or Indian Health Service. It does not include long-term care policies, dental or vision-only plans, supplemental coverage, or cancer-only policies.) The notice must also tell you the reason for the decision, the information the plan used in making the decision, and any appeals that may be available to you.

The plan may change its first decision if it later finds that you did not have the creditable coverage you claimed. In this case, the plan must tell you about this change. And until a final decision is made, the plan must act according to its first decision about covering medical services.

How do newly hired employees prove that they had prior health coverage to be credited under HIPAA?

Under HIPAA, an employee's former group health plan and any insurance company or HMO providing such coverage is required to give the employee a statement of prior health coverage. This is called a *certificate of creditable coverage*.

This certificate must be given to you when you lose coverage under the plan or otherwise become eligible for COBRA health insurance coverage. It must also be given to you when you stop working or when your COBRA coverage stops. COBRA (Consolidated Omnibus Budget Reconciliation Act) is the name of a federal law that gives workers or their family members a chance to buy group health coverage through their employer's health plan for a limited period of time (18, 29, or 36 months) if they lose coverage due to certain events, including the end of employment, divorce, or death.

You may request a certificate for up to 24 months after your coverage ended. You also may request a certificate even before your coverage ends.

For more information on COBRA see our document *What Is COBRA?*

I have my certificate from my former plan. What do I do now?

You should:

- Make sure the information on the certificate is correct. Contact the plan administrator of your former plan if any information is wrong.
- Keep the certificate in case you need it. You will need the certificate if you enroll in a grandfathered group health plan that has a pre-existing condition exclusion period or if you buy an individual health policy from an insurance company.

Can my old plan simply call my new plan to give them information about my creditable coverage for HIPAA?

Yes. If you, your new plan, and your old plan all agree, the information may be transferred by telephone. You are also entitled to ask for a written certificate for your records when your coverage information is given over the phone or by other means.

My employer has a waiting period for enrollment in the health plan. Does this change the pre-existing condition exclusion period under HIPAA?

The HIPAA law does not stop a plan or company from having a waiting period for health insurance enrollment. For group health plans, a waiting period is the period that must pass before an employee or a dependent can enroll in the health plan. If a plan has both a waiting period and a pre-existing condition exclusion period, the pre-existing condition exclusion period begins when the waiting period begins.

Example: If your company has a 4-month waiting period and a 6-month pre-existing exclusion period, your pre-existing condition exclusion is still only 6 months total. You have only 2 months of pre-existing exclusion time left if you sign up after the 4-month waiting period. (Of course, if you had prior creditable coverage, you might have no pre-existing exclusion time left after the 4-month waiting period, as noted above.)

Does the new health law change the waiting period?

Starting January 1, 2014, the waiting period for eligible employees to enroll in an available group health care plan can't be longer than 90 days.

I changed jobs and the group health plan there imposes a pre-existing condition exclusion period. How does my new plan decide how long my pre-existing condition exclusion period will be under HIPAA?

A grandfathered health plan may impose a pre-existing condition exclusion period only if you did not have creditable health insurance coverage in your old job, or you were without coverage for more than 63 days.

The maximum length of a pre-existing condition exclusion period is 12 months after the enrollment date, or 18 months in the case of a "late enrollee." (A late enrollee is a person who enrolls in a plan after the earliest date on which coverage can become effective under the terms of the plan. If you enroll during an open enrollment period or due to a family change, you are not considered a late enrollee.) This 12- or 18-month period may be shorter in some states due to differences in state laws. Check with your State Insurance Commissioner's Office to see whether your exclusion period might be shorter.

A plan must shorten a person's pre-existing condition exclusion period by the number of days the person had creditable health insurance coverage before. But if you were without coverage for 63 days or more (called a *significant break in coverage*), HIPAA does not require the new insurance plan to count any days of creditable coverage that came before the break. Keep in mind that some states may require employers to count coverage that

came before a break that was longer than 63 days. Check with your State Insurance Commissioner's Office to see whether your state lets coverage count even though it's been a longer time since you had it. (See the "To learn more" section to find out how to get contact information.)

I started a new job 45 days after my previous group health plan coverage ended. That coverage lasted 24 continuous months, during which I had cancer treatment. Will any future cancer claims be subject to the 12-month pre-existing condition exclusion period imposed by my new employer's plan?

Not if you enroll when you are first eligible for the grandfathered health insurance plan, as long as you have no future breaks in coverage longer than 63 days. The 45-day break in coverage does not count as a significant break in coverage under HIPAA. Under federal law, a significant break in coverage is at least 63 consecutive days. Since you had more than 12 months of creditable coverage from your previous group plan without a significant break, you would not be subject to the pre-existing condition exclusion period imposed by your new employer's plan if you enroll when you are first eligible.

How can I avoid a 63-day break in coverage to keep HIPAA protection?

There are some things you can do to avoid coverage breaks.

- If your last coverage was very recent, and you were under a group health plan, you may be able to elect COBRA continuation coverage. Workers in companies with 20 or more employees generally qualify for COBRA. Some states have laws much like COBRA that apply to smaller companies. (See our document called *What is COBRA?* for details.)
- If you are married, you can try to get onto your spouse's group policy at work soon after losing your own.
- You can try to buy an individual health insurance policy.

HIPAA, your health history, and health insurance coverage

The following questions and answers apply to grandfathered plans, those that existed before September 23, 2010. Check with your employer to find out your health care plan's start date, to learn if it's grandfathered. If it isn't, this section does not apply to you.

Under HIPAA, can I lose or be charged more for coverage if my health changes? I have been treated for cancer.

Group health plans and issuers may not set up rules for one person's eligibility (including continued eligibility) to enroll under the terms of the plan based on "health status-related factors." These factors include your health status, medical conditions (physical or mental), past medical claims, receipt of health care, medical history, genetic information, and evidence of insurability or disability. For example, you cannot be excluded or dropped from coverage under your group health plan just because you develop cancer.

Also, group plans and issuers may not require a person to pay a premium or contribution that's greater than that for a similarly situated person based on a health status-related factor. So, you cannot be charged more just because you've had cancer in the past. On the other hand, if the employer raised everyone's rates or completely stopped offering health coverage, it would not violate HIPAA.

Can a group health plan or group health insurance issuer require me to pass a physical exam before I can enroll in the plan? I have some side effects from the cancer treatment that may take a long time to go away.

No. A group health plan or group health insurance issuer cannot make you pass a physical exam for enrollment. Even if you're a late enrollee, you cannot be required to pass a physical exam to get coverage.

My group health plan requires that I complete a detailed health history questionnaire and subtracts Health Points for prior or current health conditions. In order to enroll in the plan, I must score 70 out of 100 total points. I scored only 50 points and was denied eligibility in the plan. Is this allowed?

No. But the HIPAA non-discrimination provisions do not automatically forbid health care questionnaires. It depends on how the information on them is used. In this case, the plan

requires people to score a certain number of Health Points that are related to current medical conditions in order to enroll in the plan. This is not allowed and is considered discrimination in rules for eligibility based on a health factor.

My group health plan has a 12-month pre-existing condition exclusion period but, after the first 6 months, the exclusion period is dropped for people who have not had any claims since enrollment. Is this allowed under HIPAA?

No. A group health plan may impose a pre-existing condition exclusion period, but the exclusion must be applied in the same way to all similarly situated people. Here, the plan's provisions do not apply uniformly because people who have medical claims in the first 6 months after enrollment are not treated the same as those with no claims during that time. This means the plan provision violates the HIPAA non-discrimination provisions.

My group health plan excludes coverage for benefits for a health condition that I have (no matter whether it pre-existed or not). Is my plan violating HIPAA's non-discrimination provisions by imposing this exclusion?

Group health plans may decide not to cover a certain disease. They may limit or exclude benefits for certain types of treatments or drugs, or limit or exclude benefits based on their decision of whether the benefits are experimental or medically needed. But they can only do this if the benefit restriction is applied uniformly to all people in similar situations and is not directed at anyone in the plan based on a health factor. So, if the same standard applies to everyone in the group, it may be allowed. An example might be coverage of a treatment that has not been scientifically proven.

My health plan had a $500,000 lifetime limit on all benefits covered under the plan. The plan also had a $5,000 annual limit on all benefits provided for one of my health conditions. Are these limits allowed under HIPAA?

HIPAA no longer governs these issues, but the Affordable Care Act (ACA) passed in 2010 does. Lifetime limits are not allowed in any plan, even grandfathered plans.

I like to sky-dive. Can I be excluded from enrolling in my employer's health plan because I sky-dive?

No. You may not be denied eligibility to enroll in your employer's plan because you sky-dive. But sky-diving injuries might not be covered under your health plan. See below.

Can my health plan or issuer deny benefits for an injury based on the source of that injury? When my mother developed cancer, I became very depressed and I took an overdose of sleeping pills.

If the injury results from a medical condition or an act of domestic violence, the health plan or issuer may not deny benefits for the injury, as long as it's an injury the plan would otherwise cover.

For example, a plan may not exclude coverage for self-inflicted injuries (or injuries resulting from attempted suicide) for a person in the plan if the injuries are otherwise covered by the plan and if the injuries are the result of a medical condition, such as depression.

But a plan or issuer is not required to cover injuries that do not result from a medical condition or domestic violence. This means that injuries sustained in high-risk activities, such as bungee jumping, sky-diving, or whitewater rafting may not be covered.

Still, a plan cannot exclude people from enrollment because of their high-risk hobby. And it would still cover treatment for other medical conditions that were not related to the high-risk activity. Check with your insurance plan about their coverage of injuries related to risky sports.

I have a history of high claims. As a person with cancer, I've had 3 different types of treatment and many medicines. Can I be charged more than similarly situated people based on my claims?

No. Group health plans and group health insurance issuers cannot charge one person more for coverage than a similarly situated person based on any health factor.

Making benefits claims

Do you have any tips on filing a health benefits claim?

Yes. The first step you should take even before filing a claim is to carefully read your health plan's summary plan description (SPD). This is a document that your health plan administrator must give you (in writing or electronically) after you join the health insurance plan. This plan summary will tell you how the plan works, what benefits it provides, and how the benefits may be obtained or the process for filing your claim. It should also describe your rights and protections under ERISA (the Employee Retirement Income Security Act).

Each SPD should show you the procedure for filing a claim. Some plans may require you to file a claim (or get *prior authorization*, which is permission for treatment) before you can get medical treatment. Some have special rules for urgent (emergency) care. For other plans, you must turn in a claim for reimbursement (to get paid back the covered portion) after you pay for the care yourself.

Follow the steps outlined in your SPD when filing your claim. If you cannot find the steps, or don't understand them, call your plan administrator. You may also contact the Department of Labor's Employee Benefits Security Administration to help you understand your rights; see the "To learn more" section for contact information.

Your plan should state the time within which it must give you the decision on each claim you turn in. Be sure to look for this time limit in your SPD. When you submit a claim to your plan, note the date and keep track of the time as you wait for a decision. Some plans have different time periods depending on the nature of the benefit claim. For example, the claim for urgent care may be different and the claim may be filed before or after medical care is received. If you don't get a response from your plan within the stated time period, contact your plan administrator. See our document *Health Insurance and Financial Assistance for the Cancer Patient* for more information.

What if my claim is denied?

Your plan may deny a claim for many reasons. For example, you may not have yet paid the amount of the yearly deductible. The requested treatment may be something the plan says is not covered or medically needed. Or you may not have given enough information for the plan administrator to process the claim. Look for the reason and other information provided in the notice of denial so that you can figure out if you want to appeal the decision.

If they deny a claim, your insurer must explain your right to appeal their decision. If you ask for it, they must give you all the information about the decision. Plans that were

started before September 23, 2010 are still under the old rules of coverage (grandfathered plans), although the way you appeal the denial will be the same as for newer plans.

Before you appeal, you may want to take these steps:

- Ask for a full explanation of why the claim was denied.
- Review your health insurance plan's benefits. This may require looking at the more detailed Summary of Benefits notice.
- Contact your health plan administrator to find out more about the refusal.
- Ask the doctor to write a letter explaining or justifying what was done or what's being requested.
- Ask your insurer if your employer's health plan is self-insured, and on what date the plan started. (This is to learn if the ACA requirements apply or if the plan is grandfathered.) This will help you figure out which rules apply and which appeals process to follow.
- Talk to your state insurance department or commission, which regulates your insurance company, to verify that the insurance company has acted properly and that the denial has not been made in error. (Check the blue pages of your local phone book or visit the National Association of Insurance Commissioners online at www.naic.org/state_web_map.htm.)

You can then re-submit the claim with a copy of the denial letter and your doctor's explanation, along with any other written information that supports using the test or treatment that's been denied. Sometimes the test or service will only need to be coded differently to be paid.

If questioning or challenging the denial in these ways doesn't work, you may need to:

- Put off payment until the matter is resolved. Keep the originals of all the letters you get; your cancer care team may be able to help you make copies if you need them.
- Keep a record of dates, names, and conversations you have about the denial.
- Formally request an *internal appeal* (or *internal review*) which is done by the insurance company. Complete any forms the insurer requires, or write them a letter explaining that you're appealing the insurer's denial. Include your name, claim number, and health insurance ID number, along with any extra information such as a letter from your doctor. Your cancer care team may be able to help with this.
- You have 6 months (180 days) from receiving your claim denial to file an internal appeal.

- Find out if you live in one of the US states that also have a special Consumer Assistance Program (CAP) that can help you file an appeal.
- If you don't live in a CAP state, get help from the consumer services division of your state insurance department or commission. Check the blue pages of your phone book or contact the National Association of Insurance Commissioners online at http://naic.org/state_web_map.htm, or you can call them at 1-866-470-6242.
- If your internal appeal is denied, find out about getting an external review. See our document called *Health Insurance and Financial Assistance for the Cancer Patient* for more information.

You also may wish to get in touch with the Department of Labor's Employee Benefits Security Administration about your rights under ERISA. See the "To learn more" section for contact information. You can learn more about claim denials in our document called *Health Insurance and Financial Assistance for the Cancer Patient*.

HIPAA and certain policy provisions

Is it OK for a health insurance issuer to charge a higher premium to one group health plan that covers people with costly health problems, than it charges another employer for their group health plan which covers fewer people with costly health problems?

As of 2014, health plans are no longer be able to take health factors into account when determining rates. Only age and where you live can be used to determine the cost of a plan.

My group health plan has a "non-confinement provision." It states that if a person is confined to a hospital at the time they would normally become eligible for enrollment, they aren't eligible until they leave the hospital. What if I'm in the hospital with a low white cell count due to chemotherapy at the time I become eligible for enrollment? Is this allowed?

No. Even grandfathered group health plans may not restrict a person's eligibility, benefits, or the effective date of coverage based on the person being in a hospital or other health care facility. Also, a health plan may not set a person's premium based on their being in the hospital.

Information sharing

What kinds of information do group health plans have to give to participants and beneficiaries under HIPAA?

HIPAA and other laws have made important changes under the Department of Labor disclosure rules. Under these rules, group health plans must improve the documents employers are required to give to employees at certain key intervals, such as summary plan descriptions (SPDs) and summaries of material modifications (SMMs) to make sure they:

- Inform participants and beneficiaries of “material reductions in covered services or benefits” (for example, reductions in benefits or increases in deductibles and co-payments), generally within 60 days after the change is adopted.
- Give participants and beneficiaries information about the role of issuers (such as insurance companies and HMOs) with respect to their group health plan. For instance, they must include the name and address of the issuer, whether and to what extent benefits under the plan are guaranteed under a contract or policy of insurance issued by the issuer, and the nature of any administrative services (for example, payment of claims) the issuer provides.
- Tell participants and beneficiaries which Department of Labor office they can contact for help or information on their rights under ERISA (Employee Retirement Income Security Act) and HIPAA.
- Tell participants and beneficiaries that federal law generally prohibits the plan and health insurance issuers from limiting hospital stays for childbirth to less than 48 hours for normal deliveries and 96 hours for Cesarean sections.

The new health care law (ACA) requires plans to provide a Summary of Benefits and Coverage (SBC), a short and simple summary of coverage with coverage examples that help people make “apples to apples” comparisons of different coverage options.

Can employers use e-mail to give this information to employees? If so, do employees still have a right to get a paper copy of their health plan information?

Yes to both questions. The disclosure rules provide a “safe harbor” for using electronic media (e-mail) to share summary plan descriptions (SPDs) and summaries of material modifications (SMMs). But employees must be able to get the electronic documents at their worksite (there are also some other requirements). Participants also have the right to get the information on paper free of charge when they ask for it.

Who enforces HIPAA?

States enforce the legal requirements on health insurance issuers. If a state does not act in its areas of responsibility, the Secretary of Health and Human Services may decide that the state has failed to “substantially enforce” the law. Federal authority can be used, through the Centers for Medicare and Medicaid Services, to enforce the law and penalize the insurers.

The US Secretary of Labor also has the authority to enforce the health care portability requirements on group health plans under ERISA (Employee Retirement Income Security Act), including self-insured arrangements. And participants and beneficiaries can file lawsuits to enforce their rights under ERISA, as amended by HIPAA.

Can states change HIPAA’s insurance requirements?

The following answer applies to grandfathered plans, those that existed before September 23, 2010. Check with your employer to find out your health care plan’s start date, to learn if it’s grandfathered. If it isn’t, this section does not apply to you.

Yes, in certain circumstances. States may impose stricter requirements on health insurance issuers in the 7 areas listed below. States may:

- Shorten the 6-month “look-back” period before the enrollment date to decide what’s a pre-existing condition
- Shorten the 12-month maximum pre-existing condition exclusion periods (or the late enrollee’s 18-month maximum condition exclusion)
- Count prior insurance coverage as creditable even though there’s been more than a 63-day break in coverage
- Increase the 30-day period for newborns, adopted children, and children placed for adoption to enroll in the plan so that no pre-existing condition exclusion period may be applied thereafter
- Further limit the circumstances in which a pre-existing condition exclusion period may be applied beyond the exceptions described in federal law. (The “exceptions” under federal law are for certain newborns, pregnancy, and genetic information in the absence of a diagnosis.) Also remember that the Affordable Care Act law does not allow insurance plans to deny coverage based on pre-existing conditions.
- Require more periods of special enrollment

- Reduce the maximum HMO affiliation period to less than 2 months (3 months for late enrollees)

States may sometimes impose other requirements on insurance companies and HMOs. If your health coverage is offered through an HMO or an insurance policy issued by an insurance company, you can check with your state insurance department's office to find out the rules in your state. Find your State Insurance Department in the blue pages of your local phone book, or visit the National Association of Insurance Commissioners online at www.naic.org/state_web_map.htm.

Getting and keeping health insurance coverage under HIPAA

The following questions and answers apply to grandfathered plans, those that existed before September 23, 2010. Check with your employer to find out your health care plan's start date, to learn if it's grandfathered. If it isn't, this section does not apply to you.

If I can't get group coverage and have no other options, what do I do?

There's a special provision of the HIPAA law which is intended to allow people to get health coverage after other options are exhausted. But before HIPAA can help a person with no insurance options get coverage, special requirements must be met, and you have to act quickly after you lose your coverage:

- You need to have had 18 months of group health coverage without a break of more than 63 days and your most recent coverage must have been through a creditable health plan.
- You cannot be eligible for Medicare or Medicaid, or be eligible for a group health insurance plan.
- You need to have elected and exhausted (used up) your COBRA coverage or any similar ongoing coverage, or you cannot be eligible for COBRA continuation coverage (or continuation coverage under a similar state program).
- You did not lose your group coverage because of fraud or non-payment of premiums.

People who meet these requirements are called "HIPAA eligible individuals." If you are eligible and act within 63 days of losing your coverage, HIPAA guarantees that you can buy some type of coverage and that you will have a choice of at least 2 options. HIPAA can help those left out of health coverage after they've lost eligibility for group plans and COBRA.

HIPAA does not limit what health insurance companies charge (although some state laws do), but it does assure that some coverage is offered. Again, depending on the health plan and the situation, HIPAA prevents an insurance plan from denying coverage based on a person's health history or a pre-existing condition.

People often do not take advantage of this because they don't know that they're eligible. Sometimes people find out they would have been eligible, but it may not help if the 63-day time limit has passed. If you think you might qualify for this, contact your state insurance department or commission right away to find out what's available to you. You can find your State Insurance Department in the blue pages of your phone book, or visit the National Association of Insurance Commissioners online at www.naic.org/state_web_map.htm.

What if I can't afford the premiums for an individual insurance policy? Things have been pretty tight since my wife has been diagnosed with cancer.

HIPAA does not limit premium rates. HIPAA does not have control over state laws that regulate the cost of insurance. But the ACA does not allow companies to charge more for a plan based on health status or history. Under the ACA, people below certain income levels may qualify for help buying an individual policy. For information on how your state law may limit premium rates for individual insurance policies, contact your State Insurance Commissioner's Office. You can also find more information in our document *Health Insurance and Financial Assistance for the Cancer Patient*.

Is my individual insurance policy renewable? Can it be taken away?

It's generally your option to renew or continue individual health coverage. Most individual health insurance policies expire each year and must be renewed. Federal and state laws do not allow insurers to refuse to renew health insurance policies because of the health status of the individual. Note that this is not true of short-term policies that are sold as non-renewable (see below).

There are some exceptions to the guaranteed renewability of a policy if the insurer is unable to meet their financial obligations or leaves the market. Your insurance may also be canceled or discontinued if you failed to pay premiums, committed fraud, terminated the policy, or moved outside the service area. Note that the Affordable Care Act does not allow insurance companies to retroactively take away a person's legitimate (paid-up) health insurance because of a small technical error or mistake on the application.

Some insurers sell short-term policies that are clearly marketed as non-renewable. If you buy a short-term non-renewable policy and then get sick, you will not have the right to renew the policy when it expires.

If I change jobs, can HIPAA guarantee the same benefits that I have under my current plan?

No. When a person moves into a new plan, the benefits the person receives will be those provided under the new plan. Coverage under the new plan can be different from the coverage under the former plan. However, the ACA sets up certain requirements for what new health insurance plans must cover.

Does HIPAA require employers to offer health coverage or require plans to provide specific benefits?

No. An employer voluntarily provides health coverage. HIPAA does not require specific benefits nor does it bar a plan from restricting the amount or nature of benefits for groups of people in similar situations. The ACA requires some employers to offer health coverage and also cover certain basic benefits. For more on these points, see our document called *Health Insurance and Financial Assistance for the Cancer Patient*.

Does HIPAA extend COBRA continuation coverage?

In general, no. But HIPAA makes 2 changes to the length of the COBRA continuation coverage period.

- Qualified beneficiaries who are found to be disabled under the Social Security Act within the first 60 days of COBRA continuation coverage will be able to buy an additional 11 months of coverage beyond the usual 18-month coverage period. This extension of coverage is also available to non-disabled family members who are entitled to COBRA continuation coverage.
- COBRA rules now ensure that children who are born or adopted during the continuation coverage period are treated as “qualified beneficiaries” in plans that offer family or dependent coverage.

Even though it doesn’t extend COBRA, HIPAA may still help you if you’ve used all of your COBRA coverage and are not eligible for other kinds of insurance. You may qualify for special HIPAA eligibility for other health coverage. See the section called “If I can’t get group coverage and have no other options, what do I do?” for more information.

Does HIPAA apply to self-insured group health plans?

Yes.

Glossary of terms

Affordable Care Act of 2010 (ACA) or the Patient Protection and Affordable Care Act (PPACA): A federal law aimed at increasing the number of people with health insurance, which also offers certain protections for those who buy health insurance. Parts of it start at different times until it's in full effect in 2015.

Certificate of creditable coverage: A written certificate issued by a group health plan or health insurance issuer that shows a person was covered under that health plan. A certificate must be issued automatically and free of charge when an individual loses coverage under a plan, when an individual is entitled to elect COBRA continuation coverage, and/or when a person loses COBRA continuation coverage. A certificate must also be provided free of charge upon request while the individual has health coverage or within 24 months after their coverage ends. See also *Creditable coverage*.

COBRA (Consolidated Omnibus Budget Reconciliation Act): COBRA gives a person who loses their health benefits in certain circumstances the right to choose to keep group health benefits provided by their health plan for a limited time. COBRA allows the employee to buy health insurance back from the employer even though they no longer work there or no longer work full-time. When COBRA coverage runs out, some people have special eligibility for individual health coverage.

COBRA also lets family members choose to keep health insurance after your job loss or other *qualifying event* that would normally cause them to lose the coverage they have through your employer. COBRA applies to nearly all employers with 20 or more employees. See the section "If I can't get group coverage and have no other options, what do I do?" under "Getting and keeping health insurance coverage under HIPAA."

Creditable coverage: This can be health coverage of an individual under a group health plan, (including while on COBRA continuation coverage), individual health insurance coverage, Medicare, Medicaid, a state health insurance risk pool, a public health plan, and certain other health programs. It may be used to offset time from any pre-existing condition exclusion if no significant break in coverage (generally 63 days) happened before starting a new group health plan.

ERISA (Employment Retirement Income Security Act of 1974): ERISA is a federal law that oversees employee benefit plans (such as group health plans) that private sector employers, employee organizations (such as unions), or both, offer to their workers and families.

Enrollment date: The first day of coverage or, if there's a waiting period, the first day of the waiting period. For people who enroll when first eligible, the enrollment date is often the first day of employment.

Explanation of benefits (EOB): A written document that explains what part of a medical or health claim was paid and/or what was not. There may also be information on how to start an appeal.

Fully insured group health plan: A health insurance plan an employer or union buys from an insurance company, an HMO, or a health care service plan. Benefits, premiums and other aspects of the plan are subject to state regulation. Compare with *self-insured group health plan*.

Genetic information: Information about genes, gene products, and inherited characteristics that may come from the individual or a family member. This includes information about carrier status and information from lab tests that identify mutations in specific genes or chromosomes, physical medical exams, family histories, and direct testing of genes or chromosomes.

Group health plan: An employee benefit plan set up or maintained by an employer or by an employee organization (such as a union), or both, to the extent that the plan provides medical care to employees or their dependents directly or through insurance, reimbursement, or otherwise.

Health insurance issuer: An insurance company, insurance service, or insurance organization (including an HMO), that's required to be licensed to engage in the business of insurance in a state and that's subject to state laws that oversee insurance.

Late enrollee: A late enrollee is a person who does not enroll in a plan on the earliest date on which coverage can become effective under the terms of the plan or does not enroll during a special/open enrollment period. Under HIPAA, a late enrollee may be subject to a maximum pre-existing condition exclusion of up to 18 months.

Pre-existing condition exclusion: A limitation or exclusion of health coverage for a condition based on the fact that the condition was present before the first day of coverage.

Pre-existing Condition Insurance Plan (PCIP): Programs in each state that offer insurance to people who have been unable to get it because of a pre-existing condition. These programs stopped accepting new enrollees in 2012. They end in 2014, when insurers must begin to cover adults with pre-existing conditions.

Self-insured group health plan: Plans set up by employers or unions which put aside funds to pay their employees' health claims, and the employer or union is acting as its own insurer. Self-insured plans often hire insurance companies to administer them (for instance, handling enrollment, paying claims, etc.), so the insurance company may be mistaken for being the actual insurer. Employers must let health plan enrollees know if an insurance company is responsible for actually insuring them or only for administering the

plan. If the insurer is only administering the plan, it's self-insured. The US Departments of Labor and Treasury regulate self-insured plans under ERISA; they are not subject to state law.

Significant break in coverage: As defined by HIPAA, a break in coverage of 63 days or more. May be longer if your state law allows the break in coverage to be longer while still counting the previous creditable coverage time.

SPD: A **summary of the plan description** of the health insurance policy.

SMM: Summary of material modifications is information (often a document) that employers are required to give to employees. The SMM informs participants and beneficiaries of "material reductions in covered services or benefits" (for example, reductions in benefits or increases in deductibles and co-payments), generally within 60 days of putting the changes into practice.

Waiting period: The period of time that an employer sets which must pass before an employee or dependent is eligible to be covered under the terms of a group health plan.

To learn more

More information from your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

Health insurance

Health Insurance and Financial Assistance for the Cancer Patient (also in Spanish)

The Health Care Law: How It Can Help People With Cancer and Their Families (also in Spanish)

What Is COBRA? (also in Spanish)

Medicare Part D: Things People With Cancer May Want To Know

Children Diagnosed With Cancer: Financial and Insurance Issues

Clinical Trials: State Laws Regarding Insurance Coverage

Medicare Coverage for Cancer Prevention and Early Detection (also in Spanish)

Women's Health and Cancer Rights Act (also in Spanish)

Keeping your job

Americans With Disabilities Act: Information for People Facing Cancer (also in Spanish)

Family and Medical Leave Act (FMLA) (also in Spanish)

Financial issues

Prescription Drug Assistance (also in Spanish)

How to Find a Financial Planner Sensitive to Cancer Issues: Financial Guidance for Cancer Survivors and Their Families

In Treatment: Financial Guidance for Cancer Survivors and Their Families (also in Spanish)

Off Treatment: Financial Guidance for Cancer Survivors and Their Families

Advanced Illness: Financial Guidance for Cancer Survivors and Their Families

Can I Be Prepared If Cancer Occurs?: Financial Guidance for Those With Concerns About Cancer

Living with cancer

Patient's Bill of Rights (also in Spanish)

After Diagnosis: A Guide for Patients and Families (also in Spanish)

National organizations and websites*

Along with the American Cancer Society, other sources of information and support include:

US Department of Labor, Employee Benefits, Security Administration (EBSA)
Toll-free number: 1-866-444-3272 (1-866-444-EBSA)
Website: www.dol.gov/ebsa

> For information on COBRA, FMLA, and HIPAA requirements of employer-based insurance coverage; self-insured health plans; and information for military reservists who must leave their private employer for active duty

Cancer Legal Resource Center (CLRC)
Toll-free number: 1-866-843-2572 (may need to leave a number for a call back)
TTY: 213-736-8310
Website: www.cancerlegalresourcecenter.org

Provides free and confidential information and resources on cancer-related legal issues, including health insurance coverage and denial of benefits, to cancer survivors, their families, friends, employers, health care professionals, and others coping with cancer

US Department of Health and Human Services (DHHS)
Toll-free number: 1-877-696-6775
Website: www.healthcare.gov

For the most current information on health care laws and insurance changes, and how they might affect you. The main DHHS web site is www.hhs.gov, which has more general health and regulatory information. This federal agency is responsible for protecting the health of all Americans and providing essential human services; it offers information on the Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), Indian Health Service (IHS) and more

National Association of Insurance Commissioners
Toll-free number: 1-866-470-6242
Website: http://naic.org/state_web_map.htm

Has information on how to find your state's Insurance Commissioner, information about insurance and insurance companies, and how to file a consumer complaint with state insurance departments

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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For additional assistance please contact your American Cancer Society
1-800-227-2345 or www.cancer.org