What Cancer Survivors Need To Know About

HEALTH INSURANCE

Types of Health Insurance

Know Your Rights and Their Limits

Using Your Health Coverage

Where to Find Help and Information

A publication of the

NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

Legal Disclaimer

This publication has been created by the National Coalition for Cancer Survivorship (NCCS) to provide cancer survivors and their loved ones general information about health insurance. This publication represents the authors' opinions regarding the subject matter covered. This publication is not designed to provide individual legal advice nor to substitute for professional counsel.

Seventh Edition

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ABOUT THE NATIONAL COALITION FOR CANCER SURVIVORSHIP

Founded by and for cancer survivors in 1986, the National Coalition for Cancer Survivorship (NCCS) created the widely accepted definition of survivorship and considers someone a cancer survivor from the time of diagnosis through the balance of life. As the oldest survivor-led cancer advocacy organization, NCCS's mission is to advocate for quality cancer care for all people touched by cancer. NCCS focuses on advancing public policy issues that affect cancer survivors and on providing tools and resources to empower people to advocate for themselves.

To learn more about NCCS, visit **www.canceradvocacy.org.**

Please Note: Find the meaning of words shown in ***blue type*** throughout this text in the "Glossary of Terms" on pages 38–42.

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WHAT CANCER SURVIVORS NEED TO KNOW ABOUT HEALTH INSURANCE

When cancer strikes, you may start thinking about health insurance in a new light. You will probably use your health insurance more than ever before. You also may have more problems with insurance than ever before. Therefore, it is critical that you know and understand your rights and responsibilities under your health insurance plan.

In this guide we discuss several aspects of health insurance that are important to cancer survivors. First, we describe the many different types of health insurance that are available. Next, we discuss what you should look for when you choose health insurance, where you can obtain coverage, and the rights you have under state and federal law when you seek health insurance. Then, we look at things you need to keep in mind when using your coverage, including your rights and where to go for help when your insurance plan refuses to pay for your health care. Finally, we list places you can turn to for information on how to solve your health insurance problems and provide a glossary of terms and definitions for reference.

The information in this booklet reflects the significant changes to health insurance that will happen or have already happened during implementation of the *Patient Protection and Affordable Care Act of 2010* (frequently referred to as "PPACA" or "ACA"). As the law is being implemented, cancer survivors will need to understand the new rights and coverage changes they already enjoy, as well as the further rights and responsibilities they will encounter when more of the law's provisions go into effect in January, 2014. This guide was published in early July 2012, just days after the June 28, 2012 Supreme Court decision that upheld the constitutionality of most of the law. The Supreme Court decision made a key change to the Medicaid expansion provision of the law, which may limit the availability of coverage for low-income individuals in 2014 (described in further detail on page 13). While ongoing developments in implementation of the law may require future updates, most of the information provided here should remain useful in helping readers understand the types of insurance, how to choose and find insurance, and where to go for help and information.

WHAT KINDS OF HEALTH INSURANCE ARE THERE?

Most people get ***health insurance*** through their employer or a spouse's employer, which is called ***group health insurance,*** or have coverage through ***public health insurance programs,*** particularly Medicare, Medicaid or the Children's Health Insurance Program (CHIP). Others purchase coverage on their own – in what is called the ***non-group or individual market.*** Beginning in 2014, individuals and small employers – generally employers with less than 50 workers – will be able to find coverage through new state-run insurance marketplaces, called ***health insurance exchanges,*** and some people will qualify for help with their health insurance costs for the policies they buy through these exchanges.

TYPES OF HEALTH INSURANCE

It is important for cancer survivors – like everyone else – to have adequate and dependable health insurance. There are many kinds of policies on the market, though not all offer the same protection.

It is best to have ***comprehensive health coverage*** that will pay for all of your basic health care needs such as hospital and doctor care, lab tests, medical equipment, and prescription drugs. Beginning in 2014, most people will be required to have comprehensive health coverage that includes a defined set of ***essential health benefits*** that provide ***minimum essential coverage.*** This requirement is called the ***individual mandate.*** Even before this mandate takes effect, it is important to understand what type of coverage you have, what services your insurance covers, and how much you are likely to pay when you need health care.

Fee-for-service, or ***indemnity*** policies, are what most people think of as traditional insurance. Under these policies you choose your own doctor or hospital, and the insurance company pays a portion of your bill after you meet your deductible. ***Managed care policies,*** by contrast, often require you to get care from their network of participating providers, including doctors, hospitals, and pharmacies. In addition, managed care plans often require their members to designate a ***primary care provider (PCP)*** or "gatekeeper" who must provide a referral for any visits to a specialist, even a specialist in the plan's network. These types of plans are most commonly referred to as ***health maintenance organizations*** or ***HMOs.***

There are advantages and disadvantages to managed care plans. Advantages include lower ***premiums*** and ***out-of-pocket costs,*** no claims to file, and good coverage for preventive and routine care. Disadvantages include a limited choice of health professionals, pharmacies and hospitals, the potential

need to obtain a referral from your PCP to see a specialist, and limited or no coverage for out-of-network care.

There are hybrid policies, sometimes called ***preferred provider organizations (PPOs)*** or ***point-of-service options (POS),*** that offer more flexibility than traditional managed care plans by allowing you to have a choice of getting care from in- or out-of-network providers, often without pre-approval. You should be aware that you usually pay more – sometimes a great deal more, including ***balance billing*** – for care received on an out-of-network basis.

In addition to the types of comprehensive coverage described above, there are other kinds of health insurance policies that you may find for sale. Cancer survivors should be especially careful to understand these policies.

Catastrophic Insurance

Catastrophic policies are limited policies that cover very high medical expenses. Catastrophic policies have very high deductibles. Some people who buy catastrophic policies also open tax-favored ***health savings accounts (HSAs)*** to put aside funds to cover these high deductibles. Cancer survivors should know that beginning in 2014, health plans will be required to cover at least 60 percent of expected health costs for their population of enrollees, which is known as the health plan's ***actuarial value.*** This means that health insurers may design policies with considerable deductibles or cost-sharing requirements – and therefore offer coverage very similar to a catastrophic policy. You will want to assess these plans' deductibles and cost-sharing requirements carefully. As of 2014, however, there will be a limit on the total out-of-pocket costs that cancer survivors and other covered persons will have to pay under their health insurance policy.

In addition, young cancer survivors should know that, beginning in 2014, catastrophic policies sold to people under 30 years old will qualify as sufficient coverage under the individual mandate, even though they don't provide comprehensive coverage or meet other requirements of the ACA. Members of this young group who purchase health insurance plans that do not cover any services, other than three primary care visits per year, until the enrollee has paid a deductible equal to $6,050 (in 2012 dollars) will satisfy the requirements of the individual mandate.

Catastrophic policies and other high-deductible policies usually are often not a good deal for cancer patients or others with serious or chronic diseases. Again, you will want to carefully compare plans and your potential risk for high cost-sharing.

Long-Term Care Insurance

Long-term care insurance provides you with a daily benefit when you can no longer take care of yourself. Whether you live at home, in an alternate care facility, or even a nursing home, a good policy will cover skilled, intermediate, or custodial care. However, the companies that sell these policies may require that you be in fairly good health when you purchase them. For cancer survivors, that generally means at least five years past treatment. Companies may also consider the type of cancer you had when deciding whether you qualify for coverage. Premiums depend on your age and health. If your employer offers long-term care insurance, your health history is likely to play a smaller role in your ability to qualify for this group coverage and the premiums you are likely to pay.

Short-Term, Non-Renewable Policies

Short-term, non-renewable policies, as the name implies, offer coverage only for a limited time (e.g., for 6 months). If you get sick during that time, the insurer can refuse to renew your coverage. Short-term policies can help bridge a gap in insurance coverage and may be a good idea if you are fairly certain that another, more stable source of coverage will be available in the near future. However, these policies should not be mistaken for comprehensive coverage that is guaranteed renewable. This type of policy will still be available in 2014, but it will not enable you to meet the coverage requirement of the individual mandate.

Cancer Insurance

Cancer insurance or other limited benefit policies only pay for costs related to treatment for cancer or other specific diseases. Insurers generally will not sell these policies to cancer survivors and many states have banned or restricted their sale. Most insurance experts recommend buying a good comprehensive policy instead of cancer insurance for the following reasons:

- Comprehensive insurance usually covers the cost of cancer treatment; additional cancer policies usually duplicate coverage from other policies and are an unnecessary expense.
- The premiums for cancer policies are high and the benefits are limited. Cancer policies often do not cover complications from cancer treatment.
- Sales and administrative expenses for cancer policies tend to be much higher than for other policies.

If you choose to purchase cancer insurance, be sure to read the policy carefully. This type of limited-benefit policy will still be available in 2014, but will not enable you to meet the coverage requirement of the individual mandate.

Accident-Only Policies

Accident-only coverage, as the name implies, pays only for care that you need as a result of an accident, not care that is due to illness. Since a good comprehensive policy will cover costs associated with accidents as well as costs related to illness, accident-only policies are not a good value. This type of policy will still be available beginning in 2014, but will not enable you to meet the coverage requirement of the individual mandate.

Supplemental or Hospital Indemnity Insurance

Supplemental insurance or hospital indemnity policies generally pay a cash benefit for each day you are in the hospital. However, the cash benefit will likely be nowhere near the cost of hospital care. These policies are relatively inexpensive and simple to buy and may be appropriate if you want them to cover "extras" – such as transportation costs or other expenses – that come up when you get sick. But they should never be confused with comprehensive coverage. This type of policy will still be available beginning in 2014, but – on its own – will not enable you to meet the coverage requirement of the individual mandate.

Public Coverage

Sometimes you can get health insurance through a government program, instead of from a private employer or directly from an insurance company. Usually you can only get public coverage if you qualify based on your age, your income, or your ***health status. Medicare*** and ***Medicaid*** are the biggest public programs and are available in every state. The ***Children's Health Insurance Program*** is a smaller program – also available in every state – that provides coverage to children whose families earn incomes beyond for the income level allowed for Medicaid eligibility. In addition, residents of all states are able to access a ***Pre-Existing Condition Insurance Plan.*** In a few states, there are other smaller programs that might be able to help you buy affordable health insurance.

Pre-Existing Condition Insurance Plans

Since 2010, citizens and legal residents of all states have been able to join a pre-existing condition insurance plan (PCIP). These policies are available to people who have a pre-existing condition or who have been denied health insurance because of their condition, and have been uninsured for at least six months. The requirement that individuals be uninsured for six months is a major drawback for cancer patients and other patients with serious or chronic preexisting conditions that require immediate or near-term care. However, for cancer patients and survivors who have been uninsured for six months or more, this coverage can enable them to have meaningful health insurance that helps them pay for needed care. Plan names and plan details vary from state to state: in some cases the plan is operated by the state government and in other cases by the federal government. These plans offer comprehensive coverage, and enrollees pay premiums, deductibles and other cost-sharing. PCIP programs cannot exclude your pre-existing condition from coverage. You can learn more about the federally-operated PCIP program, including benefits and premium levels for your state, at www.pcip.gov. If your state operates its own PCIP program, this website can also direct you to your state program.

In 2014, the PCIP program will end, and people in PCIP programs will be able to transition to purchasing health insurance through Health Insurance Exchanges (discussed on page 22). At that time, plans will not be permitted to exclude people based on pre-existing conditions such as cancer.

High Risk Pools

Some states have also operated – and continue to run – ***high risk pools*** where you might be able to buy insurance coverage if a private insurer turns you down. In several of these states, a modest premium subsidy is available if you have a low income. Coverage through high risk pools is often – but not always – less comprehensive than the coverage you could obtain through a PCIP program (assuming you meet the PCIP criteria) and it may cost a lot more. In addition, some state high risk pools may temporarily refuse to cover the pre-existing condition that makes it hard for you to obtain health insurance in the private market. But before health insurance coverage is made widely available in 2014, and if individuals are not eligible for a PCIP plan, these pools may provide a source of needed health insurance coverage. See pages 32–33 for a list of states that offer high risk pools.

Medicare

Medicare is health insurance provided by the federal government. You qualify for Medicare coverage if you are 65 or older and eligible for Social Security benefits, if you are disabled (regardless of age) and have collected Social Security benefits for 2 years, or if you have been diagnosed with permanent kidney failure or Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease) regardless of your age. Medicare will not refuse you coverage or charge you more because of where you live, your age, or how sick you are.

There are several parts to Medicare, as well as options for arranging one's Medicare benefits. Anyone soon to become eligible for Medicare or interested in maximizing their rights and responsibilities as a Medicare beneficiary at any time would be wise to carefully review their needs and options in light of the costs and consequences of their available choices.

Medicare Part A covers care you receive from a hospital, skilled nursing facility, home health agency, or other facility.[1] For most people who qualify for Medicare, there is no premium for Part A. You will, however, have to pay a deductible if you need inpatient hospital care. In 2012, the deductible will be $1,156 per ***benefit period.*** (A benefit period starts the day you go to the hospital and ends when you have not received hospital care for 60 days in a row.) Also, for longer stays in a hospital or skilled nursing facility, you will have to pay coinsurance. Cancer patients should know that Medicare Part A covers chemotherapy drugs when administered in a hospital or skilled nursing facility.

Medicare Part B covers 80 percent of approved medical expenses, such as doctors' charges, lab fees, durable medical equipment, ambulance services, and certain other supplies. In 2012, the standard monthly Part B premium for most enrollees will be $96.40, which is deducted directly from your Social Security check. Medicare enrollees with higher incomes pay somewhat higher premiums, with the highest-income beneficiaries paying an additional $219.80 a month. In addition to 20 percent coinsurance, you will also pay an annual deductible of $140 for covered services. Medicare enrollees with low incomes and assets may qualify for help with Medicare premiums and cost-sharing through the Medicaid program. Medicare premiums and deductibles change year-to-year, based on changes in Medicare spending, so these amounts will change with time.

[1] While Medicare Part A covers home health care services after an inpatient stay, this benefit is limited to 100 days. Medicare Part B covers home health care services once you have exceeded 100 days of home health services. Medicare Part B also covers home health care services for individuals who are homebound and need skilled nursing care, whether or not you have had a hospital stay.

Physicians participating in Medicare "accept assignment." That means they may charge only what Medicare approves. Physicians who do not accept assignment may charge more – a practice known as ***balance billing*** – but cannot charge patients more than 15 percent above what Medicare approves. Some states limit balance billing to an even lower rate. If a provider chooses not to participate in Medicare, a typically rare practice that has been growing in some regions, these limits on their charges do not apply.

Medicare Part B covers some specific cancer-related services. These are:

- Annual wellness visit, with no cost-sharing;
- Annual screening mammograms (starting at age 40), with no cost-sharing;
- Routine pap smear every two years, with no cost-sharing;
- Screening pelvic exams every two years, or every year for women considered at "high risk" for ovarian cancer, with no cost-sharing;
- Colorectal cancer screening for people age 50 and older;
- Prostate cancer screening for men age 50 and older;
- Tobacco-use cessation counseling (8 visits in 12-month period), with no cost-sharing;
- Limited physical, speech, and occupational therapy;
- Limited prosthetic devices, including breast prostheses and surgical bras;
- Ostomy products;
- Routine healthcare costs for beneficiaries involved in a clinical trial, including hospital and physicians' visits, routine lab tests, and costs resulting from problems associated with participation in the trial;
- Clinical laboratory procedures—such as blood tests, urine tests, and cultures; and
- Chemotherapy drugs that are injected intravenously or by intravenous pump, chemotherapy drugs you can take in pill form if they are also available as injectable or infusible drugs, and certain anti-nausea drugs.

Part B does not cover:

- Private duty nursing;
- Any services provided outside of the United States, unless you are close to the border of Canada or Mexico and the closest hospital is in one of those countries;
- Prescription drugs, with a few important exceptions that are mentioned above. Medicare coverage of prescription drugs is described in the section on Part D;
- Syringes or insulin for diabetic patients. (these are covered under Part D); and
- Custodial care, such as help with bathing, eating, and getting dressed.

Medicare Advantage

Another option for some Medicare beneficiaries who are looking for ways to lower their out-of-pocket costs is to enroll in a Medicare Advantage plan. These are private managed care plans that contract with the government to offer Medicare-covered services. Some Medicare Advantage plans include Medicare prescription drug coverage (known as Medicare Advantage Prescription Drug Plans or MAPDs) and some do not. Some Medicare Advantage plans also offer extra services that are not covered in traditional Medicare, such as vision care or a wellness program. Medicare Advantage plans cannot turn you down or charge you more because of your health or your age. These plans must provide all of the benefits that traditional Medicare provides, but all plan options are not available everywhere.

Medicare Advantage is also not available to everyone. To be eligible for a Medicare Advantage plan, you must:

- Be enrolled in Medicare Part B and continue paying your Part B premium;
- Live in the plan's service area;
- Not be receiving care from a certified Medicare hospice; and
- Not be diagnosed with permanent kidney failure.

You should carefully consider the pros and cons before enrolling in a Medicare Advantage plan. (See advantages and disadvantages of managed care on pages 2–3.) Just like all other managed care plans, you will have limited coverage if you choose to get your healthcare from doctors, hospitals, and other providers NOT in the plan's network. If you choose a Medicare Advantage plan with

an HMO network, you will receive no coverage for services obtained outside the network. If you are considering a managed care plan because your current doctor or hospital is in its network, keep in mind that these doctors and hospitals may not be able to provide you with the same services in a managed care plan as in traditional Medicare. Often, doctors must follow the managed care plan's rules on care and obtain approval for referrals and costly services. Additionally, your doctor may leave the network at any time. Some plans offer a Preferred Provider Organization (PPO) option to Medicare beneficiaries, allowing members to choose care from out-of-network providers at an increased cost. When looking into this option, find out what extra premiums and fees you would be responsible for and what limits the health plan puts on out-of-network coverage. Health plans have been known to leave the Medicare Advantage market, forcing members to choose different coverage. If you become dissatisfied with your Medicare managed care plan, or the plan makes changes, you can return to traditional Medicare, although you are only able to make this switch during specific enrollment periods. Also, when you leave a managed care plan to return to traditional Medicare, you may have only a limited choice of Medigap plans (supplemental insurance that wraps-around Medicare's coverage gaps — see page 11) available to you.

You can get more information about Medicare from the Centers for Medicare and Medicaid Services (CMS), the federal agency that runs this program. They can also provide more information about Medigap and Medicare Advantage plans. To speak with a customer representative, call the Centers for Medicare & Medicaid Services at 800.MEDICARE or visit the agency's Internet site at www.cms.gov. A separate government Web site can help you compare plans at www.medicare.gov.

Other helpful resources that can provide more detail on state-specific rules for Medicare supplemental coverage and health plans in your region include your state health insurance assistance program, or SHIP. You can find contact information for your state's SHIP program at https://shiptalk.org.

Medicare Prescription Drug Coverage (Part D)

Medicare Part D provides Medicare enrollees with outpatient prescription drug coverage through private drug plans approved by Medicare. Part D is an optional benefit for anyone eligible for Parts A and B, although those with prescription drug coverage from an employer or retiree group plan that is just as good as or better than a Medicare plan probably do not need to enroll in Part D. By law, your current health plan must notify you if your prescription drug coverage meets this criterion (known as ***creditable coverage***).

Part D plans require beneficiaries to cover significant cost-sharing, including monthly premiums, coinsurance, and copayments, although the details vary by plan. Individuals who qualify for Part D Extra Help (with separate application and enrollment procedures administered by the Social Security Administration), Medicaid or the Medicare Savings Programs pay much less, while individuals with high income pay higher premiums. Under a provision of the *Affordable Care Act,* Part D cost-sharing for people with very high drug costs will be gradually reduced until the so-called "donut hole" or "coverage gap" in Part D coverage – the gap in coverage where enrollees used to pay their entire drug costs – is filled in.

Part D selection and enrollment requires many informed choices by beneficiaries choosing to take best advantage of them. People with Medicare coverage may choose a stand-alone prescription drug plan, or they may choose a Medicare Advantage plan that includes prescription drug coverage. Although stand-alone drug plans vary in numerous ways, all must be approved by Medicare and offer benefits of an equivalent value. Medicare's Web site, www.medicare.gov/find-a-plan/, contains comprehensive information to help beneficiaries review details about plan options available to them.

You may enroll in a Part D plan when you first become Medicare eligible. Like Part B, if you delay enrolling in Part D, you will pay a premium penalty if you sign up later. You may change plans (or enroll after your initial eligibility) once a year during the annual Medicare Open Enrollment Period (October 15 to December 7).

It is important to know that if you enroll in a Medicare Part D plan, you cannot also get prescription drug coverage from a Medigap policy. If you purchased a Medigap policy with prescription drug coverage before January 1, 2006, you may still have this benefit, but new Medigap policies do not include drug benefits. You should also know that you cannot participate in a Medicare Advantage plan that covers prescription drugs and also purchase a stand-alone drug plan. If you want a stand-alone drug plan, you must participate in traditional Medicare.

Medicare Supplemental or Medigap Insurance

Because of Medicare's high cost sharing and the services it does not cover you may want to supplement your Medicare coverage with a private supplemental insurance policy (also known as Medigap insurance). Congress has regulated the Medigap market to make it easier for Medicare beneficiaries to shop among different companies offering the same selection of plans, so insurance companies that sell these policies can only sell the standard Medigap policies.

Table 1: Medigap Plan Benefits 2012

	A	B	C	D	F*	G	K**	L**	M	N
Hospital Coinsurance										
Part B Coinsurance Coinsurance for Part B services, such as doctors' services, laboratory and x-ray services, durable medical equipment, and hospital outpatient services							50%	75%		Except $20 for doctors visits and $50 for emergency visits
First three pints of blood							50%	75%		
Hospital Deductible							50%	75%	50%	
Skilled Nursing Facility (SNF) Daily Coinsurance							50%	75%	50%	
Part B Annual Deductible										
Part B Excess Charges										
Emergency Care Outside US										
Hospice Care Coinsurance for respite care and other Part A-covered services							50%	75%		
Out-of-Pocket Maximum Pays 100% of Part A and B coinsurance after annual maximum has been spent							$4,660	$2,330		

** Plan F also offers a high-deductible option in which you pay a $2,070 deductible in 2012 before Medigap coverage starts. The benefits remain the same, but the deductible must be met each year before any claims will be paid.*

*** Plans K and L pay 100% of your Part A and Part B copays after you spend a certain amount out of pocket. The 2011 out-of-pocket maximum is $4,660 for Plan K and $2,330 for Plan L.*

Note: As of June 1, 2010, Plans E, H, I, and J are no longer sold. Beneficiaries may keep their existing plan, but these benefits are different from (and not included in) the chart above. Benefits may also vary by state.

Source: Medicare and You 2012

Table 1 on page 12 displays the ten Medigap plans currently available and lists the benefits that each plan provides. As stated above, as of 2006, Medigap policies no longer cover prescription drugs, although Medicare Part D enrollees may still benefit from the added coverage that Medigap provides for other healthcare needs. It is wise to carefully consider their benefits and costs before purchasing one of these plans. Each state's insurance commissioner decides which of the ten plans are made available for sale in their state.

Medigap policies go by letter names (A through N, although E, H, I and J are no longer sold) and insurance companies are not allowed to change the labels of the various Medigap policies. They may, however, add names or titles to the labels. Although companies are not required to offer all of the plans that the state approves for sale, they must also offer Plan A if they sell any of the other nine policies.

Congress has set a six-month ***open enrollment*** period for buying Medicare supplemental insurance. The law guarantees that, for a period of six months following enrollment in Medicare Part B, persons age 65 and older cannot be denied Medigap insurance due to a health condition or medical history. Individuals with disabilities who qualify for Medicare before age 65 do not participate in this open enrollment period until they turn 65, although some states require insurance companies to offer at least one type of Medigap policy to individuals under age 65 regardless of health condition or medical history.

Medicaid

Medicaid is a government program that provides health insurance for low-income people and families. Today, each state has its own Medicaid program with its own rules about whom and what it covers, although in general, in addition to meeting income requirements, you must be a child, a parent of dependent children, elderly, or an individual with a disability to qualify for Medicaid coverage. However, because the federal government helps states fund their Medicare programs, there are some national rules that apply everywhere.

Starting in 2014, under the Affordable Care Act, states will have the option to expand Medicaid to all people under 133% of the federal poverty level, whether or not they fall into one of the eligibility categories described above. (In 2012, the federal poverty level is an annual income of $19,090 for a family of three in all states other than Alaska and Hawaii, and 133% of the federal poverty level is $25,390). The June 2012 Supreme Court decision upheld this option for states, but said that the federal government can't withhold existing Medicaid funds from states that choose not to expand their programs. As a result, we may see some states that choose to expand Medicaid in

2014 (or even earlier), and others that do not expand coverage. If states elect not to expand coverage under Medicaid, this may impact coverage availability for persons with an income less than 133% of the federal poverty level, especially childless adults who do not otherwise qualify for a Medicaid eligibility category.

Since 2000, each state has the option to make uninsured women with breast and cervical cancer eligible for Medicaid, and all 50 states plus the District of Columbia have done so. To be eligible for coverage, women must have been screened through the Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) – services generally provided through clinics or community health centers – and found to have breast or cervical cancer, including precancerous conditions. When states elect this option, coverage for the full range of Medicaid services will be available to these women as long as they are in treatment for breast or cervical cancer. For more information about eligibility for Medicaid for women with breast and cervical cancer, see the CMS Web site at www.cms.hhs.gov/medicaidspecialcovcond/.

You may be eligible for both Medicare and Medicaid. If you are eligible for either the full Medicaid benefit, or for the Qualified Medicare Beneficiary (QMB) program, Medicaid will pay for all Medicare premiums, deductibles, and coinsurance. If you are eligible for the Specified Low- Income Medicare Beneficiary Program (SLMB) or the Qualified Individual Program (QI), Medicaid will cover your Medicare Part B premiums. You may sometimes see QMB, SLMB and QI referred to as the "Medicare Savings Programs." To qualify, you will need to have low income (approximately $15,000 in annual income for a family of two for QMB, roughly $18,000 in annual income for a couple for SLMB, and $20,500 in annual income for two to qualify for QI) as well as low assets. Neither QMB, SLMB nor QI offers any Medicaid benefits beyond help with Medicare costs.

For more information about the Medicaid program in your state, check the government pages of your phone book, visit the Centers for Medicare & Medicaid Services at www.medicaid.gov, or visit www.healthcare.gov.

[2] In 2007, states that offered CHIP coverage to parents of CHIP-enrolled children included Arkansas, Idaho, Minnesota, Nevada, New Jersey, New Mexico, and Wisconsin. In addition, Arizona covered parents using Medicaid funds, and Minnesota, which covered parents through CHIP in 2007, has since converted parents over to the Medicaid program.

Children's Health Insurance Program

In addition to Medicaid, the Children's Health Insurance Program (CHIP) offers health insurance coverage to low income, uninsured children under the age of 19. Children can qualify for this free or subsidized health insurance if their family's income is twice as high as the federal poverty level, although in some states, kids in families with incomes up to 400 percent of the federal poverty level can qualify. Typically, children cannot be in CHIP if they are eligible for private health insurance. However, the eligibility requirements vary from state to state and you will want to determine your state's eligibility criteria. In all states, children who are eligible for both Medicaid and CHIP must be enrolled in Medicaid. Some states have used flexibility under federal law to expand CHIP coverage to parents of CHIP-enrolled children, and CHIP coverage may be an option for low-income parents in a limited number of states.[2]

In some states, the CHIP program is part of the Medicaid program; in others, it is a separate program with somewhat different benefits. To learn more about CHIP, contact your state public welfare or social services department or visit www.healthcare.gov.

CHOOSING YOUR HEALTH INSURANCE

As you examine your health insurance options, you will want to consider your coverage choices from several angles, including:

- How much is the premium?
- What services are covered?
- How much will I have to pay in cost-sharing?
- Will I be able to choose my provider, or will my options be limited?

As discussed earlier, beginning in 2014, everyone will need to hold ***minimum essential coverage*** that covers a defined set of ***essential health benefits.*** This requirement is called the ***individual mandate.*** If your policy does not qualify as minimum essential coverage, you will likely need to pay a fine for not complying with the mandate. While most insurance policies are likely to include essential health benefits and qualify as minimum essential coverage, these questions – what is covered, how much will I pay for covered services, and what kind of policy can I buy – will still be very important.

What services are covered?

Look at the list of services the policy covers. Starting in the fall of 2012, private insurance plans (that you buy on your own, as well as coverage provided by an employer) must provide you with a simple, 4-page summary of what policies cover. Look also at what services are explicitly excluded from the policy. The simplified summary will also list excluded benefits. For example, many policies exclude coverage for care in clinical trials, drugs that are not on a formulary or approved list, and other important services. Until 2014, many policies can also temporarily exclude services related to a ***pre-existing condition*** (see page 6 for more information on pre-existing conditions). And until 2014, some may add "riders" that permanently exclude coverage for services relating to a specific condition, organ system, or body part.

Beginning in 2014, most health insurance policies will cover essential health benefits that are required by the new health reform law. However, it appears that states will have considerable flexibility to determine how ***essential health benefits*** will be defined within their jurisdiction, and health plans will have some flexibility to determine how, exactly, they will cover these services. You should also know that the law will require health plans to cover clinical trials—an important benefit for cancer survivors. The precise scope of the services plans will be required offer is still being determined. When considering a policy, it is important that you find out whether the services you may need during your cancer treatment are covered by the plan. If you don't already have a care plan and know what cancer treatments you may be getting, ask your oncologist to provide you with a written plan.

If you are considering joining a ***managed care plan,*** you should also find out whether your current doctors belong to the plan's network. Many cancer patients have developed a strong relationship with their doctors and may want to continue receiving treatment from them. Remember, however, that just because your doctor is a member of a certain network today does not guarantee that he or she will remain in that network forever. Also, it is important for you to review the policy to find out what steps are needed to see a specialist.

How much will I pay for covered services?

The amount of money you pay to purchase health insurance is called a ***premium.*** If your employer sponsors your insurance, you will probably pay a share of this premium (and may not know the total premium beyond your share). If you purchase coverage on your own, you will pay the full price. Depending on state law, health insurance premiums purchased today in the ***individual*** or ***non-group market*** -- that is, the state-level health insurance market that sells policies to individuals and families

-- can vary based on your health history, but beginning in 2014, premiums will only be able to vary based on your age, where you live, your family size and whether you use tobacco.

When considering a health insurance policy:

- Also look at the annual ***deductible*** (the amount you pay each year before coverage kicks in). Some policies also have separate deductibles for certain services, such as hospitalization or drugs.
- Look, too, at the ***copayment*** (a flat fee, such as $10 or $20, that you pay the ***provider*** at the time of service) and ***coinsurance*** (a percentage of the bill that you pay) that apply to covered services.
- Also, watch out for ***balance billing*** – something that happens when the plan limits its payment to the part of the fee that it considers reasonable, leaving you responsible for the rest. See if your policy requires doctors and hospitals to accept the plan's payment as payment-in-full.
- Determine whether the policy has an ***out-of-pocket limit*** or ***"stoploss" feature*** that caps the amount you must pay in deductibles, coinsurance or copayments (although any balance billing charges usually do not apply to this out-of-pocket limit). After that, the plan pays 100 percent. Most policies have this feature.
- Check whether the plan imposes an ***annual limit*** on what they will pay – plans may apply this type of limit through 2013. Beginning in 2014, plans may no longer establish an annual limit on essential health insurance benefits.

FINDING HEALTH INSURANCE

You can find information on health insurance a number of places. For example, the Department of Health and Human Services operates a web site to help people locate and compare public and private insurance options, including Medicare, Medicaid, the Pre-existing Condition Insurance Plan and individual insurance policies. This website, which you can access at www.healthcare.gov, includes links to on-line Medicaid applications and insurance company applications. State Medicaid and CHIP programs also often offer internet-based applications, and can also be reached through www.healthcare.gov or through state or county-based social services offices.

Even prior to the full implementation of the health reform legislation in 2014, you have rights under federal and state law to help you buy and keep coverage, as well as protections when you use your coverage. But these rights are not comprehensive, and they may vary depending on where you live, what kind of coverage you have or seek, and other factors.

To find out about your rights, it helps to know who regulates your kind of health insurance. This is not always easy to find out. States regulate many health insurance plans, including many group plans sponsored by small employers and most individual coverage you buy on your own.

If you have or are trying to buy coverage under these kinds of plans, it is best to call your state insurance commissioner. (See pages 34–37 for contact information.)

The federal government regulates some coverage, including most health plans offered by very large employers. In this case, you need to contact the Employee Benefits Security Administration of the United States Department of Labor to find out about your rights. Visit www.dol.gov/esa or call EBSA's Employee and Employer Hotline at 866.444.EBSA (3272). When in doubt, your state insurance commissioner is often a good place to start.

In addition, most states now have Consumer Assistance Programs or CAPs that can help you understand what coverage options may be available to you and what rights you have. For a list of CAPs and other resources, see http://www.healthcare.gov/law/features/rights/consumer-assistance-program/.

In this section, we will discuss how to find health coverage and the rights you have if you are trying to buy or keep your coverage.

Employer-based Coverage

If you work for a larger employer, chances are you can obtain coverage for yourself (and perhaps your dependents) through your job. People who work for small employers are less likely to be offered employer-sponsored health coverage. Beginning in 2014, health insurers offering coverage in the ***employer group market*** will be required to accept every employer that applies for coverage. In addition, firms with 50 or more employees will be required to provide health insurance coverage that meets minimum federal standards, and includes the ***essential health benefits.*** If they do not provide this coverage to their workers, the firm may owe penalties to the federal government. (Federal law also includes some federal financial assistance for certain small firms to help them offer such coverage.)

You can contact your human resources department or manager to learn whether you have coverage available at work. If you are offered group health coverage, you have rights under federal and, for state regulated plans, state law.

Nondiscrimination

Your eligibility for coverage under a group health plan cannot be conditioned on your health status, which includes how healthy you are now or have been in the past. This means you cannot be refused health benefits under an employer's health plan or charged a higher premium simply because you are a cancer survivor. You might be ineligible for other reasons unrelated to your health status, such as if you only work part time.

Special enrollment periods

You must be offered a special enrollment period of at least 30 days when you get married, divorced or widowed, have a baby or adopt a child, lose other health insurance (for example, coverage that another family member had through his or her employer), or your employer stops contributing to your premium. If your employer provides family coverage, all of your dependents must be offered this special enrollment opportunity as well.

Coverage for pre-existing conditions

Sometimes group health plans will temporarily exclude coverage for a health condition you already have when you join. This is called a ***pre-existing condition exclusion period,*** or pre-ex, for short. If your group health plan does this, you will have insurance coverage, but it will not pay for any care related to your pre-existing condition during the exclusion period. Group health plans cannot impose a pre-ex longer than 12 months, or 18 months if you are a ***late enrollee.*** Also, there are limits on what can be subject to a pre-ex.

In group health plans, a pre-existing condition is one for which you actually received a diagnosis, treatment, or medical advice in the 6-month period – known as the look back period – prior to joining the group health plan. (In some state-regulated group plans, the maximum pre-ex or look back period may be shorter.) So, if your cancer treatment ended some time in the past and you have received no related care in the past 6 months, your group insurer cannot say that cancer is a pre-existing condition for you. In addition, group insurers cannot consider pregnancy or genetic information as a pre-existing condition. So if you have a family history of cancer or a positive genetic test indicating you are at risk for getting cancer, this alone cannot be the basis for a pre-ex.

Since September, 2010, plans have not been able to impose a pre-existing condition exclusion on children. Beginning in 2014, group health plans cannot impose a pre-existing condition exclusion on any enrollee.

Credit for prior coverage. When a group plan imposes a pre-existing condition exclusion, it has to "count" other health coverage you may have had in the past; this prior insurance might balance-out whatever coverage exclusion they want to apply to you. Whenever you leave a health plan, you should be given a ***certificate of creditable coverage*** as proof of the coverage that you had. To be ***creditable,*** your prior coverage must have been ***continuous,*** which means it cannot have been interrupted by a lapse of 63 days in a row or longer. In some state regulated group plans, the maximum lapse of coverage may be longer than 63 days---in other words, some states allow consumers in certain group plans to have a gap in coverage in excess of 63 days. These states often define a different permitted timeframe for a lapse in coverage. Most kinds of health insurance are creditable toward a group health plan pre-existing condition exclusion, including other group plan coverage, individual coverage, state high risk pool coverage, Medicare, Medicaid, and military healthcare (TRICARE).

So if you join a new group health plan with a 12-month pre-existing condition exclusion, but you just left a job last week where you had health benefits for a year, your prior coverage will cancel out the pre-ex. Your new group health plan will cover your pre-existing condition immediately.

COBRA continuation coverage. A federal law, the Consolidated Omnibus Budget Reconciliation Act (known as COBRA) lets you and your family stay covered under your group health plan even if you no longer are connected to that employer due to certain circumstances. All employers with 20 or more employees must offer this COBRA continuation coverage option. In addition, some states require similar continuation coverage for people when they leave smaller employers. Employees and beneficiaries are given 60 days from the date they lose coverage to make a decision

about continued coverage through COBRA. Continued coverage must be offered regardless of any health condition, including cancer, and must extend to surviving, divorced, or separated spouses and to dependent children. If you quit, retire, or lose your job, you and your covered dependents can remain in your employer group health plan for up to 18 months. However, if your spouse or children lose access to your group benefits because of your death or divorce or because you drop coverage when you become eligible for Medicare, they can remain in the plan for up to 36 months. In addition, your children can stay on your group plan for up to 36 months after they reach the age when they no longer qualify as your dependent.

When you take COBRA coverage, you have to pay the entire premium (including the portion the employer used to pay on your behalf). This will probably seem like a big rate increase for you, but it may turn out to be less expensive than other coverage available to you.

The Employee Benefits Security Administration (EBSA) of the United States Department of Labor enforces COBRA for most employers in the private sector. The Centers for Medicare and Medicaid Services of the United States Department of Health and Human Services regulates COBRA compliance by state and local government employers. Should you encounter a problem, the first step to resolving a COBRA complaint is to try to work it out with your employer. If that fails, you should contact either the Department of Labor or CMS, depending on your circumstances (see page 30 Department of Labor and CMS).

Medicare

If you qualify for Medicare, you can enroll through your local Social Security office, which will be listed in the government section of your phone book. You may also enroll in a Medicare Advantage plan or a Part D prescription drug plan through www.medicare.gov. You can also apply for Extra Help with your Part D premiums and cost-sharing at the Social Security office or by calling 800.772.1213. You can also apply on-line at www.socialsecurity.gov/i1020.

It is important to enroll in Medicare when you first become eligible for coverage. For most people, this happens when you turn 65 or qualify for Social Security Disability Insurance. Note that individuals turning 65 today become Medicare-eligible before they become eligible for regular Social Security retirement benefits. If you decline Medicare Part B coverage and later decide you want to enroll, you may pay a late-enrollment penalty. If you continue working and have health coverage through your job, or have coverage through a working spouse, you will not face this penalty. If you wish to purchase Medigap coverage, as discussed on pages 11–12, you will probably want to enroll during your first six months of Medicare eligibility.

There are exceptions to this rule, so you should verify the coordination of your benefits with the administrator of your group benefits. If you believe that you have been unfairly assessed a late enrollment penalty, you should consult with representatives from your local Social Security Office or your local State Health Insurance Assistance Program. If necessary, you can appeal this decision through the Social Security appeals process.

Medicaid/Children's Health Insurance Program

Beginning in 2014, many more low-income people will be eligible for Medicaid coverage, including people who do not qualify today because they are not elderly, nor disabled, nor a parent or a child. You can find information on Medicaid and CHIP eligibility and enrollment through www.healthcare.gov, your state Medicaid and/or CHIP agency's website, or your local social services office. As state insurance exchanges begin to operate, they will also be able to provide you with information on Medicaid and CHIP eligibility, and will be required to coordinate with Medicaid and CHIP to ensure that you receive appropriate coverage.

If your application for Medicaid coverage is denied, or if you believe the state has not given you a decision within a reasonable amount of time, you have the right to a fair hearing before a state agency. The state Medicaid agency must give you notice of your fair hearing rights when they deny your application for coverage; this notice must explain how you can request a hearing. At the hearing, you may present evidence – and refute evidence – to show why the decision to deny you Medicaid coverage was incorrect.

Individual Coverage and Insurance Exchanges

Individual Coverage

People who do not have health insurance coverage through their job sometimes purchase coverage in the ***individual market or non-group market.*** Until 2014, policies sold in the non-group market may be hard to obtain, have less generous benefits or higher premiums than group health insurance available through an employer and, as discussed earlier, may impose pre-existing condition exclusions until 2014, unless state law provides additional protections. You can find information on individual health insurance policies through an insurance agent or at www.healthcare.gov, among other places.

In most states today, buying individual coverage can be harder if you are a cancer survivor – especially if it has been less than 5 years since your treatment ended. Where not prohibited by law,

individual insurers can turn you down, charge you more, or permanently exclude coverage for cancer – though not all insurers will do so. Also, unless state law requires otherwise, individual health plans can use a much broader definition of pre-existing conditions than is permitted for group plans, in some cases barring coverage for any condition you ever had. You may also have trouble buying a policy that includes specific services you need, such as prescription drugs or mental health care services.

The rights you have today when buying individual health insurance depend on where you live, although this will change in 2014. State laws regulating individual health insurance vary a lot. Consult your state insurance commissioner for more information (see pages 34–37 for a listing of state insurance departments). Some states have very comprehensive laws that require health insurance companies to sell you any individual policy they offer. This is called ***guaranteed issue.*** Some other states require insurers to hold ***open enrollment*** seasons. In these states insurers cannot turn you down during open enrollment, but you might be turned down at other times during the year. In about a dozen states, your right to buy individual coverage from an insurance company is protected only if you qualify as "federally eligible" or "HIPAA eligible." (HIPAA stands for the *Health Insurance Portability and Accountability Act.*) This means that you must have had at least 18 months of prior continuous credible coverage, your most recent coverage was under a group health plan, a government plan, or a church plan, you used up any available or state COBRA continuation coverage, and you meet other requirements.

Some states prohibit insurers from charging you more because of your health status or health history. Some other states let insurers charge higher premiums to cancer survivors and others based on health-related factors, but only within limits. However, in most states there are no limits on how much you can be charged for individual health insurance. In these states, premiums can vary significantly due to health status.

Some states limit the use of pre-existing condition exclusion periods in individual policies. However, pre-existing condition exclusion rules for individual coverage usually are not as protective as the rules for group coverage. For example, in many states, individual health insurance policies can permanently exclude coverage for a pre-existing condition. This is called an ***elimination rider.*** Also, individual insurance policies often are not required to give you credit for prior coverage against any pre-existing condition exclusion they might impose.

Beginning in 2014, you will have more rights when you purchase an individual insurance policy. Whether you find a policy through the state-run ***health insurance exchange*** (see below), or in the

individual market outside of the exchange, insurance companies will not be able to deny you coverage, charge you more or permanently exclude coverage for cancer on the basis of your cancer history. Insurance companies will also have to renew your health insurance policy, even if you have incurred a lot of health care costs over the last year.

In addition, the federal health reform law contains certain protections to help ensure that the package of ***essential health benefits*** offered to individuals and small employers does not discriminate against individuals based upon their age, disability, or how long they are expected to live. While the details of these provisions have not yet been fully spelled out in regulation, these provisions provide important protections for cancer survivors, along with others facing potentially life-threatening illnesses.

Health Insurance Exchanges

Beginning in 2014, states will operate health insurance exchanges, which will provide another place for individuals and small businesses to find and compare health insurance options. In some states, the federal government may facilitate a health insurance exchange on the state's behalf.

Individuals and families with incomes up to 400 percent of poverty will also be able to apply for help with insurance premiums for the policies they purchase through the exchange. States and the federal government are currently working on setting up these exchanges, which should open enrollment in exchange-contracting health plans by late 2013. If states do not establish an exchange, the health reform law requires the federal government to make sure there that there will be an exchange operating in those states by 2014. You can contact your state insurance department to learn more about the health insurance exchange in your state.

Small Employers and Self-Employed Individuals

Small Employer Coverage

Currently, if you own a small business or are self-employed, you have special protections when buying coverage for yourself and your employees. If you have 2 to 50 employees, you cannot be turned down for any small group health plan that insurers sell to other small employers. In addition, all group health plans are guaranteed renewable. Your group's coverage cannot be canceled because someone in the group gets sick.

If you are self-employed with no other employees, in most states you are not eligible to buy group coverage on your own (though you may be able to get coverage under a family member's group health plan). However, in a few states, you are considered to be a small employer and are protected by state laws governing other small group health plans. Contact your state insurance commissioner to see if you qualify for a small group health plan (see pages 34–37 for a listing of state insurance departments).

Some small businesses currently qualify for tax credits to help with the cost of providing health insurance to their employees. If you have fewer than 25 employees, and pay average annual wages of less than $50,000 you may qualify for a tax credit of up to 35 percent of your health insurance costs. This credit will grow to up to 50 percent for coverage purchased through an exchange beginning in 2014. Also beginning in 2014, significant insurance reforms – including new rules on how plans may price policies – will make health insurance more affordable for small businesses. In addition, small businesses will be able to purchase coverage through state-based health insurance exchanges.

Buying Small Employer Coverage through the Health Insurance Exchange

States may choose to have small employers purchase coverage through the same insurance exchange as individuals, or to establish a separate ***Small Business Health Options Program (SHOP) Exchange*** for small businesses. In addition, up until 2016, states may limit the size of the ***small employer market*** –and hence the number of small businesses eligible to purchase coverage via the exchange--to firms with no more than 50 employees. In 2016, the health reform law requires states to include employers with up to 100 employees in the small employer market and, by extension, the insurance exchange. In 2017, states can decide whether they wish to permit employers with more than 100 employees to purchase coverage through an exchange.

Help with Prescription Drugs

Paying for prescription drugs can be very expensive, especially if you do not have health insurance, or your health insurance only includes limited prescription drug coverage. If you do not have coverage for prescription drugs that meets your needs, some options do exist. As mentioned earlier, Medicare Part D offers coverage for prescription drugs for Medicare beneficiaries (see pages 10–11 for more information on Medicare Part D). Retiree health benefits sometimes include good prescription drug coverage, so it is often beneficial to try to keep those benefits, if you have them, as long as possible. Private pharmacy discount

programs, which operate like clubs with benefits for their members, provide discounted prescription drugs through their network of participating pharmacies for a flat fee per year. AARP (formerly the American Association of Retired Persons) operates the best known of the programs, but has competitors around the country. Many states have created special programs for low-income elderly or disabled persons. Contact your state office on aging or social services to see if you qualify.

Finally, drug companies offer some of their products to patients in need. Eligibility for these programs varies by company. Ask your provider or office staff to help you find out if you qualify for no or low-cost drugs directly from the manufacturer, or contact Cancer*Care* at 800.813.HOPE or www.cancercare.org. The Patient Advocate Foundation at 800.532.5274 or www.patientadvocate.org, is also a helpful resource. You can also obtain a directory of prescription drug patient assistance programs by contacting the Pharmaceutical Research and Manufacturers of America (PhRMA) at 800.762.4636 or www.phrma.org.

USING YOUR HEALTH COVERAGE

When you need to make a claim on your health insurance, it is important to remember a few things.

Read your policy.

If possible, read your policy before you go for care in the first place. You may need to get permission (a referral) to see a specialist or to get a lab test. You might be restricted to a network of doctors or hospitals. Going out of network might mean you pay more or that the plan will deny your claim. You might need to submit the claim within a certain number of days following the service in order for it to be paid. Reading your policy is important to understanding what coverage you have and how to use it. You may want to develop a list of questions that you can ask your insurer or health care provider before beginning treatment, so you can make sure that your recommended treatments will be covered by your health insurance, and understand which services may not be covered.

Keep good records.

Include copies of all bills and correspondence. Ask for names, addresses, and phone numbers of people you talk to, and note the dates of your conversations. It is a good idea to keep all original bills for follow-up purposes unless your insurance carrier is one of the few that insists you send the originals. In that case, you should keep very good copies for your records. It may be helpful to ask a

friend or family member to help keep your records organized and ensure that you have the copies you need, at least while you are in active treatment.

Submit your claims on time and in the right order.

Your insurer will pay some bills directly to the appropriate parties if you request that on the claim form. Other bills you must pay yourself and then send copies of the bills to your insurer who then reimburses you directly. Most insurance companies have a time limit for submitting claims. It could be one year from the date of service or by the end of the calendar year. Make sure you know what your policy defines as the time limit. If you have more than one policy, you must send the right bills to the right company in the right order. Remember that the patient's insurance is always primary, the spouse's is secondary.

If a claim is denied, appeal it.

Always ask if the payment was denied due to a billing or clerical error first. Then, send the claim back again and again if necessary. Gather health records and other documents relevant to your claim. Ask your doctor to help make your case. Keep records of all your correspondence: who you talked to, what you talked about, and when you talked to them. And again, be aware of any time deadlines that might apply. Sometimes you can only appeal a denial within a certain number of days following the decision and deadlines may vary by insurer, by state, and at each level of appeal.

Most states now have Consumer Assistance Programs, or CAPs, to help you with your problems related to private health insurance. One important duty of CAPs is to help you file an appeal if your claim is denied and you disagree with the insurer's decision. So if you are uncertain as to how to pursue an appeal or if you just need help, be sure to contact your CAP. In their first year of operation, CAPs helped consumers file more than 22,000 appeals and recover more than $18 million in health benefits that should have been covered. For a list of CAPs in each state, see http://www.healthcare.gov/law/features/rights/consumer-assistance-program/.

Because of health reform, most insurance appeals are now standardized under federal law. First, you will want to find out if your plan is "grandfathered" and therefore exempt from the new appeals process. ***Grandfathered plans*** are plans that were in place when the Affordable Care Act passed (March 23, 2010) and have not made significant changes to benefits or cost-sharing since then – you can check with your insurer if you need to know whether your plan is grandfathered. Even if your plan is not subject to these new protections, you should check with your health plan, your state insurance department or your employer to see if you have similar rights.

If you have these new appeal rights, you must first appeal to your health plan through an ***internal appeal,*** which means your plan will have to review its decision. You have the right to learn why your claim was denied, see your file and materials that supported the denial, and to present evidence as part of your appeal. If your appeal is denied, check with your insurer and your state to determine whether or not you have the right to additional internal appeals. If not, you will have the right to an external appeal, no matter whether your plan is regulated by state or federal law. An ***external appeal*** will be reviewed by an Independent Review Organization; these panels overturn plan denials about half of the time, so it is worth it to hang in there. For more information, go to http://www.healthcare.gov/law/features/rights/appealing-decisions/ or contact your state insurance commissioner for more information about your appeal rights

You also have appeal rights if you have insurance through Medicare. These rights give you five levels of potential appeals.

- First, you can request a redetermination – a review of your coverage denial -- by filing Form CMS-20027 within 120 days.
- If this is denied, you can ask for a reconsideration, which is an independent review of your claim. This must be requested within 180 days of your redetermination request being denied.
- Next, if your claim is worth at least $130 and your reconsideration is denied, you may request a hearing by an Administrative Law Judge (ALJ).
- Fourth, if the ALJ denies your claim, you may appeal within 60 days to the Medicare Appeals Council for review.
- Finally, if the Appeals Council denies your appeal and your claim is worth more than $1,300, you may appeal to a U.S. District Court.

For more information on the Medicare appeals process, see: http://www.hhs.gov/omha/index.html.

If you have Medicaid coverage, you have the right to a fair hearing before a state agency if your request for services is turned down or not acted upon within a reasonable timeframe. If you belong to a Medicaid-participating managed care plan, you have the right to internally appeal a plan action, such as when Medicaid plan refuses to pay for a health care service, or reduces the amount of care they will authorize for you. You may also file an internal grievance for other

types of problems with your Medicaid plan, such as poor quality care. You may also go to federal court by filing suit against the state Medicaid program. For more information on your Medicaid appeal rights and the appeals process, Families USA provides an easy-to-follow outline at http://www.familiesusa.org/issues/medicaid/making-it-work-for-consumers/medicaid-denial.html.

Understand your coverage for experimental therapies and clinical trials.

Sometimes an insurer will deny coverage for care they say is experimental. Insurers generally regard drugs, devices, and courses of treatment still under study as experimental. In other cases, some patients may want to enroll in a clinical trial. A cancer clinical trial is a study designed to compare the efficacy of a particular drug with the standard method of treatment. Medicare and some state laws now mandate coverage for routine patient costs associated with cancer clinical trials, and beginning in 2014, all group health plans and individual policies will be required to cover these costs.

If your plan denies coverage for care related to a clinical trial, appeal the denial, following the external review procedures outlined above.

Know how you can protect the privacy of your medical information.

Under federal privacy protections, information related to the treatment of your cancer is treated the same as any other health information. Federal law restricts how your health information can be used by your health-care provider, health plan, and other related organizations. However, these restrictions are limited and generally permit your health information to be used fairly freely for purposes related to treatment, payment, and many other transactions by health-care related organizations, including by insurers in the underwriting process. In addition, if you are covered under an employer sponsored group plan, your employer may have access to your health information. However, federal law does prohibit your health plan from sharing your health information with your employer for employment related activities. To learn more about the rules protecting the privacy of your medical information under federal law contact the U.S. Department of Health and Human Services, Office of Civil Rights at 866.627.7748 or visit http://www.hhs.gov/ocr/hipaa/. Additionally, some states have protections that go beyond those provided under federal law. To learn more about your protections under state law, contact your local consumer protection office. The Federal Citizen Information Center of the U.S. General Services Administration publishes a Consumer Action Handbook that includes a list of state, county, and

city government consumer protection offices. The Handbook can be downloaded at http://www.usa.gov/topics/consumer.shtml. Finally, under federal law, you have the right to inspect, copy, and add information to your medical records to make it more correct or complete. These protections vary state to state. Georgetown University, Center of Medical Rights and Privacy has written consumer guides for most states that review these protections. To read or download the free guide for your state visit http://hpi.georgetown.edu/privacy/records.html.

WHERE CAN I TURN FOR MORE INFORMATION?

It is always best to ask your insurance company or your employer for help answering your questions or solving your insurance problems. If this does not work though, there are other resources.

Your state Consumer Assistance Program is always a good place to begin. Most states have such a program now, thanks to federal funding provided under the Affordable Care Act. CAPs can help you answer your insurance questions, find coverage options, and appeal denied health insurance claims in any kind of private health insurance – whether a policy you purchased on your own or coverage provided through an employer. For a list of state CAPs see http://www.healthcare.gov/law/features/rights/consumer-assistance-program/.

Your state insurance commissioner can also be an important resource. They can help you understand state laws and programs and direct you to other sources of assistance. They also can help you figure out whether your plan is one that they regulate (see pages 34–37 for contact information).

The United States Department of Labor, Employee Benefits Security Administration (EBSA) regulates group health plans sponsored by employers in the private sector. EBSA's Web site and publications provide consumers with important information about protecting personal rights to health-care coverage. Visit http://www.dol.gov/ebsa/hbec.html or call EBSA's Employee and Employer Hotline at 866.444.EBSA (3272) for free copies of these booklets and others:

- Health Benefits Under the Consolidated Omnibus Budget Reconciliation Act (COBRA)
- Job Loss: Important Information Workers Need to Know to Protect Their Health Coverage and Retirement Benefits
- Employer Bankruptcy: How Will it Affect Your Employee Benefits
- Women and Job-Based Health Coverage

EBSA also makes available a wealth of information on the Affordable Care Act, with particular emphasis on issues that fall within the Department of Labor's jurisdiction. Many of their materials are more technical than consumer-oriented. You can find these materials at www.dol.gov/ebsa/consumer_info_health.html.

The Centers for Medicare & Medicaid Services (CMS) of the U.S. Department of Health and Human Services regulates HIPAA and COBRA compliance by group health plans sponsored by state and local governments. In addition, it runs the Medicare program, partners with the states on the Medicaid program, and provides Federal oversight and guidance on the insurance reforms and insurance exchanges included in the Affordable Care Act. For more information contact CMS at 877.267.2323 or visit www.cms.gov.

Your state health insurance assistance program, or SHIP, can also help you with questions about Medicare, Medicare Advantage and Medigap coverage. You can find contact information for your state's SHIP program at https://shiptalk.org.

For very complicated problems, you may need to consult a lawyer or another expert for professional advice and help. Or you may want to ask a friend to help you make some of these calls, gather information, and keep track of the paperwork. If a professional is needed, however, make sure he or she has expertise in health insurance (not all lawyers or accountants do). Health insurance can be complicated and frustrating, but you are not alone. Be persistent and take advantage of the help that is available for you.

STATES WITH HIGH RISK POOLS

Updated March 14, 2012

Alabama (for portability only)
https://www.alseib.org/
Phone 866.836.9737 or 334.263.8341

Alaska
http://www.achia.com/
Phone 888.290.0616

Arkansas
http://www.chiparkansas.org/
Phone 800.285.6477

California
http://mrmib.ca.gov/
Phone 800.289.6574 or 916.324.4695

Colorado
https://www.covercolorado.org/
Phone 866.787.9129 or 303.863.1960

Connecticut
http://www.hract.org/hra/index.htm
Phone 800.842.0004

Florida (not open for new enrollees)
Phone 850.309.1200

Idaho
http://www.doi.idaho.gov/
Phone 208.334.4250

Illinois
http://www.chip.state.il.us/default.htm
Phone 866.851.2751 or 217.782.6333

Indiana
http://www.onlinehealthplan.com/
Phone 866.674.1461 or 317.614.2032

Iowa
https://www.hipiowa.com/Default.asp
Phone 877.793.6880

Kansas
http://www.khiastatepool.com/
Phone 800.362.9290

Kentucky
https://www.kentuckyaccess.com/index.cfm
Phone 866.405.6145 or 800.313.4750

Louisiana
http://lahealthplan.org/
Phone 800.736.0947 or 225.926.6245

Maryland
http://www.marylandhealthinsuranceplan.state.md.us/
Phone 888.444.9016

Minnesota
http://www.mchamn.com/
Phone 866.894.8053

Mississippi
http://www.mississippihealthpool.org/index.php
Phone 888.820.9400

Missouri
http://www.mhip.org/
Phone 800.821.2231

Montana
http://www.mthealth.org/
Phone 800.447.7828

Nebraska
http://www.nechip.com/
Phone 402.343.3574 or 877.348.4304

New Hampshire
http://www.nhhealthplan.org/
Phone 877.505.0508

New Mexico
http://www.nmmip.org/hrp1/
Phone 866.622.4711

North Carolina
http://www.nchirp.org/
Phone 866.665.2117

North Dakota
http://www.chand.org/
Phone 800.737.0016 or 701.277.2271

Oklahoma
http://www.healthcare.gov/law/features/choices/pre-existing-condition-insurance-plan/ok.html
Phone 877.885.3717

Oregon
http://www.oregon.gov/OHA/OPHP/OMIP/
index.shtml
Phone 800.848.7280 or 503.225.6620

South Carolina
http://doi.sc.gov/Pages/default.aspx
Phone 803.737.6160

South Dakota
http://riskpool.sd.gov/
Phone 605.773.3148

Tennessee
http://www.accesstn.gov/
Contact Tennessee area county medical assistance offices, or Phone 866.268.3786

Texas
http://www.txhealthpool.org/
Phone 888.398.3927

Utah
http://selecthealth.org/plans/government/Pages/HIPUtah.aspx
Phone 801.442.5000

Washington
https://www.wship.org/Default.asp
Phone 800.877.5187

West Virginia
http://apps.wvinsurance.gov/accesswv/
Phone 866.445.8491 or 304.558.8264

Wisconsin
http://www.hirsp.org/
Phone 800.828.4777 or 608.221.4551

Wyoming
http://insurance.state.wy.us/WHIP.html
Phone 1-800-442-2376 or outside Wyoming at 307.634.1393

STATE HEALTH INSURANCE REGULATORS

Every effort has been made to provide accurate information. Updated April 2012.

Alabama Department of Insurance
Phone: 334.269.3550
Fax: 334.241.4192
www.aldoi.gov

Alaska Department of Community and Economic Development
Division of Insurance
Phone: 907.269.7900
Fax: 907.269.7910
E-mail: insurance@alaska.gov
www.commerce.alaska.gov

Arizona Department of Insurance
Phone: 800.325.2548 (in state)
602.364.2499
602.364.2505 (Spanish)
Fax: 602.364.2505
E-mail: consumers@id.state.az.us
http://www.azinsurance.gov

Arkansas Insurance Department
Phone: 800.282.9134 (in state)
501.371.2600
www.insurance.arkansas.gov

California Department of Insurance
Consumer Communications Bureau
Phone: 800.927.4357 (in state)
213.897.8921
Fax 213.897.5961
www.insurance.ca.gov

Colorado Division of Insurance
Phone: 800.930.3745 (in state)
303.894.7499
Fax: 303.894.7455
www.dora.state.co.us/insurance

Connecticut Insurance Department
Phone: 800.203.3447 (in state)
860.297.3900
Fax: 860.297.3872
www.ct.gov

Delaware Department of Insurance
Phone: 302.674.7300
http://www.delawareinsurance.gov

District of Columbia
Department of Insurance and Securities
R egulation
Phone: 202.727.8000
Fax: 202.535.1196
www. disb.dc.gov/

Florida Department of Insurance
Bureau of Consumer Affairs
Phone: 850.413-3137

Georgia Department of Insurance
Office of Insurance and Safety Fire
Commissioner
Phone: 800.656.2298 (in state)
404.656.2070
Fax: 404.657.8542
http://www.oci.ga.gov/

Hawaii Division of Insurance
Department of Commerce and Consumer Affairs
Phone: 808.586.2790
Fax: 808.586.2806
http://hawaii.gov/dcca/ins

Idaho Department of Insurance
Phone: 208.334.4250
800.721.3272 (in state)
Fax: 208.334.4398
www.doi.idaho.gov

Illinois Department of Insurance
Phone: 217.782.4515
Fax: 217.782.5020
http://insurance.illinois.gov

Indiana Department of Insurance
Phone: 317.232.2385
Fax: 317.232.5251
http://www.in.gov/

Iowa Insurance Division
Phone: 877.955.1212 (in state)
515.281.5705
Fax: 515.281.3059
www.iid.state.ia.us

Kansas Insurance Department
Phone: 785.296.3071
Fax: 785.296.7805
www.ksinsurance.org

Kentucky Department of Insurance
Phone: 800.595.6053
502.564.3630
Fax: 502.564.1453
www.insurance.ky.gov/

Louisiana Department of Insurance
Office of Health
Phone: 800.259.5300 (in state)
225.342.5900
Fax: 225.342.5711
www.ldi.la.gov

Maine Bureau of Insurance
Department of Professional & Financial Regulation
Consumer Health Care Division
Phone: 800.300.5000 (in state)
207.624.8475
Fax: 207.624.8599
http://www.maine.gov/pfr/insurance/

Maryland Insurance Administration
Baltimore, MD 21202
Phone: 800.492.6116
410.468.2000
www.mdinsurance.state.md.us

Commonwealth of Massachusetts
Division of Insurance
Phone: 617.521.7794
Fax: 617.753.6830
www.mass.gov/doi

Michigan Division of Insurance
Office of Financial and Insurance Regulation
Phone: 877.999.6442
517.373.0220
Fax: 517.335.4978
www.michigan.gov/ofir

Minnesota Department of Commerce
Enforcement Division
Phone: 651.296.4288
Fax: 651.296.9434
www.mn.gov/commerce/

Mississippi Insurance Department
Phone: 800.562.2957 (in state)
601.359.3569
Fax: 601.359.1077
www.mid.state.ms.us/

Missouri Department of Insurance
Division of Consumer Affairs
Phone: 800.726.7390 (in state)
573.751.4126
www.insurance.mo.gov

Montana Department of Insurance
Phone: 800.332.6148 (in state)
406.444.2040
Fax: 406.444.3497
www.sao.mt.gov/

Nebraska Department of Insurance
Phone: 877.564.7323 (in state)
402.471.2201
http://www.doi.ne.gov

Nevada Department of Business and Industry
Division of Insurance
Phone: 775.687.0700
Fax: 775.687.0787
www.doi.nv.gov/

New Hampshire Insurance Department
Consumer Affairs
Phone: 603.271.2261
Fax: 603.271.1406
www.nh.gov/insurance/

New Jersey Department of Banking and Insurance
Phone: 800.446.7467
609.292.7272
www.njdobi.org

New Mexico Public Regulation Commission
Insurance Division
Santa Fe, NM 87504-1269
Phone: 888.427.5772
www.nmprc.state.nm.us

New York Department of Insurance
Phone: 800.342.3736 (in state)
212.480.6400
Fax: 212.486.2312
http://www.dfs.ny.gov/insurance/dfs_insurance.htm

North Carolina Department of Insurance
Phone: 800.546.5664 (in state)
919.733.6750
www.ncdoi.com

North Dakota Department of Insurance
Phone: 800.247.0560 (in state)
701.328.2440
Fax: 701.328.4880
www.nd.gov/ndins/

Ohio Department of Insurance
Phone: 800.686.1526 (in state)
614.644.2658
www.insurance.ohio.gov/

Oklahoma Department of Insurance
Phone: 800.522.0071 (in state)
405.521.2828
Fax: 405.521.6635
www.ok.gov/oid/

Oregon Division of Insurance
Department of Consumer and Business Services
Phone: 503.947.7980
Fax: 503.378.4351
www. insurance.oregon.gov/

Pennsylvania Insurance Department
Bureau of Consumer Services
Phone: 877.881.6388 (in state)
717.787.2317
Fax: 717.787.8585
www.ins.state.pa.us/

Rhode Island Insurance Division
Phone: 401.462.9500
Fax: 401.462.9532
http://www.dbr.state.ri.us/divisions/insurance/

South Carolina Department of Insurance
Consumer Services Division
Phone: 803.737.6160
Fax: 803.737.6205
www.doi.sc.gov

South Dakota Division of Insurance
Department of Commerce and Regulation
Phone: 605.773.3563
Fax: 605.773.5369
http://www.dlr.sd.gov/insurance/

Tennessee Department of Commerce and Insurance
Phone: 615.741.2241
http://www.tn.gov/commerce/

Texas Department of Insurance
Phone: 800.578.4677 (in state)
512.463.6169
Fax: 512.475.2005
www.tdi.texas.gov/

Utah Insurance Department
Phone: 800.439.3805 (in state)
801.538.3800
Fax: 801.538.3829
www.insurance.utah.gov

Vermont Division of Health Care Administration
Department of Banking, Insurance, Securities and Health Care Administration
Phone: 802.828.3301
www.bishca.state.vt.us

Virginia Bureau of Insurance
Phone: 800.552.7945 (in state)
804.371.9741
Fax: 804.371.9944
www.scc.virginia.gov/boi/

Washington Office of the Insurance Commissioner
Phone: 800.562.6900 (in state)
360.725.7000
Fax: 360.407.0186
www.insurance.wa.gov

West Virginia Insurance Commission
Phone: 888.879.9842
304.558.3386
www.wvinsurance.gov

Office of the Commissioner of Insurance State of Wisconsin
Phone: 800.236.8517 (in state)
608.266.3585
www.oci.wi.gov

Wyoming Department of Insurance
Phone: 800.438.5768 (in state)
307.777.7401
Fax: 307.777.2446
http://insurance.state.wy.us

GLOSSARY OF INSURANCE TERMS

Actuarial Value: The proportion of expected health care spending paid for by a health plan, with respect to a defined population of enrollees and for a defined set of covered benefits.

Annual Limit: Total benefits that the insurance company will pay per individual over a benefit year. Beginning in 2014, plans are not allowed to impose an annual limit on health insurance benefits.

Balance Billing: The practice of billing a patient for the amount that remains after the insurer's payment and patient's copayment have been made.

Benefit: An amount payable by the insurance carrier.

Benefit Period, Medicare: The period of time that begins the first day a person enters a hospital or skilled nursing facility and ends 60 days after discharge without being readmitted to either type of facility.

Catastrophic Insurance: A type of limited health insurance that serves the purpose of covering very high medical expenses. The deductibles are very high ($2,000 or above) and the premiums are low.

Certificate of Creditable Coverage: A document provided by your health plan that lets you prove you had coverage under that plan. Certificates of creditable coverage will usually be provided automatically when you leave a health plan. You can obtain certificates at other times as well.

Children's Health Insurance Program (CHIP): A joint federal and state health insurance program that offers health insurance coverage to uninsured children who live in families with incomes that are too high to qualify for Medicaid coverage.

Coinsurance: The portion of the bill for which the insured is responsible.

Comprehensive Coverage: Insurance is either comprehensive or limited. Comprehensive means broader coverage and/or higher indemnity payments than limited coverage.

Consumer Assistance Program: An agency or program, supported by federal grants, that is established to help you with any private health insurance related question or problem. CAPs can help you identify coverage options when you are uninsured, help you enroll in new coverage, and file an appeal on your behalf if a health insurance claims is denied. Most states have established CAPs. A list of state CAPs (and related consumer resources) can be found at **http://www.healthcare.gov/law/features/rights/consumer-assistance-program/.**

Continuous Coverage: Health insurance is continuous if it is not interrupted by a break of 63 or more consecutive days. In some state regulated plans, the maximum lapse in coverage may be longer than 63 days.

Copayment: In managed care plans, the amount the insured must pay directly to the provider of the service. Copayments typically range between $5 to $25.

Creditable Coverage: Health insurance coverage you had before you enrolled in your new health plan, as long as it was not interrupted by a period of 63 or more days. The amount of time you had "creditable" health insurance coverage can be used to offset a pre-existing condition exclusion period in your new health plan. For Medicare Part D, prescription drug coverage from an employer or retiree group plan that is equal to or better than the Medicare Outpatient Prescription Drug benefit is also referred to as creditable coverage. See also Continuous Coverage, Group Health Plan, Individual Health Plan.

Deductible: The amount of money the insured must pay out of pocket before benefits begin. Deductibles are usually on a calendar year or policy year basis. Some policies have deductibles per diagnosis—the least desirable—or family deductibles. A policy may have a $250 deductible per individual with a $500 deductible per family. This means that when two individuals have each satisfied a $250 deductible, the remaining family members will not have to meet any deductible.

Employer Group Market: A term that refers to the combination of state regulations, and health plan practices that determine the nature of employer-sponsored health insurance. Many states establish different regulatory structures for plans offered to small and large employers, with plans given greater latitude to examine applicants' medical histories to determine premium rates and pre-existing condition exclusions for the policies they offer to small employers (typically firms with less than 50 employees).

Elimination Rider: A feature permitted in individual health plans that excludes coverage for a pre-existing condition. Unlike preexisting condition exclusion periods, which are temporary, elimination riders can last indefinitely. Elimination riders cannot be imposed if you are HIPAA eligible.

Essential Health Benefits: The core set of benefits that all policies sold in the non-group market and in health insurance exchanges must include. Benefit categories include ambulatory care, emergency care, hospital care, maternity and newborn care, mental health and substance use disorder services, prescription drugs, rehabilitative and habilitative services, laboratory services, preventive care, chronic disease management and pediatric care. The Department of Health and Human Services will determine how states and health plans will implement this requirement in 2012.

Explanation of Benefits (EOB): One of these forms comes with or without an insurance check to explain what portion of the submitted bill was covered and why. If the patient has more than one policy, this is proof of what his or her primary coverage paid.

Exclusions: Specified illnesses, injuries, or conditions listed in the policy that are not covered. Experimental therapies, cosmetic surgery, and eyeglasses are common exclusions.

Fee-for-Service: See indemnity insurance.

Grandfathered Plans: Health insurance plans that were in place when the Affordable Care Act passed (March 23, 2010) and have not made significant changes to benefits or cost-sharing since that date. Grandfathered plans are exempt from some insurance and coverage reforms, such as coverage for recommended preventive services, but are required to comply with other reforms, such as the prohibition on lifetime limits on health insurance benefits. You can ask your employer or insurance company whether your plan is grandfathered or not.

Group Health Insurance: Health coverage obtained through an employer or other organization, rather than purchased on an individual basis.

Guaranteed Issue: A public policy – typically a law or regulation – that requires health plans to offer coverage to all applicants, regardless of health status.

Health Insurance: An insurance policy that covers costs related to medical and surgical care, hospitalization, prescription drugs and other health care services and supplies.

Health Insurance Exchange: An organized marketplace where individuals and small employers may seek and purchase health insurance coverage. Plans participating in the exchange must offer policies that meet the coverage, cost-sharing and insurance reform requirements of the Affordable Care Act.

Health Maintenance Organization (HMO): The first and most traditional type of managed care plan. Like other types of managed care, HMOs are organizations that both finance healthcare (provide insurance) and provide the care by collecting fees in advance.

Health Savings Account (HSA): A tax-favored savings account available to eligible individuals that are covered by a federally qualified high deductible health plan. Funds accumulated in a HSA can be used to pay for certain health-care costs.

Health Status: Refers to your medical condition (both physical and mental illness,) claims experience, receipt of healthcare, medical history, genetic information, evidence of insurability, (including conditions arising out of acts of domestic violence,) and disability.

High Risk Pool: A program offered in 31 states that sells health insurance to people who need to buy coverage on their own but can't because insurance companies consider them "medically uninsurable." A cancer diagnosis or history can render someone uninsurable in the individual health insurance market unless state laws require health insurers to sell coverage to everyone.

Indemnity Insurance: Traditional insurance that pays providers on a fee-for-service basis.

Individual Mandate: A national requirement that all individuals hold qualifying health insurance or pay a penalty, which at full implementation would be the greater of a flat amount ($695/person, with a maximum of $2,085 per family) or 2.5 percent of family income. This requirement becomes effective January 1, 2014. Individuals and families may claim a hardship exemption from this requirement if they cannot find affordable coverage.

Individual Market: The state-based and state-regulated health insurance market for individuals. Also referred to as the non-group market. States often have different regulatory schemes for group and non-group insurance.

Late Enrollee: An individual who chooses to enroll in group health insurance after their initial enrollment period or outside of special enrollment period. A late enrollee may be subject to a pre-existing condition exclusion of up to 18 months.

Lifetime Limit or Maximum: Total benefits that the insurance company will pay per individual over a lifetime. Beginning in 2011, plans are not allowed to impose a lifetime limit or maximum on health insurance benefits.

Managed Care Plan: Organization that functions as both insurer and provider of healthcare simultaneously. HMOs were the first type, but variations include preferred provider organizations (PPOs) and independent practice associations (IPAs). HMOs tend to operate with stricter rules than other types of managed care plans.

Medicaid: A joint federal and state health insurance program that assists individuals with low incomes and limited resources. Medicaid programs vary from state to state.

Medicare: The federal health insurance program for people 65 years of age or older, certain younger people with disabilities, and people with permanent kidney failure.

Minimum Essential Coverage: The health insurance coverage an individual must hold to fulfill the individual responsibility requirement, or individual mandate, of the Affordable Care Act. Minimum essential coverage includes Medicare, Medicaid, CHIP, TRICARE, most employer-sponsored coverage, and most health plans purchased in the health insurance exchange or the individual market.

Non-group Market: The state-based and state-regulated health insurance market for individuals and small businesses. States often have different regulatory schemes for group and non-group insurance.

Open Enrollment: The period of time in which eligible individuals may enroll in, or transfer between, health-care insurance programs. Plans must accept all individuals who enroll during open enrollment.

Out-of-Pocket Limit: A cap or limit placed on a patient's out-of-pocket costs, after which the plan provides
full coverage for all costs for the remainder of the year.

Participating Provider: A health-care provider who has joined a managed care plan and is willing to accept its contracts.

Portability: Insurance that can be retained even if one leaves employment or the group plan.

Pre-Existing Condition: A health condition that existed before a policy was purchased. Companies' definitions of pre-existing conditions vary, but usually anything for which a patient has seen a doctor during the previous 6 months is a pre-existing condition and will not be covered during the waiting period, which is typically six to twelve months after the effective date of coverage.

Pre-Existing Condition Exclusion Period: The first days of an illness that are not covered by insurance.

Pre-Existing Condition Insurance Plan: A plan administered by either your state or the U.S. Department of Health and Human Services which provides health insurance options to citizens and legal residents who have a pre-existing condition or have been denied health insurance because they have a pre-existing condition, and have been uninsured for at least six months. This program will offer insurance through 2013.

Preferred Provider Organization (PPO): A PPO is a type of managed care plan that allows members to access service both from in-network providers and out-of-network providers. Members pay higher out-of-pocket costs when they receive care outside the PPO network.

Premium: The amount paid to an insurance company for providing insurance coverage.

Point-of-Service (POS) Plan: A type of managed care plan that gives the insured the option of seeing providers within the plan's network and paying the copayment amount only, or seeing providers out of the network and getting reimbursed as one would under an indemnity policy. Although these plans are increasingly popular because they allow for choice of providers, the premiums are higher than plans that provide no coverage for providers outside the network.

Primary Care Provider (PCP): Sometimes referred to as "gatekeepers," PCPs are non-specialty physicians that enrollees choose to serve as their coordinator for all the services they may need. In many managed care plans, PCPs must pre-approve referrals to specialists and use of services, including emergency room care.

Provider: The supplier, physician, psychologist, pharmacist, or other health-care professional providing a service to the insured.

Public Health Insurance Programs: Government-administered and subsidized health insurance programs such as Medicare, Medicaid and CHIP. These programs offer low-cost health coverage to individuals who meet their eligibility requirements, which are usually tied to age, disability, family status and/or income. The federal government manages the Medicare program, while states jointly administer and finance the Medicaid and CHIP programs in partnership with the federal government.

Small Business Health Options Program (SHOP) Exchange: An organized marketplace for small businesses may seek and purchase health coverage. Plans participating in the exchange must offer policies that meet the coverage, cost-sharing and insurance reform requirements of the Affordable Care Act.

Stop-Loss: The point during a calendar year when your insurance policy pays 100 percent of costs for the remainder of the year. Thus, your out-of-pocket expenditures, or losses, stop. Most policies pay 80 percent and the individual pays 20 percent. If the policy has a $5,000 stop-loss point, 20 percent of that equals $1,000. This means that when you have spent $1,000 out of your pocket plus your deductible, the policy will pay 100 percent rather than 80 percent.

Waiting Period: The time after the beginning date of a policy when benefits are not payable.

PUBLICATIONS AND RESOURCES ON OTHER SURVIVORSHIP ISSUES

Cancer Survival Toolbox®: An audio program that uses patient stories to teach self-advocacy skills to meet the challenges of a cancer diagnosis. The resource includes sections on financial issues, as well as others on communicating, problem-solving, decision-making and more. The program is developed by NCCS in collaboration with the Oncology Nursing Society, the Association of Oncology Social Work and the National Association of Social Workers and is available in English and Spanish from NCCS.

Journey Forward®: A software tool that enables oncologists to create a treatment summary and a survivorship care plan to be shared with patients, primary care physicians and other healthcare providers as guidance for post-treatment care. This tool also includes a Medical History Builder for patients to create and maintain an electronic record of their medical history in one place. Available at **www.journeyforward.org.**

Pocket Cancer Care Guide: A smart phone application that allows users to make effective use of their time with providers by helping create a personalized list of questions to ask, link the list to an appointment, and record the conversation for playback at a convenient time. Available from iTunes and from NCCS.

All NCCS resources can be ordered by calling **301.650.9127** or **877.622.7937** or by visiting **www.canceradvocacy.org.**

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Reviewed by Ivy Ahmed, MPH, MCHES, Cancer Support Community

NOTES

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301.650.9127
877.622.7937
www.canceradvocacy.org

NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.