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WHEN AN EMPLOYEE OR FAMILY MEMBER BECOMES DISABLED HELPING PATIENTS, FAMILIES, & THEIR EMPLOYERS COPE

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WHEN AN EMPLOYEE OR FAMILY MEMBER BECOMES DISABLED TIPS & TOOLS FOR HELPING PATIENTS, FAMILIES, & THEIR EMPLOYERS COPE

Americans, their employers, and our society increasingly are struggling to cope with the practicalities and costs of caring for the chronically ill, disabled, and elderly members of our society.

Unquestionably, the highly publicized, and much discussed, challenge of paying for and accessing quality medical care constitutes one of the most significant and intractable challenges for patients, the family members that care for them, employers, health care providers and the social institutions involved in providing, and paying for the medical care of the ill, elderly and disabled. These challenges remain intractable, despite ongoing efforts at reform. In 2004, for example, U.S. costs for health care were estimated to be about \$6,300 per person. By 2015, this is projected to increase to about \$12,300 per person.¹ Even while costs continue to rise and despite our massive expenditures, however, most Americans do not necessarily know what is the “right” or best” care, how to access it, how to pay for it, and what to do when they can’t.²

As baby boomers continue to age, Americans and American social institutions increasingly are forced to confront the high financial, productivity and other practical realities costs and demands of caring for the elderly. The growing demands of caring for our elderly are staggering. In 1990, there were about 31.2 million persons age 65 and over in the United States. Of these, about 2.1 million elderly persons living in the community were disabled in one or more of the five core activities of daily living. In addition, there were also approximately 2.0 million persons age 65 and over who were not impaired in activities of daily living, but who experienced limitations in one or more instrumental activities of daily living such as meal preparation, grocery shopping, housework, and so on. Finally, in 1990, there were about 1.6 million elderly persons living in nursing homes and other facilities that provide 24-hour residential care.³

However, the demands of the elderly tell only a portion of the story. At any given point of time, the likelihood that a person will become seriously ill or disabled generally far exceeds the likelihood that he will die during the same period. According to the

¹ Borger, C., et al. (February 22, 2006). "Trends: Health Spending Projections Through 2015: Changes on the Horizon." Health Affairs Web Exclusive. See also, "The Health Report to the American People," Citizens Healthcare Working Group (March 31, 2006).

² See The Health Report to the American People," Citizens Healthcare Working Group (March 31, 2006).

³ B. Burwell and B. Jackson, "The Disabled Elderly and Their Use of Long-Term Care, U.S. Department of Health & Human Services (July, 1994).

Disability Management Sourcebook, the number of folks between 17 and 44 with severe disabilities has increased 400 percent over the past 25 years. One in seven people will become disabled for five years or more before they reach 65. The Society of Actuaries, one in seven people will become disabled for at least five years before age 65.⁴

The needs of the elderly and the disabled vary. Many elderly and disabled persons with relatively mild impairments do not require the active help of other people on a daily basis, although they may require the occasional assistance of other people to help with certain activities such as shopping, cleaning, doing the laundry, yardwork, preparing medications, using the telephone and so on. Many have mild impairments in mental functioning, but are not so impaired that they require continuous supervision. This group relies almost exclusively on family members and other informal caregivers for assistance. At the other end of the spectrum, are people with multiple health problems and severe limitations in mental and/or physical functioning who require very intensive (often 24 hour) levels of care. This group, in turn, is highly differentiated. Some people are severely impaired because they have recently had an acute illness and need intensive levels of care during their recovery period. Another group is severely impaired because they are close to death. Yet a third group has chronic severe impairments over an extended period of time and require intensive levels of care for months or years. In between these two extremes is the third group of persons with moderate impairments affecting one or two activities of daily living or having mild cognitive impairments requiring substantial care from institutions, family members or both.⁵ While much attention has been paid to the cost of providing institutionalized or professional long term care, long-term care provided in the United States in fact continues to be provided by informal caregivers: wives taking care of husbands; daughters taking care of their mothers; a neighbor mowing the lawn and buying groceries for someone who can no longer do it herself; a community group calling someone who lives alone to see if they're doing okay, or providing a ride for someone who can no longer drive himself. Informal caregivers form the bedrock of our country's long-term care system.⁶

⁴ See <http://www.efmoody.com/insurance/disabilitystatistics.html>, indicating that the odds of a person having at least one long term disability that lasts three months or longer before that person reaches age 65 are as follows:

Age	Probability
25	44
30	42
35	41
40	39
45	36
50	33
55	27

⁵ B. Burwell and B. Jackson, "The Disabled Elderly and Their Use of Long-Term Care, U.S. Department of Health & Human Services (July, 1994).

⁶ B. Burwell and B. Jackson, "The Disabled Elderly and Their Use of Long-Term Care, U.S. Department of Health & Human Services (July, 1994).

American businesses will recognize the burdensome business costs of dealing with aging and ill employees and their family members. The growing financial and productivity costs long have captured the attention of American employers. According to Commonwealth Fund survey data estimates, labor time lost due to health reasons represents lost economic output totaling \$260 billion annually.⁷ In 2003, an estimated 18 million adults ages 19 to 64 were not working and had a disability or chronic disease, or were not working because of health reasons. Sixty-nine million workers reported missing days due to illness, for a total of 407 million days of lost time at work. Fifty-five million workers reported a time when they were unable to concentrate at work because of their own illness or that of a family member, accounting for another 478 million days.⁸ As staggering as these numbers are, however, experts indicate they understate the true costs as dollar values placed on public and private expenditures for long-term care generally exclude costs of providing informal care from these measures. When the sick or elderly need help with activities of daily living, they overwhelmingly rely on family and friends to provide help. Often, this is provided by a “primary” caregiver who lives with them such as a spouse or adult child, generally a daughter. The economic value of informally-provided care is enormous. Informal caregivers report that they spend an average of four extra hours per day performing caregiving tasks. Thus, over 3 billion hours of informal caregiving are provided to disabled elderly persons with activities of daily living limitations each year.⁹

While this informal care is “free care” for purposes of the public treasury, it is not “free” to those who provide care or the businesses that employ these care givers. The competing demands of work and informal caregiving can be particularly difficult to juggle. About 31 percent of all primary caregivers are employed. Of those who work, many informal care givers report that they cut back on their total work hours (81%), or rearranged their work schedules (42%), in order to meet their informal caregiving responsibilities.¹⁰ Surveys indicate that caregivers feel particularly stressed by: (1) having to provide care when they are sick; (2) having to provide constant attention to the care-recipient; (3) experiencing financial burdens beyond what they can afford; and (4) feeling that informal caregiving has worsened their own health.¹¹ Thus, the stresses of caring for the ill and elderly are borne by both the families that love and care for them, and the businesses that employ the disabled and their care givers.

While American’s increasingly are fearful about their ability to handle these challenges, Americans devote relatively little energy to planning or preparing to deal with their own or a family member’s serious illness before they or a family member is diagnosed and find it hard if not impossible to cope when confronted with the necessity of coping with an aging or seriously ill family member.

⁷ K. Davis, Ph.D., S. Collins, Ph.D., M. Doty, Ph.D., A. Ho, and A. Holmgren, The Commonwealth Fund (August 2005).

⁸ Id.

⁹ Id.

¹⁰ Id.

¹¹ Id.

What's more, the guidance provided to Americans that do attempt to engage in serious advance planning for a serious illness or disability often is limited. For instance, families often are counseled about the need for durable powers of attorneys and living will and even, in recent years, the possible desirability of executing an authorization to disclose protected health information that complies with the medical privacy standards of the Health Insurance Portability and Accountability of 1996. In some cases, they even are encouraged to read and/or keep handy their health and disability benefit information. Rarely, however, do Americans come away from such endeavors with anything but the most passing understanding about when and how to use these materials, much less an appreciation of the broader ranges of challenges that they are likely to confront when a serious illness or disability arises.

When confronted with a serious illness or disability, however, patients and their families readily become apparent and often overwhelming for patients and their families. When an individual becomes seriously ill or disabled, he and his family generally face the dual burden of coming to grips with the realities and necessities of coping with the care and treatment of the medical condition itself, while simultaneously deciphering and addressing the implications of the illness on the families' employment, insurance, and other financial affairs. Whether or not the illness in question is expected to be terminal, patients and family members inevitably struggle to come to grips with the physical, emotional and financial realities of a serious illness or injury. Where the illness physically or mentally impairs the patient, family and friends often struggle to negotiate the maze of rules and administrative procedures that impede their efforts to help the patient investigate and deal with patient care and other personal affairs. While negotiating these hurdles, patients and their families often also face overwhelming financial challenges. Whether or not the patient is covered by public or private insurance, negotiation of the requirements for maximizing coverage, evaluating and responding to coverage denials, and monitoring and paying for uncovered medical expenses frequently presents a Herculean challenge. Meanwhile, where the illness or injury requires that the patient or a family member take time away from work, a patient and his family often also must confront questions and concerns about the implications of the illness on the employment, income and benefit security of the patient and his family. The patient's entitlement to medical and health care and disability coverage and benefits, privacy, health care decision-making, financial accountability, and other rights increasingly depend upon a complex array of contracts supplemented by laws such as the newly enacted Medicare Prescription Drug, Improvement and Modernization Act of 2003; other Medicare, Medicaid and VA regulations; the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"); the Employee Retirement Income Security Act; disability and other employment laws, state insurance, health care, and guardianship laws; the Fair Credit Reporting Act and other credit collection laws; and a plethora of other statutes, regulations, and rules. Patients already emotionally and physically drained from the stress of coping with the medical realities of a patient's illness rarely are in a position to optimally organize themselves to handle the practical, legal and financial challenges that often go hand in hand with a serious illness and the circumstances rarely

allow patients and their families the luxury of time to get up to speed. Consequently, Americans caring for ill and aging family members frequently are caught by surprise when they or a family member becomes seriously ill and are unprepared and lack the tools to handle these responsibilities at the time they are most needed.

Historically, patients in crisis have looked (or assumed that they could look) to employers, health care providers, community service agencies, neighbors and others to help them cope in these times of medical crisis. Patients and families overwhelmingly assume that medical and disability benefits provided by employment based or governmental programs will provide adequate protection for the patient and his family against the financial costs and income losses associated with the illness. They assume or hope that health care providers will look to these insurers, and not the patient or his family, to pay the costs of medically required care. They hope that health care providers or someone will explain to them how to find suitable home health care or nursing home providers, and a way to pay for those services. Unfortunately, changes in American society and in an age where employers, health plans, health care providers and government are placing increasing emphasis on “consumer driven health care” and “patient self-responsibility,” these hopes and assumptions increasingly go unfulfilled. Instead, American families increasingly must rely upon their own ingenuity to develop the understanding and tools that they need to effectively cope with the practical, legal and financial demands of dealing with an illness while struggling to reorganize their lives to deal with the human realities of life with a serious illness. Therefore, while Americans generally recognize the inevitability of sickness, death and taxes, most are ill-equipped to meet the medical, financial, legal and other practicalities of coping with a serious illness in their family at the onset of the illness.

While the particular needs and circumstances vary based on the illness and other circumstances affecting any particular family, most American families share a need for certain core information and tools in order to prepare for and cope with the challenges that commonly arise when they or a family member suffers a serious illness. Whether and how quickly and effectively a seriously ill patient and his family are able to cope with many of the practical and financial challenges of dealing with the illness in their family often depends upon their ability to effectively access and utilize these tools of patient empowerment. The problem for most employees and their families is that there is no expressway for locating, organizing, and deploying this information in the context of their family’s particular circumstance. The foundation for many of these tools already exist the employment and employee benefit practices of employers, applicable government and social agency services, and/or applicable laws, but are poorly understood by employees and their families. In other instances, the information vitally important to employees, patients and family members is not easily accessible, presented in obscure, patient-unfriendly mediums and terms. In an age where reimbursement for medical social work virtually has become as distinct as dinosaurs, employees, patients and families are forced to try to piece together relevant information and solutions with few roadmaps.

While many of the realities of dealing with an ill or aging family member are unavoidable, employers, insurers, government agencies, and social activists can help ease these burdens, and in the process help prevent or mitigate the absenteeism and other productivity disruptions that frequently arise while an employee struggles through this process through a variety of means. Where appropriate for a particular workplace, many employers increasingly are restructuring job positions, altering working hours, and making other short term or long term changes in job positions of workers with the goal of helping affected employees to remain productive performers in their workplaces. Many employers also are expanding the services offered by employee assistance programs, health plans, and other benefit arrangements, demanding that employee assistance programs provide more meaningful assistance to employees and families coping with aging or ill family members, and organizing other tools to help employees, patients, and families cope better faster. While employers, insurers, and others reaching out to provide this assistance generally must exercise care to avoid violating applicable privacy or other laws, early or other timely assistance in providing tools to families to cope often pays off by heading off performance, attendance or other problems that too often prove financially and legally costly for businesses. To facilitate the availability of these tools and coping skills, however, employers and others need to abandon the myth that employees and family members generally possess the tools and abilities to cope on their own and develop a more accurate understanding of the misperceptions and other shared limitations that are likely to impact the ability of employees, patients and families to cope. Based on this more realistic appreciation, employers and others can identify and develop the facilitative tools that make sense in their organization and how best to organize and deploy them for the mutual benefit of the organization and their employees.

➤ **Employment Implications of Employees Caring For Ill or Aging Family Members**

Employees whose families are affected by their own or a family members' illness or disability often depend upon their continued employment not only to pay for the ongoing expenses of living, but also rely upon employment for health care, disability or other critical coverage. Reduced or terminated employment associated with an illness in the family frequently gives rise to a financial crisis within the family.

Federal, state, and local employment discrimination laws provide a number of potentially valuable protections for employees affected by illness, disability, or aging. Depending on the particular circumstances, these laws may help insulate an affected employee against unfair discrimination.

For example, Congress has enacted a number of Federal statutes that prohibit employment discrimination based on certain characteristics. These nondiscrimination mandates often provide important protections for patients and families seeking to claim the maximum available coverage under an ERISA-covered health or other benefit plans, as well as valuable employment rights.

- The disabilities discrimination prohibitions of the Americans With Disabilities Act of 1990 (ADA) prohibit an employer¹² and any of its agents from discriminating against any “qualified individual with a disability”¹³ in any term, condition, or privilege of employment. Although Section 501(a) of the ADA contains special rules for health and other benefit plans,¹⁴ the Equal Employment Opportunity Commission (EEOC) has indicated that it views the disability discrimination prohibition as generally applicable to health and other benefit plans.¹⁵ The ADA also requires that all information regarding the medical condition or history of applicants or employees be maintained in separate medical files and treated as a confidential medical record. Disclosure of this information is permitted only to specified individuals.¹⁶ Most of the medical information that an employer or administrator obtains undoubtedly qualifies for protection as a confidential medical record under the ADA (e.g. doctor’s reports describing a disability).
- The Age Discrimination in Employment Act (ADEA), as amended by the Older Worker Benefit Protection Act (OWBPA) also provides valuable protections for many workers by prohibiting discrimination against individuals over age 40 on the basis of their age. The EEOC interprets the ADEA as requiring that the actual amount of payment made or cost incurred on behalf of an older worker equals the cost incurred on behalf of a younger worker. Meanwhile, Title VII of the Civil Rights Act prohibits sex-based discrimination within employee benefit plans. Under amendments enacted as part of the Pregnancy Act, employers generally cannot discriminate against an employee in the terms and conditions of employment based on the pregnancy of the employee or the spouse of an employee. Health and other employer-sponsored welfare plans also generally cannot limit or exclude coverage for pregnancy in a discriminatory manner. Rather, they must provide benefits for pregnancy on the same terms as any other illness or disability.

¹²Under the ADA, Federal law extends the prohibition against discrimination in employment based on disability to private employers, private educational institutions, and private business and service providers. On July 26, 1992, the employment provisions included employers with 25 or more employees. On July 26, 1994, however, the reach of the employment provisions of the ADA was extended to employers with 15 or more employees.

¹³The ADA defines a "qualified individual with a disability" as an individual with a disability who meets the skill, experience, education and other job-related requirements of the position and who, with or without reasonable accommodation, can perform the essential functions of the job. The ADA broadly defines an individual with a disability as including any of the following persons: (1) a person who has a physical or mental impairment that substantially limits a major life activity; (2) a person having a record of such an impairment; (3) a person regarded as having an impairment; and (4) a person who associates with a person with a disability. Certain conditions that may have fit under the definition of a disability are specifically excluded by the ADA.

¹⁴Section 501(a) of the ADA provides that, unless used as a subterfuge to evade the purposes of the ADA, the ADA does not prohibit or restrict: (1) an employer's establishment, sponsorship, observation, or administration of the terms of bona fide benefit plan; or (2) an insurer, hospital or medical service company, health maintenance organization, or any agent, or entity that administers benefit plans, or similar organizations from underwriting risks, classifying risks, and administering such risks consistent with state law.

¹⁵See 42 U.S.C. Section 12201(c); EEOC Technical Assistance Manual Section 7.9.

¹⁶See EEOC Technical Assistance Manual Section 6.5.

While these and other laws provide valuable protection against unfair discrimination, it is critical that employees not overestimate their protections. Under each of these, and other similar federal, state, and local laws, employees generally are not protected against discipline or discharge based on legitimate performance concerns or nondiscriminatory business decisions.

In addition to applicable non-discrimination laws, employees frequently may enjoy some temporary protections against an employment loss due to illness related absence under applicable federal and state laws, voluntarily adopted policies, or both. The Family and Medical Leave Act of 1993 (FMLA), for example, guarantees eligible employees of a covered employer who experience a qualifying family situation the right to take up to 12 weeks of unpaid leave of absence in each 12-month period from a covered employer. The FMLA also contains special rules concerning the right of covered employees to continue coverage during a qualifying family leave and to reinstatement of coverage after returning from a qualifying family leave. Many employers need to amend their welfare plans, practices, and policies to comply with these rules. The FMLA requirements apply to any plan an employer maintains or contributes to (including a self-insured plan) for providing health care (directly or otherwise) to the employer's employees, former employees, or their families. The continuation of coverage requirements extend to any medical benefits provided in an employer's health plan, including a supplement to a health plan, whether or not provided through a flexible spending account or other component of a cafeteria plan.

During a family leave, the FMLA requires that a covered employer allow an eligible employee to continue to receive coverage under the employer's group health plans as if the employee were not on leave. An employer may require an eligible employee to continue making employee contributions to continue group health plan coverage as if the employee were actively at work. The Department of Labor final regulations regarding the continuation of coverage during family leave state that the employer's obligation to maintain health coverage ceases if an employee's premium payment is more than 30 days late. The employer may recover the employee's share of any premium payments missed by the employee for any family leave period during which the employer maintained health coverage by paying the employee's share. However, the employer still must reinstate coverage to the employee upon return from family leave. When attempting to comply with this FMLA mandate, employers must consider other legal requirements affecting the funding arrangements of the health and other welfare plans, including the trust requirements of ERISA and, if applicable, the requirements applicable to cafeteria plans under Section 125 of the Code.

Except as required by COBRA, an ERISA-covered health plan's obligation to maintain health benefits under the FMLA ends when an employee informs the employer of his intent not to return from leave, when the employee fails to return from leave and thereby terminates employment, or when the employee exhausts his family leave entitlement. Published guidance about the relationship between the FMLA and COBRA states that the FMLA generally precludes a covered employer from applying the family leave

continuation period to reduce the COBRA period. The FMLA provides, however, that a covered employer may require an employee to reimburse the employer for the portion of the premium that the employer paid to maintain the employee's medical coverage during an unpaid family leave if an employee fails to return to work at the end of his family leave, and the failure to return is not a result of a serious health condition that would entitle the employee to family leave or other circumstances beyond the control of the eligible employee. An employee who returns to work for at least 30 calendar days is considered returned to work under the regulations. The employer may recover its share of health premiums paid during the entire period of unpaid family leave taken by the employee. The amount that a self-insured employer may recover is limited to the employer's share of allowable premiums calculated in accordance with COBRA, excluding the two percent fee for administrative costs. According to the Department of Labor regulations, an employer may either initiate legal action against the employee to recover its share of the premiums, or, unless otherwise prohibited by law, recover its share of health insurance premiums through deduction from any sums due the employee (e.g., unpaid wages, vacation pay, profit sharing, etc.). Attempts to recover health premiums through offset against other sums due the employee should not be undertaken without prior consultation with counsel to avoid incurring significant liability for unintentional violation of the FMLA, COBRA or other laws.

When the eligible employee returns to work after taking family leave guaranteed under the FMLA, the covered employer must restore any coverage under the health plan that the employee and his family enjoyed before he began his leave. The regulations state that an employee is entitled to be reinstated in medical coverage on the same terms as before his family leave without any qualifying period, physical examination, pre-existing condition exclusions, etc. According to the Department of Labor, an employee may choose to not retain health coverage during family leave without giving up his right to reinstatement of coverage following leave. Absent additional guidance, this regulatory position presents particular concerns where the medical coverage is provided through a medical spending account included in a cafeteria plan. An employee apparently remains eligible for this annually elected benefit amount and he can avoid making contributions for up to 12 weeks while he is on family leave.

In addition to these FMLA rights, an employee also may be entitled to be protected against termination during certain temporary periods of absence due to illness or disability under applicable state employment or disability laws and/or voluntarily adopted employer leave of absence policies. As valuable as these policies may be for many employees, however, the limitations on the availability and use of these policies and the limitations on their duration often prevents these protections from resolving the time conflicts faced by employees coping with chronic or long term illnesses or disabilities. Moreover, these legally mandated or voluntarily adopted employer leave policies provide little protection for lapses in productivity and performance often experienced by employees caring with their own or a family member's disabilities. As a consequence, many employees caring experience employment losses or other employment as a consequence of absences or other job performance concerns associated with the demands

of caring for the ill or disabled. Meanwhile, their employers often experience lost productivity and other costs associated with the employment or termination of employment of otherwise productive employees who find themselves overwhelmed by circumstances beyond the control of the employee or the employer.

➤ **Provide Information & Resources To Help Patients & Families Get, Organize and Use Relevant Information and Documents**

One of the biggest challenges that patients and their families often confront is getting organized. During the course of an illness, patients and their families can be expected to share and receive a diverse array of information. Before the onset of a medical condition, few Americans appreciate the desirability of organizing the core documents and information that the patient and his family are likely to need to monitor and communicate effectively with health care providers about the condition and health history of the patient, to identify and utilize their health and other insurance coverages, to monitor and manage their medical and disability related finances, and to carry out certain other core tasks. Once a family member becomes ill, the failure or inability of patients and their family to organize and maintain this information often unnecessarily complicates the ability of the patient and his family to access efficiently the information needed to coordinate patient care, pursue medical, disability and other benefits, and address other patient needs. A well-organized personal health care management file or notebook containing necessary documents and other health care factual information can facilitate the ability of patients and their family members to respond promptly, accurately and effectively to anticipatable demands family members, health plans, and others may make for this information and to monitor and respond to relevant developments impacting on patient care or other responsibilities.

To facilitate the ability of the patient and family members to accurately communicate with health care providers about the medical history of the patient, for instance, it often is desirable to for patients and their families to maintain in a patient notebook or file up-to-date information about the patients' current and prior medical condition and care such as health history details, current medications and vitamins, names and contact information for current and former physicians and health care providers, patient and/or family member notes of meetings with health care providers, lists of new or unresolved symptoms, pending questions and concerns of the patient and his family, and the like. Organization of this information in a central location can help patients, health care providers and family members accurately share relevant information necessary to the proper care of the patient. The ability to care for a patient can also be enhanced by including names and contact information for the patient's family members, current and former physicians, holders of powers of attorney or others authorized to manage affairs, attorneys, accountants, and financial planners. Additional relevant information that should be maintained in this collection includes allergy and other relevant-medical information, medical records, medical expense and payment records, health coverage explanation of benefits letters, and any other information that might expedite the handling of personal and medical affairs during a period of illness.

Ideally, the patient's personal health care management file also should include copies of documents relevant to the care and benefit coverage of the patient. For instance, most patients will find it helpful to include in their file copies of health insurance cards, health insurance and disability policies and booklets, employer leave of absence and vacation policies, and other information about procedures affecting the ability of the patient to qualify for and claim relevant benefits. Individuals should also consider including appropriate HIPAA compliant medical authorizations allowing health care providers and health plans to disclose medical information about the patient to family members and emergency contacts that the patient expects to assist in caring for the patient or handling other relevant responsibilities. This will reduce the risk that HIPAA's privacy rules will impede their ability to access important health information. Examples of other commonly helpful documentation includes durable medical powers of attorney, advance directives, custody and guardianship documents, wills, life insurance and annuity contracts, trusts, and beneficiary designations commonly prepared as part of an estate or financial planning process.

➤ **Facilitate Patient & Families Understanding About Their Health, Disability and Other Coverage, What It Covers & Does Not, How To Use It, & What To Do When They Aren't Covered**

Although employer provided coverage has declined across the past decade, employment based insurance remains the most common source of private medical coverage for most employed workers. Under the governing terms of the applicable employer or union sponsored health plans, medically-related or other absences as well as various other events may impact the eligibility or other rights of a patient or his family for enrollment in employer or sponsored health plan coverage. Patients and their family members who rely upon employment-based coverage need an appropriate understanding of the circumstances under which applicable health plan rule may result in a loss of coverage or allow the patient to be enrolled in coverage under an ERISA covered health plan.

Federal law traditionally has allowed employers broad freedom to decide the employees and dependents, if any, who are eligible for coverage under employer-sponsored health and welfare plans, subject to the plan sponsor's compliance with the generally applicable plan document and summary plan description requirements of ERISA and other applicable laws. Nevertheless, the courts have consistently ruled that employers may forfeit their ability to limit enrollment in their plans by failing to carefully craft the eligibility language contained in the plan documents and summary plan descriptions used in connection with those programs. Meanwhile, Congress has mounted an incremental assault on this freedom through a series of legislation such as the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA), the Family and Medical Leave Act of 1993 (FMLA), the Omnibus Budget Reconciliation Act of 1993 (OBRA '93), the portability requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and a host of other laws.

○ HIPAA Health Plan Eligibility Mandates

Among some of the most potentially significant federal eligibility mandates for seriously ill patients and their families are the “Group Health Plan Portability, Access and Renewability Requirements” set forth in Title 7 of ERISA and Subtitle K, Chapter 100 of the Internal Revenue Code (the Code). In February, 2005, the Departments of Labor, Treasury and Health and Human Services issued final regulations that supersede the jointly published interim regulations previously governing these provisions.

The portability requirements of HIPAA generally apply to all group health plans and health insurance issuers offering group coverage. However, certain arrangements are excepted. Its requirements regarding access, portability, and renewability do not apply to any group health plan (and group insurance offered under that plan) if the plan has less than two participants who are current employees on the first day of the plan year of the plan. Certain other exceptions also may apply if the requirements of HIPAA are satisfied and the group health plan provides only limited types of coverage. For purposes of these rules, “group health plan” generally includes any employee welfare benefit plan to the extent that it provides medical care to employees (including partners in a sponsoring partnership) or their dependents directly or through insurance, reimbursement or otherwise. “Health Insurance issuer” means an insurance company, insurance service, or insurance organization (including an HMO) which is licensed to engage in the business of insurance in a State and which is subject to State laws regulating insurance.

HIPAA generally provides that a group health plan or health insurance issuer may not establish rules regarding eligibility for health care coverage based on any of the following factors with respect to an individual or a dependent of an individual: health status; medical conditions (including both physical and mental conditions); claims experience; receipt of health care; medical history; genetic information; evidence of insurability (including conditions arising out of domestic violence); or disability. Similarly, a plan may not establish premium contribution rules based on any of the above-listed factors.

HIPAA also provides for special enrollment periods for persons who had previously declined enrollment in a group health plan because they had other coverage and subsequently lost that coverage. HIPAA requires that group health plans, and health insurance issuers offering group health insurance coverage, permit eligible employees or dependents to enroll under the terms of the plan if each of the following conditions is met: (1) the employee or dependent was already covered when the plan was previously offered; (2) if required by the plan sponsor or issuer, and provided that they gave notice to the employee, the employee stated in writing at such time that another source of coverage was the reason for declining enrollment; (3) the person was covered under COBRA’s continuation coverage which was exhausted, or coverage was not under a COBRA continuation provision and was terminated as a result of loss of eligibility for the coverage (including as a result of legal separation, divorce, death, termination of employment, or reduction of hours of employment) or termination of employer

contributions toward such coverage; and (4) the person requested enrollment not later than 30 days after the loss of the other coverage.

HIPAA requires that, if a group health plan offers dependent coverage, it must offer a dependent special enrollment period for persons becoming a dependent through marriage, birth, or adoption or placement for adoption. The dependent special enrollment must last for at least 30 days. If the individual is eligible and is not already enrolled in the plan, he may enroll at such time as he enrolls the dependent.

In addition, HIPAA provides portability of health care coverage for previously covered individuals by providing that such individuals may be covered by health insurance despite any preexisting conditions. HIPAA imposes three restrictions on the use of preexisting conditions in group health plans:

- A group health plan or health insurance insurer may not impose any preexisting condition exclusions relating to pregnancy.
- A group health plan or insurer may not impose any preexisting condition exclusion with respect to a newborn child, an adopted child who is under 18 years old, or a child who is placed for adoption who is under 18 years old, provided that such individual is covered under creditable coverage within 30 days of birth, or adoption or placement for adoption, respectively. However, a plan or insurer may exclude such newborn, adopted child or child placed for adoption if there is a break in coverage for more than 63 days.
- A group health plan or insurer cannot limit coverage for any preexisting conditions unless the following conditions are satisfied: (1) the definition of preexisting condition is limited to conditions for which medical advice, diagnosis, care or treatment was recommended or received within the 6 month period ending on the enrollment date; (2) the permitted duration of any limitation or exclusion of coverage for a preexisting condition is limited to a period after the enrollment date equal to 12 months (or 18 months for a late enrollee); and (3) the period of any such preexisting condition exclusion is reduced by the length of the aggregate of the periods of creditable coverage (if any) applicable to the participant or beneficiary as of the enrollment date.

Under HIPAA, a participant is entitled to have the otherwise applicable preexisting condition limitation period reduced by any period of prior coverage under another health plan, i.e. “creditable coverage.” In order to allow a person to prove that they had creditable coverage under another plan, all health plans are required to issue certificates of creditable coverage to participants. The certificates must state the duration of the participants’ coverage under the plan. Certificates must be issued automatically when coverage terminates and upon request. In many cases, the insurance company or TPA issues these certificates but, if not, it is the employer’s responsibility to do so.

HIPAA provides that an individual establishes a period of “creditable coverage” through presentation of certification(s) describing such prior creditable coverage. Such creditable

coverage is established by the individual's coverage under a group health plan (including a governmental plan), health insurance coverage (either group or individual insurance, including COBRA coverage periods), Medicare, Medicaid, military sponsored health care, or other programs outlined in HIPAA. Prior creditable coverage does not qualify as creditable coverage if there was longer than a 63-day break in an individual's health care coverage. However, any waiting periods prior to an individual's enrollment in an employer's health plan or a health maintenance organization ("HMO") will not count toward the 63-day period. Beginning July 1, 1997, HIPAA generally requires that the group health plan and health insurance issuer provide the certification describing the creditable coverage when the individual ceases to be covered under the plan or after a COBRA continuation period ceases. In addition, the group health plan and health insurance issuer may be required to provide such certification on the request of an individual within 24 months after the individual's coverage ceased. Plans may charge a fee to employers or insurers, but not to individuals, for preparing the certification.

HIPAA imposes certain guaranteed renewability requirements that apply only to health insurance issuers. Every health insurance issuer offering coverage in the small group health care market must accept every small employer that applies for coverage, subject to certain capacity or financial limitations. For this purpose, a small employer is defined as one having an average of 2 to 50 employees on a business day during the preceding calendar year and who employed at least two employees on the first day of the plan year. HIPAA also requires that health insurance issuers offering coverage to small employers make "reasonable disclosure" in solicitation and sales materials of the availability of information concerning (1) the issuer's right to charge premium rates and factors that may affect changes in premium rates; (2) renewability of coverage provisions; (3) preexisting condition exclusions; and (4) the benefits and premiums available under all health insurance coverage for which the employer is qualified. A health insurance issuer offering coverage in any employer group market is generally required to renew or continue coverage at the option of the plan sponsor. Although HIPAA does not limit the ability of a health insurance issuer to adjust premiums for a group on renewal, state law may regulate such premium adjustments. HIPAA waives a health insurance issuer's obligation to comply with the renewability requirements under certain limited circumstances. Furthermore, HIPAA's group market reform rules do not apply to any group health plan (and health insurance coverage offered in connection with a group health plan) for any plan year if, on the first day of the plan year, the group health plan has less than 2 participants who are current employees. Certain other specified arrangements also are exempt from these requirements.

The Final Regulations added a new requirement that all certificates of creditable coverage must contain an educational statement explaining HIPAA portability and the importance of the certificate. The final rules contain model certificates with the necessary educational statement as well as a host of other guidance about the application of these rules. The Final Regulations indicate that the updated model language will be the required language when the regulations take effect with the first plan year beginning on or after July 1, 2005. The Final Regulations also address a wide range of other issues. For instance, the

final rules clarify that health plans must have written procedures that describe how a person can go about requesting a certificate. Meanwhile, newly proposed rules issued at the same time as the final rules explain the interaction between HIPAA and the Family and Medical Leave Act (FMLA) and contain a model certificate of creditable coverage with FMLA language. While these rules and the newly issued guidance provide valuable rights for affected workers, the context in which these rules are communicated continues to obscure the relevance and usability of these rights for many workers.

○ **COBRA Medical Coverage Eligibility Requirements**

The Consolidated Omnibus Reconciliation Act of 1985 (COBRA) also affords important protections to employees and dependents that otherwise would lose eligibility for employment based medical coverage under certain specified circumstances.

COBRA generally requires private employers¹⁷ who normally employ 20 or more employees to offer their employees, and their immediate family members who are qualified beneficiaries, the opportunity to elect continued group health coverage after the occurrence of certain qualifying events. COBRA specifies what the qualifying events are, the length of time that the qualified beneficiary can maintain coverage under the health plan, minimum standards about notifications about COBRA rights, the election procedures and periods applicable to qualified beneficiaries, and the premium the employer can charge qualified beneficiaries for the group health coverage.

The qualifying events under COBRA include: (1) the employee's termination, other than for gross misconduct; (2) a reduction in hours that would cause the employee to cease to qualify for benefits; (3) the divorce or legal separation of a covered employee; (4) the death of the covered employee; (5) the covered employee's becoming entitled to Medicare; (6) a dependent child's ceasing to be a dependent child under the terms of the plan; or (7) Chapter 11 bankruptcy of an employer from whose employ a covered retired employee retired at anytime.

Under COBRA, continuation coverage generally must be provided for 18 months after the date of the qualifying event when a covered employee is terminated or has a reduction in hours. The period for qualified beneficiaries who are disabled at the time of a termination of employment or reduction in hours may be extended to 29 months. For other qualifying events, continuation coverage must be provided for 36 months. If, during the 18-month period following a termination or reduction in hours, an additional qualifying event occurs, the period is extended to 36 months.

COBRA also requires specific notice and election procedures. COBRA mandates that the plan administrator provide initial notice of COBRA rights to covered persons when coverage begins. When a qualifying event occurs, COBRA mandates that the plan

¹⁷ Similar mandates also generally apply to health plans sponsored by public employers pursuant to COBRA provisions applicable to those programs.

administrator send a specific notification to the qualified beneficiaries that contains detailed information about their COBRA rights and the applicable election procedures. The Department of Labor Regulations dictate specific content that must be included in each of these notifications, as well as provides rules regarding their delivery and other matters.

The May 26, 2004 Department of Labor Regulations interpret these mandates to require written notification including specific requirements for providing initial notification when coverage begins, notice when a qualifying event causes a loss or reduction in coverage, and at other key points. Despite these notifications, however, many employees and their families fail to appreciate their COBRA rights and responsibilities. For instance, COBRA requires that qualified beneficiaries timely notify the plan administrator in order to preserve their COBRA eligibility where coverage otherwise would end due events such as divorce or a dependent ceasing to qualify as a dependent or to preserve the entitlement of a qualified beneficiary to qualify for an extension of his otherwise applicable period of COBRA eligibility due to disability following an employment termination-related loss of coverage or a second qualifying event associated with other types of qualifying events. Where a group health plan offers conversion rights upon termination, qualified beneficiaries also generally have a right to elect to convert when COBRA coverage ends by making certain timely elections. Unfortunately, affected qualified beneficiaries and their families often unintentionally forfeit these options because they are unaware of, or fail to act promptly, to take advantage of these options.

- **Options To Add, Drop or Modify Enrollments Under Section 125 Cafeteria Plan Rules**

While most health and welfare plan sponsors that offer health or group term life insurance as benefit options under a cafeteria plan arrangement will want to amend and restate their cafeteria plans to comply with Temporary Treasury Regulation Section 1.125-4T, many employees overlook or do not understand how to use these options when dealing with their own or a family member's illness.

Code Section 125 regulates the circumstances under which an employer may allow employees to choose to elect to pay for certain health and other welfare benefit premiums on a pre-tax basis or choose welfare benefits from a menu of welfare benefit programs, cash or other taxable benefits, or some combination of both of these options. Arrangements that offer these options commonly are referred to as "cafeteria plans" or "flexible benefit plans."

Section 125 generally requires that elections made by an employee be irrevocable during the applicable plan year except under certain carefully prescribed circumstances. Where certain conditions are satisfied and the cafeteria plan document so prescribes, however, employees may qualify to make mid-year changes in their cafeteria plan elections to add or drop coverage under a broad range of circumstances including the acquisition or loss of a dependent, changes in their own or a family member's employment, loss in group

health coverage provided by a spouse or other family member's plans, and a host of other circumstances. Employees concerned about declining income associated with lost hours of work often are tempted to drop valuable health or other coverage to realize short term increases in cash flow. On the other hand, other employees often overlook the opportunity to elect enhanced coverages that frequently may be available in the event of a change in status or other event that qualifies them to make a mid-year election change under the cafeteria plan.

IRS Notice 2005-42, published on May 18, 2005, modifies the "use-it-or-lose-it" requirement traditionally applicable to cafeteria plans under Code § 125. This modification creates a new 2-1/2 month grace period immediately after the close of the plan year during which participants can still incur expenses for qualified benefits. Under the modified rules, Code § 125 continues to prohibit cafeteria plans that allow participants to defer compensation beyond the close of the plan year. Under IRS Notice 2005-42, however, a cafeteria plan document now may, at the employer's option, be amended to provide for a grace period of up to 2-1/2 months immediately following the end of each plan year during which unused contributions or benefits remaining in an employee's dependent care, health flexible spending or other cafeteria plan account may be used. The effect of the grace period is that the participant may have as long as 14 months and 15 days (the 12 months in the current cafeteria plan year plus the grace period) to use the benefits or contributions for a plan year before those amounts are "forfeited" under the "use-it-or-lose-it" rule. While many employers have elected to add this option to their plan, many employees may unnecessarily forfeit their right to reimbursement under these loosened reimbursement rules.

➤ **Patients Need To Understand How To Determine What The Scope and Limits Of Their Health, Disability & Other Coverage**

Patients and their families often fail to adequately understand the adequacy, scope and limits of their health and disability coverages and their role and responsibilities in maintaining and claiming benefits of that coverage.

As a starting point, many Americans lack any detailed understanding about the particulars of the coverage afforded to them under the medical benefit programs, if any, in which they participate. Misperceptions about the existence and adequacy of medical and disability coverage stem from a variety of sources. As a starting point, few Americans possess a realistic understanding about the true cost of medical services or medical coverage generally. As a result, Americans generally underestimate the cost of the medical services that a seriously ill family member is likely to need and the premium costs to secure coverage for that care. Meanwhile, Americans as a group tend to overestimate the coverage provided under their chosen health benefit program. For most American workers, cost considerations remain the primary consideration behind the medical and disability coverages, if any, in which an employee chooses to enroll himself and his family. Despite the delivery of summary plan descriptions and/or insurance certificates providing detailed descriptions of benefits, few American workers engage in

any detailed evaluation of the scope of coverage and benefits actually provided by the respective medical benefit programs, if any, in which they participate before the onset of a serious illness or injury. Prior to the onset of an illness or injury in their families, Americans generally operate on a presumption that except for co-payments and deductibles, their health benefit program generally will provide adequate coverage for any charges that a family member might be expected to incur for medically necessary care of a serious illness without making any significant effort to critically evaluate the specifics of their particular health benefit program. Even when seeking medical care, most Americans at the time they pursue care have not reviewed, and in fact are unaware of the potential need to review, the terms and conditions of the summary plan description, certificate of insurance, policies and plan documents and other documentation that governs their benefit entitlement, much less the identity and location of those documents. Rather, Americans seeking medical care commonly operate on a “no-news-is-good-news” mentality and presume that the required expense will be covered by their medical benefit program until their health plan denies coverage for a procedure, their health care provider bills them for the charges, or both. As a result, patients and their families often underestimate their true financial responsibility for payment of medical expenses incurred for treatment.

The Social Security Act prohibits discrimination against certain Medicare-eligible persons, and prohibits the offering of certain incentives to such individuals. The Social Security Act also specifies that a Medicare entitled individual whose current employer provides a health plan has a right to refuse group health plan coverage offered by an employer.¹⁸ If the employee or spouse refuses the group health plan coverage, Medicare is the primary payer for that individual.¹⁹ However, employers and other entities may not offer any financial or other incentive to an aged individual to induce him not to enroll or to terminate his enrollment in a group health plan in favor of Medicare unless that incentive also is offered to all individuals who are eligible for coverage under the group health plan.²⁰ Entities that violate the prohibition against the offering of such financial inducements are subject to up to a \$5,000 civil penalty per violation.²¹ Regulations issued by the Health Care Financing Administration in August, 1995 state that the prohibition against the offering by an employer or other entity (such as an insurer) of any incentives to a Medicare-eligible individual not to participate in a group health plan precludes offering Medicare beneficiaries an alternative to the employer’s primary plan unless the beneficiary has primary coverage other than Medicare.²²

¹⁸See HCFA Reg. Section 411.72(c).

¹⁹See HCFA Reg. Section 411.72(c).

²⁰See HCFA Reg. Section 411.72(c).

²¹See Social Security Act Section 1862(b)(3).

²²See 60 Fed. Reg. 45344-45372.

➤ **Patients Need A Greater Appreciation of The Importance of Monitoring The Status of Claims For Coverage And Timely Appealing Adverse Claims Decisions**

Because patients often fail to appreciate their potential financial responsibility for certain medical expenses, patients often view the submission and processing of claims for medical coverage as the responsibility of the health care provider. As a consequence, patients frequently fail to maintain records apart from the health care provider of charges incurred for specific treatments or to adequately monitor the success of the provider in obtaining coverage for these expenses from the patient's applicable health plan. As a result, by the time that a health care provider bills the patient for charges that the patient's health plan refused to coverage, the patient generally both lacks the documentation he needs to determine the appropriateness of the coverage denial and has allowed the time for appealing the plan's determination to expire.

Even when a patient or his family recognizes the potential need to participate in the claims or appeals process, he often may lack an awareness or understanding of the procedures and timetables that he should observe to best pursue his claim. Pursuant to requirements established by the Employee Retirement Income Security Act of 1974, as amended ("ERISA") participants and beneficiaries in employer or union sponsored health plans generally are entitled to expect health plan fiduciaries to prudently administer their claims in accordance with the written plan documents governing the health plan using reasonable claims and appeals procedures.

Pursuant to regulation, all ERISA-covered health plans must provide reasonable claims procedures.²³ All claims and appeals of claim denials under welfare plans must be administered in accordance with reasonable claims and appeals procedures mandated by Department of Labor regulations.²⁴ After relying upon its originally published regulations for more than two decades, the Department of Labor on November 21, 2000, published a final regulation that sets new standards for processing benefit claims and appeals of participants and beneficiaries covered under disability and health plans governed by ERISA. All ERISA-covered health plans have been required to comply with these new claims and appeals standards since January 1, 2003. This is true whether the plan is "self-insured," "fully-insured," or some combination thereof.²⁵ The restated ERISA claims and appeals regulations substantially expand the requirements that disability and health benefit programs must adhere to meet the Labor Department's definition of "reasonable claims procedures."

²³See Labor Reg. 2560.503-1.

²⁴See Labor Reg. 2560.503-1.

²⁵Insurers processing health benefit claims under non-employment based or other non-ERISA covered insurance policies generally are required to comply with mandates for the appropriate processing and payment of claims established under applicable state law. Pursuant to the "Savings Clause" set forth in Section 514(b) of ERISA,, insurers administering insured ERISA-covered health plans generally also are required to comply with certain state insurance law mandates regarding the processing of claims and appeals. Pursuant to the preemption provisions of ERISA Section 514, however, an ERISA-covered health plan that qualifies as "self-insured" for purposes of ERISA generally is not required to comply with such state mandates.

To ensure that participants and beneficiaries are properly advised about the claims procedures, Department of Labor regulations require that the summary plan description for a health and welfare or other benefit plan must include a description of the claims and appeals procedures for filing and appealing claims. Those procedures must not unduly hamper or inhibit the processing of claims. The procedures must comply with Federal requirements for the processing of claims, including notifying participants of claim denials and administering appeals of claims denials. Additionally, restated regulations impose a series of specific requirements on the processing of health and disability plan claims.

With respect to group health plans, for instance, Labor Regulation § 2560.503-1(c), defines specific procedures with substantially shortened time frames from processing claims and appeals on urgent care, concurrent care and pre-service claims for benefits and substantially expands the responsibilities of plan administrators for communicating information needed to perfect claims, the basis of claims decisions, and other matters. For both group health and disability plans, the Labor Regulation imposes new requirements on plan administrators when making medical judgment related decisions. A host of other new procedural safeguards also have been added.

Although Department of Labor Regulations mandate that ERISA-covered health plan administrators inform participants and beneficiaries about relevant claims and appeals procedures by including explanations of these procedures in the ERISA-mandated summary plan description as well as when providing written notification of an adverse decision regarding a claim, participants and beneficiaries often are aware of, or fail to appropriately follow these procedures for a variety of reasons. By understanding and maintaining ongoing participation and oversight of the submission, processing, determination, and appeal of claims determinations relating to their care, patients can help ensure that they obtain the maximum benefits available under their health plan and monitor their personal financial liability for uncovered health care expenses.

Lack of understanding of these rules often fuels unnecessary administrative and litigation expense, while undermining the employee benefit value of the benefits that employer have paid so much to provide. Employers and their health and disability benefit plan administrators and insurers often can facilitate their realization of the benefits of consumer drive health care and other benefit and leave of absence cost and liability management initiatives by improving their efforts to communicate and educate employees, participants and beneficiaries about the proper understanding and use of their benefits, including procedures for submitting, monitoring, and processing claims and appeals.