# PATIENT'S RIGHTS AND RESPONSIBILITIES

# Patients' Bill of Rights

#### I. Information Disclosure

You have the right to receive accurate and easily understood information about your health plan, health care professionals, and health care facilities. If you speak another language, have a physical or mental disability, or just don't understand something, assistance will be provided so you can make informed health care decisions.

#### II. Choice of Providers and Plans

You have the right to a choice of health care providers that is sufficient to provide you with access to appropriate high-quality health care.

#### III. Access to Emergency Services

If you have sever pain, an injury, or sudden illness that convinces you that your health is in serious jeopardy, you have the right to receive screening and stabilization emergency services whenever and wherever needed, without prior authorization or financial penalty.

#### IV. Participation in Treatment Decisions

You have the right to know all your treatment options and to participate in decisions about your care. Parents, guardians, family members, or other individuals that you designate can represent you if you cannot make your own decisions.

#### V. Respect and Nondiscrimination

You have a right to considerate, respectful and nondiscriminatory care from your doctors, health plan representatives, and other health care providers.

#### VI. Confidentiality of Health Information

You have the right to talk in confidence with health care providers and to have your health care information protected. You also have the right to review and copy your own medical record and request that your physician amend your record if it is not accurate, relevant, or complete.

### VII. Complaints and Appeals

You have the right to a fair, fast, and objective review of any compliant you have against your health plan, doctors, hospitals or other health care personnel. This includes complaints about waiting times, operating hours, the conduct of health care personnel, and the adequacy of health care facilities.

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## **Statement of Responsibilities**

In a health care system that protects consumers' rights, it is reasonable to expect and encourage consumers to assume reasonable responsibilities. Greater individual involvement by consumers in their care increases the likelihood of achieving the best outcomes and helps support a quality improvement, cost-conscious environment. Such responsibilities include:

- Take responsibility for maximizing healthy habits, such as exercising, not smoking, and eating a healthy diet.
- Become involved in specific health care decisions.
- Work collaboratively with health care providers in developing and carrying out agreed-upon treatment plans.
- Disclose relevant information and clearly communicate wants and needs.
- Use the health plan's internal complaint and appeal processes to address concerns that may arise.
- Avoid knowingly spreading disease.
- Recognize the reality of risks and limits of the science of medical care and the human fallibility of the health care professional.
- Be aware of a health care provider's obligation to be reasonably efficient and equitable in providing care to other patients and the community.
- Become knowledgeable about his or her health plan coverage and health plan
  options (when available) including all covered benefits, limitations, and
  exclusions, rules regarding use of network providers, coverage and referral rules,
  appropriate processes to secure additional information, and the process to appeal
  coverage decisions.
- Show respect for other patients and health workers.
- Make a good-faith effort to meet financial obligations.
- Abide by administrative and operational procedures of health plans, health care providers, and Government health benefit programs.
- Report wrongdoing and fraud to appropriate resources or legal authorities.

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#### Rationale

In providing consumers with a set of rights and protections, the Commission believes that individual consumers must assume certain responsibilities. Responsibilities create benefits not only for individual consumers and their families but also for the health care system and society as a whole. Improved health status reduces medical costs for the patient, the payer, and society.

The Commission, however, does not intend to create a link between an individual's conduct in meeting his or her responsibilities and the obligations of plans and providers to provide covered services.

Increased patient responsibility can improve consumers' sense of self-worth. For example, increased responsibility among individuals living with disabilities has resulted in increased independence for that population (Rodwin, 1994; National Health Council, 1995). In fact, this is the principle behind the independent living movement, where people with disabilities live in their homes with personal assistant services rather than in institutions. Individuals report that increased responsibility for their health has led to improved self-esteem and a greater sense of empowerment.

Promoting consumer responsibility is an essential component of the effort toward involving consumers directly in decisionmaking about their health and medical care. Consumers often perceive that the medical professionals who care for them are acting in a condescending or paternalistic manner. They resent being put in a position of dependence and being treated as if they are infantile and object to the presumption that they are incapable of making choices themselves (Rodwin, 1994).

While the Commission believes that consumers must assume certain responsibilities, it also recognizes that reasonable accommodations must be made for numerous consumers with disabilities. For example, some individuals with physical and mental disabilities require assistance with self care; for some individuals with mental disabilities, noncompliance with treatment regimes is a manifestation of their disability; and some individuals with mental and physical disabilities are unable -- due to their disability -- to clearly communicate their wants and needs and, therefore, rely on the assistance of a designated representative. In each case, the health care system must recognize these issues and accommodate these needs. The Commission also recognizes that there are many other factors, such as occupational hazards, language, and income status, that may pose significant barriers to consumers meeting these responsibilities.

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Consumers who are able should take the opportunity to educate themselves with respect to the specifics of their benefit coverage and to learn how to access the health care and services available to them as a result of that coverage. This includes:

- Reading and understanding written information that explains benefit coverage.
- Reading and understanding information that describes health plan processes and procedures to follow when seeking care by a physician, hospital, or other provider.
- Seeking information or clarification of information from the health plan as necessary.
- Using the health plan's processes for addressing complaints or grievances when disputes with providers or health plan procedures arise.

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Consumer responsibility is particularly relevant to the broad right to information established in this Consumer Bill of Rights and Responsibilities. The Right to Information requires the disclosure of information to consumers either directly or upon request on such things as benefits, cost-sharing, complaints and appeals processes, licensure, accreditation, and performance measures. The Right to Information will improve health outcomes only to the extent that consumers have a choice of health plans and use that information in exercising the choice.

Although there is significant value in promoting the consumers' participation in their own health care by increasing their level of responsibility, it is important to set limits on the amount of responsibility expected. The patient's responsibility to comply with medical advice is limited by the principle of informed consent (Benjamin, 1985). The patient retains the right to choose whether to follow medical advice or not, as long as he or she is willing to accept the health outcome consequences that may result from noncompliance, and the noncompliance does not adversely affect the public (Brock and Wartman, 1994).

Consumers do not have a duty to be subjected to a treatment regime they have good reason to avoid -- for instance, one whose negative side effects outweigh its benefits (Mayer, 1992), or when excessive medication in an institutional setting is used to "control" residents. Most consumer responsibilities do not extend to those who are incompetent to make decisions, including infants, those who are judged to be mentally incompetent, and comatose patients (Emson, 1995; Mayer, 1992; National Health Council, 1995).

In addition, certain high-risk behaviors (smoking, use of smokeless tobacco, illegal drug use) are addictive and cannot be considered fully under the volitional control of the individual consumer. Caution must be used to avoid "blaming the victim." For example,

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Bayer (1996) notes that during the history of the AIDS epidemic, "the emphasis on personal responsibility was often associated with condemnation of those whose sexual or drug-using behavior had exposed them to HIV, as well as with calls for invasion of privacy and deprivations of liberty."

Compliance with agreed-upon treatment protocols is a particularly important consumer responsibility. Noncompliance with the taking of medication has particular implications for the health status of consumers. Noncompliance includes taking too much medication, taking medication not prescribed, not taking medication prescribed, altering the prescribed dosage, or altering the time between doses.

Finally, it is important to recognize that while consumers should seek to assume the responsibilities discussed in this report, many factors influence consumers' acceptance of medical advice. Some are related to the health care system itself and others are related to the patient's individual psychology. Imanaka, Araki, et al. (1993) identified patient dissatisfaction with their health care providers and plans as a primary cause of patient

noncompliance. Several studies have identified inadequate provider-consumer communication as a contributing factor (Imanaka, 1993; Ross, 1991; Donovan and Blake, 1992; Sluijs, Kok, et al., 1993). This leads to situations where:

- The patient and the prescriber have a different understanding of what the patient is supposed to do.
- The patient lacks information or understanding about the disease, pathology, or symptoms.
- The patient does not understand the correct purpose of the intervention.
- The patient and the health care provider have insufficient time to discuss the full range of issues concerning compliance.

Noncompliant patients also may have underlying psychiatric disorders. Yellowless and Ruffin (1989) found that 40 percent of patients who experience a life-threatening asthma episode have psychiatric disorders. Patients often are trying to balance the requirements of their prescribed medical regimen with other aspects of their life (Donovan and Blake, 1992). Finally, some patients choose not to comply with medical instructions as a way of expressing their attempts to cope with their disease; as a reaction to the way they have been treated by doctors; or as a way of fighting the system by breaking its "symbolic" rules (Ross, 1991).

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# Implications of the Responsibilities

Consumers will have to play an active role in the treatment and management of their health. Consumers will need to ask more questions of their health care providers, insurers, and institutions. They will need to express their wishes and desires clearly to those who care for them and to their family members in the event of incapacity; this should be done *before* an incapacity occurs. They will need to make sure that they understand a treatment regimen that is prescribed for them before they agree to follow it. Once they have made such an agreement, consumers will need to make every effort to comply and, if they cannot, to notify their provider of their desire or need to change that regimen. Consumers will need to recognize the financial and societal impact of their health care decisions and their health care choices should reflect this consideration.

**Health care providers** will need to communicate more clearly with their patients and their patients' families about diagnoses, treatment options, and treatment protocols. They will need to make greater efforts to ensure that those matters are clearly understood and agreed to. They will need to work with their patients to ensure that treatment regimens are possible to follow and that changes in treatment are made when possible to meet patients' needs or demands.

**Health plans** will need to consider ways to encourage greater communication between consumers and health care professionals, including incentives for such communication and acceptance of treatment regimens.