

Code of Ethics for Patient & Health Care Advocates

The National Association of Healthcare Advocacy (NAHAC) in association with HealthAdvocateX (HAdvX) and the Patient Advocacy Certification Board (PACB) is pleased to present this update to the Code of Ethics first written by NAHAC in 2011 for the Health Care Advocacy profession.

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NAHAC
NATIONAL ASSOCIATION OF
HEALTHCARE ADVOCACY



Patient Advocate
Certification Board

HEALTHADVOCATE[™]

PREAMBLE

The National Association of Healthcare Advocacy (NAHAC) in association with HealthAdvocateX (HAdvX,) and the Patient Advocacy Certification Board (PACB) is pleased to present this update to the Code of Ethics first written by NAHAC in 2011 for the Health Care Advocacy profession. Acceptance and adherence to this Code is a mandatory requirement of Membership in NAHAC, a requirement for Professional Membership in HAdvX, and is required to obtain and maintain the Board Certified Patient Advocate Certification.

This document aims to frame the essential ethical standards for health care advocacy professionals who assume the profound responsibility and privilege of helping individuals and their families navigate the healthcare system. The term "Advocate" has been selected for this document to represent all professionals who work on behalf of clients/patients, families, communities, and caregivers toward the goal of safe, effective, equitable, and compassionate health care for all. "Advocate" was chosen given the broad and varied backgrounds of these professionals as well as the different labels and titles used in the field of health care advocacy.* (see Glossary for definitions)

Advocates work with clients who need assistance navigating complex medical, behavioral, or insurance/financial situations by partnering with them and supporting their ability to make individual and well-informed decisions. Advocates strive to uphold the legal and ethical principles of voluntary, understanding and informed consent, as well as those of shared decision-making between patients and providers. They do so by ensuring clients have the relevant information, an appropriate understanding of the matters in question, and trying to ascertain clients are not being coerced. Advocates make sure the clients' voices and choices are heard. At no time do Advocates make decisions or recommendations regarding specific treatment choices, provide clinical opinions, or perform medical care of any type, even if they possess clinical training or credentials.

Essential to the profession of advocacy is the belief that equal access to appropriate health care and treatment is the right of each individual. Advocates strive for clients' equal access to health services without regard to age, race, religious/spiritual practice, mental/physical disability, culture, ethnicity, sexual orientation or gender identity, citizenship, or immigration status. Advocates respect diversity, equity, and inclusivity and may not discriminate in any way. Advocates seek to provide effective, equitable, understandable, and respectful services that are appropriately responsive to each client's unique situation.

We recognize that effective advocacy is both an art and a science, grounded in the bioethical principles of self-determination (autonomy), doing good (beneficence), doing no harm (non-maleficence), and justice (the equitable distribution of benefits and burdens). Advocates respect and support the uniqueness of every person's culture, beliefs, and preferences. Therefore, Advocates share a commitment to the values of compassion, dignity, integrity, and the importance of human relationships.

AFFIRMATION

**We affirm that Advocates aim to assist clients in obtaining
healthcare that is safe, effective, patient-centered,
timely, efficient, and equitable.**

THE STANDARDS



Professional Integrity

Advocates practice with compassion and respect for the clients/patients, and families with whom they work. Advocates understand and respect the boundaries between health care advocacy and the professional services of the healthcare team. Reciprocally, clients should provide practicing Advocates the recognition and professional respect required and acknowledge appropriate professional boundaries. Should clients breach professional boundaries that impede the quality of the professional arrangement, Advocates must withdraw their services but may assist with finding appropriate alternatives for them.

Advocates providing services are obligated to maintain the highest ethical standards and to practice transparently by providing clients with documents that define the Advocate's education, training, experience, credentials (including license/s), and a written agreement that defines the scope of practice, fee schedule or pricing structure, and terms of working together. References and proof of professional liability insurance may be provided upon request.

Advocates must disclose any conflicts of interest. This is defined as a situation in which a person is in a position to derive personal benefit from actions or decisions made in their official capacity. These may include personal beliefs or contractual relationships the Advocate or their spouse/partner has with other service providers, Advocate's conditions of other employment, and any financial relationships they hold with other professionals, businesses, or institutions.



Client Privacy and Confidentiality

Although not legally bound under HIPAA, Advocates recognize that privacy is an essential component of every client relationship. Advocates, therefore, respect each client's right to privacy and confidentiality and commit to protecting all forms of client records, all forms of communications, and any and all identifiable personal information in compliance with the Health Insurance Portability & Accountability Act/HIPAA*. Respect for privacy and confidentiality notwithstanding, Advocates are required to be familiar with the respective reporting mandates in the states where they practice and comply with the procedures in place to report suspected abuse or neglect of clients or other individuals to the appropriate authorities. Advocates have a responsibility to protect vulnerable persons and may execute a call to the appropriate authorities for a welfare check as needed. Furthermore, Advocates have a responsibility to warn and may breach confidentiality when clients pose an imminent threat to either themselves or others, including the Advocate.



Technology Safeguards

Advocates recognize the ever-increasing technological advances in health care communications. Consistent with the Health Insurance Portability and Accountability Act/HIPAA*, Advocates commit to safeguarding all forms of electronic communications, including information obtained from telehealth and virtual appointments/meetings, electronic medical records (EMRs), client/patient portals, and any other form of electronic communications.



Best Practices and Professional Education

Advocates are committed to promoting the health, safety, and rights of all their clients; as such they only advise clients within their areas of competency or expertise and in accordance with applicable state laws and regulations. To best serve their clients, Advocates are committed to lifelong learning to keep their knowledge and skills current, hone their professional expertise, and stay abreast of current conditions in the rapidly changing healthcare environment. Advocates must participate in continued learning by pursuing continuing education credits, actively participating in professional organizations and networking with their colleagues to share information and resources for the benefit of the profession, their clients, and the public. If a client needs assistance in an area where the Advocate does not have sufficient knowledge or training, Advocates will refer the client to the appropriate system or resource for assistance. Advocates should ensure that they have adequate referral systems and networks in place to assist those clients who need services they are unable to provide.



Fostering Informed Decision Making

Advocates strive to provide their clients with all the information that will facilitate informed decision-making including care and treatment options, potential risks and benefits, insurance implications, and available treatment or provider alternatives. Advocates shall treat all legally designated surrogates with respect that honors their best understanding of their client's individual values, wishes, and best interests regarding their health care decisions. This fosters the autonomy and empowerment of each client's exercise of meaningful, voluntary, and legally required informed consent* in a framework of shared decision-making* between clients, their representatives, and providers.

Advocates recognize that clients' health literacy and confidence around informed decision-making must be assessed and supported. Advocates recognize that these variables may be impacted by the dynamics inherent in negotiating ongoing medical conditions/events and provider operations/systems. While Advocates will guide and assist their clients/patients with medical decision-making, at no time will Advocates make those decisions on their client's behalf.

Advocates should strongly encourage clients to complete necessary state-specific advance care planning documentation* as appropriate and to revisit these as circumstances and preferences change over time. Knowledgeable consent must exist in order for these forms to be valid. If the Advocate has any concerns regarding a client's capacity to complete such documents, they should consult with the appropriate medical and/or legal professionals. Advocates who may become enlisted as a Health Care Proxy must have prior, clear, and transparent written documentation to support serving in such a role thereby enforcing the client's previously expressed health care wishes. This function may only occur in the context of a well-established relationship between Advocate and client/patient, and only become effective once a client/patient is unable to speak for themselves.



Professional Conduct

Advocates are personally and professionally accountable for their actions; they must avoid impropriety and maintain professional boundaries and practices at all times. Such boundaries extend to interpersonal relationships with clients, clients' families, and other professionals or members of the healthcare team. Advocates who cross professional boundaries must remove themselves from the situation and, if possible, assist the client in finding an appropriate alternative. Such violations may include but are not limited to fulfilling requests to perform illegal or unethical actions; developing a romantic or sexual relationship with a client or someone related to the client; agreeing to perform duties outside of contracted terms; or any other circumstance that could result in the inability to fully perform the work the two parties had originally agreed upon. Advocates must avoid conflicts of interest where they stand to materially gain beyond the explicit fee arrangements. For example, Advocates may not accept remuneration for making referrals to other providers or services; may not steer clients to products or services from which the advocate will profit financially or earn a commission; may not accept paid advertising on their websites from outside product or service providers, and may not require a client to purchase or subscribe to any outside service in order to benefit from the Advocate's services. Advocates will not discriminate and will abide by the federal protections for protected classes, including but not limited to: race, nationality, religion or creed, national origin or ancestry, sex gender identity, pregnancy, maternity/paternity, sexual orientation, age, physical or mental disability, veteran status, genetic information, citizenship, or immigration status.



Respect for Diversity, Equity, Inclusivity & Justice

Advocates respect diversity, equity, justice and inclusivity. Advocates will practice with cultural sensitivity and work to provide services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs. Advocates strive to reduce health disparities and achieve health equity.

*GLOSSARY

Advance care planning is a process, not an event, and is planning for future care based on a person's values, beliefs, preferences, and specific medical issues. An advance directive is the record of that process. It is both an umbrella term for defining and expressing how one wants to live and be treated and for state-approved advance directive documents which allow you to specify those things and usually to appoint a person (healthcare power of attorney or health proxy) to speak when you are unable to speak for yourself.

<https://www.caringinfo.org/planning/advance-directives/>

Advance care planning documents include but are not limited to HIPAA Authorization Forms; Durable Power of Attorney for Healthcare; Healthcare Proxy; Durable Power of Attorney for Financial Affairs; Living Wills and Advance Directives.

Advocate: Such professionals include but are not limited to health and health care advocates, patient advocates, patient navigators, health or patient advisers, care managers, and case managers, as well as those who work on behalf of communities, consumers, and family caregivers (including advocacy on legislative and health policy initiatives). Advocates may work independently, in a medical setting, or on behalf of communities or disease-specific populations across organizations and agencies.

HIPAA Privacy Rule: The HIPAA Privacy Rule establishes national standards to protect individuals' medical records and other personal health information and applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically. The Rule requires appropriate safeguards to protect the privacy of personal health information and sets limits and conditions on the uses and disclosures that may be made of such information without patient authorization. The Rule also gives patient's rights over their health information, including rights to examine and obtain a copy of their health records and to request corrections. Advocates are not considered covered entities under HIPAA, but make a conscious choice to safeguard client information according to HIPAA guidelines.

Informed consent is a process of communication between a patient or surrogate and their health care provider that often leads to agreement or permission for care, treatment, or services. Every patient has the right to get information and ask questions before procedures and treatments. Signing informed consent means the patient has received all the information about treatment options, their respective risks, and benefits as well as potential complications and consequences, including those of doing nothing from the health care provider; by signing the consent form, the patient acknowledges their understanding of said information and their willingness to proceed.

<https://www.cancer.org/treatment/treatments-and-side-effects/planning-managing/informed-consent/what-is-informed-consent.html>

Informed choice (aka informed decision-making) means that patients and families make decisions that are consistent with their goals and values. Individuals can disagree about the benefits or burdens of any particular therapy and based on their goals and values may choose different options. Patients vary in their willingness to tolerate side effects or risk of bad outcomes. Only the patients and their families can determine what may be acceptable to them/their quality of life.

Shared decision making (SDM) is defined as "...a formal process or tool that helps physicians and patients work together to choose the treatment option that best reflects both medical evidence and the individual patient's priorities and goals for their care (American Medical Association, 2012)."

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ATTRIBUTION

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