

NATIONAL ASSOCIATION OF SOCIAL WORKERS

N A S W S t a n d a r d s f o r

Palliative & End of Life Care



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Standards

for Palliative and End of Life Care

Standard 1. Ethics and Values

The values, ethics, and standards of both the profession and contemporary bioethics shall guide social workers practicing in palliative and end of life care. The NASW Code of Ethics (NASW, 2000) is one of several essential guides to ethical decision making and practice.

Standard 2. Knowledge

Social workers in palliative and end of life care shall demonstrate a working knowledge of the theoretical and biopsychosocial factors essential to effectively practice with clients and professionals.

Standard 3. Assessment

Social workers shall assess clients and include comprehensive information to develop interventions and treatment planning.

Standard 4. Intervention/Treatment Planning

Social workers shall incorporate assessments in developing and implementing intervention plans that enhance the clients' abilities and decisions in palliative and end of life care.

Standard 5. Attitude/Self-Awareness

Social workers in palliative and end of life care shall demonstrate an attitude of compassion and sensitivity to clients, respecting clients' rights to self-determination and dignity. Social workers shall be aware of their own beliefs, values, and feelings and how their personal self may influence their practice.

Standard 6. Empowerment and Advocacy

The social worker shall advocate for the needs, decisions, and rights of clients in palliative and end of life care. The social worker shall engage in social and political action that seeks to ensure

that people have equal access to resources to meet their biopsychosocial needs in palliative and end of life care.

Standard 7. Documentation

Social workers shall document all practice with clients in either the client record or in the medical chart. These may be written or electronic records.

Standard 8. Interdisciplinary Teamwork

Social workers should be part of an interdisciplinary effort for the comprehensive delivery of palliative and end of life services. Social workers shall strive to collaborate with team members and advocate for clients' needs with objectivity and respect to reinforce relationships with providers who have cared for the patient along the continuum of illness.

Standard 9. Cultural Competence

Social workers shall have, and shall continue to develop, specialized knowledge and understanding about history, traditions, values, and family systems as they relate to palliative and end of life care within different groups. Social workers shall be knowledgeable about, and act in accordance with, the NASW Standards for Cultural Competence in Social Work Practice (NASW, 2001).

Standard 10. Continuing Education

Social workers shall assume personal responsibility for their continued professional development in accordance with the NASW Standards for Continuing Professional Education (NASW, 2002) and state requirements.

Standard 11. Supervision, Leadership, and Training

Social workers with expertise in palliative and end of life care should lead educational, supervisory, administrative, and research efforts with individuals, groups, and organizations.

All social workers, regardless of practice settings, will inevitably work with clients facing acute or long-term situations involving life-limiting illness, dying, death, grief, and bereavement. Using their expertise in working with populations from varying cultures, ages, socioeconomic status, and nontraditional families, social workers help families across the life span in coping with trauma, suicide, and death, and must be prepared to assess such needs and intervene appropriately.

Social work practice settings addressing palliative and end of life care include health and mental health agencies, hospitals, hospices, home care, nursing homes, day care and senior centers, schools, courts, child welfare and family service agencies, correctional systems, agencies serving immigrants and refugees, substance abuse programs, and employee assistance programs. Thus, social work is a broadly based profession that can meet the needs of individuals and families affected by life-limiting illness and end of life issues.

Social workers are challenged to provide expertise and skill in direct services to clients and their families. At the same time, they have the opportunity to influence a range of professionals, consumers, and laypersons regarding life-limiting illness, care of the dying, and the bereaved. The need for social workers trained and skilled in working with palliative and end of life care situations has increased, because of advancements in medical technology, rising rates of chronic illness, increasing number of elderly people, and longer life spans.

Palliative and end of life care is a growing area of practice, and social workers may feel unprepared to deal with the complex issues it encompasses (Csikai & Raymer 2003; Christ & Sormanti, 1999). These standards are designed to enhance social workers' awareness of the skills, knowledge, values, methods, and sensitivities needed to work effectively with clients, families, health care providers, and the community when working in end of life situations.

End of Life Care

End of life care refers to multidimensional assessment and interventions provided to assist individuals and their families as they approach end of life. Whether sudden or expected, the end of a person's life is a unique experience that has a great impact on the person, his or her family system, and the family legacy.

End of life decisions encompass a broad range of medical and psychosocial determinations that each individual may make before the end of his or her life. No person has to make decisions; one can delegate, with or without an advance directive, depending on one's capacity to do so. Individuals may address such decisions through advance planning, or in emergencies, when careful consideration is not possible, they may leave the difficult decisions to be made by family members and friends who may be ill prepared to decide what their loved ones might have wanted. Such decisions can include where one plans to spend the final months before death and the degree of self-sufficiency one wishes at that time. The use of personal, family, and societal resources to attain these decisions may change, depending on the course of a particular illness, and are among some of the most important decisions individuals and family members may face.

Health care and end of life decision making crosses ethical, religious, cultural, emotional, legal, and policy areas. The complexity of issues includes aspects such as weighing risk and benefit; allocation of individual, family, and societal resources; and the recognition of changing goals of care. It concerns individuals'

deepest and most dearly held fears, values, and beliefs. Palliative and end of life issues are often delicate and controversial and require skilled, insightful interdisciplinary care.

There is increasing agreement that attending to needs along the continuum of illness, coming to terms with end of life issues, making informed decisions and ensuring society honors them, are vital life tasks. It is with just such a constellation of responsibilities that social work's values and skills can make a significant contribution (Kaplan, 1995).

Palliative Care

Palliative care is an approach that improves quality of life for patients and their families facing the problems associated with life-limiting illness. This is accomplished through the prevention and relief of suffering by means of early identification and comprehensive assessment and treatment of pain and other physical, psychosocial, and spiritual problems. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor to postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;

- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- enhances quality of life and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organization, 2003).

Hospice and Palliative Care

Considered the model for quality, compassionate care for people facing life-limiting illnesses or injuries, hospice and palliative care involve a team-oriented approach to expert medical care, aggressive pain and symptom management, and emotional and spiritual support expressly tailored to the patient's needs and wishes.

Support is also provided to the patient's loved ones. At the center of hospice and palliative care is the belief that each of us has the right to live and die free of pain, with dignity, and that our families should receive the necessary support to allow us to do so.

Hospice focuses on caring, not curing and, in most cases, care is provided in the patient's home. Care also is provided in freestanding hospice centers, hospitals, and nursing homes, and other long-term care facilities. Services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. No specific therapy is excluded from consideration. An individual's needs are continually assessed, and treatment options should be explored and evaluated in the context of the individual's values, symptoms, and changing goals. Palliative care may segue into hospice care if the illness progresses (National Hospice and Palliative Care Organization, 2003).

NASW endorses the Last Acts Precepts for Palliative Care. (The precepts can be obtained from <http://www.lastacts.org>)

Bereavement

Bereavement has been defined by several experts as the objective situation of a person who has experienced the loss of a significant person or other attachment figure.

Grief

Grief is a reaction to loss, and, for each person who has sustained a loss, is an individual experience. Certain losses affect entire group systems such as families, communities, cultures, and countries. Grief affects people from every standpoint, including physical, emotional, behavioral, cognitive, and spiritual.

During the past decade, consumer advocacy groups, health professional organizations, and government agencies have paid increased attention to the quality and accessibility of care along the continuum of illness and at the end of life. As a result, health care professions are focused on their own ability to train members of their respective disciplines and to contribute to the building of a knowledge base for excellence in care. Social work is no exception.

A 2002 Social Work Leadership Summit on End of Life and Palliative Care addressed the need for a formalized collaborative effort in the social work profession that focuses on palliative and end of life care. During this meeting, participants designed an agenda for the profession to improve care and to elevate social work's role and contributions in this arena (Project on Death in America, 2002).

Building on this foundation, the National Association of Social Workers (NASW) has developed Standards for Social Work Practice in Palliative and End of Life Care, a useful practice tool for social workers. The standards reflect core elements of social work functions in palliative and end of life care and professional social work practice, and are targeted toward social workers practicing in various settings dealing with these issues. For many practicing social workers in palliative and end of life care, these standards reinforce current practices. For others, they provide an objective to achieve and guidelines to assist in practice.

Social workers have unique, in-depth knowledge of and expertise in working with ethnic, cultural, and economic diversity; family and support networks; multidimensional symptom management; bereavement; trauma and disaster relief; interdisciplinary practice; interventions across the life cycle; and systems interventions that address the fragmentation, gaps, and insufficiency in health care. These are critical areas for implementing change in palliative and end of life care.

Social workers also have expertise in analyzing, influencing, and implementing policy change and development at local, state, and federal levels that can be used to make important improvements in the care of patients living with life-limiting illness and the dying. Social work research in the care of the dying is also developing and addressing many previously overlooked areas of end of life care, such as issues concerning ethnic, cultural, and economic diversity, substance abuse, incarceration, interventions at different life cycle stages, problem-solving interventions, and intervention in community contexts.

Social workers are concerned with enhancing quality of life and promoting well-being for individuals, families (defined broadly), and caregivers. When confronting issues related to palliative and end of life care, social workers have a multidimensional role as clinicians, educators, researchers, advocates, and community leaders. When confronting ethical dilemmas in palliative and end of life care, social workers can draw on the principle of client self-determination in matters where clients or their proxies are faced with such issues (National Association of Social Workers, 2003).

The scope of social work in palliative and end of life care extends across many practice settings and populations, and requires intervention at the individual, family, group, community, and organizational levels. The standards may be regarded as a basic tool for social work practice in palliative and end of life care, although practice priorities may vary among settings.

Standard 1. Ethics and Values

The values, ethics, and standards of both the profession and contemporary bioethics shall guide social workers practicing in palliative and end of life care. The NASW Code of Ethics (NASW, 2000) is one of several essential guides to ethical decision making and practice.

Interpretation:

Social workers who practice in palliative and end of life care must be prepared for challenges that encompass evaluation of ethical dilemmas and value conflicts and consider questions related to religion, spirituality, and the meaning of life.

To be an effective practitioner in this area, specialized training in palliative and end of life care is preferred.

The minimal knowledge base needed for work in this practice area includes an understanding of the following basic ethical principles:

- Justice: the duty to treat all fairly, distributing the risks and benefits equally
- Beneficence: the duty to do good, both for individuals and for all
- Nonmaleficence: the duty to cause no harm, both for individuals and for all
- Understanding/Tolerance: the duty to understand and to accept other viewpoints, if reason dictates that doing so is warranted
- Publicity: the duty to take actions based on ethical standards that must be known and recognized by all that are involved
- Respect for the person: the duty to honor others, their rights, and their responsibilities, as showing respect for others implies that we do not treat them as a mere means to our end

- **Universality:** the duty to take actions that hold for everyone, regardless of time, place, or people involved
- **Veracity:** the duty to tell the truth
- **Autonomy:** the duty to maximize the individual's right to make his or her own decisions
- **Confidentiality:** the duty to respect privacy of information and action
- **Equality:** the duty to view all people as moral equals
- **Finality:** the duty to take action that may override the demands of law, religion, and social customs

In addition, the social workers working in palliative and end of life care are expected to be familiar with the common and complex bioethical considerations and legal issues such as the right to refuse treatment; proxy decision-making; withdrawal or withholding of treatment, including termination of ventilator support and withdrawal of fluids and nutrition; and physician aid in dying. End of life issues are recognized as controversial, because they reflect the varied value systems of different groups. Consequently, NASW does not take a position concerning the morality of end of life decisions, but affirms the right of the individual to determine the level of his or her care. Particular consideration should be given to special populations, such as people with mental illness, with developmental disability, individuals whose capacity or competence is questioned, children, and other groups who are vulnerable to coercion or who lack decisional capacity.

Standard 2. Knowledge

Social workers in palliative and end of life care shall demonstrate a working knowledge of the theoretical and biopsychosocial factors essential to effectively practice with clients and professionals.

Interpretation:

The social worker possesses knowledge about navigating the medical and social systems that frequently present barriers to clients. Social workers have expertise in communication, both within families and between clients/families and health care or interdisciplinary teams. Drawing on knowledge of family systems and interpersonal dynamics, the social worker is able to examine the family's experience in a unique way, to conduct a comprehensive assessment, and to assist the team to integrate biopsychosocial, spiritual factors into their deliberations, planning, and interactions.

Social work's view includes an appreciation of the socioeconomic, cultural, and spiritual dimensions of the family's life. As experts in helping individuals and families maximize coping in crisis—and at addressing the psychosocial domains of symptoms, suffering, grief, and loss—social workers are able to provide intensive counseling as well as practical services for those confronted by life-limiting illnesses and assist with complex problems.

Essential areas of knowledge and understanding about palliative and end of life care include:

- the multifaceted roles and functions of social worker clinicians
- the physical and multidimensional stages of the dying process

- the physical, psychological, and spiritual manifestations of pain
- the range of psychosocial interventions that can alleviate discomfort
- the biopsychosocial needs of clients and their family members;
- the impact of ethnic, religious, and cultural differences
- illness-related issues such as decision making, relationship with health care providers, dying and death
- the range of settings for palliative and end of life care, including home care, nursing homes, and hospice settings
- the available community resources and how to gain access to them
- the impact of financial resources on family decision making along the continuum of illness and at the end of life
- the development, use, support, and revision of advance directives throughout the progression of the illness
- disparities across cultures in gaining access to palliative and end of life care
- the accreditation and regulatory standards governing settings providing palliative and end of life care
- the needs faced by members of special populations and their families, such as children; those with physical, developmental, mental, or emotional disabilities; and those in institutionalized settings such as nursing homes and nonmedical settings such as correctional facilities.

Standard 3. Assessment

Social workers shall assess clients and include comprehensive information to develop interventions and treatment planning.

Interpretation:

Assessment is the foundation of practice. Social workers plan interventions with their clients based on assessments and must be prepared to constantly reassess and revise treatment plans in response to newly identified needs and altered goals of care. Comprehensive and culturally competent social work assessment in the context of palliative and end of life care includes considering relevant biopsychosocial factors and the needs of the individual client and the family (as defined by the client).

Areas for consideration in the comprehensive assessment include:

- relevant past and current health situation (including the impact of problems such as pain, depression, anxiety, delirium, decreased mobility)
- family structure and roles
- patterns/style of communication and decision making in the family
- stage in the life cycle, relevant developmental issues
- spirituality/faith
- cultural values and beliefs
- client's/family's language preference and available translation services
- client's/family's goals in palliative and end of life treatment
- social supports, including support systems, informal and formal caregivers involved, resources available, and barriers to access
- past experience with illness, disability, death, and loss
- mental health functioning including history, coping style, crisis management skills and risk of suicide/homicide

- unique needs and issues relevant to special populations such as refugees and immigrants, children, individuals with severe and persistent mental illness, and homeless people
- communicating the client's/family's psychosocial needs to the interdisciplinary team.

Standard 4. Intervention/Treatment Planning

Social workers shall incorporate assessments in developing and implementing intervention plans that enhance the clients' abilities and decisions in palliative and end of life care.

Interpretation:

Social workers in all practice areas use various theoretical perspectives and skills in delivering interventions and developing treatment plans. Initial assessments and team input inform and guide plans of care. Social workers must be able to adapt techniques to work effectively with individuals from different age groups, ethnicities, cultures, religions, socioeconomic and educational backgrounds, lifestyles, and differing states of mental health and disability, and in diverse nonmedical care settings.

Essential skills for effective palliative and end of life care include:

- the ability to recognize signs and symptoms of impending death and prepare family members in a manner that is guided by clinical assessment
- competence in facilitating communication among clients, family members, and members of the care team
- competence in integrating grief theories into practice

- competence in determining appropriate interventions based on the assessment
- competence in advocating for clients, family members, and caregivers for needed services, including pain management
- competence in navigating a complex network of resources and making appropriate linkages for clients and family members
- competence in supporting clients, families, and caregivers including anticipatory mourning, grief, bereavement, and follow-up services.

Interventions commonly provided in palliative and end of life care include:

- individual counseling and psychotherapy (including addressing the cognitive behavioral interventions)
- family counseling
- family-team conferencing
- crisis counseling
- information and education
- multidimensional interventions regarding symptom management
- support groups, bereavement groups
- case management and discharge planning
- decision making and the implications of various treatment alternatives
- resource counseling (including caregiving resources; alternate level of care options such as long term care or hospice care; financial and legal needs; advance directives; and permanency planning for dependents)
- client advocacy/navigation of systems.

Standard 5. Attitude/Self-Awareness

Social workers in palliative and end of life care shall demonstrate an attitude of compassion and sensitivity to clients, respecting clients' rights to self-determination and dignity. Social workers

shall be aware of their own beliefs, values, and feelings and how their personal self may influence their practice.

Interpretation:

To practice effectively, social workers in palliative and end of life care must demonstrate empathy and sensitivity in responding to the pain, suffering, and distress of others. Specific social work attitudes and responses that encompass compassion and sensitivity in caring for clients shall include, but not necessarily be limited to, the following:

- flexibility and adaptability on a daily basis, to be able to confront human suffering
- consistent individualization of client/client system needs as the primary care unit
- facilitative interactions with clients/client systems
- ability to communicate and work collaboratively as an interdisciplinary team member to achieve care goals
- willingness to advocate for holding the focus in palliative and end of life care on client/client system choices, preferences, values, and beliefs
- awareness of compassion fatigue and the ethical responsibility to mitigate this condition
- confidence and competence in professional identity and in empowering the profession in its vital role in palliative and end of life care.

Standard 6. Empowerment and Advocacy

The social worker shall advocate for the needs, decisions, and rights of clients in palliative and end of life care. The social worker shall engage in social and political action that seeks to ensure that people have equal access to resources to

meet their biopsychosocial needs in palliative and end of life care.

Interpretation:

In advocacy efforts, social work provides unique and essential skills and perspectives such as a rich understanding of the person-in-environment, communication skills, expertise in group process and systems, a social justice commitment, a strong background in values and ethics, and a broad psychosocial and spiritual knowledge base. Among the crucial components of effective empowerment and advocacy are identifying and defining needs from the client's perspective, including cultural and spiritual beliefs, and communicating the concerns and needs of the client to decision makers and providers of care. Advocacy and empowerment come into practice at both the micro and macro level.

Practice examples include linking clients with resources, identifying and supporting the family of choice, assisting individuals and families negotiate their goals of care, navigating through systems of care, monitoring pain and symptom management, addressing quality-of-life issues, team conferencing, consulting, and providing caregiver support. Broader examples of advocacy include advocacy with special populations, institutions, and communities, as well as the health care policy arenas where efforts need to integrate cultural and ethnic variation. It is essential to identify barriers to effective palliative and end of life care at the macro level by addressing issues of financial inequities, lack of culturally competent services, and other access issues and to address those barriers so that individuals experience the highest quality of life possible to the end of life.

Standard 7. Documentation

Social workers shall document all practice with clients in either the client record or in the medical chart. These may be written or electronic records.

Interpretation:

Ongoing documentation of social work service should reflect the assessment, issues addressed, treatment offered, and plan of care, and must assure continuity of care between all settings (for example, hospital to hospice, nursing home to hospital).

The transfer of medical records must be conducted in compliance with current federal and state law with an emphasis on confidentiality/privacy of medical information. Compliance with agency policy, particularly regarding the transfer of electronic records, is essential.

Standard 8. Interdisciplinary Teamwork

Social workers should be part of an interdisciplinary effort for the comprehensive delivery of palliative and end of life services. Social workers shall strive to collaborate with team members and advocate for clients' needs with objectivity and respect, to reinforce relationships with providers who have cared for the patient along the continuum of illness.

Interpretation:

Interdisciplinary teamwork is an essential component in palliative and end of life care. Social workers are integral members of a health care team. Social workers should advocate for the views and needs of individuals and families in palliative and end of life care within the team,

and should encourage and assist clients in communicating with team members. Often, clients, families, and team members rely on the expertise of the social worker in problem solving concerns and conflict resolution.

Teamwork requires collaboration, and an ability to empower and advocate when necessary. The psychosocial expertise of the social worker assists the interdisciplinary team to enhance understanding, form interventions and decisions, and formulate treatment plans. In addition, the social worker identifies resources, provides counseling, support services, and practical interventions.

Standard 9. Cultural Competence

Social workers shall have, and shall continue to develop, specialized knowledge and understanding about history, traditions, values, and family systems as they relate to palliative and end of life care within different groups. Social workers shall be knowledgeable about, and act in accordance with, the NASW Standards for Cultural Competence in Social Work Practice (NASW, 2001).

Interpretation:

Social workers respect and integrate knowledge about how individuals and families are influenced by their ethnicity, culture, values, religion- and health-related beliefs, and economic situations. Social workers should understand systems of oppression and how these systems affect client access to, and utilization of, palliative and end of life care. Many cultures maintain their own values and traditions in the areas of palliative and end of life care.

Culture influences individuals' and families' experience as well as the experience of the practitioner and institution. Social workers should consider culture in practice settings involving palliative and end of life care. Each cultural group has its own views about palliative and end of life practices and these need to be understood as they affect individuals' response to dying, death, illness, loss, and pain.

Social workers who understand how culture affects the illness and end of life experience of an individual and family will be better able to individualize care and intervene in the psychosocial impact of illness, pain, dying, and death. Therefore, social workers should be familiar with the practices and beliefs of the cultural groups with whom they practice to deliver culturally sensitive services.

Standards for Professional Preparation and Development

Standard 10. Continuing Education

Social workers shall assume personal responsibility for their continued professional development in accordance with the NASW Standards for Continuing Professional Education (NASW, 2002) and state requirements.

Interpretation:

Social workers must continue to grow in their knowledge of theories and practices in palliative and end of life care to effectively work with individuals and families. Palliative and end of life care is a rapidly expanding and changing field, which crosses all practice settings. In addition to

clinical competence, social workers need to enhance their skills and understanding by keeping abreast of research, so their practice reflects the most current knowledge.

Numerous opportunities in professional development are available through NASW and other professional organizations, institutions, coalitions, and service agencies at local, state, and national levels. Social workers should participate in and contribute to professional conferences and training activities on a regular and consistent basis to provide the highest possible level of care. Social workers should also assist in identifying palliative and end of life professional development needs by participating in research and encouraging organizations and institutions to collaborate, advocate, and provide appropriate education for the field.

Standard 11. Supervision, Leadership, and Training

Social workers with expertise in palliative and end of life care should lead educational, supervisory, administrative, and research efforts with individuals, groups, and organizations.

Interpretation:

Social workers shall offer their expertise to individuals, groups, and organizations as well as offering training and mentoring opportunities to beginning social workers or those transitioning into palliative and end of life care. When able, skilled social workers shall work in conjunction with schools of social work to advocate for programs in palliative and end of life care and enhance and encourage interest in this specialization.

Social workers shall offer supervision to practicing social workers, interns, and students to provide a guiding expertise to clinicians in this area. Social workers shall contribute to research initiatives not only to demonstrate the efficacy of the social work profession and social work interventions, but also to advance the recognition among colleagues in other professions of the essential need to address psychosocial needs of individuals and their families.

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Resources

NASW has developed several policy statements, which are published in *Social Work Speaks: National Association of Social Workers Policy Statements, 2003 – 2006* (6th ed.), related to palliative and end of life care. These statements are listed below:

Client Self-Determination in End of Life Decisions
Health Care
Hospice Care
Long-Term Care
Managed Care

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