Comfort and Compassion at the End of Life

A Palliative Care Tool Kit for Clinicians

NEW JERSEY HOSPITAL ASSOCIATION
Institute for Quality & Patient Safety

HRET
HEALTH RESEARCH AND EDUCATIONAL TRUST OF NEW JERSEY

Comfort and Compassion at the End of Life

A Palliative Care Tool Kit for Clinicians

PUBLISHED BY: NJHA INSTITUTE FOR QUALITY AND PATIENT SAFETY
760 Alexander Road, PO Box 1, Princeton, NJ 08543-0001.

NEW JERSEY HOSPITAL ASSOCIATION
Institute for Quality & Patient Safety

HRET
HEALTH RESEARCH AND
EDUCATIONAL TRUST OF NEW JERSEY

INTRODUCTION

The need to improve care for patients with serious, complex and potentially life-threatening or life-limiting medical conditions is unquestioned. Implementing a palliative care program helps to prevent and relieve suffering and supports the best possible quality of life for patients and their families through communication, shared decision making, holistic care and continuity of care.

WHAT IS PALLIATIVE CARE?

Palliative care is specialized medical care for people with serious illnesses. It is a specialty that focuses on relieving pain and suffering. Palliative care uses a team approach to address the needs of patients and their families, ensuring comfort and relief of symptoms with the goal of improving quality of life. This team is comprised of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with curative treatment. It is not designed to replace treatment; rather it complements the primary treatment received by the patient.

Many of the symptoms addressed by the palliative care team include pain, shortness of breath, fatigue, anxiety, depression, constipation and anorexia.

WHO CAN BENEFIT FROM PALLIATIVE CARE?

Palliative care is appropriate for anyone diagnosed with a chronic, progressive or serious illness. This includes, but is not limited to, heart, kidney, liver or respiratory disease, cancer, stroke or a neurological disorder.

The palliative care team often includes a combination of: physician, advanced practice nurse, nurses, pastoral care, social work, case management, dietician, pharmacist, physical therapist, speech therapist, occupational therapist and respiratory therapist.

IS PALLIATIVE CARE THE SAME AS HOSPICE?

No. Hospice is designed to provide care for those approaching the final stage of life. Hospice care focuses on relieving symptoms and supporting patients with a life expectancy of less than six months. Palliative care allows the potentially curative treatment to continue where appropriate while focusing on relieving the symptoms that may come with the disease progression or the treatments received.

WHAT IS END-OF-LIFE CARE?

End-of-life care is given during the time surrounding death. It is medical care that ensures comfort to those with a terminal illness or terminal condition that has become advanced, progressive and incurable. These often include both the physical aspects of suffering, along with the psychosocial and spiritual factors that interplay with patients who have an advanced illness. Palliative care providers are trained specifically to deal with the many aspects of suffering present in a patient approaching end of life, thereby easing anxieties for the patient and the family.

"At the end of life, each story is different. Death comes suddenly, or a person lingers, gradually failing. For some older people, the body weakens while the mind stays alert. Others remain physically strong, and cognitive losses take a huge toll."

– End-of-Life Care: Helping with Comfort and Care. National Institute of Aging, 2008 *www.nia.nih.gov.*

COMFORT CARE

Comfort care is an essential part of medical care at the end of life. It is care that helps or soothes a person who is dying. The goal is to prevent or relieve suffering as much as possible while respecting the dying person's wishes and maintaining his or her dignity.

COMPARISON OF SERVICES

	Palliative Care	Hospice	End-of-Life Care	Comfort Care
Interdisciplinary Team	✓	✓	✓	✓
Treatment to Improve Quality of Life	✓			
Diagnostic Testing				
Bereavement Support	✓	✓	✓	✓
Social Support	✓	✓	✓	✓
Psychosocial Support	✓	✓	✓	✓
Curative Treatment	✓			
Symptom Management	✓	✓	✓	✓
Treatment to Improve Function	✓	✓		

Once educated, consumers are extremely positive about palliative care and want to have access to this care.

According to a recent poll by the American Cancer Society and the Center to Advance Palliative Care:

- 95 percent of respondents agree that it is important that patients with a serious illness and their families be educated about palliative care.
- 92 percent of respondents say they would be likely to consider palliative care for loved ones if they had a serious illness.
- 92 percent of respondents say it is important that palliative care services be made available at all hospitals for patients with a serious illness and their families.

CLINICIAN GUIDELINES

Practice of Palliative Care

Palliative care is the comprehensive care and management of the physical, psychological, emotional and spiritual needs of patients and their families with chronic, serious or life-threatening illness. Palliative care may be complementary to curative or life-prolonging therapies that are being used to meet patient-defined goals of care.

The palliative care team may include some or all of the following: physician, advanced practice nurse, nurses, pastoral and/or spiritual care, social work, case management, dietician, pharmacist, physical therapist, speech therapist, occupational therapist and respiratory therapist.

The palliative care team will:

- Assist the patient/family in defining goals of care
- Address symptoms relating to disease and treatment
- Promote the highest quality of life for patient and family
- Coordinate care among providers
- Educate the patient and family on disease and expected course of the illness
- Establish an environment that is comforting and healing
- Plan for discharge to the appropriate level of care and appropriate services.

INITIATING A PALLIATIVE CARE CONSULTATION

A referral to palliative care services may come from many sources such as physicians, nurses, patient, family members, social work and clergy. If the referral for palliative care services comes from anyone other than the attending physician, a member of the palliative care team will notify the primary care physician of the referral and request permission to provide a consultation. The requirement for permission from the primary care physician will vary by organization.

EDUCATING PATIENTS AND FAMILIES ABOUT PALLIATIVE CARE

The palliative care team will provide education to the patient, family and caregiver. The most commonly provided education is:

- Pain and symptom management
- Advance care planning and advance directives
- Appropriate healthcare services
- What to expect through the course of the disease.

As educational needs are defined, they are incorporated into the plan of care.

ASSESSMENT

The palliative care team strives to understand and treat the patient's physical and emotional symptoms. This includes but is not limited to pain, nausea, dypsnea, anxiety, depression, constipation, anorexia and fatigue. One way the team accomplishes this is through a comprehensive patient assessment.

The comprehensive assessment identifies:

- Diagnosis
- Presenting problems
- Current treatments, medications and side effects
- Pain level
- Symptom inventory
- Patient, family/caregiver concerns and preferences
- Spiritual and cultural beliefs or concerns.

Once the assessment is completed, the palliative care team creates a comprehensive treatment plan with the patient and family/caregiver. Once the plan is finalized the palliative care team works with the clinical team to ensure the implementation and monitoring of the treatment plan. The treatment plan is modified based on ongoing assessment.

GOALS OF CARE

Palliative care specialists often address many of the difficult and painful conversations that need to take place with patients and their families. The palliative care team specializes in such communication where the patient and family goals are addressed and a feasible, evidence-based plan is offered, thereby helping guide patients through a complex health system.

When developing the goals of care, we need to ask the question: what are we trying to achieve?

Consider asking the patient:

- What are your hopes for the future?
- How do you define quality of life?
- Is there a special event that you wish to attend (wedding, birthday, graduation)?
- What activities do you want to continue or what activities do you wish to be involved in?

COMMUNICATION

Communication is the foundation upon which relationships are built. Early communication with patients and families will increase trust, knowledge and satisfaction.

Effectively communicating with patients and families will help the palliative care team understand the needs and wishes of all involved. When communicating with patients and families about series illness, healthcare professionals should remember to give attention to the environment and the physical comfort of all concerned. Privacy is of the utmost importance. Therefore when having conversations about needs and wishes it is important to consider where these conversations are taking place. Some healthcare facilities have designated rooms for discussions that often times are painful and difficult. Many patients, however, prefer to stay in their own bed.

The palliative care team will prepare for the meeting with the patient, family and healthcare providers by first consulting with the patient's primary clinician, reviewing the patient's chart and determining the objective of the meeting. The team also will examine what has occurred so far and what the patient and family has been told about the patient's condition. There are many scripts and communication models that the palliative care team may utilize for the meeting. The "ASCEND" mnemonic, developed by Dr. Karen Knops[1], is one model that is simple to use.

A **Anticipate** (pre-meeting planning). This will include members of the palliative care team, healthcare providers and patient/family members. This may involve setting up and establishing the objective of the meeting.

S **Summarize** The patient/family summarize their understanding of the patient's condition and what the doctor has told them.

C **Acknowledge concerns** of patient/family

E **Explore/Explain** The goals of patient care, medical information, appropriate course of treatment.

N **Next steps**

D **Document**

The palliative team also can indicate that the facility's Ethics Committee is an available resource to help the patient and family with communication and decision making.

---

[1] Knops K, Lamba S. Palliative Care Program, Morristown Memorial Hospital, Morristown, New Jersey 07962, USA. J Palliat Med. 2010 Jul;13(7):825-30.

ADVANCED CARE PLANNING

The conversation for advanced care planning should begin before the onset of an illness. As clinicians we should be having these conversations with our patients early on so they may begin to plan for the future. It is important that we all communicate our wishes to loved ones, appoint a healthcare power of attorney and address financial issues such as wills and paying for long-term care.

Not only is it important for healthcare clinicians to have these conversations with patients, it is equally important for patients to have these conversations with their family or loved ones. These conversations are not easy to have, as many people would prefer not to think about serious illness, death and dying. The palliative care team often is an integral part of advanced care planning. Here are some tips that the palliative care team and healthcare clinicians may offer patients to help them talk with their family or a loved one about advanced care planning:

- Share what motivated you to start thinking of advanced care planning
- Discuss your views on religion and spirituality and how this impacts your view on death and dying
- Discuss how you feel about the dying process
- Address the level of importance in regards to living independently, living at home and if you want to die at home.

Culture, religious and spiritual beliefs also should be taken into consideration with advanced care planning.

ADVANCE DIRECTIVES

An advance directive (often called living will) indicates a person's wishes as it relates to medical treatment at the end of life. An individual creates this plan with written instructions. It is a set of instructions that a person wants medical professionals to follow, especially when the patient has lost the ability to communicate.

There are three kinds of advance directives:

1. Designating a healthcare representative or proxy. Patients may designate a person (a proxy) they trust and give that person the legal authority to make decisions for them if they are unable to make decisions for themselves. This chosen healthcare representative or proxy is the patient's substitute and takes part in discussions with the patient's physician and others responsible for their care.
2. Instruction Directives (commonly referred to as a Living Will). This is another way to have patients' wishes spelled out ahead of time relating to medical treatment. It provides those responsible for the patient's care with a statement of medical treatment preferences. It indicates medical treatments the patient wishes to accept or refuse and the circumstances in which the patient wants his or her wishes implemented. These instructions will serve as a guide to those responsible for the patient's care.
3. Combined Directives. This is a combination of designating a healthcare representative/proxy and having written instruction directives (living will). This will be a combined document where patients select a healthcare representative/proxy and provide him/her with a statement of their medical treatment preferences.

Healthcare clinicians should speak to their patients about completing an advance directive. Patients may need help from the healthcare or palliative care team in clarifying treatments and discussing options. It is recommended that the healthcare clinician obtain a copy of the patient's living will and provide a copy to at least one family member or healthcare proxy.

WHY HAVE AN ADVANCE DIRECTIVE?

The importance of an advance directive is to be sure that one's wishes and concerns are documented. This legal document provides healthcare professionals with a patient's wishes for treatment, and it also assists family and loved ones in making difficult decisions on the patient's behalf. A clearly written directive helps prevent disagreements among those close to the patient and alleviates the burden of decision making for family and healthcare providers.

DESIGNATING A HEALTHCARE REPRESENTATIVE/ PROXY

The persons chosen as healthcare representatives have the legal right to accept or refuse medical treatment on the patient's behalf. They represent and assure that the wishes relating to medical treatment are carried out. The healthcare clinician should advise the patient that the healthcare representative should be familiar with the patient's feelings about different types of medical treatment and the conditions under which the patient would choose to accept or refuse specific treatment.

Healthcare representatives must have a clear understanding of their responsibility to implement the patient's wishes even if they vary from their own. When having this conversation with your patient, encourage the patient to consider selecting someone whose judgment the patient trusts and has confidence in. People who may be considered to be one's healthcare representative include:

- A member of the patient's family or a close friend
- The patient's spiritual advisor, priest, rabbi or minister
- A trusted healthcare provider, however this cannot be the patient's attending physician as he/she cannot act as the patient's physician and healthcare representative at the same time.

PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT (POLST)

The Physician Orders for Life-Sustaining Treatment (POLST) program first started in Oregon in 1991. POLST was created to address the barriers in the healthcare delivery system as it relates to the care of seriously ill and dying patients. It is a standardized medical order form that indicates which types of life-sustaining treatment a seriously ill patient wants or doesn't want if his or her condition worsens. The POLST form, signed by both the healthcare professional and the patient, becomes a tool to capture these discussions and make them part of the patient's medical record. The form moves with the patient and must be honored across all settings of care (i.e. hospital, rehab, nursing home, the individual's home, by EMTs and paramedics).

In December 2011, Gov. Chris Christie signed New Jersey's POLST legislation into law. The state is in the process of developing the program.

N.J. UNIVERSAL TRANSFER FORM

The N.J Universal Transfer Form (UTF) must be used by all licensed healthcare facilities and programs when a patient is transferred from one care setting to another. To access the UTF, go to *http://www.state.nj.us/health/forms/hfel-7.pdf*.

The purpose of the UTF is to ensure that accurate communication of pertinent clinical patient care information is conveyed at the time of a transfer between healthcare facilities or programs. The UTF conveys patient information that a physician or nurse need to appropriately begin caring for a patient when the patient arrives at a new facility. This includes codes status.

NATIONAL QUALITY STANDARDS FOR PALLIATIVE CARE

In 2004, Clinical Practice Guidelines for Quality Palliative Care were released by the National Consensus Project. The guidelines were a response to the need for creating efficient, effective and compassionate care for patients and families facing life-threatening illness. The guidelines were intended to ensure quality care by establishing a standard for existing programs as well as encouraging the continued development and expansion of palliative care in the healthcare system.

The guidelines include eight domains: Structure and Process of Care, Physical Needs, Psychological and Psychiatric, Social, Spiritual/Religious and Existential, Cultural, the Imminently Dying Patient and Ethics and Law. The complete guidelines are available on the National Consensus Project Web site at *www.nationalconsensusproject.org/*.

TOOLS AND RESOURCES

The online version of *Comfort and Compassion at the End of Life* offers links to additional forms, tools and resources from groups such as the National Palliative Care Research Center, the Center to Advance Palliative Care and Society of Critical Care Medicine. Visit *www.njha.com/qualityinstitute/palliativecareresources.aspx* to find these helpful links.

ACKNOWLEDGMENTS

The Institute for Quality and Patient Safety extends its thanks and gratitude to the committee members who contributed their expertise, time and effort to develop this valuable tool.

- Bill Pierce
- Darlyn Paul
- Dawn Pavla
- Elizabeth Eble
- Jessica Capone
- Jill Jackson
- Judy Surki
- Karen Visich
- Marianne Herman
- Mark Angelo
- Martha Chambers
- Maureen Bowe
- Theressa Blum
- Valerie Ramsberger