Palliative and End of Life Care in the Outpatient Setting

PURPOSE:
The purpose of this policy is to guide the health care team in providing palliative and end of life care.

DEFINITIONS:

• **End of Life Care** is the care given during the last phase of life.

• **Palliative care** is medical care focused on the prevention and relief of suffering and to support the best possible quality of life for patients and their families, regardless of the stage of their disease. Its goals include enhancing quality of life for patient and family, helping with decision making, and providing opportunities for personal growth. Palliative care can be given along with life-prolonging treatment and at the end of life.

• **Patient Rights**

  o Patients have a right to symptom control, pain management, communication and advance care planning at any stage of cancer (or disease) care and treatment.
  o Patients have a right to choose to pursue clinical trials and receive palliative care as well.
  o Patients have a right to treatment that does not prolong suffering.
  o Patients have a right to be informed if their medical condition reaches a point where recovery or cure is not realistically possible.
  o Patients have a right to care that is respectful of their cultural, psychosocial and spiritual preferences.
  o Patients have a right to care that supports their privacy, personal dignity, and individual needs.

POLICY:

**Palliative Care:** In support of the patient rights listed above, the Fred Hutch ambulatory clinic has a Palliative Care Consult Service available to all adult patients and their families. The Palliative Care Service provides expert consultation about pain and symptom management; assists patients with difficult decisions and advance care planning; and provides supportive care at the end of life. The consultant coordinates and communicates the plan of care to the UWMC Palliative Care Service. Seattle Children's Hospital provides a Pediatric Advanced Care Team Consultant that meets with the pediatric patients and families during their arrival conference with the attending physician. The consultant will follow the pediatric patient throughout the course of treatment both in and out of the hospital.
End-of-Life Care:
Patients have a right in both the inpatient and ambulatory clinic settings to experience a natural death supported by humane comfort measures. Comfort measures are designed to relieve pain or discomfort. It is not implemented to hasten death. The goals of comfort care are to optimize comfort and dignity as defined by the patient and supported by the family and surrogate decision-maker.

The end of life experience is unique to each individual and the care plan should be developed to meet the patient's and family's needs. The discussion of the care plan and its goals should include the patient, family, and decision-maker as appropriate. This discussion is sometimes challenging and there may be differing viewpoints among the patient, family, and health care providers. The health care providers at the Fred Hutch believe that their obligation is to the patient and all decisions will be based on the best interest of the patient and the patient's expressed desires. Concerns may be addressed in patient care conferences with the patient's primary health care team, by requesting a palliative care consult or an ethics consult, or by seeking additional medical opinions. For eligible patients that wish to participate in Washington's State Death with Dignity Act, the Fred Hutch does allow faculty physicians and pharmacists (who otherwise qualify by statute) to participate in the Washington State Death with Dignity Act, if they so choose. Fred Hutch also allows other Fred Hutch providers/employees to participate in relevant supporting roles.

The end of life care plan will be reevaluated if the patient would like to review the plan or make changes, or if the patient's medical condition changes and requires a different treatment plan. All changes will be discussed with the patient, family and surrogate decision maker and documented in the medical record. New physician orders will reflect and communicate the changes.

The Washington State Natural Death act provides that any physician or medical staff may elect to refuse to participate in withdrawing life-sustaining care. In such cases the physician or medical staff member must take appropriate steps to transfer care to another staff member before withdrawing from the patient’s care. Employees will not be discriminated against in employment or professional privileges if they decline in withholding life-sustaining care.

PEDIATRIC PATIENTS – The goal of end of life care for pediatric patients is the same as it is for adults. Because the Physician Orders for Life-Sustaining Treatment (POLST) form and the Washington State Emergency Medical Services (EMS) - No CPR Guidelines only applies to persons 18 years of age or older, pediatric patients who wish to be designated as Do Not Attempt Resuscitation (DNAR) or wish to receive end of life/comfort care only will be handled on a case by case basis with care team members, including social work, transition nursing, attending physician, team nurse, chaplaincy, and the palliative care team.

FRED HUTCH-OVERLAKE: OVL clinical staff should consult with Palliative Care and Social Work leadership at SLU for assistance in addressing patient Palliative Care and end-of-life concerns.

Procedure for initiating "Comfort Care Only" order:
1. In order to initiate an order for "Comfort Care Only" in the ambulatory clinic setting, a fully executed POLST with a Do Not Attempt Resuscitation (DNAR) must be in the medical record. See the Medical
Staff Policy and Procedure: "Patient's Right to a Natural Death/Do Not Attempt Resuscitation (DNAR) Orders and the Physician Orders for Life-Sustaining Treatment (POLST)". The POLST allows the physician to document patient preferences as specific orders for medical interventions, use of antibiotics, and artificially administered fluids and nutrition. (The POLST is not a substitute for Advance Directives, and it is encouraged that the patient has advance directives to provide more detailed information regarding patient preferences.)

2. Decisions regarding the end of life care plan will follow the POLST orders.

3. A progress note should accompany a copy of the POLST in the medical chart to reflect the underlying rationale and that the potential outcomes have been discussed with the patient or surrogate decision maker. The POLST will reflect whom the treatment plan was discussed with and the basis for the orders. The progress note should also include the name of the surrogate decision maker.

4. When the patient, family and health care team have made the decision for a POLST, comprehensive supportive care will be provided at a level consistent with goals of comfort and quality of life at the end of life.

5. POLST orders as well as other orders in the medical record will be written to focus on keeping the patient comfortable, alleviating pain, and treatments to control secondary symptoms. The end of life care plan should eliminate any procedures or interventions that make no contribution to the goal of comfort.

6. Fred Hutch is committed to ensuring that each patient's and family's psychosocial, emotional and spiritual needs are met by making available care from social work, chaplaincy, the palliative care team, psychiatry and nutrition.