MANAGEMENT OF IMMINENT DEATH IN HOSPICE CARE
Acknowledgements

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Introduction

The Medicare Hospice Benefit (MHB) regulations require a hospice provider to control the pain and symptoms of the patient, address the emotional, psychosocial, and spiritual issues of the patient and family, educate and prepare the patient and family for death and dying, and coordinate an individualized plan of care that is focused on provision of a comfortable and supportive death.1 The MHB is designed to provide hospice care to patients whose prognosis is 6 months or less if the disease follows its normal course. During hospice care, the hospice team develops a trusting relationship with the patient and their family (caregiver), which is essential in preparing them for the best possible death experience and subsequent bereavement.2

Data from the National Hospice and Palliative Care Organization (NHPCO) indicates there is an upward trend of patients who are admitted to hospice care in their last week or last days of life.3 Additional research shows that patients who are admitted to hospice care in the late stage of their terminal illness and receive shorter exposure to hospice services undergo a smaller chance of achieving optimal end-of-life closure and preparation for death and bereavement.4 Hospice experts also agree that the ideal length of stay in hospice is approximately 6 months before death. A longer length of stay allows the hospice team to accomplish this multifaceted care to achieve the best possible end-of-life experience for the patient and family.5 However, providing a positive and full hospice experience in a short amount of time can be accomplished with thoughtful planning and resource utilization by the hospice provider.

Purpose of the Resource

The goal of this resource is to identify opportunities for quality assessment and performance improvement for patients and their families in the last days of life when the patient is receiving care at the routine home care (RHC) level of care. The resource provides information and resources related to managing imminent death of patients receiving hospice care in their last 7 days of life, whether they are admitted to a hospice program close to death or transition to imminent death during a longer length of stay.

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The Data Facts

Care management of imminently dying patients in hospice is a two-pronged issue and data from NHPCO and CMS provide information related to each issue.

- **Short Length of Patient Stay from Admission**

  The first is admission of patients to hospice with a short length of stay. Short length of stay can mean less than 7 days or even hours. In the Medicare Payment Advisory Commission, (MedPAC) March 2019 Report to Congress, MedPAC reports that indicates that more than one-quarter of hospice decedents enroll in hospice only in the last week of life, a length of stay that is commonly thought to be of less benefit to patients than enrolling somewhat earlier.

  Research over the past decade shows that patients who are admitted to hospice care in the late stage of their terminal illness and receive hospice care for a shorter period experience less chance of achieving optimal end-of-life closure and preparation for death and bereavement. In one study completed by several hospice industry experts, the researchers scrutinized the timeliness of hospice referrals and the impact of hospice experience on caregiver satisfaction. Interviews were conducted with bereaved family members of patients who received 7 days or less of hospice care, and outcomes showed that 99 respondents of 100 stated they felt their loved one was referred too late to hospice care. Patient referral to hospice care in the late stage of the disease process gives the patient less chance of achieving optimal end-of-life closure and preparation for death and grieving.

- **Skilled Visits in the Last Days of Life**

  The Centers for Medicare and Medicaid Services (CMS) is concerned that many hospice beneficiaries may not be receiving skilled visits during the last days of life. An analysis of FY 2017 claims data shows that on any given day during the last 7 days of a hospice election, almost 45 percent of the time the patient had not received a visit by a skilled nurse, and 89 percent of the time the patient had not received a visit by a social worker. CMS believes that

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patient needs normally increase and intensify immediately preceding death, so they expect that provision of care would proportionately escalate to meet the increased clinical, emotional, and other needs of the beneficiary and his or her family and caregiver(s). CMS writes, “the last week of life is typically the period within the terminal illness trajectory that is associated with the highest symptom burden, typically marked by impactful physical and emotional symptoms, necessitating attentive care and engagement from the integrated hospice team”,9 They state hospice providers must ensure that beneficiaries and their families and caregivers are, in fact, receiving the care necessary during critical periods such as the very end of life.10


Regulatory Requirements

CMS defines hospice care in Federal statutes and in federal hospice regulations at §418.3 - Definitions as, “a comprehensive set of services identified and coordinated by an interdisciplinary group (IDG or IDT) to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care”. The federal hospice Conditions of Participation (CoPs) require that imminence of death be assessed by the IDT during the initial and comprehensive assessment (§418.54 Condition of Participation: Initial and Comprehensive Assessment of the Patient). The hospice team is required to assess the physical, emotional, psychosocial, and spiritual needs of the patient/family/caregiver as well as imminence of death.

Hospice Quality Reporting

Hospice providers are required to submit data to CMS as part of the Hospice Quality Reporting Program (HQRP) which includes Hospice Item Set (HIS) measure data and an experience of care survey, the Hospice Consumer Assessment of Healthcare Providers and Systems (CAHPS®). CMS implemented the Hospice Visits when Death is Imminent quality measure pair in 2017 which is a measure pair that assesses hospice staff visits to patients at the end of life. The measure description follows:

Measure 1: Percentage of patients receiving at least one visit from registered nurses, physicians, nurse practitioners, or physician assistants in the last 3 days of life.

Measure 2: Percentage of patients receiving at least two visits from medical social workers, chaplains or spiritual counselors, licensed practical nurses or hospice aides in the last 7 days of life.13

The rationale for the measure pair is supported in literature which shows that patients in their last week of life may have a higher symptom burden, especially during the last several days before death.

death. Common physical symptoms that are frequent in the last week of life include fatigue, pain, dyspnea, respiratory secretions/death rattle, anorexia, dry mouth, nausea and/or vomiting. Psychosocial symptoms with high incidence in the last week of life include confusion, anxiety, depression and delirium. Studies indicate that caregivers of dying patients agree that preparation at the end of life is important. The hospice team provides a variety of services directed towards preparing hospice patients and their families for imminent death. This provision of physical comfort and emotional support to dying patients and their families is an essential aspect of high-quality care.14

CMS stated in the FY 2016 and FY 2017 Hospice Wage Index and Rate Update final that they were concerned many hospice beneficiaries may not be receiving skilled visits during the last days of life.

Development of the Hospice Visits when Death is Imminent quality measure represented an effort by CMS to encourage visits to hospice beneficiaries during the last days of their life.15 The Hospice Visits when Death is Imminent quality measure data for Measure 1 (3-day measure) will first be reported on Hospice Compare in 2019. The seven-day Hospice Visits when Death is Imminent measure will not be publicly reported at this time because it did not currently meet readiness standards for public reporting.16 Hospice providers should monitor the CMS HQRP ‘Spotlight & Announcements’ webpage for updates about the timeframe for Measure 2 reporting.

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Care Management Considerations

Determining a prognosis for a patient is based on the physician’s or medical director’s clinical judgment regarding the normal course of a patient’s illness and is not an exact science. The patient’s trajectory is affected by many factors which will always make prognostication a difficult process. However, assessment of a patient’s clinical symptoms can serve to determine if a patient is actively dying or close to transitioning to actively dying. Consideration should be given to a discussion of hospice services when the patient is nearing death during the admission visit, so that patients and families know what to expect, and the team sets the expectation of “we will provide more visits, and more care to you and your family.”

1. Short Length of Patient Stay Timepoints
   
   A. New Patient Admission
      
      Patients admitted to hospice in their last days of life impacts how the hospice interdisciplinary team delivers comprehensive care to patients and their families. The hospice IDT generally needs to accelerate and intensify services to manage patient and family needs in a very limited amount of time. Intensity of care provision requires optimal assessment, coordination of care and communication among the IDT members to ensure that all patient and family needs are identified and addressed. Employing an intensified and accelerated approach facilitates collaboration among the IDT and prioritizing services that are needed to provide individualized care.17 Providers may consider structuring the admission visit to be less stressful and intrusive to promote the patient’s comfort and lessen family/caregiver anxiety.

   B. Patient on Hospice Service - Transition to Imminently Death
      
      Patients and families who receive hospice services for a longer amount of time may have less emergent needs when the patient approaches imminent death unless the patient

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experiences a symptom crisis.18 Even so, the patient or family may experience increased need for support at this time and the hospice IDT should assess and provide the support that is required.

Patients/families/caregivers may require intensity of care provision from the IDT members in their last days of life to ensure that all patient and family needs are identified and addressed. Employing an intensified and accelerated approach requires increased collaboration among the IDT and prioritization of services that are needed to provide continued individualized care.19

2. Suggestions for Care Management

A. Utilization of an Imminent Death Protocol

Some hospice providers have developed and implemented specialized hospice teams (imminent death IDT or Rapid Response Team) to manage short length of patient stay from admission. The team would be skilled in assessment of patient/family/caregiver needs and developing/implementing an accelerated and intensified plan of care. Others developed and implemented a specific protocol or process for their hospice teams to utilize with patients and families admitted to hospice in their last days of life who exhibit signs and symptoms of imminent death.

Application of specialized protocols or processes should ensure the hospice team respects the patient’s/family’s wishes related to the amount and timing of care visits and incorporation of patient/family/caregiver goals for care. Any hospice staff member or the family/caregiver can initiate the protocol when they observe a change in the patient’s status. The appropriate skilled hospice team member validates if the patient is ready to receive care via an Imminent Death Protocol or a Rapid Response Team.

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B. Assessment Suggestions

- Members of the hospice team can be taught to identify and report physical and behavioral indicators of approaching death to an appropriate and competent clinician.

- **Patients may require higher levels of care** - Continuously assess for higher levels of care during the initial assessment and on every visit.
  - Continuously assess the need to make a home visit by any member of the IDT and communicate need to the rest of the IDT.
    - i.e. A nurse should visit the patient when a fall is reported by the caregiver to a hospice team member.
  - Proactively assess for increased visit need related to status change
  - Assess for need and engage hospice aide services as soon as possible
  - Increase IDT monitoring of patient/family/caregiver to assess needs and proactively alleviate any issues before they become active problems.
  - Consider focusing patient/family/caregiver assessment elements to include only what is pertinent v. entire assessment (Providers may need to work with their electronic medical record vendor to determine if this may be possible).

- **New admissions** - Consider documenting initial assessment visit in a narrative style v. Electronic Medical Record (EMR) form to shorten completion of mandatory elements included in an EMR assessment form.
  - Consider including elements that are aligned with the Hospice Item Set (HIS) content in the abbreviated focused assessment.
  - Require point of care documentation from IDT members providing services to imminently dying patients/families so that the clinical record is updated for all team members.
  - If the patient dies before specific team members complete their specific component of the comprehensive assessment, document that the patient died before it could be completed.
  - Document the acuity of the symptoms of the patient/family/caregiver
C. Care Planning Suggestions

- Consider initiating a focused patient plan of care (POC) interventions that incorporate focused comprehensive assessment outcomes. **Note:** providers may need to work with their electronic medical record vendor.
- Ensure that the patient’s POC reflects the intensity of services required to meet patient/family/caregiver needs.
- Initiate imminent protocol when a patient decides to discontinue dependent treatment (i.e. dialysis, transfusions, etc...).
- Ensure goals for care are individualized, patient/family/caregiver centered, and measurable.
- Anticipate and proactively manage issues to reduce occurrence (i.e. Provide dark bedsheets for a patient who has potential bleeding issues; plan to have medication in the home if terminal agitation is a likely symptom for the patient).
- Ensure comfort of patient as a priority in the last days/hours of life; see examples below:
  - Manage care of patient incontinence
  - Increase provision of mouth care as needed or tolerated by patient
  - Ensure patient has adequate supplies to maintain comfort (i.e. oral care supplies, chux pads, diapers)
    - Consider developing an admission kit that includes essential supplies for patients that have only days to live. (Chux, diapers, gloves, oral care supplies, list of items that the patient may need)
  - Change medication route for symptom management per patient need
  - Discontinue medications as appropriate
  - Discontinue assessment of vital signs and other system specific assessment as appropriate.
C. Coordination of Care and Collaboration Suggestions
  
  – Listen to the patient/family/caregiver. Ensure that their communication and collaboration preferences and needs are determined and met.
  
  – The status of patients nearing death should be discussed among the hospice team daily and as well as timing for activation of an Imminent Death Protocol or Rapid Response Team.
    
    o Activation of an Imminent Death Protocol or Rapid Response Team should be reported to the hospice provider's clinical management staff.
  
  – Consider implementing a daily clinical management ‘huddle’ and hospice teams at the start of the business day to discuss which patients are receiving care via an Imminent Death Protocol or Rapid Response Team or patients who are exhibiting indicators of imminent death as appropriate.
  
  – Clinical management staff should track patients who are receiving care via an Imminent Death Protocol or Rapid Response Team. The tool is updated throughout the day. See example tracking log below.

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</table>

  – Hospice team members should consider making joint visits with other team members if possible to coordinate care with the patient/family/caregiver as needed.
  
  – After-hours (after weekday business hours and weekend days/night) staff activity:
    
    o Ensure that after-hours staff receive information (i.e. tracking log) about patients who are receiving care via an Imminent Death Protocol or Rapid Response Team.
      
      ▪ These staff will require education about the provider’s specific Imminent Death Protocol or Rapid Response Team.
    
    o Proactively communicate with patients/families/caregivers.
Consider implementing contact from after-hours to patient/family/caregiver for determination of any needs and provision of support and reassurance using patient/family/caregiver preferred communication methods.
- Ensure arrangements are in place with a pharmacy for medication ordering and dispensing during hospice after-hours.

3. **Patients Admitted to Hospice Care in Last Hours of Life**
A patient may be referred to hospice care in their last day or hours of life. These patients and families/caregivers require their most basic of needs fulfilled as a priority by the hospice IDT which could include:
- Medications for symptom control
- Comfort care supplies (i.e. oral care supplies, chux pads, diapers)
- Intense supportive care which could include:
  - Provision of daily emotional support for patient/family to help them prepare for death
  - Provision of personal care assistance (i.e. hospice aide services)
  - Education with family about the signs and symptoms of death
  - When to contact the hospice provider
  - Making funeral arrangements for patient
  - Provision of spiritual care to patient/family/caregiver (i.e. patient wish for last rites)

4. **Considerations for Decision Not to Admit to Hospice Care**
Literature review shows that death is a process and there are characteristics associated with achieving a good death at the end of that process. Patient and family dynamics at the end of life can be complex and difficult, but ultimately the goals of both are the same: to achieve a death that is symptom free, self-directed, dignified, and supported with respect and communication from health care providers. A hospice provider should consider the value

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proposition of hospice care for the patient and family/caregiver who is referred in the last
day or hours of life on a patient-by-patient basis

**Quality Assessment Performance Improvement Considerations**

The federal hospice CoPs require hospice providers to develop, implement, and maintain a hospice wide quality assessment performance improvement (QAPI) program in their organization. The QAPI CoP sets a clear expectation that hospices are required to take a proactive approach in improving their performance and focus on improved patient/family/caregiver care and activities that impact patient health and safety. The QAPI program must demonstrate continuous self-assessment of a performance with application of solutions, evaluation of the effectiveness of the solutions, and critical thinking related improvement strategies.\(^{21}\)

1. **Self-Assessment of Your Hospice Program**

   It is important to know your median length of stay in your hospice program and how it benchmarks with the national trend. An increase in shorter median length of stay, particularly patients of 7 days or less from admission to hospice care could be an indicator for adoption of a specialized imminent death protocol. Suggested data points for annual assessment include:

   - Admission volume trends
   - Median length of stay
   - Percentage of length of stay = 7 days or less from admission
   - Diagnoses of short length of short stay patients
   - Location of care of short stay patients
   - Percentage of patient deaths that received care via an Imminent Death Protocol or Rapid Response Team
   - IDT disciplines who provided services short stay patients
   - Patient/family/caregiver complaints that were related to care in the last 7 days of life

2. **Evaluation of Care Processes**

   - Evaluate program processes and areas for streamlining.
     - i.e. abbreviate admission processes; tracking visits made visits in last 7 days of life for all patients (short stay from admission and length stay patients); Patients who accessed after-hours services in last 7 days of life.

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– Evaluate documentation in clinical record for review of:
  – Discussion of organization protocol about visits when death is near during the admission visit
  – Services provided to patient/family/caregiver in the last 7 days of life
  – Coordination of care and communication among the IDT, attending physician and external resources (as applicable)
  – Refusal of specific IDT services by patient/family/caregiver
  – Patient/family/caregiver needs and response to care and timeframe of response
  – Provision of patient/family/caregiver education and their understanding related to signs and symptoms of imminent death
  – Presence of POLST/MOLST form and advance care directives
  – When to contact the hospice for support (business and after-hours)

3. **Management of IDT Staffing**

The federal hospice regulations at §418.100(c)(2) require hospice providers to maintain nursing and physician services, and access to drugs and biologicals on a 24/7 basis. Other covered services must be available on a 24-hour basis when reasonable and necessary to meet the needs of the patient and family. Depending on the outcomes of a hospice provider’s self-assessment, the provider may consider restructuring their staffing model to ensure that targeted IDT core services are available after routine office hours and weekends to visit and support imminently dying patients and their families per their needs. Providers may also consider requiring the after-hours nurse/team to routinely call the patients that have been identified with signs/symptoms of imminent death or who are receiving care via an Imminent Death Protocol or Rapid Response Team to assess their status and needs. Providers could also assess the team distribution of patients/families/caregivers who are receiving care via an Imminent Death Protocol or Rapid Response Team to redistribute staff as needed to lower staff stress levels and promote optimal patient/family/caregiver care.

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**Note:** Even if self-assessed hospice-wide data indicates a trend of refusal for a specific discipline, the hospice should review who describes the services of that discipline and how the services of that discipline are set up in discussions with patients and families at admission. The issue should be revisited during the service period as appropriate.

**Questions to consider related to staffing imminently dying patients:**

- Could your hospice program easily admit a patient/family/caregiver who is their last days of life after-hours? (after weekday business hours or weekend day/night)
- Could you ensure delivery of medications to the patient after weekday business hours or weekend day/night?
- How soon could you ensure delivery of durable medical equipment to the patient after weekday business hours or weekend day/night?
- Could you ensure provision of basic patient supplies after weekday business hours or weekend day/night?

4. **Assessment of Caregiver Satisfaction**

The Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey measures the experiences that patients and their caregivers have with hospice care. The survey considers the hospice patient and his or her primary informal caregiver as the unit of care and it is sent to caregivers (i.e., family members and friends) two months following the month of patient death. The standardized 47-question CAHPS Hospice Survey instrument contains eight CAHPS Hospice Survey quality measures (Six composite (multi-item) measures and two single-item global measures). The six composite measures review how well the hospice team communicates, how easily the decedent was able to access care, how often the hospice team treated the decedent with respect, how much emotional and religious support was provided by the hospice team, how well the hospice team provided help for symptom management, and how well the hospice team provided education/teaching to the caregiver. The
two global measures discuss a number rating of the hospice care, and if the caregiver would recommend the hospice to others.\textsuperscript{23}

**Composite Measures:**

- Communication with Family (formerly Hospice Team Communication)
- Getting Timely Help (formerly Getting Timely Care)
- Treating Patient with Respect (formerly Treating Family Member with Respect)
- Emotional and Spiritual Support (formerly Getting Emotional and Religious Support)
- Help for Pain and Symptoms (formerly Getting Help for Symptoms)
- Training Family to Care for Patient (formerly Getting Hospice Care Training)

**Global Measures:**

- Rating of this Hospice
- Willingness to Recommend this Hospice\textsuperscript{24}

While all CAHPS survey questions provide feedback from the caregiver about their perception of hospice care, the following specific questions could reflect family/caregiver care evaluation in the last 7 days of life include the following:

- While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
- While your family member was in hospice care, how often did the hospice team keep you informed about your family member’s condition?
- While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
- While your family member was in hospice care, how often did the hospice team keep you informed about your family member’s condition?


– Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?
– How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?
– While your family member was in hospice care, how much emotional support did you get from the hospice team?

One question that isn’t part of a publicly reported composite measure, but is asked by survey vendors is:

– Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?

5. **Suggestions for CAHPS and Visits When Death is Imminent Measure Evaluation**

- Work with your vendor to stratify data for short stay patients from admission to correlate caregiver satisfaction with application of imminent death protocol or process.
- Review CAHPS individual questions to determine links to short stay.
- Identify strategies for assessing and improving caregiver satisfaction through the QAPI process.
- Track percentage of patients receiving at least one registered nurse (RN), physician, nurse practitioner, or physician assistant visits in last three days of life (routine home care).
- Percent of patients receiving at least two social work (SW), spiritual care counselor, licensed practical nurse/ licensed vocational nurse, or hospice aide visits in last 7 days of life (routine care, LOS > 1 day).
- Percent of patients receiving at least one RN or SW visit in the last 7 days of life (routine care, Service Intensity Add-on eligible).
Resource Tools

Imminent Death Protocol for Hospice Admissions
Imminent Death Protocol for On-service Patients
Interdisciplinary Team Imminent Death Checklist
Interdisciplinary Focused Assessment and Plan of Care Interventions for Short Length of Patient Stay

(7 days or less)
Imminent Death Protocol (IDP) for Hospice Admissions

**Identification before or at admission**
Clinician assesses signs and symptoms of imminent death (7 days or less) and level of care

**NOTE:** Patients who are admitted in their last day or hours of life may require modified application of this protocol to meet their basic needs as a priority.

**Admitting Clinician or Team Nurse**
- Notifies nurse case manager (as applicable), SW and SCC of patient’s status
- Appropriate clinician obtains physician orders to address patient needs (including comfort medication kit).
- The hospice physician is updated related to imminence of death signs and symptoms and focused plan of care is updated

**Social Worker**
- Call or visit with patient and family on start of care date
- Coordinate psychosocial needs of patient/family as appropriate
- Provide emotional counseling and support to patient/family
- Coordinate volunteer needs and with Volunteer Manager
- Assess for advance care directives
- Educate and assist patient/family with completion of Do Not Resuscitate (DNR) or state specific form (POLST/ MOLST) as applicable
- Assist patient/family with final arrangements for patient
- Coordinate bereavement needs as appropriate
- Life review per patient wishes

**Nurse Case Manager**
- Complete medication reconciliation
- Coordinate accelerated and intensified IDT plan of care for new admission
- Update and accelerate plan of care for current patient
- Increase visit frequency as needed to meet patient/family needs
- Establish/update the hospice aide care plan (as applicable)
- Determine and coordinate new hospice aide duties related to patient/family needs
- Ensure adequate comfort related supplies
- Provide teaching to family about signs/symptoms of imminent death and what to expect; leave written teaching materials with family

**Spiritual Care Counselor (SCC)**
- Make contact with patient and family on start of care date
- Coordinate/manage patient/family spiritual care needs as appropriate
- Assessing for spiritual death rituals based on patient needs and preferences (i.e. last rites)
- Coordinate with community based spiritual care or counselor

**Interdisciplinary Team (IDT) Plan for Care Management**
- Initiate daily IDT collaboration to discuss patient/family status, needs, and plan for care.
- Initiate daily contact with patient/family (visits or phone calls per patient/family need and preference); this could include a daily call from the on-call nurse.
- Initiate complementary therapies and other services as appropriate and per patient/family preference (i.e. aromatherapy, vigil volunteer, We Honor Veterans ceremony); re-offer services for current patients
- Initiate volunteer services with the patient/family (per their wishes)
- Re-evaluate patient’s imminent death status on each visit and update plan of care (notify RN/ SW per “Interdisciplinary Team Imminent Death Checklist”
- Provide teaching to family about signs/symptoms of imminent death and what to expect; leave written teaching materials with family
- **Patients may require higher levels of care** - Continuously assess for higher levels of care during the initial assessment and on every visit.
- Ensure after-hours staff are aware of all patients receiving care via the Imminent Death Protocol or Rapid Response Team process.
- After-hours staff to call patients receiving care via the Imminent Death Protocol or Rapid Response Team process as needed to determine any patient/family/caregiver needs, provide emotional support, and decrease family/caregiver anxiety.

**Patient death no longer imminent or patient died**
Nurse notifies hospice operations, social worker, and spiritual care counselor and the rest of the IDT; primary care physician

**Patient death remains imminent dying**
IDT Continues with Imminent Death Protocol

This is designed as a 24/7 protocol that can be implemented at any time of the day/night

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Imminent Death Protocol (IDP) for On-service Patients

IDT Member
- Notifies other IDT members of observed physical/behavioral indicators which may be associated with imminent death
- The patient’s attending physician and hospice physician are updated related to physical/behavioral indicators

Social Worker
- Call or visit with patient and family to assess emotional and psychosocial needs of patient/family as appropriate
- Provide emotional counseling and support to patient/family
- Coordinate volunteer needs and with Volunteer Manager if not already involved and patient/family are willing
- Educate and assist patient/family with completion of Do Not Resuscitate (DNR) or state specific form (POLST/ MOLST) as applicable
- Coordinate bereavement needs as appropriate
- Life review per patient wishes

Nurse Case Manager
- Complete medication reconciliation
- Update comprehensive assessment
- Coordinate accelerated IDT plan of care interventions
- Increase visit frequency as needed to meet patient/family needs
- Establish/update the hospice aide care plan (as applicable)
- Determine and coordinate new hospice aide duties related to patient/family needs as applicable
- Ensure adequate comfort related supplies
- Review teaching to family/caregiver about signs/symptoms of imminent death and what to expect; leave written teaching materials with family/caregiver

Spiritual Care Counselor (SCC)
- Make contact with patient
- Coordinate/manage patient/family spiritual care needs as appropriate
- Assist with coordination or facilitation of spiritual death rituals based on patient needs and preferences (i.e. last rites)
- Coordinate with community based spiritual care or counselor

Interdisciplinary Team (IDT) Plan of Care
- Initiate daily IDT collaboration to discuss patient/family status, needs, and plan for care.
- Initiate daily contact with patient/family (visits or phone calls per patient/family need and preference); this could include a daily call from the on-call nurse.
- Initiate complementary therapies and other services as appropriate and per patient/family preference (i.e. aromatherapy, vigil volunteer, We Honor Veterans ceremony); re-offer services for current patients
- Initiate volunteer services with the patient/family (per their wishes)
- Re-evaluate patient’s imminent death status on each visit and update plan of care
- Review teaching with family/caregiver about signs/symptoms of imminent death and what to expect; leave written teaching materials with family
- Patients may require higher levels of care - Continuously assess for higher levels of care during the initial assessment and on every visit.
- Ensure after-hours staff are aware of all patients receiving care via the Imminent Death Protocol or Rapid Response Team process.
- After-hours staff to call patients receiving care via the Imminent Death Protocol or Rapid Response Team process as needed to determine any patient/family/caregiver needs, provide emotional support, and decrease family/caregiver anxiety.

Patient death no longer imminent or patient died
Nurse notifies hospice operations, social worker, and spiritual care counselor and the rest of the IDT; primary care physician

Patient death remains imminent dying
IDT Continues with Imminent Death Protocol

This is designed as a 24/7 protocol that can be implemented at any time of the day/night

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Interdisciplinary Team Imminent Death Checklist

**Patient Physical and Behavioral Indicators**

All hospice team members can identify physical indicators or behaviors associated with imminent death at either at the time of admission or within the first days of care. The hospice nurse (and team) also educates the patient's family members to recognize signs and symptoms of approaching death as part of the patient plan of care goals. It is important that an appropriate and competent clinician educates the hospice team to recognize the physical and behavioral indicators associated with imminent patient death.

This checklist outlines the physical and behavioral indicators that can be associated with patient death in a 7 day or less timeframe. These indicators may be observed by any hospice team member or reported to the hospice team by the patient or family. Observations or reports of these indicators from patient/family/caregiver should be reported to the registered nurse (RN) for determination of the need for clinical assessment.

**Note:** The following are general physical and behavioral indicators and do not include disease specific clinical indicators that may be associated with a patient’s imminent death. Hospice clinicians should consider disease specific indicators in conjunction with general indicators to ascertain if a patient is approaching death.

<table>
<thead>
<tr>
<th>General Patient Physical Indicators Associated with Imminent Death Which Indicate Need to Notify RN</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Expression/worsening pain (patient verbal or hospice team/family/caregiver non-verbal observation)</td>
</tr>
<tr>
<td>• Expression/worsening symptoms (i.e. nausea, vomiting)</td>
</tr>
<tr>
<td>• Changes in temperature of extremities (i.e. cooling)</td>
</tr>
<tr>
<td>• Changes in breathing (i.e. shortness of breath, slower or faster breaths, pauses between breaths)</td>
</tr>
<tr>
<td>• Decreased/no fluid and food intake</td>
</tr>
<tr>
<td>• New incontinence (bladder and/or bowel)</td>
</tr>
<tr>
<td>• Difficulty swallowing/unable to take oral medications</td>
</tr>
<tr>
<td>• Delirium - abrupt onset of fluctuating confusion, inattention, and reduced awareness of the environment which can include hallucinations</td>
</tr>
<tr>
<td>• Significant functional ability changes</td>
</tr>
<tr>
<td>– I.e. New profound weakness, patient becomes bedbound</td>
</tr>
</tbody>
</table>

**Clinical Indicators Associated with Imminent Death Related to RN Specific Assessment:**

- Decreasing blood pressure (from patient’s norm)
- Decreasing in heart rate (from patient’s norm)
- Rapid decline in Karnofsky (0-20%) or Palliative Performance Scale (PPS) score (0-20%)
General Patient Behavioral Indicators of Imminent Death Which Indicates Need to Notify RN

- Increased sleeping
- Agitation
- New or increased confusion
- Less responsive
- Restlessness not relieved by medications
- Fixed stare
- Picking at air, visual or auditory hallucinations, particularly of people who have died
- Talking with a person not visible to others

Family/Caregiver Behavioral Indicators

Family members or caregivers for the patient may also display behavioral indicators as the patient approached death. The following indicators may be observed by any hospice team member or reported to the hospice team by the family/caregiver. Observations or reports of these indicators from patient/family should be reported to the social worker (SW) for determination of the need for clinical assessment.

General Family/Caregiver Behavioral Indicators of Imminent Death Which Indicates Need to Notify SW

- Absent, anxious or insufficient caregiver support
- Display of increased anxiety
- Display of being stressed
- Display of active grieving
- Minor children in home
- Known substance abuse or drug diversion, etc.
- New, elevated, or changed family dysfunction (i.e. conflict)
- New, increased, or changed emotionally lability
- Display of helplessness or feeling helpless
- Increased caregiving demands necessitating discussion of options
Clinical Indicators Associated with Imminent Death Related to SW Assessment

- Cultural or family belief systems that become challenging

<table>
<thead>
<tr>
<th>Patient Indicators Associated with Imminent Death Within 3 days Which Indicates Need to Notify RN</th>
</tr>
</thead>
<tbody>
<tr>
<td>• New or increase in apneic periods</td>
</tr>
<tr>
<td>• Cheyne-Stokes breathing pattern</td>
</tr>
<tr>
<td>• Respiratory congestion, rattling or noisy breathing (death rattle)</td>
</tr>
<tr>
<td>• Peripheral cyanosis</td>
</tr>
<tr>
<td>• Significant worsening of skin breakdown (i.e. Kennedy Terminal Ulcers)</td>
</tr>
<tr>
<td>• Purple discoloration to underside of body</td>
</tr>
<tr>
<td>• Decreased to no urine output</td>
</tr>
<tr>
<td>• Decreased response to verbal or visual stimuli</td>
</tr>
<tr>
<td>• Inability to close eyelids</td>
</tr>
</tbody>
</table>

Physical Indicators Associated with Imminent Death Related to RN Specific Assessment:

- Pulselessness of radial artery
- Decreased blood pressure (from patient's norm)
- Respiration with mandibular movement (depression of jaw with inspiration)
- Non-reactive pupils
- Drooping of nasolabial fold
- Hyperextension of neck
- Upper gastrointestinal bleed

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## Interdisciplinary Focused Assessment and Plan of Care Suggestions
### For Short Length of Patient Stay (7 days or less)

**Suggested Focused Interdisciplinary Team Assessment**

*IDT = Interdisciplinary team*

<table>
<thead>
<tr>
<th>*IDT Discipline</th>
<th>Assessment item(s)</th>
</tr>
</thead>
</table>
| **Nurse**             | • Assessment of physical symptoms that may indicate imminent death  
                        | • Assessment of patient caregiver ability to care for imminently dying patient  
                        |   - Medication administration  
                        |   - Comfort measures implementation  
                        | • Assessment for caregiver assistance with symptom management  
                        |   - Additional support needed?  
                        |   - Additional medications or non-pharmacological interventions needed?  
                        |   - Assessment of family/caregiver understanding of what is happening with the patient  
                        | • Assessment for hospice aide services  
                        | **Social Worker**          | • Assessment for emotional pain (patient/family)  
                        | • Assessment of psychosocial needs (patient/family)  
                        | • Assessment for bereavement intervention (patient/family)  
                        | • Assessment and monitoring for potential trauma triggers  
                        | • Assessment for final arrangements  
                        | • Assess for veteran recognition (veterans)  
                        | • Assess patient caregiver care giving plan for current situation and when active dying occurs which can be very different. What happens when care is needed overnight, assignment of roles, enlarging the circle of support if needed, etc...  
                        | • Assess family/caregiver members for those who have additional needs or for families who may need more than one SW to meet varying needs  
                        | **Spiritual Care Counselor** | • Assessment of spiritual pain (patient/family)  
                        | • Assessment and coordination of EOL rituals  
                        | • Assessment for existential pain/suffering (patient/family)  
                        | • Explore/determine who needs to be present at bedside and work with social worker to facilitate  
                        | • Introduce/provide meaningful rituals per patient/family wishes  

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<tr>
<th>*IDT Discipline</th>
<th>Assessment item(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All IDT Members</strong></td>
<td></td>
</tr>
</tbody>
</table>
  - Observation of physical symptoms that may indicate imminent death
  - Assessment of patient coping
  - Assessment of family/caregiver coping
  - Assessing for complementary therapies
  - Assessing for Volunteer services
  - Assessment of family understanding of what to expect – did they get enough information
  - Assessment of perception of death (religious and culture aspects; new-assessing for any; ongoing, carrying out our role per patient/family)
  - Assessment of needs and preferences |

**Suggested Focused Interventions Related to Imminent Death:**

<table>
<thead>
<tr>
<th>IDT Discipline</th>
<th>Assessment item(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td></td>
</tr>
</tbody>
</table>
  - Re-evaluate patient’s imminent death status on each visit and update plan of care.
  - Provide teaching to family about signs/symptoms of imminent death and what to expect; leave written teaching materials with family.
  - Patient/family teaching – what to expect, protocol for death at home (county specific); what will happen at time of death, signs and symptoms of imminent death and what to do. |
| Hospice Aide |  
  - Provision of patient personal care (assistance or provision)
  - Provision of patient mouth care
  - Help with toileting or incontinent care |
| Social Worker |  
  - Initiation of the POLST/MOLST (patient or representative)
  - Final arrangement conversation
    - Location of death
    - Funeral home of choice
    - Who do they want at the bedside or in the home
    - Outside coordination as applicable to being family members to patient (Red Cross, military)
    - Who is contacted when patient dies
  - Provide emotional counseling and support to patient/family.
  - Assess for bereavement counselor support for patient/family. |
### IDT Discipline | Assessment item(s)
--- | ---
**Spiritual Care Counselor**  
- Provide spiritual counseling and support to patient/family  
- Initiate funeral service conversation.  
- Coordinate services or rituals with local clergy/spiritual care provider for death event and other postmortem practices

**All IDT Members**  
- IDT collaboration daily related to patients/family status and needs, and plan of care.  
- Initiate daily contact with patient/family (visits or phone calls per patient/family need and preference); this could include a daily call from the on-call nurse.  
- Ensure appropriate disciplines are involved to provide supportive care.  
- Observe for of physical symptoms that may indicate imminent death on every visit.  
- Reinforce teaching with family about signs/symptoms of imminent death and what to expect.  
- Initiate volunteer services per patient/family agreement and preference.  
- Initiate complementary therapies and other services as appropriate and per patient/family preference (i.e. aromatherapy, vigil volunteer, We Honor Veterans ceremony); re-offer services for current patients.  
- Teach and role model for family/caregivers how to interact with a person who is dying.

### Focused General Plan of Care Goals Related to Imminent Death:

A patient’s plan of care is developed using outcomes of the comprehensive assessment at the start of care and updates to the plan of care as often as the patient’s status requires. Therefore, a plan of care should be individualized to the patient’s physical, emotional, psychosocial, and spiritual needs. Plan of care goals also must be measurable. The following are examples of focused general plan of care goals related to imminent death.

- The hospice team will manage patient’s symptoms within 24-48 hours symptoms.
- Family/caregiver can verbalize signs and symptoms of approaching death and display positive coping behaviors within 2 visits.
- Family/caregiver understand when to contact the hospice team for care concerns and questions about patient status and care by the first home visit.
- Patient will identify and express sources of spiritual pain within 2 visits.
- Patient will identify and express sources of emotional pain within 2 visits.