# CCHCS Care Guide: Palliative Care

## SUMMARY

### GOALS

- Identify patients in early stages of a progressive disease
- Timely identification and documentation of goals of care
- Reduce performing unnecessary invasive interventions
- Identify/refer patients who would benefit from Hospice
- Document on a CDCR 7421, Advance Directive and CDCR 7465, POLST
- Consider compassionate release or expanded medical parole
- Optimize pain relief and quality of life

### ALERTS

Early identification of patients nearing the end of life is subjective and challenging. Common indicators:
- Frequent hospitalizations/interventions
- End stage progressive illness or cancer diagnosis
- Cognitive decline, dementia
- Progressive weight loss and/or frailty
- Frequent or high risk for falls
- Polypharmacy

## DIAGNOSTIC CRITERIA

Palliative care is an approach that focuses on improving the quality of life for patients facing chronic debilitating and life-limiting illness. Early identification is a key first step in engaging the eligible patient to consider this approach to care.

- Factors that may suggest eligibility include various clinical manifestations, lab parameters, service utilization, and/or declining functional performance (page 3).
- The CCHCS Medical Classification System may assist with identifying patients at highest risk for life-limiting conditions and patients who are HIGH RISK (especially High Risk 1) are most likely appropriate for palliative care.

## EVALUATION

Comprehensive assessment and development of an individualized plan of care both guide the prevention and relief of suffering and reduce unnecessary and/or unwanted interventions. Assessment considers needs in each of these domains:

- Ethical and legal
- Spiritual and religious
- Social
- Cultural
- Psychological
- Physical

A key characteristic of palliative care is the interdisciplinary and collaborative process for treatment planning that involves providers, nurses, chaplains, social workers, behavioral health providers, pharmacists, dieticians, etc.

- When feasible, and in accord with the patient’s wishes, involvement of family members in family conferences and/or care coordination may also be included.
- Considerations for referral to hospice (page 17) and/or referral for consideration of compassionate release or expanded medical parole (pages 14-16) may be appropriate for many patients.
- If a patient lacks decision-making capacity, initiating the conservatorship process (PC 2604) (page 4) and/or a referral to the CCHCS Ethics Committee (page 7) may be appropriate.

## TREATMENT

Palliative care/treatment covers a broad range of strategies that focus on comfort and quality rather than duration of life.

- Identifying the patient’s end-of-life wishes is the primary objective of the Goals of Care Conversation (GoCC) (page 5).
- Treatment approaches should align with the patient's goals and wishes and thus may vary accordingly.
- It is important to anticipate the patient's needs as their condition progresses and to frequently revisit their goals of care.
- Specific recommendations for optimizing the patient’s care/comfort in the six domains listed above should be considered (pages 7-12). Managing physical symptoms can often be complex, but very rewarding (pages 9-12).

## MONITORING

- To ensure smooth care transitions across settings or providers, communication with the entire care team should be anticipated, planned, and coordinated whenever the patient changes housing, level of care, or institution.
- Ideally, interdisciplinary care coordination occurs throughout the course of a patient’s condition.
- It is important that care teams create an environment of resilience, self-care, and mutual support to alleviate the stress of caring for patients with serious illness nearing the end of life.

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Information contained in the guidelines is not a substitute for a health care professional’s clinical judgment. Evaluation and treatment should be tailored to the individual patient and the clinical circumstances. Furthermore, using this information will not guarantee a specific outcome for each patient. Refer to “Disclaimer Regarding Care Guides” for further clarification. [Link](https://cchcs.ca.gov/clinical-resources/)
Patient presents with new or established diagnosis of a progressive, debilitating and/or potentially life-limiting condition

Identify eligible patients (page 3)
- Patient presents with new or established diagnosis of a serious illness
- Review QM Master Registry to identify High Risk 1 patients

Does patient have medical decision-making capacity? (page 4)
- Yes
  - Initiate CCHCS Goals of Care Conversation (GoCC) - (pages 5-6)
    - Elicit patient’s values, goals, preferences
    - Palliative Care Worksheet can assist with defining patient’s specific preferences for life-sustaining treatment (page 19)
    - Provide Patient Education (PE1-4)
  - Document GoCC (page 6)
    - Complete POLST (CDCR 7465)/Advance Directive (CDCR 7421) ASAP (These forms are scanned into EHRS)
    - Complete POLST Ad Hoc Form in EHRS – This triggers EHRS banner bar alert
  - Assess patient’s palliative care needs based on the following domains of palliative care (pages 7-12)
    - Ethical and legal
    - Social
    - Psychological
    - Spiritual and religious
    - Cultural
    - Physical

- No
  - Contact surrogate medical decision-maker OR see PC 2604 process (page 4)

Is patient eligible for Compassionate Release or Expanded Medical Parole? (page 14)
- Yes
  - Develop or revise palliative care plan based on patient’s/surrogate’s goals
  - Reassess end-of-life wishes frequently
  - Document conversation/changes in EHRS and update POLST (Scan & AdHoc) as necessary
- No
  - Does patient meet hospice criteria and wish to consider? (page 17)*
    - Yes
      - Implement palliative care plan ensuring all 6 domains of care needs are being met (pages 7-12)
    - No
      - Refer to Hospice (page 17)
        - Women: CIW and CCWF
        - Men: CMF
        - Hospice care team coordinates care

*Use general/disease specific prognostic tools as needed (Attachment A-E)
IDENTIFYING ELIGIBLE PATIENTS

Clinical factors that may be useful in identifying eligible patients are shown in the following table:

<table>
<thead>
<tr>
<th>Clinical Manifestations</th>
<th>Lab Parameters</th>
<th>Service Utilization</th>
<th>Functional Performance</th>
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<tbody>
<tr>
<td>&gt; 4 high risk chronic conditions</td>
<td>Albumin &lt; 2.5</td>
<td>&gt; 2 hospitalizations/6 months</td>
<td>Adjustment difficulty</td>
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<tr>
<td>Cancer diagnosis</td>
<td>Creatinine &gt; 2.0</td>
<td>&gt; 2 urgent admissions/12 months</td>
<td>Falls</td>
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<tr>
<td>Cognitive decline/dementia</td>
<td>INR &gt; 2.0</td>
<td>TTA/ OHU/SNF admissions</td>
<td>Lay-ins</td>
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<td>Weight loss/frailty</td>
<td>Bilirubin &gt; 2.0</td>
<td>Bone marrow biopsy</td>
<td>ADL assistance needed (bath, dress, toilet, eat, transfers)</td>
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<td>Pressure ulcers</td>
<td>PSA &gt; 10</td>
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<tr>
<td>Infections</td>
<td>AFP &gt; 500</td>
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<td>Dysphagia</td>
<td>CA125 &gt; 35 U/mL</td>
<td>Recurrent Antibiotic RXs</td>
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<td>Cardiac disease</td>
<td>FIB4 &gt; 3.25</td>
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Note that palliative care is applicable early in the course of illness in conjunction with other therapies (including curative) 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.

- As the patient’s disease state progresses, more of a palliative care approach is used as shown in the figure below. See Attachments A-E for general and disease-specific prognostic tools.

Palliative Care:
- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten or 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.
- Uses a team approach to address the needs of patients.
- Enhances quality of life and may also positively influence the course of illness.
- Is utilized in hospice settings, but hospice is not required to receive palliative care.
## Determining Medical Decision-Making Capacity

Medical decision-making capacity is the basis of informed consent. Patients have medical decision-making capacity if they can:

1) **Understand** information relevant to a decision; and  
2) **Appreciate** the reasonably foreseeable consequences of a decision (or lack of decision).

- No particular form or specific process is needed to determine capacity in most cases. During a typical interaction, the Primary Care Provider (PCP) can see that the patient is following the conversation, asking pertinent questions and demonstrates understanding of what is being said including the risks/benefits of possible testing/treatments. Presence of capacity should be documented in EHRS.

- In cases where medical decision-making capacity is NOT clearly evident, the PCP may use the validated Aid to Capacity Evaluation (ACE) tool to help evaluate and document capacity in a more formal manner. Examples for when to use the ACE:
  - The patient has an acute change in mental status.
  - The patient refuses clearly beneficial recommended treatment.
  - The patient readily agrees to an invasive or risky procedure without considering the risks and benefits.

### Tips on Capacity Assessment:

- The PCP is responsible for determining whether a patient is capable of making health care decisions in most cases. Mental Health (MH) input should be sought if the patient has a significant co-existing mental illness.
- Capacity is assessed intuitively at every medical encounter and is usually readily apparent.
- Remember that people are *presumed* to have medical decision-making capacity, therefore, if there is some modest uncertainty, generally err on the side of considering the patient to have capacity.
- Request assistance from the CEO/CME/CP&S if the patient’s medical decision-making capacity remains in question.

### Patients Without Medical Decision-Making Capacity Who Have A Surrogate Medical Decision-Maker

If a patient lacks medical decision-making capacity, a surrogate medical decision-maker will need to be contacted.

- Ideally the patient has completed a CDCR 7421, Advance Directive naming the person(s) they wish to be their surrogate medical decision-maker(s). In this case, the care team is able to immediately utilize the identified surrogate for decisions when the patient lacks capacity.
- It is important for the patient to talk with those individuals they are considering to designate as their surrogate medical decision-maker, and the surrogate should be agreeable to serve in this role.
- Anytime a surrogate is appointed, be sure to document contact with the surrogate for any significant patient care decisions.
- A new CDCR 7421 should never be completed if a patient’s medical decision-making capacity is in question.

### PC 2604: Court Appointment of a Surrogate Medical Decision-Maker (AKA Medical Conservator)

Some providers think a “crisis” situation is needed to initiate a PC 2604, to the contrary, this process should be started early for any patient who does not have an identified surrogate medical decision-maker and who lacks capacity.

- Contact the Office of Legal Affairs (OLA) at (916) 445-0495 for help with identifying the patient’s next of kin and the PC 2604 process.
- Any insight on possible surrogates or knowledge of bias, conflict of interest, etc., about a potential surrogate should be shared with OLA.
- Be cautious with informal contact with a family member not previously identified by the patient; it’s best to get formal assignment.
- Where medical decision-making is needed urgently for “unrepresented patients,” the CCHCS Health Care Ethics Committee may be of assistance (page 7).

**PC 2604 Process:**

- The PCP will complete a CDCR 7702, Petition for Capacity Determination, which describes a summary of medical and mental health problems.
- OLA initiates the PC 2604 process by filing with the Office of Administrative Hearings.
- The PCP will be expected to appear for the court proceeding(s) which are usually held at the institution or facility where the patient is located.
- PC 2604 requires annual renewal.

**Important to note:**

- Send surrogate assignment (PC 2604) with a patient if they transfer to a hospital or other external facility.
- At time of release, county conservatorship may need to be arranged.
- All patients who have an assigned surrogate via PC 2604 process are on the PC 2604 patient registry (with flags on Patient Summary and Master Registry) to support providers and care teams in managing this subset of patients.

Contact Office of Legal Affairs at (916) 445-0495 to help guide you if you have questions throughout the process.
### Elicit Patient’s Values, Goals, and Preferences

Once a patient is determined to possess medical decision-making capacity, the table below provides a 6-step strategy along with examples that can help with defining patient’s wishes and goals of care. The Goals of Care Conversation (GoCC) should occur early and often in the course of a life-limiting illness. Expect that patients will need time to process information and make decisions.

Good communication is a cornerstone of high-quality medical care, and is linked with better patient outcomes and improved patient and family satisfaction with care.

- Active discussion about an individual’s goals and preferences, specifically as they relate to end-of-life issues, is linked to reductions in hospital utilization and aggressiveness of care at the end of life.
- Keep in mind, however, even when providers use good communication techniques, progress toward big decisions may be slow, especially if a patient has just realized that his/her illness is imminently terminal. People need time to process this information and will likely need to hear the information repeatedly. Be deliberate but patient with this process.
- The effects of a conversation may not be apparent until much later. Simply initiating the conversation will likely have a big impact on the patient’s thinking, even when there is apparent refusal/difficulty. If there are differences of opinion, it’s particularly important to reinforce that the patient won’t be abandoned. Proceed to kindly agree to disagree and make sure the patient understands that you’re always going to be there for them. When confronted with refusal such as, “I don’t want to talk about code status,” consider a response such as, “I want to make sure your wishes are heard.”

Motivational interviewing techniques can be useful in helping to explore and resolve ambivalence. Please select the link provided for additional information on motivational interviewing: [http://healtheknowledge.org/course/view.php?id=190](http://healtheknowledge.org/course/view.php?id=190).

| Setting | When introducing the GoCC, think about what you want to say in advance.  
Select a quiet and private space, and allow time for the patient to express their emotions and ask questions. |
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| Perception | **Assess the patient’s understanding of their medical condition using open-ended questions:** Open-ended questions can be more efficient because they elicit reliable and complete information, but need to be skillfully managed so to not lead to lengthy discussions.  
- “What do you understand about your medical condition?” |
| Invitation | **Ask permission to engage in conversation about a sensitive topic:** When the patient gives permission, they are open to the conversation.  
- “Would it be okay if we talk about services and treatments that might be needed to support your health care goals?” “Have you ever thought about who should make health care decisions for you if you are too sick to speak for yourself?” |
| Knowledge | **Give the patient information about their condition, treatment plan, discuss the prognosis, and provide support.** Remember to use language that is nontechnical and at their comprehension level, give information in small chunks, and check in with the patient regularly to make sure he/she understands: This builds the patient’s confidence that they have been heard and are being taken seriously, helps the patient feel more comfortable and open to feedback, and builds a therapeutic alliance. Providing options whenever possible can be helpful. Options offered should not include futile therapies (i.e., feeding tubes in patients with dementia).  
- “Here are some typical changes that occur with your condition...I understand this can be very confusing, do you mind telling me your general understanding of what I have been saying to make sure I have explained it clearly?” (Reinforce what is accurate in their words).  “Do you have any concerns?” |
| Empathy | **Being empathetic can soften the impact of bad news and permits moving forward to discuss strategies that address the disease and its implications:** This aids in building rapport, particularly in difficult discussions.  
- “I can see that this is a difficult time for you.” |
| Summarize or Strategize | **Ask the patient if they understand the plan and if it makes sense.** Using reflection is often helpful: Hearing someone repeat back to you what you are saying often increases insight and self-reflection.  
- “What I hear you saying is that you’re afraid of dying and aren’t ready to make such difficult decisions.”  
**Close with a clear summary of the situation and ask if the patient has any more questions:** Summaries help patients and surrogates organize their experience and brings closure, consensus, and sets up for next steps.  
- “The information you have provided is very important and I want to make sure I understand…” |
The Palliative Care Worksheet (page 19) is an interactive tool to assist the patient in defining his or her specific preferences for life-sustaining treatment under certain circumstances. Once the conversation is introduced, offer the Palliative Care Worksheet to the patient as a tool to encourage further thought and consideration about their preferences, and to identify questions/topics they would like additional information about or would like to discuss at their next visit.

DOCUMENTING GOALS OF CARE CONVERSATION(S)

The GoCC should be explicitly documented in an easily searchable location or separate document. The POLST Ad Hoc form in the EHRS provider documentation folder is a useful place to document and track ongoing discussions about the patient’s goals and preferences for life-sustaining treatments.

Keep in mind that a patient’s goals for care can, and do, change over time and it is important to update documentation so that the patient’s evolving wishes are evident to other team members and can be carried out. These discussions help to inform later conversations between the patient (or surrogate) and clinician as the patient’s wishes/goals evolve with their illness.

Once the patient can clearly express their preferences for care, the provider must complete a POLST and the patient must complete an Advance Directive (AD). Be sure to indicate on the Ad Hoc form if a signed POLST and/or AD is completed and scanned.

Documenting the GoCC should efficiently describe and reflect the patient’s:
- Medical decision-making capacity
- Next of kin or identified surrogate medical decision-maker
- Understanding of their health condition
- Goals, preferences, and values

While similar, the POLST and AD each have distinct features which are outlined in the table below.
- It is important to share patient education material that explains each of these forms (see PE 1-4).
- Many patients confuse these documents with a “Last Will and Testament” likely because an AD used to be called “Living Will” so patients may need education/reassurance that AD is solely related to health care decisions.

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<thead>
<tr>
<th>POLST - CDCR 7465 (Physician Orders for Life-Sustaining Treatment)</th>
<th>Advance Directive - CDCR 7421</th>
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<td>Appropriate for patients who are frail, elderly, or have a life-limiting illness or injury.</td>
<td>Appropriate for all patients regardless of age and health status.</td>
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<td>The provider completes the form to reflect the patient’s wishes.</td>
<td>Patient completes form - discusses with the PCP.</td>
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<td>Four parts:</td>
<td>Four parts:</td>
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<td>• Part A: Resuscitation Status (CPR - Yes/No)</td>
<td>• Part 1: Power of Attorney for Health Care</td>
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<td>• Part B: Medical Interventions (Full/Selective/Comfort-Focused Treatment)</td>
<td>• Part 2: Instructions for Health Care</td>
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<td>• Part C: Artificially Administered Nutrition (Feeding Tube - Yes/No/Limited Trial)</td>
<td>• Part 3: Donation of Organs at Death</td>
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<td>• Part D: Signatures/Summary of Medical Condition</td>
<td>• Part 4: Verification of Understanding, Signature, Witnesses</td>
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<td><strong>What you should know:</strong></td>
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<tr>
<td>➢ The POLST does not have space for a patient to designate a surrogate medical decision-maker. This is an important item to identify in the GoCC and can ideally be documented with an AD or alternatively, in a progress note.</td>
<td>➢ The AD provides instructions for health care and does not function as an order.</td>
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<tr>
<td>➢ During GoCC, ensure the patient has an up-to-date contact on custody next-of-kin form and determine if this is the person they would like to speak for them if needed. A CDCR 7385, Authorization for Release of Protected Information will need to be filled out prior to talking to next of kin.</td>
<td>➢ Patient preferences are optional, so often there is no explicit documentation/expression of whether the patient wants CPR, ventilation, hospital transfer, feeding tube, etc.</td>
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The overarching goal of palliative care is to reduce suffering and optimizing quality of life throughout the course of a progressive illness and throughout the dying process.

Often, focus is predominantly placed on physical symptom management, whereas ALL of the six domains of palliative care need to be considered. Each domain is briefly described below.

### Ethical and Legal Aspects of Care

When a patient loses decision-making capacity, having previously identified surrogate medical decision-makers and documented medical care preferences/goals are very helpful in supporting the autonomy of the patient and guide ongoing palliative care.

- This is why engaging a patient in the GoCC early in the course of illness is so important. If the patient was not able to identify a surrogate medical decision-maker and a surrogate medical decision-maker is needed, the search for family or other suitable surrogates should be reasonable and should be documented to show diligence.
- The Office of Legal Affairs, (916) 445-0495, is an important resource to contact when the patient lacks or loses medical decision-making capacity especially when the need for legal conservatorship (PC 2604) is identified (page 4).
- The CCHCS Ethics Committee can be used as a resource in difficult end of life cases, such as when a patient lacks capacity and is unrepresented, or when the patient or family is insisting on care which has no chance of benefiting the patient, (previously called "futile care"). This multidisciplinary committee provides guidance based on standard practices from the ethics literature in order to facilitate resolution of bioethical dilemmas.
- For Ethics Committee consultation requests, please contact the warmline at CDCR CCHCS HQ Ethics Committee.

### Social Aspects of Care (Including family and friends)

Serious illness can be a frightening and lonely experience. Involving family in the patient’s care can be helpful. Many patients will consider reaching out to long estranged family members or friends during this period. For other patients, their cellmate or other friends in the prison now serve as their family and they wish to remain in their current housing as long as possible. There are many ways the treatment team can help patients and their families including:

- Having appropriate team members encourage/facilitate difficult, but important, discussions between patients and families.
- Providing emotional support by just sitting and talking with the patient about their fears, anxiety, and sadness.
- Assisting patients who have been estranged from family for years and want closure. A chaplain or other team member may be able to assist in trying to reconnect the patient and family members.
- Hints for finding information on family members/friends: SOMS, Electronic Records Management System (ERMS), visiting office records, or inmate record (C-File). In addition, there are a handful of free websites that can be used, and hospital admissions or attorney records may also contain information regarding next of kin.
- All patients receiving palliative care should have an initial consult with an identified treatment provider to assist with obtaining a [CDCR 7385](#) and to assist with facilitating family contact for support and placement if compassionate release (page 14) is approved.

### Visits and Phone Calls

**Visits:** [Availability and some processes may vary depending on institution and patient’s custody factors]. If a family member wishes to visit the patient, the patient (or treatment team if patient needs assistance) will need to do the following:

- The patient signs and sends the [CDCR 106 - Visiting Questionnaire](#) to the prospective visitor.
- The visitor sends the completed/signed CDCR 106 to the institution’s Inmate Visiting Department.
- If the visitor is approved, the patient will be notified and they must notify the visitor. If the visitor is disapproved, the patient and visitor will receive a Notice of Disapproval and information on how to appeal the decision.
- Approved visitors may visit during regular visiting days and hours and must comply with all visitation rules.
- Visits for patients in a community hospital may be approved under the following conditions: the patient has a life-threatening or critical illness/injury; the visitor is an immediate family member, including a registered domestic partner; the visitor has prior approval to visit the patient in the institution/facility; head, or designee, approves it, or the attending physician authorizes the visit.
- Hospice patients: staff may assist in the notification of the family member or friend if requested by the patient. Custody can make adjustments to this process if the patient is on VIGIL (having 72 hours or less to live). All hospice patients on VIGIL may receive visits seven days a week from approved visitors. The initial visit can be any time within a 24 hour period.
- See [CDCR Department Operations Manual](#), Chapter 5, Article 42, Section 54020.8 – Visitor Application Procedure for detail.

**Phone Calls:** Many times a patient wants to discuss health care decisions with family before agreeing to a specific plan of care. This is allowed but must involve custody. There is no specific policy regarding seriously ill (often hospitalized) patients discussing their health care with family, but custody will need to approve and monitor the call to ensure security for all involved.
Psychological Aspects of Care

Psychological aspects of care include assessing for anxiety, depression, delirium, cognitive impairment, stress, and anticipatory grief. It is important to differentiate grief from depression.

- Depression can be triggered by different factors as the terminally ill patient begins to contemplate death. Sometimes depression can be triggered by a need for reconciliation with family members or friends before death occurs.
- Depression can also be associated with the loss of control over life events experienced by the patient. As death nears, it is easier to slip into a state of passive resignation and despair.
- Depression in dying persons may be either “primary” (the person is pre-disposed to depression in response to stress) or “secondary” (depression is a result of the disease itself or the result of treatments).

Treatment strategies may include both pharmacologic and non-pharmacologic modalities.

- Assess for suicidal risk and underlying clinical conditions (e.g., metabolic, endocrine).
- Assess for medication toxicities (e.g., beta-blockers, corticosteroids).
- An MH referral is often necessary especially if pharmacotherapy is anticipated.
- Educating the patient/correcting misconceptions regarding their condition/treatment, can be consoling.

Simply acknowledging the possibility of underlying grief can improve one’s rapport with a patient and open the conversation to exploring other related aspects of care. Consultation requests are recommended as needed to leverage the expertise of MH and pastoral colleagues and can be key to addressing/relieving psychological sources of suffering adding to a multidisciplinary approach to patient care. Delirium can be common in the week or two before death and at any time in patients with pre-existing dementia. Be aware of other possible contributors such as urinary retention, constipation, inadequate oxygenation, metabolic abnormities, infection, or drug toxicities. Neuroleptic agents such as haloperidol are commonly used to calm agitation without interfering with cognition.

Spiritual and Religious Aspects of Care

Spirituality refers to the way individuals seek and express meaning and purpose in regards to the spirit, soul or what they hold sacred, as opposed to their physical or material well-being. Chaplaincy services are available to assist with this aspect of assessment and care. Every institution has several chaplains from a variety of religious traditions available for consultation. The CDCR Chaplain Directory or your local leadership can provide a list of resources. If a patient is located in restricted housing they may submit CDCR 22, Inmate/Parole Request For Interview, Item or Service to request a chaplain visit.

Spiritual/Religious/Chaplain Services:

- Assesses and supports the patient’s faith and unique spiritual and cultural beliefs (identifies what gives them hope)
- Provides religious materials when needed/requested
- Solicits/Secures the assistance of community spiritual leaders of a patient’s particular spiritual/religious practice
- Maintains the psycho-spiritual dignity of the patient
- Provides interventions for specific symptom relief from spiritual pain (e.g., guilt, anxiety, anger, loss, and aloneness)
- Assists staff in locating a patient’s family/next of kin
- Assists patients with visiting forms (CDCR 106), letters, cards when needed/requested
- Supports/facilitates the patient’s decision to create a living legacy or life review
- Prepares the patient and their family for reconciliation and restoration when needed/requested
- Provides supervised phone calls with families and patients
- Provides a safe environment for a patient to explore and grow in their chosen faith
- Consults and collaborates with the interdisciplinary team
- Provides grief and bereavement follow-up as needed
- Assesses patient satisfaction of the psycho-spiritual care and support
- Provides a follow-up bereavement letter to the family of the deceased, including a patient family satisfaction sheet (gives the family a voice and helps the program make positive adjustments if needed)

Cultural Aspects of Care

Culture plays a significant role in shaping the way people make meaning of illness, suffering, and dying.

- Culture helps guide decisions about what kind of care a patient chooses to receive, who it should be provided by, and under what conditions.
- Cultural aspects of care may include language (interpreters), values, rituals, and dietary needs.
- In order to provide the best possible care to patients in end of life situations, it is important to understand their cultural constructs as well as their individual preferences.
- There are multiple language versions of the POLST and AD on Lifeline under Medical Services > Medical Forms > Forms. It is very important for a patient to sign a POLST and/or AD in both an English version as well as a version in their primary language to ensure personnel can interpret the patient’s wishes.

It is also important to remember that each provider brings their own set of biases to these discussions based on their own cultural and religious background and personal experiences. The CDCR Approved Inmate Religious Vendors list can be used to identify allowable religious items.
ASSESSMENT OF PALLIATIVE CARE NEEDS (continued)

Physical Aspects of Care

Common physical symptoms of patients receiving palliative care include, but are not limited to: pain, anorexia/cachexia, dyspnea, excess secretions, fatigue, agitation, nausea and vomiting, cough, hiccups, ascites/pleural effusions, skin breakdown, pruritus, sleep disturbances, and bladder/bowel control issues. Some of the most common symptoms are described below. A list of commonly used medications for palliative care that are on the CCHCS formulary are listed on page 13. Additional support for managing complex physical symptoms can be obtained at: CCHSPainManagement@cdcr.ca.gov.

PAIN

Pain can be one of the most prevalent symptoms near the end-of-life. Unrelieved pain can be a source of great distress for patients and may exacerbate other symptoms. Therefore, the adequate management of pain at the end of life is imperative. See CCHCS Pain Management Guidelines for additional information. General principles include the application of non-pharmacologic therapies; consider radiotherapy for bone pain and tumor infiltration; physical therapy, braces, and support items when needed; and the role of relaxation, distraction; and other coping strategies. The emphasis is on reducing suffering and optimizing quality of life during the dying process.

Consider multiple underlying etiologies for pain:
- Tumor infiltration
- Nerve compression
- Skin breakdown
- Other comorbid conditions such as arthritis

Depending on the setting of care, aggressive analgesic delivery can be achieved. See CCHCS Pain Management Guidelines Part 3 Opioid Therapy.

Tips:
- Consider breakthrough pain dosing using Immediate Release (IR) medications and more frequent dosing as setting permits.
- Transition to Sustained Release (SR) medications once a baseline analgesia requirement is determined.
- Use the oral route wherever possible.
- Avoid polypharmacy where possible to minimize adverse effects.
- Opioid rotation may be helpful if tolerance develops, there is poor response, or in cases of toxicity.
- Consultation with a pain management specialist and/or pharmacist may be useful (especially with converting to Methadone).

STOMATITIS (inflammation and/or ulceration of the oral mucosa)

Commonly caused by chemo or radiation therapy, other causes may include poor dental hygiene, infection, poorly fitting dentures, and blood dyscrasias. Treatment generally includes the use of opioid analgesics and attention to regular mouth care.

Tips:
- Magic mouthwash which contains Maalox and viscous lidocaine can offer relief.
- Avoid any mouthwashes or rinses that contain alcohol.
- Alternative nutritional support may need to be considered.
- Limit use of petroleum based products to prevent lip cracking.
- Patients on immunosuppressive drugs should be examined regularly for thrush.
- Treat evident candidiasis or thrush with Nystatin or Fluconazole.

EXCESS SECRETIONS

Either as a result of avoiding painful swallowing (which occurs with severe stomatitis), dysphagia (caused by other conditions such as stroke, head injury, dementia), or oral/esophageal cancers, managing excess secretions may become necessary.

Tips:
- Positioning the patient on their side or semi-prone can facilitate postural drainage.
- Gentle periodic suctioning can be useful when available.
- Opioids may mitigate excess secretions.
- Addition of an anti-sialogogue (i.e., atropine, amitriptyline) may be needed.

ANOREXIA / CACHEXIA

Loss of appetite and lean body mass can be due to a variety of metabolic, neuroendocrine, and/or immunologic abnormalities induced by tumor, catabolic states, or prolonged inactivity. Minimizing dietary and consistency restrictions may facilitate improved intake. There are generally limited roles for nutritional supplements and parenteral hydration at end of life. Appetite stimulants such as megace, mirtazapine, or decadron, may be considered.
## ASSESSMENT OF PALLIATIVE CARE NEEDS (continued)

### Physical Aspects of Care (continued)

#### COUGH / HICCUPS

Often caused by irritation of the airway or other structures (such as the pleura, pericardium, diaphragm) triggering the cough reflex such as that created by tumor infiltration, infection, pulmonary edema, gastroesophageal reflux disease (GERD)/aspiration, post-nasal drip, or chronic obstructive pulmonary disease (COPD).

**Tips:**
- Depending on the underlying cause, positioning or chest physiotherapy may be useful.
- Opioids may suppress cough; Dextromethorphan may have a synergistic effect.
- Chlorpromazine can help with intractable hiccups.
- Haloperidol and metoclopramide have been used successfully.
- Anticonvulsant agents (e.g., phenytoin, valproic acid, and carbamazepine) have effectively treated intractable hiccups.

#### DYSPNEA

Subjective air hunger that may or may not be accompanied by hypoxia.

**Tips:**
- First rule out/rectify contributors such as airway obstruction, interrupted oxygen source, or bronchospasm.
- Positioning more upright and increasing air movement (fan, open window, blow-by oxygen) can be helpful.
- Offer supportive reassurance.
- Opioids can effectively relieve the discomfort of air hunger.
- Anxiolytics may be useful if there is a severe anxiety component.

#### FATIGUE

Most patients living with a terminal illness will experience fatigue at some point. Fatigue can be upsetting and frustrating for patients so they should be specifically asked about it to encourage open discussions about its impact and acknowledge fatigue as a common experience.

**Tips:**
- Treat reversible causes when feasible
- Conserving energy
- Keeping active
- Use good pacing techniques

#### DEPRESSION / GRIEF

Psychological distress is common in terminally ill persons and can be a source of great suffering. Grief is an adaptive, universal, and highly personalized response to the multiple losses that occur at the end of life. This response may be intense early on after a loss manifesting itself physically, emotionally, cognitively, behaviorally, and/or spiritually; however, the impact of grief on daily life generally decreases with time.

**Tips:**
- Pharmacologic interventions are not warranted for uncomplicated grief.
- Support patients by acknowledging their grief and encouraging the open expression of emotions.
- Feelings of pervasive hopelessness, helplessness, worthlessness, guilt, lack of pleasure, and suicidal ideation are present in patients with depression, but not in those experiencing grief; if these symptoms are present, consult MH.
- Antidepressant medications can be administered to improve symptoms of depression in patients with life-limiting illnesses.

#### SKIN CARE

Skin may become mottled or discolored near the end of life. Patches of purplish or dark pinkish color can be noted on the back and posterior arms/legs. See the CCHCS Wound Care Guide for guidance. Goals of wound care for Stage III and IV decubiti should be to promote comfort and prevent worsening rather than healing since healing most likely will not occur. Consider application of specialized products such as charcoal or metronidazole paste (compounded) if odors are present.

**Tips:**
- Keep sheets clean and dry.
- Apply lotion as tolerated.
- Decubitus ulcers may develop from pressure of being bedbound and/or decreased nutritional status.
- Red spots to bony prominences are first signs of Stage I decubiti and open sores may develop.
- Relieve pressure to bony prominences or other areas of breakdown with turning, positioning, and cushioning as tolerated.
- Use Duoderm or specialized skin dressings as needed.
### ASSESSMENT OF PALLIATIVE CARE NEEDS (continued)

#### Physical Aspects of Care (continued)

#### PRURITUS

Pruritus (itching) is a common and often distressing symptom near the end of life. Pruritus can be described as an unpleasant sensation of the skin or mucous membranes that provokes the desire to scratch or rub. The pathophysiology of pruritus is important and guides effective therapeutic choices.

**Tips:**
- Histamine release does not play a meaningful role in the pruritus typically observed in palliative patients; therefore, antihistamines are not usually beneficial.
- Emollients should be considered, as dry skin is often an exacerbating factor for most palliative patients with pruritus.
- Consider treating pruritus secondary to uremia, cholestasis, or malignancy with paroxetine or mirtazapine.
- In certain cases, stenting for biliary obstruction is an effective non-pharmacologic treatment that often obviates pharmacotherapy, eliminating potentially adverse side effects.

#### SLEEP DISTURBANCES

Insomnia affects a majority of palliative care patients and evaluation should start with factors that may be contributing and potentially addressed. There is no single pharmacologic approach that can be recommended for all patients and the lowest effective dose should be administered. As with most drugs, patients in palliative care must be carefully and continually monitored for both positive effect and the development of adverse effects, particularly as the patient’s disease progresses.

**Tips:**
- Addressing factors such as room temperature, ventilation, lighting, and limiting other stimuli may be useful.
- Reducing or avoiding daytime naps, large meals before bedtime, large fluid intake in the evening, or use of stimulants.
- Increasing daytime light exposure and activity levels when possible.
- Behavioral therapies should be tried initially because they avoid the potential risks associated with medications.
- Patients may be more susceptible to adverse effects of pharmacotherapy due to the presence of end-organ impairment.
- Consult MH for consideration of pharmacotherapy.

#### EDEMA/ASCITES/PLEURAL EFFUSIONS

Fluid volume, pressure, and levels of sodium and albumin are the keys to maintaining fluid balance between the intracellular and extracellular spaces. As metabolic imbalances set in at the end of life and serum protein levels decline, capillary permeability and lymphatic congestion increase, and fluid begins to shift from the intravascular space to the interstitial space. Further, as the heart gets weak and kidney filtration reduces, fluids move from the intravascular space into the surrounding tissues. This causes edematous extremities, asities, and/or pulmonary edema.

**Tips:**
- Diuretics generally do not have a role here.
- It is generally futile and unrealistic to try to fix this problem.
- Decrease fluid intake and offer a wet cloth to have the patient suck on and moisten the mouth; this reduces the sensation of thirst without adding more water to the edema, or body swelling.

#### BLADDER CONTROL

Numerous factors may contribute to urinary incontinence at the end of life including, but not limited to, neurological problems, cognitive impairment, metastatic disease of the spine or pelvis, stroke, and drug toxicities. Urinary incontinence can be deeply distressing so its assessment and symptomatic management should be as important as that of all other end-of-life symptoms.

**Tips:**
- Ensuring a person has a regular toilet or pad regimen will help to promote comfort and dignity.
- A commode near the bed, bedpan, or urinal can facilitate continence until very close to the end of life.
- Incontinence pads may be the least invasive option.
- Indwelling catheters are a suitable option to improve skin care or to reduce movement and suffering.
- The choice of catheterization is generally based on the estimated time it will be in place and patient preference.
- Catheter management at the end-of-life requires attention to comfort, infection prevention, and dignity.
- Skin care is part of continence management in the frail and immobile.
- Barrier creams, repositioning, and constant reevaluation are key to preventing pressure ulcers and further discomfort.
ASSESSMENT OF PALLIATIVE CARE NEEDS (continued)

Physical Aspects of Care (continued)

NAUSEA / VOMITING

It is helpful to determine the underlying etiology of nausea which can be caused by a multitude of possibly overlapping factors:

- Intermittent nausea associated with early satiety and postprandial fullness or bloating:
  - Nausea is relieved by vomiting that is usually small volume, occasionally forceful, and may contain food.
  - This clinical picture suggests impaired gastric emptying.
  - This is the cause in 35%–45% of cases of nausea and vomiting.

- Persistent nausea, aggravated by the sight and smell of food, unrelied by vomiting:
  - This suggests chemical causes, activating the chemoreceptor trigger zone.
  - It is found in 30%–40% of cases.

- Intermittent nausea associated with abdominal cramps and altered bowel habit:
  - The nausea is relieved by vomiting that may become large in volume and bilious or feculent.
  - This suggests a bowel obstruction and is the cause in 10%–30% of cases.

The variety of drug classes utilized in management of nausea reflects the complex pathophysiology:

- **Prokinetics**
  - Metoclopramide, Mirtazapine

- **Dopamine Antagonists**
  - Prochlorperazine, Chlorpromazine, Haldol

- **Antihistamines**
  - Meclizine, Hydroxyzine, Diphenhydramine, Promethazine

- **5-HT3 Antagonists**
  - Odansetron

- **Other**
  - Benzodiazepines (Lorazepam)
  - Corticosteroids (Dexamethasone)
  - Octreotide

Tips:
- In the setting of delayed gastric emptying, prokinetics are agents of first choice.
- Antihistamines, Dopamine Antagonists, and 5-HT3 antagonists are often first-line agents used for persistent nausea.
- Combination therapy (agents from different classes) is often needed to manage persistent nausea.
- Benzodiazepines are best suited for the anticipatory component of post-operative or chemotherapy-induced nausea.
- Corticosteroids and Octreotide are useful in malignant bowel obstruction.
- Chronic symptoms are challenging and the central pathways are very close to chronic neuropathic pain. Thus, similar therapeutic options may be utilized including low dose tricyclic antidepressants.

BOWEL CARE

Attention to maintaining bowel function is important in palliative care. Opioids and anticholinergic agents commonly used in palliating other symptoms, as noted above, can aggravate the development of constipation in patients already at risk because of poor oral intake, dehydration, and decreased mobility.

Whenever starting an opioid agent, simultaneously initiating a regularly administered bowel stimulant such as senna can help to prevent significant constipation and or bowel obstruction. Attention to maintaining bowel function, especially when using opioids, is a crucial aspect of care.

Tips:
- Dosage adjustments and additional adjuvants such as Colace, Bisacodyl, Lactulose, or Milk of Magnesia should be utilized as needed to assure the patient has a reasonably soft and formed bowel movement every 1-2 days.
- If there is no bowel movement in 3 days, the use of an enema or Magnesium Citrate may be needed. Once a response is achieved, additional daily bowel regimen dose adjustments will be necessary in order to maintain regular bowel activity.
- Different agents (softeners, stimulants, osmotic, and lubricant laxatives) can play a useful and potentially synergistic role.
- Bulk-forming (fiber) laxatives (FiberCon, Citrucel, Metamucil) have little role in palliative care and should be avoided.
- Enemas to facilitate a bowel movement come in various formulations from plain water, to solutions containing osmotic agents, such as sodium chloride or baking soda, that help draw water out of the bloodstream back into the colon, to solutions with a lubricant such as mineral oil or a cleansing agent, such as soap. The liquid solution softens the stool and make it easier to pass. When possible, use the least invasive combination of oral agents, diet and mobility first.
- Symptomatic care for concerning bowel obstruction may include one or more of the following: glucocorticoids, octreotide, anticholinergics, and/or analgesics, with or without gastrointestinal (GI) decompression.
<table>
<thead>
<tr>
<th>Medication</th>
<th>Formulations</th>
<th>Palliative Care Indication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetaminophen</td>
<td>325 mg tablets; Rectal suppository 650 mg</td>
<td>Pain — mild to moderate</td>
</tr>
<tr>
<td>Acetaminophen/Codeine</td>
<td>30/300 mg tabs; Elixir 12/120/5ml</td>
<td>Pain — mild to moderate</td>
</tr>
<tr>
<td>Amitriptyline</td>
<td>10 mg, 25 mg tablets</td>
<td>Neuropathic pain, bladder spasm, excess secretions</td>
</tr>
<tr>
<td>Atropine</td>
<td>Injectable: 0.1 mg/ml; Ophthalmic solution: 1%</td>
<td>Excess secretions (apply 1-2 gtts ophthalmic solution under tongue)</td>
</tr>
<tr>
<td>Bisacodyl (e.g. Dulcolax)</td>
<td>5 mg tablets; 10 mg rectal suppositories</td>
<td>Stimulant laxative</td>
</tr>
<tr>
<td>Chlorpromazine</td>
<td>10, 25, 50,100, and 200 mg tablets; Injectable: 25 mg/ml</td>
<td>Intractable hiccups</td>
</tr>
<tr>
<td>Citalopram</td>
<td>10 , 20, 40 mg tablets</td>
<td>Depression</td>
</tr>
<tr>
<td>Dexamethasone</td>
<td>0.5, 0.75, 4, 6 mg tabs; Injectable:4 mg/ml</td>
<td>Anorexia, nausea/vomiting</td>
</tr>
<tr>
<td>Diphenhydramine</td>
<td>Injectable 50 mg/ml (all other forms non-formulary/restricted)</td>
<td>Nausea/vomiting, itching, anaphylaxis</td>
</tr>
<tr>
<td>Docusate Sodium</td>
<td>100 mg capsule</td>
<td>Stool softener</td>
</tr>
<tr>
<td>Duloxetine</td>
<td>20, 30, 60 mg capsules</td>
<td>Neuropathic pain</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>0.5, 1, 2, 5, 10, 20 mg tabs; Oral Soln: 2 mg/ml; Inj: 5mg/ml</td>
<td>Delirium, terminal restlessness</td>
</tr>
<tr>
<td>Ibuprofen</td>
<td>200, 400, 600, mg tablets; Suspension 100mg/5 ml</td>
<td>Pain — mild to moderate</td>
</tr>
<tr>
<td>Lactulose</td>
<td>Oral Solution: 10 gm/15 ml - 473 ml</td>
<td>Osmotic laxative</td>
</tr>
<tr>
<td>Loperamide</td>
<td>2 mg tablets</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>Lorazepam</td>
<td>1 mg tablets; Injectable 2 mg/ml</td>
<td>Anxiety, insomnia, nausea</td>
</tr>
<tr>
<td>Magic Mouthwash</td>
<td>Maalox 60 ml + viscous lidocaine 2% 30 ml</td>
<td>Stomatitis</td>
</tr>
<tr>
<td>Magnesium Citrate</td>
<td>300 ml oral solution</td>
<td>Osmotic laxative</td>
</tr>
<tr>
<td>Magnesium Hydroxide</td>
<td>400 mg/5 ml, 1200 mg/5 ml oral solution</td>
<td>Osmotic laxative, constipation, indigestion</td>
</tr>
<tr>
<td>Meclizine</td>
<td>25 mg tablet</td>
<td>Antiemetic</td>
</tr>
<tr>
<td>Megestrol Acetate (e.g. Megace)</td>
<td>20, 40 mg tablets; Oral Soln: 40 mg/ml</td>
<td>Anorexia; caution: thromboembolism</td>
</tr>
<tr>
<td>Methadone</td>
<td>5, 10 mg tablets</td>
<td>Pain — moderate to severe</td>
</tr>
<tr>
<td>Metoclopramide</td>
<td>5, 10 mg tablets; Injectable 10 mg/2 ml</td>
<td>Prokinetic — nausea/vomiting</td>
</tr>
<tr>
<td>Mirtazapine</td>
<td>7.5 mg, 15 mg, 30 mg, 45 mg tablet</td>
<td>Depression, anorexia, insomnia, nausea, itching</td>
</tr>
<tr>
<td>Morphine</td>
<td>IR: 15, 30 mg tabs; SR: 15, 30, 60 mg tabs; Soln: 10mg/5ml; Inj: 10mg/ml</td>
<td>Pain — moderate to severe; dyspnea</td>
</tr>
<tr>
<td>Odansetron</td>
<td>4 mg, 8 mg Orally Dissolving Tablet</td>
<td>Antiemetic</td>
</tr>
<tr>
<td>Octreotide</td>
<td>100 mcg/ml Subcutaneous Soln; 10 mg Long-acting depot IM</td>
<td>Malignant bowel obstruction</td>
</tr>
<tr>
<td>Prochlorperazine</td>
<td>5, 10 mg tablets; Injectable 5 mg/ml</td>
<td>Nausea/vomiting</td>
</tr>
<tr>
<td>Promethazine</td>
<td>25 mg tablets; Injectable 50 mg/ml</td>
<td>Nausea/vomiting</td>
</tr>
<tr>
<td>Sennosides (e.g. Senna)</td>
<td>8.6 mg tablets</td>
<td>Stimulant laxative/constipation</td>
</tr>
<tr>
<td>Sennosides/Docusate</td>
<td>8.6 mg/docusate 50 mg tablets</td>
<td>Stimulant laxative/constipation</td>
</tr>
<tr>
<td>Sodium Phosphate (FLEET enema)</td>
<td>Rectal solution: 118 ml</td>
<td>Additional doses not recommended within 24 hours</td>
</tr>
</tbody>
</table>
Unless a patient with a terminal or significantly incapacitating illness is either serving a sentence of life without parole or is condemned (sentenced to death), consider the need to initiate an application for compassionate release or expanded medical parole. The differences between each of these programs are outlined below:

### Compassionate Release

#### Title 15
- Terminally ill with an incurable condition that is expected to cause death within 6 months
- Permanently medically incapacitated with a condition that renders him/her permanently unable to perform activities of basic daily living, and results in the patient requiring 24-hour total care including, but not limited to, coma, persistent vegetative state, brain death, ventilator dependency, loss of control of muscular or neurological function, and the incapacitation from the terminal illness did not exist at the time of the original sentencing

#### Parole Status
- Recalls original sentence, meaning patient will not be returned to custody if condition improves
- Ultimate determination made by the Board of Parole Hearings (BPH) for indeterminate cases, and a judge makes the determination for determinate cases

#### Monitoring Release
- Released as free citizen

#### Payment
- Family, self, insurance plan, or county aid (if qualifies)

### Expanded Medical Parole

#### CDCR Expanded Medical Parole Program Guide
- Suffers from a significant and permanent condition, disease, or syndrome resulting in the patient being physically or cognitively debilitated or incapacitated
- Patient qualifies for placement in a licensed health care facility, as determined by the Resource Utilization Group Assessment form (RUG IV)

#### Parole Status
- Original sentence cannot be recalled
- Conditions set by Division of Adult Parole Operations (DAPO) and/or Board of Parole Hearings. May include electronic monitoring
- Medical parole voided if the patient recovers
- Returned to prison unless the parole date is reached

#### Monitoring Release
- DAPO and CCHCS (for medical condition improvements)

#### Payment
- Medi-Cal or Medicare if qualifies; CDCR will make the hospital provider whole

### Compassionate Release Application Process - See the Compassionate Release Flowchart

#### California Correctional Health Care Services - CCHCS

A) A Primary Care Provider (PCP) completes the CDC 128-C, Medical Chrono and submits it to the institution Chief Medical Executive (CME) for review/signature.

B) The CME and Deputy Medical Executive shall have five working days to review and sign the CDC 128-C, approving the PCP’s prognosis. The signed CDC 128-C shall be submitted to the Classification and Parole Representative (C&PR).

#### Classification and Parole Representative (C&PR)

A) The C&PR shall review the CDC 128-C and the inmate’s central file.
   1) If the inmate is not sentenced to death or to life without possibility of parole, health care staff shall explain the recall of commitment process to the inmate within 48 hours of notification and arrange for the inmate to designate a family member or other outside agent on the CDCR 7385, Authorization for Release of Protected Health Information, which is incorporated by reference. The inmate’s designee shall be informed about the recall of commitment process and the patient’s medical condition. The C&PR shall submit the CDC 128-C to the inmate’s Correctional Counselor (CC I).

B) The CC I shall have five working days to prepare the Diagnostic Study and Evaluation Report.

C) The C&PR shall review the Diagnostic Study and Evaluation Report and forward the evaluation report to the Warden or Chief Deputy Warden within three working days.

D) The Warden or Chief Deputy Warden shall review and sign the evaluation report and ensure it is forwarded to the Classification Services Unit (CSU) within three working days.
Let's break down the text into more digestible pieces:

### COMPASSIONATE RELEASE VS. EXPANDED MEDICAL PAROLE

**Compassionate Release (continued)**

**Classification Services Unit (CSU)**

- A) The CSU reviews case for statutory requirements.
- B) The CSU completes evaluation report and packet goes to the CSU Chief for review and recommendation.
- C) The packet goes to the Statewide Deputy Director for recommendation and signature.
- D) The CSU forwards to the Undersecretary for review and consideration.
  1. If a positive recommendation for recall is made, and the inmate is sentenced to a determinate term, the recommendation shall be referred directly to the sentencing court and shall include one or more medical evaluations, the findings of which must determine the inmate meets the criteria set forth in PC section 1170(e)(2), and a post-release plan.
  2. If the inmate is sentenced to an indeterminate term, the Undersecretary or designee's recommendation, whether positive or negative, shall be referred to the Board of Parole Hearings for review and consideration.
- E) Pursuant to PC section 1170(e)(9), if the sentencing court grants the recall and resentencing application, the inmate shall be released by the Department within 48 hours of receipt of the court's order unless a longer time period is agreed to by the inmate or ordered by the court. If the inmate has agreed to waive the 48-hour release requirement, the Department shall request the sentencing court include in its order that the inmate shall be released within 30 calendar days to allow for the coordination of his or her housing and medical needs in the community to a location where access to care is available.
- F) If the Division of Adult Parole Operations (DAPO) is coordinating the inmate's placement within the community, the C&PR shall provide a copy of the release order to DAPO upon receipt from the sentencing court.
- G) At the time of release, health care staff shall ensure the inmate has each of the following in his or her possession; a discharge medical summary, full medical records, state identification, parole medication, and all property belonging to the inmate. After discharge, any additional records shall be sent to the inmate's forwarding address.

### Determinate vs. Indeterminate Sentencing:

The difference between determinate sentencing and indeterminate sentencing lies in whether the court has any flexibility in assigning a sentence.

- **Determinate sentencing** is the process by which a judge sentences an offender to a specific amount of time in prison or jail, the judge does not have authority to alter the sentence.
- **Indeterminate sentencing**, however, is the more common method of sentencing. This is the process by which an offender is sentenced to a range of time in custody e.g., five years to life.

**All Compassionate Release forms can be found under the End-of-life Planning and Treatment heading in the Provider Resource Library.**

### Expanded Medical Parole Application Process - See EMP Flowchart

**California Correctional Health Care Services - CCHCS**

- A) The Primary Care Physician (PCP) completes the **RUG IV**, and sections 1 - 4 on page 1 and the top of page 2 (Inmate’s Name and CDCR Number) of the CDCR 7478-EMP, (Expanded Medical Parole) form.
- B) A **CDCR 7385-MP**, Medical Parole Authorization for Release of Information, must be filled out by the patient or the patient’s designee (surrogate medical decision-maker) if they are able to provide consent to release the patient’s medical information. If the patient/designee is unable to provide consent to release patient’s medical information, the corresponding box shall be marked in Section 4 of the CDCR 7478-EMP form.
- C) The PCP signs the CDCR 7478-EMP and forwards the original form to the institution’s Chief Medical Executive (CME), and a copy of all paperwork to the Utilization Management (UM) mailbox at MedicalParole@cdcr.ca.gov. The CME shall have three working days to review the CDCR 7478-EMP form and determine if the patient is eligible.

**The PCPs are reminded the CDCR 7478-EMP is for use in the EMP review process by non-health care personnel. Terms used to describe the inmate’s medical condition should be easily understood by non-health care personnel.**

**Classification and Parole Representative (C&PR)**

- A) Upon receipt of the RUG IV, CDCR 7478-EMP, and CDCR 7385-MP (if applicable) from the CME, the C&PR shall have three working days to review the forms and the inmate’s case factors to ensure the inmate meets the custody requirements of the EMP Program.
- B) C&PR completes and signs page 2, section 5 of CDCR-EMP. Within three working days, the C&PR shall ensure a copy of the CDCR 7478-EMP is forwarded to the inmate’s CC I (Correctional Counselor) to request that the CC I prepare the Expanded Medical Parole Evaluation Report.
Expanded Medical Parole (continued)

Correctional Counselor (CC I)

A) Upon direction from the C&PR or his/her supervisor, the CC I shall prepare an EMP Evaluation Report (Example of EMP Evaluation Report) within five working days. The CC I will also complete a CDCR 611, Release Program Study and will submit both the EMP Evaluation Report and the CDCR 611 to the C&PR for review.

B) The C&PR shall have three working days to review and forward the EMP Packet (see below) to the Warden or Chief Deputy Warden for signature. The Warden or Chief Deputy Warden shall review and sign the EMP Evaluation Report and will ensure the EMP Packet is forwarded to the CSU within three working days, with a copy of all paperwork sent to the UM mailbox at MedicalParole@cdcr.ca.gov.

Classification Services Unit (CSU)

A) Upon receipt of the EMP Packet from the institution, the CSU shall have three working days to ensure the packet is complete and contains the documentation required by the Board of Parole Hearings (BPH) to process the case. The CSU will obtain the supporting documentation noted below as a. through f., in the patient’s Electronic Records Management System (ERMS) to complete the EMP packet. The CSU must ensure all forms are complete and appropriately signed and send the EMP packet to the BPH.

The complete Expanded Medical Parole Packet consists of the following documents:

1. Expanded Medical Parole Evaluation Report
   a. Abstract of Judgement (AOJ)
   b. Probation Officer’s Report (POR)
   c. Legal Status Summary (LSS)
   d. Institutional Staff Recommendation Summary (ISRS)
   e. Criminal Identification and Information Number issued by the California Department of Justice, Bureau of Identification
   f. Most recent CDC Form 128-G, Classification Chrono, with the inmate’s full case factors.

2.) CDCR 7478-EMP
3.) CDCR 7478-A, Expanded Medical Parole Form Addendum (if provided by DAPO or the UM Unit)
4.) CDCR 7385-MP (included only if the inmate or inmate’s surrogate medical decision-maker was able to provide consent for the release of the inmate’s medical information)
5.) CDCR 611, Release Program Study
6.) RUG IV Form

Board of Parole Hearings (BPH)

A) Upon receipt of the EMP Packet from the CSU, the BPH shall confirm the packet is complete. If the packet is complete, the BPH will schedule the inmate for an Expanded Medical Parole Hearing within three working days.

B) The BPH shall be responsible for notifying any registered victims of the inmate’s hearing 90 days in advance, as well as the District Attorney (DA) of the inmate’s county of commitment at least 30 days in advance.

C) The BPH shall be responsible for compiling and distributing hearing packet documents to the hearing panel, DA, and the inmate’s attorney.

D) The BPH shall notify the Case Records Unit and the CSU of the scheduled EMP hearing date within five working days.

Notification of BPH Decision

A) The BPH shall provide a copy of its proposed decision to the inmate’s institution, UM, CSU, and DAPO within 10 working days of the hearing.

B) If approved for medical placement, the proposed decision shall include any facility requirements and inmate restrictions imposed by the BPH. The proposed decision shall become invalid if an appropriate medical facility is not verified by DAPO within 120 days of the hearing. Notification that an appropriate medical facility has been verified by DAPO shall be submitted by DAPO to the BPH via a CDCR 7478-EMP, indicating the placement has been approved. The CDCR 7478-EMP shall be submitted via electronic mail to the BPH at BPHMedicalParole@cdcr.ca.gov.

All Expanded Medical Parole forms can be found under the End-of-life Planning and Treatment heading in the Provider Resource Library.
HOSPICE SERVICES

Hospice care is a type of palliative care which involves a multidisciplinary team of providers, nurses, chaplains, social workers and others who work to address all of the patient’s needs within the six domains. A patient does NOT need to be in an “official” hospice unit to receive palliative care. That said, many hospice units are set up to offer focused end-of-life care as their primary mission.

MEN - California Medical Facility (CMF) - Vacaville

The nation’s first licensed prison hospice is located within CMF and has a 17-bed unit that uses an interdisciplinary team approach in care planning and delivery. This closed unit attempts to maintain a “homelike” inpatient setting within the prison. Hospice services available as follows:

- An interdisciplinary team who specializes in end-of-life care
- Spiritual support services and access to the pastoral care services workers (inmate caregiver supports)
- Assistance in locating and contacting family
- A relaxed and open four-day weekly visiting policy (children can visit in a supportive environment)
- Friends from the mainline may visit (if cleared by custody)
- A decrease in unnecessary/futile hospitalizations
- Timely submission of compassionate release and medical parole application processes.

Admission Criteria:

- Documented clinical progression of disease and prognosis for imminent death within six months.
- Custody review (some custody levels require housing in single cell only and single rooms are limited).
- POLST completed; DNR recommended, but not required.
- Advance Directive; recommended, but not required.

Referral Process

- **Hospice Admission Forms** - Documentation can be compiled from EHRS or any available source to include with referral submission.
- Sometimes there is a waiting list for admission, but this varies and providers are encouraged to communicate with CMF if they have an urgent referral.

WOMEN - California Institution for Women (CIW) AND Central California Women’s Facility (CCWF)

CIW and CCWF offer palliative care/hospice type services within their Outpatient Housing Unit (OHU) and Correctional Treatment Center (CTC) - (CIW) and Skilled Nursing Facility (SNF) - (CCWF) settings. All settings offer 24-hour nursing care, assistance with activities of daily living (ADLs) and other services as outlined in the Specialized Housing Policy. Both institutions have onsite physical therapy, registered dieticians, and recreation therapy services.

CIW offers a Compassionate Companions Program (CCP) and CCWF offers a Comfort Care Program. Both of these programs involve trained inmate volunteers who provide support to patients dealing with the effects of a terminal illness. These inmate volunteers can be present at the patient’s bedside in designated settings offering support by way of letter writing, reading to the patient, basic grooming, and at the end of life may be present for a bedside vigil to ensure no one dies alone should the patient choose to accept the services.

Patients housed in the CTC at CIW, or in the SNF at CCWF who are too ill to facilitate a visit in the designated visiting area may, with Warden approval, have authorized family/friend visitation at the bedside within the CTC or SNF.

Admission Criteria:

- The patient has a prognosis of ≤ six months if the disease follows its expected course (referring provider identifies patient and CIW/CCWF leadership/Palliative Care staff concur).
- The patient and/or designated legal representative request & agree to the palliative/comfort care goals and philosophy.
- The patient requires assistance with ADLs and/or skilled nursing care at a level that is appropriate for the specific unit.
- POLST/Advance Directive completed; DNR recommended, but not required.

Referral Process

- Providers with patients meeting admission criteria should contact the Chief Medical Executive at CIW or CCWF.
The validated tools below (and attached) can be used as general or disease-specific prognostic tools to help assess a patient and help begin some estimate of prognosis based on the stage of the illness and the patient’s overall condition.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Prognostic Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>Karnofsky or Palliative Performance Scale (PPS)</td>
</tr>
<tr>
<td></td>
<td>(See Attachment A)</td>
</tr>
<tr>
<td>Dementia</td>
<td>Functional Assessment Staging (FAST)</td>
</tr>
<tr>
<td></td>
<td>(See Attachment B)</td>
</tr>
<tr>
<td>Cancer</td>
<td>Eastern Cooperative Oncology Group (ECOG)</td>
</tr>
<tr>
<td></td>
<td>(See Attachment C)</td>
</tr>
<tr>
<td>Heart Failure</td>
<td>New York Heart Association (NYHA)</td>
</tr>
<tr>
<td></td>
<td>(See Attachment D)</td>
</tr>
<tr>
<td>Liver</td>
<td>Child-Pugh and Model for End-Stage Liver Disease</td>
</tr>
<tr>
<td></td>
<td>(MELD) (See Attachment E)</td>
</tr>
</tbody>
</table>

REFERENCES

2. LeBlanc TW, Tulsdy MD. Discussing Goals of Care-UpToDate [Internet]. Available from: https://www.uptodate.com/contents/discussing-goals-of-care
It’s never easy to think about dying, but doing so now will help to decide what you would like to have happen at the end of your life; then you can tell your family and health care team your wishes. What you may want at the end of your life may be very different from someone else. What is important to each person is different.

- For some people, the main goal is to be kept alive as long as possible, even if they have to be kept alive on machines and are suffering.
- For other people, the main goal is to focus on their quality of life and being comfortable, meaning they would prefer a natural death and not to be kept alive on machines.
- Other people are somewhere in between.

Answering the questions below can help you think about the care you would like at the end of your life. It is a good way to tell your wishes to your health care team.

### I have a family member or friend that can make medical decisions for me if I become too sick to make my own medical decisions:

<table>
<thead>
<tr>
<th>Yes</th>
<th>Name</th>
<th>Phone</th>
<th>Address</th>
<th>No</th>
</tr>
</thead>
</table>

### As I become sicker, I would like to:

- Receive all treatments necessary even though it might cause me to be in pain or uncomfortable.
- Be as comfortable as possible, even though I might not live as long.

<table>
<thead>
<tr>
<th>Specific treatments that might keep me alive longer are listed below. I want the following treatments even if it causes pain/discomfort (See PE-1 - Life Sustaining Treatments)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing Machine (You can’t breathe on your own):</td>
</tr>
<tr>
<td>CPR (Your heart stops beating):</td>
</tr>
<tr>
<td>Dialysis (Your kidneys are no longer working):</td>
</tr>
<tr>
<td>Feeding Tube (You can’t eat on your own):</td>
</tr>
</tbody>
</table>

### The following is important to me:

| Being able to recognize my family and friends: | Yes | Unsure | No |
| Not being in constant pain and/or discomfort: | Yes | Unsure | No |
| Being able to make my own medical decisions: | Yes | Unsure | No |

### How important is spirituality or religion to you?

<table>
<thead>
<tr>
<th>I am very religious and/or spiritual</th>
<th>Unsure</th>
<th>I am not religious and/or spiritual</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want to speak to a Chaplain/Spiritual Leader:</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
### GENERAL—Karnofsky Performance Status Scale Definitions Rating

<table>
<thead>
<tr>
<th>Rating (%)</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Normal no complaints; no evidence of disease.</td>
</tr>
<tr>
<td>90</td>
<td>Able to carry on normal activity; minor signs or symptoms of disease.</td>
</tr>
<tr>
<td>80</td>
<td>Normal activity with effort; some signs or symptoms of disease.</td>
</tr>
<tr>
<td>70</td>
<td>Cares for self; unable to carry on normal activity or to do active work.</td>
</tr>
<tr>
<td>60</td>
<td>Requires occasional assistance, but is able to care for most of his personal needs.</td>
</tr>
<tr>
<td>50</td>
<td>Requires considerable assistance and frequent medical care.</td>
</tr>
<tr>
<td>40</td>
<td>Disabled; requires special care and assistance.</td>
</tr>
<tr>
<td>30</td>
<td>Severely disabled; hospital admission is indicated but death not imminent.</td>
</tr>
<tr>
<td>20</td>
<td>Very sick; hospital admission necessary; active supportive treatment necessary.</td>
</tr>
<tr>
<td>10</td>
<td>Moribund; fatal processes progressing rapidly.</td>
</tr>
<tr>
<td>0</td>
<td>Dead</td>
</tr>
</tbody>
</table>

### GENERAL—Palliative Performance Scale (PPS)

The Palliative Performance Scale (PPS) is a modification of the Karnofsky and was designed for measurement of physical status in Palliative Care. Only 10% of patient with PPS score of ≤ 50% would be expected to survive for > 6 months.

<table>
<thead>
<tr>
<th>%</th>
<th>Ambulation</th>
<th>Activity and Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Level of Consciousness</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Full</td>
<td>Normal Activity</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90</td>
<td>Full</td>
<td>No Evidence of Disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80</td>
<td>Full</td>
<td>Normal Activity with Effort</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70</td>
<td>Reduced</td>
<td>Unable to do Normal Job</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60</td>
<td>Reduced</td>
<td>Unable to do Hobby / House Work</td>
<td>Occasional Assistance Necessary</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50</td>
<td>Mainly Sit/Lie</td>
<td>Unable to do Any Work Extensive Disease</td>
<td>Considerable Assistance Required</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40</td>
<td>Mainly in Bed</td>
<td>As Above</td>
<td>Mainly Assistance</td>
<td>Normal or Reduced</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>30</td>
<td>Totally Bed Bound</td>
<td>As Above</td>
<td>Total Care</td>
<td>Reduced</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>20</td>
<td>As Above</td>
<td>As Above</td>
<td>Total Care</td>
<td>Minimal Sips</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>10</td>
<td>As Above</td>
<td>As Above</td>
<td>Total Care</td>
<td>Mouth Care Only</td>
<td>Drowsy or Coma</td>
</tr>
<tr>
<td>0</td>
<td>Death</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>
Check highest consecutive level of disability:

- □ 1. No difficulty either subjectively or objectively.
- □ 2. Complains of forgetting location of objects. Subjective work difficulties.
- □ 3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
- □ 4. Decreased ability to perform complex tasks, instrumental ADLs, (e.g., handling personal finances, difficulty shopping, etc.)
- □ 5. Requires supervision with ADLs (e.g., choosing proper clothing to wear for the day, season)
- □ 6. a) Needs assistance with dressing (e.g., may put street clothes on over night clothes, or have difficulty buttoning clothing) occasionally or frequently
   b) Unable to bathe properly (e.g., difficulty adjusting the bath-water temperature) occasionally or more frequently in the past weeks. *
   c) Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe proper or properly dispose of toilet tissue) occasionally or more frequently over the past weeks. *
   d) Urinary incontinence (occasionally or more frequently over the past weeks).
   e) Fecal incontinence (occasionally or more frequently over the past weeks).
- □ 7. a) Ability to speak limited to approximately a half a dozen intelligible different words or fewer, in the course of an average day or in the course of an intensive interview.
   b) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over).
   c) Ambulatory ability is lost (cannot walk without personal assistance).
   d) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair).
   e) Loss of ability to smile.
   f) Loss of ability to hold head up independently.

* Scored primarily on the basis of information obtained from knowledgeable informant and/or category.

DEMENTIA–Mortality Risk Index Score (MRI)17

The Mortality Risk Index (MRI), a composite score based on 12 risk factor criteria has been suggested as an alternative to FAST. Mitchell developed and validated the MRI by examining data from over 11,000 newly admitted nursing home patients. Among patients with an MRI score of ≥ 12, 70% died within 6 months. Compared to FAST Stage 7C, the MRI had greater predictive value of six month prognosis.

<table>
<thead>
<tr>
<th>Points</th>
<th>Risk factor</th>
<th>Risk factor</th>
<th>Score</th>
<th>Risk %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.9</td>
<td>Complete dependence with ADLs</td>
<td>Complete dependence with ADLs</td>
<td>0</td>
<td>8.9</td>
</tr>
<tr>
<td>1.9</td>
<td>Male gender</td>
<td>Male gender</td>
<td>1.2</td>
<td>10.8</td>
</tr>
<tr>
<td>1.7</td>
<td>Cancer</td>
<td>Cancer</td>
<td>3-5</td>
<td>23.2</td>
</tr>
<tr>
<td>1.6</td>
<td>Congestive heart failure</td>
<td>Congestive heart failure</td>
<td>6-8</td>
<td>40.4</td>
</tr>
<tr>
<td>1.6</td>
<td>O2 therapy needed w/in 14 day</td>
<td>O2 therapy needed w/in 14 day</td>
<td>9-11</td>
<td>57.0</td>
</tr>
<tr>
<td>1.5</td>
<td>Shortness of breath</td>
<td>Shortness of breath</td>
<td>≥ 12</td>
<td>70.0</td>
</tr>
<tr>
<td>1.5</td>
<td>&lt; 25% of food eaten at most meals</td>
<td>&lt; 25% of food eaten at most meals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.5</td>
<td>Unstable medical condition</td>
<td>Unstable medical condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.5</td>
<td>Bowel incontinence</td>
<td>Bowel incontinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.5</td>
<td>Bedfast</td>
<td>Bedfast</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.4</td>
<td>Age &gt; 83 y</td>
<td>Age &gt; 83 y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.4</td>
<td>Not awake most of the day</td>
<td>Not awake most of the day</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ATTACHMENT C

DISEASE-SPECIFIC PROGNOSTIC TOOLS (ATTACHMENTS-continued)

CANCER – Eastern Cooperative Oncology Group \(^{18}\) (ECOG)

The Eastern Cooperative Oncology Group (ECOG) is one of the largest clinical cancer research organizations in the United States, and conducts clinical trials in all types of adult cancers. They developed the ECOG Performance Status. These criteria are used by providers and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis.

<table>
<thead>
<tr>
<th>Grade</th>
<th>ECOG</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction.</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, (e.g., light house work, office work).</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours.</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self care, confined to bed or chair more than 50% of waking hours.</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry on any self care. Totally confined to bed or chair.</td>
</tr>
<tr>
<td>5</td>
<td>Dead</td>
</tr>
</tbody>
</table>

Scoring: ECOG > 3 roughly correlates with median survival of 3 months

ATTACHMENT D

HEART FAILURE – New York Heart Association \(^{20}\) (NYHA)

Based on data from SUPPORT, Framingham, IMPROVEMENT, and other studies, 1-year mortality estimates are below. The National Hospice and Palliative Care Organization’s guidelines for Heart Disease admission criteria include: NYHA class IV heart failure (Symptoms at rest).

<table>
<thead>
<tr>
<th>Class</th>
<th>Symptom Severity</th>
<th>1 year Mortality Estimates (Support Study)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Class II  Patients with slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea, or anginal pain.</td>
<td>Mild</td>
<td>5-10%</td>
</tr>
<tr>
<td>Class III Patients with marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes fatigue, palpitation, dyspnea, or anginal pain.</td>
<td>Moderate</td>
<td>10-15%</td>
</tr>
<tr>
<td>Class IV Patients with cardiac disease resulting in inability to carry on any physical activity without discomfort. Symptoms of heart failure or of the anginal syndrome may be present even at rest. If any physical activity is undertaken, discomfort is increased</td>
<td>Severe</td>
<td>30-40%</td>
</tr>
</tbody>
</table>
**DISEASE-SPECIFIC PROGNOSTIC TOOLS (ATTACHMENTS-continued)**

## LIVER DISEASE– Child-Pugh

Childs-Turcotte-Pugh is a tool used to help assess prognosis in patients with liver disease. Variations in the timing and subjectivity inherent in the scoring (e.g., in grading ascites or encephalopathy) are its major limitations.

### Child-Pugh Points

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encephalopathy</td>
<td>None</td>
<td>Grade 1-2</td>
<td>Grade 3-4 (or chronic)</td>
</tr>
<tr>
<td>Ascites</td>
<td>None</td>
<td>Mild/Moderate (diuretic-responsive)</td>
<td>Severe (diuretic-refractory)</td>
</tr>
<tr>
<td>Bilirubin (mg/dl)</td>
<td>&lt; 2</td>
<td>2-3</td>
<td>&gt; 3</td>
</tr>
<tr>
<td>Albumin (g/dl)</td>
<td>&gt; 3.5</td>
<td>2.8-3.5</td>
<td>&lt; 2.8</td>
</tr>
<tr>
<td>PT (seconds prolonged)</td>
<td>&lt; 4</td>
<td>4-6</td>
<td>&gt; 6</td>
</tr>
<tr>
<td>INR</td>
<td>&lt; 1.7</td>
<td>1.7-2.3</td>
<td>&gt; 2.3</td>
</tr>
</tbody>
</table>

### Child-Pugh Cirrhosis Scoring

<table>
<thead>
<tr>
<th>Class</th>
<th>Points</th>
<th>One year survival (%)</th>
<th>Two year survival (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Class A</td>
<td>5-6</td>
<td>95</td>
<td>90</td>
</tr>
<tr>
<td>Class B</td>
<td>7-9</td>
<td>80</td>
<td>70</td>
</tr>
<tr>
<td>Class C</td>
<td>10-15</td>
<td>45</td>
<td>38</td>
</tr>
</tbody>
</table>

### Encephalopathy Grading

- **Grade 1**: Mild confusion, anxiety, restlessness, fine tremor, slowed coordination
- **Grade 2**: Drowsiness, disorientation, asterixis
- **Grade 3**: Somnolent but arousable, marked confusion, incomprehensible speech, incontinence, hyperventilation
- **Grade 4**: Coma, decerebrate posturing, flaccidity

### LIVER DISEASE– Model for End-Stage Liver Disease (MELD)

Originally derived from patients with cirrhosis undergoing elective Transjugular Intrahepatic Portosystemic Shunt (TIPS) procedures to predict 3 month mortality post procedure. Adopted by the United Network for Organ Sharing (UNOS) in 2002 for the prioritization of patients waiting for liver transplants.

- **Note**: There are some conditions associated with chronic liver disease that may result in impaired survival but are not directly accounted for in the MELD scoring system; such as: HCC, Hepatopulmonary Syndrome; therefore these should not be the only tools used for accessing overall prognosis.

- **MELD formula**:  
  \[
  \text{MELD} = 3.78 \times \ln(\text{serum bilirubin (mg/dL)}) + 11.2 \times \ln(\text{INR}) + 9.57 \times \ln(\text{serum creatinine (mg/dL)}) + 6.43
  \]
  
  \( \ln = \) natural logarithm

- **MELD Score Three Month Mortality**:

<table>
<thead>
<tr>
<th>MELD Score</th>
<th>3 Month Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>40 or more</td>
<td>71.3% mortality</td>
</tr>
<tr>
<td>30-39</td>
<td>52.6% mortality</td>
</tr>
<tr>
<td>20-29</td>
<td>19.6% mortality</td>
</tr>
<tr>
<td>10-19</td>
<td>6.0% mortality</td>
</tr>
<tr>
<td>&lt;9</td>
<td>1.9% mortality</td>
</tr>
</tbody>
</table>

- **Online Calculator**: [https://www.hepatitisc.uw.edu/page/clinical-calculators/ctp](https://www.hepatitisc.uw.edu/page/clinical-calculators/ctp)
### What Are Life–Sustaining Treatments?

Life-sustaining treatments are treatments that might help you live a short time longer in some cases. Examples of these treatments are:

1. **Feeding tubes:** Carry liquid nutrition, fluids, and medications directly into your stomach or intestines. There are two kinds of feeding tubes. One goes into the nose, down through the throat, and into the stomach. The other goes through your skin into your stomach or intestines (requires minor surgery). A feeding tube might be considered if you can't eat or you can't eat safely due to swallowing problems.

2. **Mechanical ventilation (Breathing Machine):** Helps you breathe when you can't breathe on your own. Being on a breathing machine can be uncomfortable and sometimes patients will need additional medications to help them feel more comfortable.

3. **Dialysis:** Cleans a person's blood to remove waste products when the kidneys can no longer do the job. This requires large tubes to be placed in the blood vessels and to stay in the blood vessels between treatments.

4. **Cardiopulmonary Resuscitation (CPR):** Used in an emergency when someone's heart has stopped beating. CPR can help blood and oxygen flow to your brain while medical staff try to get your heart to beat normally again. This may help prevent brain damage. CPR may include:
   - Someone pushing on your chest with their hands (chest compressions).
   - Artificial breathing. Staff will use a small bag attached to a mask to push air into your lungs.
   - Someone giving you medications to stimulate your heart.
   - Someone putting a tube into your throat to help air reach your lungs.
   - A machine giving you one or more quick electrical shocks to your chest, also known as defibrillation [pronounced: duh-fi-bruh-lei-shn].

Life-sustaining treatments might, or might not work to help you live a short time longer. Life-sustaining treatments do not cure disease or chronic illness. Sometimes they are used for a short time to get a person through a health crisis, like when a chronic illness suddenly gets worse or while a person is being treated for a sudden serious illness. Sometimes life-sustaining treatments cause complications or discomfort.

Your treatment team can give you more information about life-sustaining treatments. Talk with them about how these treatments relate to your health care goals.
**What is Hospice?**

Hospice is:

- A type of palliative care
- Usually for a patient that has six months or less to live.
- Care provided by a team made up of doctors, nurses, social workers, other health care staff and chaplains who work together to keep the patient comfortable physically, mentally and spiritually.
- Offered at CMF for men and CCWF and CIW for women.

The hospice care team can help the patient deal with any “unfinished business,” can help the patient get in touch with family, and can provide spiritual/religious support if that is wanted by the patient. Most of the time, your primary doctor will ask you if you are interested in the hospice program when the time is right. You are welcome to ask your health care team about hospice care at any time if you have questions.

**Do you have to be in hospice to be considered for Compassionate Release or Expanded Medical Parole?**

- No, these programs are different and it does not matter if you are on hospice. Speak to your medical provider if you think you are eligible.
What is a POLST?

- POLST is short for Physicians Orders for Life Sustaining Treatment
- This is a form used by all hospitals in California (and other states)
- The CDCR 7465, POLST is used to write a patient’s wishes about end-of-life care
- The POLST allows a patient to say they want to:
  - Try CPR or Do NOT want to try CPR (allow natural death).
  - Focus on being kept comfortable or want to try all treatments offered, or want something in between.
  - Try a feeding tube or NOT try a feeding tube if eating/swallowing becomes difficult.
- If you are seriously ill, especially if you have been in the hospital, your health care team should talk with you about filling out a POLST.
- If your doctor or health care team has not asked you about your wishes, you should bring it up yourself so that any questions you have can be answered and your wishes can be written down and followed.

What happens if I don’t have a POLST form?

Without a POLST form, emergency medical staff will not know your treatment wishes. You will most likely receive all possible treatments, whether you want them or not. Talking about your treatment choices with your loved ones and doctor before a problem occurs can guide them and help ensure you get the care you want.

What is an Advance Directive?

- An Advance Directive is a document that allows you to write your wishes about end-of-life care.
- It allows you to say what you want so that family, friends, doctors, nurses, and other health care staff will know for sure what you want if you can no longer speak for yourself.
- In CDCR we use the CDCR 7421, Advance Directive for Health Care.
- You may request a CDCR 7421 at any time, even when you are young and perfectly healthy.
- The CDCR 7421, allows you to:
  - Name someone to speak for you when you can no longer speak for yourself (medical decision-maker).
  - Say what your wishes are (e.g., “I don’t want CPR, or a breathing machine, a feeding tube is okay.”)

NOTE: The Advance Directive is NOT a “Will” and has NOTHING to do with your possessions.

Choosing a Medical Decision-Maker:

A medical decision-maker can be a family member or friend. He/she should be someone who:
- You can trust and is willing to do the job.
- Can separate his/her own wishes from your wishes and can carry out your wishes if necessary.
- Can handle it if others want you to get treated differently than what you want.
- Can easily be reached if he/she was needed.

Your medical decision-maker cannot be your doctor or another medical provider.

What is a Medical Decision-Maker?

- A medical decision-maker is a person that you pick to make health care choices for you if there comes a time when you cannot speak for yourself.
- The medical decision-maker is very important.

What a Medical Decision-Maker Can Do (once you can no longer speak for yourself):

- They can talk with your doctor about your medical problems and agree to start or stop medical treatment including: Medicines, tests, CPR, breathing machines (ventilators), and feeding tubes.
- They can tell others about your wishes for treatment at the end of life and make sure they are followed.

CCHCS Care Guide: Palliative Care

November 2019
## Myths About Death and Dying

<table>
<thead>
<tr>
<th>Myth</th>
<th>Fact</th>
</tr>
</thead>
<tbody>
<tr>
<td>An Advance Directive means “do not treat”</td>
<td>An Advance Directive is a way to tell your health care team what treatment you want or do not want. In an Advance Directive or POLST you tell your wishes. Some people say they do not want a lot of treatment when it is clear they are dying, others want to try more things. It is up to the patient.</td>
</tr>
<tr>
<td>If I name a medical decision-maker, I will be giving up my rights to make my own decisions</td>
<td>Naming a medical decision-maker does not take away any of your authority. You always have the right to make decisions while you are still mentally capable. You may cancel or change your medical decision-maker at any time.</td>
</tr>
<tr>
<td>Choosing hospice means my doctor has given up on me and my medical needs won’t be met</td>
<td>The hospice team usually consists of a doctor, nurse, social worker, chaplain, volunteers, and other specialists if needed. The hospice team will work together to help you feel comfortable and can help support the more personal aspects in your life stage: helping you think about your family and other relationships, how you want to be remembered, and what gives your life meaning.</td>
</tr>
<tr>
<td>Hospice is giving up</td>
<td>Hospice care is not giving up. Hospice services provide comfort and improve quality of life to patients who are dying and to help carry out their wishes. In some cases, a patient’s health can improve, and the patient may be discharged from hospice care.</td>
</tr>
<tr>
<td>Dying is painful</td>
<td>Many people die without having pain. If a patient’s condition causes pain, in most cases the pain can be controlled with medications and other treatments.</td>
</tr>
<tr>
<td>If I go to hospice, I will be stuck there and won’t be able to leave my bed</td>
<td>Patients in the hospice unit can leave their rooms to attend activities including going to the gym and other activities such as groups as long as they are strong enough.</td>
</tr>
<tr>
<td>I don’t want to be around a bunch of patients that are dying</td>
<td>The fact is, patients do die in the hospice unit, but there are also many patients that end up living a long time. Patients respond well to holistic care (when the mind, body, and spirit are treated) and at times, end up living longer than what was expected. Families can usually visit more often and most patients find hospice to be a very positive place.</td>
</tr>
<tr>
<td>Palliative care is just for people with cancer</td>
<td>Palliative care is for anyone suffering with a life limiting illness, including chronic diseases such as kidney, liver, lung, and heart failure, dementia, and other neurological illnesses.</td>
</tr>
<tr>
<td>A Will and Advance Directive are the same</td>
<td>A “Will” is a written set of instructions that allows a person to say what they would like to have happen with their possessions when they die. An Advance Directive is TOTALLY different. An Advance Directive allows a patient to state their wishes for the type of health care they do or do NOT want and also to say who they want to make decisions for them if in the future they cannot make their own decisions.</td>
</tr>
</tbody>
</table>
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¿Qué son los Tratamientos de Soporte Vital?

Los tratamientos de soporte vital son cuidados que podrían ayudarlo a vivir un poco más en algunos casos. Ejemplos de estos tratamientos son:

**Sondas de alimentación:** llevan alimentos líquidos, fluidos y medicamentos directo a su estómago o intestinos. Hay dos tipos de sondas de alimentación. Uno va en la nariz, baja por la garganta y llega al estómago. El otro pasa a través de la piel hasta el estómago o los intestinos (requiere cirugía menor). Se considera el uso de una sonda de alimentación si no puede comer o no puede comer con seguridad debido a problemas de deglución.

**Respiración mecánica (respirador):** lo ayuda a respirar cuando no puede hacerlo solo. Tener un respirador puede ser incómodo y en ocasiones, los pacientes necesitan medicamentos adicionales para ayudarlos a sentirse mejor.

**Diálisis:** limpia la sangre de una persona para eliminar los productos residuales cuando los riñones ya no pueden hacer el trabajo. Esto requiere que se coloquen sondas largas en las venas y que permanezcan allí entre los tratamientos.

**Reanimación cardiopulmonar (RCP):** se usa en una emergencia cuando el corazón de una persona deja de latir. La RCP puede ayudar a que la sangre y el oxígeno lleguen a su cerebro mientras el personal medico intenta hacer que su corazón vuelva a latir. Esto puede ayudar a prevenir el daño cerebral. La RCP incluye:

- Una persona presionando su pecho con las manos (compresiones de pecho).
- Respiración artificial. El personal usará una bolsa pequeña conectada a una máscara para enviar oxígeno a sus pulmones.
- Una persona dándole medicamentos para estimular su corazón.
- Una persona colocando un tubo en su garganta para ayudarlo a llevar aire a sus pulmones.
- Una máquina dándole uno o más choques eléctricos, mejor conocido como desfibrilación.

Los tratamientos de soporte vital pueden o no ayudarlo a vivir un poco más. Estos no curan enfermedades o afecciones crónicas. A veces se utilizan durante un corto período de tiempo para ayudar a una persona a superar una crisis de salud, como cuando una enfermedad crónica empeora repentinamente o cuando una persona está siendo tratada por una enfermedad grave y repentina. Algunas veces, los tratamientos de soporte vital causan complicaciones o molestias.

Su equipo de tratamiento puede darle más información sobre los tratamientos de soporte vital. Hable con ellos acerca de cómo estos tratamientos se relacionan con sus objetivos de atención médica.
## ¿Qué es el hospicio?

El hospicio es:
- Un tipo de cuidado paliativo
- Usualmente para un paciente que tiene 6 meses o menos de vida.
- Cuidados por parte de un equipo formado por médicos, enfermeras, trabajadores sociales, otro personal sanitario y religiosos que trabajan juntos para mantener al paciente cómodo física, mental y espiritualmente.
- Ofrecido en el Centro Médico de California (California Medical Facility, CMF) para hombres y en el Centro de Mujeres de California (Central California Women's Facility, CCWF) y en la Institución de California para Mujeres (California Institution for Women, CIW).

El equipo de cuidados de hospicio puede ayudar al paciente a tratar cualquier “asunto pendiente”, puede ayudarlo a ponerse en contacto con su familia y puede proporcionarle apoyo espiritual/religioso si así lo desea el paciente. La mayoría de las veces, su médico de atención primaria le preguntará si está interesado en el programa de hospicio cuando sea el momento adecuado. Si tiene alguna pregunta, puede preguntar a su equipo de atención médica sobre el cuidado de hospicio en cualquier momento.

### ¿Tiene que estar en un hospicio para ser considerado para la Liberación por Compasión o la Libertad Condicional Médica Ampliada?

- No, estos programas son diferentes y no importa si usted está en un hospicio. Hable con su proveedor médico si cree que es elegible.
¿Qué es el POLST?
El POLST es la abreviación de Physicians Orders for Life Sustaining Treatment (órdenes del médico sobre el tratamiento para el mantenimiento de la vida).
- Es un formulario usado en todos los hospitales de California (y otros estados).
- El formulario de POLST 7465 se usa para escribir los deseos del paciente sobre el cuidado para la terminación de su vida.
- El POLST le permitirá al paciente decir si quiere:
  - Intentar o no la RCP (permitir la muerte natural).
  - Enfocarse en mantenerse cómodo o probar todos los tratamientos ofrecidos, o si quiere algo entremedio.
  - Usar una sonda de alimentación o NO usar una sonda de alimentación si se hace difícil comer/tragar.
  - Si usted está gravemente enfermo, en especial si ha estado en el hospital, su equipo de atención médica debe hablar con usted sobre cómo llenar un formulario POLST.
  - Si su médico o equipo de atención médica no le ha preguntado acerca de sus deseos, debe mencionarlo usted mismo para que se pueda responder a cualquier pregunta que tenga y se puedan anotar sus deseos y hacer un seguimiento de los mismos.

¿Qué sucede si no tengo un formulario POLST?
Sin un formulario POLST, el personal médico de emergencia no conocerá sus deseos de tratamiento. Lo más probable es que usted reciba todos los tratamientos posibles, los quiera o no. Hablar sobre sus opciones de tratamiento con sus seres queridos y su médico antes de que ocurra un problema puede guiarlos y ayudar a asegurarse de que obtenga la atención que desea.

¿Qué es una directiva anticipada?
La directiva anticipada es un documento que le permite escribir sus deseos de cuidado para la terminación de su vida.
- Le permite decir lo que quiere para que su familia, amigos, médicos, enfermeras y demás personal de atención médica sepan con seguridad lo que quiere si ya no puede hablar por sí mismo.
- En el Departamento de Correcciones y Rehabilitación de California (California Department of Corrections and Rehabilitation, CDCR) usamos el formulario 7421 de CDCR de directivas anticipadas de atención médica.
- Puede solicitar el formulario 7421 en cualquier momento, incluso si es joven y goza de buena salud.
- El formulario 7421 de directivas anticipadas le permite:
  - Nombrar a alguien que hable por usted cuando ya no pueda hablar por sí mismo (responsable de decisiones médicas).
  - Decir cuáles son sus deseos (por ejemplo, "No quiero RCP, o un respirador, una sonda de alimentación está bien").

NOTA: La directiva anticipada NO es un "testamento" y NO tiene nada que ver con sus posesiones.
<table>
<thead>
<tr>
<th><strong>Mitos Sobre la Muerte</strong></th>
<th><strong>Realidad</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Una directiva anticipada significa “no tratar”</td>
<td>Una directiva anticipada es una manera de decirle a su equipo de atención médica qué tratamiento quiere o no quiere. En una directiva anticipada o POLST usted dice lo que desea. Algunas personas dicen que no quieren mucho tratamiento cuando está claro que están muriendo, otras quieren probar más cosas. Depende del paciente.</td>
</tr>
<tr>
<td>Si nombro a un responsable de decisiones médicas, renunciaré al derecho de tomar mis propias decisiones</td>
<td>Nombrar a un responsable no le quita ninguna de sus facultades. Usted siempre tiene el derecho de tomar decisiones mientras esté mentalmente capacitado. Puede cancelar o cambiar a su responsable de decisiones en cualquier momento.</td>
</tr>
<tr>
<td>Elegir un hospicio significa que mi médico se ha rendido y que mis necesidades médicas no serán satisfechas</td>
<td>El equipo de hospicio usualmente consta de un doctor, enfermera, trabajador social, capellán, voluntarios y otros especialistas si es necesario. El equipo de hospicio trabajará en conjunto para ayudarlo a sentirse cómodo y puede ayudarlo en los aspectos más personales de esta etapa de vida: ayudarlo a pensar en su familia y en otras relaciones, cómo quiere que lo recuerden y qué es lo que le da sentido a su vida.</td>
</tr>
<tr>
<td>El hospicio es rendirse</td>
<td>El cuidado de hospicio no es rendirse. Los servicios de hospicio proporcionan comodidad y mejoran la calidad de vida de los pacientes que están muriendo y ayudan a llevar a cabo sus deseos. En algunos casos, la salud del paciente puede mejorar y puede ser dado de alta del cuidado de hospicio.</td>
</tr>
<tr>
<td>Morir es doloroso</td>
<td>Muchas personas mueren sin tener dolor. Si la condición de un paciente causa dolor, en la mayoría de los casos el dolor puede ser controlado con medicamentos y otros tratamientos.</td>
</tr>
<tr>
<td>Si voy a un hospicio, me quedare atrapado allí y no podré salir de mi cama</td>
<td>Los pacientes de la unidad de hospicio pueden salir de sus habitaciones para asistir a actividades como ir al gimnasio y otras actividades como grupos, siempre y cuando sean lo suficientemente fuertes.</td>
</tr>
<tr>
<td>No quiero estar cerca de un grupo de pacientes que se están muriendo</td>
<td>La realidad es que los pacientes sí mueren en la unidad de hospicio, pero también hay muchos pacientes que terminan viviendo mucho tiempo. Los pacientes responden bien al cuidado holístico (cuando la mente, el cuerpo y el espíritu son tratados) y, a veces, terminan viviendo más de lo que se esperaba. Por lo general, las familias pueden visitar más a menudo y la mayoría de los pacientes encuentran que el hospicio es un lugar muy positivo.</td>
</tr>
<tr>
<td>Los cuidados paliativos son solo para personas con cáncer</td>
<td>Los cuidados paliativos son para cualquier persona que sufra de una enfermedad que limite su vida, incluyendo enfermedades crónicas como insuficiencia renal, hepática, pulmonar y cardíaca, demencia y otras enfermedades neurológicas.</td>
</tr>
<tr>
<td>Un testamento y una directiva anticipada son lo mismo</td>
<td>Un testamento es un conjunto de instrucciones escritas que le permite a una persona decir lo que le gustaría que sucediera con sus posesiones cuando muera. Una directiva anticipada es TOTALMENTE diferente. Esta le permite al paciente expresar sus deseos sobre el tipo de atención médica que desea o no desea y también decir quién quiere que tome decisiones por él si en el futuro no puede tomar sus propias decisiones.</td>
</tr>
</tbody>
</table>