CCHCS Care Guide: Palliative Care

SUMMARY | DECISION SUPPORT | PATIENT EDUCATION/SELF MANAGEMENT

GOAL

- ✓ **Identify patients in the early stages of a progressive disease who would benefit from palliative care services**
- ✓ **Identify and refer patients who would benefit from Hospice care**
- ✓ **Identify and document patients' end of life preferences using Advance Directive 7421 and POLST 7385**
- ✓ **Refer for Compassionate Release or Medical Parole as medically appropriate**
- ✓ **Provide relief from pain and other distressing symptoms**

ALERTS

- **Frequent hospitalizations/interventions**
- **Uncontrolled pain**
- **Uncontrolled dyspnea**
- **Intolerable side effects with current treatment plan**
- **Patient with progressive illness without Advance Directive/Code Status**
- **Patients with progressive end stage disease including dementia, cirrhosis**

DIAGNOSTIC CRITERIA/EVALUATION

	PALLIATIVE CARE	HOSPICE
Who	**Patient** has *either* ♦ a limited life expectancy (regardless of symptom burden or goals for care) ♦ or a significant symptom burden or goals for care exclusively to achieve and maintain comfort (regardless of prognosis or symptom burden) **Provider:** Can/should be provided by all Physicians, mid-levels and nurses	**Patient** has *both* ♦ a limited life expectancy (specifically < 6 mos) (See Table pg 13 for disease specific criteria) ♦ goals for care are exclusively to achieve and maintain comfort, regardless of the symptom burden **Provider:** Multidisciplinary team physician or mid-level with special training or experience
Where	All institutions/ most settings	Men CMF, Women CCWF

EVALUATION

Step 1: Ask "Would I be surprised if this patient died within 2 years" Available tools include Performance Scales (Karnofsky/Palliative Performance Scale) and Disease Specific Prognostic Tools. (See **pages 3-5**)

Step 2: Initiate palliative care discussion. Discuss prognostic uncertainty and assess patient's goals. Utilize Advance Directive CDCR 7421 to elicit patient's choice of surrogate decision- maker and end of life wishes. (See **page 6**)

Step 3: Assess patient's palliative care needs including the domains of palliative care: Physical, Psychological, Social, Spiritual, Ethical, Cultural. Palliative care can be provided even as curative treatment is attempted. (See **page 6**)

Step 4: Develop or revise palliative care plan as indicated by the patients condition. Document plan in progress notes. (See **pages 7-12** for Medications/ Symptom Management). Consider whether patient meets criteria for Compassionate Release or Medical Parole.

Step 5: Consider does the patient meet hospice criteria? (P**g 13-14**) As disease progresses complete POLST CDCR7385.

TREATMENT OPTIONS

Nonpharmacologic

General: Step back– can medical treatment plan can be simplified? (e.g. stop statin in patient with severe dementia?, stop labs?)

Ambulatory: Educate patient. Mental Health referral if anxious or depressed. Involve whole Primary Care Team as support.

Debilitated/Bed-bound: Position patient -watch for skin breakdown, artificial nutrition/hydration is rarely indicated.

Pharmacologic

Pain: Opioids are medication of choice in moderate -severe pain. Usually start with Immediate Release (IR) formulation for titration in acute pain and switch to long-acting when pain under control. Have breakthrough doses available. (See **pages 7 & 9**)

Constipation: Prevention is paramount, treatment choices for established constipation. (See **page 12**)

Dyspnea: Opioids are treatment of choice, anxiolytics can reduce anxiety component.

Nausea/Vomiting: Medication depends on causative mechanism, Metoclopramide a good first line choice.

MONITORING

- Continually reassess if care plan is accomplishing patients goals
- Periodically assess and document patient's end of life wishes in Progress Notes

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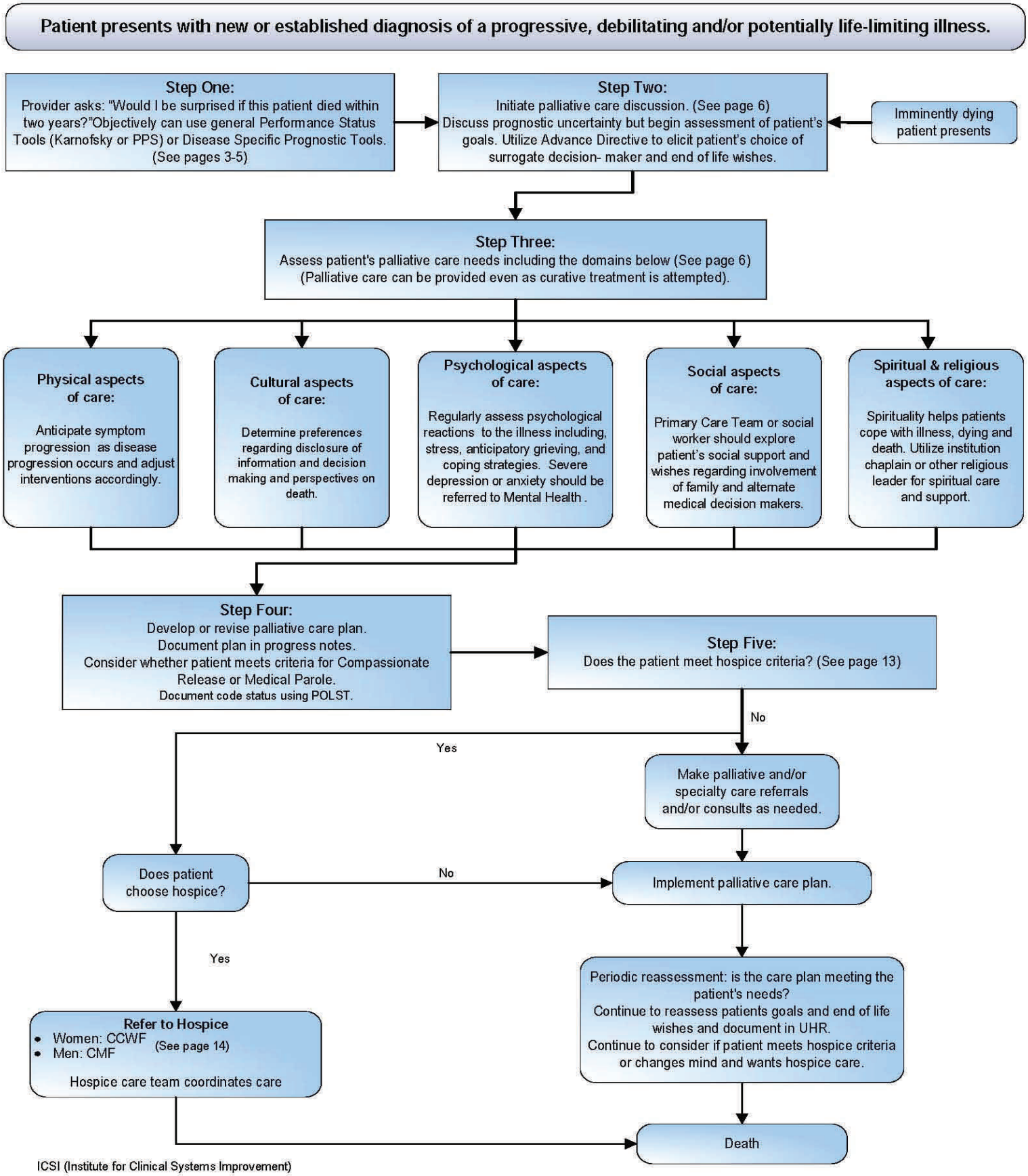

ICSI (Institute for Clinical Systems Improvement)
Health Care Guideline: Palliative Care, Third Edition, November 2009

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Provider asks:"Would I be surprised if this patient died within two years?" Can use general Performance Status Tools (Karnofsky or PPS)

Tools available from page 1 step 1

Karnofsky Performance Status Scale Definitions Rating (%) Criteria

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated but death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

Palliative Performance Scale

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.

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

STEP 1 (cont.)

Provider asks:

"Would I be surprised if this patient died within two years?" Can use Disease Specific Prognostic Tools.

Disease Specific Prognostic Tools:

CANCER:

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

ECOG Performance Status

Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction.
1	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.
2	Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours.
3	Capable of only limited self care, confined to bed or chair more than 50% of waking hours.
4	Completely disabled. Cannot carry on any self care. Totally confined to bed or chair.
5	Dead

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

Oken, M.M., et. Al. Am J Clin Oncol 5:649-655, 1982 The Eastern Cooperative Oncology Group

LIVER DISEASE:

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 of the CTP (e.g. in grading ascites or encephalopathy) are its major limitations.

Child's-Turcotte-Pugh Points *

	1	2	3
Encephalopathy	None	Grade 1-2 (or participant-induced)	Grade 3-4 (or chronic)
Ascites	None	Mild/Moderate (diuretic-responsive)	Severe (diuretic-refractory)
Bilirubin (mg/dL)	<2	2-3	>3
Albumin (g/dL)	>3.5	2.8-3.5	<2.8
PT (sec prolonged or INR)	<4 <1.7	4-6 1.7-2.3	>6 >2.3

Child's-Turcotte-Pugh Scoring

Class	Points	Survival
Class A	5-6	95% 1 year survival 90% 2 year survival
Class B	7-9	80% 1 year survival 70% 2 year survival
Class C	10-15	45% 1 year survival 38% 2 year survival

HEART FAILURE:

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)

New York Heart Association Functional Classification

Class	Symptom Severity	1 year mortality estimates (Support Study)
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.	Mild	5-10%
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.	Moderate	10-15%
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	Severe	30-40%

STEP 1 (cont.)

Provider asks:

"Would I be surprised if this patient died within two years?" Can use Disease Specific Prognostic Tools.

DEMENTIA:

The National Hospice and Palliative Care Organization (NHPCO) guidelines state that a FAST stage 7A is appropriate for hospice enrollment, based on an expected six month or less prognosis, **if** the patient also exhibits one or more specific dementia-related co-morbidities:

- aspiration
- multiple stage 3-4 ulcers
- upper urinary tract infection
- persistent fever
- sepsis
- weight loss >10% w/in six months

The FAST scale has 7 stages:

1 which is normal adult
2 which is normal older adult
3 which is early dementia
4 which is mild dementia
5 which is moderate dementia
6 which is mod-severe dementia
7 which is severe dementia

Tsai S, Arnold R. Prognostication in Dementia. Fast Facts and Concepts. February 2006

FAST: Functional Assessment Staging

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 ADL's, e.g., handling personal finances , difficulty shopping etc.

☐ 5. Requires supervision with ADL's (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.* Reisberg, B. Functional assessment staging (FAST), *Psychopharmacology Bulletin 1988*; 24: 653-659

The Mortality Risk Index (MRI), a composite score based on 12 risk factor criteria has been suggested as an alternative to FAST. Mitchell (2004) developed and then validated the MRI by examining data from over 11,000 newly admitted nursing home patients. Among patients with a MRI score of ≥ 12, 70% died within 6 months. Compared to FAST Stage 7C, the MRI had greater predictive value of six month prognosis.

Mitchell SL, Kiely DK, Hamel MB, et al. Estimating prognosis for nursing home residents with advanced dementia. JAMA. 2004; 291:2734-2740.

Mortality Risk Index Score (Mitchell)

Points	Risk factor
1.9	Complete dependence with ADLs
1.9	Male gender
1.7	Cancer
1.6	Congestive heart failure
1.6	O2 therapy needed w/in 14 day
1.5	Shortness of breath
1.5	<25% of food eaten at most meals
1.5	Unstable medical condition
1.5	Bowel incontinence
1.5	Bedfast
1.4	Age > 83 y
1.4	Not awake most of the day

Risk estimate of death within 6 months

Score	Risk %
0	8.9
1.2	10.8
3-5	23.2
6-8	40.4
9-11	57.0
=12	70.0

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STEP 2 → Step 3 listed below

Initiate palliative care discussion. Discuss prognostic uncertainty but begin assessment of patient's goals. Utilize Advance Directive to elicit patient's choice of surrogate decision - maker and end of life wishes.

Discussing Prognosis

Where: Quiet, private setting **Who**: Provider (Or patient's surrogate if patient lacks medical decision-making capacity)+ Patient +/- nurse, Chaplain, MSW, Translator (w/out custody if security level allows)

1. Determine what the patient knows; make no assumptions. (Examples: What have the other doctors/nurses told you?)
2. Before presenting bad news, consider reviewing patient's course up till now.
3. Provide information in small chunks. Check patient's understanding frequently.
4. Give fair warning – "I am afraid I have some bad news" – then pause for a moment.
5. Present bad news in a simple, direct manner. Be prepared to repeat information and give additional information as patient requests.
6. Pause. Allow the news to sink in. Wait for the patient to respond.
7. Listen and acknowledge/validate patient's emotions: feeling numb, angry, sad, fearful
8. Present as much information as the patient wishes. Don't overwhelm with detail in the first conversation unless requested.
9. Provide prognostic information using a range: few days to weeks; 2-4 months
10. Assess thoughts of self-harm- offer Mental Health referral
11. Agree on a specific follow-up plan ("I will see you again tomorrow" , "Write down any questions"). Be sure patient is okay with plan

Ambuel B, Weissman DE. Delivering Bad News – Part 1, 2nd Edition. Fast Facts and Concepts. July 2005; 6. Available at: http://www.eperc.mcw.edu/fastfact/ff_006.htm.

Establishing End-of-Life Goals:

- **When:** Begin soon after the diagnosis of a life-limiting condition.
- **Who:** Physician & patient (or patient's surrogate if patient lacks medical decision-making capacity) others: family, nurse, chaplain, etc.
- **How:** Begin by expressing a need and interest to understand the patient's views.
  Initial goal is to develop a broad understanding of the patient's hopes and goals, then specific treatment decisions are made after the patient and health care team have developed an understanding of the patient's broader goals.
- **What to say:** "Given what we now know about your medical condition…"
  - How can we help you live your remaining life as you want to live it?
  - What activities or experiences are most important for you to feel your life has quality?
  - What fears or worries do you have about your illness or medical care?
  - If you have to choose between living longer and quality of life, how would you approach this balance?
  - What do you hope for your family?
  - Do you have religious or spiritual beliefs that are important to you?

Ambuel B. Establishing End-of-Life Goals: the Living Well Interview, 2nd Edition. Fast Facts and Concepts. July 2006; 65. Available at: http://www.eperc.mcw.edu/fastfact/ff_065.htm.

Advance Directive for Health Care

Advance Directive for Health Care CDCR **Form 7421**

- Appropriate for all patients regardless of age and health status
- Patient completes form– discusses with PCP
- Four parts:
  - Part 1: Power of Attorney for Health Care
  - Part 2: Instructions for Health Care
  - Part 3: Donation of Organs at Death
  - Part 4: Verification of Understanding, Signature, Witnesses
- Notary not required– can be witnessed by medical staff (MD's PA's, NP's, RN's, LVN's, PT's) who do not currently have primary responsibility for the patients medical care.
- Filed in UHR– under Medicolegal section
- Bright orange sticker placed on front of UHR
- PCP to note on Problem List and in Progress Note

POLST-Physician Orders for Life-Sustaining Treatment

Physician Orders for Life-Sustaining Treatment (POLST) **Form 7385**

- Appropriate for patients who are frail, elderly or have a life threatening illness or injury.
- Provider completes form to reflect patient's wishes
- Four parts:
  - Part A: Resuscitation Status (CPR-yes/no)
  - Part B: Medical Interventions (Intensity of Care– Comfort Measures Only vs Full Treatment vs Limited Interventions)
  - Part C: Artificially Administered Nutrition (Feeding tube yes/no/limited trial).
  - Part D: Signatures/Summary of Medical Condition
- Filed in UHR– in Physicians Orders section
- Bright orange sticker placed on front of UHR
- PCP to note on Problem List and in Progress Note

Step 3

Assess patient's palliative care needs including the domains below. Palliative care can be provided even as curative treatment is attempted.

The overriding goal of palliative care is to reduce suffering and maintain an acceptable quality of life throughout the course of a progressive illness, including the periods of advanced illness and active dying. Specific goals of palliative care include ensuring that:

ICSI (Institute for Clinical Systems Improvement) recommends assessing palliative care needs utilizing the "domains" of palliative care:

- **Physical Aspects of Care**
- **Psychological Aspects of care**
- **Social Aspects of Care**
- **Spiritual and Religious Aspects of Care**
- **Ethical and Legal Aspects of Care**
- **Cultural Aspects of Care**

Develop or revise the palliative care plan. Document the plan in progress notes & consider whether the patient meets criteria for Compassionate Release or Medical Parole.

IAHPC* LIST OF ESSENTIAL MEDICINES FOR PALLIATIVE CARE

MEDICATION	FORMULATION	COMMENTS	IAHPC INDICATION FOR PALLIATIVE CARE
Acetaminophen	325 mg tablets Rectal suppose. 650 mg		Pain—mild to moderate
Ibuprofen	200, 400, 600, 800 mg tablets Suspension 100mg/5 ml	Can be useful in bone and soft tissue pain Long term use limited by GI bleeding risk and renal effects	Pain—mild to moderate
Codeine **Acetaminophen/ Codeine**	15, 30, 60 mg tablets **(NF)** 30/300 mg tabs Elixir 12/120 /5ml	Weakest of the opioid analgesics and may result in greater constipation. May be good for cough.	Pain—mild to moderate Diarrhea
Methadone	5-10 mg tablets Soln: 10mg/mL **DOT/NAT only, crush & float**	**Initial dose :** First 3-5 days in opioid naïve patients 2.5 mg-5mg q 8-12 h [Max 2.5 mg q 8-12 h in elderly] **Titrate**: ♦ Long and variable half-life makes titration difficult ♦ Methadone accumulates with repeated doses and dose reduction may be needed after 3-5 days to prevent CNS depression. ♦ Full effect 2-4 weeks ♦ Consult with pain specialist or pharmacist if not experienced with methadone use. ECG baseline, month 1, annually Prolongs QT interval– (see CCHCS Pain Management Guidelines for details).	Pain—moderate to severe
Morphine	IR: 15-30 mg tablets SR: 30 mg tablets Soln: 10mg/5ml **DOT/NAT only** **Cannot crush SR**	♦ In acute or uncontrolled pain use immediate release (IR) ♦ Titrate using IR then switch to SR with breakthrough doses ♦ Frequent dosing of IR morphine required, may not be feasible in General population setting. **Initial dose**: Morphine IR 5 mg po q4h (See Breakthrough below) **Titrate** : ♦ ↑ dose by 30-50% of the previous dose – (depending on the severity of the pain) ♦ Alternatively new dose can be determined by adding the total of the breakthrough doses to the current dose. (e.g. Current dose 120 mg/day; breakthrough doses used in past 24 H = 60 mg : new dose 120 + 60 = 180 mg/day given as morphine IR 30 mg q4h) **Breakthrough**: Dose usually 10% of total daily opioid dose given prn (immediate release) between scheduled opioid doses	Pain—moderate to severe Dyspnea
Fentanyl (transdermal patch)	25 micrograms/hr (**NF**) 50 micrograms/hr **(NF)**	For patients unable to swallow or GI compromised; difficult to titrate. Should be used only under guidance of Palliative Care/ or Hospice specialist or oncologist.	Pain—moderate to severe
Tramadol	50 mg tablets 100 mg/1 ml oral solution **(NF)** 50 mg/ml injectable	Can lower seizure threshold.	Pain—mild to moderate

*The International Association for Hospice and Palliative Care

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IAHPC* LIST OF ESSENTIAL MEDICINES FOR PALLIATIVE CARE

MEDICATION	FORMULATION	COMMENTS	IAHPC INDICATION FOR PALLIATIVE CARE
Carbamazepine	200 mg tablets	Adjuvant for chronic pain–Use with caution in patients undergoing marrow-suppressant therapies such as chemo or radiotherapy. Periodic monitoring of CBC is recommended Initial dose 100 mg b.i.d p.o. increase over 2 weeks to a maximum of 400 mg t.i.d	Neuropathic pain
Gabapentin	Tablets 100, 300, 400, 600 or 800 mg **(NF)**	Adjuvant for neuropathic pain–Generally start at 100-200 mg bid Titrate over 2 weeks to maximum 1800-3,600 mg/24 h divided bid	Neuropathic pain
Bisacodyl	5 mg tablets 10 mg rectal suppositories	Stimulant laxative–do not use in undiagnosed abdominal pain or if obstruction or ileus present.	(Bowel med)
Senna	8.6 mg tablets (187-600 mg) **(NF)**	Contact cathartic; for opioid induced constipation	Constipation
Loperamide	2 mg tablets	Loperamide should also be available if drugs that can cause diarrhea are prescribed. Discontinue when no longer needed.	Diarrhea
Metoclopramide	5, 10 mg tablets Injectable 10 mg/2 ml	Generally first line treatment for nausea Used for anorexia due to early satiety and gastroparesis.	Nausea/ Vomiting
Prochlorperazine (Compazine)	5—10 mg tablets Injectable 5 mg/ml	Good for opioid related nausea. Usual adult Dose: 5-10 mg po Q6-8h	Nausea/ Vomiting
Promethazine (Phenergan)	25 mg tablets Injectable 50 mg/ml Rectal Suppository 25 mg	Caution: Respiratory Depression. Adult Dose: 12.5-25 mg po / IM / IV Q4-6h	Nausea/ Vomiting
Dexamethasone	0.5, 0.75, 4, 6 mg tabs Injectable:4 mg/ml	Starting dose is empiric and varies widely: Dexamethasone 2-8 mg t.i.d to q.i.d p.o. or s.q. Can reduce cerebral and spinal cord edema. Is occasionally used in bone or neuropathic pain. Potential early side effects are loss of glucose control, increased risk of infection and acute psychiatric disorders.	Anorexia Nausea/Vomiting Neuropathic pain
Haloperidol	0.5, 1, 2, 5, 10 mg tabs Oral Soln: 2 mg/ml Injectable: 5mg/ml	Used in Terminal Delirium (0.5-1.0 mg q 8-12 hrs) and occasionally for nausea unresponsive to first line agents.	Delirium Nausea/Vomiting Terminal restlessness
Citalopram *(Clexa)*	10 , 20, 40 mg tablets	If depression suspected consult with Mental Health. IAHPC states Citalopram *or any other equivalent generic SSRI except paroxetine and fluvoxamine.*	Depression
Lorazepam	1 mg tablets Injectable 2 mg/ml	If significant anxiety or insomnia consult Mental Health Used occasionally as adjuvant to treat dyspnea and nausea	Anxiety Insomnia
Megestrol Acetate	20, 40 mg tablets Oral Soln: 40 mg/ml	Can produce temporary appetite stimulation. No survival benefit has been shown. Caution: thromboembolism.	Anorexia

Symptom Management

The following pages (9-12) contain suggested symptom management for pain, stomatitis, anxiety/depression, delirium, fatigue, excessive secretions, dyspnea, cough, anorexia/cachexia, constipation, nausea and vomiting in the palliative care or hospice patient based on recommendations from:

The International Association for Hospice and Palliative Care Manual of Palliative Care, 2nd Edition

Alberta Hospice Palliative Care Resource Manual 2nd Edition 2001

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Develop or revise the palliative care plan as indicated by patient condition. Document the plan in progress notes & consider whether the patient meets criteria for Compassionate Release or Medical Parole.

Causes / Evaluation	General Measures	Medications
PAIN **Chronic Conditions:** • Early in course of progressive chronic illness it may be appropriate to follow Chronic Pain Guidelines. (See CCHCS Pain Management Guidelines). • Once patient's disease progresses shift pain management strategy to "malignant pain". **Palliative Care/Malignant Pain:** • **More aggressive dosing** • Addiction and dependence not a concern • Goal is to improve quality of life as the patient dies. **Determine nature and possible causes:** Examples of causes of pain in palliative care patients include pain: • Due to the primary disease e.g.: ◆ tumor infiltration ◆ nerve compression • Associated with treatment e.g.: ◆ diagnostic/staging procedures ◆ surgery • Due to general debilitating disease e.g.: ◆ pressure sores • Other comorbid conditions e.g.: ◆ arthritis	• Consider radiotherapy for the control of bone pain and tumor infiltration. • Occupational and physical therapy • Supports such as collars and slings to immobilize fractures • Relaxation therapy **General Measures for Medication dosing**: • Use a regular schedule not solely PRN • Provide **breakthrough dosing** ◆ Usually 10% of total daily opioid dose ◆ Can dose as frequently as q 1 H if setting permits ◆ Use immediate release (IR) formulation of patient's SR med if possible • Anticipate and treat side effects • Use the **oral route** wherever possible • **Maximum opioid dose** limited only by toxicity and varies widely . ◆ If treating malignant pain and dose needed is ↑↑ contact hospice or palliative care specialist for guidance. • **Opioid rotation** sometimes needed due to poor response or toxicity ◆ Calculate total daily opioid dose including breakthrough doses. ◆ Use table to find equianalgesic dose of new opioid. ◆ Decrease dose by 25-50% to accommodate cross-tolerance. ◆ Consult with Pharmacist especially when converting to methadone.	***Mild –Moderate pain*** Start with a non-opioid • acetaminophen 325 -650 mg q4hr po or • Ibuprofen 400-800 mg bid-t.i.d or • codeine 30-60 mg q4hr po regularly **Moderate-Severe pain** After optimizing dose of above switch to a stronger opioid (*e.g.*, morphine or methadone) See page 7 for dosing • **Opioids are treatment of choice** • **Adjuvants may be used but *first* optimize the opioids** ◆ Adjuvant analgesics are less reliable than the opioids for cancer-related pain and have troublesome side effects. ◆ Avoid polypharmacy where possible in order to minimize adverse effects.
STOMATITIS Can range from mild inflammation to ulceration that can bleed or become infected. **Causes of stomatitis** • Infection • Medication (e.g. chemotherapy) • Radiotherapy • Poor dental hygiene • Poorly fitting dentures • Blood dyscrasias	• Provide regular mouth care before and after meals (if the patient is able to eat) and at bedtime; or routinely with other care, (e.g. q2h turns). • Ensure dentures are properly fitted. • Use water soluble lip balms or lubricants, rather than petroleum based products, to keep lips moist. • Avoid mouthwashes that contain alcohol as they dry the oral mucosa.	• If pain is severe, suggest analgesic rinses with xylocaine 2%. • Treat candidiasis or thrush with nystatin, fluconazole or ketoconazole. Oral medications should be swallowed as thrush may extend into the esophagus. • Patients on immunosuppressive drugs should be examined regularly for thrush. • Treat herpes simplex; consider acyclovir.

Equianalgesic Dosing

Medication	PO Dose	SC/IV Dose
Codeine	100 mg	50 mg
Morphine	10 mg	5 mg
Methadone †	1 mg	too irritating
Oxycodone * (NF– May be stated at outside hospital)	5 mg	--
Hydromorphone (Dilaudid NF)	2 mg	1 mg
Fentanyl patch (Use limited to hospice or oncologist)	use chart supplied by manufacturer	

* The equianalgesic dose ratio of morphine to oxycodone is controversial. It appears to be between 1.5:1 and 2:1.

† Many tables quote the equianalgesic dose ratio of morphine to methadone as being 1:1, i.e., morphine 1 mg po = methadone 1 mg po. This ratio was determined using single dose studies. In cancer pain, when multiple doses are required, the ratio of morphine to methadone becomes approximately 10:1, i.e., morphine 10 mg po = methadone 1 mg po.

From: Alberta Hospice Palliative Care Resource Manual 2nd Edition 2001

Develop or revise the palliative care plan. Document the plan in progress notes & consider whether the patient meets criteria for Compassionate Release or Medical Parole.

Causes / Evaluation	General Measures	Medications
ANXIETY / DEPRESSION • Anxiety and depression are common in seriously ill patients and ↓quality of life. • Can cause physical symptoms such as nausea, dyspnea and insomnia. **Evaluate** • It is important to differentiate grief from depression. • Grieving can be an appropriate response to loss, but persistence of symptoms mandates consideration of depression. • **Always assess for suicidal risk.** • **Look for clinical conditions that may mimic depression and treat these:** ♦ Metabolic (e.*g*., hypercalcemia) ♦ Endocrine (e.*g*., hypothyroidism) ♦ Drugs (e*g*., anticonvulsants, beta-blockers, corticosteroids, tamoxifen)	• Social supports provided by current prison community, outside family and friends and religious groups are important. • Patient education is vital. Correct misconceptions regarding the illness, treatment or the dying process. • Legitimize the difficulty of the situation – the "right" to be upset reduces the fear of being perceived to be "weak" or "inappropriate." • Respect the desire of the patients to maintain hope. • **Refer to mental Health if medications are needed**.	**For anxiety** • Short acting benzodiazepines, e.g., **Lorazepam** 0.5-1 mg q 6 hrs prn . • Emphasis on supportive measures rather than pharmacological modalities. • Chronic anxiety often responds to SSRI's **In depression** • Selective serotonin re-uptake inhibitors (SSRI's) are drugs of first choice. • Mental Health provider will need to evaluate the patient and prescribe medication as needed. . *Antidepressant drug treatment is usually well tolerated, some expert consensus statements recommend a low threshold for treatment, but evidence on the effectiveness of antidepressants at the end of life is poor.*
DELIRIUM • Delirium is a clinical syndrome, not a disease in itself. • Prevalent in patients with preexisting dementia. • Common in the week or two before death. **Common causes of delirium include:** • Drugs (anticholinergics, antihistamines, anti-emetics, sedative hypnotics, and opioids)- discontinue drug if possible • Metabolic abnormalities (↑Na+, ↑ Ca+2, hypoglycemia, hypoxia, etc). • Dehydration • Infections • CNS pathology-brain metastases	• Non-pharmacological treatments should always be used first in delirium management. • Keep an eye out for things such as urinary retention, constipation, uncontrolled pain, kinked oxygen tubing, etc. • Reduce the sensory stimulation in the environment as needed.	Drug of choice for most patients is a neuroleptic, usually haloperidol. This class of drugs calms patients without interfering with cognition. **Haloperidol** start at 0.5-1 mg po/sq q 8-12 hrs and 1 mg q1h po/sq prn for agitation. Titrate up as needed .
FATIGUE • Fatigue may be a consequence of the primary illness or of the treatments used (such as radiation and chemotherapy). • **Evaluate** for underlying causes (such as anemia or hypoxia). • Management includes treating the underlying cause as well as using non-pharmacologic and pharmacologic therapy directed toward the symptom itself.	• Non-pharmacologic treatment includes: • patient education about fatigue • modifying the activities of daily living • scheduling rest periods during the day • Clinicians should counsel patients to prioritize activities and pace themselves accordingly. • Mild exercise for brief periods may be beneficial in reducing the perception of fatigue for some patients	• Medications that may make the patient more tired should be administered at bedtime rather than in the morning. • *Erythropoietin* should be reserved for very select patients with documented anemia under the care of an oncologist due to the high cost of treatment and lack of evidence of benefit in other clinical situations
EXCESSIVE SECRETIONS As the level of consciousness decreases in the dying process, patients lose their ability to swallow and clear oral secretions.	• Position the patient on their side or semi-prone to facilitate postural drainage. • Gentle oropharyngeal suctioning is used although ineffective when fluids are beyond the reach of the catheter. • Reduction of fluid intake.	The drug class of choice is muscarinic receptor blockers (anti-cholinergic drugs). These include: ♦ *Scopolamine*-Transderm Patch 1.5 mg q3d ♦ *Hyoscyamine (Levsin)* 0.125 mg po/SL ♦ **Atropine** 0.1 mg SQ/IV

CCHCS Care Guide: Palliative Care

Develop or revise the palliative care plan. Document the plan in progress notes & consider whether the patient meets criteria for Compassionate Release or Medical Parole.

Causes / Evaluation	General Measures	Medications
DYSPNEA Dyspnea is a subjective symptom, and may or may not be accompanied by hypoxia. **Causes** • Airway obstruction: tumor, infection, bronchospasm. • Impaired ventilatory movement: chest wall weakness, ascites. • Cardiovascular: CHF, anemia, pericardial effusion. **Evaluate** • Consider simple problems: - Is the Oxygen turned on? - Is the tubing kinked? • If the patient is clearly dying and the goal is comfort, then pulse oximetry, arterial blood gases, EKG, or imaging are not indicated.	General measures such as: • calm, reassuring attitude • positioning (sitting up) • increasing air movement via a fan or open window • use of bedside relaxation techniques are all helpful • In the imminently dying patient, discontinuing parenteral fluids is appropriate. • Treatment with oxygen is often, but not universally, helpful. When in doubt, a therapeutic trial, based on symptom relief, not pulse oximetry, is indicated.	**Opioids are drug of choice:** **Dosing** • **Morphine IR 5mg-10 PO Q3-4H,** titrated for effect. (May be converted to Morphine SR once effective dose established.) • SQ is quicker acting, but must be dosed more frequently. • No ceiling dose when titrated for effect. • Other opioids may help, but Morphine is "gold standard". **Anxiolytics can reduce the anxiety component of dyspnea**. • **Lorazepam 0.5-2mg Q4-6H PO/SQ/SL prn** • Observe for sedation Nebulized bronchodilators and/or steroids can be used if bronchospasm noted.
COUGH **Causes** • Airway irritation: tumor, GERD, infection, post-nasal drip, aspiration. • Lung pathology: infection, tumor, fibrosis, pulmonary edema, COPD. • Irritation of other structure associated with cough reflex: pleura, pericardium, diaphragm. **Evaluate** • H&P and CXR usually define the cause. • Whether investigations should be done depends on patients goals of care and patients stage in the terminal illness trajectory.	Nonpharmacologic therapy is directed at the symptom rather than the underlying etiology. Goal is to control rather than eliminate cough. • Humidify air, Saline via nebulizer. • Avoid fumes. • Proper positioning reduces coughing secondary to reflux or aspiration. • Chest physiotherapy helps expectorate mucus.	Opioids suppress cough, but there is no scientific evidence allowing comparison of one opioid with another. • **Codeine** 8-20 mg PO q 4-6 h • **Morphine** 2.5-5 mg PO q 4-6 h • For patients already using substantial doses of opioids, one might increase the dose by 20% every 24-hour period, until control of coughing or side effects. • *Dextromethorphan* 10-20 mg PO q 4-6 h may have a synergistic effect with opioid *Little evidence to support the use of nebulizer in the management cough related to malignancy, or chronic cardiac disorders. May be effective if underlying COPD or asthma.*
ANOREXIA/CACHEXIA • Anorexia refers to the loss of desire to eat. • Cachexia refers to weight loss, especially of lean body mass. • Risk of pressure sores. **Primary Anorexia/Cachexia** Syndrome is due to a complex of abnormal metabolic, neuroendocrine and immunological pathways e.g. induced by the tumor. **Secondary Cachexia** Potentially reversible causes of Anorexia/ Cachexia including: • Factors causing ↓food intake or impaired GI absorption, e.g. dysphagia, nausea, depression, diarrhea. • Catabolic states e.g. infection, poorly controlled diabetes. • Loss of muscle mass due to decreased muscle activity e.g. prolonged inactivity.	• Frequently offer easily eaten small portions. • Minimizing dietary and consistency restrictions may tempt the patient to improve his or her intake. *The role of medical nutrition and hydration (also known as artificial nutrition and hydration) is not clear cut.* • The patient's end of life preferences should be respected. • A recent meta analysis of randomized clinical trials studying the effectiveness of nutritional supplementation (either oral, or via enteral or parenteral routes) identified *no evidence for clinical benefit* in a variety of clinical settings, including cancer, chronic lung or liver disease, and critical care settings *(Koretz, 2007)*.	Control nausea with gastric motility agent: **Metoclopramide** 10 mg po qid Stimulation of appetite:. *Megestrol Acetate* starting at 160 mg/day and increasing up to 800 mg/day depending on response. • Associated with an ↑ risk of thromboembolic events, peripheral edema, hyperglycemia, ↑ BP, and adrenal suppression. • For most conditions, there is scant information about improved quality of life, and no survival benefit has been shown. *Dexamethasone* 4-10 mg bid has been used but because of significant side effects it should generally be limited to terminally ill patients who are taking for another indication.

CCHCS Care Guide: Palliative Care

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Causes / Evaluation	General Measures	Medications
CONSTIPATION & BOWEL CARE **Common causes** • Poor oral intake or dehydration. • Malnutrition: related to the anorexia/ cachexia syndrome. • Poor fluid intake. • Drugs: opioids, anticholinergic drugs, diuretics, iron, etc. • Decreased mobility. • Abdominal tumors. • Hypokalemia, hypercalcemia. ***N.B.: Patients can become constipated even if they are not eating!*** **Diagnosing constipation** • Can present as diarrhea • Perform a digital rectal examination. • Occasionally a plain abdominal radiograph may assist in the diagnosis.	**Prevention** • General measures: encourage generous fluid intake (8-10 glasses/day). • FIBER NOT HELPFUL as patient becomes debilitated. • Encourage exercise as tolerated. **Suggested bowel routine for patients on regular opioids:** When starting a patient on an opioid, start laxatives simultaneously and give regularly not prn. • Start with a bowel stimulant and a stool softener (eg: senna 1-2 tabs h.s. + docusate 100 mg-200 mg bid po.) • Adjust dosages and frequencies as needed to ensure the patient has a soft, formed bowel movement every 1-2 days. • Patients often require senna 2-4 tabs bid up to qid prn, and docusate 200 mg tid up to qid prn. • If no bowel movement within 3 days, administer a fleet enema or Bisacodyl suppository rectally on day three. ***N.B.: One good response to a laxative or enema may not treat the constipation fully. The sigmoid may be clear but the rest of the colon may still be full of stool.***	**Treatment of established constipation** If stool in rectum: • Hard: glycerin suppository, Fleets enema, disimpaction. • Soft: bisacodyl (Dulcolax) or docusate (Colace) suppository, Fleets enema disimpaction. If no stool in rectum: Do plain x-ray. • No bowel obstruction: bisacodyl or docusate suppository , oral medication. • Bowel obstruction: appropriate therapy. **Doses** • Stool Softener: **Colace** 100mg 1-2 PO BID (also comes in liquid form for PEG tube feedings) • Stimulant Laxative: ♦ **Bisacodyl tablet** 5 mg 1-2 po QD-BID ♦ **Bisacodyl** suppository 10 mg PR QD-BID ♦ **Senokot** (NF) Senna 2-4 tabs PO QD-BID • **Lactulose** (10gm/15ml) 30-45ml PO BID-QID. • **Milk of Magnesia** (magnesium hydroxide 400mg/5 ml) 30ml PO TID-QID prn. • **Fleets enema** (Sodium phosphates) • **Magnesium citrate** (300 ml) 1 bottle in 24 hrs (especially if KUB shows large amount of stool in ascending or transverse colon).
NAUSEA/VOMITING There are multiple reasons for nausea. Identifying the cause will help determine the best course of treatment. **Cause -** frequently due to multiple causes • **Irritation or obstruction of the GI** tract:cancer gastritis, constipation, hepatitis, bowel obstruction, chemotherapy, gastric compression. • **Related to chemoreceptor trigger zone (CTZ)**: biochemical abnormality, ↑Ca+2, renal or hepatic failure, medication (opioids, antibiotics), sepsis. • **Related to vestibular system**: e.g. ASA. • **Related to cortical centers**: sites, smells, tastes, anxiety, conditioned vomiting, raised intracranial pressure.	• Avoid strong smells/perfumes • Small meals, eaten slowly • Limiting oral intake during periods of frequent emesis . • Relaxation techniques. Cornerstone is pharmacologic therapy: • Use in combination if necessary • Give before vomiting starts is possible • Match antiemetic medication to presumed causative mechanism. • **Prochlorperazine (Compazine)** works on CTZ-preferred for opioid related nausea. • **Promethazine (Phenergan)** muscarinic blocking effect may be responsible for antiemetic activity. Most useful in vertigo and gastroenteritis due to infections and inflammation. • **Metoclopramide (Reglan)** direct gastrokinetic effect and works on CTZ. • **Ondansetron (Zofran)** prevents vagal stimulation in GI tract and may also have central action. • **Haloperidol (Haldol)** works on CTZ. • **Chlorpromazine (Thorazine)**works on CTZ. • **Lorazepam (Ativan)** at cortical level.	**Nausea** • **Reglan** 10mg PO/SQ Q6H prn or QID (AC and HS) (**Good first-line** as works on CTZ and GI. Contraindicated in bowel obstruction). • **Compazine** 10mg PO/SQ/PR Q6H prn • **Phenergan** 25mg PO/IM Q6-8H prn **Nausea (persistent)** • *Ondansetron* 4-8mg PO BID-QID (**NF**). • **Decadron** 4mg PO/SQ/IV Q6H may help in nausea associated with chemotherapy, radiation, increased intracranial pressure • **Lorazepam** 0.5-2mg PO/SQ/IV/IM Q6H prn may help in anxious patient as adjuvant. • **Haloperidol** and **Thorazine** may be effective, but should only be used if other modalities are ineffective.

CCHCS Care Guide: Palliative Care

Consider Hospice Criteria. Hospice entry criteria are based on medical findings. However decisions to admit patients to hospice are influenced by nonmedical factors such as the patients decision to forgo life-prolonging care and focus on symptom management. Emphasis should be placed on evaluating the whole person and the entire burden of their illnesses). A patient may have multiple medical problems , none of which taken individually amount to terminal condition , but when taken together do indicate a terminal condition.

	Palliative Care	Hospice
Debility/ Failure to Thrive	• Greater than three chronic conditions in patient over 75 years old • Functional decline • Weight loss • Increasing frequency of outpatient visits, emergency department visits, hospitalizations	• Documentation of clinical progression of disease • ECOG score of three or more • No desire for aggressive treatment • Not a candidate for aggressive treatment • Frequent emergency room visits/frequent hospitalizations
Cancer	• Uncontrolled signs and symptoms due to cancer or treatment • Introduced at time of diagnosis - if disease terminal • Introduced when disease progresses despite therapy	• Aggressive or progressive malignancy with increasing sx , worsening lab values or evidence of metastases • Palliative Performance Score < 70% • Patient does not want further curative intent therapy • Decline supported by: Ca+2 > 12, WT Loss ≥ 5% in past 3 mos, recurrent disease after radiation or chemotherapy, S/S of advanced disease (i.e. malignant ascites, pleural effusion, need for transfusions) • Generally need tissue diagnoses (explain if not available)
Heart Disease	• Stage III or IV heart failure despite optimal medical management • Angina refractory to medical or interventional management • Frequent emergency department visits or hospital admissions • Frequent discharges from implanted defibrillators despite optimal device and antiarrhythmic management	• Heart failure symptoms at rest (NYHA Class IV) • Recurrent episodes HF despite optimal medical RX • Ejections fraction less than 20% • Rx resistant supraventricular or ventricular arrhythmias • H/O Cardiac arrest or resuscitation • H/O unexplained syncope • Brain embolism of cardiac origin (recent) • Concomitant HIV disease
Pulmonary Disease	• Oxygen-dependent, O2 saturation less than 88% on room air • Unintentional weight loss • Dyspnea with minimal to moderate exertion • Other pulmonary diagnoses, e.g., pulmonary fibrosis, pulmonary hypertension	• End Stage pulmonary disease documented by :Dyspnea at rest, ↓ functional capacity (bed to chair), fatigue, ↑ED visits or hospitalizations for infections and/or respiratory failure • Hypoxia at rest with O2 saturation ≤ 88% or pO2 < 55 mmHg on supplemental oxygen or hypercapnia PCO2 > 50 • Supportive evidence: right heart failure due to pulmonary disease, WT Loss >5 % over past 3 mos, resting pulse >100
Dementia	• Behavioral problems • Feeding problems - weight loss • Frequency of ED visits • Increased safety concerns	• Unable to walk, bathe or dress self without assistance • Incontinence • Less than six intelligible words • Frequent ER visits
Liver Disease	• Increased need for paracentesis for removal of ascitic fluid • Increased confusion (hepatic encephalopathy) • Increased safety concerns • Symptomatic disease	• INR > 1.5 with albumin <2.5 gm/dl • Evidence ESLD with refractory ascites or encephalopathy, SBP, recurrent variceal bleeding, or Hepatorenal syndrome • One of the following: WT Loss >5% in 3 mos, muscle wasting or Hepatocellular carcinoma
Renal Disease	• Dialysis • Stage IV or Stage V chronic kidney disease	• Not a candidate for dialysis or refuses dialysis • Creatinine clearance < 10 mL/min (< 15 mL/minute if DM) • Serum creatinine > 8.0 (> 6.0 if DM) • Supportive Comorbid conditions: advanced heart, lung, or liver disease, malignancy, AIDS, age >75, alb <3.5 • Supportive S/S uremia, intractable ↑K+, fluid overload
Neurologic	• Stroke • Parkinson's • ALS - amyotrophic lateral sclerosis • MS - multiple sclerosis	• Frequent emergency room visits • Albumin less than 2.5 • Unintentional weight loss • Decubitus ulcers • Homebound/bed confined

Based on Institute for Clinical Systems Improvement (ICSI) Health Care Guideline: Palliative Care Third Edition 2009
Hospice criteria based on National Hospice and Palliative Care Organization (NHPCO) criteria and are consistent with CMF criteria.

Consider Hospice Criteria. Hospice entry criteria are based on medical findings. However decisions to admit patients to hospice are influenced by nonmedical factors such as the patients decision to forgo life-prolonging care and focus on symptom management. Emphasis should be placed on evaluating the whole person and the entire burden of their illnesses). A patient may have multiple medical problems , none of which taken individually amount to terminal condition , but when taken together do indicate a terminal condition.

Women-CCWF

Central California Women's Facility (CCWF) has a Skilled Nursing Facility (SNF) where Palliative or Comfort Care (CC) is provided. Comfort Care admission criteria:

- The SNF attending Physician, CMO or designee certifies a prognosis of six months or less if the disease follows its expected course.
- The patient-inmate and or designated legal representative agree to Palliative/CC goals/philosophy of CC services.
- The SNF has the ability to meet the needs of the patient-inmate, according to the level and intensity of care required.
- There are adequate, cooperative efforts by the patient-inmate to follow safety measures and the plan for medical and non-medical emergencies.
- A Do not Resuscitate (DNR) must be signed and on file for the inmate-patient

Providers with women inmates meeting the criteria and requesting comfort care can contact the Medical Executive at CCWF.

Men-CMF

California Medical Facility (CMF) has a 17 bed Hospice unit that accepts referrals from all CDCR (men's) institutions. The CMF Hospice uses an interdisciplinary team approach in care planning and delivery. This closed unit attempts to maintain the patient in an inpatient setting as homelike as possible within the prison. Family visits are facilitated.

- Admission Criteria: General criteria see below, disease specific criteria see page 13.
  - Prognosis 6 mos or less– if prognostic uncertainty contact Hospice staff to discuss patient
- Custody requirements: Custody C&PR reviews each Hospice referral to see if custody level allows for admission. (Some custody levels require housing in a single cell only and single rooms are limited.)
- Waiting List: Varies but often there is no waiting list and providers are encouraged to communicate with CMF if they have an urgent referral.

Providers with men meeting the criteria and requesting Hospice care should contact Frank Santos, CMF Hospice Administrator at (707) 453-4009 to request a referral package.

CMF Hospice Referral Requirements- What Referring Institution Must Submit:

All Patients:

1. Current Medication Profile (both CDCR and outside hospital)
2. Last 3 months and other pertinent labs
3. All relevant imaging (x-ray, CT, other)
4. Last 3 months of physician progress notes
5. H&P done within the last 30 days
6. Hospice Agreement
7. Progress note stating that the patient has **6 months** or less to live
8. Advance Directive / DNR (if one exists)
9. Pre-Transfer Checklist
10. Level of Care Assessment
11. Discharge Summary

CMF-General Criteria for all Patients Considered for Hospice

*Patient has **either** of the following:*

A. **Documented clinical progression of disease**:

1. Progression of primary disease as listed in the disease-specific criteria, documented by serial physician assessment, laboratory, radiologic or other studies.
2. Multiple Emergency Department visits or inpatient hospitalizations over the last six months
3. For patients who do not qualify under 1 or 2, a recent decline in functional status may be documented:

   A. Recent functional decline to distinguish patients who are terminal from those with reduced baseline.
   B. Functional status may be documented by:

   - Karnofsky Performance Status
   - ECOG
   - PPS
   - Dependence in 3 of 6 activities of daily living ADL's are: Bathing, dressing, feeding self, transfer (chair to bed, lying to sitting) , continence of urine and stool, and ability to ambulate outside of cell.

B. **Documented recent impaired nutritional status related to the terminal process.**

1. Unintentional, progressive weight loss of >5% over the last 3 months.
2. Serum albumin less than 2.5gm/dl is helpful, but not used in isolation from other factors.

WHAT YOU SHOULD KNOW

Q: What is Palliative Care?

- Palliative care has also been known as "Comfort Care".
- Palliative care is medical care that tries to keep patients with serious medical illnesses comfortable.
- Palliative care tries to help patients with their worries, fears and stress as well as any pain or other physical problem they may have.
- Palliative care can be started at any time in the patient's illness, even when there is still hope for a cure.
- Palliative care can be provided by most, if not all, doctors, physician assistants, NP's and nurses.
- Palliative care can be done in many places (including General Population, OHU, CTC or hospital) depending on a persons illness and what medical needs they have at that time.

Q: What is Hospice?

- Hospice care also tries to keep patients comfortable as they die.
- Hospice care is usually used when a person has six months or less to live.
- Hospice care is given by a team made up of doctors, nurses, social workers, and Chaplains who work together to keep the patient comfortable.
- Hospice care tries to help the patient deal with any "unfinished business". If the patient wants getting in touch with family or wants religious support the hospice team can usually help.
- In CDCR hospice care is offered at CMF for men, and hospice-like comfort care is offered at CCWF for women.
- Most of the time your Primary Care doctor or cancer doctor will ask you if you are interested in the hospice program when the time is right.
- You are welcome to ask your doctor about hospice care at any time if you have questions.

Q: Do you have to have cancer to be accepted into hospice?

- No, persons with many types of illnesses (such as Heart Failure, liver disease, COPD, dementia, kidney failure) are allowed into hospice.

Q: Do you have to be in hospice to be considered for Compassionate Release or Medical Parole?

- No, these programs are different and it does not matter if you are in hospice.

Q: What is advance care planning?

- Thinking ahead about what kind of medical care you want as you get sicker.
- The kind of medical treatment you want usually depends on what is important to you.
- Talking about your wishes with loved ones and your doctors and nurses will help make sure that your wishes are followed.
- Writing down your wishes in an "Advance Directive" form is another way to be sure they will be followed.

  It's important to remember that…
  - Your wishes can be changed any time.
  - Advance care planning is done over time and your wishes may change as your health changes.
  - It is best to think about what you want before you get really sick

Q: What is an Advance Directive?

- Advance directives are papers that allow you to write your wishes about end of life care.
- They allow you to say what you want so that family, friends, doctors and nurses will know for sure what you want if you can no longer speak for yourself.
- In CDCR we use CDCR Form 7421 Advance Directive for Health Care .
- You may request an CDCR Form 7421 at anytime, even when you are young and perfectly healthy.
- The Form 7421Advance Directive allows you to:
  - Name someone to speak for you when you can no longer speak for yourself (called a surrogate/agent)
  - Say what your wishes are (e.g. "I don't want CPR, or a breathing machine", "feeding tube ok")

WHAT YOU SHOULD KNOW

Q: What is a Health Care Surrogate/Agent?

- A health care surrogate (also called an agent) is a person that you pick to make health care choices for you when you cannot speak for yourself.
- The health care surrogate is very important.

What a Health Care Surrogate Can Do (*once you can longer speak for yourself*)

- Talk with your doctor about your medical problems and agree to start or stop medical treatments including: medicines, tests, CPR, breathing machines (ventilators), feeding tubes
- Tell others about your end of life wishes and make sure they are followed

Choosing a Health Care Surrogate:

A health care surrogate is often a family member, but does not need to be. He/she should be someone who:

- you can trust;
- will be able to talk with your family
- is willing to do the job
- knows about what you want

Your Health Care Surrogate cannot be your doctor or other medical provider.

Q: What is a DNR order?

- A do not resuscitate (DNR) order is another way you ask that your wishes are followed.
- DNR is a request not to have cardiopulmonary resuscitation (CPR) if your heart stops or if you stop breathing.
- In most cases doctors and nurses will try to help all patients if their heart stops or if they stop breathing by doing CPR unless the patient has asked not to have this done.
- Unfortunately when a person has a serious or terminal illness CPR does not usually work and trying it can cause the person more pain and only slow their dying.
- In CDCR a POLST form (see below) is used to allow a patient to say whether he or she wants or does not want CPR to be tried.

Q: What is a POLST?

- POLST is short for Physicians Orders for Life Sustaining Treatment.
- This is a form that is used by all hospitals in California (and other states).
- In CDCR POLST Form 7385 is used to write a patient's wishes about end of life care.
- The POLST allows a patient to say:
  - Try CPR or Do Not Try CPR (Allow Natural Death)
  - I want comfort care only or I want full treatment (or something in between).
  - I want a feeding tube tried or I don't want a feeding tube tried.
- If you are seriously ill, especially if you have been in the hospital your doctor should talk with you about filling out a POLST.
- If your doctor has not asked 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 YOU SHOULD KNOW

Myths About Death and Dying:	
"Death is too frightening to talk about" "It's not normal to talk bout death"	• In the United States death is often hidden away in the back rooms of hospitals. Many people do not like talking about death even though death is a normal part of life. • In the past grandparents died at home and children learned death was a normal part of life. • Thinking about dying can be scary, but often learning more of the facts can make it less scary. • Feel free to ask questions of your doctor or nurse.
"Dying is always painful"	• This is one of the most common myths about dying. • Many people die without having pain. • If pain does occur, it can usually be treated and the patient can be made comfortable.
"It is not legal to stop a treatment such as a breathing machine once it is started".	• This is not true. • In the early 1980's the courts said that there is no legal difference between stopping a treatment once it is started and never starting the treatment. • Patients or families can decide to *withhold* treatment that is not wanted (never start it) • Patients or families can decide to *withdraw* treatment that is no longer wanted (stop it)
"No matter what the patient must continue to be fed and be given liquids during the dying process"	• There comes a time in some cases where giving the dying person food (tube feeding) and liquids is no longer helpful and so these are stopped. • For persons at the end of their life stopping or not starting tube feeding and fluids is not painful. • In fact the opposite is true: giving tube feeding and liquids to dying persons can prolong their discomfort and prevent nature from taking its course. • This is never done without a lot of thought. • The choice to withhold or stop tube feeding and/or liquids is made only when it is clear that using them would not help. • It is best to think about whether you would want tube feeding and discuss your wishes with your doctor and nurse.

WHAT YOU SHOULD DO

MY END OF LIFE WISHES / VALUES

Think about which of the following are important to you and you think about dying:

___physical comfort ___relief of pain and distress ___to die naturally
___live as long as possible no matter what ___other_____

Which of the following are important to your quality of life?

___able to care for my physical needs ___recognizing family & friends ___making my own decisions
___having a say about my care needs ___receiving palliative (comfort) care & hospice
___other_____

Have you thought about whether you would want to have CPR done? __use __don't use __not sure

Have you thought about whether you would want a feeding tube? __use __don't use __not sure

Would you want to be kept alive by machines (ventilator) in the following cases?:

- If my brain's thinking functions were destroyed? __use __don't use __not sure
- If I were near death with a terminal illness? __use __don't use __not sure

Are you a member of a religion? __No __Yes If yes, is there a person you would want to help attend to your spiritual needs as death nears? (Specific faith or congregation)_____

If your medical team believes that your death is near is there a family member you would like to be told? (Must be on CDCR Form 127) _____

Following your death is there a family member you would like to be told? (Must be on CDCR Form 127)
_____

Are there other things important for someone to know about you, in the event that you become unable to communicate or your death is near?

How do you feel about death and dying? (Have you had someone close to you die? Did that person's illness or medical treatment change your thinking about death and dying?)

Note: Complete and share this with your doctor, family and caregivers.

MY DIAGNOSIS/MEDICATIONS

- It is important that you understand your medical conditions and ask your medical team any questions you have.

My major health conditions:

_____

_____

- It is important to know what medications you are taking and why you are taking them.

Questions about my medications:

_____

_____

ADVANCE DIRECTIVES

Have you completed either?:

___**Advance Health Care Directive** (CDCR 7421)

If so approximately when? _____

Who did you chose to speak for you if you can not speak for yourself? _____

_____

_____**POLST** (CDCR Form 7385)

If so, approximately when? _____