

Palliative Care Collaborative Care Plans CCPs

End-of-Life Stage

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Collaborative Care Plan End-of-Life Stage Palliative Performance Score 30 – 0

Background Information

Collaborative Care Planning is a process used by interdisciplinary teams to improve quality and efficiency of care for specific patient populations. Teams develop collaborative care plans to:

- Guide the care of patients
- Promote the critical review of care processes
- Promote quality patient care
- Promote interdisciplinary collaborative practice
- Promote patient satisfaction

What are the Collaborative Care Plans

These Collaborative Care Plans (CCPs) build on the work of the Kingston Frontenac Leeds and Addington Palliative Care Integration Project¹ and align with the Canadian Hospice Palliative Care Association's (CHPCA) Model for Hospice Palliative Care². These revised CCPs were developed by a provincial working group³ that was tasked with developing a tool targeted at the generalist provider that would improve the quality of patient care by increasing consistency across providers and settings.

The CCPs uses the CHPCA Model as a framework. Each "Domain of Issue" from the Model (e.g., Disease Management) is listed on a separate page and is broken down by the Model's Essential and Basic Steps During a Therapeutic Encounter. The Palliative Performance Scale⁴ (PPSv2) is used to determine which plan is appropriate. A separate Care Plan is provided for each stage; Stable (PPS 100 - 70%), Transitional (PPS 60 - 40%), and End-of-Life (PPS 30 - 0%). The Edmonton Symptom Assessment System (ESAS)⁵ is being used as a common symptom self screening tool for cancer patients in Ontario and therefore is referenced throughout the document.

Definition of Collaborative Care Plans

CCPs are interdisciplinary guides to practice designed to place the patient at the focal point of care, to promote continuity and coordination of care, and to promote communication amongst all disciplines. The CCPs define the activities, interventions and expected patient outcomes that should occur for patients requiring palliative services based on their functional performance as defined by the Palliative Performance Scale (PPS). The CCPs provide a guide to clinical practice but should never replace sound clinical judgment. Each patient is an individual and treatment should be modified according to the individual patient's needs and the particular circumstances.

Disclaimer

Care has been taken in the preparation of the information contained in this report. Nonetheless, any person seeking to apply or consult the report is expected to use independent clinical judgment in the context of individual clinical circumstances or seek out the supervision of a qualified clinician. Cancer Care Ontario makes no representation or guarantees of any kind whatsoever regarding the report content or use or application and disclaims any responsibility for its application or use in any way.

Acknowledgements

We would like to acknowledge the work of the Palliative Care Integration Project, Palliative Care Medicine, Queen's University who developed the original version of the CCPs. We would also like to acknowledge the provincial CCPs Working Group members who generously donated their time and expertise toward the development of this resource (refer to Table entitled CCPs Working Group for a complete list of the members).

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Palliative Performance Scale (PPSv2) version 2 (developed by Victoria Hospice Society)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work 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 Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable 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	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	•

^{*}Home is defined as the person's usual residence (may include long term care facility)

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	COLLABORATIVE CARE PLAN FOR END-OF-LIFE PATIENTS		
DOMAINS OF ISSUES	THE PROCESS OF PROVIDING CARE IN THE END-OF-LIFE STAGE: ESSENTIAL & BASIC STEPS DURING A THERAPEUTIC ENCOUNTER		
DISEASE MANAGEMENT	STEP 1: ASSESSMENT	STEP 4: CARE PLANNING	
 Primary diagnosis, prognosis, evidence Secondary diagnoses (e.g., dementia, psychiatric diagnosis, substance use, trauma) Co-morbidities (e.g., delirium, seizures, organ failure) 	Assess: Person and/or family members' understanding of disease, possible/expected co-morbidities and prognosis Relevance of current disease management protocols e.g. ongoing investigations, medications, treatments, clinic visits Monitor PPS scores daily Reassess investigations, clinic visits, goals of care and the plan of treatment Confirm if the physician will make home visits	 Develop a plan of treatment related to disease management that takes into account the person's values and goals Mutually determined goals of care provide a foundation for all care planning 	
Advance events (e.g. side	STEP 2: INFORMATION SHARING	STEP 5: CARE DELIVERY	
 Adverse events (e.g., side effects, toxicity) Allergies 	 Determine need for translation Confirm confidentiality limits Address any deficits in understanding of disease, co-morbidities and prognosis 	 Identify the most responsible physician Determine the professional care team member who will lead, coordinate and facilitate the functions and activities of the team Provide family and informal caregivers with the orientation, ongoing education, training and support required to promote confidence and competence in the provision of care If relocation of care delivery occurs, facilitate communication of the plan of care to the appropriate health care professional in the new setting through transfer forms, or telephone consultation 	
	STEP 3: DECISION-MAKING	STEP 6: CONFIRMATION	
	 Determine who the person wants to include in the decision making process (e.g., substitute decision maker if the person is incapable) Obtain consent from the capable person or the substitute decision maker if the person is incapable for an end-of-life plan of treatment that includes: Setting for care Resuscitation status Having, withholding and or withdrawing treatments (e.g. lab tests, medications, etc.) 	Determine the person/family/team's understanding of: the prognosis expected course of the illness Determine the person/family/team's satisfaction with the current plan of treatment as it relates to management of the disease and co-morbidities	

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COLLABORATIVE CARE PLAN FOR END-OF-LIFE PATIENTS			
Domains of Issues	THE PROCESS OF PROVIDING CARE IN THE END-OF-LIFE STAGE:		
DOMAINS OF 1330ES	ESSENTIAL & BASIC STEPS DURING A THERAPEUTIC ENCOUNTER		
PHYSICAL Pain & Other Symptoms (other symptoms include, but are not limited to): Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns, effusions (pleural, peritoneal) Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea,	STEP 1: Assessment Assess the person and/or family's' knowledge and understanding of the ESAS score Utilize person or caregiver completed ESAS daily to identify any physical issues of concern Conduct a comprehensive physical assessment to identify any issues related to any of the body systems Only techniques with the potential to provide beneficial information without undue risk or burden are used Any identified issue will require further in depth assessment Utilize validated assessment tools (e.g., comprehensive pain assessment) Assess for urinary retention/infection, oral intake, skin	STEP 4: CARE PLANNING Consider consult to Palliative Care Team for complex symptom management issues Initiate other interdisciplinary referrals Customize a plan of treatment that is flexible and aims to: address the identified symptoms respect the person's choices respect the person's culture, values, beliefs, personality and preferences support the desire for control, independence, intimacy and sense of dignity for as long as possible proactively address emergent issues (e.g. who	
bloating, dysphagia, dyspepsia Oral conditions: dry mouth, mucositis Skin conditions: dry skin, nodules, pruritus, rashes General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo Level of consciousness & cognition	 integrity, mobility and need for assistive devices Reevaluate the need for routine assessments (e.g., vital signs, blood glucose) Assess swallowing ability STEP 2: INFORMATION SHARING Determine the person and/or family's desire for information at each visit Share information related to issues identified in a timely manner and in a language and manner understandable and acceptable to the person and/or family Openly discuss any requests related to management of physical symptoms (e.g., nutrition, hydration, dyspnea) Provide information regarding physiological changes with progression of disease (e.g., appetite, hydration, fatigue) 	to call, what to do, escalating symptoms)	
Motor Function	STEP 3: DECISION-MAKING	STEP 6: CONFIRMATION	
 (e.g. mobility, swallowing) Sensory Function (hearing, vision) Physiologic Function (e.g. breathing, circulation, sexual) Fluids, nutrition Wounds Habits (e.g. alcohol, smoking) 	 Assess the person's decision making capacity whenever a decision related to treatment is being made Encourage person and/or family to consider their options and current goals and prioritize the importance of each of the identified issues Obtain informed consent for treatments based on options offered Use an ethical framework to guide decision making around end-of-life care (e.g., palliative sedation, artificial hydration) 	 Determine the person/family/team's satisfaction with the plan of treatment as it relates to the management of physical issues Anticipate the need for alternative routes of medication administration (e.g., PO to SC) Anticipate the need for crisis management (e.g., symptom response kit, dark towels available for hemorrhage) 	

	COLLABORATIVE CARE PLAN FOR END-OF-LIFE PATIENTS		
DOMAINS OF ISSUES	THE PROCESS OF PROVIDING CARE IN THE END-OF-LIFE STAGE: ESSENTIAL & BASIC STEPS DURING A THERAPEUTIC ENCOUNTER		
PSYCHOLOGICAL	STEP 1 : ASSESSMENT	STEP 4: CARE PLANNING	
Personality strengths, behaviour, motivation	 Review ESAS scores for anxiety, depression and well being daily to identify any psychological issues of concern Listen for subtle cues in conversation that reflect anxiety, depression and fear (e.g., I am tired of 	Customize a plan of care that is flexible and aims to: address the identified psychological issues (fears, anger, anxiety, depression, etc.) respect the person's choices respect the person's culture, values, beliefs, personality	
 Depression, anxiety Emotions (e.g., anger, distress, hopelessness, loneliness) 	this") Observe for behavioural cues (e.g., withdrawn, facial expression) If required a comprehensive assessment should	 and preferences support the desire for control, independence, intimacy and sense of dignity for as long as possible With the permission of the person and/or family, refer to other 	
Fears (e.g., abandonment, burden, death)	 be done by a health care professional Utilize validated assessment tools (e.g., comprehensive depression assessment tools) Identify: 	team members/community resources as appropriate Consider referral to Social Work/Mental Health/Spiritual/ Pastoral Care Consultant, Hospice and other volunteers	
Control, dignity, independence	strengths & vulnerabilities		
Conflict, guilt, stress, coping responses	 emotional and behavioural responses methods of coping realistic and unrealistic expectations 		
Self-image, self-esteem	 previous losses level of tolerance for inconsistency and changes in the plan of treatment conflicted relationships Explore person and/or family's fears, as appropriate 		
	STEP 2: INFORMATION SHARING	STEP 5: CARE DELIVERY	
	Respect the confidentiality limits as defined by the person Share information in a timely manner and in a setting where privacy can be ensured Be prepared for open discussion of topics such as euthanasia, assisted suicide, withdrawal of treatment, etc Provide clear and consistent responses Identify need for team meetings Foster realistic hopes as illness progresses	 Promote a setting of care that is safe, comforting and provides ample opportunity for privacy and intimacy Be sensitive to changes that may cause anxiety for the person and/or family 	
	STEP 3: DECISION-MAKING	STEP 6: CONFIRMATION	
	 Offer therapeutic interventions aimed at relieving suffering and enhancing quality of life and that are not associated with undue risk or burden (e.g., music therapy, massage, guided imagery) Voluntary consent is required for any treatment options offered 	Determine the person/family/team's satisfaction with the plan of treatment as it relates to the management of psychological issues	

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COLLABORATIVE CARE PLAN FOR END OF LIFE PATIENTS				
DOMAINS OF ISSUES	THE PROCESS OF PROVIDING CARE IN THE END-OF-LIFE STAGE: ESSENTIAL & BASIC STEPS DURING A THERAPEUTIC ENCOUNTER			
SOCIAL	STEP 1 : ASSESSMENT	STEP 4: CARE PLANNING		
Cultural values, beliefs, practices	 Assess changes in roles and the impact within family unit (e.g., caregiver strain and fatigue, lack of privacy/intimacy). If children living with person assess their level 	 Scheduling of visitors may be restricted at this time to close family and friends Encourage activities that will strengthen family bonds (reminiscence, life review) 		
Relationships, roles with family, friends, community	of comfort with person's presence in home ldentify issues of isolation, abandonment, conflicted relationships, mental health, socio	Consider referral to Social Work, Legal/Financial Consultant, Hospice and other volunteer programs, First Nations and other cultural groups		
Isolation, abandonment, reconciliation	 economic status Identify the need for assistance with financial, legal affairs and issues related to future 			
Safety, comforting environment	 incapacity Identify the person and/or family's current and potential support systems 			
Privacy, intimacy	Consider an in-depth assessment by a Social Worker			
Routines, rituals,	STEP 2: INFORMATION SHARING	STEP 5: CARE DELIVERY		
 recreation, vocation Financial resources, expenses Legal (e.g., powers of attorney for business, for business, advanced directives, last will/ 	 Inform the person and/or family of the resources available in the community to address social issues Facilitate family members' awareness of compassionate care benefits Share information about advance care planning 	 Maintain a calm peaceful and comfortable environment in all settings for persons and family Maintain meaningful interaction with the person without the expectation of a response Be respectful of person's culture, values, beliefs, personality and preferences 		
testament, beneficiaries)	STEP 3: DECISION-MAKING	STEP 6: CONFIRMATION		
Family caregiver protectionGuardianship, custody Issues	 With person and/or family's permission, encourage family and close friends to organize shifts for respite Facilitate identification of goals and social priorities (e.g., financial, relationship, legal) 	Determine the person/family/team's satisfaction with the plan of treatment as it relates to the management of social issues		

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	COLLABORATIVE CARE PLAN FOR END-OF-LIFE PATIENTS				
Domains of Issues The process of providing care in the end-of-life stage					
		ESSENTIAL & BASIC STEPS DURING A THERAPEUTIC ENCOUNTER			
SPI	RITUAL	STEP 1 : ASSESSMENT	STEP 4: CARE PLANNING		
•	Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, Icons	 Review ESAS scores for anxiety, depression and well being daily to identify any spiritual issues Utilize comprehensive spiritual assessment tools Explore with person and/or family: their meaning of life, death and illness their relationships the concept of anticipatory grieving their hopes and fears beliefs and practices that have sustained them in the past Consider an in-depth assessment by a Spiritual Advisor STEP 2: INFORMATION SHARING Facilitate timely and uninterrupted 	Customize a plan of treatment that is flexible and aims to: Respect the persons' and family's culture, values, beliefs, personality and preferences incorporate the icons, symbols, rites and rituals that have particular meaning to the person make the environment conducive to reflection, compassion, tenderness, transcendence, love, the sacred acknowledge hope reframe goals into short term tasks that can be accomplished Consider referral to Pastoral/Spiritual Advisor or other appropriate team member STEP 5: CARE DELIVERY Team members employ the appropriate communication		
		 interactions Allow the person to express fears and suffering without hesitation or shame Discuss goals STEP 3: DECISION-MAKING	skills that are key to sensitive discussions Avoid quick fix responses and religious clichés Meaning comes from within the person and is best discovered by the person telling his or her story and the caregiver listening		
		Offer options to both person and family	Determine the person/family/team's satisfaction with the		
		 Offer options to both person and family members in support of spiritual healing (e.g. journaling of thoughts and feelings, meditation, music) Determine what rituals and devotional practices would have meaning in the circumstances and obtain consent to incorporate them into the plan of treatment 	plan of treatment as it relates to the management of spiritual issues		

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	COLLABORATIVE CARE PLAN FOR END-OF-LIFE PATIENTS		
DOMAINS OF ISSUES	THE PROCESS OF PROVIDING CARE IN THE END-OF-LIFE STAGE ESSENTIAL & BASIC STEPS DURING A THERAPEUTIC ENCOUNTER		
PRACTICAL Activities of daily living (e.g., personal care, household activities) Dependents, pets	STEP 1 : ASSESSMENT Assess practical needs: Functional assessments (e.g., activities of daily living) Children's needs Caregiver's needs	Develop a plan of treatment that incorporates interventions to maintain independent functioning for as long as possible (e.g., transfer techniques) Facilitate timely access to equipment (e.g., hospital bed, walker, commode, continence supplies, raised toilet seat) Anticipate equipment, support needs and follow-up with change in setting of care (e.g., hospital to home) Facilitate appropriate referrals (e.g., physiotherapy, occupational)	
Telephone access, transportation	STEP 2: INFORMATION SHARING • Facilitate family members' awareness of available local community resources STEP 3: DECISION-MAKING • Determine what services/resources the	 therapy) STEP 5: CARE DELIVERY Minimize changes in care plan If relocation of care delivery occurs, facilitate communication of the most current plan of care to the appropriate health care professional in the new setting through transfer of forms, or telephone consultation STEP 6: CONFIRMATION Determine the person/family/team's satisfaction with the plan of 	
	person/family are prepared to accept	treatment as it relates to the management of practical issues	

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	Collaborativ	VE CARE PLAN FOR END-OF-LIFE PATIENTS		
DOMAINS OF ISSUES	THE PROCESS OF PROVIDING CARE IN THE END-OF-LIFE STAGE:			
	ESSENTIAL & BASIC STEPS DURING A THERAPEUTIC ENCOUNTER			
END OF LIFE CARE/ DEATH	STEP 1 : ASSESSMENT	STEP 4: CARE PLANNING		
Life closure (e.g., completing business, closing relationships, saying goodbye) Gift giving (e.g., things, money, organs, thoughts) Legacy creation Preparation for expected death Anticipation & management of physiological changes in	Assess person and family's understanding of and preparedness for death (i.e., assess needs of child of dying family member) Assess level of burden and stress being experienced by the caregivers Assess and review resuscitation status Explore what the person and family know and what they don't knot (e.g., prognosis, dying process)	 Facilitate the implementation of a plan of treatment that addresses the physical, psychological, cultural and spiritual needs of the person, family and informal caregivers Develop a plan of treatment that addresses symptoms such as upper airway secretions, restlessness, delirium Develop a plan with the family regarding access to 24/7 telephone support Confirm the completion of the Do Not Resuscitate Confirmation Form (DNRC) in Ontario (for persons at home, in LTC and retirement home settings) Discuss the (in)appropriateness of calling 911 Develop a plan for expected death which includes: the desired setting of care how and to whom the death will be communicated any post mortem rites or rituals that family desire (e.g. time alone with the body, bathing and dressing, prayers led by a minister or priest) plan for pronouncing and certifying the death funeral, celebration of life service, memorial care of the body after death including who will notify the funeral home 		
the last hours of life	STEP 2: INFORMATION SHARING	for transport of the body STEP 5: CARE DELIVERY		
 Rites, rituals Pronouncement, certification Perideath care of family, handling of the body Funerals, memorial services, celebrations 	 Introduce information to family and other informal caregivers related to the physiological changes that are expected to occur in the last hours of life Introduce information about the benefits and burdens of interventions that have the perception of prolonging life such as artificial nutrition and artificial hydration, administration of antibiotics, blood transfusions, etc. Explore and discuss questions Encourage the person and family to consider arrangements regarding: support desired at time of death rites or rituals (care of body after death) funeral, celebration of life service, memorial Introduce information about the process of pronouncing and certifying death 	 Promote a calm, peaceful and comfortable environment for the person and family regardless of the setting Encourage and support life review, when appropriate At the time of death: Implement the pre-determined plan for expected death Arrange time with the family for a follow-up call or visit, if appropriate Provide bereavement resources (e.g. booklet) 		
	STEP 3: DECISION-MAKING	STEP 6: CONFIRMATION		
	 Review desired setting for ongoing care delivery and determine family/caregiver ability/willingness to participate in care at end-of-life Identify goals and expectations of care 	Determine the family/team's satisfaction with the plan of treatment as it relates to the management of end-of-life care/death issues		

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COLLABORATIVE CARE PLAN FOR END-OF-LIFE PATIENTS			
THE PROCESS OF PROVIDING CARE IN THE END-OF-LIFE STAGE: ESSENTIAL & BASIC STEPS DURING A THERAPEUTIC ENCOUNTER			
DOMAINS OF 1330ES			
Loss, GRIEF • Loss • Grief (e.g., acute, chronic, anticipatory) • Bereavement planning • Mourning	Determine person and family understanding of and preparedness for death Identify previous losses Identify person and family members' previous and current coping (e.g., alcohol use and substance use) Assess for evidence of suicidal ideation Identify person and family members who are at risk for complicated grief (e.g., multiple unresolved losses, death of a child) Utilize comprehensive assessment tools	 Incorporate cultural and spiritual rites and rituals that have meaning for the family into the plan of treatment (e.g., gift giving, legacy creation, memory boxes, hand casts) Consider referral for person and family to address anticipatory grief Encourage the bereaved to make an appointment with an appropriate health care provider within weeks of the death Encourage the bereaved to make an appointment with the family physician within weeks of the death Refer to appropriate Health Care Providers for advanced interventions (e.g., suicidal ideation) Consider referral of bereaved family member to appropriate local resources Consider referral to, Spiritual Advisor, Pastoral Care, Grief Counselor, Hospice and other Volunteer programs 	
	Encourage the person and/or family to express feelings and emotions Share information about the grieving process and anticipatory grief Provide examples of rituals that can facilitate healthy grieving Provide age appropriate information about grief responses. STEP 3: DECISION-MAKING The person and/or family to determine the support desired unless there is evidence of suicidal ideation.	Provide age specific resources for those who are grieving STEP 6: CONFIRMATION Determine the person/family/team's satisfaction with the plan of treatment as it relates to the management of loss and grief issues	

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References

- 1. Kingston Frontenac, Addington and Leeds Palliative Care Integration Project, Collaborative Care Plans, Palliative Care Medicine Queen's University March 2006
- 2. Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Ottawa, ON: Canadian Hospice and Palliative Care Association, 2002 http://www.chpca.net/
- 3. Refer to Table below for list of Working Group Members
- 4. Victoria Hospice, 2003 Palliative Performance Scale (PPSv2)
- 5. Alberta Health Services (previously Capital Health) Regional Palliative Care Program. Edmonton Symptom Assessment System (ESAS)

Regional Educational Programs

CAPCE - Comprehensive Advanced Hospice Palliative Care Education Program for Nurses - The program focuses on developing a Hospice Palliative Care Resource Nurse within the health care provider organization in which they work – long-term care homes, hospices, hospitals, Community Care Access Centres` and community nursing agencies.

LEAP- Learning Essential Approaches to Palliative and End-of-Life Care - The 2.5 day LEAP course offers an opportunity for active learning about current best-practice in caring for patients with life-threatening and life-limiting illness, with a special focus on family practice and community settings.

CCPs Working Group Members

Ool 3 Working Group Members	
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