Priority Topics and Key Features for the Assessment of Competence in Palliative Care

This collection of priority topics and key features for assessment was developed by the College of Family Physicians of Canada (CFPC) Working Group on the Assessment of Competence in Palliative Care from 2013 to 2016. It outlines what to assess to determine competence at the enhanced skills level, following the CFPC’s traditional approach of developing priority topics, procedures, and their key features.

The goal of these priority topics and key features is to guide the assessment of competencies required for awarding Certificates of Added Competence (CAC), both for residents in enhanced skills programs and for practice-eligible candidates, and to inform curriculum and training development.

When using this document, it is critical to remember that the priority topics and key features listed are not meant to be an exhaustive scope of practice in palliative care, nor do they represent a checklist for the determination of competence. They represent a guide to focus the sampling of performance. When trainees consistently demonstrate most of the key features across a good sample of the priority topics, it can be inferred that they have competence in palliative care.

It is also important to bear in mind that, because there is a great overlap between crucial competencies that are required for different priority topics, the tendency was to avoid repetition and list key features selectively.

Successful candidates for a Certificate of Added Competence in Palliative Care are expected to have demonstrated core competence in family medicine, including the Six Essential Skills and Procedures.

The order of the appearance of the priority topics listed reflects the frequency in which the topics appeared in the validation survey of the topics.

Finally, this is a living document that will be regularly revisited and updated to ensure its relevance.
How the priority topics and key features were developed

The Working Group on the Assessment of Competence in Palliative Care (6 members) acted as the nominal group, generating an initial list of priority topics through an individual survey followed by group discussion and consensus. A survey to a larger group of family practitioners (196 recipients at a 33% response rate), representative of physicians from across the country, generated another independent list.

The lists of priority topics generated by the nominal group and the larger reference group were almost identical, both in the topics named and the priorities assigned, with a strong positive correlation of 0.83. A final list of 17 priority topics was identified.

Key features were developed and finalized for all topics using the nominal group technique, which included four iterations of individual comments, discussions and consensus building.
PALLIATIVE CARE

Priority Topics for the Assessment of Competence: Enhanced Skills
Key Features

How to use the priority topics and key features

It is important to note that materials in this booklet are intentionally selective and not comprehensive. It is most desirable and useful to assess what will best discriminate between competent and less competent individuals. Priority topics do not represent an extensive list of topics that should be covered in training, but rather a selective list of areas for assessment that can help teachers/assessors to infer overall competence in palliative care. Key features represent the critical or essential steps in the resolution of a clinical situation or problem, so the achievement of underlying competencies can be inferred. All key features refer to observable actions, not knowledge. They do not cover all necessary steps (e.g., history, physical examination, diagnosis, management), but only those that are critical and most likely to be missed.

As such, the priority topics and their features are not meant to be used in a checklist approach when assessing competence. They are best used for guiding assessment efforts (sampling, observation, reflection) over time to build a case for overall competence or the lack thereof. They may also be useful in the following situations:

For trainees:
- Use as a guide for self-reflection on competence and development of a learning plan, particularly prior to and during clinical experiences
- Use as a guide for soliciting feedback from teachers/assessors

For teachers/assessors:
- Compare and contrast materials in this document with your assessment strategies and adjust as necessary
- Use as a guide assessment of your trainees, including soliciting feedback, developing questions to ask trainees, and completing field notes
- Use as a guide to help develop learning plans for your trainees
- Use as a self reflection guide to assess your teaching

For programs:
- Use as assessment standards when making decisions about residents’ successful completion of training
- Use as a guide to develop assessment strategies
- Use as a guide to plan curriculum that can adequately expose trainees to the priority topics and procedures
PALLIATIVE CARE

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Special thanks to Dr. Tim Allen, past Director of Certification and Assessment, for his guidance and invaluable contribution to this project.
Priority Topics

1. Pain
2. Families
3. Advance planning and goals of care
4. Working as a team
5. Nausea/vomiting/bowel obstruction
6. Imminent death
7. Despair and suffering
8. Community resources
9. Breathlessness
10. Delirium
11. Anxiety and depression
12. Palliative sedation therapy
13. Maintaining the clinician’s well-being
14. Emergencies
15. Medical assistance in dying (MAID)
16. Anorexia/cachexia/nutrition/fatigue
17. Non-malignant terminal illness
Priority Topic 1: Pain

1. For a patient in palliative care with pain, assess:
   - The pain (e.g., intensity, character, descriptors, and impact on function), using appropriate pain assessment tools
   - The type and origins of the pain (e.g., cancer-related visceral pain, bone pain from metastases, neuropathic pain)
   - The total suffering experience (physical, psychological, spiritual, social, cultural) related to the pain of the patient and family

2. For a patient in palliative care who is being treated for pain, follow up in a timely manner and adjust the plan appropriately.

3. For patients in palliative care with pain, identify those with high risk factors (e.g., history of substance abuse, cognitive impairment, communication difficulties), who may require a more complex management plan.

4. For a patient in palliative care with pain, recognize a pain crisis, to plan urgent specific treatment of the underlying cause(s).

5. When managing pain in a patient in palliative care, including breakthrough pain, consider the use of opioids (including methadone) when required and adjust dosing appropriately.

6. For a patient in palliative care whose pain is being treated with opioids, look for, recognize, and manage the side effects and complications of opioid use, including neurotoxicity/opioid-induced hyperalgesia.

7. For a patient in palliative care with complicated pain (e.g., bone pain from metastases, neuropathic pain, complex pain syndrome, intractable pain, and incident pain), manage the pain using multiple approaches including:
   - Medications
   - Non-pharmaceutical options, such as surgery, nerve blocks, and radiotherapy
   - Expertise of other health care providers, such as psychologists, music therapists, pastoral care, etc.
Priority Topic 2: Families

1. When facilitating discussion with families of palliative care patients when there are differences of opinion about care:
   a) Recognize that pre-existing conflicts may be more difficult to resolve
   b) Explore management options, considering the patient’s wishes and focus on what is best for the patient
   c) Assess the potential impact of cultural values and beliefs especially when different from your own
   d) Recognize the different information needs of the family and of the team, and when they are not aligned (e.g., family does not want the patient to know the "bad news" or the diagnosis)

2. For families of palliative care patients, look for and identify family members who are at high risk for severe distress (e.g., suicidal ideation) or complicated grief, and facilitate treatment as appropriate.

3. When withdrawal of some aspect of care is being considered for patients in palliative care (e.g., intravenous fluids, medications) and it raises concerns amongst family members, address their concerns (e.g., review the treatments in the context of the patient’s goals of care, discuss the options, focus on what will be done rather than not done).

4. When speaking to children about the death of a family member, speak gently and honestly at an age-appropriate level, and provide help and advice to parents/family about how to discuss death and dying with a child.

5. When a child in your care dies or is dying, anticipate a strong emotional reaction from the parents, family, and the health care team, including yourself, and arrange for the appropriate support.
Priority Topic 3: Advance planning and goals of care

1. For a patient in palliative care, establish the patient’s goals of care based on their values and beliefs by:
   - Addressing the patient’s understanding of their illness
   - Reviewing the pros and cons of the options that have been offered, that may become available, or that the patient wishes to explore
   - Helping the patient to set or change priorities, and to translate these into practical decisions about treatment and other care
   - Helping to reframe meaning and hope when facing the end of life

2. For more complex situations in palliative care (e.g., for a patient or substitute decision maker(s) with a different culture or beliefs, when there is conflict within the family) help establish goals of care effectively by using patient-centred communication skills (e.g., active listening, being attentive to non-verbal behaviour) to resolve misunderstandings or conflicts.

3. When there are transitions in a patient’s palliative illness (e.g., change of place of care, treatment, patient’s wishes), actively review and revisit goals of care with the patient and their family.

4. When a patient in palliative care has advance care directives, always review their currency with the patient and the family as appropriate before applying them, as situations and preferences change.
Priority Topic 4: Working as a team

1. When providing care with an inter-professional team, use communication and professional skills to develop and facilitate team effectiveness and productivity and ensure the family physician who initiated the care and requested the consultation remains engaged.

2. When team membership changes, do not assume that function will stay the same, and invest extra effort in integrating new members, developing healthy team relationships, and optimizing team function.

3. When conflict, discord, and emotions run high in a team context, avoid taking things personally and participate in a calm, constructive, and respectful dialogue to diffuse the situation, involving all team members in the process.

4. For all palliative patients and family care, use a team/collaborative approach proactively (e.g., anticipated changes in clinical status, psychosocial issues) whenever possible (i.e., do not limit use only to problematic or difficult cases).

5. When other teams or individuals are involved in the care of a patient, reduce mixed messages by clarifying and clearly documenting treatment plans.
Priority Topic 5: Nausea/vomiting/bowel obstruction

1. For a patient in palliative care with nausea and vomiting, use an organized and thorough approach to look for the cause(s), based on pathophysiology, being careful not to miss commonly overlooked causes (e.g., anxiety, candidiasis, neurological and other non-gastrointestinal causes).

2. For a patient in palliative care with nausea and vomiting, assess to establish its contribution to the total suffering experience for the patient and family.

3. For a patient in palliative care with nausea or vomiting or abdominal pain, distinguish a bowel obstruction from constipation, by appropriate history, physical exam, and investigations.

4. For a patient in palliative care with nausea and vomiting, reverse the cause(s) if possible and manage the symptoms using anti-emetics and other medications, based on the pathophysiological cause(s) and based on the patient’s overall condition (e.g., considering comorbidities, interactions with other medications, available routes of administration).

5. For a patient in palliative care with a bowel obstruction:
   a) Look for and recognize the indications and the contraindications for surgical treatment
   b) Include the patient and family in the discussions of the available options and the expected outcomes
   c) Involve the surgical team as necessary
   d) Use appropriate medications (e.g., prokinetics, antispasmodics, corticosteroids) and strategies according to the pathophysiology, (e.g., gastric outlet, small bowel, large bowel), if the obstruction is not managed surgically.

6. For all patients in palliative care, screen for, prevent, and treat constipation by appropriate use of laxatives and other medications (e.g., subcutaneous methylnaltrexone).
Priority Topic 6: Imminent death

1. For the patient in palliative care whose condition is deteriorating, look for and recognize the signs of imminent death (e.g., changed patterns of breathing, varying levels of consciousness including being unresponsive, decreased urine output, peripheral mottling) in order to be able to inform the family and health care providers, and adjust management appropriately.

2. When death is imminent, modify the treatment plan, in discussion with the patient, the family, and health care providers, by:
   - Reviewing all treatments including medications that the patient is no longer able to swallow, discontinuing those that are no longer necessary, and providing alternatives appropriate to the context
   - Addressing symptoms that cause distress and suffering (e.g., upper airway secretions, pain, delirium)

3. When death is imminent, inform the family and health care providers, and prepare them for the various signs and symptoms that may be disturbing and intermittent during the dying process (e.g., changing patterns of breathing, varying levels of consciousness and periods of agitation, noisy upper airway secretions), so that they may better understand and prepare for the process.

4. For a patient who is dying at home, ensure the available resources and documentation (e.g., DNR, arrangements for transfer of the body after death) are in place.

5. When death is imminent, support the family throughout in an appropriate fashion, honouring and following their cultural rituals prior to and after death, and assisting them with the grieving process according to their preferences and needs (e.g., physician presence may or may not be desirable).
Priority Topic 7: Despair and Suffering

1. For a patient in palliative care who is in despair or is suffering, do not assume that it is physical alone, but assess all the other domains (psychological, spiritual, social, cultural) as well, to appreciate the total suffering experience, and to identify possible management strategies.

2. For a patient in palliative care who is in despair or is suffering, assess to rule out major depression or other mood disorders.

3. For a patient in palliative care who is in despair or is suffering, talk to the family:
   - They too may be distressed
   - A patient’s primary concern is often for their family’s well-being

4. For a patient in palliative care who is in despair or suffering, incorporate all the domains of suffering (physical, psychological, spiritual, social, cultural) in management by:
   - Using available resources (e.g., social work, pastoral care, volunteers, nurses, family, dignity therapy) in a team approach to deal with the different domains and the total suffering experience
   - Using communication skills to maintain a close relationship with the patient, to help the patient maintain their dignity when experiencing despair and suffering, and to receive and respond to specific requests or needs (e.g., request for hastened death, medication changes)
Priority Topic 8: Community resources

1. When providing care for palliative patients who are not in hospital, use available community resources to support patients and families in an optimal, integrated, and effective fashion.

2. When planning for a patient's end-of-life care at home, anticipate that care in another facility (e.g., hospice, palliative unit, hospital) may be necessary, in order to ensure a smooth transition and minimize the patient's and/or family's discomfort.

3. When planning a patient's care at home with the help of community resources, ensure that the roles, tasks, and the responsibilities of the various health care providers are appropriate for the designated providers, and clearly understood by the patient, family, and providers.

4. When caring for a patient with the help of community resources, ensure communication amongst all caregivers and health care providers, including the family physician, to ensure collaborative and coordinated care.

5. When caring for a patient at home who is at the end of life, ensure that the family and caregivers are aware of and have access to available grief and bereavement services.
Priority Topic 9: Breathlessness

1. For a patient in palliative care who is breathless, assess to establish the:
   - Underlying cause(s) of the breathlessness, paying particular attention to those that might be reversible, and in a manner appropriate to the clinical context and the patient’s goals of care
   - Total suffering experience, of the patient, family, and caregivers, related to the breathlessness

2. For a patient in palliative care who is breathless, look for and recognize degrees of distress that require immediate intervention and constant attention or reassessment.

3. For a patient in palliative care who is breathless, in whom the underlying causes have been or are being identified, manage the breathlessness as appropriate to the clinical context and the patient’s goals of care by:
   - Providing symptomatic relief for the breathlessness using medical and non-medical means, including psychosocial support for the patient and family
   - Treating the underlying cause(s) or condition(s) (e.g., heart failure, anxiety and comorbidities)
   - Not stopping the basic underlying medical treatment if the treatment is still of benefit to the patient
   - Using opioids appropriately to manage breathlessness; deal effectively with concerns/anxiety of the patient, family, or colleagues about using opioids in this situation

4. For a breathless patient (both acute and chronic) in palliative care, manage anxiety appropriately, using pharmacological and non-pharmacological means.
Priority Topic 10: Delirium

1. For a patient in palliative care who has changing cognitive function, assess to distinguish between delirium (hyperactive, hypoactive, or mixed), dementia, and depression, and recognize superimposed presentations (e.g., delirium superimposed on a pre-existing dementia).

2. For a patient who has decreasing cognitive function (e.g., responding less, quiet, sleeping more), particularly those being treated for pain, look for and recognize hypoactive delirium:
   - Do not presume it is depression
   - Do not presume it is a simple progression of the underlying disease

3. For a patient in palliative care with delirium, investigate to establish the cause and potential reversibility appropriate to the context and the patient’s goals of care:
   - Do not under-investigate by assuming the patient’s delirium is terminal, before ruling out reversible causes
   - Do not over-investigate when the patient’s delirium has been established as a terminal event

4. For a patient with delirium (reversible or non-reversible), manage the symptoms effectively by:
   - Considering the total suffering experience of the patient, family, and the caregiver team caused by the delirium
   - Treating symptomatic hyperactive delirium in an urgent manner, to avoid further harm (e.g., aggression, risk for falls, psychological distress)
Priority Topic 11: Anxiety and depression

1. For all patients in palliative care, assess for the presence of anxiety or depression, paying attention to non-classical symptoms or presentations, such as somatization, increasing medication needs, or behavioural change.

2. When a patient in palliative care appears to be depressed:
   a) Do not assume this to be an unavoidable response to the end of life
   b) Assess methodically to determine if a clinical diagnosis of depression is present
   c) Rule out alternative diagnoses such as hypoactive delirium, hypothyroidism, adjustment disorder, or existential distress
   d) Assess for suicidal risk

3. For a palliative patient with depression, start treatment early, using non-pharmacologic and pharmacologic means as indicated.

4. For a palliative patient with depression who is being treated pharmacologically, select the antidepressant medication considering:
   • Its likely effects (beneficial or aggravating) on the patient’s other symptoms (e.g., anxiety, neuropathic pain, nausea, anorexia)
   • Interactions with other medications
   • The indications and contraindications of the use of psychostimulants

5. When a patient in palliative care appears to be anxious:
   a) Rule out alternative diagnoses, such as uncontrolled physical symptoms
   b) Assess methodically to determine a clinical diagnosis of an underlying anxiety disorder (e.g., general anxiety disorder, panic disorder, obsessive compulsive disorder)

6. When a patient in palliative care is experiencing severe or persistent physical symptoms (e.g., pain, nausea, dyspnea), assess for anxiety as a potential contributor to the patient’s symptoms.

7. For a patient in palliative care who needs a pharmacological treatment for anxiety:
   a) Consider the use of selective serotonin reuptake inhibitors (SSRIs), serotonin-norepinephrine reuptake inhibitors (SNRIs), atypical antipsychotics, and benzodiazepines, depending on the clinical situation and goals of care
   b) Be judicious if using benzodiazepines:
      • To avoid complications associated with excessive and long-term use
      • In high-risk populations (e.g., elderly, dementia)
Priority Topic 12: Palliative sedation therapy

1. For a patient in palliative care for whom palliative sedation therapy is being considered:
   a) Assess for intolerability of the symptoms and their contribution to the total suffering experience (physical, psychological, social, and spiritual)
   b) Assess whether symptoms are refractory by a comprehensive assessment and management of symptoms using all available modalities and health professionals, and addressing all domains of care (physical, psychological, social, and spiritual)
   c) Determine if further therapies (e.g., addition of non-sedating medications, radiation therapy for brain metastases) would be associated with excessive or intolerable side effects
   d) Educate the patient, family, and health care team about the differences between palliative sedation therapy and medical assistance in dying

2. For a patient for whom palliative sedation therapy is being considered, before initiating treatment seek a second opinion from an appropriate source to review the decision and make sure that there has not been an inadvertent oversight (e.g., missed reversible cause of delirium, untreated depression).

3. For a patient for whom palliative sedation therapy is being considered, ensure all care elements (e.g., code status, hydration, nutrition) and goals of care are aligned.

4. When palliative sedation has been determined to be the most appropriate management strategy, and consent by the patient or substitute decision maker has been given:
   a) Use and titrate sedating antipsychotics and benzodiazepines proportionately to achieve the desired level of sedation required to effectively treat the intolerable and refractory symptoms
   b) Avoid using inappropriate medications (e.g., opioids and haloperidol) for the purposes of sedating
   c) Regularly monitor the patient and review the plan with the health care team and family to address all concerns
   d) Continue appropriate symptom management (e.g., opioids for pain or dyspnea)
Priority Topic 13: Maintaining the clinician’s well-being

1. When providing palliative care, demonstrate self-care while mindfully choosing the times when it is important to put a patient’s needs ahead of personal needs.

2. When providing palliative care, self-assess regularly, and seek and accept constructive feedback from peers regarding observed behaviours that may indicate stress or becoming overwhelmed.

3. When providing palliative care, if your own mood or behaviours indicate a risk of burnout or stress, seek help and implement wellness strategies (e.g., share with colleagues and team, adjust your schedule).

4. When experiencing a distressing reaction to a situation while providing palliative care, maintain composure and consider that your response(s) may be influenced by your personal experiences of death and dying.

5. Following a major incident that could threaten your well-being (e.g., death of a child, major conflicts, perceived failures), actively seek support and guidance.

6. When a colleague’s or other team member’s behaviour or mood suggest stress or being overwhelmed, initiate a constructive and supportive exchange that may help them address the situation.
Priority Topic 14: Emergencies

1. When providing palliative care, while respecting goals of care, anticipate likely emergencies (e.g., delirium, spinal cord compression, seizure, major bleeding), and plan measures in consultation with the patient and/or family to deal with these possible emergencies.

2. When assessing a patient in palliative care, identify clinical elements (e.g., symptoms, signs, appropriate investigations) that may suggest an early emergency situation that may require a change in management.

3. When a palliative care emergency or crisis has been identified, manage the situation effectively and compassionately, considering the reversibility/irreversibility of the underlying cause(s) and the patient’s goals of care.
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April 2017

Priority Topic 15: Medical Assistance in Dying

1. When a patient or family member asks about and/or requests Medical Assistance in Dying (MAID), explore in detail the possible reasons behind the request and help reach common ground by:
   - Clarifying all the elements of the total suffering experience (patient and family)
   - Assessing for depression
   - Assigning priority to the wishes of the patient while still recognizing family concerns

2. When concerns are raised—by the patient, family members, or members of the health care team—that the palliative treatment may be hastening death, either intentionally or inadvertently, explore the reasons for the concerns and seek common ground with the ongoing management by:
   - Reviewing the total suffering experience, including particular fears or perceptions about the current treatment
   - Reviewing the goals of care, based on the patient’s wishes in order to facilitate their understanding of the intention of the treatment plan, including palliative sedation

3. When a patient requests a discussion about Medical Assistance in Dying (MAID), conduct an in-depth discussion with the patient and/or family or, depending on personal beliefs, refer the patient to a colleague for this discussion.
Priority Topic 16: Anorexia/cachexia/nutrition/fatigue

1. For palliative care patients, assess early for the presence of unreported anorexia or cachexia and their possible contributing factors, as this may be a source of significant distress to the patient and their family/health care providers.

2. For a patient in palliative care who has anorexia, cachexia, and/or fatigue, develop a management plan that includes:
   - Investigation consistent with the goals of care to rule out reversible causes
   - Education of the patient and caregivers about its normalcy in these circumstances
   - Reconciliation, as much as possible, of patient and caregiver expectations to reduce guilt and tension about food intake
   - Nutritional advice and symptomatic treatment consistent with the patient’s goals of care
   - Clarification that symptomatic therapy will continue to be offered to patients with severe end-stage illness, although aggressive management to attempt to reverse the anorexia/cachexia/fatigue is usually not helpful or indicated in this situation

3. For all patients in palliative care, encourage and facilitate regular activity as tolerated (including non-weight bearing) as a strategy to prevent or reduce fatigue.

4. For patients with anorexia and cachexia at the end of life, use a patient-centred approach to discuss when to stop the use of supplements, artificial nutrition, and parenteral feeding.
Priority Topic 17: **Non-malignant illness**

1. For patients with chronic progressive non-malignant illness, (e.g., cardiac, pulmonary, renal) assess for palliative issues (e.g., pain, shortness of breath), recognizing that the disease trajectory and prognosis are more variable and may be harder to predict than for malignant diseases.

2. For patients with chronic progressive non-malignant illness, initiate early advance care planning and goals of care discussions, and facilitate access to available palliative care resources.

3. When caring for a patient nearing the end of life with non-malignant illness, continue to optimize the management of the underlying illness (e.g., some medication should be continued, some may be discontinued), as well as provide additional palliative symptom management.

4. When caring for a patient nearing the end of life with non-malignant illness, use a palliative approach by appropriately prescribing medications such as opioids for pain and dyspnea, adjusting as needed for the underlying disease (e.g., renal or hepatic failure, nausea in Parkinson disease).

5. When caring for a patient with a chronic progressive non-malignant illness, encourage communication amongst all caregivers and health care providers, to ensure collaborative and coordinated care.