

Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care

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Background

Currently, patients and families living with advanced cancer experience significant distress when the transition from cancer-directed therapies to ongoing palliative-focused care occurs abruptly.¹ Late or no palliative care use is associated with more aggressive and costly end-of life care.² In Alberta, 60% of patients with metastatic gastrointestinal cancers had a late (within 2 months of death) or no palliative care referral.^{3,4} This was associated with aggressive care in 50% of those patients, as compared to 25% in those who received early palliative care. Choosing Wisely Canada,⁵ the American Society of Clinical Oncology (ASCO),^{6,7} and other guidelines⁸⁻¹¹ all recommend that palliative care should not be delayed or avoided in patients with metastatic cancer who are also pursuing disease-directed treatment. Additionally, the Accreditation Canada standards include a recommendation for “a process for initiating palliative and end of life care” (<https://accreditation.ca/standards/>). There is extensive evidence that *integrating an early palliative approach with cancer care* improves outcomes for patients with advanced cancer.¹²⁻¹⁹ This approach has been described by Temel’s five elements of an early palliative approach to care,¹³ Hannon’s elements of early palliative care,²⁰ and Boucher’s best supportive care checklist.²¹ Improved methods of tracking and addressing symptoms are associated with less emergency room usage and improved quality of life and survival.²² Refer to the accompanying **Evidence Table** for a comprehensive review of the literature.

Definitions

To create clarity around the concepts in this guideline, the following definitions are provided:

1. How is advanced cancer defined?

Advanced cancer is defined as those with distant metastases, late-stage disease, cancer that is life limiting, and/or with prognosis of 6 to 24 months.⁶

Advanced colorectal cancer is generally not amenable to surgical resection of all sites of disease, and usually represents an incurable situation. As a small number of advanced colorectal cancer patients may achieve prolonged remission or cure, the potential for cure is not an exclusion for use of this guideline.

2. What is the palliative approach to care?

Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms.

- affirms life and regards dying as a normal process.
- intends neither to hasten or postpone death.
- integrates the psychological and spiritual aspects of patient care.
- offers a support system to help patients live as actively as possible until death.
- offers a support system to help the family cope during the patient’s illness and in their own bereavement.
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- will enhance quality of life, and may also positively influence the course of illness.
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”²³

In brief, the palliative approach to care includes whole person care, quality-of-life focus, and mortality acknowledgement.²⁴

3. When is palliative care defined as “early”?

Early palliative care starts close to the initial diagnosis of advanced cancer, specifically the “Integration of palliative care into standard oncology care: ASCO clinical practice guideline update” suggests within 8 weeks of diagnosis.⁶ Palliative care continues as an added layer of support throughout a disease trajectory, including concurrently with cancer modifying therapy (e.g., chemotherapy), or when patients choose to not have cancer modifying therapy, or when there are no cancer modifying options available. Palliative therapy options may include best supportive care, radiation, surgical or systemic therapy.

Figure 1 shows how the early palliative care pathway is intended to be used in conjunction with the CancerControl Alberta [Metastatic Colorectal Cancer Guideline](#) and forms a continuum of care with other guidelines and pathways.

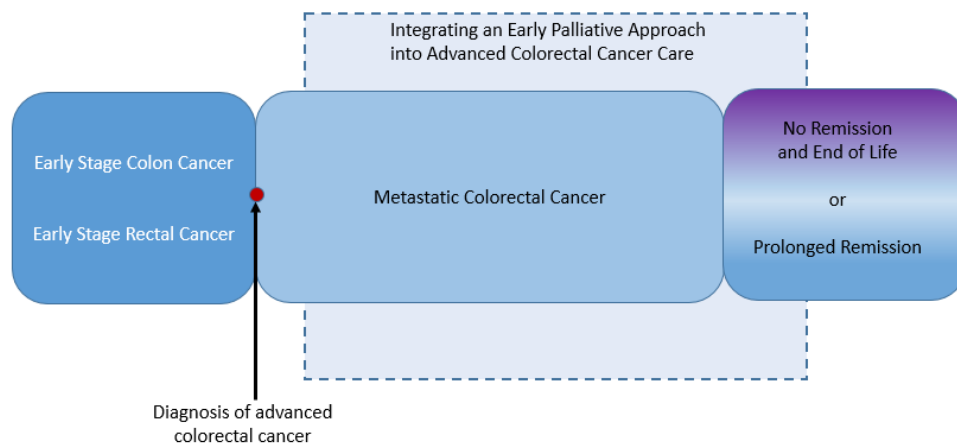


Figure 1. Integrated CancerControl Alberta colorectal care pathways.

1) CancerControl Alberta guidelines for diagnosis and treatment of [early stage colon cancer](#) and [early stage rectal cancer](#). 2) [Metastatic colorectal cancer](#) guideline. 3) Integrating an early palliative approach into advanced colorectal cancer care. 4) Acknowledging the prognostic uncertainty and the possibility that either disease progression to death or prolonged remission are potential outcomes when entering each of the pathways. While there are no CancerControl Alberta guidelines for this final box, there are Alberta Health Services (AHS) resources for both end of life care and prolonged remission/survival.

4. Who provides the palliative approach to care?

The Canadian Society of Palliative Care Physicians identifies that a palliative approach “specifically acknowledges the capability of health care professionals who do not specialize in palliative care to attend to the needs of people who have advancing serious illnesses, regardless of the sector of care (e.g., home care, residential, hospital) and the stage the patient is at in the disease trajectory.”²⁵

In Alberta, the Palliative and End of Life Care (PEOLC) Alberta Provincial Framework²⁶ outlines three levels of palliative and end of life care provincially accessible to patients and families/caregivers^a:

- **Primary Level:** All health care providers should have primary palliative care basic core competencies, and this approach to care should be available in all care settings.^{26,27} Care is delivered by interdisciplinary *primary care providers* (e.g., oncology, family practice teams, urban integrated home care), which provide “clinical management and care co-ordination, including assessments, interventions, referrals and triage”. Providers manage psychosocial, physical and spiritual aspects of care along with communication (e.g., discussion of prognosis, [Advance Care Planning](#), initial management of symptoms). Clinicians may utilize secondary and tertiary palliative care services through consultative processes to further support patients and their families.
- **Secondary Level:** Secondary palliative care provides specialized palliative care consultation, advice, and services to primary providers, their patients and families.²⁶ This includes care in various and specialized settings, such as the patient’s home, long term care, and hospice. Secondary palliative care providers (e.g., palliative care consultants) give advice and support in an interdisciplinary team setting. Not all patients with palliative care needs will require secondary level of care.
- **Tertiary Level:** Tertiary palliative care is delivered by specialized interdisciplinary palliative care teams for complex cases, symptom management, or psychosocial concerns not responding to interventions.^{26,28,29} This level of care is supported by tertiary resources, for example, interventional procedures, diagnostics, in-patient palliative care units and frequent skilled assessments.

^a Family/caregiver is defined in this guideline as inclusive of those the patient self-identifies as family (biological and family of choice) and any caregivers (outside of the health system including legally appointed and patient selected).

4. What is meant by integrated?

There are many definitions of integrated care.³⁰ In this guideline, integrated care is understood as care that combines a palliative approach to care with disease-specific management, in a collaborative, coordinated and flexible manner dependent on a person's and family/caregiver's range of needs.²⁷

Guideline Goal

To improve the quality of life for people affected by advanced colorectal cancer by integrating an early palliative care approach into advanced cancer care.

Guideline Questions

1. What triggers should be used to indicate the need to apply an early, integrated palliative approach to care?
2. What are the essential components of an early palliative approach to care?
3. How can these components be integrated into advanced colorectal cancer care?

Search Strategy

This guideline was developed to outline the integrated early palliative approach to care recommendations for patients with advanced colorectal cancer. It was informed by the results of randomized controlled trials and systematic reviews up to 2018 (see **Evidence Table**). It takes into consideration related information presented at local, national, and international meetings, as well as the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams' interpretation of the data. This guideline was informed from the following clinical practice guidelines:

- Cancer Care Ontario, based on the [Gold Standards Framework](#)³¹
- Accreditation Canada (<https://accreditation.ca/standards/>)
- British Columbia clinical practice guidelines and protocols (<BCGuidelines.ca>)

Target Population

The recommendations outlined in this guideline apply to adults over the age of 18 years with advanced colorectal cancer. Different principles may apply to pediatric patients.

Discussion

This guideline has been summarized in the “Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care Pathway” (www.ahs.ca/GURU under “Gastrointestinal” heading then “Metastatic Colorectal Cancer: Early Palliative Approach” and select “Interactive Care Pathway”).

What are the Essential Components of an Early Palliative Approach to Care?

Several recent analyses of trials integrating oncology and palliative care point towards specific key elements of an early palliative care approach that support whole person care, quality-of-life focus, and mortality acknowledgement.^{6,13,21,32} In Alberta, these have been synthesized into four components, as shown in **Figure 2**.



Figure 2. Four essential components of an early palliative approach to care.

What is Illness Comprehension & Coping?

Illness comprehension is the extent to which the person understands and internalizes the scope of their illness including prognosis, treatment and care options. It is a complex psychological construct that is dynamic and is interrelated with illness adjustment and coping.³³

What is Advance Care Planning?

Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.³⁴ ACP is not the same as Goals of Care Designation (GCD) determination. In Alberta, the ACP process is aimed at all adults and includes five elements that a person undertakes:

- **Think about:** Thinking about their own values related to their health and well-being.
- **Learn:** Learning about their health or illness conditions, including prognosis and the kind of decisions they might be faced with in the future.
- **Choose:** Choosing an alternate decision maker (ADM) in the event they lose capacity for decision making.
- **Communicate:** Communicating with their ADM, other family or people close to them and with their health care provider about who their chosen ADM is and the kind of wishes and values they would like to guide their care in the event they lose capacity.
- **Document:** Documenting in a Personal Directive to legally appoint their agent (ADM) for personal decision making in the event they lose capacity. The Personal Directive also allows a person to document those wishes, beliefs and values that they want the agent to understand when making decisions about their personal matters.

What is Coordination of Care?

The definition is malleable based on perspective. The Agency for Healthcare Research and Quality uses the following working definition: "care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care."³⁵ The five key elements comprising care coordination are: a) numerous health care providers are involved; b) providers are dependent upon each other to carry out separate activities in a patient's care; c) each provider needs adequate knowledge about their own and others' roles, and available resources; d) providers rely on exchange of information; and e) integration of care activities has the goal of facilitating appropriate delivery of health care services. As complexity increases, the patient's ability to coordinate care themselves decreases and the need for participatory provider coordination increases.

Recommendations and Implementation Strategy

Step 1: SCREENING

Clinicians caring for patients with advanced cancer should use the following opportunities to screen for those who may benefit from an early, integrated palliative approach to care:

1. During assessment for symptom burden (physical and psychosocial)
2. With transition points in care or indication of advanced disease trajectory
3. When patient or family/caregiver asks for palliative or supportive care
4. Clinician judgement

All advanced colorectal cancer patients should be *screened* to identify those who may benefit from an early palliative approach to care on a systematic basis.³⁶ Opportunities for screening include:

1.1 Symptom burden and patient concerns:

- Review symptom burden in combination with the Edmonton Symptom Assessment System Revised (ESAS-r) scores.^{37,38} A score $\geq 7/10$ on the ESAS-r is considered severe.^{36,39,40} ESAS-r data are available for Alberta patients from the “Putting Patients First” (PPF) form (**Appendix 1**).
- Utilize the CancerControl Alberta Patient Reported Outcome (PRO) dashboards proactively. The PRO Clinic List dashboard shows the symptom burden of all patients booked into a clinic. It highlights which patients had high symptom burden on their last visit, for review in the current visit. The Clinic List has a direct link to each patient’s individual PRO trended dashboard where the clinician can view each patient’s symptom trajectory (PPF data from ESAS-r and Canadian Problem Checklist (CPC) responses) over the last 6 visits in more detail (**Appendix 2**). This is an Alberta specific method in cancer centres entering PPF data into the electronic medical record.

1.2 Monitoring for transition points in care or indicators of advanced disease trajectory:

- Progression on current therapy.
- When disease is recognized as incurable.
- When on second-line systemic therapy.^{41,42}
- There are no further disease-modifying treatments available.
- When unable to receive first-line systemic therapy, or patient declines further disease-modifying treatment.
- There is a decrease in performance status or functional decline (e.g., the patient is confined to bed or chair more than 50% of waking hours). (ECOG ≥ 3 , **Appendix 3**)
- When the clinician estimates the patient’s prognosis as 12 months or less. One way this can be achieved is by clinicians asking themselves the Surprise Question: “Would I be surprised if the patient were to die in the next 12 months?” An answer of no indicates a higher likelihood of death within the next year.^{31,43,44}
- When a patient with incurable cancer is discharged from the cancer centre for ongoing care in the community.

1.3 When patient or family/caregiver requests palliative care services or information.

1.4 When clinician judgement determines the patient or family/caregiver would benefit from an early palliative approach to care:

- Patient and/or family/caregiver are having (or anticipating) difficulties with illness understanding, including naming the diagnosis, illness history, symptoms, causality and prognosis, ACP, mortality distress.⁴⁵

Patients who screen positive for one or more of these screening methods meet criteria for use of an early integrated palliative approach to care. Patients who screen negative should be rescreened regularly.

Step 2: IDENTIFY PATIENT NEEDS

Once patients have been screened and meet criteria, clinicians should identify unmet patient needs. This can be guided by the four essential components of an early palliative approach to care (**Figure 2**) and corresponding assessment tools (**Table 1**). Patient needs should be re-assessed at regular intervals.

Once screened and meeting criteria, routinely and systematically identify the patient’s *unmet needs* and *functional status*. This is a critical step to determine the most appropriate supportive care interventions and service type needed. Evidence points to the need to use an assessment tool systematically, in order to not miss suffering.^{22,46} Assessment tools allow identification of the specific issues of concern to the patient and family/caregiver. Randomized controlled trials (RCTs) demonstrate that intentional monitoring and addressing of symptoms and problems as identified by patients is helpful in maintaining quality of life and possibly associated with increased survival.^{13,22,46,47} There is limited high grade evidence to guide which exact assessment tools to use.⁴⁸ We recommend the use of CancerControl Alberta’s standardized tools to assess patient needs (**Table 1**).⁴⁹ The frequency of reassessment of need varies between the RCTs, but all agree that “routine” monitoring is needed. Thus, we recommend assessment of patient needs at most clinical encounters. Note that clinical encounters can be initiated by patients (e.g., patient portal entered symptom scores or phone calls to clinics regarding worsening symptoms).

Table 1. Provincial assessment tools for each component of an early palliative approach to care.

	Component	Assessment Tool
	Illness comprehension and coping	PPF: CPC and ESAS-r (anxiety and depression scales) SICP
	Symptoms and functional status	PPF: CPC and ESAS-r ECOG PPS
	Advance care planning and patient’s preferred method of decision making	ACP/GCD Tracking Record PPF: CPC SICP
	Coordination of care	PPF: CPC

PPF, Putting Patients First; CPC, Canadian Problem Checklist; ESAS-r, Edmonton Symptom Assessment System-revised; SICP, Serious Illness Care Program; ECOG, Eastern Cooperative Oncology Group; PPS, Palliative Performance Scale; ACP/GCD, Advance Care Planning/Goals of Care Designation.

2.1 Putting Patients First (PPF)

The PPF tool includes the CPC and the ESAS-r and has been adopted as a provincial standard in Alberta.⁴⁹ The CPC was developed by the Screening for Distress Working Group of the Canadian Partnership Against Cancer;⁵⁰ it is a comprehensive standardized tool for assessment that has been validated for screening for distress and encapsulates domains relevant to many of the early palliative care intervention studies.¹³ Assessment domains include: emotional, social/ family/ spiritual, practical, physical, mobility, nutritional, informational and the option to include open ended “other” concerns. The ESAS-r is an internationally validated tool to assess patient symptoms.^{37,38}

2.2 Serious Illness Care Program (SICP)

Beyond the CPC, there are more in-depth methods to assess illness understanding and coping. One of these is the SICP (**Appendix 4**), which also elicits patient values as a part of ACP.⁵¹ Refer to section 3.3 for more detail.

2.3 Eastern Cooperative Oncology Group (ECOG) and Palliative Performance Scale (PPS)

There are many ways to assess functional status and needs.⁵² The ECOG (**Appendix 3**) functional scale can indicate declining function that might be associated with increasing patient needs. The ECOG score might suggest both the level (e.g. ambulatory, home care, supportive living) and type of supports (e.g., mobility aids, hospital bed, toileting assistance) needed by the patient.⁵³ The PPS is the standard tool used in palliative care to measure performance status using five observable parameters: ambulation, ability to do activities, self-care, food/fluid intake, and consciousness level (**Appendix 4**).⁵⁴ Similar to ECOG, the PPS can indicate the need for additional support including hospice care.

2.4 Advance Care Planning/Goals of Care Designation (ACP/GCD) Tracking Record

Existing literature has several methods for assessing the degree to which a patient has engaged in prior ACP or their preferences related to decision-making.³⁴ The PPF tool includes the items “Would you like information on Goals of Care or advance care planning (green sleeve)?”, “Understanding my illness and/or treatment”, “Talking with my health care team” and “Making treatment decisions”, which allow patients to indicate their self-perceived need for more information related to ACP. In Alberta, the [ACP/GCD Tracking Record](#) also provides prompts for clinicians, with five suggested questions to assess prior ACP activities, and is the document in use provincially to record patient needs related to ACP (**Appendix 5**). The SICP also guides clinicians to elicit a patient’s informational needs related to their prognosis, “How much information about what is likely to come with your illness would you like from me?”⁵¹

2.5 Coordination of Care

Patients with cancer are at high risk of receiving poorly coordinated care in multiple settings from many providers, and lack of coordination is associated with poor symptom control, medical errors, and higher costs,^{2,55} Improvement in cancer care coordination leads to better patient experience and higher quality of end of life care.^{55,56} Many factors impact patient complexity, including personal factors (e.g., social determinants of health), interactions with providers (e.g., no family physician),

system complexities (e.g., rural location), societal influences, and changes over time.⁵⁷ Care coordination needs tend to increase with complexity. It is important to assess care coordination needs (e.g., patient and family/caregiver factors, number of providers, complexity of treatment plan), however there is limited evidence to recommend one assessment tool over another.⁵⁸ Practical concerns identified on the PPF may indicate higher needs around care coordination for issues such as financial concerns, difficulty getting to and from appointments, and language barriers.

Step 3: PRIMARY PROVIDER MANAGEMENT OF UNMET NEEDS

Primary palliative care management of unmet patient needs is strongly recommended using the four essential components of an early palliative approach to care as a guide:

1. Illness comprehension and coping
2. Management of symptoms by providers and patients' self-management
3. Advance care planning and patient's preferred method of decision making
4. Coordination of care

Primary providers should initiate management of unmet needs.²⁶ Defining which care provider is primarily responsible and whether they refer to additional care providers for support and interventions can be dependent on both the referring clinicians' own competencies in managing the issue and on the locally available consultation services.

3.1 Illness Comprehension and Coping

Evidence has shown that addressing a patient's understanding of their illness, how they are coping and how those close to them are coping, is associated with improved patient outcomes.^{12,32,45,51,59,60}

In addition to consulting secondary palliative care providers, **Table 2** shows some other methods that can be used to support patients and family/caregivers.

Table 2. Potential methods to address illness comprehension and coping.^{51,61,62}

	Method	Description
Specialist provided	Spiritual care	Existential and faith based supports
	Art therapy, music therapy	Facilitated creative art therapies
	Psychosocial counselling	Including: psychotherapy, Cognitive Behavioral Therapy, family therapy, individual and group therapy, CALM (Managing Cancer and Living Meaningfully)
Provided by family physicians, oncologists and nurses (with training)	Vital talk (www.vitaltalk.org/resources/)	Strategies and clinician resources for responding to difficult conversations
	SICP	Program of resources, education workshop and systems change processes to increase meaningful conversations between people living with serious illness and their clinicians about their values and priorities
	Dignity conserving therapy (including life review)	Question guides and approaches e.g. asking "what do I need to know about you as a person to give you the best care possible?"

Patient preference, available time and clinician skills may be factors in the extent to which exploring patient illness understanding and coping occurs during clinical encounters, and clinician judgment is required about whether and when to refer for additional formal coping supports. This guideline encourages primary providers to explore and identify techniques to use in their practice.

3.2 Management of Symptoms by Providers and Patients

Providers: Management of symptoms is a cornerstone of palliative care.²³ Symptoms may be managed pharmacologically (e.g. steroids, opioids), non-pharmacologically (e.g., behaviour modification, meditation), and/or by physical interventions (e.g., stents, palliative surgery, radiation).

Treatment of advanced colorectal cancer symptoms should be based on patient preferences, wishes, and goals for care. Symptoms that are complex may require palliative care consultation and collaboration with other care teams (see Section 3.4). Clinical practice guidelines and/or symptom management tip sheets and links are available for some symptoms at www.ahs.ca/GURU, under the Cancer and Treatment Related Adverse Events heading:

- [Anxiety](#)
- [Bowel obstruction in advanced cancer](#)
- [Constipation in advanced illness](#)
- Decreased appetite & cachexia
- [Delirium in advanced cancer and those who are imminently dying](#)
- [Depression](#)
- Diarrhea
- [Dyspnea](#)
- Fatigue
- [Nausea and vomiting](#)
- [Oral care](#)
- [Sleep disturbance](#)
- [Pain](#)
- [Tenesmus](#) (a feeling, sometimes painful, of constantly needing to pass stool despite an empty rectum)

Patient self-management strategies: Patient self-management strategies, including upfront information shared by providers, can enhance symptom management, ability to cope and quality of life.⁴⁹ Providers should encourage use of the following resources:

- Telephone triage or nurse navigator available for cancer patients within each Alberta cancer centre. Each cancer centre has its own “Emergency Contact” cards, which are available on the internal AHS website for each cancer site through patient education on Insite under “Treatment (Systemic Treatment, Radiation, and Surgery)” then under “Systemic Treatment” (<https://insite.ahs.ca/cca/Page13453.aspx>)

- Healthlink (811) for health questions, or Inform Alberta (211) for questions about services available within the community.
- Patients on Palliative Home Care can call for support 24/7. Local numbers can be obtained through the patient’s home care coordinator.
- Patient information on palliative care in Alberta: <https://myhealth.alberta.ca/palliative-care/resources>
- CancerControl Alberta Patient Education Resources:
 - Education guides for patients and families exist for: Systemic Treatment, Radiation Treatment and Immunotherapy. These books cover a variety of topics (cancer treatments, symptoms, living your best while on treatment) and self-help strategies. Providers should review these books and their content with patients on a regular basis. PDF copies are available at <https://www.albertahealthservices.ca/cancer/Page16308.aspx> (select treatment type for resources).
 - “Sources of Help” booklets have been developed provincially, which cover community, government and local business supports and services: <https://www.albertahealthservices.ca/cancer/Page16318.aspx>
 - Patients also value support groups,⁶³ see “Sources of Help” or contact your local cancer centre for support group listings.
- Some patients/families may want to use the AHS CancerControl Alberta My Care Conversations Cancer Consult Recording App with the aim of improving their recall of key conversations and enhancing their self-management and ease of decision-making. More information is at www.ahs.ca and search “My Care Conversations Cancer Consult Recording App” or visit: <https://www.ahs.ca/cancer/Page16144.aspx>.

3.3 ACP and Patient’s Preferred Method of Decision Making

By preparing patients and those who may have to make in-the-moment decisions on their behalf, ACP is associated with a number of benefits.⁶⁴ [Choosing Wisely Canada](#) recommends “don’t delay advance care planning conversations”. The AHS procedure on ACP and GCD states, “all adults who have capacity should be given the opportunity to participate in ACP as a part of routine care, started early in a longitudinal relationship with a health care provider and revisited when the health or wishes of an adult changes”.^{65,66}

Encourage patients to have conversations about ACP throughout cancer treatment. Clinicians, within their scope of practice, can be instrumental in:

- Encouraging reflection on and expression of personal values, beliefs and preferences related to personal goals, health care and their preferred method of decision making (e.g., shared decision making, supported decision making with family/caregiver, self-determined, physician-directed).

- Sharing prognostic information, tailored to the patient’s readiness and preferences around illness understanding.
- Supporting the patient in selecting an appropriate ADM.
- Encouraging the patient to communicate with their ADM, family/caregivers, other health care team members about their values, beliefs and preferences and who they have selected as ADM.
- Encouraging the patient to create a Personal Directive.
- Documenting ACP conversations on the ACP/GCD Tracking Record.

Resources: Patient and health care provider resources are available at www.conversationsmatter.ca.

The SICP was developed in a cancer outpatient clinical context to provide a systematic approach to increasing meaningful conversations between seriously ill people and their clinicians about their values and priorities.⁵¹ It has been adapted for use in family physician clinics and other settings⁶⁷ and is in an early phase of adoption within AHS. This is a helpful bridging process between ACP and GCD determination, as shown in **Figure 3**.

Goals of Care Designations:^{65,66} In Alberta, Goals of Care Designations (GCD) are medical orders that describe the general and sometimes specific focus of a patient’s desired care approach, harmonized with what is medically appropriate to provide. They also create awareness of a person’s care choices in relation to the care sector they are living in or being cared for. They ideally arise from fully informed conversations between patients (or their alternate decision-maker) and health care providers. The use of GCD is described in an AHS level 1 provincial policy and procedure. GCD should be determined when clinically indicated and should be reviewed at the request of the patient or ADM, after transfers, or if there is a significant change in the patient’s condition or circumstances. GCD are a useful component of an early palliative approach to care because they are a mechanism that “helps make our system more patient-centred, improves continuity of care, supports care quality and safety for patients, reduces unwanted transfers and procedures, reduces decisional burden and moral distress for families and caregivers, and helps prevent inappropriate consumption of resources.”

Per AHS, “once a Goals of Care Designation conversation has been held, and if clinically indicated, a Goals of Care Designation order shall be created and documented in the Advance Care Planning/Goals of Care Designation Tracking Record.” By documenting in a common place, follow up can be shared between the care team. The [Green Sleeve](#) is a plastic pocket used in Alberta as the specific resource to contain and transfer ACP documentation (e.g., GCD order, Advance Care Planning/Goals of Care Designation Tracking Record, Personal Directive copies, Guardianship Orders).



Figure 3. Conceptual model of where SICP fits within AHS’s model of ACP and GCD determination.

3.4 Coordination of Care

Coordination of care is usually the responsibility of all health care providers. The important coordination activities are:³⁵

- Establish accountability or negotiate responsibility
- Communicate
- Facilitate transitions
- Create a proactive plan of care
- Support self-management goals
- Link to community resources
- Align resources with patient and population needs
- Monitor, follow up, and respond to change

In certain zones this coordination might be achieved through a patient navigator and/or home care case manager. These coordinators are particularly valued by rural zone patients.⁶³

Advanced Cancer Resources: To assist health care providers in coordination activities, compilations of advanced cancer resources are available. These Zone-specific tips are being made in collaboration with local palliative programs as “Local Tips for Providers”:

- Calgary (www.ahs.ca/GURU > Guidelines > Gastrointestinal > Metastatic Colorectal Cancer: Early Palliative Approach > “[Local Tips For Providers](#)”). Includes information on caregiver support and community based resources, and these provincially funded programs:
 - Alberta Aids to Daily Living (AADL)
 - Financial benefits
 - Palliative Coverage Program (also known as “Palliative Blue Cross” or “Palliative Drug Coverage”)
 - Palliative Oxygen

- Provincial Palliative & End of Life Care (www.ahs.ca/info/Page14559.aspx): General information for healthcare professionals on accessing palliative care resources and management of symptoms.

Referral Based Services for Advanced Cancer Care: Lack of provider role clarity and variation in service availability, along with variation in patient need (i.e. functional and ambulatory status), can make it challenging to identify when and which specialist palliative care or other supportive care services are needed. Relevant supportive services that may assist in fulfilling an early palliative approach to care include: integrated home care, EMS Assess Treat and Refer program, community paramedic program, psychosocial oncology, and rehabilitation oncology. See “[Referral Based Services for Advanced Cancer Care](#)” document for provider types available, their description and referral criteria. Note that the [Alberta Referral Directory](#) (ARD) is the centralized location for referral information. More resources for improving referrals and access to services can be found at “Access Improvement” (<https://www.ahs.ca/info/Page13719.aspx>).

Specialist Palliative Care Services: Specialist palliative care services provide secondary or tertiary advice or care when needs of the patient are complex and beyond the scope of the primary care team.²⁵ The palliative consultant can also support the primary care team in providing a primary palliative approach to care. Quality indicators suggest that palliative-focused home care nursing support is an important element in improving quality of care and reducing inappropriate use of resources.^{3,68,69} When providers are making referrals to palliative care services, clarification should be provided to the patient explaining that palliative care is an added layer of support that can be used alongside cancer treatments.⁷⁰ Patient friendly palliative care descriptions are available in the CancerControl Alberta patient education guides (see Section 3.2). Some examples of when referral to specialist palliative care would be appropriate are:

- severe symptoms (≥ 7 ESAS-r). Note clinician judgement is required as patients with severe psychosocial-related symptoms (e.g., depression and anxiety) might instead need a referral to psychosocial oncology providers.
- palliative care unit or hospice referral.
- assisting with conflict resolution or health care decision making.
- clarification of goals of treatment or management plan.

Communication and Documentation: Standardized communication increases consistency, minimizes duplication and improves teamwork while promoting patient safety. All providers involved in the patient’s care should send updates to other providers when there are changes in the patient’s condition, needs, or status. Important elements include patient’s cancer illness understanding, prognosis, and details of ACP and GCD (Green Sleeve). Effective communication reduces the need for patients and families to repeat information. Patients and families need information to prepare for and improve care transitions; this may include written information or instructions, action plans, goals, signs or symptoms of declining health status, and contact information for the team. Family physicians also want to be kept informed and involved.⁷¹

The following communication tools should be used to enable standardized communication:

- **Shared care letters:** At transition points in care, communication between the cancer centre and family physician should be emphasized by use of a “Shared Care” letter. The [physician version](#) of the letter outlines collaborative care where primary palliative care and symptom management can be shared between providers. It indicates cancer modifying care to be managed by medical oncology and non-cancer related care to be managed by family physician. This letter is initiated when second-line therapy is ordered or patient is determined to have advanced disease. The [patient version](#) of the letter should be given to the patient during the clinic visit.
- **Green Sleeve:** The [Green Sleeve](#) is a plastic pocket used in Alberta as the specific resource to contain and transfer ACP documentation (e.g., GCD order, ACP/GCD Tracking Record, Personal Directive copies, Guardianship Orders).

Step 4: EXPLORING END OF LIFE TOPICS

Clinicians are recommended to support patients who are exploring end of life topics. The following topics may be addressed depending on individual patient needs:

1. End of Life Planning
2. Estate and Funeral Planning
3. Hospice Access
4. Medical Assistance in Dying (MAID)
5. Grief and Bereavement

At any point after a cancer diagnosis and often as cancer progresses, patients and their families/ caregivers may have questions, worries or preferences about dying, death or preparation for after death. Clinicians are a valued source of information or guidance about end of life topics and can help ensure that key activities, like preparing a will or addressing guardianship issues for dependents, have been addressed. Topics that people may want to inquire about include:

- How to recognize when death is near and what dying may look like, including modes of death e.g. “natural death”, [palliative sedation](#) for intractable symptom issues in final hours or days, death during resuscitation or medical management in hospital, or MAID.
- How to proactively anticipate and manage changing needs (e.g., if a patient is likely to lose the ability to take oral medication or become bed bound).
- Possible care locations before death (home, care facility, hospice, hospital).

Managing existential distress, death anxiety and changes in personal role or close relationships may involve the supports outlined in section 3.1; other topics in end of life care are listed below.

4.1 End of Life Planning

- Review ACP discussions and patient preferences for care at end of life.

- Determine the most appropriate GCD that reflects the person’s values and clinical context.
- Revisit caregiver supports.
- Ensure patient is on Alberta Health [Palliative Coverage Program](#) (also known as “Palliative Blue Cross” or “Palliative Drug Coverage”).
- Discuss possible and preferred location(s) of care towards end of life (e.g., home, hospice, hospital, or other facility).
 - Develop a plan for expected death in the community if patient would like to remain at home:
 - AHS expected death in the home toolkit can be found on Insite or at <https://www.albertahealthservices.ca/info/Page15828.aspx>
 - Resources that help prepare for death can be found on Insite by searching “Care before death” or “What to expect when a loved one is dying”
 - For information on “Care after death” in acute care visit <https://insite.albertahealthservices.ca/cad/Page12024.aspx>

4.2 Estate and Funeral Planning

Remind patients and their family/caregivers to begin this planning early on. For example, a will and financial enduring power of attorney are part of estate planning. Assist them to connect to the appropriate resources to fulfill this planning, such as social work or their lawyer.

4.3 Hospice Access

Hospice care is a specialized service available in certain locations that provides 24/7 facility-based palliative care to those who are approaching end of life and whose needs cannot be met at home/other location. There are *highly specific criteria* for referral to hospice and access is determined by secondary palliative care clinicians. See the “[Referral Based Services for Advanced Cancer Care](#)” document and/or talk to your local palliative care clinician about whether hospice may be appropriate for a specific patient and family/caregiver.

4.4 Medical Assistance in Dying (MAID)

AHS has developed the MAID policy to guide medical assistance in dying services. This policy is posted on the [AHS Medical Assistance in Dying](#) website and available from the [Care Coordination Service](#) upon request. A [physician FAQ](#) sheet is available.

4.5 Grief and Bereavement

Ask patients about their emotional supports and let patients and caregivers know that grief and bereavement resources are available both before and after death. Most services are accessed by self-referral and clinicians can help by providing the access information. See “[Referral Based Services for Advanced Cancer Care](#)” document for grief and bereavement resources.

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Appendix 1: Putting Patients First (ESAS-R)



Patient Label

Talking About What Matters To You Putting Patients First

Your answers will help us understand how you have felt since your last visit, and how you feel today. Knowing this will help us care for you. If you cannot or do not wish to fill out this form for any reason please let us know.

Note: Please make sure to fill out both sides of the form

A member of your healthcare team will go over the form with you and talk to you about what concerns you the most today. If we are not able to talk about all of your concerns today, we will decide the next steps together.

Date (yyyy-Mon-dd)	Completed by: <input type="checkbox"/> Patient <input type="checkbox"/> Family <input type="checkbox"/> Assisted by family/health professional		
Please answer the yes/no questions:			
1. Have you been to Emergency and/or been admitted to hospital since your last visit?			<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Have your medications changed since your last visit?(e.g. stopped, started, dose change)			<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Have you had a fall since your last visit?			<input type="checkbox"/> Yes <input type="checkbox"/> No
4. Would you like information on Goals of Care or advance care planning (green sleeve)?			<input type="checkbox"/> Yes <input type="checkbox"/> No
5. Are you receiving home care services?			<input type="checkbox"/> Yes <input type="checkbox"/> No
6. Have you used tobacco in the past year? <input type="checkbox"/> Yes <input type="checkbox"/> No	In the past 30 days?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Please circle the number that best describes how you feel NOW			
0 means you do not have that symptom, 10 means it is at its worst			
No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain	
No tiredness <i>(Tiredness=lack of energy)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness	
No drowsiness <i>(Drowsiness=feeling sleepy)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness	
No nausea	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea	
No lack of appetite	0 1 2 3 4 5 6 7 8 9 10	Worst possible lack of appetite	
No shortness of breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness of breath	
No depression <i>(Depression=feeling sad)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression	
No anxiety <i>(Anxiety=feeling nervous)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety	
Best well-being <i>(Well-being=how you feel overall)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst possible wellbeing	
No _____ Other problem (e.g. constipation)	0 1 2 3 4 5 6 7 8 9 10	Worst possible _____	

Continue on back side →

What concerns have you had since your last visit? Check any boxes that have concerned you.

<p>Emotional</p> <input type="checkbox"/> Fears/Worries <input type="checkbox"/> Sadness <input type="checkbox"/> Frustration/Anger <input type="checkbox"/> Changes in appearance <input type="checkbox"/> Intimacy/Sexuality <input type="checkbox"/> Thoughts of ending my life	<p>Physical</p> <input type="checkbox"/> Fever/Chills <input type="checkbox"/> Bleeding/Bruising <input type="checkbox"/> Cough <input type="checkbox"/> Headaches <input type="checkbox"/> Concentration/Memory <input type="checkbox"/> Vision or hearing changes <input type="checkbox"/> Numbness/Tingling <input type="checkbox"/> Sensitivity to cold <input type="checkbox"/> Changes to skin/nails <input type="checkbox"/> Bladder problems <input type="checkbox"/> Lymphedema/Swelling <input type="checkbox"/> Range of motion <input type="checkbox"/> Strength <input type="checkbox"/> Speech difficulties <input type="checkbox"/> Sleep	<p>Nutrition</p> <input type="checkbox"/> Weight gain (amount) _____ <input type="checkbox"/> Weight loss (amount) _____ <input type="checkbox"/> Special diet _____ <input type="checkbox"/> Difficulty swallowing <input type="checkbox"/> Mouth sores <input type="checkbox"/> Taste changes <input type="checkbox"/> Heartburn/Indigestion <input type="checkbox"/> Vomiting <input type="checkbox"/> Diarrhea <input type="checkbox"/> Constipation
<p>Social/Family/Spiritual</p> <input type="checkbox"/> Feeling alone <input type="checkbox"/> Feeling like a burden to others <input type="checkbox"/> Worry about friends/family <input type="checkbox"/> Support with children/partner <input type="checkbox"/> Meaning/Purpose of life <input type="checkbox"/> Faith	<p>Mobility</p> <input type="checkbox"/> Dizziness <input type="checkbox"/> Walking/Mobility <input type="checkbox"/> Trouble with daily activities (e.g. bathing, dressing)	<p>Informational</p> <input type="checkbox"/> Understanding my illness and/or treatment <input type="checkbox"/> Talking with my health care team <input type="checkbox"/> Making treatment decisions <input type="checkbox"/> Knowing about available resources <input type="checkbox"/> Taking medications as prescribed
<p>Practical</p> <input type="checkbox"/> Work/School <input type="checkbox"/> Finances <input type="checkbox"/> Getting to and from appointments <input type="checkbox"/> Home Care <input type="checkbox"/> Accommodation <input type="checkbox"/> Quitting tobacco <input type="checkbox"/> Drug costs <input type="checkbox"/> Health insurance <input type="checkbox"/> How much alcohol you drink	<p>Other Concerns: _____</p> <p>Thank you for filling out the form. The rest of the form will be completed by your healthcare professional</p>	

To be filled out by a health care professional only - Screening Intervention Documentation

Review of Form:

 Patient declined to fill out form Language barrier Other _____
 Form reviewed through conversation with patient
 If form not reviewed why: Patient declined discussion Other: _____
 Is patient at falls risk? Yes No
 Patient Priority Concern Identified Patient indicated no concerns_

Specify ONE priority concern (either ESAS or CPC):

ESAS:	<input type="checkbox"/> Pain	<input type="checkbox"/> Drowsiness	<input type="checkbox"/> Appetite	<input type="checkbox"/> Depression	<input type="checkbox"/> Well-being
	<input type="checkbox"/> Tiredness	<input type="checkbox"/> Nausea	<input type="checkbox"/> Shortness of breath	<input type="checkbox"/> Anxiety	<input type="checkbox"/> Other
CPC:	<input type="checkbox"/> Emotional	<input type="checkbox"/> Practical	<input type="checkbox"/> Mobility	<input type="checkbox"/> Social/Family/Spiritual	
	<input type="checkbox"/> Nutrition	<input type="checkbox"/> Physical	<input type="checkbox"/> Informational	<input type="checkbox"/> Other _____	

Specific area indicated under the CPC domain: _____

Actions taken:

 Provided information/Education Offered Tobacco Cessation Advice Prescription provided
 Provided emotional support Referral suggested but patient declined No further action required

Referrals:

 Social Work Palliative Care Fatigue Tobacco Clinic Dyspnea/Respiratory
 Psychology Nutrition Home Care OT/Physio/Speech CO Navigation
 Spiritual Care Pharmacy Pain Clinic Other _____

Further details on action taken:

See progress notes/nursing documentation for further information

Reviewed By (Name of Health Care Professional)	Signature (of Health Care Professional)	Date (yyyy-Mon-dd)
--	---	--------------------

Appendix 2: PRO Dashboard

Individual Symptom Tracking Report (or Individual Trended Dashboard):

This report can be generated for any patient in CancerControl Alberta (CCA) who has completed a Putting Patients First (PPF) form and the staff have entered it as part of the clinical documentation. It is intended to support both the patient and the provider team to visualize the patient's symptom burden over time and to highlight areas of high symptom burden. It also links clinical response and referrals made to each clinical visit/PRO report.

It pulls all info from ARIA (CancerControl Alberta's EMR) entered by clinicians regarding all previous visits. Patients get a "patient friendly" simplified version when they check in for their visit as a reference for when they fill in today's "Symptom Tracking Report" (which we refer to as the Putting Patient's First form).

For access to this report, contact EBI.program@ahs.ca.



Individual PRO Dashboard

EBI-2017-001
 Generation date: 2018-Sep-11
 Produced by Enterprise Business Intelligence Program
 Contact: ACB.EBIProgram@albertahealthservices.ca

Patient Reported Outcomes Report

Trend Report from 2018-Apr-30 to 2018-Jul-25

Patient Name: **ESAS Self-Reported Outcomes**
 Patient ID: Age: 55
 Diagnosis: Breast
 Clinic:

Date of Birth: Dec 27, 1962

Date	Apr 30	May 30	Jun 25	Jul 11	Jul 25
Visit Type	FU	FU	FU	TX	TX

Date	Apr 30	May 30	Jun 25	Jul 11	Jul 25
Response			Y		
Physical			Y		
ESAS concern					Y
Depression					Y
Shortness of breath		Y		Y	
Well-being			Y		

CPC Domains	Response	Jun 25	Jul 11	Jul 25
Emotional	Fears / Worries			Y
	Frustration / Anger	Y	Y	
	Thoughts of ending my life		Y	
Mobility	Trouble with daily activities	Y		Y
	Walking / Mobility	Y	Y	Y
Nutrition	Weight loss	Y	Y	
	Concentration / Memory		Y	Y
Physical	Headaches	Y	Y	Y
	Lymphedema / Swelling	Y	Y	
	Numbness / Tingling		Y	Y
	Range of motion		Y	Y
	Strength	Y	Y	Y

Date	Apr 30	May 30	Jun 25	Jul 11	Jul 25
Actions Taken	Y				
Prescription provided				Y	Y
Provided emotional support		Y	Y	Y	Y
Provided information / Education		Y	Y	Y	Y

EQ5D Completed

No data returned for this view. This might be because the applied filter excludes all data.

Date	Jun 25
Response	
Nutrition	Y

Clinic List Report:

This report can be generated for any clinic in CancerControl Alberta (CCA) based on location, date and provider, and is intended to support clinic preparation or team huddle prior to the start of clinic.

It pulls all information from ARIA (CancerControl Alberta's EMR) about the clinic including notes entered by clinicians regarding a patient's next visit, as well as the symptom burden the patient reported on their last PRO symptom screen (Putting Patients First form), along with when that screen was filled out, and other relevant information re: goals of care and % weight change in the last 3 months.

Clinicians can easily click on the patient name or ACB# to link to each individual's Trended PRO Dashboard.

Clinic List Report											
Clinic List Report	Height & weight		Additional Information								
Clinic List Report											
From Clinic Date Sep 11, 2018 to Sep 11, 2018											
Gener. Produr. Contar											
Alberta Health Services											
<input checked="" type="checkbox"/> (All) <input checked="" type="checkbox"/> BR <input checked="" type="checkbox"/> GI <input checked="" type="checkbox"/> GU <input checked="" type="checkbox"/> LNG <input checked="" type="checkbox"/> UNK											
Clinic Date	Visit Time	Event	Visit Provider	ACB #	Patient	Comments	Qstr Entry Date	Symptom Complexity	Request for Goals of Care (PPF)	Goals of Care on file in ARIA	Weight Change(%)
Sep 11, 2018	06:00 to 06:10	Other-CC		e47i	is F	Non Attending - CC: check status re: Pt approved for Durvalumab?	2018-Sep-04	L	N	N	3.36%
				e39i	ce N	Non Attending - CC: check PSA and order CT and bone scan PSA/Testos done Sept 7 PSA = 0.6 (compared to last PSA done Aug 3 = 0.8) Testos = <0.2	2018-Aug-28	M	N	N	
				r014	d G	Non Attending - CC: BW Due for cycle 1 maint Gem tomorrow BW done	2018-Sep-04	H	N	N	0.39%
				e49i	H	Non Attending - cc: 2 week status check/in	2018-Aug-28	M	Y	N	
				r01f	L	Non Attending - CC: UJA results from yesterday /as	2018-Sep-10	H	Y	N	-3.79%

Appendix 3: Eastern Cooperative Oncology Group (ECOG)

ECOG Performance Status

These scales and criteria are used by doctors 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. They are included here for health care professionals to access.

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 selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead

* As published in Am. J. Clin. Oncol.:
Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.:
Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol
5:649-655, 1982.

Appendix 4: Serious Illness Program (SICP) Conversation Guide

Serious Illness Conversation Guide



CONVERSATION FLOW

PATIENT-TESTED LANGUAGE

1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?"

2. Assess understanding and preferences

What is your understanding now of where you are with your illness?
"How much information about what is likely to be ahead with your illness would you like from me?"

3. Share prognosis

- Share prognosis
- Frame as a "wish...worry", "hope...worry" statement
- Allow silence, explore emotion

"I want to share with you my understanding of where things are with your illness..."
Uncertain: "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility." OR
Time: "I wish we were not in this situation, but I am worried that time may be as short as _____ (express as a range, e.g. days to weeks, weeks to months, months to a year)."
OR
Function: "I hope that this is not the case, but I'm worried that this may be as strong as you will feel, and things are likely to get more difficult."

4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

"What are your most important goals if your health situation worsens?"
"What are your biggest fears and worries about the future with your health?"
"What gives you strength as you think about the future with your illness?"
"What abilities are so critical to your life that you can't imagine living without them?"
"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"
"How much does your family know about your priorities and wishes?"

5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

"I've heard you say that _____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we _____. This will help us make sure that your treatment plans reflect what's important to you."
"How does this plan seem to you?"
"I will do everything I can to help you through this."

6. Document your conversation

7. Communicate with key clinicians



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Appendix 5: Advance Care Planning/Goals of Care Designation Tracking Record



Affix patient label within this box

Advance Care Planning/Goals of Care Designation Tracking Record

■ Purpose: to document the content of Advance Care Planning (ACP)/Goals of Care Designation (GCD) conversations and/or decisions.

Benefits:

- Assists healthcare providers in being aware of previous conversations and to understand the reasons underlying the current GCD order.
- Gives clues about where to pick up the conversation if decisions need to be reviewed or confirmed.
- The ACP GCD Tracking Record is a continuous record that goes in the Green Sleeve. Documenting on both Tracking Record and progress note may be necessary to ensure transfer of critical information.
- The original form is kept in the patient's Green Sleeve. When the patient moves to a new care setting, including home, a copy remains with the sending facility.

Date (yyyy-Mon-dd)	Site/ Attendees	Conversation Summary Notes	
			Required Documentation
			Any member of the healthcare team can record conversations on this form.
			Include who was involved in today's discussions (<i>i.e.</i> patient, family, healthcare provider Include name and relationship/discipline)
			Summarize conversation and/or key decisions from today's discussion
			It helps to document responses to the following speaking prompts.
			■ Have you completed a Personal Directive?
			■ Have you selected an alternative decision maker? If so do they know your wishes?
			■ What is your understanding now of where you are with your illness?
			■ If your health situation worsens what are your important goals?
			■ Do you know if you have a Green Sleeve?
			■ Do you know if you have a Goals of Care Designation (GCD) order?



Advance Care Planning/Goals of Care Designation Tracking Record

Date <i>(yyyy-Mon-dd)</i>	Site/ Attendees	Conversation Summary Notes	
			Required Documentation
			Any member of the healthcare team can record conversations on this form.
			Include who was involved in today's discussions <i>(i.e. patient, family, healthcare provider Include name and relationship/discipline)</i>
			Summarize conversation and/or key decisions from today's discussion
			It helps to document responses to the following speaking prompts.
			■ Have you completed a Personal Directive?
			■ Have you selected an alternative decision maker? If so do they know your wishes?
			■ What is your understanding now of where you are with your illness?
			■ If your health situation worsens what are your important goals?
			■ Do you know if you have a Green Sleeve?
			■ Do you know if you have a Goals of Care Designation (GCD) order?

Appendix 6: Palliative Performance Scale



Palliative Performance Scale (PPSv2) version 2

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 <i>with</i> 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	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.
2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

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Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. Ambulation

The items 'mainly sit/lie,' 'mainly in bed,' and 'totally bed bound' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'Reduced ambulation' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

2. Activity & Extent of disease

'Some,' 'significant,' and 'extensive' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

3. Self-Care

'Occasional assistance' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'Considerable assistance' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

'Mainly assistance' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'Total care' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake

Changes in intake are quite obvious with 'normal intake' referring to the person's usual eating habits while healthy. 'Reduced' means any reduction from that and is highly variable according to the unique individual circumstances. 'Minimal' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. Conscious Level

'Full consciousness' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. 'Confusion' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. 'Drowsiness' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. 'Coma' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

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The Palliative Performance Scale version 2 (PPSv2) tool is copyright to Victoria Hospice Society and replaces the first PPS published in 1996 [J Pall Care 9(4): 26-32]. It cannot be altered or used in any way other than as intended and described here. Programs may use PPSv2 with appropriate recognition. Available in electronic PDF format by email request to edu.hospice@viha.ca. Correspondence should be sent to the Director of Education & Research, Victoria Hospice Society, 1952 Bay Street, Victoria, BC, V8R 1J8, Canada

Development and Revision History

This guideline was reviewed and endorsed by the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams. Members of the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams include: medical oncologists, radiation oncologists, palliative care consultants, surgical oncologists, family physicians, allied health professionals, nurse practitioners, registered nurses, and patient and family advisors. Evidence was selected and reviewed by a working group comprised of members from the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams and a knowledge management specialist from the Guideline Resource Unit. A detailed description of the methodology followed during the guideline development process can be found in the [Guideline Resource Unit Handbook](#).

This guideline was originally developed in October, 2018 and underwent revisions in July 2019.

Maintenance

A formal review of the guideline will be conducted in 2022. If critical new evidence is brought forward before that time, however, the guideline working group members will revise and update the document accordingly.

Abbreviations

ACP, advance care planning; ADM, alternate decision maker; AHS, Alberta Health Services; ARD, Alberta Referral Directory; ASCO, American Society of Clinical Oncology; CPC, Canadian Problem Checklist; ECOG, Eastern Cooperative Oncology Group; EMR, electronic medical record; EOL, end of life; ESAS-r, Edmonton Symptom Assessment Scale - revised; GCD, goals of care designation; GI, gastrointestinal; MAID, medical assistance in dying; PEOLC, palliative and end of life care; PPF, Putting Patients First; PPS, Palliative Performance Scale; PRO, patient reported outcome; RCT, randomized controlled trial; SICIP, Serious Illness Care Program.

Disclaimer

The recommendations contained in this guideline are a consensus of the Alberta Provincial Gastrointestinal and Palliative Care Tumour Teams and are a synthesis of currently accepted approaches to management, derived from a review of relevant scientific literature. Clinicians applying these guidelines should, in consultation with the patient, use independent medical judgment in the context of individual clinical circumstances to direct care.

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