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## **Palliative Care Common Referral Form (PC-CRF) Frequently Asked Questions**

The Palliative Care Common Referral Form (PC-CRF) has been in use by palliative care organizations across the City of Toronto since 2004. The PC-CRF was originally developed by the Toronto In-Patient Palliative Care subcommittee of the Toronto Palliative Care Network (now known as the Toronto Central Palliative Care Network) in order to standardize the application process to access palliative care services throughout the city.

In November 2010, the PC-CRF was revised to a shorter, more comprehensive version. The form is a multiuse form for referral to a number of palliative care resources within Home and Community Care Support Services Toronto Central. We hope that the following information will be helpful to you and your colleagues as you continue to provide support to palliative individuals and their families.

Note: The term “individual” is used to represent the “patient” or “client” who requires palliative care. The term “family” is as defined by the individual.

### **Q: Why a Palliative Care Common Referral Form (PC-CRF) for palliative care?**

A: The PC-CRF is a communication tool. It simplifies communication and captures detailed information so that the individual does not have to remember and repeat their history or story again and again. For this reason, it is in the best interest of the individual requiring palliative care.

The PC-CRF also fosters quality communication among multiple care providers involved with the individual and family. The PC-CRF provides a baseline of information to new providers who may be involved in the care. Multiple referrals can also be made using this one form.

### **Q: Can I use my own referral form to refer for palliative care services?**

A: No. The PC-CRF has been endorsed for use in Home and Community Care Support Services Toronto Central. The purpose of the PC-CRF is to support the use of common language for effective communication between service providers and across care settings to ensure that all relevant information is shared in a comprehensive manner.

**Q: What “relevant information” is to be included?**

A: Only the most current and updated information is relevant. This includes any consultative notes, results of tests and imaging and other reports dated within the last two weeks, and current at time of referral (see the checklist).

**Q: Are all sections in the PC-CRF mandatory?**

A: No, but completing all sections of the PC-CRF as thoroughly as possible assists palliative services to initiate care and palliative support for the individual and family with the most comprehensive information available. Where indicated medical consultations notes and medication lists can be attached for ease of completion.

**Q: Does the individual have to be informed that a referral is being made for palliative care services?**

A: Yes. An explicit consent is required, by law, for the capable individual or substitute decision-maker. The capable individual or substitute decision-maker must be aware of the reason for referral unless they have expressed an explicit wish not to be informed

**Q: Who can complete the PC-CRF?**

A: Any provider can initiate a palliative referral by completing the PC-CRF and act as the point of contact for the referred palliative service.

**Q: Does the PC-CRF have to be completed and signed by a physician?**

A: No. The information obtained for the form may be from the interdisciplinary team, however, the referral source should ideally be one person who knows the individual well. The individual's family physician should be notified that referrals for palliative care services are being made.

**Q: Can more than one person complete the form?**

A: The PC-CRF is divided into various sections. The referral source must take ownership to ensure that the form is complete. Pertinent information is missed if the form is completed separately. The most efficient and time-saving method is to have all information available and accessible to the referral source through patient care rounds, team rounds, etc.

**Q: Why do you need to know who communicated the prognosis to the patient?**

A: To facilitate any followup if it becomes clear that the patient had additional related questions or did not understand the discussion.

**Q: What do each of the services mean in *Types of Services Requested*?**

A: The following is an explanation of the services (see page 1 of the PC-CRF) which the individual may require:

- Home and Community Care Support Services Toronto Central:: Home and Community Care Support Services Toronto Central provides support services in the individual's home. Services include nursing, personal support, and assessments or follow up from allied health services such as dietitian, social work, occupational therapy, physiotherapy, etc.
  - Pages 1-4 are required for all Home and Community Care Support Services Toronto Central referrals \*\*\* a Medical Referral Form is required
- Community Palliative Care Physician: Physicians in the community who provide palliative care expertise.
  - Pages 1-3 are required for all physician referrals, Page 4 can be completed for information but is not required. \*\*\*medical notes, tests results are mandatory
- Consultative care: request for consultation and support for the family physician, who continues to care for the individual
- Primary care: request for the community palliative care physician to assume the role of the most responsible physician for the individual
- Hospice Program: Hospice support includes care coordination, integrative wellness, bereavement support, spiritual support, volunteer support
  - Pages 1-4 are required for all hospice referrals
- Home visiting: care provided in the home
- Day Program: time-limited activities provided at the hospice
- Residential Hospice: end of life care provided within the residential hospice
  - \*\*Specify the Hospice program to which the individual will be referred.
- Inpatient Palliative Care Unit: Individuals who require admission to an inpatient setting with dedicated beds for palliative care provision. Admission criteria may vary.

- **\*\*Specify the Palliative Care Unit(s) to which the individual will be referred.**  
Pages 1- 4 are required for all PCU referrals

- Other: examples - HPC nurse consultants; Palliative care clinics, APNs, NPs

**Q: If a PC-CRF was completed before and I want to refer to another service, do I have to complete another form??**

A: No. A PC-CRF update form is available as a separate document which can be completed with new or updated information and attached to the original PC-CRF when referring to another service or when updating the information.

**Q: Can I put my own agency's logo at the top?**

A: The form was created with a generic format to allow for individual Hospice/Palliative Care Network logos to be added at the top. To support the recognition of the form, it is preferable that only Network logos be used. If your organization must insert its own logo, it may do so by requesting a word version of the form from your Hospice Palliative Care Network. To ensure that the benefits of a common referral form are not lost, the form must not be changed. All organizations that request a word version of the form are reminded of the disclaimer on the PC-CRF.

**Q: What does resuscitation refer to?**

A: Definition of Cardiopulmonary Resuscitation (CPR) by Ministry of Health and Long-Term Care (MOHLTC)—is an immediate application of life-saving measures to an individual who has suffered sudden respiratory or cardiorespiratory arrest. These measures include basic cardiac life support involving chest compressions, and/or artificial ventilation e.g., mouth-to-mouth resuscitation, bagging, and where available, defibrillation, intubation and other procedures considered to be Advanced Cardiac Life Support procedures by the Heart and Stroke Foundation of Ontario.

**Q: What Palliative Performance Scale (PPS)?**

A: Refer to enclosed handout titled: Provincial Palliative Care Integration Project. Resource Manual: Palliative Performance Scale (PPS)"

**Q: What ESAS (Edmonton Symptom Assessment System)?**

A: Refer to enclosed handout titled: Edmonton Symptom Assessment System (ESAS)

## Provincial Palliative Care Integration Project Resource Manual

### Palliative Performance Scale (PPS)

#### Description

The Palliative Performance Scale is a reliable and valid tool used for palliative care patients. Developed by Victoria Hospice Society, British Columbia, the PPS guides the assessment of a patient's functional performance.

The PPS is divided into 11 categories that are measured in 10% decremental stages (100% to 0%). These 11 categories are organized into three stages:

1. Stable
2. Transitional
3. End-of-Life

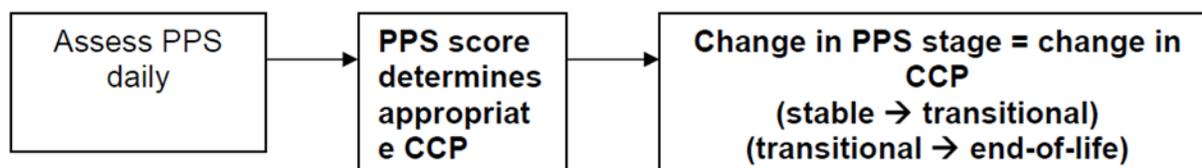
There are five observable parameters included in the functional assessment:

1. Degree of ambulation
2. Ability to do activities
3. Ability to do self-care
4. Intake
5. Level of consciousness

#### Purpose of the PPS

The PPS provides a framework for measuring progressive decline over the course of illness. It also provides a "best guess" projection of length of survival (i.e., suggests if patient is moving closer to death) and serves as a communication tool for the team. It also can act as a workload measurement tool. For example, patients who score between 0-40% usually require increased hands-on nursing care and their family members often need more support compared to those patients with higher PPS scores.

For the purpose of the Project, the PPS will also be used to guide the appropriate selection of the Palliative Collaborative Care Plan (i.e., Stable, Transitional or End-of-Life).



Palliative Performance Scale Feb 05; 1st printing January, 2003; Revised February 2005

## 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 Effort</i> 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	-	-	-	-

## How to do the PPS

The PPS score is determined by reading horizontally at each level to find the best fit for the patient. Leftward columns are stronger determinants, thereby taking precedence over others.

1. Begin at the left column until the appropriate ambulation level is found
2. Read across to the next column until the correct activity/evidence of disease is located
3. Read across to the self-care column, intake and conscious level columns before assigning the PPS score to the patient

### Ambulation:

- Reduced ambulation occurs at PPS 70% and 60%. The difference between 70% and 60% is subtly related to the activity columns—that is whether the patient is unable to do work (70%) or unable to do hobbies or house work (60%). Also note that the patient at 60% requires occasional assistance with self-care.
- There are subtle differences between “mainly sit/lie” and “mainly in bed.” The difference is subtly related to items in the self-care and intake columns. Use these adjacent columns to help decide. As well, the difference between mainly sit/lie and mainly in bed is proportionate to the amount of time the patient is able to sit up versus the need to lie down.

### Activity and Evidence of Disease:

- Some, significant and extensive disease refer to physical and investigative evidence showing degree of disease progression.
  - Example: Breast Cancer
    - local recurrence = some disease
    - one or two metastases = significant disease
    - multiple mets = extensive disease
- The extent of disease is also judged in the context of the patient’s ability to maintain work, hobbies and activities. For example, reduced activity may mean playing nine holes of golf instead of 18, or continuing with morning walks but at a reduced distance.

### Self-Care:

- Occasional Assistance—most of time the patient can transfer, walk, wash, toilet, eat own meals but sometimes needs help (e.g., once a day or few times a week)
- Considerable Assistance—regularly every day the patient needs help (e.g., to get to the bathroom but can brush own teeth; needs food cut but can feed self)

- Mainly Assistance—this is an extension of the considerable assistance category. (e.g., patient needs help getting to bathroom and washing)
- Total Care—the patient is unable to eat, toilet or do any self-care without help

**Intake:**

- Normal—refers to patient’s usual eating habits while healthy
- Reduced—a reduction of the patient’s normal eating habits
- Minimal—very small amounts, usually pureed or liquid, which are well below nutritional sustenance

**Conscious Level:**

- Full consciousness—full alertness, orientation, good cognitive abilities
- Confusion—presence of delirium or dementia and a reduced level of consciousness, which may be mild, moderate or severe.
- Drowsiness—may be due to fatigue, drug side-effects, delirium, closeness to death
- Coma—absence of response to verbal or physical stimuli. Depth of coma may fluctuate.

**Making Best Fit Decisions**

- Only use the PPS in 10% increments (e.g., cannot score 45%)
- Sometimes one or two columns seem easily placed at one level but one or two columns seem better at higher or lower levels. In these cases, use your clinical judgment and the leftward dominance rule to determine a more accurate score the patient.

(Example case studies are provided at end of PPS section.)

**When to do the PPS**

- Patients at Home  
It is good practice to complete the PPS each visit. The PPS should only be completed on a daily basis for those patients receiving more than one nursing visit per day.
- Patients Admitted to Hospital, Palliative Care Unit, or Long-Term Care Facility  
It is good practice to complete the PPS every day. It may be more helpful to complete the PPS at the end of the day shift.

**Who Should Complete the PPS**

The PPS can be used by any regulated health care provider. It is anticipated that in most cases, the PPS will be completed by a registered nurse or registered practical nurse.

## Where to Document the PPS

The PPS score is transcribed into the medical chart, e.g., on the flow sheet or in progress notes as per organization policy.

### Example Case Study #1

The patient spends the majority of the day sitting in bed or lying down due to fatigue from advanced disease. She requires considerable assistance to walk even short distances. She is fully conscious. She has good nutritional intake.

What is the patient's PPS score? (see bottom of page for best fit score)

### Example Case Study #2

The patient is very weak and remains in a chair a couple of hours a day. The rest of the time, he is in bed. He has advanced disease and is requiring almost complete assistance with self-care and feeding. He is experiencing decreased food intake, with a few small snacks that remain mostly unfinished. He has adequate fluid intake. The patient is drowsy but not confused.

What is the patient's PPS score? (see bottom of page for best fit score)

### Example Case Study #3

The patient is up and about on her own. She has experienced a recent recurrence of disease. She can do household chores with adequate rest periods. The patient requires occasional assistance with self-care whereby her caregiver watches her get in and out of the shower. Her intake is reduced from normal but still adequate. The patient is fully conscious with no confusion.

What is the patient's PPS score? (see bottom of page for best fit score)

#### PPS Case Study Answers:

Case study #1: PPS score 50%

Case study #2: PPS score 40%

Case study #3: PPS score 70%

[Reference: Victoria Hospice Society]

## Edmonton Symptom Assessment System (ESAS)

### Edmonton Symptom Assessment System (ESAS)

Please circle the number that best describes:

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain

Not tired 0 1 2 3 4 5 6 7 8 9 10 Worst possible tiredness

Not nauseated 0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea

Not depressed 0 1 2 3 4 5 6 7 8 9 10 Worst possible depression

Not anxious 0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety

Not drowsy 0 1 2 3 4 5 6 7 8 9 10 Worst possible drowsiness

Best appetite 0 1 2 3 4 5 6 7 8 9 10 Worst possible appetite

Best feeling of wellbeing 0 1 2 3 4 5 6 7 8 9 10 Worst possible feeling of wellbeing

No shortness of breath 0 1 2 3 4 5 6 7 8 9 10 Worst possible shortness of breath

Other problem 0 1 2 3 4 5 6 7 8 9 10

Patient's Name \_\_\_\_\_

Date \_\_\_\_\_ Time \_\_\_\_\_

Complete by (check one)

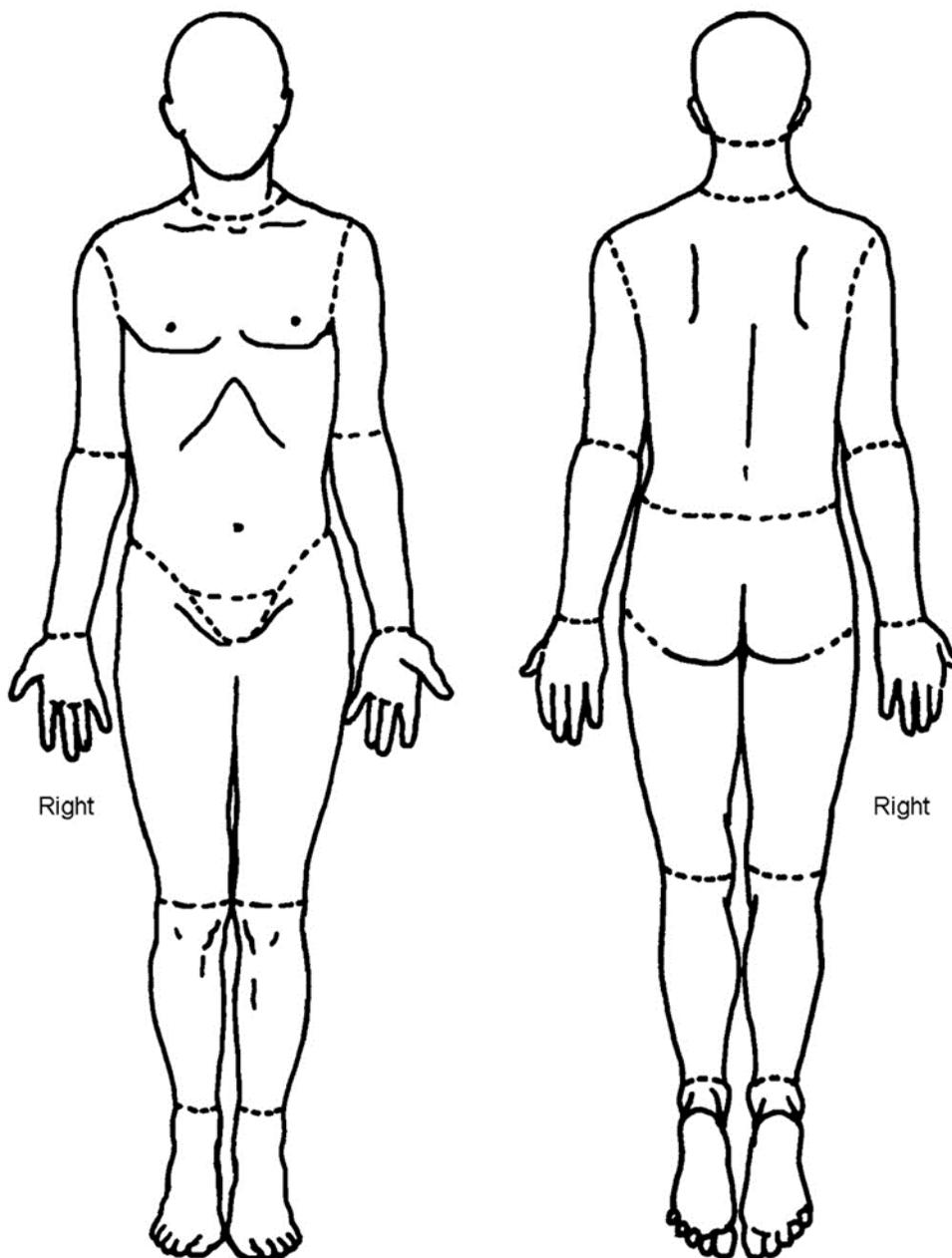
Patient

Caregiver

Caregiver assisted

**BODY DIAGRAM ON REVERSE SIDE**

Please mark on these pictures where it is you hurt.



## Edmonton Symptom Assessment System (ESAS)

### Description

The Edmonton Symptom Assessment System (ESAS) is a valid and reliable assessment tool to assist in the assessment of nine common symptoms experienced by cancer patients. The ESAS is one of the key assessment tools used in the Palliative Care Integration Project. The original tool was developed by the Regional Palliative Care Program, Capital Health in Edmonton, Alberta and slightly modified for this project.

### Purpose of the ESAS

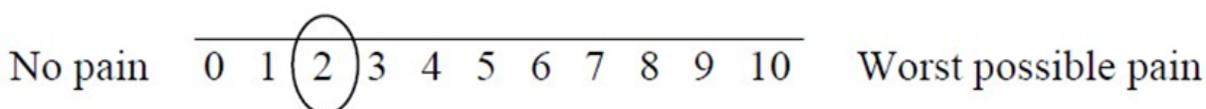
This tool is designed to assist in the assessment of: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. One blank scale is available for patients to use to assess another problem as needed. The severity at the time of assessment of each symptom is rated from 0 to 10 on a numerical scale; with 0 meaning that the symptom is absent and 10 that it is the worst possible severity.

The ESAS was designed so that the patient, or his/her family caregiver, could self-administer the tool. Therefore, the patient should be taught how to complete the scale. It is the patient's opinion of the severity of the symptoms that is the gold standard for symptom assessment.

The ESAS provides a clinical profile of symptom severity over time. It provides a context within which symptoms can be understood. However, it is not a complete assessment in itself. For good symptom management to be attained, the ESAS must be used as one part of a holistic clinical assessment.

### How to do the ESAS

The patient circles the most appropriate number to indicate where the symptom is between the two extremes.



ESASInstruction.doc; 1st printing February 2003; Revised 2003 August, 2005 February

The circled number is then transcribed onto the medical chart (e.g., flow sheet) or the ESAS form is graphed and placed in the medical chart.

Words for symptoms that may be difficult for some patients to understand include the following:

- Depression—sad or blue
- Anxiety—nervousness or restlessness
- Tiredness—decreased energy level (but not necessarily sleepy)
- Drowsiness —sleepiness
- Well-being—overall comfort, both physical and otherwise; truthfully answering the question “How are you?”

If patients are in pain, they should mark on the Body Diagram where they hurt. This does not need to be done every day, but changes need to be recorded. Discuss with your patient the best way to do this.

### **When to do the ESAS**

- Patient at home  
It is good practice to complete the ESAS during each telephone contact or home visit (maximum of once per day). If symptoms are in good control and there are no predominant psychosocial issues, the ESAS can be completed weekly.
- Patients Admitted to Hospital, Palliative Care Unit, or Long-Term Care Facility  
It is good practice to complete the ESAS every day. Patients with good symptom control with no predominant social issues can complete the ESAS on a weekly basis.
- Time of Day  
Ideally, it is good practice to have patients complete the ESAS at the same time of day.

### **Who Should Complete the ESAS**

Ideally, patients fill out their own ESAS. However, if the patient is cognitively impaired or for other reasons cannot independently do the ESAS, then it should be completed with assistance by the caregiver (a family member, friend) or a health professional closely involved with the patient’s care. If the patient cannot participate in the symptom assessment, the ESAS is completed by the caregiver or professional.

The method in which the ESAS is completed must be indicated on the flowsheet in the space provided as follows: by patient, caregiver assisted, by caregiver, or by health professional.

### Where to Document the ESAS

The ESAS is always done on the ESAS numerical scale and the scores are transcribed into the medical chart, flowsheet, or the ESAS form is graphed and placed in the medical chart.

**Note:** When the caregiver or professional completes the ESAS alone the subjective symptom scales are not done (i.e., tiredness, depression, anxiety, and well-being are left blank) and the caregiver assesses the remaining symptoms as objectively as possible, i.e., pain is assessed on the basis of a knowledge of pain behaviours, appetite is interpreted as the absence or presence of eating, nausea as the absence or presence of retching or vomiting, and shortness of breath as laboured or accelerated respirations that appears to be causing distress for the patient.

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