

# Appendix 7

## PALLIATIVE PERFORMANCE SCALE (PPS)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-care	Intake	Conscious Level
100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable to do normal job/work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable to do hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40%	Mainly in bed	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 bound	-	-	-	-

- ➔ PPS scores are determined by reading horizontally at each level to find a “best fit” for the patient which is then assigned the PPS% score.
- ➔ 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 at a 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 may 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 in “total care.”

- ➔ 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. The clinician should 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.
- ➔ 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. PPS has also been shown to have prognostic value in both cancer and non-cancer conditions.

#### 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 versus the 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 and extent of disease

“Some,” “significant,” and “extensive” disease refer to physical and investigative evidence which shows degrees of progression. The extent of disease also considers the person’s ability to continue work and hobbies/activities.

### For example

Some: breast cancer, a local recurrence

Significant: breast cancer with 1-2 metastatic sites

Extensive: breast cancer with multiple metastases in lung, bone, liver, brain, hypercalcemia, or other major complications.

## 3. Self-Care considers how much assistance the person requires to get out of bed, walk, bathe, toilet, and eat meals

“Occasional assistance” means that most of the time the person can transfer out of bed, walk, wash, toilet, and eat by their own means, but that on occasion they require minor assistance.

“Considerable assistance” means the patient needs help everyday. For example, the person needs help to get to the bathroom, but is then able to brush their teeth or wash their hands and face.

“Mainly assistance” means that the person needs help getting up, but also needs assistance washing his face, and 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

"Normal intake" refers 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 the levels required for sustenance.

#### 5. Consciousness level

"Full consciousness" implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc.

"Confusion" is used to denote the presence of either delirium or dementia and is a reduced level of consciousness.

"Drowsiness" implies either fatigue, drug side effects, delirium, or closeness to death.

"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.

### Does the scale consider psychological factors which may impact the items?

PPS only considers what a person is capable of doing, not what they choose to do. For example, anxiety, sadness, or demoralization may result in the patient sitting a lot, but unless they actually require some assistance to get up (PPS 50% or 60%), the PPS would be higher.

### We often see people at diagnosis who are fully ambulatory, normal activity and work, but have extensive disease where do they fit in?

This necessitates a clinical judgment decision. In this case, the aspect of full ambulatory and normal activity indicates quite a high PPS and the “extensive disease” is clinically less relevant, at least for the moment. A PPS 80% would be appropriate designation.

### People who are unable to work because chemotherapy is demanding, but only have some evidence of disease, how do I score them?

The PPS should be determined by the actual ability to do something, not by desire, or lack of. In this case, it is not clear what “demanding” means. If the patient is so physically sick or fatigued that they cannot work, then the PPS is rated accordingly – PPS 70% would be appropriate if can do some work at home, but could be reduced to PPS 50% if they were so sick that they required actual assistance at home.

### Can PPS be used in people with dementia?

In general, the answer is yes, as PPS is a functional performance scale which primarily focuses on ambulation, activity, and self care. Particularly in the advanced stages of Alzheimer's disease, the patient fits quite well into such levels as PPS 50% through PPS 10%.

### What level of staff are using this tool – nurses, physiotherapists, volunteers?

PPS can be used by many types of healthcare workers, including nurses, physicians, respiratory therapists, physiotherapists,

occupational therapists, dieticians, spiritual care providers (chaplains), and volunteers.

### How often do you recommend the use of this tool in a home care palliative care setting where there are various levels of caregivers in the home? Daily visits?

In generally, PPS should be assessed during each visit ,which of course may vary from daily to weekly or less. In our Palliative Care Unit, it is done each day or at any time the patients' condition changes.

### When a patient's mobility is limited due to a fracture in a weight bearing bone, will it translate into the same score as if the inactivity was due to extreme weakness and fatigue?

Yes, as the person will be less able to ambulate. If in full traction, PPS would likely be PPS 40% since he or she is bed-bound but can do some self care. If in a cast and using a walker or crutches, PPS might be 50%. It would also be expected that, all things being equal, the PPS will increase shortly as mobilization improves.

### How is the "Intake" domain scored for patients whose primary or total intake is via a feeding tube?

This is a situation where the intake is difficult to interpret.

Use the other four domains to determine the PPS level, regardless of intake.

Try to incorporate observations that the tolerability and the volume of fluid given via parenteral tubes usually decreases with overall decline and closeness to death.

## Can PPS be used in the paediatric population?

There is no evidence to support its use in children. Generally, the Lansky Play-Performance Scale is used in children. This scale uses a parent's description of the child's activity to assess ability and response to treatment.

Karnofsky Scale (recipient age $\geq$ 16 years)		Lansky Scale (recipient age $<$ 16 years)	
<b>Able to carry on normal activity; no special care is needed</b>		<b>Able to carry on normal activity; no special care is needed</b>	
100	Normal, no complaints, no evidence of disease	100	Fully active
90	Able to carry on normal activity	90	Minor restriction in physically strenuous play
80	Normal activity with effort	80	Restricted in strenuous play, tires more easily, otherwise active
<b>Unable to work, able to live at home cares for most personal needs, a varying amount of assistance is needed</b>		<b>Mild to moderate restriction</b>	
70	Cares for self, unable to carry on normal activity or to do active work	70	Both greater restrictions of, and less time spent in active play
60	Requires occasional assistance but is able to care for most needs	60	Ambulatory up to 50% of time, limited active play with assistance/supervision
50	Requires considerable assistance and frequent medical care	50	Considerable assistance required for any active play, fully able to engage in quiet play
<b>Unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly</b>		<b>Moderate to severe restriction</b>	
40	Disabled, requires special care and assistance	40	Able to initiate quite activities
30	Severely disabled, hospitalization indicated, although death not imminent	30	Needs considerable assistance for quiet activity
20	Very sick, hospitalization necessary	20	Limited to very passive activity initiated by others (e.g., TV)
10	Moribund, fatal process progressing rapidly	10	Completely disabled, not even passive play

### References specific to PPS

- Lau F, Downing M, Lesperance M, Karlson N, Kuziemy C, Yang J. Using the Palliative Performance Scale to Provide Meaningful Survival Estimates. *Journal of Pain and Symptom Management*. 2009 Jul 1;38(1):134-44



Medication dosing recommendations were informed by review of the following references

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