# **Questions & Answers (Q&A), Instructions & Definitions** for Use of Palliative Performance Scale (PPSv2)

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### **Victoria Hospice Society**

The following Q&A Manual covers questions that have been asked about PPS. They are grouped in headings according to the type of question and provide additional information in how to use and interpret the definitions for PPS.

This file is updated as of JULY 2020 with new information.

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### **Section 1. Introduction**

### **Copyright & License for Use of PPS**

PPSv2 is freely available in English or other language translations approved by Victoria Hospice. However, we do require a letter of agreement for its use. This can be downloaded and filled out from the website www.victoriahospice.org.

### **History & Development of PPS**

When Victoria Hospice began in 1980 as a small pilot project, we used the few available tools in the literature at that time to assist in assessing our patients. One tool we regularly used was the Karnofsky Performance Scale (KPS)(1) first published in 1948 to assess functional status in cancer patients who had been exposed to mustard gas in WW1. It provided 11 levels from KPS 100% to KPS 0%. It was also often recorded in the local Victoria Cancer Clinic. Indeed, KPS remains in regular use today in cancer patients, particularly in Europe where it originated.

Over the next several years we found KPS to be quite helpful in assessing patients and for easy written and verbal communication among staff. However, there were some minor problems which arose in the determination of some KPS scores. Our hospice program provided palliative services to patients located at home, in hospital and hospice beds. We endeavored to support death at home but when using KPS, the lower scores stated that admission to a hospital was 'recommended' or 'necessary' but that did not fit many of our patients who were able to die at home.

A second limitation of KPS we discovered was its sole focus on physical functional capacity. As we gained more experience in this new field of 'hospice' we found that along with the decline in ambulation leading to death patients also had reductions in oral intake and conscious level closer to death. Indeed, the combination of all of these factors assisted in improved assessment and communication to patient status but also in prognostication.

It was at that time in 1984 Dr. Downing began to devise such a combination of factors into a new tool – we deemed its use for palliative patients and in parallel with KPS using percentage levels the name Palliative Performance Scale (PPS). It was deemed a modification as being similar yet distinct from the original KPS.

PPS quickly became used locally and provincially with frequent positive feedback as to its utility and was incorporated into Victoria Hospice teaching. It should have been published at that time but since our program was small with limited resources and staffing, it remained a clinical tool for the next 5-10 years. By 1996 Dr. Downing and a group of nurses from both homecare and hospice gathered initial PPS data of home patients and survival. Home care nursing was finding the need for service support increased accordingly to PPS levels and medically it also had some prognostic value. The group then submitted a manuscript and was published in the *Journal of Palliative Care* in 1996 as the official emergence of PPS(2).

It became more widely used after publication and over the next few years positive feedback was received by many clinicians, but a few people raised questions regarding the 'conscious' category for example. As a result, we made a few changes by adding 'confusion' at PPS 60%. We revised PPS 30% to 'normal or reduced' intake. The ditto marks were removed to make it clear and easier to read PPS levels horizontally. We decided to call this a revision to Palliative Performance Scale version 2 (PPSv2) which is now the official PPS. It was changed in 2001 and published in Medical Care of the Dying in 2006(3). A Master's thesis on reliability of PPSv2 was conducted by nurse Lynn Cummings and completed in 2003 but not published, thus her thesis remains in grey literature.

PPS was validated in multi-sites by Morita from Japan in 1999(4), Virik and Glare from Australia in 2002(5), and Harrold(6) and Head(7) from USA in 2005. Of course, Victoria Hospice should have already conducted reliability testing by now, but we truly appreciate the initiative of these authors in using PPS. Victoria Hospice finally obtained a collaborative research

grant in 2004-08 from the Canadian Institute for Health Research and published several papers on prognosis in 2006 by Lau et al(8) and PPSv2 reliability by Ho et al(9) in 2008.

Since then, there are approximately 200 research studies on PPSv2 in areas of language translation, prognostication, clinical value, surveillance and others. Its value at this point is unquestionable and therefore a training manual is important to ensure the correct use and interpretation of PPS. The reader will see in the following Q&A that even though a simple quick tool to use, it is also easy to inadvertently misuse PPSv2 if attention is not paid to accurate definitions.

### **Learning & Teaching PPS**

# PPS is Simple, but Not Easy

#### General overview of use

It is important that PPS be used accurately particularly as it is not as easy as many people think. Teachers of PPS need to be familiar with its nuances.

It is also expected that users will receive training for PPS. There are 2 aspects – one is the use and *calculation* of the PPS table tool. The second aspect is very important which is the proper understanding and use of the *'definitions of terms'* used in the PPS table. Although PPS is quick and simple to use, it is not easy and the underlying definitions are critical to accurate PPS scores.

There are several materials that are valuable for teaching:

- 1. The "Definitions of Terms" that are on the PPS table. Words such as some, significant and extensive have specific meaning. Indeed, not knowing/using the definitions is where most errors occur.
- 2. The PPSv2 Online training course at https://vh.smarteru.com/
- 3. This material here **PPSv2 QA Instructions and Definitions updated July 2020.docx**. These Q&A are actual queries and real cases submitted from writers around the world.
- 4. **Training case examples** There are 20 'Case Scenarios' that can be used when teaching PPS. These cases were used in the reliability study of PPS, as well as studies on the translation of PPS by some countries, and are available by download from:

Victoria Hospice website: <a href="www.victoriahospice.org">www.victoriahospice.org</a>
Write to Dr. M. Downing: <a href="mailto:drgmdowning@gmail.com">drgmdowning@gmail.com</a>

### **Key Points for PPS Training**

- "Leftward" parameters take precedence
- Find the best "horizontal fit"
- *Clinical judgement* of best horizontal fit– overrides any ambiguities
- Not what patient is/observed doing, but what is able/capable to do
- **Definitions** are important
- PPS is *simple*, *but not easy*

The above are some key points for proper use and calculation of PPS scores.

### Palliative Performance Scale (PPSv2)

PPS Level	Ambulation	Activity Level & Evidence of Disease	Self -care	Intake	Conscious level
PPS 100%	Full	Normal activity & work  No evidence of disease	Full	Normal	Full
PPS 90%	Full	Normal activity & work  Some evidence of disease	Full	Normal	Full
PPS 80%	Full	Normal activity & work <i>with</i> effort Some evidence of disease	Full	Normal or reduced	Full
PPS 70%	Reduced	Unable normal activity & work Significant disease	Full	Normal or reduced	Full
PPS 60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance	Normal or reduced	Full or confusion
PPS 50%	Mainly sit/lie	Unable to do any work <b>Extensive</b> disease	Considerable assistance	Normal or reduced	Full or drowsy or confusion
PPS 40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
PPS 30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Normal or Reduced	Full or drowsy +/- confusion
PPS 20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal sips	Full or drowsy +/- confusion
PPS 10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma
PPS 0%	Dead	-	-	-	-

Instructions: PPS level is determined by reading left to right to find a 'best horizontal fit.' Begin at left column reading downwards until current ambulation is determined, then, read across to next and downwards until each column is determined. Thus, 'leftward' columns take precedence over 'rightward' columns. Also, see 'definitions of terms' below. © Victoria Hospice Society.

### **Definition of Terms for PPS**

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

- L. Ambulation (Use item Self-Care to help decide the level)
  - Full no restrictions or assistance
  - Reduced ambulation degree to which the patient can walk and transfer with occasional assistance
  - Mainly sit/lie vs Mainly in bed the amount of time that the patient is able to sit up or needs to lie down
  - Totally bed bound unable to get out of/move in bed or do self-care
- 2. Activity & Evidence of Disease (Use Ambulation to help decide the level.)
  - Activity Refers to normal activities linked to daily routines (ADL), house work and hobbies/leisure.
  - Job/work Refers to normal activities linked to both paid and unpaid work, including homemaking and volunteer activities.
  - Both include cases in which a patient continues the activity but may reduce either the time or effort involved.

### **Evidence of Disease**

- No evidence of disease Individual is normal and healthy with no physical or investigative evidence of disease.
- 'Some,' 'significant,' and 'extensive' disease Refers to physical or investigative evidence which shows disease progression, sometimes despite active treatments.
- Example 1: Breast cancer:

some = a local recurrence

significant = one or two metastases in the lung or bone
extensive = multiple metastases (lung, bone, liver or brain),
hypercalcemia or other complication

#### Example 2: CHF:

 some
 = regular use of diuretic &/or ACE inhibitors to control

 significant
 = exacerbations of CHF, effusion or edema necessitating increases or changes in drug management

 extensive
 = 1 or more hospital admissions in past 12 months for

acute CHF & general decline with effusions, edema, SOB

### 3. Self-Care

- Full Able to do all normal activities such as transfer out of bed, walk, wash, toilet and eat without assistance.
- Occasional assistance Requires minor assistance from several times a
  week to once every day, for the activities noted above.
- Considerable assistance Requires moderate assistance every day, for some of the activities noted above (getting to the bathroom, cutting up food, etc.)
- Mainly assistance Requires major assistance every day, for most of the activities noted above (getting up, washing face and shaving, etc.).
   Can usually eat with minimal or no help. This may fluctuate with level of fatigue.
- Total care Always requires assistance for all care. May or may not be able to chew and swallow food.

#### 4. Intake

- Normal eats normal amounts of food for the individual as when healthy
- Normal or reduced highly variable for the individual; 'reduced' means intake is less than normal amounts when healthy
- Minimal to sips very small amounts, usually pureed or liquid, and well below normal intake.
- Mouth care only no oral intake

#### 5. Conscious Level

- Full fully alert and orientated, with normal (for the patient) cognitive abilities (thinking, memory, etc.)
- Full or confusion level of consciousness is full or may be reduced. If reduced, confusion denotes delirium or dementia which may be mild, moderate or severe, with multiple possible etiologies.
- Full or drowsy +/- confusion level of consciousness is full or may be markedly reduced; sometimes included in the term stupor. Implies fatigue, drug side effects, delirium or closeness to death.
- Drowsy or coma +/- confusion no response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period. Usually indicates imminent death

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# Section 2. Questions & Answers

### **Questions about "General Use of PPS Tool"**

### 1. How many "Languages"?

PPS is translated into several languages and used in many countries. There are likely more language translations but the following are those we are aware of:

Translations Arabic Catalan Chinese Czech Dutch English Estonia French German	Reliability/Validity Testing validated(10) validated(11) underway - (12) underway(13) validated(2, 4, 5, 9) underway validated(14) validated(15)
India Indonesia	translation underway translation underway
Japanese Polish	validated (16) - validated(17)
Portuguese	underway(18)
Spanish	validated(11, 19)
Thai	validated(20)
Turkish	validated(21)

### 2. Are there references for the use of PPS?

Answer: Yes there are ~200 published studies; some of these are seen in the references at the end of this document.

### 3. What is the difference between PPS and PPSv2?

- Answer: The official scale to use now is PPSv2. It is almost exactly the same with the only changes being addition of 'confusion' at PPS 60%, revision to 'normal or reduced' intake at PPS 30%, replacement of ditto marks with appropriate phrases, and the inclusion of an 'instructions for use'.
- We have checked with our stats analyst who says these changes are so minor that it does not mean that reliability or validation testing needs to be repeated.

### Is there interchangeability between PPSv2 and KPS?

Answer: The short answer is Yes. PPS is a significant modification of the Karnofsky Performance Scale (KPS). However there are a few studies that looked at this question and concluded that the tools can substitute one for the other(22-25).

### 5. Who or what types of staff can use this tool - nurses, occupational therapists, pastoral workers?

Answer: PPSv2 can be used by many palliative workers - Nurses, Physicians, Respiratory Therapists, Physiotherapists, Occupational Therapists, dieticians, pastoral, social workers, counselors, volunteers, etc. Some patients and families have been taught how to interpret PPS. The tool is quick and easy to use but its accuracy is based on understanding the definitions of words in PPS and how it is calculated, not on the occupation of the health professional using it.

### 6. Should PPS be calculated from 'observed' function or 'capable' of function?

Answer: PPS is always based on what the patient is capable of doing, even if not doing so at present.

- a. "One area which could affect reliability in use of PPS in residential settings where patients have less opportunity for independent functioning, regardless of whether they are capable of such activity" (Head and Ritchie)(7).
- b. Thus, raters must be instructed to ask appropriate questions and base their calculation on **what the patient is able to do**, rather than formulating the rating solely from observation which would be incorrect and invalid use of PPS.

#### • Case Example:

66 year old female with breast cancer. There are mets to lung and bone and now progressing to her brain. She enjoys visits with her daughter where they spend time putting together puzzles. It frustrates her to not be able to get out of bed, but any weight on her femur may cause a fracture. Her daughter brings in her favorite foods pureed. Her O2 sats drop to mid 70's when she tries to eat solid food. CNA visits are scheduled 3 times a week because she has a purple area on her coccyx and family is unable to get her to the shower.

**Answer:** You note she can't get out of bed since that may cause pain and possible fracture. PPS is determined **not** by what the patient **"is doing" but** by what patient **"could do"**. In other words, the caution about being 'in bed' is not her physical limit but a practical limit. Thus, her PPS would be somewhere at 40% or higher depending on what amount of assistance she would need to sit on the bed or move to commode chair if anxiety wasn't limiting her actual ability.

Thus it is very important to only use 'what the patient could do'; otherwise the tool would not be a functional ability tool, but resort to an emotional mood/desire/energy tool in which case which is clearly not intended. It would also limit its ability to act as a prognostic tool

7. When I read horizontally to find the best fit, can I choose a level that is higher, or must it always be a lower level? That is, the instructions state that PPS level is determined by reading left to right to find a 'best horizontal fit' Eg. When the ambulation is on PPS 50%, I read horizontally right to activity and can choose from 50% or lower, but no more from 50% or higher)?

**Answer:** You may go up or down. When looking horizontally, you may find that the current level, or one below, or one above is actually the "best fit". The leftward precedence is a guideline to viewing it, but then clinical judgment as to whether the level for this patient should be higher or lower. In general, the leftward columns are 'stronger' and that is why one looks at those first.

"Diagonal	Downward"	Decline
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PPS Level	Ambulation	Activity Level & Evidence of Disease	Self -care	Intake	Conscious level
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### 8. PPS Scoring Can NOT be summed

The **summation** of individual items and subsequent overall average calculation is **not the way PPS is used**. Unfortunately, several people were incorrectly using this over the years by summing each PPS and making an average rating. Others were choosing the highest or the lowest of the scores. The instructions are a 'best horizontal fit' which is an overall clinical judgment and I don't see that there can be very different ways of using a tool and having it meaningful. For these reasons, PPS cannot be approved in a different way.

# 9. Can PPSv2 be broken into "pieces" based on different categories? For example, can a patient be referred to as a "PPS 40/20"?

- **Issue:** In this case, the patient was referred to as PPS 40% because he could still get up with much help but then was also called PPS 20% because he could only take a few sips as intake, thus a PPS 40/20.
- Answer: No. A patient cannot be identified that way. There is *only one PPS level for a patient at a specific time* and one bases this on the "clinical best fit" level. In this case, the patient was PPS 40% based on ambulation and self-care which is correct. The fact that he can only takes 'sips' is not important the columns are based on *left to right precedence*; the sips would be included in the 'reduced' intake but does not mean the patient is at a PPS 20% level. We have also heard this incorrectly called this patient a "walking 20%" which again is incompatible with the very structure of PPS.
- 10. I have placed a patient at various PPS scores among the categories but am not sure which one fits best.

Case: The patient is totally bed bound at 30%, activity is 30%, but self-care is viewed to be 50%, intake 70% and consciousness is 70%. Can we go from 30% back up to say 50%?

Answer: PPS 30% means the *combination* of total bed bound, no activity AND no self-care at all (ie. Cannot lift his arms, cannot help to turn in bed, cannot feed himself or brush teeth). But you indicate here his self-care is 50% and if this is correct, then he cannot be PPS 30%. If he requires extensive assistance in bed to turn, eat, etc then PPS would be 40% and needs 2-person help; if he can do a little more, then PPS 50% with perhaps 1 or 2 person help to sit, commode, etc.

PPS is always the "best fit" and you work from the left side first. In this case, it is the amount of self-care required that determines whether 30, 40 or 50%.

# 11. Have family members who are caring for their loved ones at home ever been educated on the use of the PPS or in your opinion would it even be useful?

- Answer: PPS is used mainly by professional staff. However, there are also some patients or family members who are very involved and meticulous in their care and wanting to know what is being assessed by clinicians and planned. For these occasional times, sharing the PPS tool has been helpful and appreciated in helping them to understand the possible or expected trajectory.
- Although intended as a professional tool, there are many families, and some patients, who have used PPS. I just
  had an email from a husband in Ontario who wanted some information on prognosis. He had already assigned
  her a PPS 40% as he had access to the tool, and then verbally described her situation which my conclusion would
  also be 40%. My anecdotal experience is that family are often quite accurate.
- See also the Section "Non-Palliative"

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

• Answer: In general, PPS should be rated on each home nursing visit which of course may vary from daily to weekly or less often. In our Palliative Care Unit, it is done each day or at anytime the patients' condition changes.(26)

### Questions about "Disease"

- 13. What are the definitions of 'some evidence' of disease, 'significant' and 'extensive' disease? Is this measured purely in terms of pathology or are the psychological impacts etc also considered?
  - Answer: 'Some,' 'significant,' and 'extensive' disease refer to both 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 indicate 'extensive' disease.
  - PPS is a physical functional scale only, so psychological aspects are **not** considered in the determination. It is based on what a person is capable of doing, not what they choose to do. For example, anxiety, sadness, demoralization or even dementia may result in the patient sitting at home a lot, or not wanting to get out of bed, but unless they actually require some assistance to get up (PPS 50% or 60%), the PPS would be higher.

### 14. Case Example (submitted):

"A patient is diagnosed with Ca Breast with metastases to lymphadenopathy and pericardial effusion. She has a history of mental retardation and Turner's Syndrome since young. Self-care is done by family as she is not able to perform it herself. Eating well and walking normally".

**Answer**: There is significant/extensive disease since a pericardial effusion is a significant or even serious complication of the breast cancer, but she can walk 'normally' [not sure what that means] so PPS would be around PPS 70%, 60% or 50%. Since self-care must be done by family, this would move her to the lower one of PPS 50% as 'considerable help' is needed. It might have even been PPS 40% for self-care but the fact that she walks well means that level is too low. The fact of mental retardation does not affect the status as this is developmental disability and not due to disease progression. If she became confused or delirious from sepsis or drug effects then that column is used but not for the ongoing disability itself.

So her performance status is PPS 50%. It is the disease and pericardial effusion that 'pulls' the level downwards and the ability to walk normally that pulls the level upwards.

#### 15. Use of PPS in various Non-Cancer Diseases

PPS is commonly used in both cancer and non-caner illnesses. Some examples include:

- General non-cancer(27)
- Heart disease(28-34)
- Renal failure(35-37)
- Lung disease(28, 38, 39)
- Cerebrovascular(28, 31, 40, 41)
- Dementia(28, 31, 39, 42)
- Parkinson's disease(43)
- Orthopedic hip fracture(44), trauma(45)

### Questions about "Ambulation"

- 16. Example 1: "We see some people at diagnosis who are fully ambulatory, normal activity and work but have 'extensive' disease so where do they fit in?"
  - Answer: PPS is determined by a "best fit" recognizing, as noted here, that some categories do not line up well. This necessitates a clinical judgment decision. In the case you describe, 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.
- 17. **Example 2**: 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 would be scored at PPS 50% whether or not intake or conscious level is altered.

- 18. "People who are 'unable to work' because chemotherapy is demanding, but only have some evidence of disease, how do I score them?"
  - Answer: 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 you mean by 'demanding'. 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 the person can do some work at home, but would be reduced to PPS 50% if they were so sick or fatigued that they required actual assistance at home.
- 19. "People who are unable to do most activities due to poor family support or depression but have only some evidence of disease, where do they fit in?"
  - **Answer**: PPS should be determined by the actual ability to do something, not by desire, or lack of. If the patient is clinically depressed and thus not getting up much, but is in fact able to do so, then the PPS level would be higher at 70% or 80% since in this case there is little evident primary disease impact.
  - The same would apply to family support. If the patient needs some assistance to get up or walk, but there are no
    family available to assist and thus stays in bed, then the PPS level is still determined by what he or she can do
    once he is assisted, not simply the observation he is usually lying down. If the family arrived and helped him up
    or to get dressed, that fits with a PPS level of 50% or 60%.
- 20. "When a patient's mobility is limited because of a pathological fracture in a weight bearing bone, or a painful vertebral compression fracture, will PPS translate into the same score as if the inactivity was due to extreme weakness and fatigue?"
  - Answer: Yes, the PPS will be lower as the patient functionally is less able to activate. PPS indicates functional
    capacity, not the diagnosis or reason for any decline. If the persons is in full traction, the PPS would likely be PPS
    40% since he or she is bed-bound but can do some self-care. If the person has a cast and is using a walker or
    crutches, the PPS would be higher at 50%. It would also be expected that, all things being the same, the PPS will
    increase shortly as mobilization improves.
- 21. We seem stuck on one particular point that relates to the definition of "totally bed-bound".

"Some of us feel that if any assistance is required to get a patient out of bed then that patient is deemed "totally bed-bound". Others feel that the PPS instructions suggest that requiring assistance to get out of bed does not render one to be "totally bedbound", so they may have a PPS score of >30%."

**Answer**: The concept of "total" bed-bound relates to actual ability of the patient to do anything by himself/herself including their own self-care. In the 'ambulation' category, this encompasses 3 levels of PPS 30%, PPS 20% and PPS 10%. Each PPS level the other 4 categories have relationship to another, so at PPS 30%, the patient is totally bed-bound in the ambulatory category **because** of the self-care limits. A person at PPS 30% is completely unable to turn, sit up or get out of bed as well as unable to raise food to the mouth or do any toileting or grooming. This is a physical inability usually related to profound weakness or possibly paralysis. This inability is not due to depression or that the person chooses not to get up but rather that they cannot.

However, staff will still have the patient moved out of bed either with 1-2 staff using a bed-sheet/stretcher or with lift equipment. If the patient is unable to assist in this, as noted above, then PPS=30% since the person would be "totally bed-bound" unless physically moved. If the patient can sit on the edge of the bed by himself/herself, or perhaps even attempt to stand or turn to sit, but needs 1-2 person transfer assist, then the PPS would be 40% if 'extensive' assist or 50% if 'considerable' assist. The decision about PPS 30% then is based on the patient being unable to do anything of their own accord, especially in bed. A patient at PPS 30% can be moved out of bed but only by the physical efforts of staff.

In many ways, "totally bed-bound really means that the patient is so affected by their condition that they are completely unable to assist in getting out themselves of bed" but with one addition. The issue is not only 'bed status' so to speak but another item is also in the column 'self-care.' So it is better to say "... completely unable to assist in getting out themselves of bed *and unable to do any self-care*" (46). That also fits within the InterRAI assessment tools to match PPS 30% as similar to the RAI #6 "total dependence".

# 22. "When we were discussing PPS in a team meeting, it seemed that there are differing opinions about PPS 40% and 50% and how we differentiate them. Could you please tell us how you differentiate these two?"

**Answer**: To distinguish, at PPS 50% people can't do their usual employment 'work' or hobbies (gardening, painting, etc) while at PPS 40% the person can't do 'most simple activities' such as setting a table, putting dishes in dishwasher, putting on a blouse or fastening buttons or holding a book to read.

For self-care category at these levels, use the following terms from the instructions, with particular emphasis noted in yellow highlighting:

'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.

In other words, it is all in the degree of limitation or energy required to do a simple activity. The "sit/lie" at 50% and "mainly in bed" 40% are based on how much time the person likes to or is able to sit in a chair versus saying they need to lie down or spend most of the day 'in bed'.

These are all subjective decisions of course and the clinician makes a 'best fit' judgment. I generally use how much physical assistance is needed – at PPS 50% they need help by one person every time to stand, sit, get washed, etc but once standing are reasonably steady walking, while at PPS 40% they require 2 person assists in that the patient has so little energy and is unable to hoist themselves or is very precarious when trying to do so. At PPS 40% they also often need help turning in bed or to sit up; they might hold a book to read but after a minute or so have to put it down.

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly <mark>Sit/Lie</mark>	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in <mark>Bed</mark>	Unable to do most activity  Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion

### 23. Case Example from a writer:

"A 94 year old man who has diagnosis of AFTT (Adult Failure to Thrive). There is no family that is local and a patient caregiver comes in for housekeeping and meal prep. At her last visit the caregiver called hospice because she found him just sitting on the couch scooting from end to end. There was no recognition of her and he yelled at her to get out of his house. She got him calmed down and then pivot-transferred him to the wheelchair. Yesterday he had been able

to self transfer. She prepared him lunch and he stuffed his sandwich into his glass of milk. After she showed him his spoon, he was able to feed himself soup but drooled most of it out."

Answer: If by 'scooting' you mean he can move himself from one end of the couch to the other and back, then he has some self abilities. He needed assistance to pivot into wheelchair. This sounds like PPS 50% or 40% depending on how much he can actually do on his own. Does he later get off the couch and go to bed on his own? (if so, then PPS would be higher at 50-60%). Although angry and difficulty with food, he does feed himself.

There is also the question of confusion, delirium or dementia – he was compulsively moving back and forth on the sofa, did not recognize the caregiver, and put the sandwich in his milk glass. This is another category factor to consider although confusion may occur at any level from PPS 60% to PPS 10%.

### Questions about "Self-Care"

#### 24. What about paralysis in determining PPS levels?

Example 1: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%.

**Answer**: Although this patient may be placed in a wheelchair (i.e. "sit/lie") and perhaps seem initially to be at 40%-50%), the accurate score is PPS 30% because he or she is 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 (fed by assistance, or G-tube) and full conscious level.

**Example 2:** However, if the patient in the above example was *paraplegic* and bed-bound but still able to do some self-care such as feed himself/herself, then the PPS would be higher at PPS 40 or 50% since he or she is not 'total care.' *Hemiplegia* would be similar to paraplegia in assessing functional status.

However, the second category also comes into play here, specifically 'activity & disease.' If the patient did **not** have 'an illness' causing the paraplegia, such as an athletic or car accident injury, then the PPS could be viewed up to PPS 70%. Levels of PPS 80% or higher require "full ambulation" which is intended to mean able to walk or run normally without aid.

Some **critics** of those with an *injury-caused paraplegia* say the PPS level should be PPS 100% since special built wheelchairs and other equipment allow people to play sports, ski, etc and are 'normal'. I am hesitant to call this PPS 100% since there is some disability (if the equipment is removed) but others still challenge this. If there is no underlying disease, then the person is 'non-palliative' and it is likely best to not use PPS for functional status. We have approved a revision as Personal Self-Assessment Scale (PSAS) by Willams-Murphy(47) for use in such circumstances, or Corrections Canada(48).

### Questions about "Coma or Semi-Conscious"

### 25. "How does one assign a PPS on a comatose patient?"

**Case (actual)**: A post-stroke patient is in the ICU. He is now off ventilation but remains comatose for 2 months. He is receiving NGT feeding. Initially, they inserted 400 cc's nutritional tube feeding and 12 hour later, upon tube suction, 50ccs returned. Now, 2 months later, 400cc's is put in but 300cc's comes back. On occasion, he responds minimally to stimulation.

Answer: This patient is comatose which by and large puts him at PPS 10%. But there is a minimal response to stimulation, his 'nutrition' initially was very good (~10,000 calories per day) via NGT and of course he requires total care. So, based on 'normal' nutrition and minimal response, we could in fact place him at PPS 30%. Later, his absorption of tube feeding has decreased and is now 'minimal' which would be the equivalent of 'sips only'. Thus, his PPS would now be decreased to PPS 20%. If there is a decision to stop tube feeding, then he would be reduce further as 'mouth care only' and thus PPS 10%.

In other words, a patient who is in a coma or vegetative state may be placed higher than PPS 10% if intake and conscious level would fit better with PPS 20% or even perhaps PPS 30%.

# Questions about "Dementia"

### 26. Can PPSv2 be used with dementia patients?

- Answer: In general, the answer is yes. PPSv2 is a functional performance tool which primarily focuses on ambulation, activity and self-care. Particularly in advanced stages of Alzheimer's disease, the patient fits quite well into such levels as PPS 60% through PPS 10%.
  - a. In the reference article by Doberman et al, PPS was demonstrated as better than several current tools in survival prediction.(28, 39, 49-51)
- The cognitive aspects of 'dementia' are not well differentiated with PPSv2 in that cognitive decline may occur while 'ambulation' is still quite good. However, in terms of activity and evidence of disease in the second column, PPS 70% and PPS 80% indicate difficulty with normal work or job function which in the case of Alzheimer's is attributed to mental status challenges from the disease rather than actual physical capacity. But in the very early stages, patients may well be able to continue some hobbies and even with some short term memory loss, that in itself would not constitute 'confusion' so that patient could be deemed PPS 70%. Other tools such as MODA(52) or FAST(53-57) are better for cognitive performance.
- The fifth column 'Conscious Level' was mainly intended to separate full 'alertness' from reduced conscious levels such as drowsiness, obtundation and coma. It does recognize confusion but primarily as it relates to these factors and possible delirium rather than dementia where full consciousness is present, at least at higher PPS levels.
- As with all diseases, PPS is a horizontal 'best fit' and judgment is always required.

### 27. Case example: Forgetfulness

Ms. Jones is a 75 year old woman who has had increasing forgetfulness over the last 3 years. She does self-care with her husband observing her. Sometimes he has to help her. She no longer drives but can walk to the grocery store 3 blocks away in a straight line by herself. She requires a list, however, of what she is to purchase and carries a label with her name, address and her husband's name to give to someone if she gets lost which has not happened so far. She generally is up during the day and sleeps most of the night. She used to read and knit at night but no longer does so, and will watch television, although she does not always remember what the content is. Meal preparation is done by her husband preparing the ingredients and her cooking the meal. She generally will eat a full meal but recently requires coaxing on occasion.

Answer: PPS is 60% in each of the five categories.

#### 28. Case Example: Constant Pacing

"A 72 year old male with dx of Alzheimer's Dementia. His constant pacing hinders his PO intake as staff can't get him to sit at the table to eat. He can eat finger foods by himself. Often, he is found urinating in other areas than the BR. He is disoriented to time, place and person but will answer to his name. Sometimes he becomes aggressive when staff try to bathe him. He has no interest in personal hygiene. He is unable to provide own ADLs and staff must anticipate/provide all needs."

**Answer:** It appears that he is able to walk on this own as you note he is 'found urinating in other rooms'. If that is correct, then his PPS has to be at least PPS 50% or PPS 60%. You note he can't do ADLs and only finger foods so this would mean he needs "considerable assistance" and thus PPS 50% would be a reasonable level for him

#### 29. Case Example: Sit for hours

"A 88 year old man with dementia. The staff at the assisted living facility get him up each day with max assist of 2. He loves to watch the birds out the window and could sit there for hours. He will eat 100% of his meal, but his favorite

PCG has to be there or he won't eat at all. He is incontinent of both bowel and bladder and today his case manager saw him leaning to the left and had to prop him with pillows."

**Answer:** With need of 2 person lift all the time, PPS is then down to about PPS 40%. Although confused and incontinent, he is able to eat well what is given which does fit with PPS 40% as well.

### 30. Other neurologic diseases(58)

### Questions about "Intake"

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

- Answer: PPSv2 is used by a 'best horizontal fit' of the 5 domains. As such, there are times where one domain such as intake is difficult to interpret, and a G-tube or JPEG makes this challenging. Two suggestions may assist in decision making.
- The main approach is that if the other 4 domains seem clear at one PPS level, then the same level is likely the best-fit regardless of intake. This is logical since the provision of some nutrition at any level becomes a non-distinguishing factor. Provision of fluid and nutrition is important at most PPS levels for comfort, medications and possibly improved condition and status.
- The second consideration is the somewhat common observation that the tolerability and the volume of fluid given via parenteral tubes usually decreases with overall decline and closeness to death. For example, an ALS patient earlier in disease may tolerate 500-700 ml at one time but later in the course can only tolerate 300 ml or 100 ml. This is also seen in advanced cancer patients.
- At death approaches, there are times where tube feeding is discontinued and only mouth care is used to maintain comfort. Other times, fluid intake at some volume is provided through to death.
- For patients with serious and progressive illness, it is very common that by PPS 30% that intake is reduced. The categories to the left indicate total bed bound, extensive illness and require total care. However, there a few patients who are totally bed bound and unable to do any personal care who may still be able to swallow and have good intake, in which case they may be stable and could be deemed PPS 30%

# 32. How would I categorize a pt's PPS when the person's disease is causing an obstruction rendering the person NPO, yet is receiving nutrition per TPN?

**Case**: "Would I be correct in rating the person a PPS 70% if she had full ambulation; significant disease with her localized ovarian cancer causing a bowel obstruction not allowing her to do her work, but could she do hobbies; was able to do full self-care including managing her TPN; was NPO; and had full conscious level?"

**Answer**: Yes, the PPS correct is PPS 70%. Although nutrition is via TPN and technically not "intake" in the usual meaning of the word, it is anticipated that sufficient nutrients are being provided to approximately equate with being able to actually eat. This also fits with the general instructions that one use a 'best fit' and that not all horizontal factors must line up exactly.

### 33. How does one assign a PPS on a comatose patient with a NGT?

**Case**: "A post-stroke patient is in the ICU. He is now off ventilation but remains comatose. He is receiving NGT feeding. Initially, they inserted 400 cc's nutritional tube feeding and 12 hour later, upon tube suction, 50ccs returned. Now, 2 months later, 400ccs is put in and 300 ccs comes back. On occasion, he responds minimally to stimulation."

**Answer:** This patient is comatose which by and large puts him at PPS 10%. But there is a minimal response to stimulation, his 'nutrition' initially was very good (~10,000 calories per day) via NGT and of course he requires total care. So, based on 'normal' nutrition and minimal response, we could in fact place him at PPS 30%. Later, his absorption of tube feeding has decreased and is now 'minimal' which could be seen as the equivalent of 'sips

only'. Thus his PPS would be decreased to PPS 20%. If there is a decision to stop tube feeding, then would be construed as mouth care only and thus PPS 10%.

In other words, a patient who is in a coma or vegetative state may be placed higher than PPS 10% if intake and conscious level would fit better with PPS 20% or even perhaps PPS 30%.

#### 34. Case Example

"A 45 year old female has a cardiomyopathy. Her case manager reported that she was unable to get her out of bed today and her O2 sats had dropped from 92% on RA to 68%. She started her on O2. BP was 70/38. The CNA reported that she had to give her a bed bath today and tried to feed her but she only drank a few sips of juice with use of a syringe and fell asleep. The case manager called the family with an update and urged them to come to the bedside."

**Answer:** Unable to get out of bed places PPS lower. The nurse aide gave a bed bath but it is unclear if the patient was able to turn or help in any way. If she cannot do anything, then PPS is 30%. But she is drowsy, took only a few sips and fell asleep. If this is persistent and more than just fatigue, then PPS may be down further at PPS 20%, which seems the case since the worker called family to attend.

#### 35. Intake at PPS 30%.

"We've been reviewing the PPSv2. For Intake at PPS 30%, the field states "Normal or reduced". The original article on the PPS from Victoria House has a different reading: "Reduced". Can you confirm that this actually changed or is this a possible typo? Obviously not a huge deal, but we're curious about this."

**Answer:** Thank you so much for your astute observation about PPSv2 and the intake at PPS 30% level!! The original PPS 30% indicated 'reduced' (2). From feedback over the next few years, we decided in 2001 to revise it to read 'normal or reduced' as some patients at that level are able to maintain normal intake even though they require total physical care and are not able to eat by their own physical means.

In 2006 when we were conducting the reliability study(9) the statistician felt it a minor change but we continued with the "v2" version. So the official version now remains PPSv2 with intake as "normal or reduced" at PPS 30%.

### 36. Intake and Actively Dying at PPS 30% and PPS 20%

"My training in using the PPS scale was that if a person had marked reduction in PO intake, and significant weight loss, the PPS would change from a PPS of 30, to a PPS of 20. The team is now saying that the PPS should never go to 20% unless the patient is actively dying. I have been seeking clarification on this point".

### Answer:

The only difference between PPS 30% and PPS 20% is based on intake but this indeed has important implications. Patients at both levels are very sick with 'extensive disease' and 'unable to do any activity'. This places them as 'total care' which means the person is unable to do anything – not able to raise arms, not roll over, not able to lift legs and thus requires heavy physical care. Being very sick at either PPS level they may still be fully conscious but more often are drowsy and confused.

The big difference then lies in oral intake. At **PPS 30%** the person may still be able to eat and have good appetite (if not dying) or may be reduced as they have some difficulty swallowing or little appetite. The query above about 'weight loss' is not relevant as part of the tool although indeed is common if intake is reduced. The issue of 'reduced' intake is seen at all levels from PPS 80% to 30% depending on what factors are causing such reduction.

Intake at **PPS 20%** is not only 'reduced' but is now 'minimal sips' which where 'sips' indicate no solid intake, and 'minimal' implies that almost any fluid is likely to cause choking or aspiration if the caregiver tries to give them more fluid. They person does however absorb a little fluid as compared to PPS 10% where only mouth care is possible to maintain moisture on lips and tongue.

In both cases of PPS 30% and PPS 20% patients are most often dying. However, a few patients at PPS 30% are able to maintain sufficient intake and remain clinically stable; they could live months or years for example if paralyzed. The person at PPS 20% is almost always dying but an exception would be a person with sepsis who is

delirious, drowsy and aspirates if given too much fluid BUT who is aggressively treated with antibiotics and IV fluid such that they could recover. Another example is where short teem sedation is necessary causing the decline to PPS 20% but who may regain function once sedation is lifted. Thus, it is not true that PPS should *never* go to 20% unless actively dying, but it is however *usually true*.

### Questions about "Children"

- 36. Can PPS be used in the pediatric population?
  - Answer: There is no solid data regarding PPS and children. Clinically, we have used this an an approximation in many children who are a little older and previously ambulatory, but it is not likely of value for newborns.
  - One would need to substitute "job/work" with school or usual activities, but otherwise most other factors are anecdotally reasonable. Also, the column for "ambulation" would need adaption. In a draft of PPS-Ped-Child under potential development, the recognition of walk, crawl, sit and roll are some benchmarks of normal age and development. With PPS decline, it would be expected that one or more of such normal levels would be lost as an illness progresses.
  - We have been working on a PPS-P or pediatric tool but is more difficult if one is trying to include neonates up to adolescents. It is likely that several subsets would be necessary.

### Questions about use of PPS in "Non-Palliative" patients

### 37. Can PPS be used for "non-palliative" patients?

**Case**: "A post-stroke patient is in the ICU. He is now off ventilation but remains comatose. He is receiving NGT feeding. Initially, they inserted 400 cc's nutritional tube feeding and 12 hour later, upon tube suction, 50ccs returned. Now, 2 months later, 400ccs is put in and 300 ccs comes back. On occasion, he responds minimally to stimulation."

Answer: This patient is comatose which by and large puts him at PPS 10%. But there is a minimal response to stimulation, his 'nutrition' initially was very good (~10,000 calories per day) via NGT and of course he requires total care. So, based on 'normal' nutrition and minimal response, we could in fact place him at PPS 30%. Later, his absorption of tube feeding has decreased and is now 'minimal' which could be seen as the equivalent of 'sips only'. Thus his PPS would be decreased to PPS 20%. If there is a decision to stop tube feeding, then would be construed as mouth care only and thus PPS 10%.

In other words, a patient who is in a coma or vegetative state may be placed higher than PPS 10% if intake and conscious level would fit better with PPS 20% or even perhaps PPS 30%.

The above case illustrates that PPS can be used for "non-palliative" patients. In this case, there was initial hope that he would improve and regain consciousness, possibly even to mobilize again. The physicians did not like nurses using PPS due to the word "palliative". Since PPS is a functional or performance assessment tool, its use does not need to be restricted to already designated palliative or hospice patients. One could "blur" or cover-up the word palliative in these circumstances to provide more ease in its use. Indeed, at the Maharaj Nakorn hospital in Chiang Mai, Thailand, PPS is recorded on most patients every day and thus includes, surgical, neonatal, oncology, ICU, CCU, ER, etc wards.

38. Case: "A client has cancer, but also had a debilitating CVA- we questioned how the PPS would be validated in this case. Would it be a true reflection of client status? CVA vs Ca?"

**Answer:** Good question. Indeed it is challenging. No tool can deal with every situation. If his stroke is old, and he has lived for some time this way, then PPS would reflect other changes or new types of decline due to cancer - for example, going from needing some assistance, to total care, etc. in terms of monitoring functional status.

For a certain size of population, these individual variations show up in PPS analysis of survival. At each level, there is an amount of significance, eg p<0.001, but also the confidence interval which catches the variations. We have just completed a study on a new tool, Prognostat, which uses PPS and other indicators, one of which is the Charlson

Comorbidity Index. Interestingly, when all factors are considered, both single and multi-variate analysis, the comorbidities "wash out' and had no impact of survival. So apart from determining which PPS level is appropriate for your patient, the stroke may have little impact.

# 39. Could the word "palliative" be substituted with "patient" in the non-palliative patient and thus maintain the word "PPS"?

Answer: The quick answer is a 'qualified yes.' Victoria Hospice has decided to allow the use of the phrase "Patient Performance Scale (PPS)" in situations where the value of the PPS as a performance or functional status tool is desired, such as ADL or IADL tools. The substitution of 'palliative' with 'patient' to create PPS allows for interchangeable use of the original PPSv2 to be used in palliative care patients but also for the broader patient population. As such, the table and instructions are almost the same, except for substitution of 'disease' with 'disability.' Either can be used as a functional assessment tool and for communication. However, studies about PPS and prognostication have been exclusively on already deemed palliative patients, and those results cannot be extrapolated to the 'non-palliative' population.

The 'qualified' aspect relates to publications and research that was on specific palliative populations. As such, one cannot simply extrapolate those results, especially studies relating to illness trajectory or survival prediction. As noted above, PPS is used in Chiang Mai with this purpose on several wards that are clearly not palliative.

#### 40. Correction Services Canada: "Palliative Performance Scale (PPS)"

The PPSv2 was revised slightly in the instruction wording for use of PPS in prisons.(48)

### 41. "Personal Self-Assessment Scale (PSAS)" & advance care planning or living wills

**Note:** A request has been granted that the substituted phrase "Personal Self-Assessment Scale (PSAS)" be used instead of PPSv2 and is included in a book chapter written in Alabama to assist patients in delineating points where interventions such as DNR/DNAR/DNI can be clarified. The material has been published in a book "It's OK to Die" by Dr. Monica Williams-Murphy, Huntsville, Alabama. www.oktodie.com.(47)

### 42. New changes in the meaning of "palliative"

- In the last 5 years, there have been changes in the use of the word 'palliative'. Patients were often registered with a hospice or palliative care program and thus referred to as a "palliative patient" or "palliative care patient." Recently the field of hospice and palliative care have focused on a 'needs-based approach' to care thus altering somewhat terminology and referring to a "palliative approach". In the new lingo, a palliative care service/program provides a palliaitve approach to patients.
- Perhaps unintentionally this has created ambiguity for some and blurred surveillance and prognostic data analysis

# Questions about "Prognostication & Tools"

### 43. How good is PPSv2 for survival prediction?

PPS has been shown to be a significant predictor of survival in over 60 studies(2, 4-9, 23, 24, 35, 38, 41, 42, 59-111). Changes in performance status due to disease progression occur in most patients and PPS includes such functional aspects as well as intake and conscious level.

Cancer(64, 65, 69, 75-77, 84, 85, 108, 109, 112-120) 1-week prediction(121), 3-day(122), 7-days(39), 6 months(40, 92) Home-based(97, 123), Emergency Dep't(66), hospital(103) COVID-19(124)

There are many different illness trajectories which lead to death and thus any prognostic tool has limitations. The studies show 'group' data and for the population in the study is valid; however, each patient is an 'individual' and clinical judgment is an important aspect as well. Thus, several tools will incorporate both performance status along

with clinician prediction as well as others include laboratory or symptom issues.

### 44. Can PPS be incorporated into other prognostic tools?

Yes, PPS has been used in other tools as part of the functional or performance status of patients. One tool is the Palliative Performance Index (PPI) from Japan(31, 125, 126). Recently we have created a new tool called the Prognostat which has been tested but not yet published(60).

### 45. Comparison of PPS with other tools

PPS has been tested against other tools(22, 24, 105). The correlation is generally high with KPS(23, 25, 32, 127), ECOG(23, 25, 128, 129), PiPS(130), EORTC(81, 131), PPI(31, 71, 90), PaP(83, 90, 91), Prognostat(60), Barthel(129), LCSS(70), BIA(82), Frailty scale(132)

# "Use of PPS for Clinical & Service Planning"

In addition to use of PPS in communication and prognosis, it can be a factor for assessing service allocation, relation to symptom control and quality of care. This is particularly due to the variation in functional abilities and need for services and staffing.

- 46. Readmission and transfers (133-135), needs(136), timing(84, 137, 138), admit/discharge(32, 77, 78, 139, 140)
- 47. Needs at home(97, 123, 141-148)
- 48. Decision-making(84, 120, 149-152), communication(42, 132, 153), knowledge/attitude(39, 153, 154)
- 49. Spirituality, time(155-159), quality(80, 81, 118, 140, 160-168), med errors(169)
- 50. Use in wounds and mattresses(94, 170-173)
- 51. Symptoms(118, 145, 174-177), Dyspnea(178-180), pain(181-183), incontinence(184), delirium(114), distress(185), embolization(67), therapeutic touch(186), fatigue(187), activity/decline(28, 80, 95, 188-191), surgery(74), infection(79), chemotherapy(192), constipation(193)
- 52. Outpatient clinic(116, 194), ER Dep't(47, 72, 100, 195, 196), ICU(38, 41, 197), consult(98)
- 53. Economic/Service planning(72, 89, 97, 98, 100, 146, 147, 165, 198-205)

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