Early Integration of Palliative Care
The Algorithm
STEP 2: ASSESS
Presentation #5

PEI Provincial Integrated Palliative Care Program

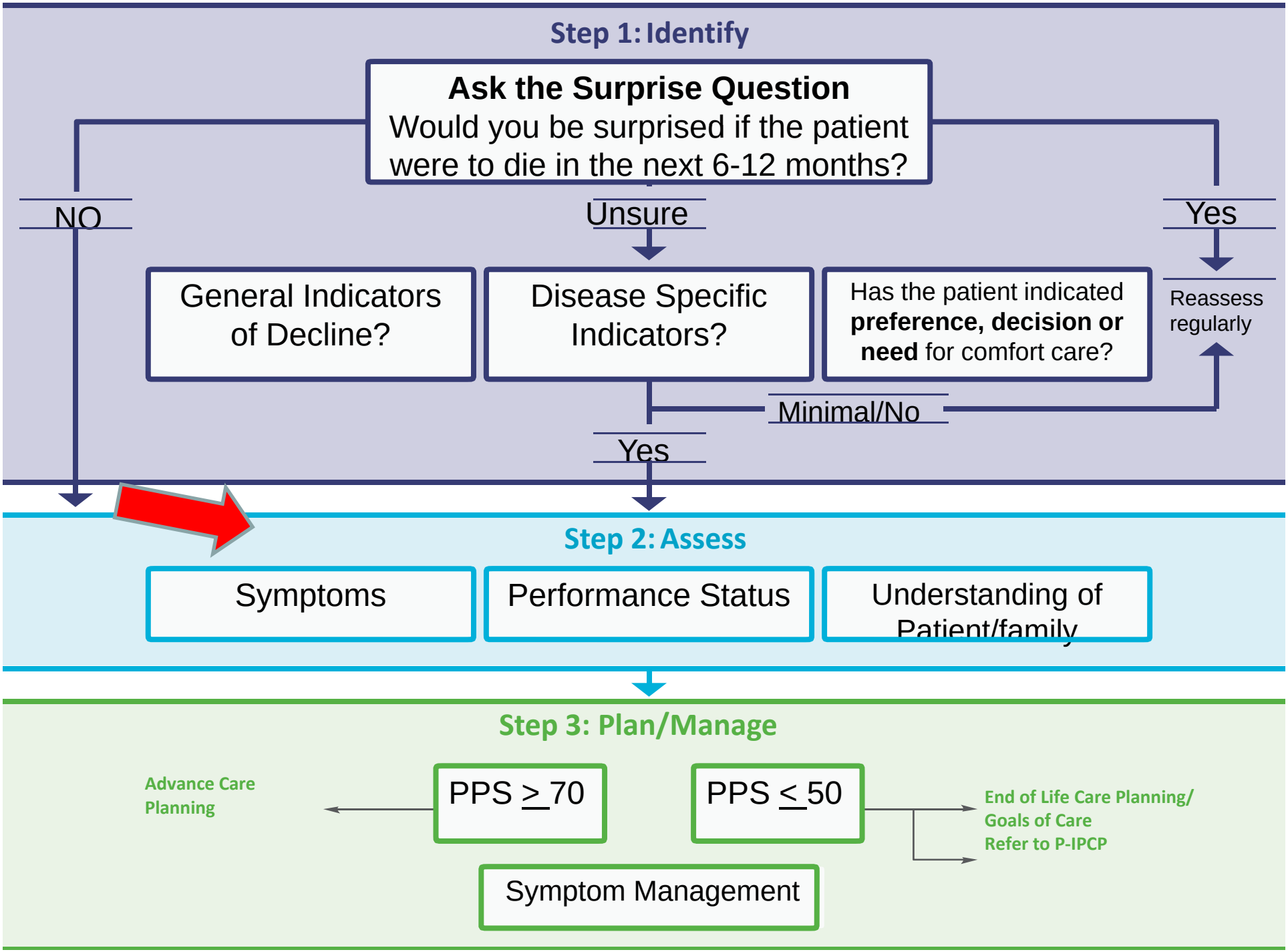
Health PEI

One Island Health System

What will you learn?

At the end of this presentation, you'll have an understanding of:

1. What is ESAS-r, its importance & purpose
2. When & how to complete & document ESAS-r
3. It's limitations & what to do with the results
4. What is the PPSv2, its importance & purpose
5. The use of other functional assessment tools including:
   - Eastern Cooperative Oncology Group (ECOG)
   - Patient Reported Functional Status (PRFS)
   - Rockwood Clinical Frailty Scale (CFS)


Step 1: Identify
Ask the Surprise Question
Would you be surprised if the patient were to die in the next 6-12 months?
NO
Unsure
Yes
General Indicators of Decline?
Disease Specific Indicators?
Has the patient indicated **preference, decision or need** for comfort care?
Reassess regularly
Minimal/No
Yes
Step 2: Assess
Symptoms
Performance Status
Understanding of Patient/family
Step 3: Plan/Manage
Advance Care Planning
PPS ≥ 70
PPS ≤ 50
End of Life Care Planning/ Goals of Care
Refer to P-IPCP
Symptom Management

Step 2: Assess

- ✓ Assess symptoms using
  - ❑ Edmonton Symptom Assessment System (ESAS-r) for 9 symptoms
- ✓ Performance Status using
  - ❑ Palliative Performance Scale (PPSv2),PRFS,CFS,EGOG
- ✓ Understanding
  - ❑ Ensure patient and family/substitute decision-maker/proxy(ies) understand nature of the illness
  - ❑ Understand the patient's values, beliefs and goals of care

What is the Edmonton Symptom Assessment System revised version (ESAS-r)?

Health PEI

One Island Health System

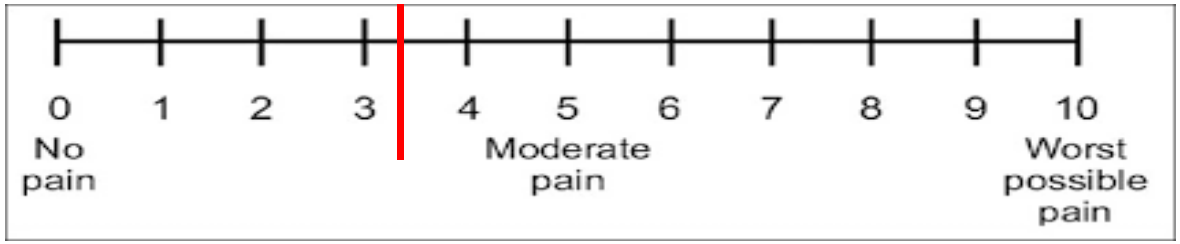
ESAS-r is the "VITAL SIGN" of Palliative Care

What is ESAS-r ?

- Clinically validated standardized assessment tool widely used in palliative care, in Canada & around world
- Developed in 1991 by Bruera and colleagues, in Edmonton, Canada & revised in 2014 & translated in over 20 languages
- Cornerstone of symptom management in palliative care
- Assessment of 9 common symptoms (pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, well-being)
- Can be used outside of oncology, e.g. heart failure, pulmonary disorders

What is ESAS-r ?

A numerical scale used to gather information on the patients perception of nine symptoms they may be experiencing & other problems & provides a clinical profile of symptom severity over time.



Why is ESAS-r Important?

- ✓ The patient and their healthcare team are partners in patient care.
- ✓ Without a standardized approach, patients reports less than 30% of their symptoms (mainly pain and nausea).
- ✓ ESAS-r helps the healthcare team understand how the patient is feeling and allows them to identify problems and offer support as soon as possible.
- ✓ ESAS-r scores are tracked over time so that the patient and their healthcare team can follow progress.

Positive Results

- Study show 92% of patients noted ESAS-r was important

“as it helped their healthcare team to know their symptoms and severity”

- 67% of physicians & 85% of nurses note ESAS-r is a beneficial tool

Nine Common Symptoms

- ❑ Pain
- ❑ Tiredness
- ❑ Drowsiness
- ❑ Nausea
- ❑ Lack of Appetite
- ❑ Shortness of breath
- ❑ Depression
- ❑ Anxiety
- ❑ Well-being
- ❑ Other (e.g.; sleep, constipation, cough)

Its Limitations

- Terminology/understanding
- ESAS was revised in 2014 to ESAS-r to include definitions
  - Depression (feeling sad)
  - Anxiety (feeling nervous)
  - Tiredness (lack of energy)
  - Drowsiness (feeling sleepy)
  - Well-being (how you feel overall)

When & How Often?

- In Palliative Care Unit - done daily
- In Acute/Hospital setting - done daily
- In Ambulatory Care setting - each visit
- In Palliative Home Care setting, done as part of each assessment of symptoms, either by telephone or personal contact
- In LTC facility - if symptoms are well controlled, done weekly

Important to note – ESAS-r should be done when there is any change in symptoms or patient status

Who completes the ESAS-r?

- ✓ Ideally, it is the **patient's opinion** of **their** symptom
- ✓ Its their perception, severity of their symptom, its their "number"
- ✓ If patient is mildly cognitively impaired or too sick to do so – then can be completed with assistance of family/caregiver/health care provider
- ✓ Patients and family should be taught, given direction if patient needs assistance to complete form
- ✓ If patient cannot participate at all, or refuses to do so – then completed by family/caregiver/health care provider alone
- ✓ When completed by family or health care provider, they assess the symptoms as objectively as possible (see next slide).
- ✓ Who completed tool, should be documented

Health Care Provider Assessment

- **Pain (use PAINAD tool)** – grimacing, guarding against painful maneuvers
- **Tiredness** – increased amount of time spent resting
- **Drowsiness** – decreased level of alertness/eyes closing
- **Nausea** – retching or vomiting
- **Appetite** – quantity of food intake
- **Shortness of Breath** – increased respiratory rate or effort that appears to be causing distress to the patient
- **Depression** – tearfulness, flat affect, withdrawal from social interactions, irritability, decreased concentration and/or memory, disturbed sleep pattern
- **Anxiety** – agitation, flushing, restlessness, sweating, increased heart rate (intermittent), shortness of breath
- **Well-being** – how the patient appears overall

Pain Assessment Tool Guidelines for use: PAINAD

Indicator	Score = 0	Score = 1	Score = 2	Total Score
Breathing:	Normal breathing	Occasional labored breathing Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respiration	
Negative vocalizations:	None	Occasional moan/groan. Low level, speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial Expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimace	
Body Language	Relaxed	Tense, distressed, pacing, fidgeting.	Rigid, fists clenched. Knees pulled up. Striking out. Pulling or pushing away.	
Consolability:	No need to console	Distracted by voice or touch.	Unable to console, distract or reassure.	
			TOTAL:	

Description: The Pain Assessment in Advanced Dementia (PAINAD) was developed to assess pain in patients who are cognitively impaired, non-communicative, or suffering from dementia and unable to use self report methods to describe pain. Observation of patients during activity records behavioral indicators of pain: breathing, negative vocalization, facial expression, body language, and consolability.

How to use: PAINAD is a five item observational tool with numerical equivalents for each of the five behavior items listed, with total scores ranging from 0 to 10. Each of the five assessments contains a range from 0 to 2 and the summation of each of the five categories results in the total numerical score. Please refer to the attached item descriptions. To use:

- Assess patient during periods of activity, such as turning, ambulating, transferring
- Assess patient for each of the 5 indicators: breathing, negative vocalization, facial expression, body language, and consolability
- Assign a numerical point value based on each of the 5 assessments observed
- Obtain a total score, by adding scores from the 5 indicators. Total score ranges from a minimum of 0 to a maximum of 10.

Populations for use: The primary population for use of the PAINAD is the adult patient with dementia who is unable to self report pain level.

Validity and reliability:
While self-report remains the "gold standard" for pain assessment, several studies have indicated that the PAINAD is an accurate assessment tool for use in the adult patient population for whom self-report is not a reliable tool due to their altered cognitive abilities.

References:
Herr, K. & Garand, L. (2001). Assessment and measurement of pain in older adults. *Clinics in Geriatric Medicine, 17,* 457-478.
Leong, I., Chong, M., & Gibson, S. (2006). The use of self-reported pain measure, a nurse-reported pain measure, and the PAINAD in nursing home residents with moderate and severe dementia: a validation study. *Age and aging, 35,* 252-256.
Warden, V., Hurley, a., Volicer, L. (2003). Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. *American Medical Directors Association, 4,* 9-15.

Please Note

Studies have shown, when it comes to numbers:

- Health care providers under estimate patient's symptoms
- Family members over estimate a patient's symptom

Where to Document ESAS-r

- Paper
- CIS
- ISM

ESAS-r Paper Form - Front & Back

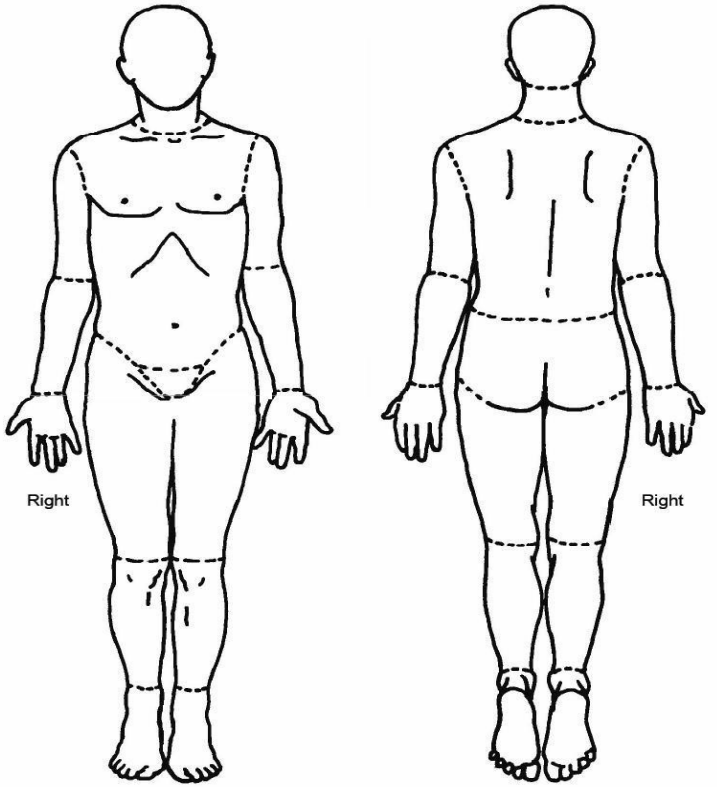
Health PEI
One Island Health System

Edmonton Symptom Assessment System (ESAS-r)

Edmonton Symptom Assessment System:
ESAS-r

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness (Tiredness = lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness (Drowsiness = feeling sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression (Depression = feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety (Anxiety = feeling anxious)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing (Wellbeing = how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing



Patient's Name _____
Date _____ Time _____

Completed by (check one):
- ☐ Patient
- ☐ Family Caregiver
- ☐ Health Care Professional Caregiver
- ☐ Caregiver-assisted

Health PEI

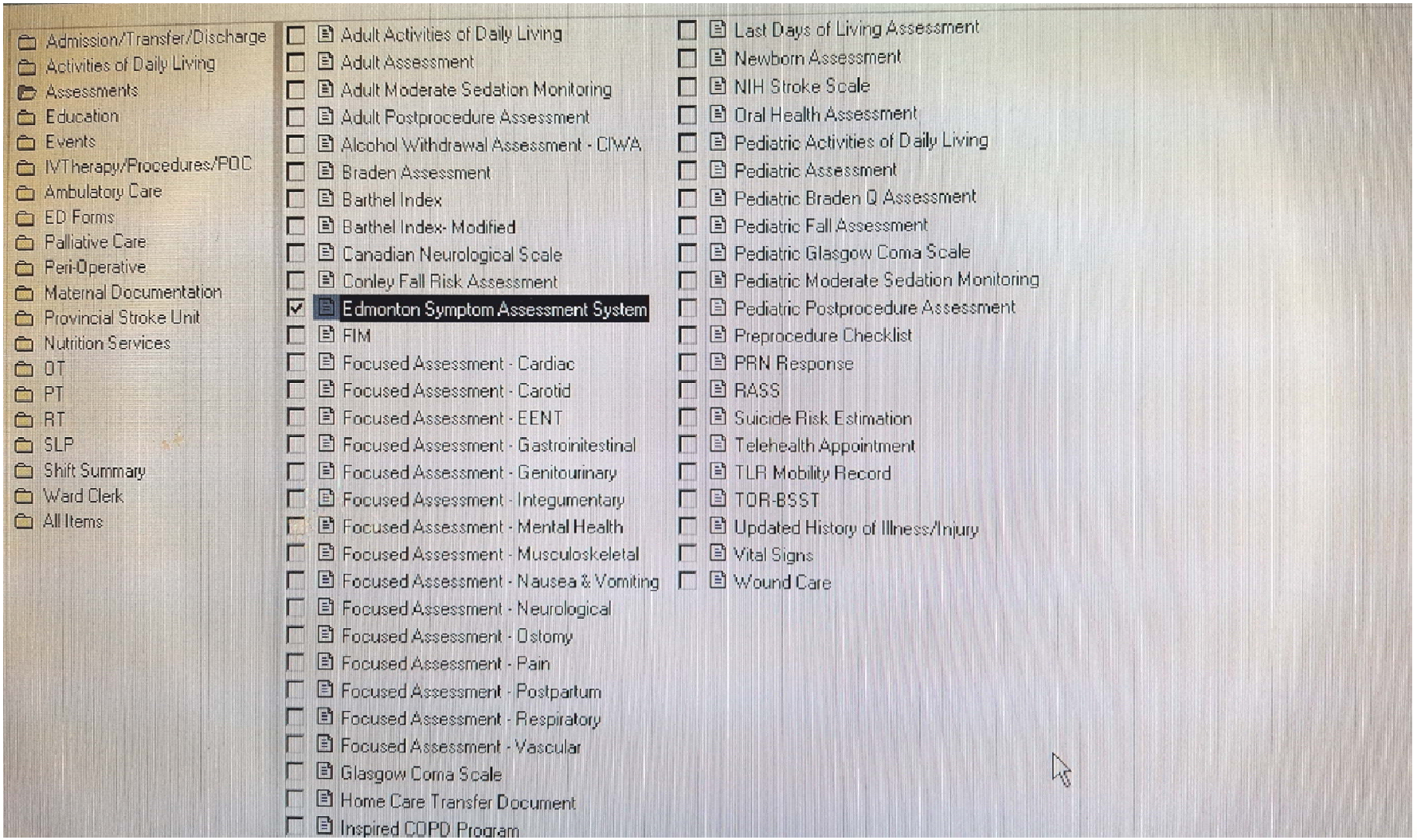
One Island Health System

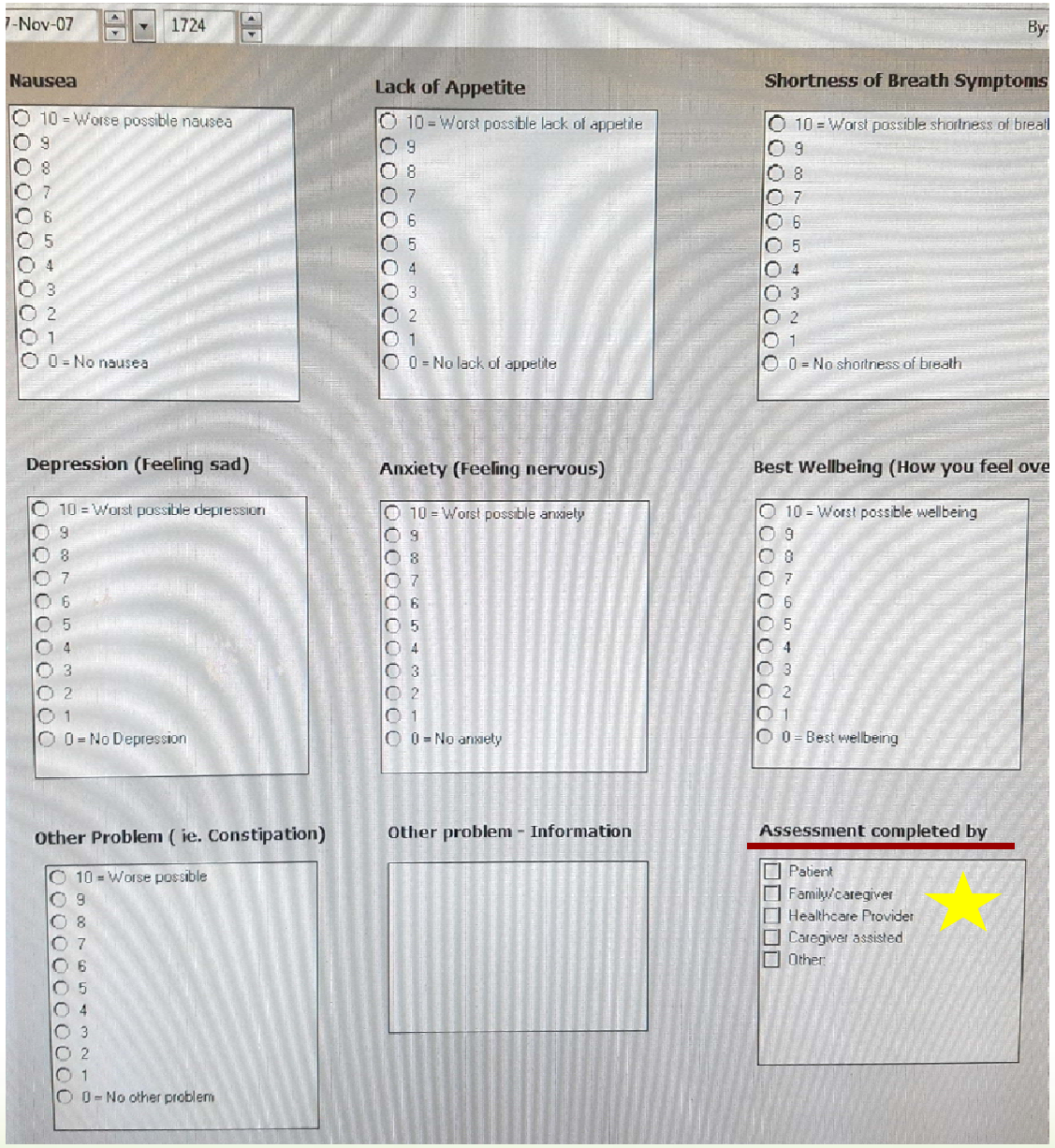
To Document in ISM

1. Find patient/client chart
2. Click assessment tab
3. Double Click ESAS-r
4. Click apply
5. Click on **?** Icon
6. Chart results/comments

To Chart ESAS-r on Cerner

1. Go to ADHOC charting
2. Click on Assessments or Palliative Care
3. Click on Edmonton Symptom Assessment System
4. Note each score 0-10
5. Right click to add comment/details
6. Click green checkmark to save


Admission/Transfer/Discharge
Activities of Daily Living
Assessments
Education
Events
IVTherapy/Procedures/POC
Ambulatory Care
ED Forms
Palliative Care
Peri-Operative
Maternal Documentation
Provincial Stroke Unit
Nutrition Services
OT
PT
RT
SLP
Shift Summary
Ward Clerk
All Items
Adult Activities of Daily Living
Adult Assessment
Adult Moderate Sedation Monitoring
Adult Postprocedure Assessment
Alcohol Withdrawal Assessment - CIWA
Braden Assessment
Barthel Index
Barthel Index- Modified
Canadian Neurological Scale
Conley Fall Risk Assessment
Edmonton Symptom Assessment System
FIM
Focused Assessment - Cardiac
Focused Assessment - Carotid
Focused Assessment - EENT
Focused Assessment - Gastroinitestinal
Focused Assessment - Genitourinary
Focused Assessment - Integumentary
Focused Assessment - Mental Health
Focused Assessment - Musculoskeletal
Focused Assessment - Nausea & Vomiting
Focused Assessment - Neurological
Focused Assessment - Ostomy
Focused Assessment - Pain
Focused Assessment - Postpartum
Focused Assessment - Respiratory
Focused Assessment - Vascular
Glasgow Coma Scale
Home Care Transfer Document
Inspired COPD Program
Last Days of Living Assessment
Newborn Assessment
NIH Stroke Scale
Oral Health Assessment
Pediatric Activities of Daily Living
Pediatric Assessment
Pediatric Braden Q Assessment
Pediatric Fall Assessment
Pediatric Glasgow Coma Scale
Pediatric Moderate Sedation Monitoring
Pediatric Postprocedure Assessment
Preprocedure Checklist
PRN Response
RASS
Suicide Risk Estimation
Telehealth Appointment
TLR Mobility Record
TOR-BSST
Updated History of Illness/Injury
Vital Signs
Wound Care

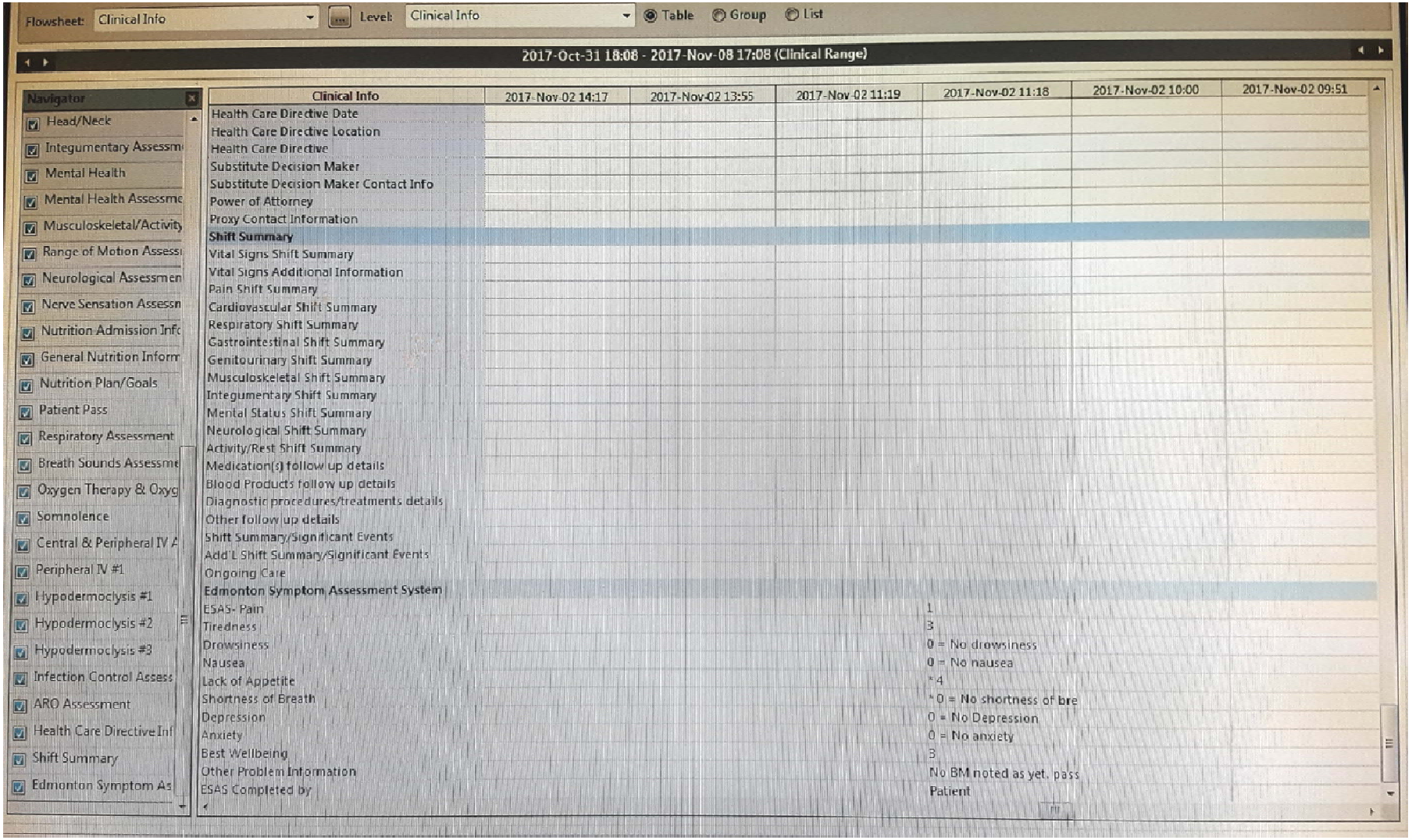


Health PEI

One Island Health System

To View ESAS-r Results on Cerner

- Found under assessment tab
- Last on a very long list



Health PEI

One Island Health System

Symptom Assessment and the Edmonton Symptom Assessment Scale - Palliative Care

Dr. Robin Fainsinger, Division Director of Palliative Medicine, Grey Nuns Community Hospital, discusses the use of symptom assessment tools and specifically the Edmonton Symptom Assessment Scale.

https://youtu.be/zw01ikrTXpU

Health PEI

One Island Health System

What Now?

- ✓ Need for continued/consistent assessment & re-assessment (*ESAS-r is only a screening tool!)*
- ✓ Need for use of additional tools to further assessment, e.g. Brief Pain Inventory, PAINAD
- ✓ Evaluate, share & communicate results
- ✓ Continued support, listening, therapeutic conversations
- ✓ Change in medication/orders/treatment
- ✓ Further referral to specialist team member, e.g. spiritual care, social worker

Future Developments

- Ongoing research and validation –

  Canadian Partnership Against Cancer(CPAC) is already collecting ESAS-r testing across Canada
- Incorporation into electronic health records
- ESAS-r to trigger/triage clinical action/referral

WHAT to do with completed ESAS in my office

- We will be collecting data for CPAC over the next 4 years, so keep the papers.
- We can also supply your office with a **spreadsheet** (input the results and follow your patient's progress easily).

Provincial Integrated Palliative Care Program

SCORES FOR EDMONTON SYMPTOM ASSESSMENT SCALE (ESAS) AND PALLIAITVE PERFORMANCE SCALE

Key: ESAS completed by
P = Patient F = Family H = Health Professional
A = Assisted by Family or Health Professional

Year: Date:	Nov 14/18	Nov 16	Nov 18	Nov 19	Nov 21	Nov 23	Nov 25	Nov 26	Nov 27	Nov 29	Nov 04	Nov 30	Dec 1	Dec 2
Time:	1600	1615	1100	1535	1500	1500	1300	1130		1300	1230	1200	1500	1400
ESAS completed by	P+HCP	P	P	A	H	A	A HCP	A		A	A	A	A	A
Pain Score 0 – 10	2	3	4	5	5	6	4	4	8	7	6	7	8	6
Tiredness Score 0 – 10	7	7	6	5	6	7	7	7	7.5	5	7	5	5	5
Drowsiness Score 0 – 10	3	7	6	5	4	7	7	7	7	5	7	5	5	5
Nausea Score 0 – 10	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Lack of Appetite Score 0 – 10	4	2	3	2	3	5	4	3	3	3	2	2	2	1
Shortness of Breath Score 0 – 10	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Depression Score 0 – 10	4	0	0	0	0	0		0	3	0	0	0	0	0
Anxiety Score 0 – 10	2	3	3	3	2	2	1	1	8	0	0	0	0	0
Wellbeing Score 0 – 10	3	5	4	4	4	5	4	4	4	5	4	4	4	4
Other Score 0 – 10														
Other Score 0 – 10														
Palliative Performance Scale (PPS)	40	40	40	40	30	30	30	30	30	30	30	30		30
Delirium Scale d		0	0	1	4	2		0	2	1	2	2	3	0
Delirium Scale e	0					3								
Delirium Scale n														
Initials			4											

Health PEI

One Island Health System

Re-assessment

"One of the most critical aspects of symptom management is routine symptom assessment and re-assessment"

It allows symptoms to be recognized, diagnosed, treated & monitored over time.

Your Symptoms Matter

Health PEI

Cancer Care Ontario, (2017)

One Island Health System

Palliative Care Functional Assessment
What is the Palliative Performance Scale version 2 (PPSv2)?

Health PEI

One Island Health System

One tool…..multiple functions

Health PEI

One Island Health System

What is PPSv2?

- Originated at Victoria Hospice, Canada in 1986 & now being used across Canada & translated into 10 languages
- Clinically validated assessment tool widely used not only in palliative care but also acute care and LTC
- Tool assesses a person's ability to perform activities of daily living & distilles it into an easy understood value from 0% to 100% on the basis of the person's functioning in five areas:
  - mobility (ambulation),
  - activity and evidence of disease,
  - ability for self-care,
  - intake, and
  - level of consciousness.
- Provides both base-line and ongoing as you do additional assessments
- Includes the main indicators of disease and patient function

Inspired by Karnofsky Performance Scale

Score	Karnofsky Performance Scale (KPS)
100%	Normal; no complaints; no evidence of disease
90%	Able to carry on normal activity; minor signs or symptoms
80%	Normal activity with effort; some signs or symptoms of disease
70%	Cares for self; unable to carry on normal work or to do active work
60%	Requires occasional assistance but is able to care for most of his needs
50%	Requires considerable assistance and frequent medical care
40%	Disabled; requires special care and assistance
30%	Severely disabled; hospitalization necessary; active supportive treatment is necessary
20%	Very sick; hospitalization necessary; active supportive treatment is necessary
10%	Moribund; fatal processes progressing rapidly
0%	Dead

Palliative Performance Scale (PPSv2)

PPS	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
PPS 100%	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
PPS 90%	Full	Normal Activity Some Disease	Full	Normal	Full
PPS 80%	Full	Normal Activity *with Effort* Some Disease	Full	Normal or Reduced	Full
PPS 70%	Reduced	Unable Normal Job/Work Some Disease	Full	Normal or Reduced	Full
PPS 60%	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance	Normal or Reduced	Full +/- Confusion
PPS 50%	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance	Normal or Reduced	Full +/- Confusion
PPS 40%	Mainly in Bed	Unable to Do Any Work Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy +/- Confusion
PPS 30%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Reduced	Full or Drowsy +/- Confusion
PPS 20%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Minimal Sips	Full or Drowsy +/- Confusion
PPS 10%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma
PPS 0%	Death	x	x	x	x

Palliative Alerts

Encourage patient to see family physician regularly or find one.

Explore pt's understanding of illness, discuss prognosis & goals of care.

Ensure ESAS & PPS/ECOG done at each visit.

Advance care planning. Discuss code status
Review treatment plan

Initiate home care

Establish plans to deal with emergencies
(e.g. pain crisis)

DNR & Advanced directives

Discuss preferred versus optimal place of death based on needs & circumstances

Consult Palliative Care Team as needed

PPS Functional Status%

80 70 60 50 40 30 20 10 0

For some patients the decline may be more gradual while for others it may be more precipitous

Seow H et al. JCO 2011;29(9):1151-1158

28 27 26 25 24 22 21 20 19 18 17 16 15 14 13 12 11 10 9 8 7 6 5 4 3 2 1 0 Death

Weeks before death

ILLNESS TRAJECTORY IN PROGRESSIVE CANCER

Health PEI

One Island Health System

How to Use PPSv2 tool

- 11 rows in increments of 10%-100%
- Normal activity & no evidence of disease to PPS 0% dead
- 5 columns describing function and abilities (ambulation, activity & evidence of disease, ability for self-care, intake, level of consciousness)
- Predominantly read left to right
- All information on left holds the most weight
  - ambulation - activity level & evidence of disease
- Determine ambulation ability then across to next and downwards until each column is determined
- Look for the best horizontal fit as each person is unique and may not fit entirely in line
- Definition of Terms is very important. – for example PPS 60% occasional assistance to PPS 50% considerable assistance
- Rather should ask yourself **what the patient is able to do** rather than formulating the rating solely from observation

Palliative Performance Scale (PPSv2)

PPS	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90%	Full	Normal Activity Some Disease	Full	Normal	Full
80%	Full	Normal Activity *with Effort* Some Disease	Full	Normal or Reduced	Full
70%	Reduced	Unable Normal Job/Work Some Disease	Full	Normal or Reduced	Full
60%	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance	Normal or Reduced	Full +/- Confusion
50%	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance	Normal or Reduced	Full +/- Confusion
40%	Mainly in Bed	Unable to Do Any Work Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy +/- Confusion
30%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Reduced	Full or Drowsy +/- Confusion
20%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Minimal Sips	Full or Drowsy +/- Confusion
10%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma
0%	Death	x	x	x	x

Instructions and Definitions

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.

Definition of Terms: 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. **1. 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 i*s able to* sit up or *needs* to lie down
   - **Totally bed bound —** unable to get out of 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.
3. **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: AIDS:

some = may mean the shift from HIV to AIDS
significant = progression in physical decline, new or difficult symptoms and laboratory findings with low counts
extensive = one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc

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

Why? Where's the Value?

- Any good tool should:
  - Make your job easier
  - Help your understanding
  - Help improve care

- How can it help patients and caregivers?
  - What do they need now? How/who?
  - What support should we put in place for discharge?
  - What can they expect in the next few weeks?

PPSv2 tool …..multiple functions

1. Assessment
2. Communication
3. Prognostication
4. Evaluation
5. Teaching

1. Assessment Tool

- Gives initial 'snapshot' of the patient's condition/function within their disease trajectory
- Additional assessments ongoing, provide further information on patient's condition, rate of decline
- Gives information about what patient might need
- Physical/emotional support
- In many palliative programs across Canada financial assistance with medication costs with PPSv2 50% and less. Some other provinces have a time limit (usually 6 months)

2. Communication Tool

- When giving report, asking for orders or charting:
  - Efficient
  - Succinct
  - Simple but Informative
  - You can say a lot in a few words
- Mr. EF, Age 56, Dx Ca pancreas, PPSv2 50%
  - You have already given a large amount of information
    - Mainly sit/lie
    - Extensive disease
    - Needs considerable assistance
- Everyone has to speak/understand the same language
- Once there is broad understanding and consistent use of the tool, exchange of information is more streamlined
  - "The patient is PPS 10%, groaning, appears in pain."
  - "The patient is PPS 80%, groaning, reports acute onset abdominal pain 10/10 past 2 hrs."

3. Prognostication Tool

- Valuable to understand how a patient is changing or declining
- Working from baseline percentage, you can immediately enquire back:
  - e.g What were you doing 1 month ago?
- Ongoing ratings over days or weeks, then expands to create 'bigger picture'
- Anticipate ongoing needs, provide teaching, prepare pt's & families; prevent crises

4. Evaluation Tool

- Mr. DM Age 69. Ca colon with diffuse abdominal metastases PPSv2 50%
- Rectal bleeding. Weak. Severe SOBOE. Hgb 51
- Transfusion 4 units
- PPSv2 gradually increased to 70%
- Scheduled for palliative RT

5. Teaching Tool

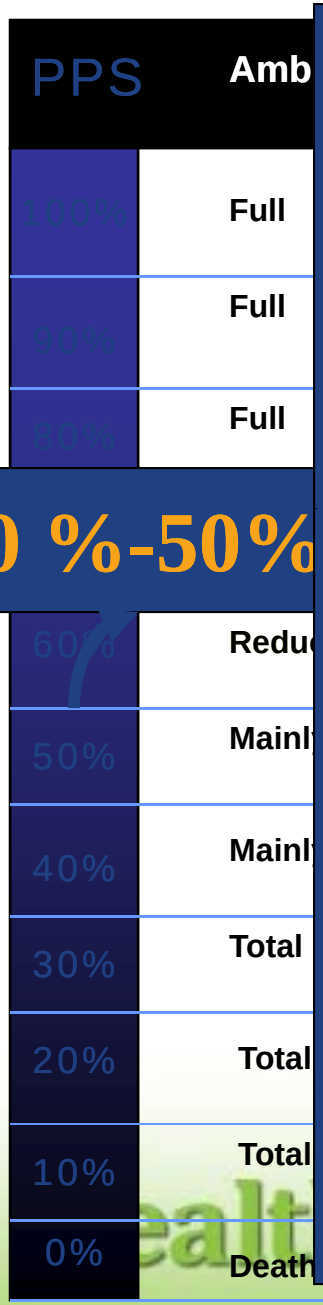
Sometimes when family members are struggling with understanding what's going on, PPSv2 can be a valuable visual tool.

- Particularly in very rapid declines
  - "There are changes everyday.
  - "What's next?"
  - "We're overwhelmed."
- Or very slow, intermittent trajectories.
  - "How long will this go on?"
  - "I don't know how much longer I can do this."

PPS	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal Activity & work No Evidence of Disease	Full	Normal	Full
90%	Full				
80%	Full				
70%					
60%					
60%	Reduced	Unable to do hobby/ housework Signif. Disease	Occasional assistance	Normal or reduced	Full or confusion
50%	Mainly sit or lie	Unable to do any work Ext. disease	Considerable assistance	Normal or reduced	Full or confusion

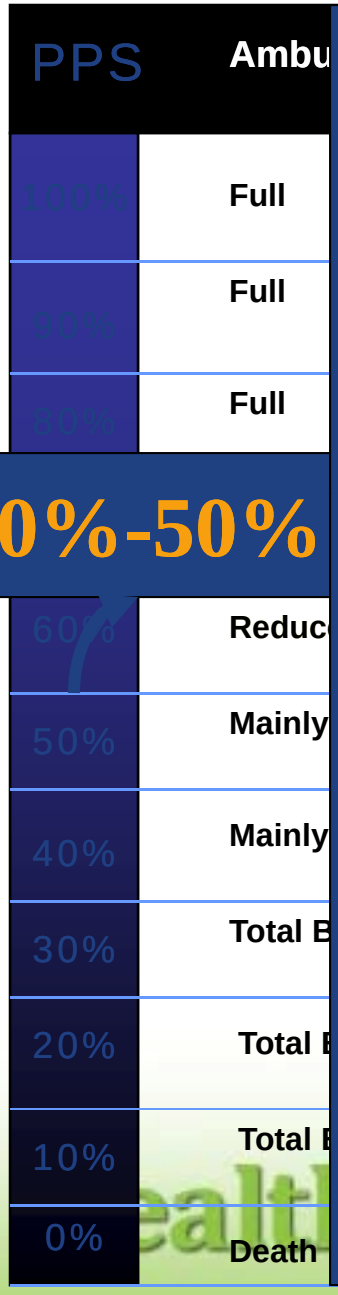
This is a time of life-threatening crisis that creates high anxiety & ambiguity.

60%-50%



"The Shift to Palliative Care"

	Change in focus	Patient/ family losses	Emotions	Communica-tion
Patients	■ From managing the disease to managing one's life	■ Shrinking world ■ Reviewing one's life	■ Ambival-ence hope/denial ■ Fears re future	■ Protecting others ■ Loss of words
Families	■ Feeling abandoned ■ New system	■Roles alter ■Reactions vary, resentments arise	■ Power-lessness ■ Fears re ability to manage	■Differences increase ■ Indirect



"The Shift to Palliative Approach to Care"

Psychosocial interventions

- Counsel patients regarding their grief, fears & the future
- Acknowledge and support expression of emotions
- Offer opportunities for life review
- Identify what's possible: hopes, choices, actions
- Counsel the family regarding the impact of the illness: strengths, struggles, supports, coping strategies
- Acknowledge and support difficult conversations; family differences

Survival Rates by Initial PPSv2

Survival Rate (%) in Days

PPS Level	Total Cases											
	1	3	5	7	14	30	45	60	90	180	365	
PPS 70%	99	97	96	95	87	77	62	**51**	35	16	7	150
PPS 60%	99	97	95	92	83	64	**49**	41	29	12	5	487
PPS 50%	97	93	87	82	67	**47**	36	28	19	8	4	1055
PPS 40%	94	82	73	66	**46**	27	19	15	9	4	1	1647
PPS 30%	84	63	**48**	40	23	12	8	6	4	2	1	1420
PPS 20%	**56**	28	15	9	4	2	2	1	1	0	0	737
PPS 10%	34	13	5	3	1	0	0	0	0	0	0	570

(Boldfaced numbers represent approximately 50% survival rates at a given PPSv2 level)

Eastern European Oncology Group(ECOG)

- First published in 1982
- Very widely used in Oncology
- Widely used for research, treatment planning and trials
- 5 levels, 0= fully active without restriction,

  5= dead

Grade	ECOG PERFORMANCE STATUS
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead

Patient Reported Functional Status(PRFS)

- This tool is a “patient reported tool” that is easy to fill out and understand.
- It can be completed in the waiting room in the office.
- It can also help patients identify their functional decline, **which can be the start of a conversation to start planning for future months.**

Cancer Care Ontario
Action Cancer Ontario

Health PEI
One Island Health System

Patient Reported Functional Status (PRFS) Tool

Activities & Function: *Over the past month I would generally rate my activity as*:

(0) ❑ normal with no limitations (0)

(1) ❑ not my normal self, but able to be up and about with fairly normal activities (1)

(2) ❑ not feeling up to most things, but in bed or chair less than half the day (2)

(3) ❑ able to do little activity & spend most of the day in bed or chair (3)

(4) ❑ pretty much bedridden, rarely out of bed (4)

Patient's Name _____

Date _____ Time _____

Completed by (check one):
- ❑ Patient
- ❑ Family caregiver
- ❑ Health care professional caregiver
- ❑ Caregiver-assisted

PRFS - English

How they all compare…

How do levels of Palliative Performance Scale (PPSv2) version 2 (developed by Victoria Hospice Society)**/ Patient Reported Functional Status (PRFS) or Patient ECOG/ECOG compare?**

	ECOG Level	Patient Reported Functional Status (PRFS) or Patient ECOG Level	PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
Stable Stage	0	0	100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
	1	1	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
Transitional Stage	2	2	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
	3	3	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
End of Life Stage	4	4	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
	5		10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
			0%	Death	-	-	-	-

Health PEI

One Island Health System

Rockwood Clinical Frailty Scale (CFS)

- Identifies 9 degrees of frailty from very frail to terminally ill
- Very user friendly
- Can be done by GP or nursing
- Takes 5 minutes
- Can help with proactive care

Clinical Frailty Scale

1 Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3 Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4 Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

5 Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7 Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9 Terminally Ill – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia,** recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia,** they cannot do personal care without help.

References/Resources

- **BC Guidelines: Palliative Care for the Patient with Incurable Cancer or Advanced Disease (2017) retrieved from http://www.BCGuidelines.ca**
- **Pallium Canada (2016) The Pallium Palliative Pocket Book (2nd Ed) Pereira, J. Ottawa, ON**
- **The Edmonton Symptom Assessment System 25 Years Later: Past, Present and Future Developments** Hui D, Bruera E. *Journal of Pain and Symptom Management* (2017).
- **Essentials in Hospice and Palliative Care: A Practical Resource for Every Nurse (2016) Murray, K. Victoria, BC.**
- **https://www.lifeanddeathmatters.ca**
-
- Dr. Robin Fainsinger – Discusses ESAS-r https://youtube/zw01ikrTXpU
- **https://www.cancercareontario.ca/en/guidelines-advice/symptom-side-effect-management/symptom-assessment-tool**