A PALLIATIVE CARE APPROACH FOR PRIMARY CARE IN NB

A collaboration between the Department of Health, Horizon Health Network, Vitalité Health Network, NB Extra-Mural Program and Social Development

Special Thanks

- Nathanael Patriquin – Palliative Care Coordinator Dep Health
- Emily Gautreau – Horizon Lead for Palliative Care
- Paryse Ouellette – Vitalité Lead for Palliative Care
- Dr. Cynthia Savoy – Vitalité Physician
- Dr. Rébecca Arseneau – Vitalité Physician
- Dr. Gabrielle Arsenault – Vitalité Physician
- Dr. Jessica Guimond-Hemming – Horizon Palliative Care Physician
- Dr. Pam Mansfield – Horizon Palliative Care Physician
- Eleanor Kenny – Horizon Palliative Care Clinical Nurse Specialist
- Jennifer Malley – Extra-Mural Palliative Resource Nurse
- Karine Levesque – Consultant Dep Health
- Christine Cohoon – Consultant Dep Social Development
- Brittany Jones – Consultant Dep Social Development
- Marie José Belliveau – Consultant Dep Health
- Michelle Virtue – Consultant Dep Social Development
- Derek Ryan- Consultant Dep Social Development

A PALLIATIVE CARE APPROACH FOR PRIMARY CARE IN NB

A collaboration between the Department of Health, Horizon Health Network, Vitalité Health Network, NB Extra-Mural Program and Social Development

Disclosure

Presenter Disclosure

- Speaker’s name: **Jennifer Malley**
- Relationships with financial sponsors: *Not Applicable*
- Membership on advisory boards or speakers’ bureaus: *Not Applicable*
- Patents for drugs or devices: *Not Applicable*
- Other financial relationships/investments: *Not Applicable*

Discloser of Financial Support

- *No External Support*

Mitigating Potential Bias

- *Not Applicable*

Disclosure

Presenter Disclosure

- Speaker’s name: **Paryse Ouellette**
- Relationships with financial sponsors: *Not Applicable*
- Membership on advisory boards or speakers’ bureaus: *Not Applicable*
- Patents for drugs or devices: *Not Applicable*
- Other financial relationships/investments: *Not Applicable*

Discloser of Financial Support

- *No External Support*

Mitigating Potential Bias

- *Not Applicable*

Learning Objectives

By the end of the session participants will be able to:

- *Recognize when a patient could benefit from a palliative care approach, equipping them with the tools to integrate palliative care into their practice.* (CANMED role: Health Advocate)
- *Describe the value of early palliative care and increase confidence starting conversations with patients and their families.* (CANMED role: Communicator)
- *Collaborate effectively with healthcare partners, using a common language among organizations to ensure seamless communication and coordination in patient care.* (CANMED role: Collaborator)

Palliative Care in NB – Timeline

- 2018 - Palliative Care in NB: A person-centered approach to care and integrated services framework was released
- September the NB Palliative Care Advisory Committee was assembled to:
  - Advise on development of an action plan for implementation and ongoing evaluation
  - Advise on implementation of a coordinated approach to palliative care
- Supported by three subgroups
  - Standardized Assessment and Monitoring Tools
  - Grief and Bereavement
  - Community Palliative Care

Palliative Care
in New Brunswick

A PERSON-CENTRED CARE AND
INTEGRATED SERVICES FRAMEWORK

Important Background Information

Settings for use of the SAMS Tools were identified as:

- Patient homes (including SCH)
- Nursing Homes
- Residential Hospices
- Hospitals
- Primary Health Care (MD & NP offices, health centers, clinics)
- Correctional Centers
- Mental Health Facilities
- Canadian Veteran Centers

Important Background Information

Criteria for SAM Tools were developed:

- Relative to Palliative Care
- Cluster Specific (ex. ESAS, general, oncology, renal)
- Can be used in all settings
- Validated
- Bilingual
- Also considered:
  - How time consuming
  - Oriented to patients and/or family
  - Frequency of use
  - Actions associated with the tools
  - Cultural Sensitivity

Important Background Information

- Tools were carefully selected with attention to the importance of providing holistic patient care. The following “domains” were addressed:
  - Clinical assessment
  - Cognitive assessment
  - Delirium screening
  - Depression assessment
  - Overall level of distress (for both patient and their caregivers)
  - Grief and bereavement
  - Pain
  - Risk for addiction

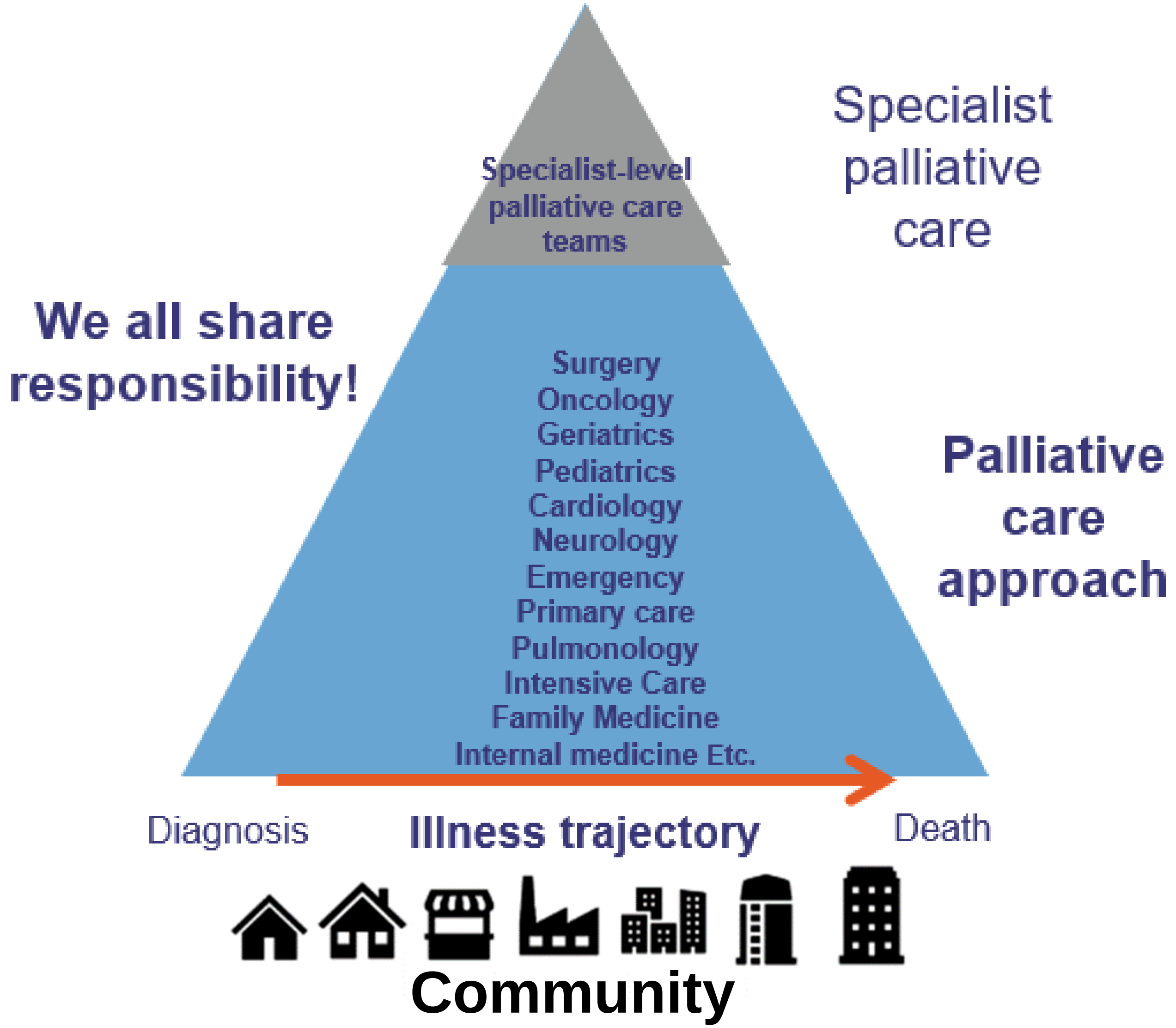
A Palliative Approach to Care:

- Is an active approach
- Is for people of all ages with life limiting illness when cure is not possible
- Is provided alongside treatments to control disease
- Is not limited to end-of-life (EOL) care
- Requires an interdisciplinary approach
- Can occur anywhere

Why is Early Palliative Care Important?

- Implementing a palliative care approach earlier in the course of a disease improves the quality of life and death, reducing suffering for both patients and their families dealing with terminal illnesses.
- Introducing palliative care early can result in less depression and anxiety.
- Those who experience an early approach can live longer (3 months).

Palliative Care is Everybody's Business!



Specialist-level palliative care teams

Specialist palliative care

We all share responsibility!

Surgery
Oncology
Geriatrics
Pediatrics
Cardiology
Neurology
Emergency
Primary care
Pulmonology
Intensive Care
Family Medicine
Internal medicine Etc.

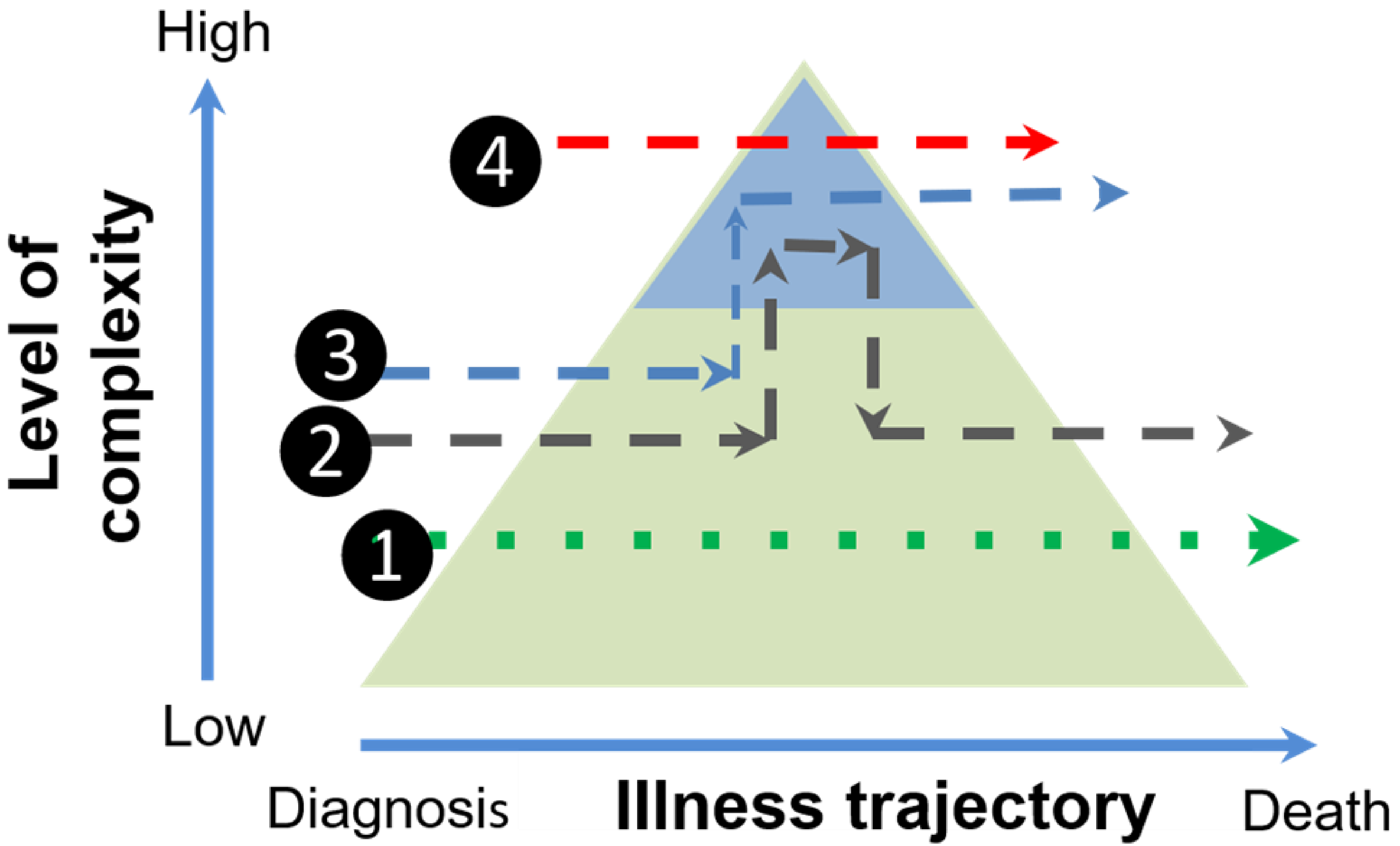
Palliative care approach

Diagnosis **Illness trajectory** Death

Community

Pallium Canada

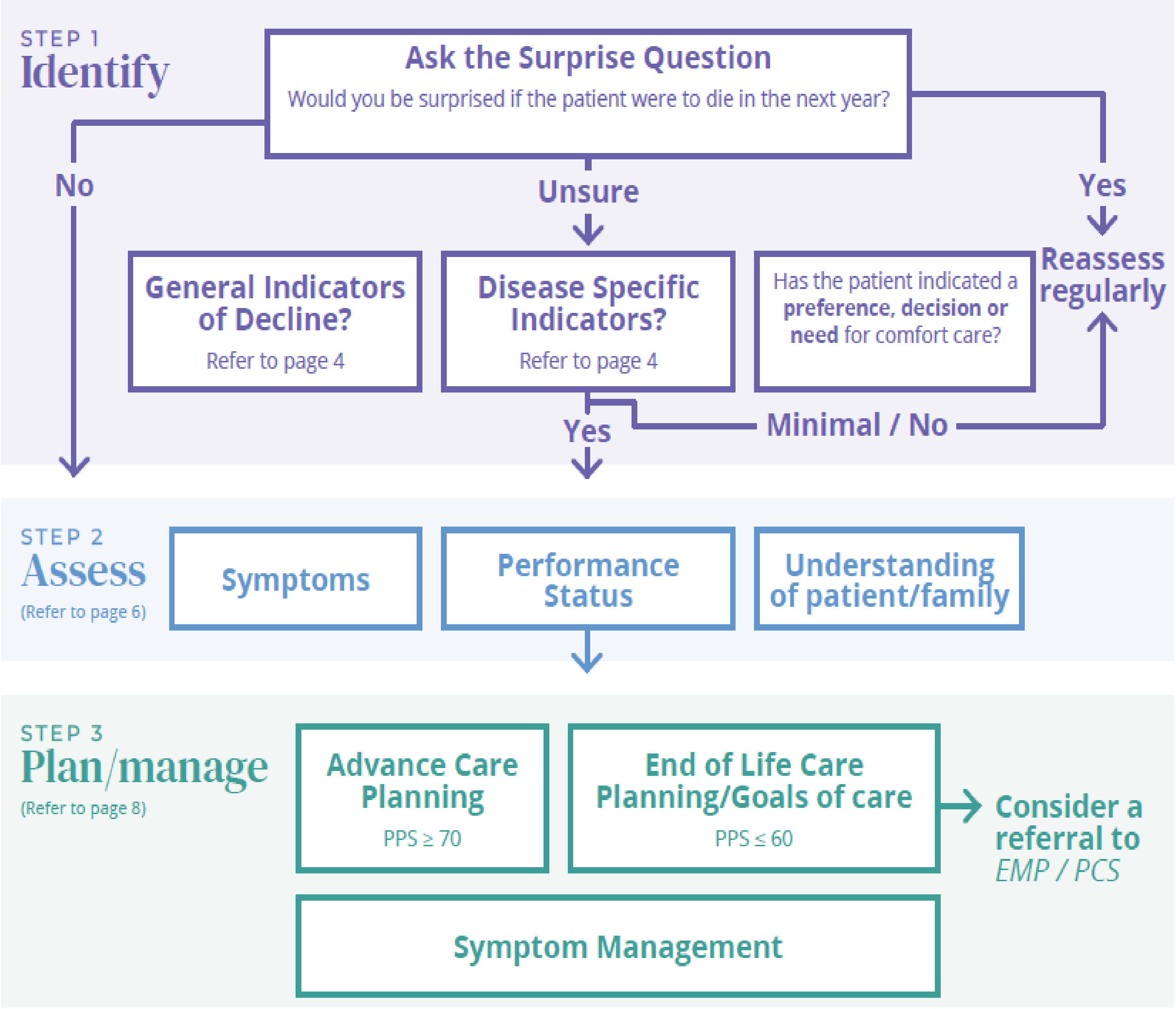
Different Needs, Different Level of Care



The Gold Standards Framework

- Identify
  - use the **“surprise question”**
- Assess
  - Symptoms
  - Performance status
  - Patient and family understanding of their illness
- Plan/Manage
  - Symptoms
  - Care planning
    - Advance Care Planning

IDENTIFY, ASSESS, PLAN/MANAGE TOOL



STEP 1
Identify

Ask the Surprise Question
Would you be surprised if the patient were to die in the next year?

No

Unsure

Yes

General Indicators of Decline?
Refer to page 4

Disease Specific Indicators?
Refer to page 4

Has the patient indicated a **preference, decision or need** for comfort care?

Reassess regularly

Yes

Minimal / No

STEP 2
Assess
(Refer to page 6)

Symptoms

Performance Status

Understanding of patient/family

STEP 3
Plan/manage
(Refer to page 8)

Advance Care Planning
PPS ≥ 70

End of Life Care Planning/Goals of care
PPS ≤ 60

Consider a referral to *EMP / PCS*

Symptom Management

Step 1. Identify

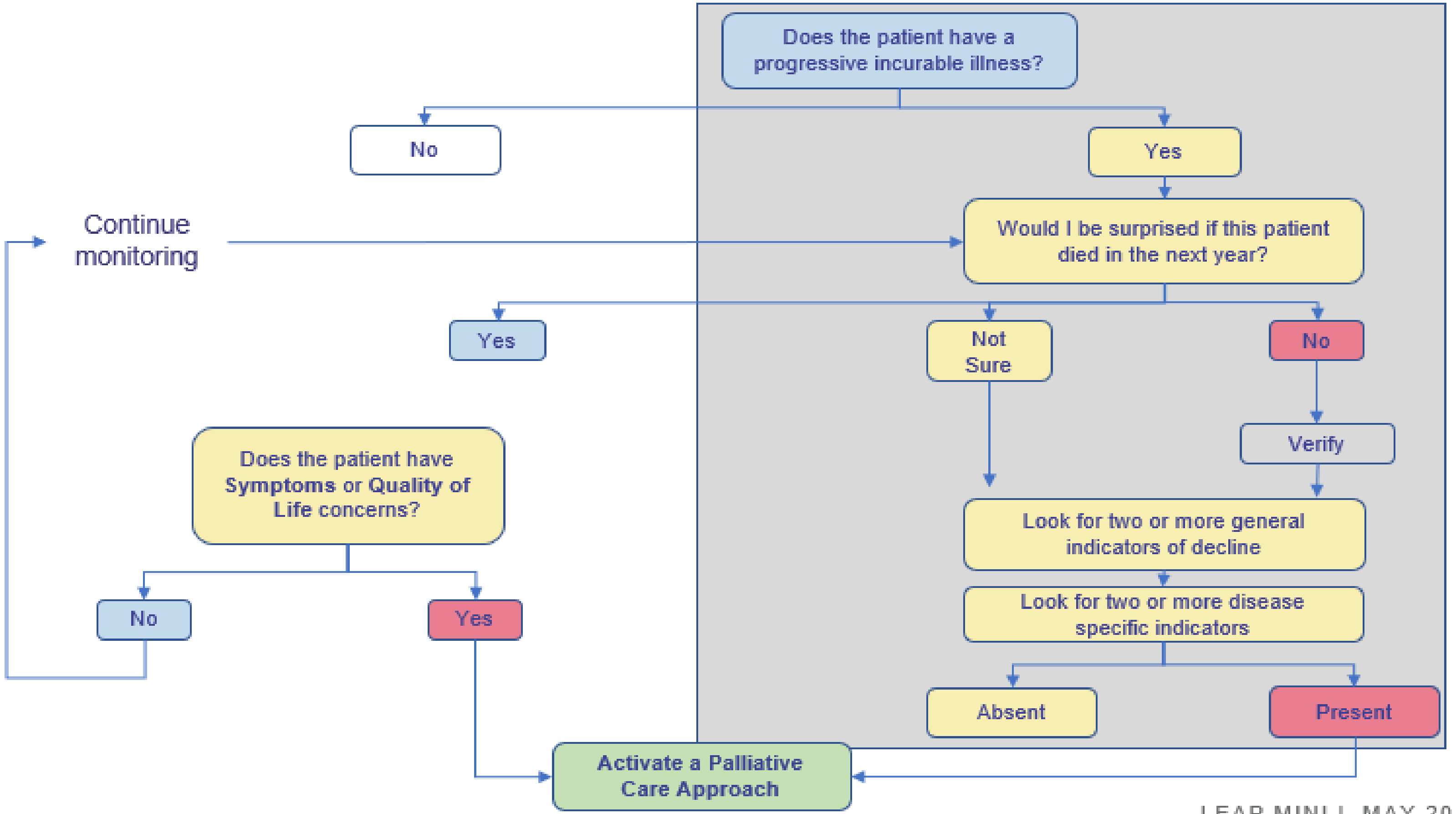
- Ask the Surprise Question:

“Would you be surprised if the patient were to die in the next year?”

- If the answer is **“no”** then a palliative approach to care is appropriate.
- If you’re unsure consider:
  - General indicators of decline
  - Disease specific indicators of decline

The Surprise Question

"Ask the question"



Adapted from GSF

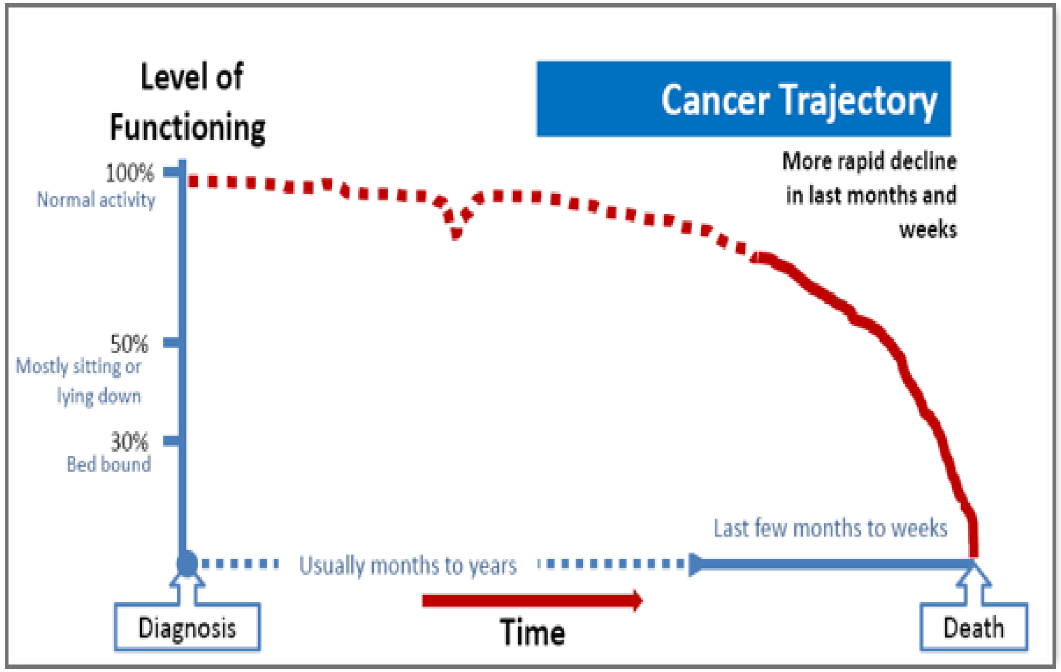
Pallium Canada

General Indicators of Decline

- Decreasing activity
- General physical decline and increasing need for support
- Advanced disease – unstable, deteriorating complex symptom burden
- Weight loss ↑10% in past 6 months
- Serum albumen <25g/l
- Repeated, unplanned hospital admissions

Cancer - predictable decline

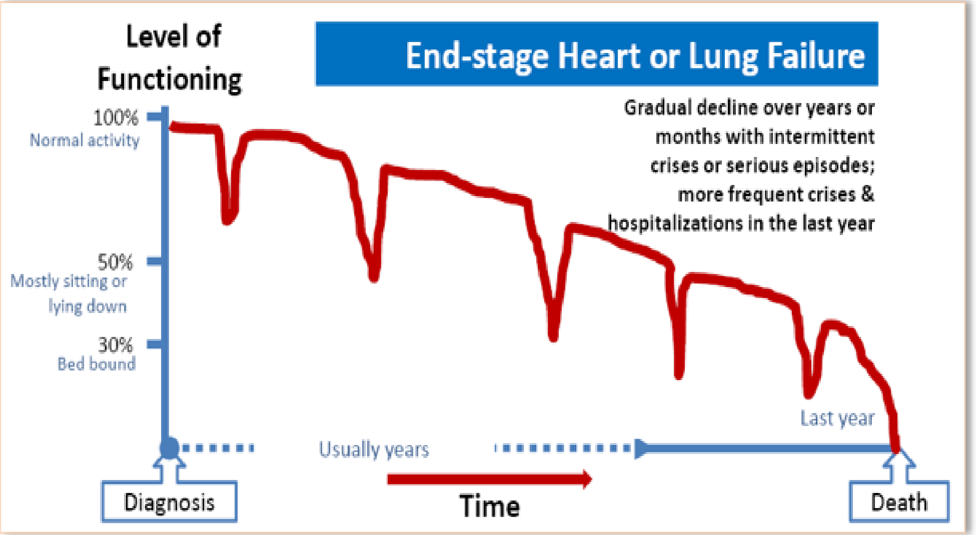
- Metastasis
- Disease progression
  - With or without treatment
- Performance status
  - More than 50% of time in bed usually prognosis is less than 3 months



Adapted from Gold Standards Framework and Lunney JR, Lynn J, Hogan C. *J Am Geriatr Soc* 2002

Organ Failure – erratic decline

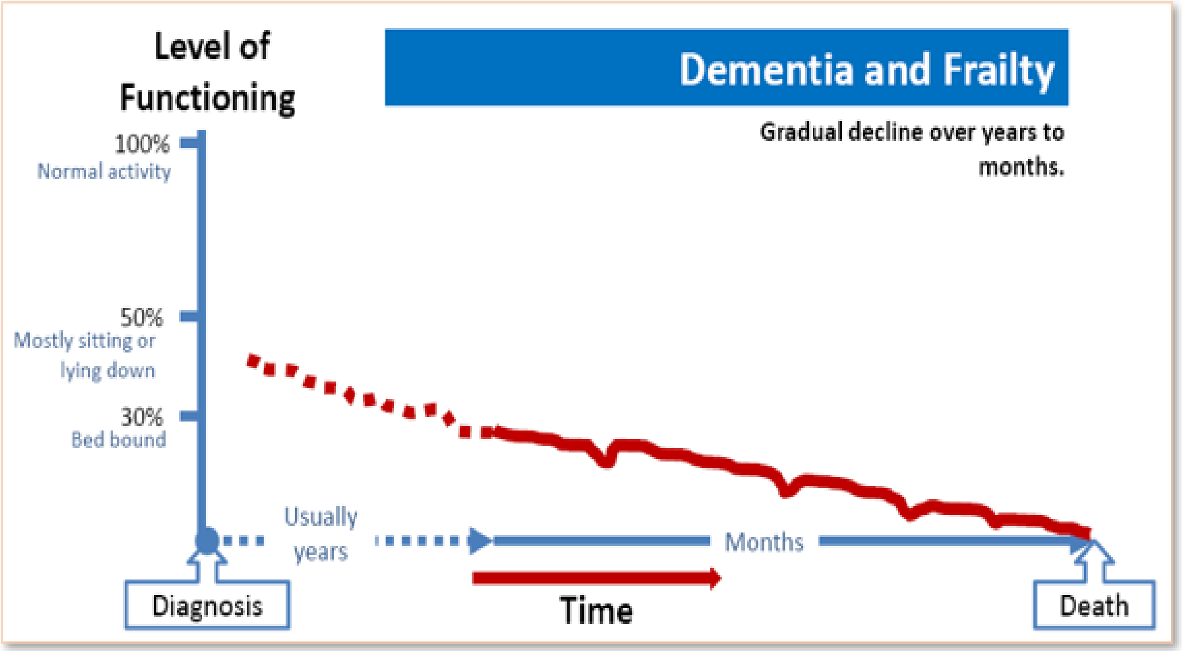
- Chronic Lung Disease e. g. Chronic Obstructive Pulmonary Disease (COPD)
- Heart Disease e. g. Congestive Heart Failure (CHF)
- Liver Disease
- Chronic Kidney Disease (CKD)
- General Neurological Diseases
  - Motor Neuron Disease
  - Parkinson’s Disease
  - Multiple Sclerosis



Adapted from Gold Standards Framework and Lunney JR, Lynn J, Hogan C. *J Am Geriatr Soc* 2002

Frailty/Dementia – Gradual Decline

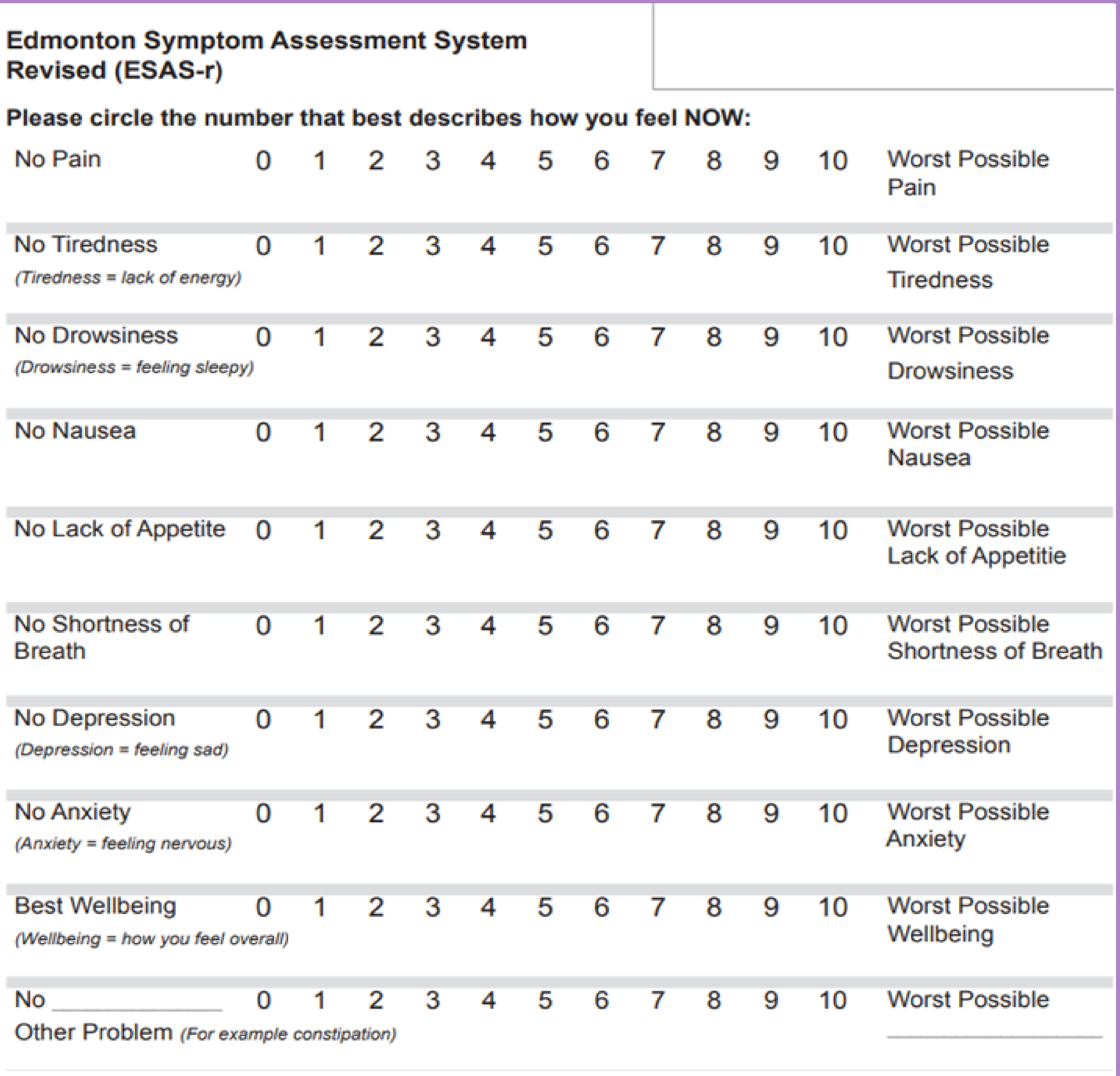
- Frailty
- Dementia
- Stroke



Adapted from Gold Standards Framework and Lunney JR, Lynn J, Hogan C. *J Am Geriatr Soc* 2002

Step 2. Assess

- Symptoms
  - Assess symptoms and needs across all domains, including emotional, physical, psycho-social, spiritual and bereavement.
  - Screen regularly using validated tools. Edmonton Symptom Assessment Tool (ESAS) should be used regularly to screen for the intensity of nine common symptoms.



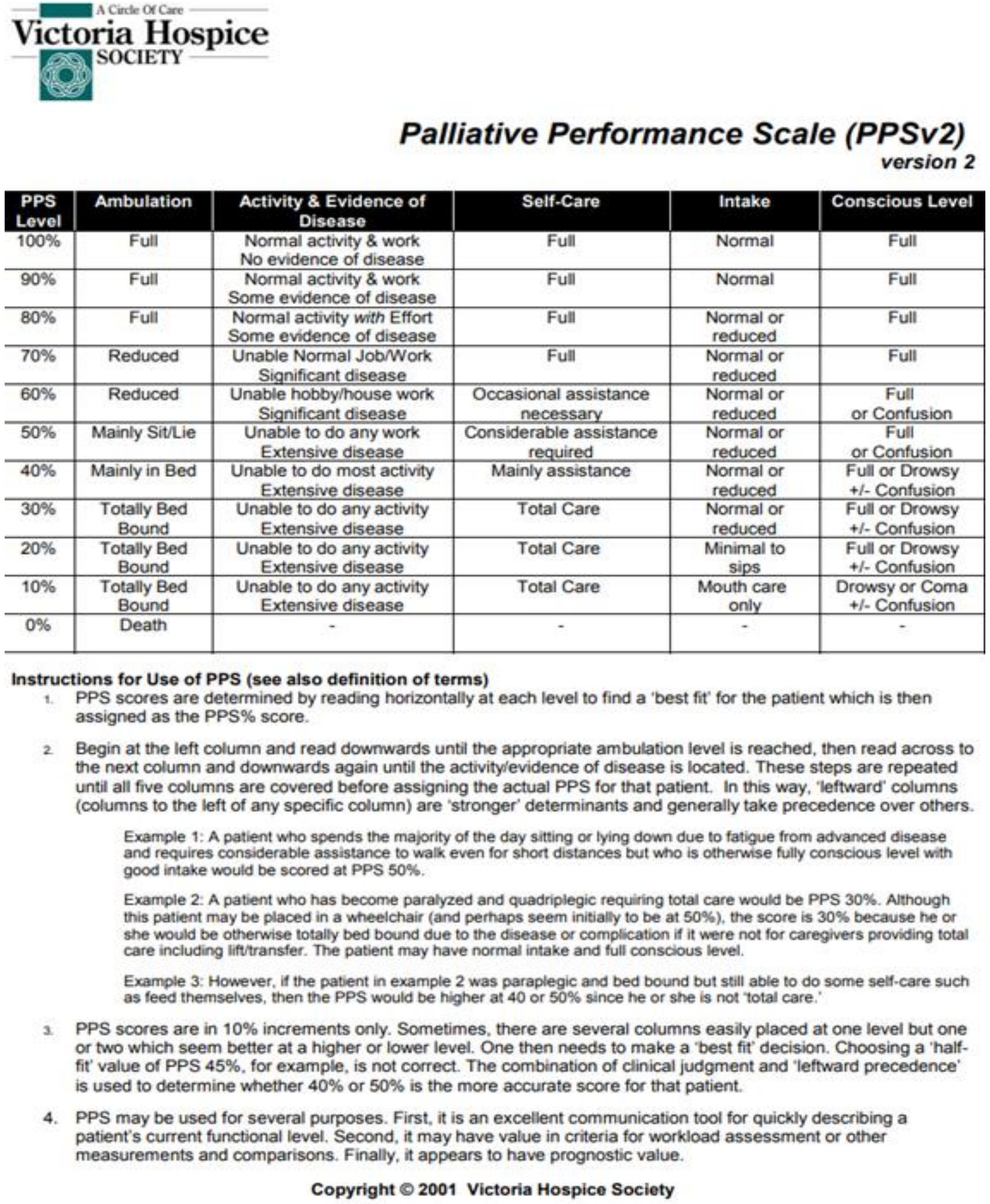
Edmonton Symptom Assessment System Revised (ESAS-r)

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 Appetitie
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 nervous)*	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
No ____________ Other Problem *(For example constipation)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible ____________

Assess

- Performance status
  - In palliative care we use the Palliative Performance Scale (PPS) as a means of tracking performance status in our patients.
  - The PPS is not designed to be prognostic; however, as functional status declines, life expectancy typically decreases as well.



A Circle Of Care
Victoria Hospice
SOCIETY

Palliative Performance Scale (PPSv2)

version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *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 Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

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

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

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

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

   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'
3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Assess

- Understanding
  - Does the patient and family understand the progressive nature of their illness?
  - Does the patient and family understand the incurable nature of their illness?
  - Explore patients’ questions, for example, is the patient asking about prognosis?

Step 3. Plan/Manage

- Care planning:
  - Advance Care Planning (ACP)
  - Goals of Care
  - End-of-life planning
- Consider the following:
  - Consider consult with or referral to palliative care for complex symptom management issues.
  - Identify most responsible physician if transfer of care required.
  - Facilitate communication of the plan of care when there is a transfer to a new setting.
- Manage symptoms

Plan/Manage

- Manage symptoms
  - Promptly manage symptoms and needs through use of symptom guides such as the Pallium Pocketbook.
  - Refer to other members of the interdisciplinary team to ensure holistic symptom management (Social Work, Clinical Spiritual Care, and Psychology when available).
  - Refer to palliative care specialists for complex symptom management issues.

Referrals (patients/families)

- Examples of resources that can be considered to support patients and families:
    - Community Care (EMP) – Consider for functional/performance level needs (PPS < 60)
    - Palliative/Pain/Supportive Consultation – Consider for complex symptom management issues
    - Nutrition/dietitian
    - Physical/occupational therapy
    - Spiritual services
    - Psychology/psychiatry
    - Social work
    - Community support services
    - Hospice

Recommended Tools

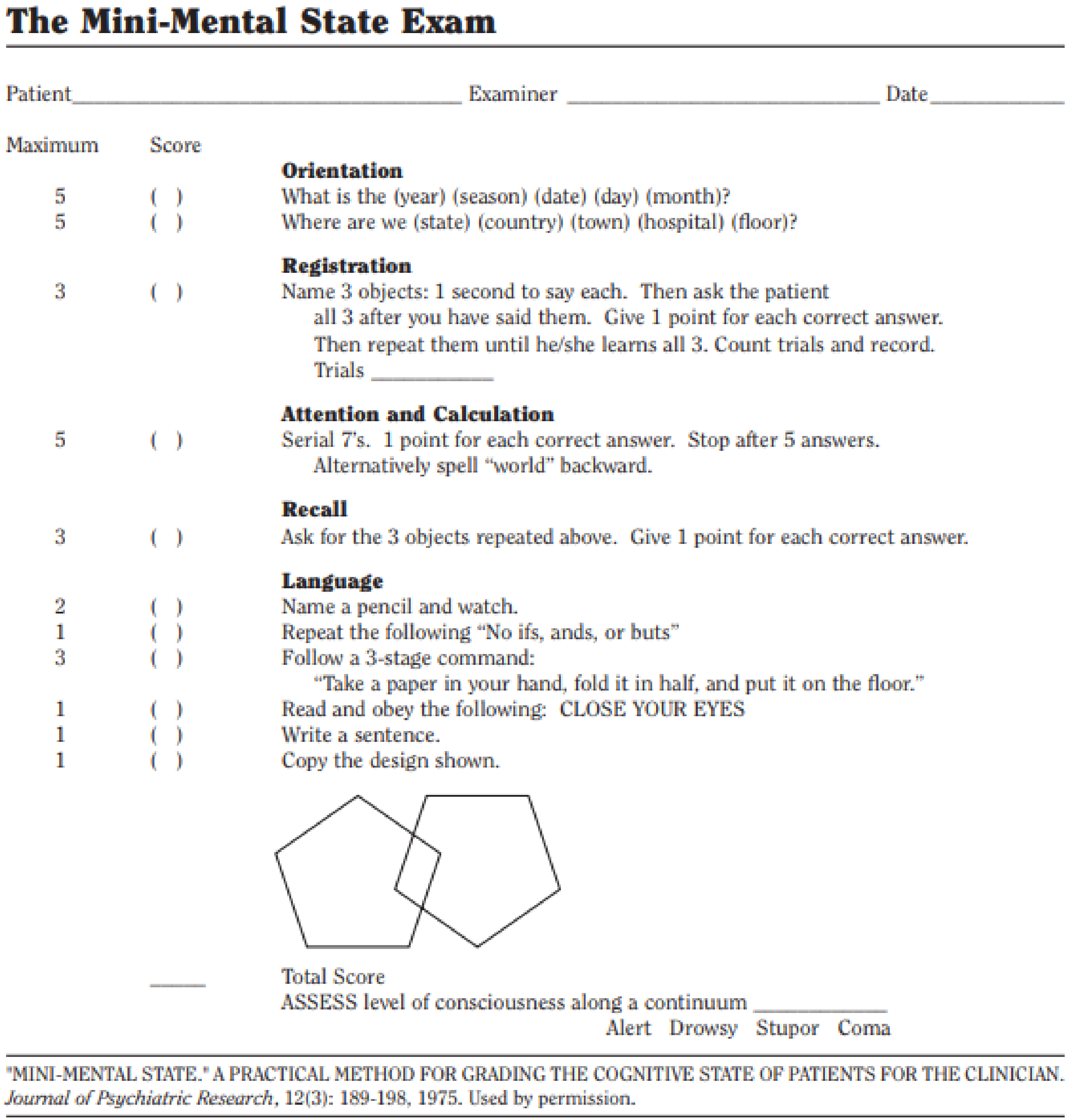
- ***The Surprise Question***
- ***Edmonton Symptom Assessment System - revised (ESAS-r / EESE-r)***
- ***Palliative Performance Scale - PPSv2***
- Standardized Mini Mental State Examination (SMMSE)
- Montreal Cognitive Assessment (MoCA)
- Confusion Assessment Method (CAM) (*Pallium and LTCF)*
- Nursing Delirium Screening Scale (NUDESC) / Delirium Rating Scale (DRS)
- Hospital Anxiety and Depression Scale (HADS)
- Distress Thermometer
- Caregiver Burden Scale
- Bereavement Assessment Tool (BRAT)
- Brief Pain Inventory (BPI)
- OPQRSTUV Pain Acronym
- Wong Baker Face Scale (for children and non-verbal patients)
- Opioid Risk Assessment

Why SAM Tools?

- The use of standardized assessment tools can improve communication and collaboration between healthcare providers and organizations.

- This will improve the patient experience across all sectors.

SMMSE – Standardized Mini Mental State Examination



The Mini-Mental State Exam

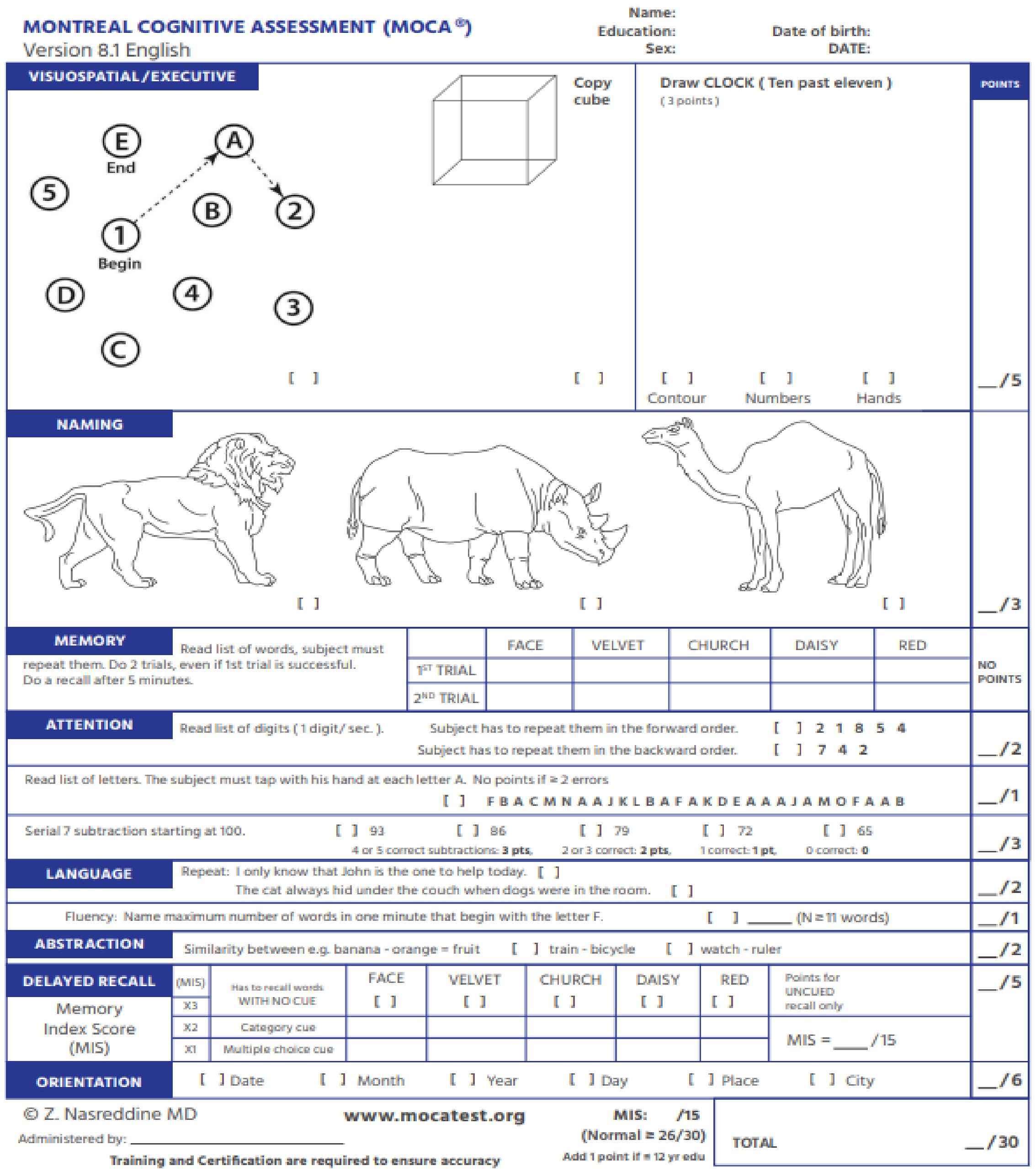
Patient_______________ Examiner _______________ Date__________

Maximum	Score	
		Orientation
5	( )	What is the (year) (season) (date) (day) (month)?
5	( )	Where are we (state) (country) (town) (hospital) (floor)?
		Registration
3	( )	Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he/she learns all 3. Count trials and record. Trials __________
		Attention and Calculation
5	( )	Serial 7's. 1 point for each correct answer. Stop after 5 answers. Alternatively spell "world" backward.
		Recall
3	( )	Ask for the 3 objects repeated above. Give 1 point for each correct answer.
		Language
2	( )	Name a pencil and watch.
1	( )	Repeat the following "No ifs, ands, or buts"
3	( )	Follow a 3-stage command: "Take a paper in your hand, fold it in half, and put it on the floor."
1	( )	Read and obey the following: CLOSE YOUR EYES
1	( )	Write a sentence.
1	( )	Copy the design shown.
	_____	Total Score
		ASSESS level of consciousness along a continuum __________ Alert Drowsy Stupor Coma

"MINI-MENTAL STATE." A PRACTICAL METHOD FOR GRADING THE COGNITIVE STATE OF PATIENTS FOR THE CLINICIAN. *Journal of Psychiatric Research*, 12(3): 189-198, 1975. Used by permission.

https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/cogimp-smmse.pdf

Montreal Cognitive Assessment – MoCA



MONTREAL COGNITIVE ASSESSMENT (MOCA®)
Version 8.1 English

Name:
Education:
Sex:
Date of birth:
DATE:

VISUOSPATIAL / EXECUTIVE

[ ]

Copy cube [ ]

Draw CLOCK (Ten past eleven) (3 points)

[ ] Contour [ ] Numbers [ ] Hands

POINTS __/5

NAMING

[ ] [ ] [ ]

__/3

MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1ST TRIAL					
2ND TRIAL					

NO POINTS

ATTENTION Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order. [ ] 2 1 8 5 4
Subject has to repeat them in the backward order. [ ] 7 4 2
__/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B
__/1

Serial 7 subtraction starting at 100. [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0**
__/3

LANGUAGE Repeat: I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ]
__/2

Fluency: Name maximum number of words in one minute that begin with the letter F. [ ] ______ (N ≥ 11 words)
__/1

ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler
__/2

DELAYED RECALL

(MIS)	Has to recall words WITH NO CUE	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only
X3		[ ]	[ ]	[ ]	[ ]	[ ]	
X2	Category cue						MIS = ____/15
X1	Multiple choice cue						

__/5

Memory Index Score (MIS)

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City
__/6

www.mocatest.org

Administered by: ____________________

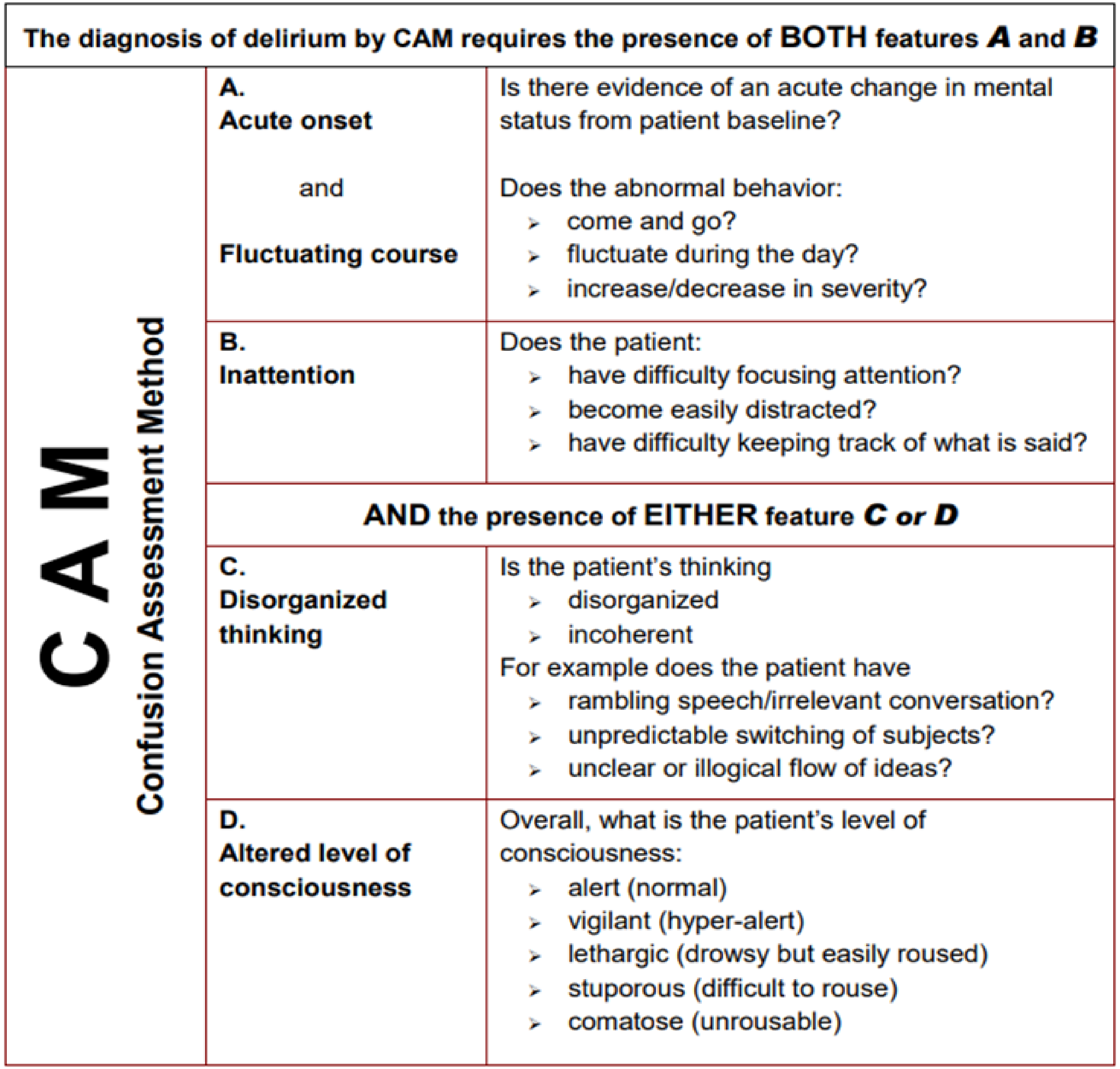
Training and Certification are required to ensure accuracy

MIS: /15
(Normal ≥ 26/30)
Add 1 point if ≤ 12 yr edu

TOTAL __/30

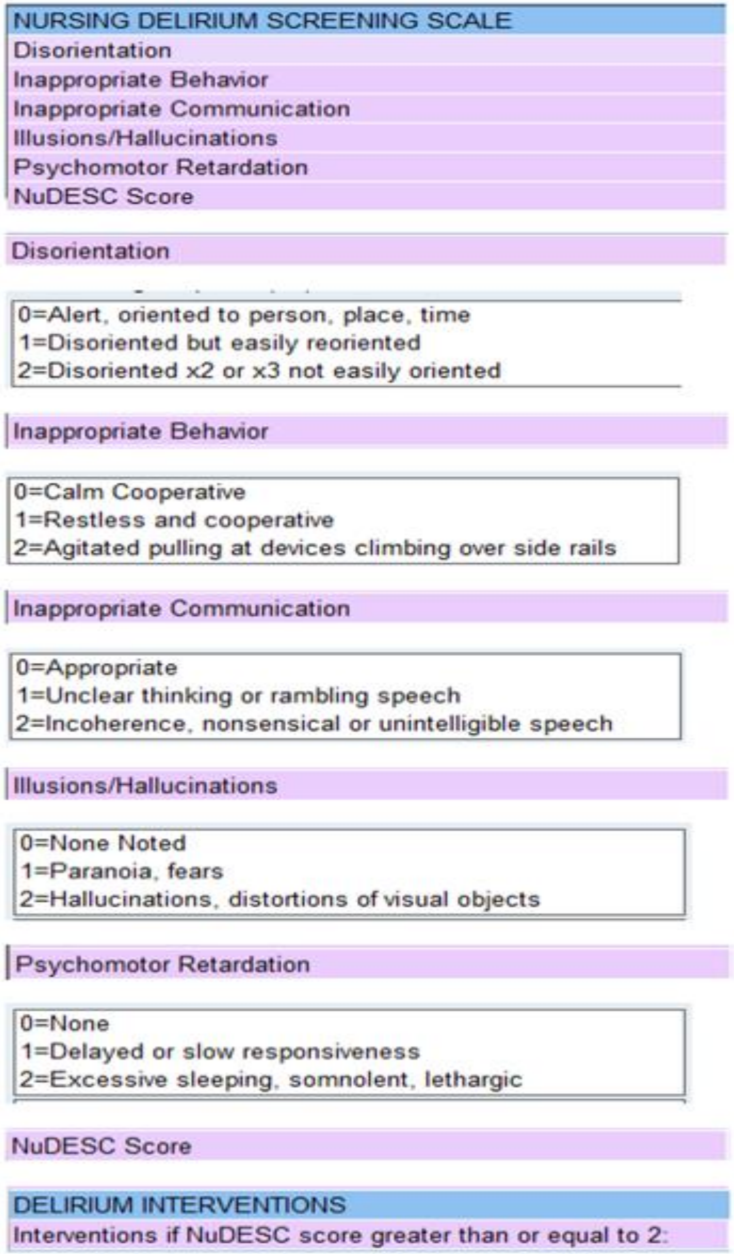
https://championsforhealth.org/wp-content/uploads/2018/12/MOCA-8.1.8.2-English.pdf

CAM - Confusion Assessment Method (Pallium and LTCF)



The diagnosis of delirium by CAM requires the presence of BOTH features *A* and *B*		
C A M **Confusion Assessment Method**	**A.** **Acute onset** and **Fluctuating course**	Is there evidence of an acute change in mental status from patient baseline? Does the abnormal behavior: ➢ come and go? ➢ fluctuate during the day? ➢ increase/decrease in severity?
	B. **Inattention**	Does the patient: ➢ have difficulty focusing attention? ➢ become easily distracted? ➢ have difficulty keeping track of what is said?
	AND the presence of EITHER feature *C or D*	
	C. **Disorganized thinking**	Is the patient's thinking ➢ disorganized ➢ incoherent For example does the patient have ➢ rambling speech/irrelevant conversation? ➢ unpredictable switching of subjects? ➢ unclear or illogical flow of ideas?
	D. **Altered level of consciousness**	Overall, what is the patient's level of consciousness: ➢ alert (normal) ➢ vigilant (hyper-alert) ➢ lethargic (drowsy but easily roused) ➢ stuporous (difficult to rouse) ➢ comatose (unrousable)

Nursing Delirium Screening Scale NUDESC / Delirium Rating Scale (DRS)



NURSING DELIRIUM SCREENING SCALE
Disorientation
Inappropriate Behavior
Inappropriate Communication
Illusions/Hallucinations
Psychomotor Retardation
NuDESC Score

Disorientation

0=Alert, oriented to person, place, time
1=Disoriented but easily reoriented
2=Disoriented x2 or x3 not easily oriented

Inappropriate Behavior

0=Calm Cooperative
1=Restless and cooperative
2=Agitated pulling at devices climbing over side rails

Inappropriate Communication

0=Appropriate
1=Unclear thinking or rambling speech
2=Incoherence, nonsensical or unintelligible speech

Illusions/Hallucinations

0=None Noted
1=Paranoia, fears
2=Hallucinations, distortions of visual objects

Psychomotor Retardation

0=None
1=Delayed or slow responsiveness
2=Excessive sleeping, somnolent, lethargic

NuDESC Score

DELIRIUM INTERVENTIONS
Interventions if NuDESC score greater than or equal to 2:

Score NuDESC every shift, every day and if there is a *change in mentation* that occurs *anytime* during the shift.

Each cell contains 3 descriptors to choose from.

This is an observational screening tool. Please use your best judgment as to what the patient is demonstrating.

Delirium can have fluctuating behaviors, one moment calm, and the other moment agitated. Please score tool again if behaviors change.

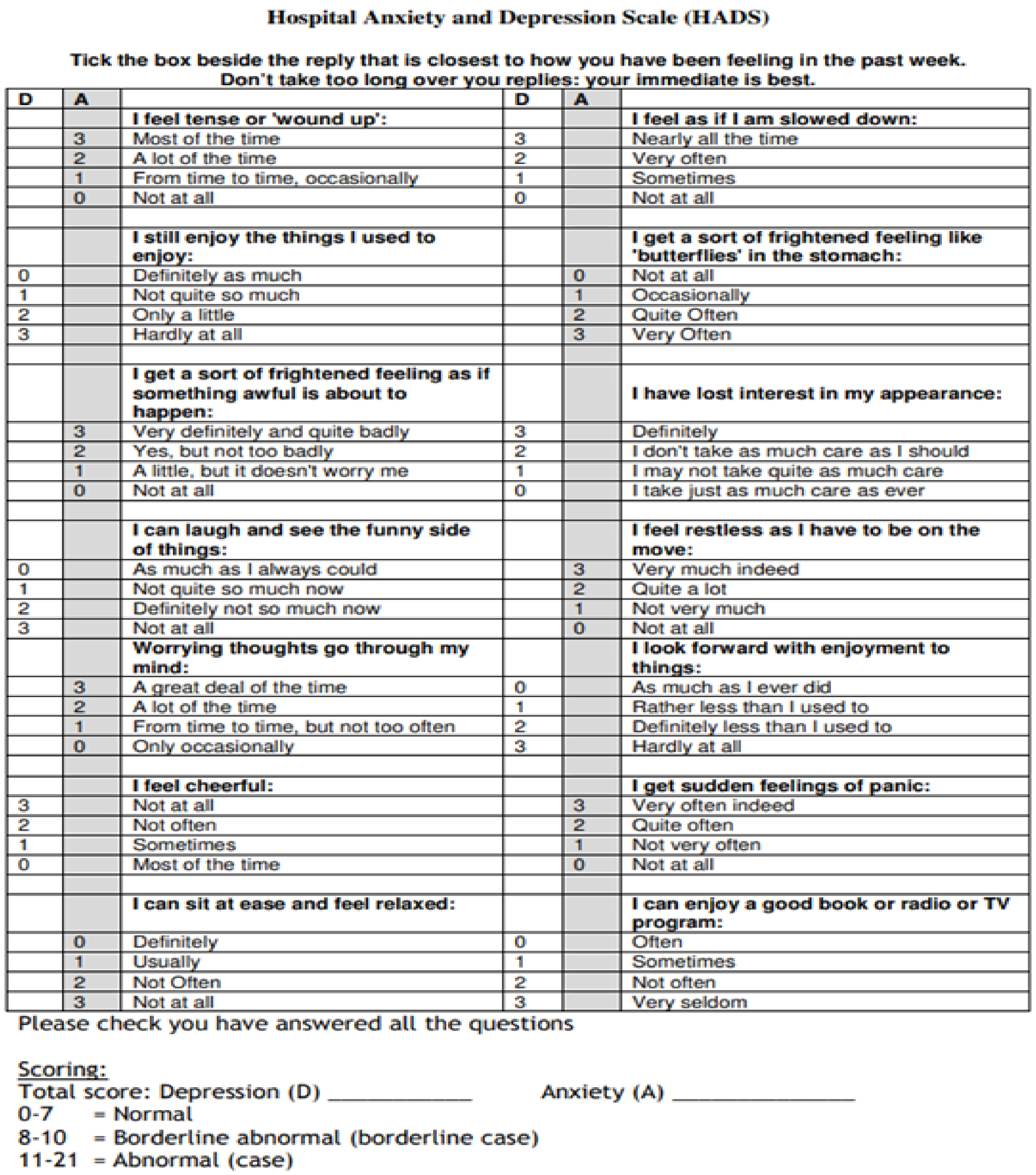
Use Family Caregiver Sheet if patient has cognitive impairment and is cared for by family members to give us insight to their needs.

Perceptual distortions accompanying delirium are usually visual.

Delirium can be hypoactive, hyperactive or mixed. Be aware that hypoactive is the least detected by clinical staff.

Score > or = to 2 indicates patient is *screening* positive for delirium.
Take action!

Hospital Anxiety and Depression Scale (HADS)



Hospital Anxiety and Depression Scale (HADS)

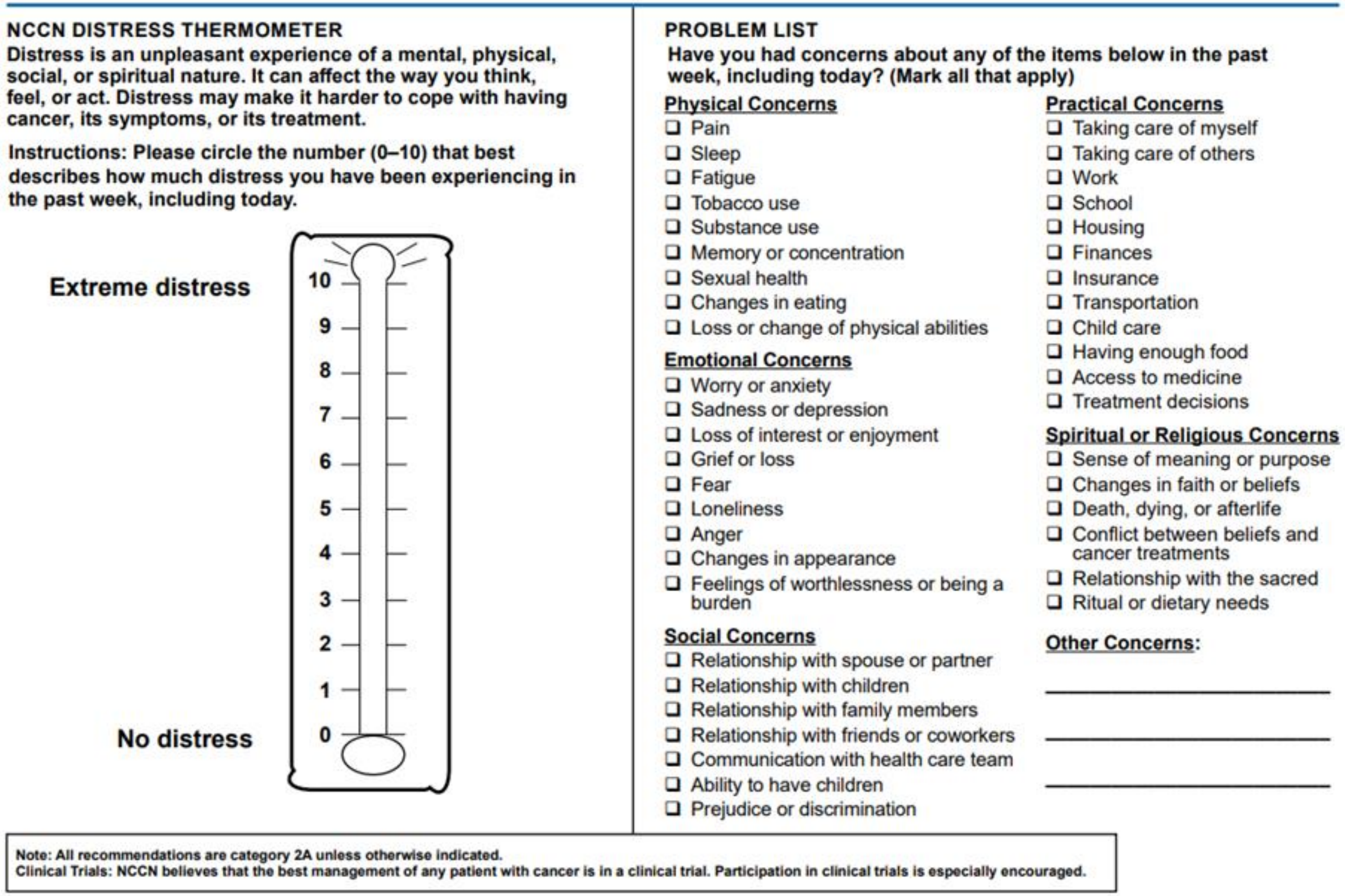
Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:
Total score: Depression (D) ____________ Anxiety (A) ______________
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)

Distress Thermometer



NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress

10
9
8
7
6
5
4
3
2
1
0

No distress

PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical Concerns
- ☐ Pain
- ☐ Sleep
- ☐ Fatigue
- ☐ Tobacco use
- ☐ Substance use
- ☐ Memory or concentration
- ☐ Sexual health
- ☐ Changes in eating
- ☐ Loss or change of physical abilities

Emotional Concerns
- ☐ Worry or anxiety
- ☐ Sadness or depression
- ☐ Loss of interest or enjoyment
- ☐ Grief or loss
- ☐ Fear
- ☐ Loneliness
- ☐ Anger
- ☐ Changes in appearance
- ☐ Feelings of worthlessness or being a burden

Social Concerns
- ☐ Relationship with spouse or partner
- ☐ Relationship with children
- ☐ Relationship with family members
- ☐ Relationship with friends or coworkers
- ☐ Communication with health care team
- ☐ Ability to have children
- ☐ Prejudice or discrimination

Practical Concerns
- ☐ Taking care of myself
- ☐ Taking care of others
- ☐ Work
- ☐ School
- ☐ Housing
- ☐ Finances
- ☐ Insurance
- ☐ Transportation
- ☐ Child care
- ☐ Having enough food
- ☐ Access to medicine
- ☐ Treatment decisions

Spiritual or Religious Concerns
- ☐ Sense of meaning or purpose
- ☐ Changes in faith or beliefs
- ☐ Death, dying, or afterlife
- ☐ Conflict between beliefs and cancer treatments
- ☐ Relationship with the sacred
- ☐ Ritual or dietary needs

Other Concerns:

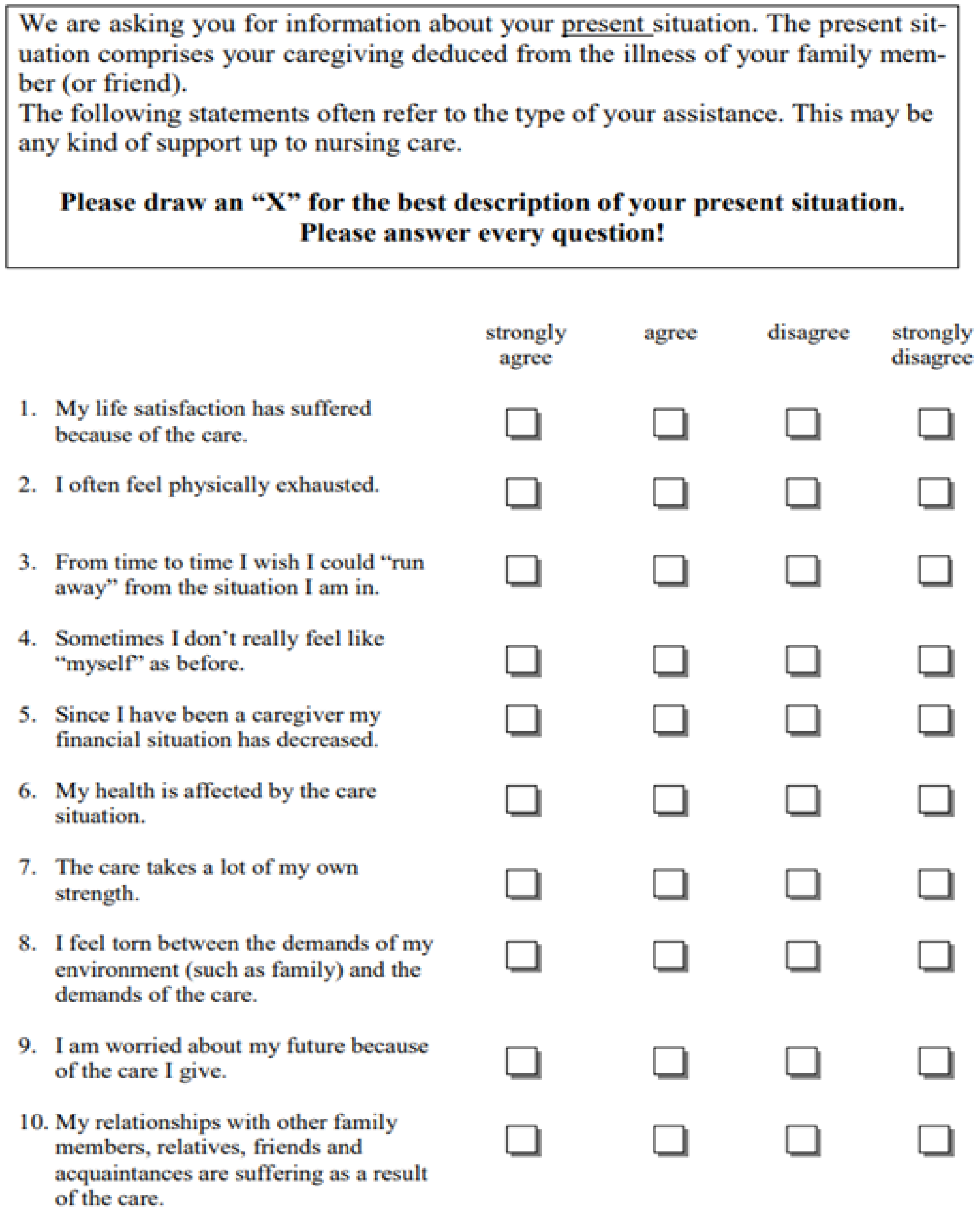
____

____

____

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

Caregiver Burden Scale

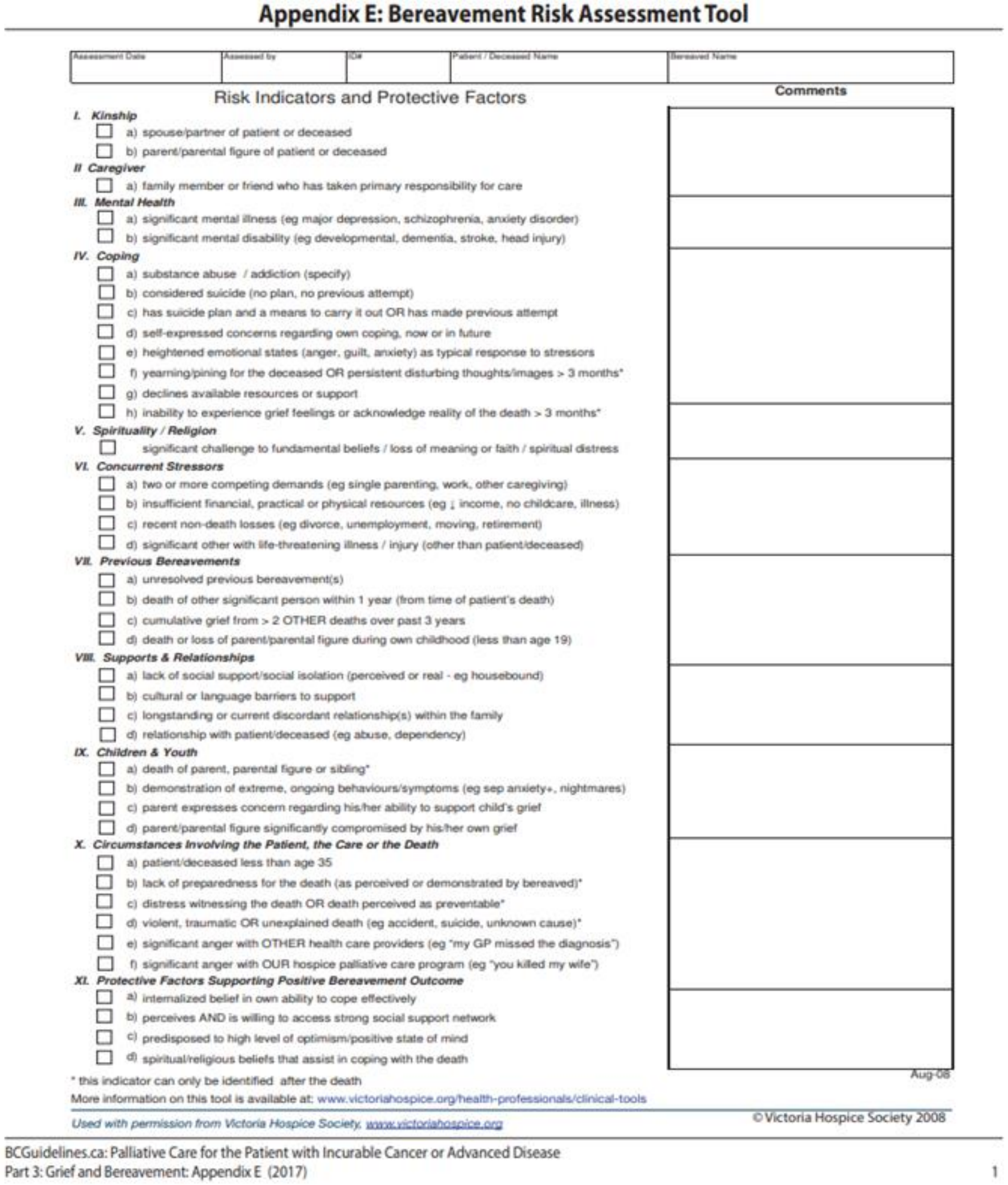


We are asking you for information about your present situation. The present situation comprises your caregiving deduced from the illness of your family member (or friend).
The following statements often refer to the type of your assistance. This may be any kind of support up to nursing care.

Please draw an "X" for the best description of your present situation.
Please answer every question!

	strongly agree	agree	disagree	strongly disagree
1. My life satisfaction has suffered because of the care.	☐	☐	☐	☐
2. I often feel physically exhausted.	☐	☐	☐	☐
3. From time to time I wish I could "run away" from the situation I am in.	☐	☐	☐	☐
4. Sometimes I don't really feel like "myself" as before.	☐	☐	☐	☐
5. Since I have been a caregiver my financial situation has decreased.	☐	☐	☐	☐
6. My health is affected by the care situation.	☐	☐	☐	☐
7. The care takes a lot of my own strength.	☐	☐	☐	☐
8. I feel torn between the demands of my environment (such as family) and the demands of the care.	☐	☐	☐	☐
9. I am worried about my future because of the care I give.	☐	☐	☐	☐
10. My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care.	☐	☐	☐	☐

BRAT – Bereavement Assessment Tool



Appendix E: Bereavement Risk Assessment Tool

Assessment Date	Assessed by	ID#	Patient / Deceased Name	Bereaved Name

Risk Indicators and Protective Factors

Comments

I. Kinship
- ☐ a) spouse/partner of patient or deceased
- ☐ b) parent/parental figure of patient or deceased

II Caregiver
- ☐ a) family member or friend who has taken primary responsibility for care

III. Mental Health
- ☐ a) significant mental illness (eg major depression, schizophrenia, anxiety disorder)
- ☐ b) significant mental disability (eg developmental, dementia, stroke, head injury)

IV. Coping
- ☐ a) substance abuse / addiction (specify)
- ☐ b) considered suicide (no plan, no previous attempt)
- ☐ c) has suicide plan and a means to carry it out OR has made previous attempt
- ☐ d) self-expressed concerns regarding own coping, now or in future
- ☐ e) heightened emotional states (anger, guilt, anxiety) as typical response to stressors
- ☐ f) yearning/pining for the deceased OR persistent disturbing thoughts/images > 3 months*
- ☐ g) declines available resources or support
- ☐ h) inability to experience grief feelings or acknowledge reality of the death > 3 months*

V. Spirituality / Religion
- ☐ significant challenge to fundamental beliefs / loss of meaning or faith / spiritual distress

VI. Concurrent Stressors
- ☐ a) two or more competing demands (eg single parenting, work, other caregiving)
- ☐ b) insufficient financial, practical or physical resources (eg ↓ income, no childcare, illness)
- ☐ c) recent non-death losses (eg divorce, unemployment, moving, retirement)
- ☐ d) significant other with life-threatening illness / injury (other than patient/deceased)

VII. Previous Bereavements
- ☐ a) unresolved previous bereavement(s)
- ☐ b) death of other significant person within 1 year (from time of patient's death)
- ☐ c) cumulative grief from > 2 OTHER deaths over past 3 years
- ☐ d) death or loss of parent/parental figure during own childhood (less than age 19)

VIII. Supports & Relationships
- ☐ a) lack of social support/social isolation (perceived or real - eg housebound)
- ☐ b) cultural or language barriers to support
- ☐ c) longstanding or current discordant relationship(s) within the family
- ☐ d) relationship with patient/deceased (eg abuse, dependency)

IX. Children & Youth
- ☐ a) death of parent, parental figure or sibling*
- ☐ b) demonstration of extreme, ongoing behaviours/symptoms (eg sep anxiety+, nightmares)
- ☐ c) parent expresses concern regarding his/her ability to support child's grief
- ☐ d) parent/parental figure significantly compromised by his/her own grief

X. Circumstances Involving the Patient, the Care or the Death
- ☐ a) patient/deceased less than age 35
- ☐ b) lack of preparedness for the death (as perceived or demonstrated by bereaved)*
- ☐ c) distress witnessing the death OR death perceived as preventable*
- ☐ d) violent, traumatic OR unexplained death (eg accident, suicide, unknown cause)*
- ☐ e) significant anger with OTHER health care providers (eg "my GP missed the diagnosis")
- ☐ f) significant anger with OUR hospice palliative care program (eg "you killed my wife")

XI. Protective Factors Supporting Positive Bereavement Outcome
- ☐ a) internalized belief in own ability to cope effectively
- ☐ b) perceives AND is willing to access strong social support network
- ☐ c) predisposed to high level of optimism/positive state of mind
- ☐ d) spiritual/religious beliefs that assist in coping with the death

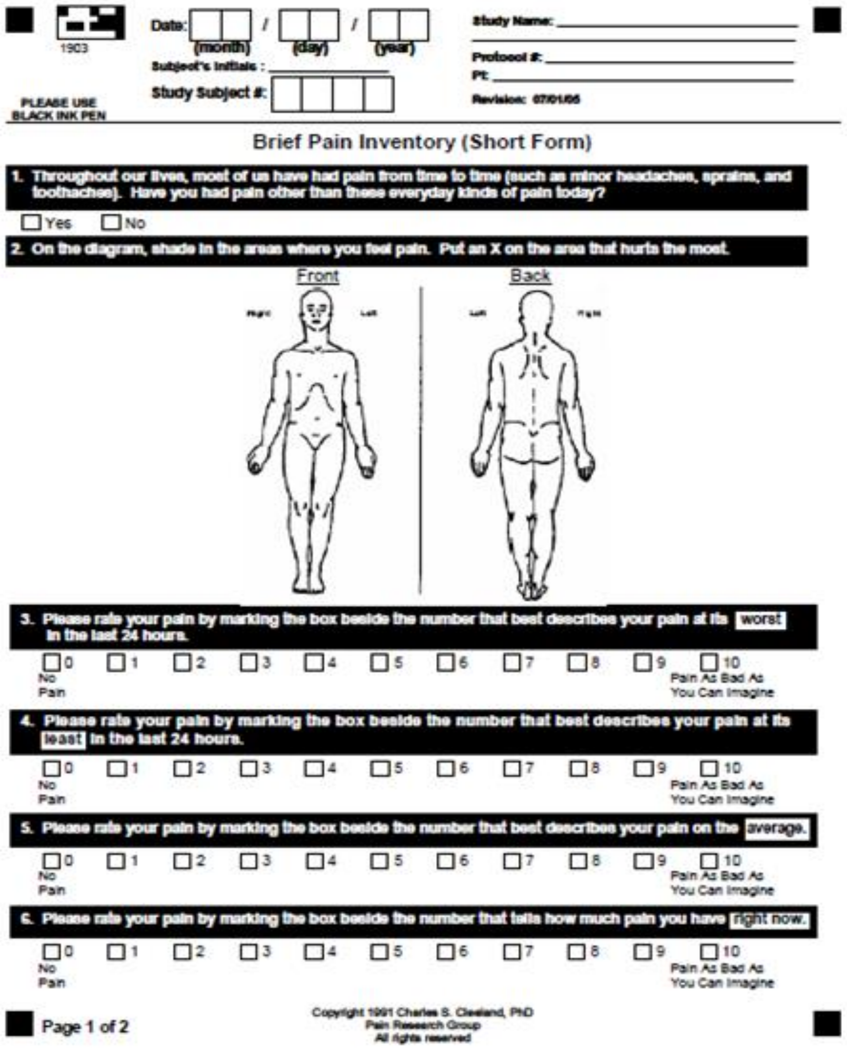
Aug-08

* this indicator can only be identified after the death

More information on this tool is available at: www.victoriahospice.org/health-professionals/clinical-tools

Used with permission from Victoria Hospice Society, www.victoriahospice.org

BPI - Brief Pain Inventory



1903

Date: ☐☐ / ☐☐ / ☐☐
(month) (day) (year)

Subject's Initials : ____

Study Subject #: ☐☐☐☐

PLEASE USE
BLACK INK PEN

Study Name: ____

Protocol #: ____

PI: ____

Revision: 07/01/05

Brief Pain Inventory (Short Form)

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

☐ Yes ☐ No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

3. Please rate your pain by marking the box beside the number that best describes your pain at its **worst** in the last 24 hours.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
No Pain — Pain As Bad As You Can Imagine

4. Please rate your pain by marking the box beside the number that best describes your pain at its **least** in the last 24 hours.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
No Pain — Pain As Bad As You Can Imagine

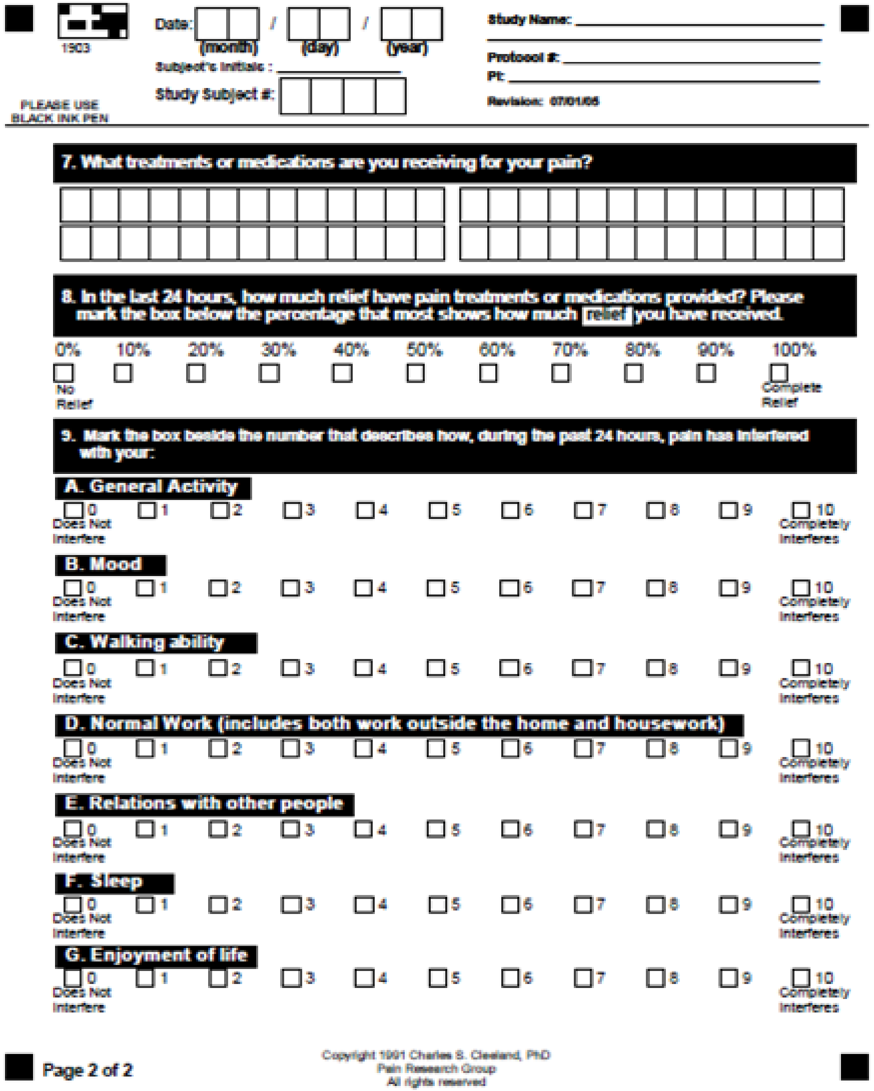
5. Please rate your pain by marking the box beside the number that best describes your pain on the **average.**

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
No Pain — Pain As Bad As You Can Imagine

6. Please rate your pain by marking the box beside the number that tells how much pain you have **right now.**

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
No Pain — Pain As Bad As You Can Imagine

Page 1 of 2



1903

Date: ☐☐ / ☐☐ / ☐☐
(month) (day) (year)

Subject's Initials : ____

Study Subject #: ☐☐☐☐

PLEASE USE
BLACK INK PEN

Study Name: ____

Protocol #: ____

PI: ____

Revision: 07/01/05

7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please mark the box below the percentage that most shows how much **relief** you have received.

0% ☐ 10% ☐ 20% ☐ 30% ☐ 40% ☐ 50% ☐ 60% ☐ 70% ☐ 80% ☐ 90% ☐ 100% ☐
No Relief — Complete Relief

9. Mark the box beside the number that describes how, during the past 24 hours, pain has interfered with your:

A. General Activity

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Does Not Interfere — Completely Interferes

B. Mood

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Does Not Interfere — Completely Interferes

C. Walking ability

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Does Not Interfere — Completely Interferes

D. Normal Work (includes both work outside the home and housework)

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Does Not Interfere — Completely Interferes

E. Relations with other people

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Does Not Interfere — Completely Interferes

F. Sleep

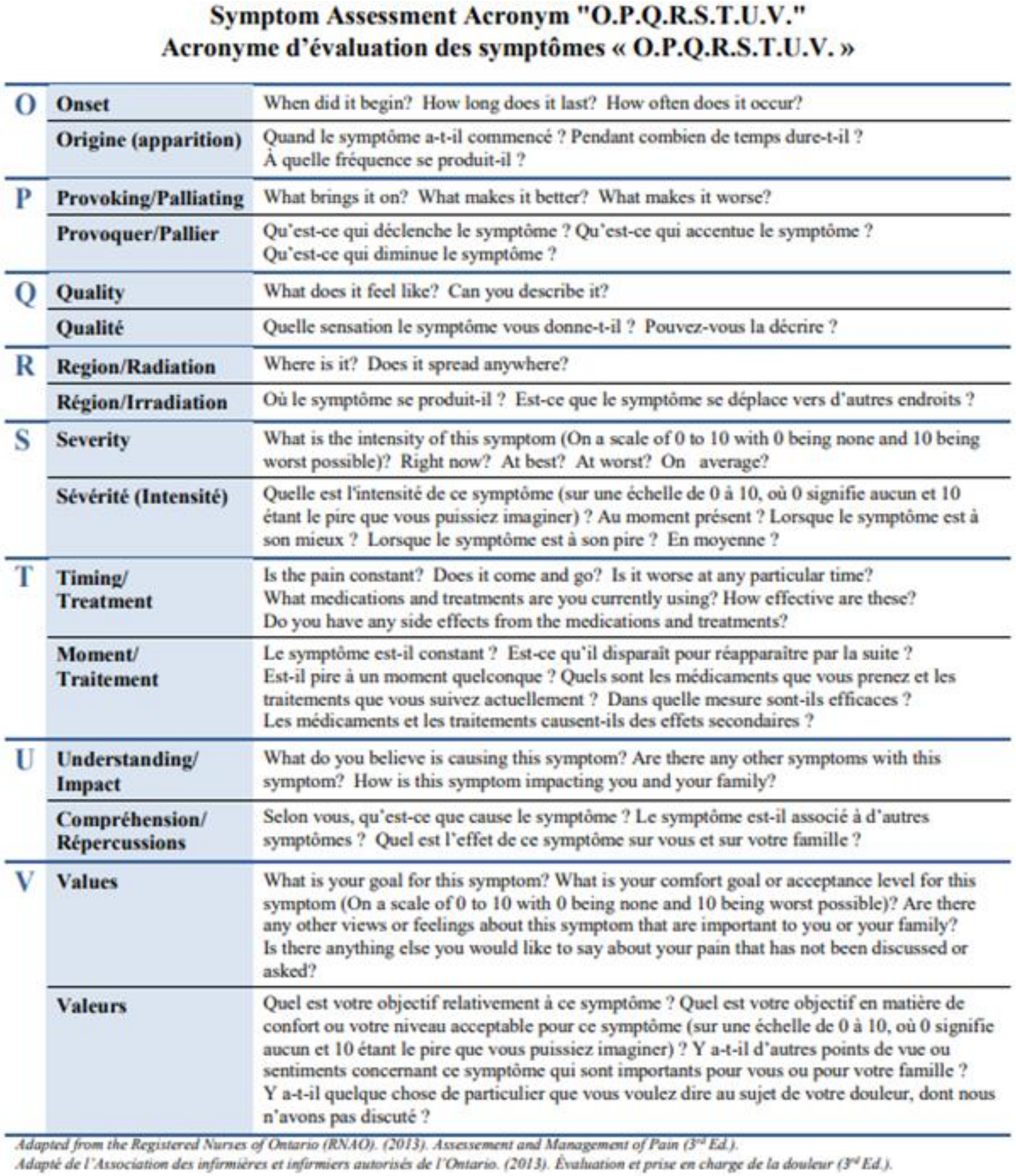
☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Does Not Interfere — Completely Interferes

G. Enjoyment of life

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10
Does Not Interfere — Completely Interferes

Page 2 of 2

OPQRSTUV Pain Acronym



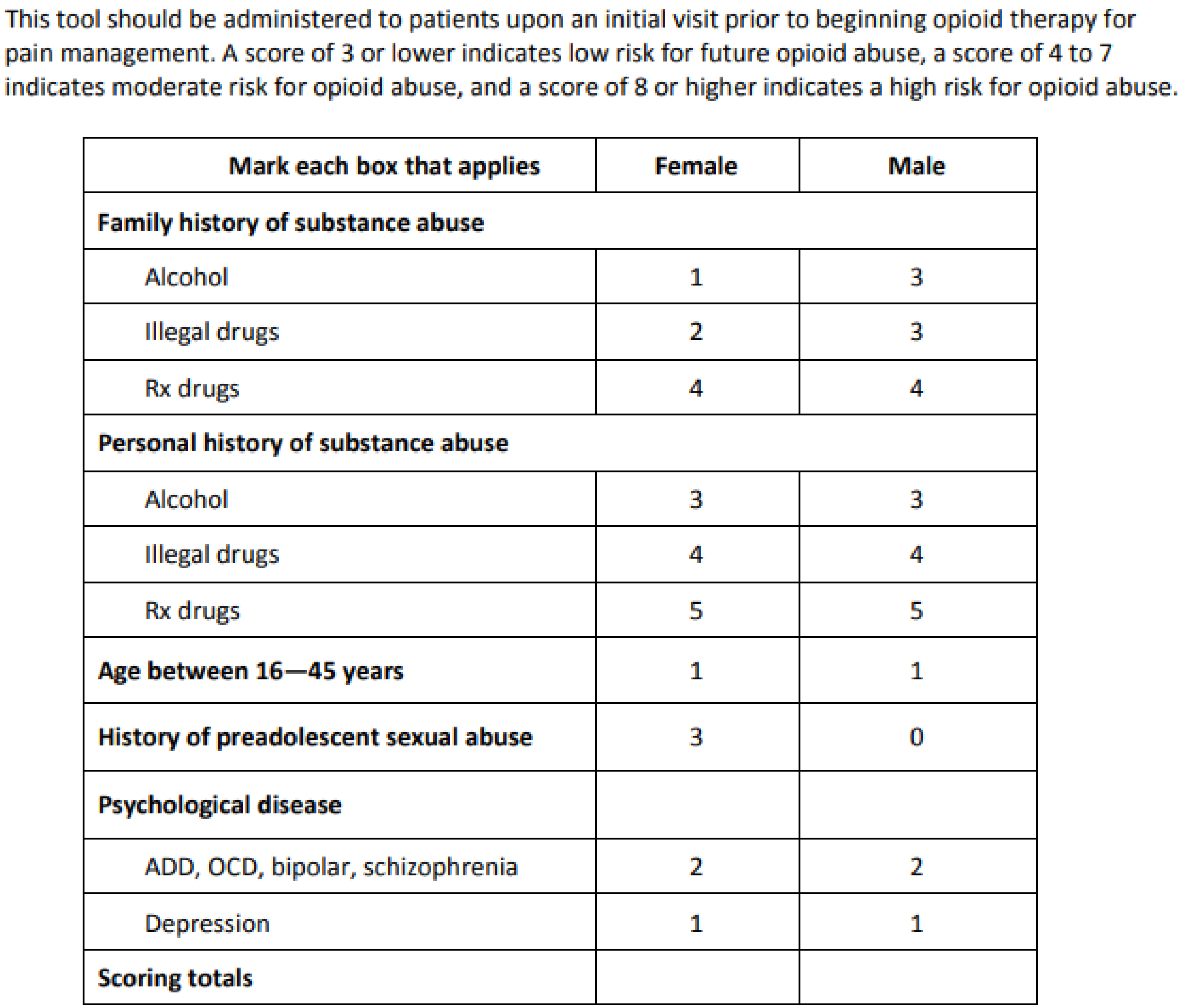
Symptom Assessment Acronym "O.P.Q.R.S.T.U.V."
Acronyme d'évaluation des symptômes « O.P.Q.R.S.T.U.V. »

O	**Onset**	When did it begin? How long does it last? How often does it occur?
	Origine (apparition)	Quand le symptôme a-t-il commencé ? Pendant combien de temps dure-t-il ? À quelle fréquence se produit-il ?
P	**Provoking/Palliating**	What brings it on? What makes it better? What makes it worse?
	Provoquer/Pallier	Qu'est-ce qui déclenche le symptôme ? Qu'est-ce qui accentue le symptôme ? Qu'est-ce qui diminue le symptôme ?
Q	**Quality**	What does it feel like? Can you describe it?
	Qualité	Quelle sensation le symptôme vous donne-t-il ? Pouvez-vous la décrire ?
R	**Region/Radiation**	Where is it? Does it spread anywhere?
	Région/Irradiation	Où le symptôme se produit-il ? Est-ce que le symptôme se déplace vers d'autres endroits ?
S	**Severity**	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average?
	Sévérité (Intensité)	Quelle est l'intensité de ce symptôme (sur une échelle de 0 à 10, où 0 signifie aucun et 10 étant le pire que vous puissiez imaginer) ? Au moment présent ? Lorsque le symptôme est à son mieux ? Lorsque le symptôme est à son pire ? En moyenne ?
T	**Timing/ Treatment**	Is the pain constant? Does it come and go? Is it worse at any particular time? What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments?
	Moment/ Traitement	Le symptôme est-il constant ? Est-ce qu'il disparaît pour réapparaître par la suite ? Est-il pire à un moment quelconque ? Quels sont les médicaments que vous prenez et les traitements que vous suivez actuellement ? Dans quelle mesure sont-ils efficaces ? Les médicaments et les traitements causent-ils des effets secondaires ?
U	**Understanding/ Impact**	What do you believe is causing this symptom? Are there any other symptoms with this symptom? How is this symptom impacting you and your family?
	Compréhension/ Répercussions	Selon vous, qu'est-ce que cause le symptôme ? Le symptôme est-il associé à d'autres symptômes ? Quel est l'effet de ce symptôme sur vous et sur votre famille ?
V	**Values**	What is your goal for this symptom? What is your comfort goal or acceptance level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family? Is there anything else you would like to say about your pain that has not been discussed or asked?
	Valeurs	Quel est votre objectif relativement à ce symptôme ? Quel est votre objectif en matière de confort ou votre niveau acceptable pour ce symptôme (sur une échelle de 0 à 10, où 0 signifie aucun et 10 étant le pire que vous puissiez imaginer) ? Y a-t-il d'autres points de vue ou sentiments concernant ce symptôme qui sont importants pour vous ou pour votre famille ? Y a-t-il quelque chose de particulier que vous voulez dire au sujet de votre douleur, dont nous n'avons pas discuté ?

Adapted from the Registered Nurses of Ontario (RNAO). (2013). Assessement and Management of Pain (3rd Ed.).
Adapté de l'Association des infirmières et infirmiers autorisés de l'Ontario. (2013). Évaluation et prise en charge de la douleur (3rd Ed.).

Wong Baker Face Scale
(for children and non-verbal patients)

Opioid Risk Assessment



This tool should be administered to patients upon an initial visit prior to beginning opioid therapy for pain management. A score of 3 or lower indicates low risk for future opioid abuse, a score of 4 to 7 indicates moderate risk for opioid abuse, and a score of 8 or higher indicates a high risk for opioid abuse.

Mark each box that applies	**Female**	**Male**
Family history of substance abuse		
Alcohol	1	3
Illegal drugs	2	3
Rx drugs	4	4
Personal history of substance abuse		
Alcohol	3	3
Illegal drugs	4	4
Rx drugs	5	5
Age between 16—45 years	1	1
History of preadolescent sexual abuse	3	0
Psychological disease		
ADD, OCD, bipolar, schizophrenia	2	2
Depression	1	1
Scoring totals		

Key points

- Early implementation of a palliative care approach will improve quality of life and overall patient and family experience
- The minimum recommendation is to implement the Surprise Question, ESAS, and PPS
- Use of SAM Tools can improve communication and collaboration between healthcare providers/organizations

Questions ?

Bibliography

Canadian Hospice Palliative Care Association. The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care [Internet]. 2015. Available from: https://www.chpca.ca/wp-content/uploads/2023/12/TWF-framework-doc-Eng-2015-final-April1.pdf

Temel Jennifer S., Greer Joseph A., Muzikansky Alona, Gallagher Emily R., Admane Sonal, Jackson Vicki A., et al. Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. N Engl J Med. 2010;363(8):733–42.

Thomas. K et al. Prognostic Indicator Guidance. Gold Stand Framework Cent End Life Care. 2011 Oct;4th Edition.

Alberta Health Services. Edmonton Symptom Assessment System Revised (ESAS-r) [Internet]. 2015. Available from: https://www.albertahealthservices.ca/frm-07903.pdf

Pallium Canada. The Pallium Palliative Pocketbook:a peer-reviewed, referenced resource. 2nd ed. Ottawa, Canada; 2018.

Interior Health. Edmonton Symptom Assessment System Revised (ESAS-r) Guidelines [Internet]. 2016. Available from: https://www.interiorhealth.ca/sites/default/files/PDFS/esasr-guidelines.pdf

Downing G. Q&A Manual, Instructions & Definitions for Use of Palliative Performance Scale (PPSv2). Vic Hosp Soc [Internet]. 2020 Jul 24; Available from: www.victoriahospice.org

Vertesi A, Lever JA, Molloy DW, Sanderson B, Tuttle I, Pokoradi L, et al. Standardized Mini-Mental State Examination. Use and interpretation. Can Fam Physician Med Fam Can. 2001 Oct;47:2018–23.

Mendez M. Chapter 16 - General Mental Status Scales, Rating Instruments, and Behavior Inventories. In: Mendez M, editor. The Mental Status Examination Handbook [Internet]. Philadelphia: Elsevier; 2022. p. 181–99. Available from: https://www.sciencedirect.com/science/article/pii/B9780323694896000164

Island Health. Confusion Assessment Method (CAM) [Internet]. cgatoolkit.ca. 2014. Available from: https://cgatoolkit.ca/Uploads/ContentDocuments/camshortform.pdf

Bibliography

Systematic, and Continuous Delirium Assessment in Hospitalized Patients: The Nursing Delirium Screening Scale. J Pain Symptom Manage. 2005 Apr 1;29(4):368–75.

Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatry Scand. 1983 Jun;67(6):361–70.

National Comprehensive Cancer Network. Distress Thermometer Tool Translations [Internet]. NCCN. Available from: https://www.nccn.org/global/what-we-do/distress-thermometer-tool-translations

Ownby KK. Use of the Distress Thermometer in Clinical Practice. J Adv Practice Oncology. 2019 Mar;10(2):175–9.

Virtual Hospice. New: Short version of the Burden Scale for Family Caregivers in 20 European languages [Internet]. Available from: https://www.virtualhospice.ca/Assets/BSFC-s_english_s%20(Caregiver%20Burden%20Scale-Short%20Version)_20170306133440.pdf

Mayo Clinic. Complicated grief - Symptoms and causes [Internet]. Mayo Clinic. 2022. Available from: https://www.mayoclinic.org/diseases-conditions/complicated-grief/symptoms-causes/syc-20360374

Brief Pain Inventory (BPI) [Internet]. MD Anderson Cancer Center. [cited 2024 Mar 4]. Available from: https://www.mdanderson.org/research/departments-labs-institutes/departments-divisions/symptom-research/symptom-assessment-tools/brief-pain-inventory.html

Wong-Baker FACES Foundation. Wong-Baker FACES Foundation [Internet]. Wong-Baker FACES Foundation. [cited 2024 Mar 4]. Available from: https://wongbakerfaces.org/

Bibliography

Cascella M, Laudani A, Scarpati G, Piazza O. Ethical issues in pain and palliation. Curr Opin Anesthesiol. :10.1097/ACO.0000000000001345.

Edwards T, Arthur J, Joy M, Lu Z, Dibaj S, Bruera E, et al. Assessing risk for nonmedical opioid use among patients with cancer: Stability of the CAGE-AID questionnaire across clinical care settings. Palliat Support Care. 2023 Jul 13;1–5.

Brott NR, Peterson E, Cascella M. Opioid, Risk Tool. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 [cited 2024 Jul 22]. Available from: http://www.ncbi.nlm.nih.gov/books/NBK553147

Pallium Canada. (2021, October 27). LEAP core. https://www.pallium.ca/course/leap-core/