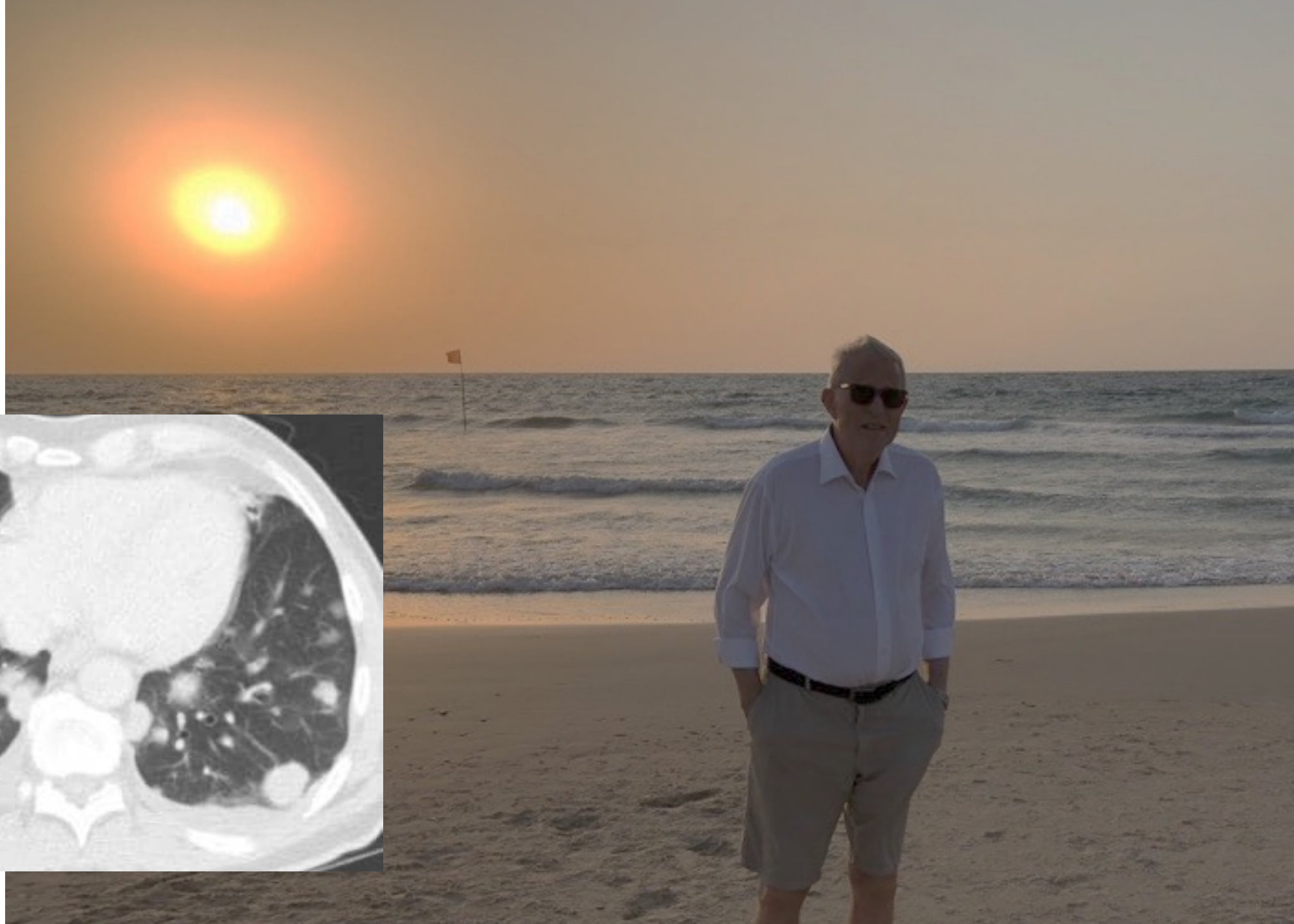
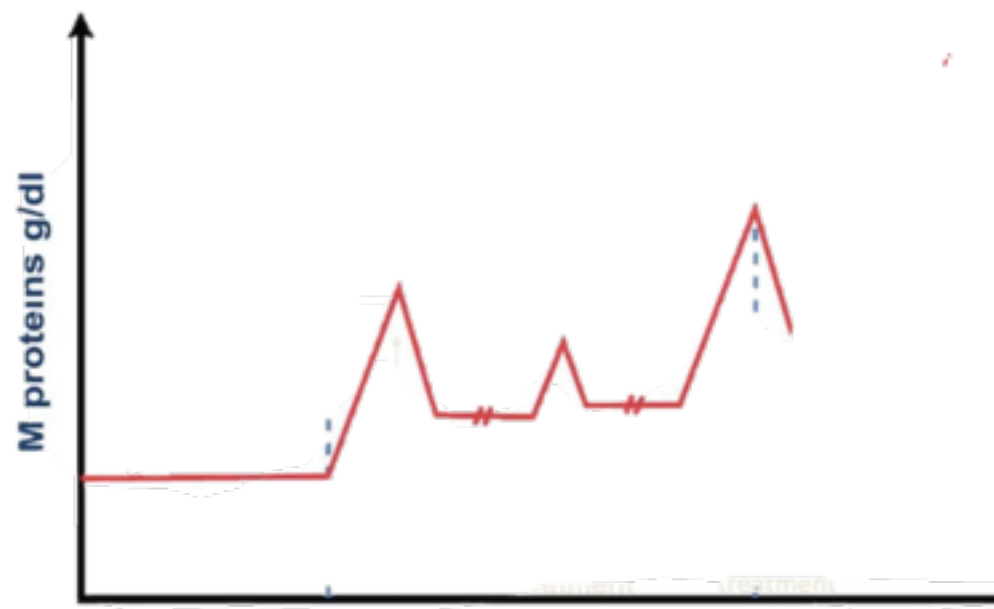


# Symptom assessment

Eva Gravdahl

NSCPM 2021





# Tumor-directed vs. host-directed

*«Systematic assessment and use of patient-reported outcomes and active patient involvement in the decisions about cancer care*

*result in better symptom control, improved physical and mental health, and better use of health-care resources»*

Lancet Oncology Commissi

## Integration of oncology and palliative care: a Lancet Oncology Commission



Stein Kaasa\*, Jon H Loge\*, Matti Aapro, Tit Albrecht, Rebecca Anderson, Eduardo Bruera, Cinzia Brunelli, Augusto Caraceni, Andrés Cervantes, David C Currow, Luc Deliens, Marie Fallon, Xavier Gómez-Batiste, Kjersti S Grotmol, Breffni Hannon, Dagry F Haugen, Irene J Higginson, Marianne J Hjerstad, David Hui, Karin Jordan, Geana P Kurita, Philip J Larkin, Guido Miccinesi, Friedemann Nauck, Rade Pribakovic, Gary Rodin, Per Sjogren, Patrick Stone, Camilla Zimmermann, Tonje Lundebj

Full integration of oncology and palliative care relies on the specific knowledge and skills of two modes of care: the tumour-directed approach, the main focus of which is on treating the disease; and the host-directed approach, which focuses on the patient with the disease. This Commission addresses how to combine these two paradigms to achieve the best outcome of patient care. Randomised clinical trials on integration of oncology and palliative care point to health gains: improved survival and symptom control, less anxiety and depression, reduced use of futile chemotherapy at the end of life, improved family satisfaction and quality of life, and improved use of health-care resources. Early delivery of patient-directed care by specialist palliative care teams alongside tumour-directed treatment promotes patient-centred care. Systematic assessment and use of patient-reported outcomes and active patient involvement in the decisions about cancer care result in better symptom control, improved physical and mental health, and better use of health-care resources. The absence of international agreements on the content and standards of the organisation, education, and research of palliative care in oncology are major barriers to successful integration. Other barriers

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See Comment p e570, and e572

\*Contributed eq

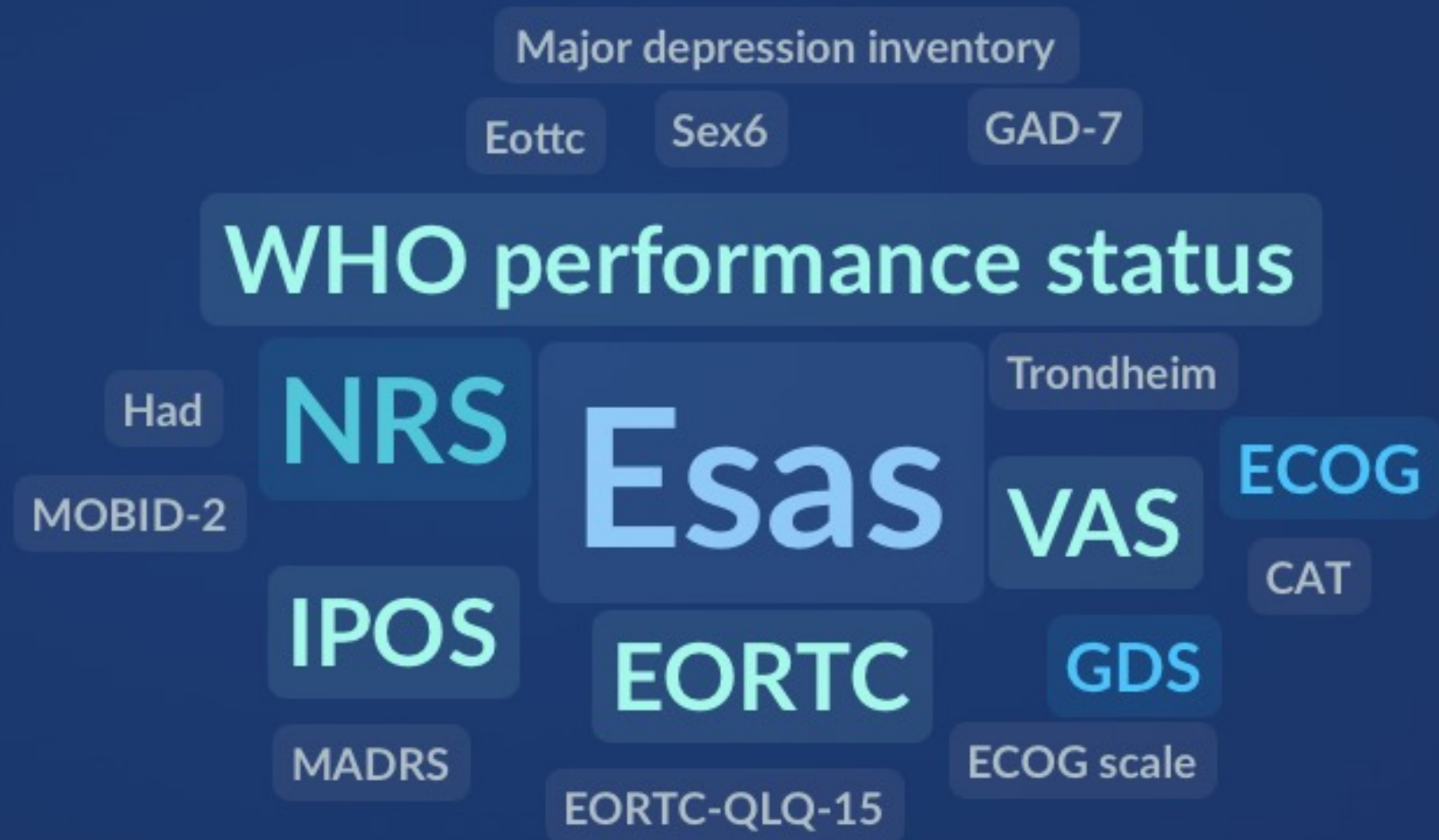
European Pallia  
Research Centre  
of Oncology, Os  
Municipal and In

Bruera –  
Key to  
improving  
palliative  
care:





# Which symptom assessment tools do you use?



# Symptom assessment tools – what do you use and why?

Indicators Tool (Highet et al., 2014; Afshar et al., 2018; De Bock et al., 2018)	(functional decline, weight decline; hospital admissions) • Requests for palliative care • Living in nursing home • Persistent symptoms • Disease-specific indicators		assessment) • Time taken: 4–5 minutes	COPD, heart vascular, • Kidney, liver disease • Dementia/fr Neurological
<b>NECPAL-CCOMS-ICO</b> Palliative Needs World Health Organization Collaborating Centre (English translation) (Gomez-Batiste et al., 2013, 2017)	<b>17 items including:</b> • Surprise question • Requests for palliative care • General indicators (functional decline, weight decline; geriatric syndromes, psychological adjustment, comorbidities, resources/admissions) • Disease-specific indicators	• Each item response yes or no	• Provider (to identify who requires a palliative care assessment)	• Primary care hospital • Advanced disease
<b>GSF; PIG</b> Gold Standard Framework; Prognostic Indicator Guide	<b>Items include:</b> • The surprise question; general indicators of decline; specific clinical indicators related to certain conditions	• Response options include yes, no, or don't know	• Providers (to determine palliative care needs)	• Primary care hospital, acute settings • Heart disease, renal failure, COPD
<b>RADPAC</b> RADbound indicators for	<b>Items include:</b> • General indicators (Functional decline, weight	• Each item response yes or no	• Provider (to identify who requires a	• Primary care • Cancer, COPD, heart

Table 20.1.1 Summary and properties of the needs assessment tools

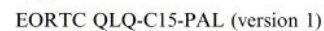




# The ideal assessment tool:

- Capture **meaningful** data
- Makes sense to those using them
- Improves day to day clinical care
- Enables better informed **management decisions**:
  - locally, sectorwide, nationally
- Serves more than one purpose:
  - capture complexity,
  - improve individual patient care
  - **quality indicators** for services, and enable national outcomes /funding/dataset
- Must be responsive to change over time
- Is psychometrically robust ... (**reliability**)
  - ...yet brief and not too burdensome
- Works in context of declining health
- Works when the patient is a child, cognitively impaired, different language/cultural background...
- Works with **different diagnoses**





Please fill in your initials:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year):

During the past week:	Not at All	A Little	Quite a Bit	Very Much
4. Were you short of breath?	1	2	3	4
5. Have you had pain?	1	2	3	4
6. Have you had trouble sleeping?	1	2	3	4
7. Have you felt weak?	1	2	3	4
8. Have you lacked appetite?	1	2	3	4
9. Have you felt nauseated?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
10. Have you been constipated?	1	2	3	4
11. Were you tired?	1	2	3	4
12. Did pain interfere with your daily activities?	1	2	3	4
13. Did you feel tense?	1	2	3	4
14. Did you feel depressed?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

15. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

For staff use  
Patient number:

--	--	--	--	--	--

## IPOS Patient Version



www.pos-pal.org

Name: .....

Date (dd/mm/yyyy): 

			/				/				
--	--	--	---	--	--	--	---	--	--	--	--

Please write clearly, one letter or digit per box. Your answers will help us to keep improving your care and the care of others.

Thank you.

### Q1. What have been your main problems or concerns over the past 3 days?

1. ....

2. ....

3. ....

### Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past 3 days.

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Nausea (feeling like you are going to be sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Vomiting (being sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor appetite	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Constipation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Sore or dry mouth	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Drowsiness	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor mobility	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Please list any other symptoms not mentioned above, and tick one box to show how they have affected you over the past 3 days.

1. .... 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐

2. .... 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐

3. .... 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐

### Over the past 3 days:

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q5. Have you been feeling depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q8. Have you had as much information as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

	On my own	With help from a friend or relative	With help from a member of staff
Q10 How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse*

# **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 <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	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 <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____
Other Problem <i>(For example constipation)</i> _____												

Patient Name \_\_\_\_\_

Date *(yyyy-MM-dd)* \_\_\_\_\_

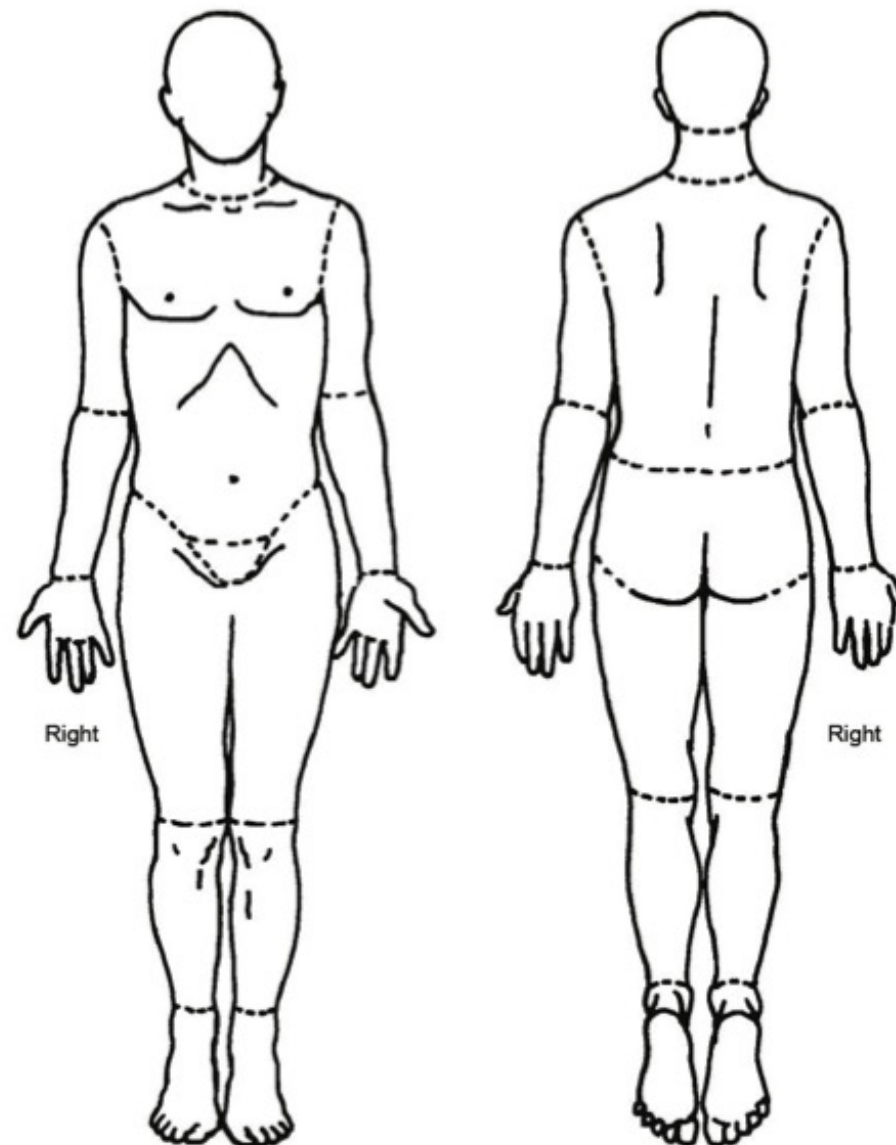
Time *(hh:mm)* \_\_\_\_\_

Completed by *(Check one)*

- ☐ Patient
- ☐ Family Caregiver
- ☐ Health Care Professional Caregiver
- ☐ Caregiver-assisted

**Body Diagram on Reverse**

Please mark on these pictures where it is that you hurt:





# Supportive and Palliative Care Indicators Tool (SPICT™)

**The SPICT™ is used to help identify people whose health is deteriorating.  
Assess them for unmet supportive and palliative care needs. Plan care.**

## Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility.  
(eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment;  
or wishes to focus on quality of life.

## Look for clinical indicators of one or multiple life-limiting conditions.

### Cancer

Functional ability deteriorating  
due to progressive cancer.

Too frail for cancer treatment or  
treatment is for symptom control.

### Dementia/ frailty

Unable to dress, walk or eat  
without help.

Eating and drinking less;  
difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by  
speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or  
infections; aspiration pneumonia.

### Neurological disease

Progressive deterioration in  
physical and/or cognitive  
function despite optimal therapy.

Speech problems with increasing  
difficulty communicating  
and/or progressive difficulty  
with swallowing.

Recurrent aspiration pneumonia;  
breathless or respiratory failure.

Persistent paralysis after  
stroke with significant loss of  
function and ongoing disability.

### Heart/ vascular disease

Heart failure or extensive,  
untreatable coronary artery  
disease; with breathlessness  
or chest pain at rest or on  
minimal effort.

Severe, inoperable peripheral  
vascular disease.

### Respiratory disease

Severe, chronic lung disease;  
with breathlessness at rest  
or on minimal effort between  
exacerbations.

Persistent hypoxia needing  
long term oxygen therapy.

Has needed ventilation for  
respiratory failure or  
ventilation is contraindicated.

### Other conditions

Deteriorating and at risk of dying with other conditions or complications  
that are not reversible; any treatment available will have a poor outcome.

### Kidney disease

Stage 4 or 5 chronic kidney  
disease (eGFR < 30ml/min)  
with deteriorating health.

Kidney failure complicating  
other life limiting conditions  
or treatments.

Stopping or not starting dialysis.

### Liver disease

Cirrhosis with one or more  
complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

## Review current care and care planning.

- Review current treatment and medication to ensure the  
person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or  
problems are complex and difficult to manage.
- Agree a current and future care plan with the person and  
their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.



## Your support needs

We would like to know what help you need to enable you to care for your relative or friend and what support you need for yourself. For each statement, please tick the box that best represents your needs at the moment.

[illegible]