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PALLIATIVE CARE OUTCOMES COLLABORATION IRELAND

Staff handbook

DEFINITIONS & SCORING GUIDE

Refer to PCOC Clinical Manual for the complete definitions

Carer Availability

- Definition of Carer: paid and/or unpaid person who provides care, support and assistance. May include family, friends, a neighbour, or a paid nursing/carer service. A carer can be different from next of kin/person responsible.
- Available means able to support the patient if required.

Delirium: Clinician-assessed presence of delirium in the last 24 hours

- Definition: an acute, fluctuating disturbance in attention, awareness, and cognition that often reflects an underlying medical, psychological, or pharmacological cause.
- Characteristics: disturbances in consciousness, attention, cognition and perception that develop over a short period of time (usually hours to a few days). Patients with delirium may be agitated and restless (hyperactive delirium), or quiet and withdrawn (hypoactive delirium). Patients may also move between these two subtypes (mixed delirium). The onset of delirium is quick (over hours to a few days) in comparison to dementia.

Edmonton Symptom Assessment System (ESAS-PCOC): Patient-reported severity of symptoms and problems in the last 24 hours

- Best-practice: patient rates their own symptoms, which is key to delivering person-centred and value-based care.
- How to use this tool: Elicit ratings from patient through conversations to understand the symptoms from the patient's perspective, then conduct a more in-depth clinical assessment as needed. Provide intervention/escalation if necessary.
- If a patient is unable to provide a score, e.g. due to confusion, unconsciousness, communication difficulties, then a proxy can be used. When using a proxy, consider a family/carer first. If family/carer unavailable, then a clinician may score.
- Patient information leaflet 'Let's Talk About Your Care' is available to support clinician and patient discussion.

Resource Utilisation Groups - Activities of Daily Living: Clinician assessment of functional dependence over a 24 hour period

Scoring guide:

For Bed Mobility, Toileting & Transfers

1. Independent or supervision only
3. Limited physical assistance
4. Other than two-persons physical assist (1 person & aid)
5. Two or more persons physical assist

For Eating

1. Independent or supervision only
2. Limited assistance
3. Extensive assistance / total dependence / tube fed

Australia-modified Karnofsky Performance Status: Clinician assessment of performance relating to work, activity and self-care over a 24 hour period

Scoring guide:

100. Normal; no complaints; no evidence of disease
90. Able to carry on normal activity; minor signs or symptoms of disease
80. Normal activity with effort; some signs or symptoms of disease
70. Cares for self; unable to carry on normal activity or to do active work
60. Able to care for most needs; but requires occasional assistance
50. Considerable assistance and frequent medical care required
40. In bed more than 50% of the time
30. Almost completely bedfast
20. Totally bedfast and requiring extensive nursing care by professionals and/or family
10. Comatose or barely rousable

Palliative Care Problem Severity Score: Clinician assessment of problems in the last 24 hours

Global assessment of four palliative care domains to summarise palliative care needs and plan care.

- Pain: overall severity of pain problems for the patient.
- Other Symptoms: overall severity of problems relating to one or more symptoms other than pain.
- Psychological/Spiritual: severity of one or more problems relating to the patient's psychological or spiritual wellbeing.
- Family/Carer: severity of one or more family/carer problems associated with a patient's condition or palliative care needs. Written, verbal or observational information can be used to assess needs if family/carer are not present.

Palliative Care Phase Type: A classification of clinically meaningful periods in an individual's care trajectory

The palliative care phase is determined by a holistic clinical assessment which considers all the above assessments.

Stable (S)	Unstable (U)	Deteriorating (D)	Terminal (T)
Adequate symptom and problem control. No change in care plan required.	Urgent change in care plan or emergency treatment required to address severe needs.	Non-urgent change in care plan required to address increasing needs.	Death likely in a matter of days. Adjust care plan to address end of life needs.

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Phase Definitions

The palliative care phase identifies a clinically meaningful period in a patient's condition. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers.	
START	**END**
Stable	
Patient problems and symptoms are adequately controlled by established plan of care and • Further interventions to maintain symptom control and quality of life have been planned and • Family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.
Unstable	
An urgent change in the plan of care or emergency treatment is required because: • Patient experiences a new problem that was not anticipated in the existing plan of care, and/or • Patient experiences a rapid increase in the severity of a current problem; and/or • Family/ carers circumstances change suddenly impacting on patient care.	• The new plan of care is in place, it has been reviewed and no further urgent changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating phase) and/or • Death is likely within days (i.e. patient is now terminal phase).
Deteriorating	
The care plan is addressing anticipated needs but requires periodic review because • Patients' overall functional status is declining and/or • Patient experiences a gradual worsening of existing problem and/or • Patient experiences a new but anticipated problem and/or • Family/carers experience gradual worsening of issues that impacts on the patient care.	• Patient condition plateaus (i.e. patient is now stable phase) or • An urgent change in the plan of care or emergency treatment and/or • Family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable phase) or • Death is likely within days (i.e. patient is now terminal phase)
Terminal	
Death is likely within days.	• Patient dies or • Patient's condition changes and death is no longer likely within days (i.e. patient is now stable, deteriorating or unstable phase).
Bereavement - post death support	
• The patient has died. • Bereavement support provided to family/carers is documented in the deceased patient's clinical record.	• Case closure Note: If counselling is provided to a family member or carer, they become a client in their own right.

M. Masso, S. Frederic. Allingham, M. Banfield, C. Elizabeth. Johnson, T. Pidgeon, P. Yates & K. Eagar, "Palliative care phase: inter-rater reliability and acceptability in a national study", Palliative Medicine 29 1 (2014) 22-30.

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Palliative Care Phase: Clinical Response

The Palliative Care Phase is determined by a holistic assessment of the needs of the patient and their family/carers, and this is often informed by other assessment tools in the suite.

The table below lists the potential actions following phase assessment.

Palliative Care Phase	Actions if this is a new Phase	Actions if Phase is the same as previous assessment
Stable	• Continue as per plan of care.	• Continue as per plan of care. • Monitor and review to ensure plan of care is effective and anticipates future care needs of patient and family/carer. • Commence discharge planning if appropriate. Ensure the following care setting is able to support patient/family/carer needs as per existing plan of care.
Unstable	• Urgent intervention and escalation required. • Change plan of care. • Urgent medical and/or allied health services review. • Review within 24 hours.	• Continue urgent action, adjust plan of care, refer, and intervene. • Monitor assessment scores for patient/family/carer change in condition; improvement in scores suggests plan is working. • When no further urgent changes to the plan of care are required, change Phase.
Deteriorating	• Change in plan of care required to address increasing needs (not urgent). • Referral to medical or allied health likely. • Family/carer support may increase.	• Review and change plan of care. • When no further changes to the plan of care are required, change Phase.
Terminal	• Commence end of life care (adjust plan of care if required). • Discuss change in condition with family and those important to the patient.	• Continue end of life care as per plan of care. • Continue to assess patient and family/care using assessment tools, responding as appropriate. • Communicate changes to family and others important to the patient. • If patient not likely to die within days, reassess Phase. • Complete a Sepration Assessment when patient dies.
Bereavement or Post Death Support*	• Provide bereavement support to family and those important to the patient.	• If family require ongoing support, refer to appropriate service (family member becomes a client in their own right).

*Bereavement/post death support phase excluded from PCOC outcome measures.

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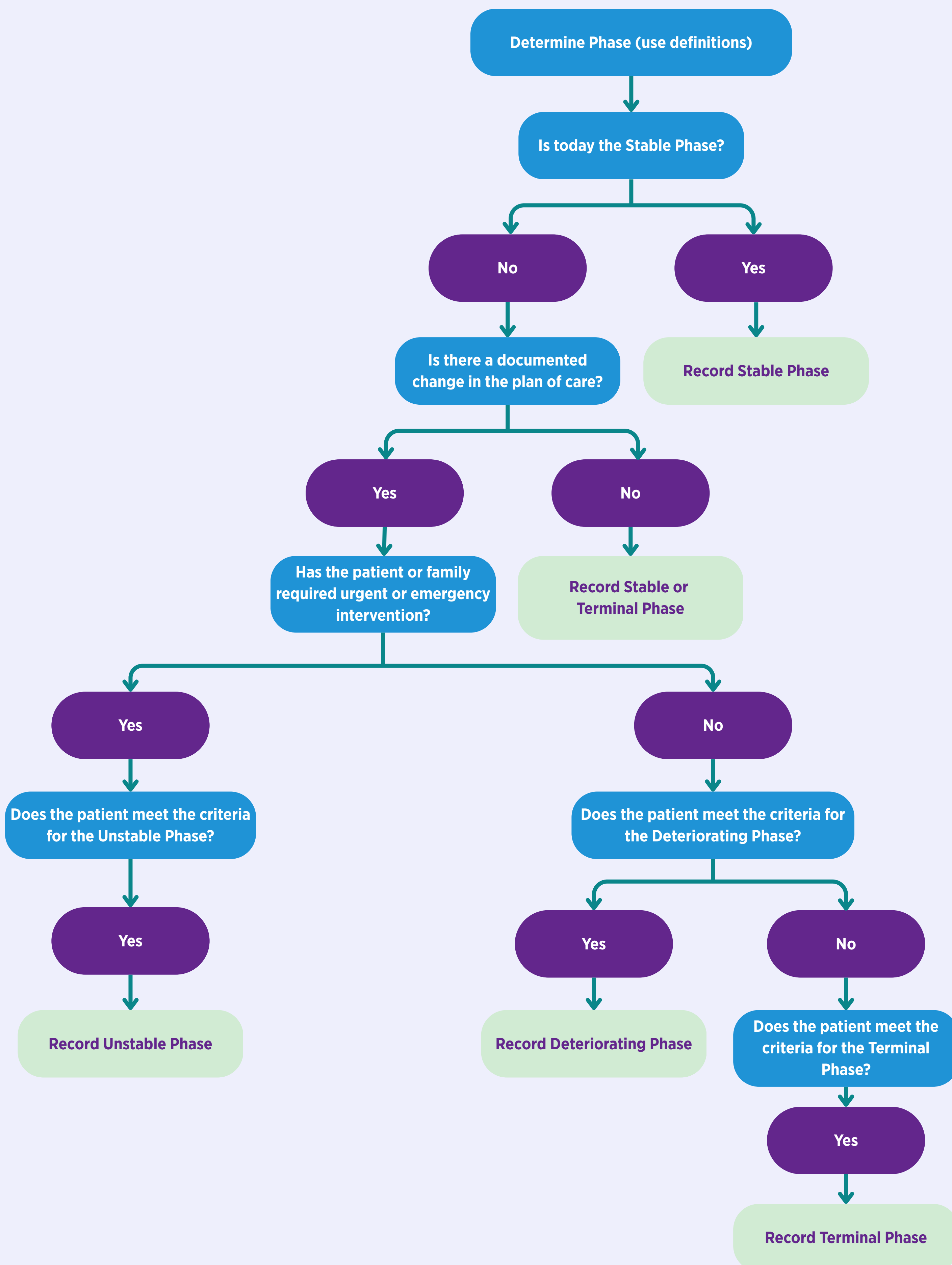
Phase algorithm



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Edmonton Symptom Assessmet System for PCOC (ESAS-PCOC)

Definition: ESAS-PCOC uses a 0-10 numerical rating scale to measure patient-reported symptom and problem severity. It includes 11 common symptoms and problems, with the option to record one additional 'other'.

SYMPTOM	SCALE
Pain	(Absent-worst possible)
Tiredness (lack of energy)	(Absent-worst possible)
Drowsiness (feeling sleepy)	(Absent-worst possible)
Nausea	(Absent-worst possible)
Appetite	(Best-worst possible)
Shortness of Breath	(Absent-worst possible)
Constipation	(Absent-worst possible)
Sleep	(Best-worst possible)
Depression (feeling sad)	(Absent-worst possible)
Anxiety (feeling nervous)	(Absent-worst possible)
Wellbeing (how you feel overall)	(Best-worst possible)
Other*	(Absent-worst possible)

*Other Symptom provides the patient with the opportunity to rate one other common symptom or problem that is troublesome, other than those listed. The options to choose from are:

- Dry or sore mouth
- Itch
- Swallowing problems
- Other
- No other symptoms present
- Not assessed

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(Please complete or affix label here)

MRN:
Surname
First name:
DOB:

Edmonton Symptom Assessment Scale

Please use this form to tell us about your symptoms and concerns. This information will help us to best manage your care.

Absent/Best **Worst**

0	1	2	3	4	5	6	7	8	9	10

0 Dark green - no problem at all

1 Light green - a small problem, but it is manageable

5 Orange - a moderate problem and more difficult to manage

10 Red - a big problem and very difficult to manage.

1. Write the date in the first row.
2. Use the scale above to choose a number between 0 and 10 which shows the severity of the symptom or concern over the last 24 hours.
3. You can add other symptoms in the blank space at the bottom of the list.

Day or date								
Pain *(0 = no pain, 10 = worst possible)*								
Tiredness (lack of energy) *(0 = no tiredness, 10 = worst possible)*								
Drowsiness (feeling sleepy) *(0 = no drowsiness, 10 = worst possible)*								
Nausea *(0 = no nausea, 10 = worst possible)*								
Appetite *(0 = best appetite, 10 = worst possible)*								
Shortness of Breath *(0 = no shortness of breath, 10 = worst possible)*								
Constipation *(0 = no constipation, 10 = worst possible)*								
Sleep *(0 = best sleep, 10 = worst possible)*								
Depression (feeling sad) *(0 = no depression, 10 = worstpossible)*								
Anxiety (feeling nervous) *(0 = no anxiety, 10 = worst possible)*								
Wellbeing (how you feel overall) *(0 = best wellbeing, 10 = worst possible)*								
Other Symptom *(D = dry mouth, S = Swallowing, Ot = Other, N = None)*								
Other Symptom Score *(0 = none, 10 = worst)*								
Rated By *(P = Patient, F = Family/Carer, C = Clinician, Ot = Other)*								

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Palliative Care Problem Severity Score (PCPSS)

Definition: The Palliative Care Problem Severity Score (PCPSS) is a clinician-rated tool designed to provide a screening assessment of the severity of problems experienced by patients in palliative care. It evaluates four key domains:

1. Pain: overall severity of pain problems for the patient.
2. Other Symptoms: overall severity of problems relating to one or more symptoms other than pain.
3. Psychological/Spiritual: severity of one or more problems relating to the patient's psychological or spiritual wellbeing.
4. Family/Carer: severity of one or more family/carer problems associated with a patient's condition or palliative care needs. Written, verbal or observational information can be used to assess needs if family/carer are not present.

Each domain is scored on a 4-point scale (0-3), reflecting the severity of problems over the past 24 hours.

Options:
0 Absent
1 Mild
2 Moderate
3 Severe

Potential actions following PCPSS and ESAS-PCOC assessments	
PCPSS & ESAS-PCOC Score	**Recommended Actions**
Absent **PCPSS = 0** **ESAS = 0**	• Problem/symptom severity absent. • Continue current care. • Routine assessment. • Phase may be Stable or Terminal.
Mild **PCPSS – 1** **ESAS = 1-3**	• Problem/symptom severity managed by existing plan of care and routine care. • Monitor and record any relevant information. • Stable or Terminal phase. - - - - - - - - - - • Problem/symptom severity not managed by existing plan of care. • Modify care plan. • Phase may be Deteriorating or Terminal.
Moderate **PCPSS = 2** **ESAS = 4-7**	• Problem/symptom severity requires change in plan of care, referral and escalation. • Document, review and implement any new interventions as per plan of care. • Phase may be Deteriorating or Terminal.
Severe **PCPSS = 3** **ESAS = 8-10**	• Problem/symptom severity requires immediate action. • Plan of care is ineffective. • Urgent intervention, referral and escalation required. • Change in plan of care indicated. • Review within 24 hours. • Phase Unstable or Terminal.

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Potential actions for PCPSS family and carer domain

PCPSS	Description/clinical indicators	Potential actions
0 **Stable**	Patient has no family/carer. If family/carer present, there are no problems (or emerging problems) identified.	Consider an advance care planning discussion with the patient and the family/carer.
1 **Mild**	The family/carer are experiencing a problem(s) but these are not impacting on the care of the patient and are beinig addressed by the current plan of care.	Document current problems and follow plan of care. Discuss family/carer situation and problems at multidisciplinary team meeting. Monitor changes to family/carer problems through daily assessment for inpatients and at every contact for patients of community and consultation services.
2 **Moderate**	The family/carer are experiencing one or more problems that are influencing the plan of care. The problem(s) may be new or existing.	Document current problems. Complete multidisciplinary review of plan of care and develop strategies for addressing problem(s). These may include (but are not limited to) : • Referral to social worker/counsellor/family therapy services. • Referral for pastoral care. • Provision of equipment. • Referral for community care assistance (personal care, cleaning service etc.) • Volunteer support. • Referral for respite care (in-home, day respite etc.) • Education for family/carer.
3 **Severe**	The family/carer are experiencing a serious problem(s) that is/are significantly impacting upon the plan of care. This may be a new (acute) problem or it may be an exacerbation of an existing problem. *Note: If family/carer domain of PCPSS is assessed as severe, the patient is likely to be in the unstable phase.*	An immediate response and review of the plan of care is required. Complete multidisciplinary review of plan of care and develop strategies for addressing problem(s). These may include (but are not limited to): • Referral to other support services (social worker, counsellor, psychologist etc.) • Referral of family/carer to their GP or other medical practitioner. • Admission to hospital/hospice/nursing home etc. for community patient.

Resource Utilisation Groups-Activities of Daily Living (RUG-ADL)

Definition: The Resource Utilisation Groups-Activities of Daily Living (RUG-ADL) scale measures a patient's level of functional dependence in performing basic motor activities of daily living.

It consists of four items: Bed mobility, Toileting, Transfers, and Eating.

Each item is rated according to the degree of assistance needed, ranging from complete independence to full dependence. The individual item scores are summed to generate a total RUG-ADL score, which reflects the patient's overall level of physical dependency.

Options: **For bed mobility, toileting and transfers**

1 Independent or supervision only
3 Limited physical assistance
4 Other than two-persons physical assist (one person and an aid)
5 Two or more person assist

For eating

1 Independent or supervision only
2 Limited assistance
3 Extensive assistance/total dependence/tube fed (by staff or family)

BED MOBILITY		The ability to move in bed after the transfer into bed has been completed
Item	**Score**	**Definition**
Independent or supervision only	1	Able to readjust position in bed, and perform own pressure area relief, through spontaneous movement around bed or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Able to readjust position in bed, and perform own pressure area relief, with the assistance of one person.
Other than two persons physical assist	4	Requires the use of a hoist or other assistive device to readjust position in bed and provide pressure relief. Still requires the assistance of one person for task.
Two or more persons physical assist	5	Requires two or more assistants to readjust position in bed and perform pressure area relief.
TOILETING		**Includes mobilising to the toilet, adjustment of clothing before and after toileting and maintaining perineal hygiene without the incidence of incontinence or soiling of clothes. If level of assistance differs between voiding and bowel movement, record the lower performance.**
Item	**Score**	**Definition**
Independent or supervision only	1	Able to mobilise to toilet, adjusts clothing, cleans self, has no incontinence or soiling of clothing. All tasks are performed independently or with prompting from carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance by one person for one or more of the tasks.
Other than two persons physical assist	4	Requires the use of a catheter/uridome/urinal and/or colostomy/bedpan/commode chair and/or insertion of enema/suppository. Requires assistance of one person for management of the device.
Two or more persons physical assist	5	Requires two or more assistants to perform any step of the task.
TRANSFER		**Includes the transfer in and out of bed, bed to chair, in and out of shower/tub. Record the lowest performance of the day/night.**
Item	**Score**	**Definition**
Independent or supervision only	1	Able to perform all transfers independently or with prompting of carer. No hands-on assistance required. May be independent with the use of a device.
Limited physical assistance	3	Requires hands on assistance of one person to perform any transfer of the day/night.
Other than two persons physical assist	4	Requires use of a device for any of the transfers performed in the day/night. Requires only one person plus a device to perform the task.
Two or more persons physical assist	5	Requires two or more assistants to perform any transfer of the day/night.

EATING		Includes the task of cutting food, bringing food to the mouth, chewing and swallowing food. Does not include the preparation of the meal.
Item	**Score**	**Definition**
Independent or supervision only	1	Able to cut/chew and swallow food, independently or with supervision, once meal has been presented in the customary fashion. No hands-on assistance required. If individual relies on parenteral or gastrostomy feeding that he/she administers him/herself then Score 1.
Limited assistance	2	Requires hands on assistance of one person to set up or assist in bringing food to the mouth and/or requires food to be modified (soft or staged diet).
Extensive assistance/total dependence/tube fed	3	Person needs to be fed meal by assistant, or the individual does not eat or drink full meals by mouth but relies on parenteral/gastrostomy feeding and does not administer feeds by him/herself or patient may be in the terminal phase requiring provision of mouth care.

NOTE

- There is no score of "2" for bed mobility, toileting and transfers. For bed mobility, toileting and transfers the change from independent/supervision to limited assistance was found to equate to a three-fold increase in resources. For eating, the same change equated to a two-fold increase in the use of resources.
- The RUG-ADL is based on what the person actually does, not what they are capable of doing. This is best achieved by asking "Do you?" rather than "Can you?"
- How do you score the unconscious or terminal patient for the item eating? Score 3 to indicate extensive assistance and total dependence as the patient does not feed him/herself.

Potential actions following RUG-ADL assessment			
Item	**Description**	**Score**	**Recommended actions**
Bed mobility, Toileting, Transfer	Independent/supervision only	**1**	• Provide equipment if required (monkey pole, walking stick etc.). • Monitor for changes.
	Limited physical assistance	**3**	• Ensure plan of care clearly describes the assistance required. • Consider a Falls Prevention Plan. • Provide equipment if required.
	Other than two persons physical assist (one person plus aid/s)	**4**	• Provide equipment/device as required. • Ensure plan of care clearly describes the assistance required and instructions regarding use of device. • Provide clear instructions to the patient regarding use of the device.
	Two or more persons physical assist	**5**	• Ensure plan of care clearly describes the assistance required. • Provide equipment.
Eating	Independent/supervision only	**1**	• Monitor for changes.
	Limited assistance	**2**	• Provide assistance required, according to service guidelines/protocols. • Ensure plan of care clearly describes the assistance required.
	Extensive assistance/total dependence/tube fed	**3**	• Ensure plan of care clearly describes the assistance required. • Provide mouth care according to service guidelines/protocols.

Total Score Range	Recommended Actions for Total Score
Total Score of 4-5	Independent. Monitor.
Total Score of 6-13	Requires assistance May be at risk of falls and pressure areas.
Total Score of 14-17	Requires assistance of 1-2 plus equipment. Greater risk of falls and pressure areas.
Total Score of 18	Requires assistance of 2 for all care. Greater risk of pressure areas.

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Australia-modified Karnofsky Performance Status (AKPS)

Definition: The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's performance across the dimensions of activity, work and self-care.

A single score between 10 and 100 is assigned by a clinician based on their observations of a patient's ability to perform common tasks relating to activity, work and self-care.

A score of 100 signifies normal physical abilities with no evidence of disease.

Options:

100 Normal; no complaints; no evidence of disease
90 Able to carry on normal activity; minor signs or symptoms of disease
80 Normal activity with effort; some signs or symptoms of disease
70 Cares for self; unable to carry on normal activity or to do active work
60 Able to care for most needs; but requires occasional assistance
50 Considerable assistance and frequent medical care required
40 In bed more than 50% of the time
30 Almost completely bedfast
20 Totally bedfast and requiring extensive nursinig care by professionals and/or family
10 Comatose or barely rousable

Potential actions following AKPS assessment	
Point on AKPS Scale	**Recommended Action**
Patient has AKPS of 100, 90, 80 or 70	• Consider completing an advance care planning discussion with the patient and their substitute decision-makers.
Patient has an AKPS of 60	• Consider referral to allied health if patient has been in active work and is no longer able to work.
Patient has AKPS of 50	• Consider discussion at multidisciplinary team meeting and review plan of care. • Provide appropriate equipment as required. • Consider referrals for community packages. • Complete a caregiver assessment.
Patient has AKPS of 40 or 30	• Consider discussion at multidisciplinary team meeting and review plan of care – patient may be physically deteriorating and further supports may be required. • Consider pressure area care. • Provide appropriate equipment as required (for example, alternating pressure mattress). • For community patients - consider impact of care on family caregiver. Complete a caregiver assessment.
Patient has AKPS of 20 or 10	• Consider pressure area care. • Commence end of life care planning if appropriate. • If death is likely in days, change to Terminal Phase.

Lansky Play – Performance Scale

The Lansky Play - Performance Scale is a validated measure of functional performance for paediatric patients, capturing a child's level of activity, play, and independence. It provides an age - appropriate alternative to the Australia – modified Karnovsky Performance Status (AKPS).

While the AKPS assesses function through work and self-care, the Lansky Scale reflects play-based activity as a marker of wellbeing. Scores range from 100 (fully active) to 10 (no play, confined to bed), enabling clinicians to track functional change.

In PCOC Version 4, the Lansky Play-Performance Scale may be used in place of the AKPS for children and young people. This ensures developmentally appropriate assessment.

Score	Lanksy Play-Performance Scale	AKPS
100	Fully active, normal	Normal; no complaints; no evidence of disease.
90	Minor restrictions in physically strenuous activity	Able to carry on normal activity; minor signs or symptoms of disease.
80	Active, but tires more quickly	Normal activity with effort; somes signs or symptoms of disease.
70	Both greater restriction of, and less time spent in active play	Cares for self; unable to carry on normal activity or to do active work.
60	Up and around, but minimal active play; keeps busy with quieter activities	Able to care for most needs; but requires occasional assistance.
50	Gets dressed, but lies around much of the day; no active play; able to participate in all quiet play and activities	Considerable assistance and frequent medical care required.
40	Mostly in bed; participates in quiet activities	In bed more than 50% of the time.
30	In bed; needs assistance even for quiet play	Almost completely bedfast.
20	Often sleeping; play entirely limited to very passive activities	Totally bedfast and requiring extensive nursing care by professionals and/or family.
10	No play; does not get out of bed	Comatose or barely rousable.

Acknowledgment

The content of this staff handbook has been adapted from original PCOC resources with the kind permission of PCOC Australia.

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