



Education Handouts

A Resource for Services

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The information in this document is to be used as handouts in conjunction with the “PCOC education” PowerPoint slides

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Handout 1: PCOC DATA DEFINITIONS VERSION 2

Level 1 - Patient Level Items

No.	Item	Item Description	Item Codes	Item Code-Set Description
2.1.1	Person/Client Identifier	Unique person identifier within the palliative care service		Any number that is unique for each patient. This number must be used at all times when recording patient, episode or phase details for this patient for PCOC. This number could be the patient record number
2.1.2	Date of Birth	Birth date of patient	dd/mm/yyyy	
2.1.3	Sex	Patient's gender	1	Male
			2	Female
			3	Indeterminate
			99	Not stated/inadequately described
2.1.4	State Identifier	State of usual place of residence	1	NSW
			2	VIC
			3	QLD
			4	SA
			5	WA
			6	TAS
			7	NT
			8	ACT
			9	Other Australian Territory (Australian Antarctic Territory, Cocos (Keeling) Islands, Christmas Island and Jervis Bay Territory)
			10	Other country
2.1.5	Postcode	Postcode of usual place of residence Leave blank if State identifier is 9 or 10		Four digit postcode
2.1.6	Indigenous status	Patient's indigenous status	1	Aboriginal but not Torres Strait Islander origin
			2	Torres Strait Islander but not Aboriginal origin
			3	Both Aboriginal and Torres Strait Islander origin
			4	Neither Aboriginal nor Torres Strait Islander origin
			99	Not stated / inadequately described
2.1.7	Main language spoken at home	The main language reported by a patient as the main language spoken in his/her home.	xx	Standard 2 digit code.
2.1.8	Country of birth	The country in which the person was born	xxxx	Standard Australian Classification of Countries (SACC) 4-digit (individual country) level. ABS catalogue no.1269.0 (1998)

Level 2 - Episode Level Items

No.	Item	Item Description	Item Codes	Item Code Set Description
2.2.9	Referral date	Date agency received a referral for this episode from another party for palliative care services	dd/mm/yyyy	
2.2.10	Referral source	Location of source of referral for this episode	1	Public hospital – other than inpatient palliative care unit
			2	Private hospital – other than inpatient palliative care unit
			3	Public palliative care inpatient unit/hospice
			4	Private palliative care inpatient unit/hospice
			5	General Medical Practitioner rooms
			6	Specialist Medical Practitioner rooms
			7	Community-based palliative care agency
			8	Community-based service
			9	Residential aged care facility
			10	Self, carer(s), family or friends
			11	Other
2.2.11	Mode of episode start	How this episode began	Overnight Admitted Patients	
			1	Admitted from usual accommodation
			2	Admitted from other than usual accommodation
			3	Admitted (transferred) from another hospital
			4	Admitted (transferred) from acute care in another ward
			5	Change from acute care to palliative care while remaining on same ward
			6	Change of sub-acute/non-acute care type
			7	Statistical admission from leave
			9	Other
			All other patients (same day admitted, outpatient and community)	
			A	First visit following new referral
B	First visit after discharge from being an overnight admitted palliative care patient			
2.2.12	Date of first contact with patient/client	First contact (telephone or face to face) by palliative care service following receipt of referral	dd/mm/yyyy	
2.2.13	Episode start date	The date a patient/client commences an episode of care	dd/mm/yyyy	For inpatients: date of admission For ambulatory patients: date of first face to face contact
2.2.14	Proposed model of care at episode start	The type of care planned at the start of this episode of care	1	Direct care
			2	Shared care with another service provider/s (cancer care, respiratory, GP, MND, community health care providers)
			3	Consultation/liaison with another service provider
2.2.15	Episode type	The location of the patient for this episode	0	Overnight admitted patient in a non-designated inpatient palliative care bed/unit Go to 2.2.19 (Patient is admitted and discharged on different dates)
			1	Overnight admitted patient in a designated inpatient palliative care bed/unit Go to 2.2.19 (Patient is admitted and discharged on different dates)
			3	Ambulatory Go to 2.2.19 (Patient receives care on a same day admitted or outpatient basis)
			4	Community Go to 2.2.19 (Patient receives care in the home or other non-hospital site)

No.	Item	Item Description	Item Codes	Item Code Set Description
			5	Consultation service (Patient is seen by a consultative service) If 5 is ticked answer 2.2.16, 2.2.17 and 2.2.18
2.2.16	Reason for consultative service visit	Type of consultative service provided <i>Complete only if Episode Type is 5 (Consultative). Otherwise leave blank</i>	1	Advice only
			2	One-off consultation
			3	Recurring consultation
			99	Not stated/inadequately described
2.2.17	Location of consultative service	Location where the consultative service was provided <i>Complete only if Episode Type is 5 (Consultative). Otherwise leave blank</i>	1	Inpatient – designated palliative care bed
			2	Inpatient – non-designated palliative care bed
			3	Hospital-based clinic or centre
			4	Community-based day centre
			5	Residential aged care facility
			6	Home
			99	Not stated/inadequately described
2.2.18	Mode of consultative service	How was this service was provided <i>Complete only if Episode Type is 5 (Consultative). Otherwise leave blank</i>	1	Face to face
			2	Telephone/electronic communication
2.2.19	Diagnosis	The broad diagnostic group established after study to be chiefly responsible for occasioning the patient's episode of palliative care.	1	Malignant (neoplasm)
				1.1 Bone and Soft Tissue
				1.2 Breast
				1.3 CNS
				1.4 Colorectal
				1.5 Gynaecological
				1.6 Haematological
				1.7 Head and Neck
				1.8 Lung
				1.9 Pancreas
				1.10 Prostate
				1.11 Skin
				1.12 Other GIT
				1.13 Other Urological
				1.14 Other Malignancy
			1.15 Unknown Primary	
			2	Non-malignant (other diagnosis)
2.1 Cardiovascular				
2.2 HIV/AIDS				
2.3 Kidney Failure				
2.4 Neurological Disease				
2.5 Respiratory Failure				
2.6 Other non-malignancy				
2.2.20	Accommodation at episode start	Type of usual accommodation at the commencement of the episode	1	Private residence (including unit in retirement village)
			2	Residential aged care, low level care (hostel)
			3	Residential aged care, high level care (nursing home)
			4	Community group home
			5	Boarding house
			6	Transitional living unit
			7	Other
2.2.21	Level of Support at episode start	Level of support received at the commencement of the episode. <i>Complete only if Accommodation at episode start is 1 (Private residence). Otherwise leave blank</i>	1	Lives alone (no support/care provided)
			2	Lives with others (no support/care provided)
			3	Lives alone with external support(s)
			4	Lives with others (who provide support/care)
			5	Lives with others, external support(s)
			6	Other arrangements
			99	Not stated/inadequately described

2.2.22	Episode end date	The date of episode end	dd/mm/yyyy	The date of discharge, death or transfer
2.2.23	Mode of episode end	How this episode ended	Overnight admitted patients	
			1	Discharged to usual accommodation
			2	Discharged to interim accommodation
			3	Death
			4	Discharged to another hospital
			5	Change from palliative care to acute care – different ward
			6	Change from palliative care to acute care – same ward
			8	Discharged at own risk
			99	Other
			Ambulatory patients	
			A	Discharge/case closure
			B	Death (Complete 2.2.26)
			C	Admitted for inpatient palliative care
			D	Admitted for inpatient acute care
E	Transfer to another palliative care service or to primary care			
G	Not known			
2.2.24	Accommodation at episode end	Type of accommodation at episode end	1	Private residence (including unit in retirement village)
			2	Residential aged care, low level care (hostel)
			3	Residential aged care, high level care (nursing home)
			4	Community group home
			5	Boarding house
			6	Transitional living unit
			7	Other
2.2.25	Level of Support at episode end	Level of support received at episode end. <i>Complete only if Accommodation at episode end is 1 (Private residence). Otherwise leave blank</i>	1	Lives alone (no support/care provided)
			2	Lives with others (no support/care provided)
			3	Lives alone with external support(s)
			4	Lives with others (who provide support/care)
			5	Lives with others, external support(s)
			6	Other arrangements
			99	Not stated/inadequately described
2.2.26	Place of death	<i>Complete only if Mode of Episode End (item 2.2.23) is B (death). Otherwise leave blank</i>	1	Private residence
			2	Residential aged care setting
			3	Other location

Level 3 - Phase level items

No.	Item	Item Description	Item Code Set	Item Code Set description
2.3.27	Date of phase start	The date this phase began	dd/mm/yyyy	
2.3.28	Phase	Palliative Care Phase. Note: The first phase begin date = episode begin date	1 2 3 4 5	Stable Unstable Deteriorating Terminal Bereaved
2.3.29	RUG-ADL functional scores at phase start	RUG-ADL scores as recorded at the start of the phase. Note: a score of 2 is not valid on the bed mobility, toileting or transfer items	For bed mobility, toileting & transfers: 1 3 4 5 For eating: 1 2 3	Independent or supervision only Limited physical assistance Other than two persons physical assist Two-person physical assist Independent or supervision only Limited assistance Extensive assistance/total dependence/ tube fed
2.3.30	Symptom Assessment Score (SAS) at phase start	SAS as recorded at the start of the phase.	0-10	Insomnia, appetite problems, nausea, bowels, breathing, fatigue and pain (7 items) Not at all - Worst Possible
2.3.31	Palliative Care Problem Severity scores at phase start	Pain score as recorded at the start of the phase	0 1 2 3	Absent Mild Moderate Severe
2.3.32	Palliative Care Problem Severity scores at phase start	Other symptom score as recorded at of the start of the phase	0 1 2 3	Absent Mild Moderate Severe
2.3.33	Palliative Care Problem Severity scores at phase start	Psychological/Spiritual score as recorded at the start of the phase	0 1 2 3	Absent Mild Moderate Severe
2.3.34	Palliative Care Problem Severity scores at phase start	Family/Carer score as recorded at the start of the phase	0 1 2 3	Absent Mild Moderate Severe
2.3.35	Karnofsky performance score at phase start	Score on the Australian Modified Karnofsky Scale as recorded at the start of the phase	100 90 80 70 60 50 40 30 20 10 0	Normal; no complaints; no evidence of disease. Able to carry on normal activity; minor signs or symptoms. Normal activity with effort; some signs or symptoms of disease Cares for self; unable to carry on normal activity or to do active work Requires occasional assistance but is able to care for most of his needs Requires considerable assistance and frequent medical care In bed more than 50% of the time. Almost completely bedfast. Totally bedfast and requiring extensive nursing care by professionals and/or family. Comatose or barely arousable Dead

No.	Item	Item Description	Item Code Set	Item Code Set description
2.3.36	Model of care at phase end	The type of care provided at the end of this phase of care	1	Direct care
			2	Shared care with another service provider/s (cancer care, respiratory, GP, MND, community health care providers)
			3	Consultation/liaison with another service provider
2.3.37	Date of phase end	The date on which a patient completes a phase of care	dd/mm/yyyy	Default to new episode
2.3.38	Reason for phase end	The reason this phase ended	1	Phase change
			2	Discharge/Case closure
			3	Died or bereavement phase start
			4	Bereavement phase end
2.3.39	Number of days seen	The total number of direct contact days during this phase <i>Note: Not collected on overnight admitted episodes</i>		
2.3.40	RUG-ADL functional scores at phase end	RUG-ADL scores as recorded within 24 hours of the end of the phase. Note: a score of 2 is not valid on the bed mobility, toileting or transfer items Complete only if reason for phase end is (2) Discharge/Case closure	For bed mobility, toileting & transfers:	
			1	Independent or supervision only
			3	Limited physical assistance
			4	Other than two persons physical assist
			5	Two-person physical assist
			For eating:	
			1	Independent or supervision only
2	Limited assistance			
3	Extensive assistance/total dependence/ tube fed			
2.3.41	Symptom Assessment Score (SAS) at phase end	SAS as recorded within 24 hours of the end of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>		Insomnia, appetite problems, nausea, bowels, breathing, fatigue and pain (7 items)
			0-10	Not at all – Worst Possible
2.3.42	Palliative Care Problem Severity scores at phase end	Pain score as recorded within 24 hours of the end of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.43	Palliative Care Problem Severity scores at phase end	Other symptom score as recorded within 24 hours of the end of the phase Complete only if reason for phase end is (2) Discharge/Case closure	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.44	Palliative Care Problem Severity scores at phase end	Psychological/Spiritual score as recorded within 24 hours of the end of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.45	Palliative Care Problem Severity scores at phase end	Family/Carer score as recorded within 24 hours of the start of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	0	Absent
			1	Mild
			2	Moderate
			3	Severe
2.3.46	Karnofsky performance score at phase end	Score on the Australian Modified Karnofsky Scale as recorded within 24 hours of the end of the phase <i>Complete only if reason for phase end is (2) Discharge/Case closure</i>	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 activity or to do active work
			60	Requires occasional assistance but is able to care for most of his needs

No.	Item	Item Description	Item Code Set	Item Code Set description
			50	Requires considerable assistance and frequent medical care
			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 arousable
			0	Dead

Handout 2: Phase Definitions

Palliative Care Phase

The palliative care phase is the stage of the patient's illness. Palliative care phases are not sequential and a patient may move back and forth between phases. Palliative care phases provide a clinical indication of the level of care required and have been shown to correlate strongly with survival within longitudinal, prospective studies.

Instructions: Record the patient/client and family/carer phase changes if and when they occur during each episode.

Phases are defined in terms of the following criteria as these highlight the essential issues to be considered when assigning phase.

Phase 1: Stable

All clients not classified as unstable, deteriorating, or terminal.

- The person's symptoms are adequately controlled by established management. Further interventions to maintain symptom control and quality of life have been planned.
- The situation of the family/carers is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.

Phase 2: Unstable

- The person experiences the development of a **new unexpected problem or a rapid increase** in the severity of existing problems, either of which require an **urgent** change in management or emergency treatment
- The family/carers experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team.

Phase 3: Deteriorating

- The person experiences a **gradual worsening** of existing symptoms or the development of **new but expected problems**. These require the application of specific plans of care and regular review but **not urgent or emergency treatment**.
- The family/carers experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person. This requires a planned support program and counselling as necessary.

Phase 4: Terminal

Death is likely in a matter of days and no acute intervention is planned or required. The use of frequent, usually daily, interventions aimed at physical, emotional and spiritual issues is required.

The typical features of a person in this phase may include the following:

- Profoundly weak
- Essentially bed bound
- Drowsy for extended periods
- Disoriented for time and has a severely limited attention span
- Increasingly disinterested in food and drink
- Finding it difficult to swallow medication
- The family/carers recognise that death is imminent and care is focussed on emotional and spiritual issues as a prelude to bereavement.

Phase 5: Bereaved

Death of the patient has occurred and the carers are grieving. A planned bereavement support program is available including referral for counselling as necessary. Record only one bereavement phase per patient - not one for each carer/family member.

Handout 3: Resource Utilisation Groups- Activities of Daily Living Definitions

Instructions: Assess RUG-ADL at the following intervals

- **Episode start** = Assess RUG-ADL at admission to the service. Record the score as soon as possible after admission (within 24hrs).
- **Phase Change** = Assess RUG-ADL when a patient/client condition changes and the phase of care changes. However this assessment is useful if completed every 24hrs as there are times when a patient/client functioning changes without the phase changing. For example patient/client may become increasingly physically dependant without the phase changing.
- **Episode end** = When the patient/client is separated from service due to death, discharge or transfer. When the patient/client is deceased leave the scores blank.

RUG –ADL Item	Score	Definition
BED MOBILITY		Ability to move in bed after the transfer into bed has been completed.
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 2 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.
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. May be independent with the use of a device.
Limited physical assistance	3	Requires hands-on assistance of 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.
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 2 or more assistants to perform any transfer of the day/night.
EATING		Includes the tasks of cutting food, bringing food to mouth and chewing and swallowing food. Does not include preparation of the meal.
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.

Triggers:

1. This assessment may be used to describe acuity and may be used to justify additional staffing.
2. In a community service a high (16-18) RUG-ADL may trigger a referral for a hospital bed or aged care facility placement.
3. RUG-ADL assessment changes may trigger Occupational Therapy assessment or increased equipment in the community or inpatient setting

References:

Eagar, K., Gordon, R., Green, J., & Smith, M. (2004). An Australian casemix classification for palliative care: lessons and policy implications of a national study. *Palliative Medicine*, 18, 227-233.

Handout 4: Karnofsky (Australian) Performance Scale

Instructions:

- Score at episode start, phase change and episode end.
- The Karnofsky used in PCOC is the Australian (modified) version which is applicable to both inpatient and community palliative care
- The Karnofsky Performance Scale assesses patient/client functioning and performance and can be used to indicate prognosis. The Karnofsky is often used in determining prognosis / survival times.

Karnofsky Performance Scale		
Definition	%	Criteria
Able to carry on normal activity and to work. No special care is needed.	100	Normal; no complaints; no evidence of disease
	90	Able to carry on normal activity; minor signs of symptoms of disease
	80	Normal activity with effort; some signs or symptoms of disease
Unable to work. Able to live at home, care for most personal needs. A varying amount of assistance is needed.	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.
Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly.	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 arousable.
	0	Dead

Triggers: A Karnofsky assessment of 60 or below may trigger a family conference to discuss functional status and disease progression

References:

1. Abernethy, A. P., Shelby-James, T., Fazekas, B. S., Woods, D., & Currow, D. C. (2005). The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [Electronic Version]. *BioMed Central Palliative Care*, 4, 1-12.
2. Grbich, C., Maddocks, I., Parker, D., Brown, M., Willis, E., Piller, N., et al. (2005). Identification of patients with noncancer diseases for palliative care services. *Palliative & Supportive Care*, 3(1), 5-14.
3. Nikoletti, S., Porock, D., Kristjanson, L. J., Medigovich, K., Pedler, P., & Smith, M. (2000). Performance status assessment in home hospice patients using a modified form of the Karnofsky Performance Status scale. *Journal of Palliative Medicine*, 3(3), 301-311.

Handout 5: Problem Severity Score

Instructions:

- The problem severity is an overall score of the patient/client and family.
- Score at episode start, at phase change and episode end

0 = Absent 1 = Mild 2 = Moderate 3 = Severe	The degree of overall pain of the patient.	Record the degree of overall other symptoms of the patient. The following list may be used as a guide:		Record the score for overall degree of psychological / spiritual problems of the patient. The following list may be used as a guide:		Record score for the overall degree of family / carer problems. The following list may be used as a guide:	
		Nausea Vomiting Constipation Dialhorrea- Dyspnoea Incontinence Irritation	Wound Confusion Delirium Oedema Weakness Fatigue Anorexia	Agitation Anxiety Fear Anger Sadness	Unrealistic Goals Request To Die Confusion Depression	Denial Caregiver Fatigue Unrealistic Goals Anger Cultural Accommodation Legal	Sensory Impairment Non English Speaking Difficult Communication Family Carer Anxiety
Date Assessed	PC pain	PC other symptom		PC Psych/ spiritual		PC Family/ Carer Score	

Triggers:

- A score of 2 or 3 for Psych/spiritual may trigger Pastoral or Social Work referral or intervention
- A score of 2 or 3 for family/carer may trigger Pastoral or Social Work referral or intervention

References

1. Smith, M. & Firms, P. (1994) Palliative care case mix Classification – Testing a Model in a Variety of Palliative Care Settings – Preliminary Results. Conference proceedings from the 6th national Case mix Conference. Commonwealth Department of Human Services and Health.
2. Eagar, K., Cromwell, D. Kennedy, C. & Lee, L. (1997) Classifying Sub-Acute and Non-Acute patients results of the NSW Case mix Area Network Study. Australian Health Review, Vol 20, No 2, 26-42
3. Smith, M. (1996) Palliative Care case mix – Stage 2 Development: a national Classification for any site of Care. The 8th national case mix Conference. Commonwealth Department of Human Services and health.
4. Eagar, K., Gordon, R., Green, J., & Smith, M (2004) An Australian case mix classification for palliative care: lessons and policy implications of a national study. Palliative Medicine, 18:227-233

Handout 6: Symptom Assessment Scale

Instructions:

- Score at episode start, at phase change, at episode end, and as clinically required/indicated.
- Assessment may be recorded daily for 1 or 2 troublesome symptoms.
- Symptoms are rated by the patient/client except where they are unable due to language barrier, hearing impairment or physical condition such as terminal phase or delirium, in which case a proxy is used. Use the most appropriate proxy. This may be the nurse or the family member.
- Highly rated or problematic symptoms may trigger other assessments or clinical interventions

As part of your assessment inform the patient that you are going to ask them about the symptoms they may be experiencing or the symptoms that are causing a problem.

When asking about these symptoms for the first time say:
 I'm going to ask you about some common symptoms you may be experiencing. We would like to know how much they affect you by rating them with a number from 0-10
 Can you think about how you have felt over the last 24hrs and when I ask you about your symptoms can you rate them by giving a score of 0 to indicate that you are not having a problem with that symptom, 10 to indicate you are having the worst possible problem and numbers 1 through to 9 indicate somewhere in between, just pick the number that best describes how you feel

Please note: Where the person has multiple pains assess each one separately
 If the person has additional symptoms add these in the blank rows

Date																	
Insomnia																	
Appetite Problems																	
Nausea																	
Bowel Problems																	
Breathing Problems																	
Fatigue																	
Pain																	
Completed by: N = Nurse D = Doctor F = Family P = Patient																	

References:

1. Kristjanson, L. J. Pickstock, S., Yuen, K., Davis, S., Blight, J., Cummins, A., et al. (1999). *Development and testing of the revised Symptom Assessment Scale*. Perth: Edith Cowan University.
2. Nightingale, E., Yuen, K., Firms, P., Duggan, G., Cummins, A., Kristjanson, L. J., et al. (2000). *Evaluation of a goal specific care model*. Perth: The Cancer Foundation Centre for Palliative Care.
3. Toye, C., Walker, H., Kristjanson, L. J., Popescu, A., & Nightingale, E. (2005). Measuring symptom distress among frail elders capable of providing self reports. *Nursing & Health Sciences*, 7(3), 184-191.

Insert service name and logo here	(Please complete or affix Addressograph Label here)										
	MRN	_____	DOB	_____							
	SURNAME	_____									
	GIVEN NAMES	_____									

PALLIATIVE CARE ASSESSMENT FORM (*sample assessment form*)

Instructions for Use: Assess on admission, daily, at phase change and at discharge

Date:											
Time:											
<u>PHASE:</u>											
<u>Problem Severity Score</u>											
Pain											
Other Symptoms											
Psychological/spiritual											
Family carer											
<u>RUG ADL</u>											
Bed Mobility											
Toileting											
Transfer											
Eating											
Total RUG-ADL											
<u>Karnofsky Performance Scale</u>											
<u>Symptom Assessment Scale</u>											
Insomnia											
Appetite Problems											
Nausea											
Bowels											
Breathing											
Fatigue											
Pain											
Other:											
Other:											
Reason for phase end											
Model of Care at phase end											
Staff Initials											

Insert Service Name here

Palliative Care Assessment Form

MR xx

<p><u>PALLIATIVE CARE PHASE:</u> Staff rated:</p> <ol style="list-style-type: none"> STABLE: Symptoms are adequately controlled by established management UNSTABLE: Development of a new problem or a rapid increase in the severity of existing problems DETERIORATING: Gradual worsening of existing symptoms or the development of new but expected problems TERMINAL: Death likely in a matter of days BEREAVED: Death of a patient has occurred and the carers are grieving 	<p><u>RUG-ADL</u> <i>(Resource Utilisation Group – Activities of Daily Living)</i> Staff rated: <i>For Bed Mobility, Toileting and Transfers For Eating</i></p> <table border="0"> <tr> <td>1. Independent or supervision only</td> <td>1. Independent or supervision only</td> </tr> <tr> <td>3. Limited physical assistance</td> <td>2. Limited assistance</td> </tr> <tr> <td>4. Other than two person physical assist</td> <td>3. Extensive assistance/total dependence/tube fed</td> </tr> <tr> <td>5. Two or more person physical assist</td> <td></td> </tr> </table>	1. Independent or supervision only	1. Independent or supervision only	3. Limited physical assistance	2. Limited assistance	4. Other than two person physical assist	3. Extensive assistance/total dependence/tube fed	5. Two or more person physical assist	
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3. Limited physical assistance	2. Limited assistance								
4. Other than two person physical assist	3. Extensive assistance/total dependence/tube fed								
5. Two or more person physical assist									
<p><u>REASON FOR PHASE END:</u> (the reason this phase ended)</p> <ol style="list-style-type: none"> Phase Change Discharge/Case closure Died Bereavement phase end <p>If the reason for phase change is bereaved, record 3 died. At the end of bereaved phase record 4</p>	<p><u>AKPS</u> <i>(Australian modified Karnofsky Performance Scale)</i> Staff rated:</p> <p>100 Normal, no complaints or evidence of disease</p> <p>90 Able to carry on normal activity, minor signs or activity</p> <p>80 Normal activity with effort, some signs or symptoms of disease</p> <p>70 Care for self, unable to carry on normal activity or to do active work</p> <p>60 Occasional assistance but is able to care for most of his needs</p> <p>50 Requires considerable assistance and frequent medical care</p> <p>40 In bed more than 50% of the time</p> <p>30 Almost completely bedfast</p> <p>20 Totally bedfast & requiring nursing care by professionals and/or family</p> <p>10 Comatose or barely arousable</p> <p>0 Dead</p>								
<p><u>MODEL OF CARE AT PHASE END:</u> (the type of care provided at the end of this phase of care)</p> <ol style="list-style-type: none"> Direct Care Share care with another service provider(s) consultation/liaison with another service provider 									
<p><u>PROBLEM SEVERITY SCORE</u> Staff rated: For the following 4 items assess the severity of distress as: 0 = Absent: 1 = Mild: 2 = Moderate: 3 = Severe</p> <p>PAIN: The degree of overall pain</p> <p>OTHER SYMPTOMS: Record the degree of overall other symptoms. The following list may be used as a guide: Nausea/vomiting: Anorexia: Itch/irritation: Constipation/diarrhoea: Wound/ulcer: Incontinence: Weakness/fatigue: Oedema: Dyspnoea: Confusion/delirium:</p> <p>PSYCHOLOGICAL / SPIRITUAL: Record the score for overall degree of psychological/spiritual problems of the patient The following list may be used as a guide: Anxiety/fear: Request to die: Anger: Depression/sadness: Unrealistic goals: Confusion: Agitation:</p> <p>FAMILY / CARER: Record score for the overall degree of family/carers problems. The following list may be used as a guide: Denial: Anger: Caregiver fatigue: Sensory impairment: Unrealistic goals: Financial: family/carers conflict: Difficult communication: Non-English speaking: Legal: Family/carers anxiety: Accommodation: Cultural:</p>	<p><u>SYMPTOM ASSESSMENT SCALE</u> Patient rated: The patient is asked to rate their experience of each symptom from 0 being none at all to 10 being worst possible.</p> <p>As part of your assessment inform the patient that you are going to ask them about the symptoms they may be experiencing or the symptoms that are causing a problem. When asking about these symptoms, especially the 1st time, say: I'm going to ask you about some common symptoms you may be experiencing. We would like to know how much they affect you by rating them with a number from 0-10. Can you think about how you have felt over the last 24hrs and when I ask you about your symptoms can you rate them by giving a score of 0 to indicate that you are not having a problem with that symptom, 10 to indicate you are having the worst possible problem and numbers 1 through to 9 indicate somewhere in between, just pick the number that best describes how you feel</p> <p>Where a person cannot rate the symptom, assign the number that most closely matches your clinical assessment. Alternatively you can ask a carer to rate the severity of each symptom. This is called a proxy assessment.</p> <ol style="list-style-type: none"> Insomnia Appetite problems Nausea Bowels Breathing Fatigue Pain 								