

The purpose of this document is to enhance the quality of symptom management for palliative care clients in collaboration between PHH/RDNS with a view to improved quality of care.

*“My job,
your job,
their job,
our job.”*



2016 – updated version

Acknowledgments

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I would especially like to thank the senior staff that has spent time engaging staff for reflections, writing up input and proof reading the document.

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Inge McGinn

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Background information

The Symptom Assessment Scale within the client information system PalCare is a tool used to assess eleven symptoms common in palliative care. This tool is based on the Revised Edmonton's Symptom Assessment Scale. The tool is used for consistent review of the key physical, psychosocial and spiritual concerns. This, when used in conjunction with care plans and communication between all staff involved in care, will aid in clinical monitoring, direct priority and focus of care, and improve outcomes for clients and their families.

The Revised Edmonton Symptom Scale that the PalCare ESAS reflects closely, has "proved to be a valid self-administered scale when evaluated in palliative care settings".¹

Client overview is enhanced with a summary of symptoms and phase of care over time, and enables a link between intervention and effectiveness. Phase of care is a clinical tool that measures stages of a person's illness, and it views client and family/carers as a unit, including their experiences in determining phase of care.

This document, or the symptom assessment tools, **is not intended** to discount relationship with clients, comprehensive clinical judgement, or to replace the policies and procedures of agencies involved. It is to be underpinned by professional codes of conduct, a needs based model of care that is inclusive of client, carers and family needs, beliefs, strengths and limitations.

The ESAS tab in PalCare also includes other clinical tools, Karnofsky (Australian) Performance Scale, Problem Severity Score and RUG – ADL. These clinical tools are not part of original or revised ESAS but are used in conjunction with ESAS.²

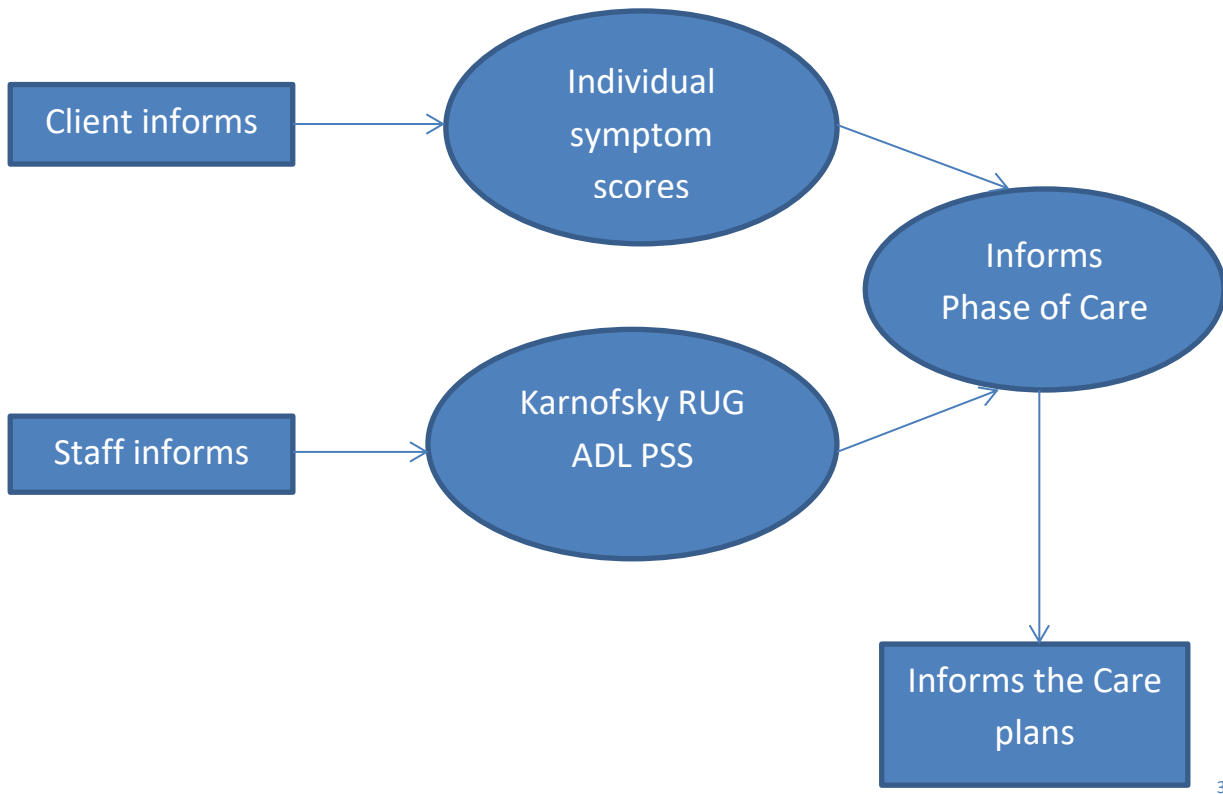
Peninsula Home Hospice operates in a shared care model with a two phase assessment. This means that all clients receive a nursing assessment and a psychosocial spiritual assessment. The ongoing multidisciplinary care team is made up of Peninsula Home Hospice and RDNS staff. It is in this context that the document was developed to support mutual understanding and consistency in practice.

¹ Cleeland, C.S., Mendoza, T.R., Wang, X.S., Chou C., Harle, M.T., Morrissey, M., & Engstrom, M. C., 2000 "*Assessing symptom distress in cancer patients*" Volume 89, Issue 7, pp. 1634–1646

² See Appendix for further definition

Context

The use of the ESAS tool (as set out in PalCare) in an integrated way meets PCA standards, PCOC reporting needs, the Victorian Service Delivery Framework 2011-2015, and supports ACHS accreditation.



Other tools imbedded in ESAS on PalCare are Phase of Care, Palliative Care Problem Severity Scale, the Australian modified Karnofsky Rating Scale and Resource Utilisation Groups/Activities of Daily Living (RUG-ADL). These scores provide additional functional, psychosocial and symptom severity information relating to each palliative care phase.

These tools allow a complete clinical profile of the patient/client to be established.

Tool	When to use
Phase of care	Each tool is to be reviewed at each visit by all disciplines
ESAS	
Karnofsky	
Problem severity score	
RUG - ADL	

Formal training in the use of the Palliative Care Problem Severity Scale, the Karnofsky Rating Scale and RUG-ADL is not required.⁴

³ Paula Street 2012

⁴ Eagar, K, Senior, K, Fildes, D et al, 2004 *"The Palliative Care Evaluation Tool Kit"*

Principles

- **Each client has a right to symptom assessment and symptom management in a timely manner**
 - The aim is to increase quality of life by decreasing the burden of suffering
 - The context of ESAS is developing a relationship rather than a form filling exercise.
 - The purpose is to enhance responding to the client's perspective in a respectful manner
- **Appropriate symptom assessment tools are available**
 - It is designed for use by all clinical staff
 - A multidimensional approach
 - It is a foundational tool and
 - is to be used in conjunction with more thorough assessment tools relevant to particular disciplines and particular symptoms
 - a starting point for more conversation with the client
- **Symptom assessment should be provided systematically and regularly**
 - To be used every time an assessment on the symptom is made, ideally at each visit
 - Not all symptoms need to be scored every visit. Professional judgement is needed regarding relevancy, keeping in mind
 - that a low score has as much meaning as a high score in influencing potential care plans and interventions
 - that scoring systematically over time creates a clearer picture of needs and changes
 - that ESAS as a tool will be more relevant for different disciplines/ roles in the care team at different times
 - Key question is - are you satisfied with reasons for not scoring or discussing this symptom?
- **A self – report approach**
 - It is a client centred tool meaning that it is the client's view of the **distress** caused by the symptom
 - It is a visual tool
 - It is assumed that clients are asked directly about their symptoms and the **distress** it causes unless there is good reason not to
 - A proxy can be used when client is unable to rate symptom **distress**
 - The score is still to reflect as close as possible the client perspective
 - If some responses are by carer and staff the majority is taken as the source
 - If a client does not perceive a problem but staff believe it is more serious, or vice versa , remember that the measure is the **distress** it causes them and may not relate to the severity
 - it does not limit further assessment discussion or intervention unless the client refuses
 - comment in the progress notes of discrepancy of perception and the agreed interventions

- **Scores have clinical meaning and client meaning**

- What is the clinical meaning of the score?
- What is the meaning the client attaches to the score?
- What symptoms, scores, concerns, require action?
- If so when, how, by whom?
- Record in care plan action taken, declined and any changes to intervention
e.g., call LMO, education, change medication routine, counselling session
- Any noticeable variation in scores over time is to be viewed in the context of who provided the score
- Identify client priorities in terms of the **distress** and burden that the symptom has for the client
- Relationship between symptoms, for example, the presence of physical symptoms can increase anxiety or the presence of unrelenting pain can lead to an increase in depressive mood
- Consider relationship between score and phase of care

Score	Principles
1-3	<ul style="list-style-type: none"> • Are largely self-managing • Focus is on prevention of exacerbation • Information and education are principle strategies • Re-evaluate regularly
4-6	<ul style="list-style-type: none"> • Acknowledge reality of the symptom and their effect on client and carer • Score increasing – needs further assessment / intervention • Score decreasing – informs a current interventions usefulness
7-10	<ul style="list-style-type: none"> • Score clearly indicates the need for thorough assessment in the context of client goals • Care planning of issue is crucial • Communication liaison is crucial • Interventions monitored and evaluated closely

- **Self-Assessment of Symptoms for Clients and Carers with low Health Literacy or low English Fluency**

Self-assessment of symptoms relies on the assumption that clinicians and clients/carers have a similar understanding of the symptoms and the ratings.

As is well understood:

- culture influences the way illness is experienced and expressed
- language fluency has an impact on communication
- low language fluency can cause misunderstandings
- health literacy levels impact on how a person understands and acts on health information

In self-assessment tools, these issues can play a larger role than in other areas of communication between clinician and client.

A number of strategies can assist in improving the efficacy of self-assessment tools for all clients:

Skill / Attitude	How to achieve this
<ul style="list-style-type: none"> Be aware of your own cultural framework and how this can affect interaction with clients in the health context: 	<ul style="list-style-type: none"> Undertake cultural diversity training Ask the client about their understanding of the illness, their goals and expectations and negotiate any differences of opinion
<ul style="list-style-type: none"> Utilise Language services appropriately 	<ul style="list-style-type: none"> Undertake training on how to work with interpreters Have appropriate policies and procedures in place
<ul style="list-style-type: none"> Understand the impact on health literacy of self-assessment tools 	<ul style="list-style-type: none"> Learn about the “teach back” technique⁵

Further information, resources and support at the Centre for Culture Ethnicity and Health:

www.ceh.org.au

- **Scores stimulate a set of actions and strategy options**

Red must prompt action, a care plan and progress note, including client refusal of action, as this informs care team of offer and client choice, and prompts discussion with client, carer and team about how best to proceed.

Abbreviations	
PHH	Peninsula Home Hospice
RDNS	Royal District Nursing Service
C/CW	Counsellor Case Worker
PSS	Psychosocial Spiritual
ADLs	Activities of daily living
CAHT	Counselling and Allied Health Team

⁵ DeWalt DA, Callahan LF, Hawk VH, Broucksou KA, Hink A, Rudd R, Brach C. Health Literacy Universal Precautions Toolkit. (Prepared by North Carolina Network Consortium, The Cecil G. Sheps Center for Health Services Research, The University of North Carolina at Chapel Hill, under Contract No. HHS290200710014.) AHRQ Publication No. 10-0046-EF) Rockville, MD. Agency for Healthcare Research and Quality. April 2010.

Symptoms

Symptoms – the aim of the measure is to track change, to guide and evaluate interventions, identify new issues and interventions as needed.

ESAS on PalCare is an eleven item tool to measure **distress** cause by symptoms. Other symptoms can also be added and measured under the same principles. The ratings are recorded to demonstrate progress and change. The symptoms also align with the Palliative Care Outcomes Collaboration' symptom assessments score seven item tool.

Applicable information for all symptoms

- Review all scores in dialogue with the client/family and discuss expectations and beliefs about support needs
- Identify concerns contributing to the **distress**
- Staff to ensure needs based interventions
- Phase, complexity, need and meaning for the client to be viewed in connection to score
- Variations in individual items is linked to clinically meaningful change
- Client encouraged to have regular LMO contact and review

- **All scores to be recorded**
- **Scores of 4+ to be recorded as a care plan issue, negotiated with the client/carer, until resolved**
- **Interventions related to scores to be recorded in the care plan**
- **Communication/Liaison with care team essential**

Notes

Phase of care

Phase of care – is the stage of the persons illness. It is holistic in that it views client and family as one unit. It is not sequential, as client and family may move back and forth between phases.

Phase	Expectations - Nursing	Expectations - Counselling and Allied health
Stable	<p>All clients not classified as unstable, deteriorating, or terminal</p> <ul style="list-style-type: none"> 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 <p style="text-align: center;">Care plan: no addition</p> <p>End of stable phase is when the needs of the patient and or family/carer increase, requiring changes to the existing plan of care.</p>	
Time frame	Contact between 2 and 4 weekly Face to face review every 28 days	Contact between 4 and 8 weekly
Unstable	<ul style="list-style-type: none"> The person experiences the development of a new unexpected problem or rapid increase in the severity of existing problems, either of which requires 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. <p style="text-align: center;">Care plan: new issue, action and outcome</p> <p>The end of the unstable phase is when the new plan of care is in place, it has been reviewed and no further 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) and/or death is likely within days (i.e. patient is now terminal)</p>	
Time Frame	Contact 24 to 48 hrs	Contact from daily to weekly
Deteriorating	<ul style="list-style-type: none"> 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. <p style="text-align: center;">Care plan: addition of new issues, action and outcomes, according to changing needs</p> <p>The end of the deteriorating phase is when the patient condition plateaus (i.e. patient is now stable), or an urgent change in the care plan 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) or death is likely within days (i.e. patient is now terminal)</p>	
Time Frame	Contact daily to weekly	Contact from 1 to 2 weekly
Terminal	<ul style="list-style-type: none"> 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. 	

	<ul style="list-style-type: none"> • The typical features of a person in this phase may include the following: <ul style="list-style-type: none"> ○ profoundly weak ○ essentially bed bound ○ drowsy for extended periods ○ disorientated for time and has a severely limited attention span ○ increasingly disinterested in food and drink ○ finding it difficult to swallow medication ○ the family/caregivers recognise that death is imminent and care is focused on emotional and spiritual issues as a prelude to bereavement <p style="text-align: center;"><i>Care plan: addition of new issues, action and outcomes, according to changing needs</i></p> <p style="text-align: center;"><i>The end of the terminal phase of care is when the patient dies or patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating)</i></p>	
Time Frame	<i>Contact daily to weekly</i>	<i>Contact daily to weekly</i>
Bereavement	For the purpose of this document not included	

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Notes

Pain

“An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”.⁷

Pain is what the client says it is.

“Pain is unpleasant sensation, suffering or distress of body or mind associated with injury and disease. Pain hurts. It is wearing and can cause immobility, tension and fatigue. Pain often accompanies cancer and other progressive disease”.⁸

Score	Expectations - Nursing	Expectations - Counseling and Allied health
1-3	All clinical staff	
	<ul style="list-style-type: none"> • Client self manages own medication and fully aware of break through medication management • Ensure client and carers are aware of RDNS 24hr support /advice • Ongoing monitoring and education as needed • Prevention where possible 	
	<ul style="list-style-type: none"> • Ensure emergency medications and authorisations are either in place or alternate plan for emergencies are discussed • Ensure clients and carers understand medication regime • Ensure updated pain medications are recorded in PalCare • Review at each visit 	<ul style="list-style-type: none"> • Ongoing assessments for PSS issues contributing to pain • Consider interventions that prevent pain <ul style="list-style-type: none"> ○ relaxation / medication ○ counseling and support ○ music therapy ○ art therapy ○ spiritual care
4-6	All clinical staff	
	<ul style="list-style-type: none"> • Assess for barriers to pain control (for both client and carer) <ul style="list-style-type: none"> ○ anxiety and depression ○ fear of addiction ○ fear of becoming tolerant to medications ○ fear of adverse effects of therapy ○ an inability to comply ○ an inability to understand ○ communication difficulties ○ confusion with medications⁹ • Develop care plan with client and carers • Support the client to share responsibility for their pain management • Ensure finances are available to meet medication costs • Gain an understanding of the meaning the client ascribes to the pain • Initiate care plan if pain is evident 	

⁷ Woodruff, R. 2003 “*Cancer Pain*” Mundipharma Pty Ltd.

⁸ Palliative Care Victoria www.palcarevic.asn.au “*Pain and pain management*” 2008

⁹ Palliative Care Expert Group 2010 “*Therapeutic Guidelines Palliative Care version 3*”. Melbourne, Therapeutic Guidelines Limited

	<ul style="list-style-type: none"> • Thorough pain assessment and contributing problems • Contact C/CW if pain is associated with psychosocial, spiritual issues (24/48 hrs) • Review of medication doses, frequency, use of break through medication • Liaise with LMO, medical director as needed • Educate client and carer regarding pain management and medication side effects • Assess for and seek equipment to aid in comfort • Contact next day by phone and visit if needed 	<ul style="list-style-type: none"> • Continual assessment for ongoing PSS issues that contribute to pain <ul style="list-style-type: none"> ○ emotional ○ cognitive ○ cultural ○ spiritual ○ social • Contact Nursing or medical support as needed (on same day) • Assess awareness and impact for carers/family • Intervention options <ul style="list-style-type: none"> ○ cognitive behavioural therapy ○ problem-solving therapy ○ interpersonal therapy ○ couple/family therapy ○ mindfulness-based therapy ○ art therapy ○ music therapy ○ spiritual care • Review at next visit
7-10	All Clinical Staff	
	<ul style="list-style-type: none"> • As above • Assess the need for medical assessment and review • Assess the need for admissions in the context of client preferences and pain causes / interventions tried • Change care management as needed e.g. subcutaneous injections • Increase visits / phone monitoring to daily until symptoms subside 	<ul style="list-style-type: none"> • Contact Nursing or medical support as needed (on same day) • Provide support and keep carers family informed of any arrangement • Intervention options <ul style="list-style-type: none"> ○ cognitive behavioural therapy ○ problem-solving therapy ○ interpersonal therapy ○ couple/family therapy ○ mindfulness-based therapy ○ art therapy ○ music therapy ○ spiritual care • Review at next visit

Notes

Tiredness-Fatigue

Fatigue is the most common side effect in palliative care, affecting 80-99% of palliative clients.¹⁰

“...it is a frequent and distressing symptom with major impact on quality of life... ability to adhere to treatment plans....more common than pain...”¹¹

Fatigue is a subjective feeling of severe tiredness, loss of energy and weakness that is not relieved by rest. It can be overwhelming and debilitating, affecting all aspects of life - physical, mental, emotional, social and spiritual. It can persist for weeks, months or years.¹²

Score	Expectations - Nursing	Expectations - Counseling and Allied health
1-3	<p style="text-align: center;">All clinical staff</p> <ul style="list-style-type: none"> • Education with handout (Cancer Council Victoria Coping with Cancer Fatigue)¹³ • Discuss Self-Management Plan e.g. energy conservation • Ongoing monitoring and education as needed • Prevention of family / carer fatigue <ul style="list-style-type: none"> ○ prompt effective relief of client symptoms ○ education in comfort care ○ communication that is honest, direct and compassionate ○ listening to concerns ○ permission to vent emotions ○ material aids and support 	
	<ul style="list-style-type: none"> • Referral to occupational therapy and or physiotherapy as appropriate 	<ul style="list-style-type: none"> • Counseling focused on adjustment
4-6	<p style="text-align: center;">All clinical staff</p> <ul style="list-style-type: none"> • Regular assessment, attention to reversible factors, and multidisciplinary approaches to treating fatigue are essential • Discuss sleep management/disturbance • Educate as to possible causes and realistic reachable goals for both client and carer • Referral to Occupational therapy for energy conservation and safety plan • Referral to Physiotherapy for gentle exercise • Education with Self-Management Plan: <ul style="list-style-type: none"> sleep patterns, diary of activities and fatigue, structured balance of gentle exercise and rest, nutrition, safety issues (driving/heavy machinery), relaxation techniques, meditation, massage, distraction, enjoyable activity • Carer/family education re sensitive communication and delegation of tasks • Cultural issues are important in understanding the significance of fatigue for a particular person¹⁴ • An activity/fatigue diary may help identify precipitants/timing of symptoms 	

¹⁰ Lane, I. 2005 *“Managing cancer-related fatigue in palliative care”*. NursingTimes.net, Vol 101 (18) pp. 38.

¹¹ Palliative Care Expert Group 2010 *“Therapeutic Guidelines Palliative Care version 3”*. Melbourne, Therapeutic Guidelines Limited

¹² National Breast Cancer Centre and national cancer Control Initiative. 2003 *“Clinical practice guidelines for the psychosocial care of adults with cancer”*. National breast cancer Centre Camperdown NSW.

¹³ *“Coping with Cancer Fatigue”* http://www.cancervic.org.au/downloads/CISS_factsheets/AP732_CopingWithFatigue.pdf

¹⁴ Care Search <http://www.caresearch.com.au/caresearch/tabid/65/Default.aspx>

	<ul style="list-style-type: none"> • Review of possible contributing factors <ul style="list-style-type: none"> ○ symptom control ○ medications ○ nutrition and hydration ○ phase of care ○ illness trajectory ○ anemia ○ reduced activity and deconditioning ○ hypothyroidism, hypogonadism, adrenal insufficiency ○ metabolic disorders ○ insomnia • Care plan and intervene on reversible factors 	<ul style="list-style-type: none"> • Review of ongoing contributing factors <ul style="list-style-type: none"> ○ depression /demoralization/emotional distress ○ impact of tiredness on well being ○ degree that it affects ADLs and psychosocial factors • Intervention options <ul style="list-style-type: none"> ○ support with household tasks (Home Help) ○ stress management ○ sleep hygiene ○ relaxation therapy ○ cognitive behavioural therapy ○ problem-solving therapy ○ Interpersonal therapy ○ couple/family therapy ○ mindfulness-based therapy ○ art therapy ○ spiritual care ○ music therapy • Review each visit
7-10	All Clinical staff	
	<ul style="list-style-type: none"> • Consider call to GP (medication review, other reversible causes) • Review each visit • <i>Alert/liaise with C/CW for Psychosocial and spiritual follow up CAHT 2-3 days</i> 	As for 4-6

Notes

Nausea

Nausea is the unpleasant, wavelike feeling that one is about to vomit.¹⁵

Nausea can either be acute, or persistent and chronic, and is not always associated with vomiting. In many cases it is possible to identify a cause, although in the palliative care population nausea is frequently multifactorial.¹⁶

Score	Expectations – Nursing	Expectations – Counseling and Allied health
1-3	All clinical staff	
	<ul style="list-style-type: none"> Client self manages own medication Ensure client and carers are aware of RDNS 24hr support /advice Ongoing monitoring and education as needed Prevent where possible Ongoing monitoring at each visit 	
	Ongoing monitoring	Ongoing monitoring
4-6	All Clinical staff	
	<ul style="list-style-type: none"> Explore what has contributed to relieving nausea in the past Provision of printed information PCV “Nausea and vomiting” 2008¹⁷ Explore if vomiting is associated with nausea 	
	<ul style="list-style-type: none"> Nurse to phone or Visit within 48hrs review until stable Assess the cause and review: <ul style="list-style-type: none"> treatments medications mouth ulcerations insomnia constipation <u>hypercalcaemia</u> palliative emergencies Education on nausea self-management strategies Review medication doses, frequency and how much breakthrough medication administered by client or carer Explain treatment and plan for client and carer Ensure break through medications are available and educate client and carer as needed 	<ul style="list-style-type: none"> Assess cause related to PSS issues <ul style="list-style-type: none"> anxiety/fear anticipatory nausea social circumstances inappropriate presentation of food Assess for impact of nausea on wellbeing and relationships and the role that food plays in relational dynamics Interventions that reduce anxiety for anxiety related nausea Supportive responses to address emotional distress, anxiety (for the client and their family) caused by nausea and vomiting Consult/liase with nursing as needed

¹⁵ “Nausea and vomiting” 2008 Palliative care Victoria <http://www.pallcarevic.asn.au/>

¹⁶ Care search <http://www.caresearch.com.au/caresearch/tabid/65/Default.aspx>

¹⁷ “Nausea and vomiting” 2008 Palliative care Victoria <http://www.pallcarevic.asn.au/>

7-10	All clinical staff	
	<ul style="list-style-type: none"> • <i>Nurse to phone or Visit within 24hrs</i> • Assess the need for medical assessment/review • Liaise with LMO, medical specialist for further evaluation and review • <i>Nurse to increase visits / phone contact to monitor more closely and support client/carer 1-2 days until stable</i> 	<ul style="list-style-type: none"> • <i>Phone CSC to request a nurse to phone or visit client within 24/48 hours nausea issues</i> • If there are other acute symptoms present with nausea (i.e. uncontrolled vomiting, bleeding, acute pain, etc.) support client\family to seek urgent medical support • As for 4-6

Notes

Depression

Depression is a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. These problems can become chronic or recurrent, and lead to substantial impairments in an individual's ability to take care of his or her everyday responsibilities.

Depression in palliative care is difficult to diagnose, as somatic symptoms, such as fatigue and insomnia may be due to depression, advanced disease or medical treatment. Also, depression in palliative care is difficult to distinguish from normal fear and sadness which often accompany terminal illness.

Low mood, loss of interest, anhedonia (inability to experience or anticipate pleasure), hopelessness and suicidal ideation are key symptoms of depression in palliative care

Score	Expectations – Nursing	Expectations – Counseling and Allied health
1-3	<p>Limited impact on the person's everyday life (as per client, caregiver or staff)</p> <ul style="list-style-type: none"> Minimal symptoms Client functioning well Effective coping skills satisfactory psychosocial-spiritual adjustment 	
	<p>All clinical staff</p> <ul style="list-style-type: none"> provide good palliative care (symptom management, monitoring) provide opportunity for client to express fears and concerns ensure informed collaboration in developing current and future care plans easy to understand (written if necessary) directions related to care, especially medications facilitate effective communication and assess social support offer brief psychosocial-spiritual counselling offer art therapy and/or music therapy 	
4-10	<p>All clinical staff</p> <p>Symptoms making it difficult for the person to function as they normally would (as per client, caregiver or staff)</p> <ul style="list-style-type: none"> Persistent low mood, tearfulness, distress Loss of interest or pleasure in daily activities, social withdrawal, irritability Feelings of hopelessness, helplessness, worthlessness or guilt Non-verbal cues (e.g. dejected demeanour, slumped posture, flat affect, reduced emotional reactivity) Suicidal thoughts, plans or actions, including requests for physician assisted suicide / euthanasia 	
	<ul style="list-style-type: none"> Alert / liaise with counsellor-caseworker Review medications for side effects Alert / liaise with GP (consider antidepressants) Consider alternative diagnoses (e.g. delirium, dementia, drug reactions, hypothyroidism) Consider contributory factors (e.g. pain, financial difficulties, family conflict, social isolation, anxiety) Assess and sensitively explore suicidal 	<ul style="list-style-type: none"> Conduct a thorough history (clinical interview): <ul style="list-style-type: none"> prior episodes of depression, anxiety, alcohol and drug use prior and current treatment by a mental health professional anxiety, post-traumatic stress disorder (PTSD) alternative diagnoses (e.g. delirium, dementia, drug reactions, hypothyroidism, demoralisation)

	<p>thoughts, plans and access to means</p> <ul style="list-style-type: none"> • Alert / liaise with C/CW 24 to 48 hrs 	<ul style="list-style-type: none"> ○ contributory factors (biological, psychological, social, spiritual) ○ explore distress ○ assess and sensitively explore suicidal thoughts, plans and access to means • Alert / liaise with GP (consider antidepressants) • Alert / liaise with nurses • Address social concerns e.g. liaise with Client Resource Advocate, offer volunteer support • Intervention options <ul style="list-style-type: none"> ○ supportive counselling, including problem solving ○ relaxation techniques ○ music therapy ○ art therapy ○ spiritual care ○ cognitive behavioural therapy ○ family / relationship counselling ○ facilitate open communication ○ mindfulness-based therapy • review at next visit
<p>In case of treatment resistant depression, refer to a mental health specialist</p>		

Notes

Anxiety

Fear of death and anxiety about dying are common reactions to approaching death. Anxiety may be recognised:

- **Physically:** insomnia, difficulty resting, increased heart rate or palpitations, rapid breathing, nausea, diarrhoea, sweating, dry mouth, chest or abdominal pain
- **Cognitively:** difficulty concentrating, hypervigilance, easily distracted
- **Emotionally and behaviourally:** feelings of apprehension, fear and dread, irritability, emotional distress, agitation, feelings of panic
- **Panic attack:** physical symptoms plus distorted thinking
 - pounding, skipping, racing heartbeat (“something terrible is happening”)
 - difficulty breathing (“I’m going to suffocate and die”)
 - tensing of muscles (“I’m going to lose control of myself”)
 - chest tightness and pain (“I’m having a heart attack and will die”)
 - sweating
 - light-headedness or dizziness (“I’m going to pass out”)
 - disorientation (“I’m going crazy”)

Aetiologies

- Anxiety may be present as part of a psychiatric disorder (generalized anxiety disorder, panic disorder, adjustment disorder, acute or post-traumatic disorder, PTSD, phobias)
- Anxiety is often a prominent component of acute or chronic pain, dyspnoea, nausea, or cardiac arrhythmias
- Adverse drug effects: corticosteroids, psychostimulants, and some antidepressants
- Drug withdrawal: alcohol, opioids, benzodiazepines, nicotine, antidepressants, and corticosteroids
- Metabolic causes: hyperthyroidism and syndromes of adrenergic or serotonergic excess
- Psychological, social or spiritual concerns about dying, disability, loss, legacy, family, finances
- **Death anxiety**
 - the pain of permanent separation from loved ones, and the familiar
 - fear of the unknown from which there is no escape
 - fear of after-life judgment and punishment
 - the fear that one will permanently cease to exist
 - the fear of suffering, the manner of dying
 - anxiety around leaving unfinished business
 - worry about the impact on the family and how they will cope

Score	Expectations – Nursing	Expectations – Counseling and Allied health
1-3	Limited impact on the person’s everyday life; minimal distress (as per client caregiver or staff) <ul style="list-style-type: none"> • Minimal symptoms • Client functioning well • Effective coping skills • Satisfactory psychosocial-spiritual adjustment 	

	<p style="text-align: center;">All clinical staff</p> <ul style="list-style-type: none"> • Provide good palliative care (symptom management, monitoring) • Provide opportunity for client to express fears and concerns • Ensure informed collaboration in developing current and future care plans • Easy to understand (written if necessary) directions related to care, especially medications • Offer brief psychosocial-spiritual counselling, relaxation therapies • Offer art and / or music therapy
4-10	<p style="text-align: center;">All clinical staff</p> <p>Symptoms making it difficult for the person or their family to function as they normally would (as per client, caregiver or staff)</p> <ul style="list-style-type: none"> • Client unable to focus and follow directions • Tearful, or crying uncontrollably • Client expressing thoughts and feelings of doom, dread, fear or terror • Moderate to severe physical symptoms • Provide interventions as above
	<ul style="list-style-type: none"> • As for 1-3 • Alert / liaise with counsellor-caseworker • Alert / liaise with GP (consider pharmacological treatment) <ul style="list-style-type: none"> ○ benzodiazepines e.g. lorazepam, alprazolam, clonazepam, diazepam, midazolam • Consider contributory factors (see above aetiologies) • Consider alternative diagnoses (agitated delirium, akathisia) • Develop a written action plan for clients with SOB • Follow up phone call 2-3 days • Alert / liaise with C/CW 24 to 48 hrs
	<ul style="list-style-type: none"> • Conduct a thorough history (clinical interview) <ul style="list-style-type: none"> ○ prior episodes of anxiety, depression, PTSD, alcohol and drug use ○ prior and current treatment by a mental health professional ○ presence of specific trigger situations or thoughts leading to anxiety ○ assess contributory factors (organic, psychological, social, spiritual) ○ explore distress ○ assess and sensitively explore suicidal thoughts, plans and access to means • Alert / liaise with GP (consider pharmacological treatments) • Alert / liaise with nurses • Address social concerns eg liaise with Client Resource Advocate, offer volunteer support • Intervention options <ul style="list-style-type: none"> ○ supportive counselling, including problem solving ○ relaxation techniques ○ music therapy ○ art therapy ○ spiritual care ○ cognitive behavioural therapy ○ family / relationship counselling ○ facilitate open communication ○ mindfulness-based therapy • Follow up at next visit

Notes

Drowsiness

Drowsiness- decreased level of alertness, and usually linked to the sensation of wanting to sleep. Mood changes (exacerbation of depression/irritability), negative effect on hope, and social isolation can increase due to unpredictability of drowsiness.

Dependant on client diagnosis-resultant fears/concerns, potential for fixated behaviours can be prompted by fear of future drowsiness.

Score	Expectations – Nursing	Expectations – Counseling and Allied health
1-3	All clinical staff	
	<ul style="list-style-type: none"> • Common cause is drug related withdrawal, infection and hypotension • Day to day deterioration due to irreversible factors can be part of disease progression and dying process • Reflection on what action has had a positive effect, (what is working well and what is not working) in self-management plan • Attentive listening to clients experience and its context of drowsiness • Client and carer education and support • Positive reinforcement of medication taking 	
	<ul style="list-style-type: none"> • Monitor for change refer to CAHT as needed 	<ul style="list-style-type: none"> • Monitor for change
4-6	All clinical staff	
	<ul style="list-style-type: none"> • Enquire about mood, sleep, recent treatment (drugs started/ withdrawn) nutrition (early in phase of care) • Rest periods between activities • Graded planned gentle exercise • Rescheduling activities for when not drowsy • Seek help with low priority activities • Review sleep and sleep environment 	
	<ul style="list-style-type: none"> • Treat cause if known • Assessment of other symptoms, • Check medication taken or change in medication • Look for issues that may have triggered a decrease in conscious state. • Is client in terminal phase? • Client carer education re symptom management and the need for communication if client status changes • Liaise with LMO, medical specialist for further evaluation and review • <i>P/call next day to assess effectiveness any changes to care that have been made</i> • <i>Visit next day if no improvement.</i> • <i>Visit daily until ESAS 1-3</i> 	<ul style="list-style-type: none"> • Attentive listening to clients experience context and impact on daily life. • Listening for the meaning in client's experience. • Assess for depressions and anxiety • Explore expectations • Exploration of any fears and concerns specific to drowsiness: • Intervention options <ul style="list-style-type: none"> ○ medication/relaxation ○ cognitive behavioural therapy ○ problem-solving therapy ○ interpersonal therapy ○ couple/family therapy ○ mindfulness-based therapy ○ art therapy ○ spiritual care ○ music therapy
7-10	All clinical staff	
	<ul style="list-style-type: none"> • Rapid onset of minutes or hours needs urgent medical review • Monitor delirium (impaired thinking, perception and awareness) associated with drowsiness 	

<ul style="list-style-type: none"> • If drowsiness is sudden check for hypoxia, needs immediate medical follow up • Assessment of symptoms, check medication taken or change in medication • Look for issues that may have triggered a decrease in conscious state. • Is client in terminal phase? • Client carer education re symptom management and the need for communication if client status changes • Visit next day if no improvement. • Visit daily until ESAS 1-3 	<ul style="list-style-type: none"> • Address emotional distress (for the client and their family) caused by drowsiness • Is the client in terminal phase? • Alert nursing same day
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Notes

Appetite

Appetite is the desire for food. It is stimulated by the sight, smell or thought of food and accompanied by the flow of saliva in the mouth and gastric juice in the stomach. Appetite is psychological, dependent on memory and associations, as compared with hunger, which is physiologically aroused by the body's need for food. Chronic loss of appetite is known as anorexia.¹⁸

Loss of weight (cachexia) and appetite (anorexia) are significant concerns for many palliative care patients, and independently predict a poorer prognosis.¹⁹

Score	Expectations – Nursing	Expectations – Counseling and Allied health
1-3	All clinical staff	
	Nutritional support <ul style="list-style-type: none"> • Small serves • In a socially normal situation • Encourage client preference • Avoid strong cooking smells • Pureed food if swallowing is difficult • Provide, discuss “Nutrition in Palliative Care’ (PCV 2008)²⁰ 	
	<ul style="list-style-type: none"> • Education of client and carer as to potential appetite changes and continue to monitor • Refer to dietician if more advice needed 	
4-6	All clinical staff	
	<ul style="list-style-type: none"> • Educate client and carer regarding disease progression and impact on appetite 	
	<ul style="list-style-type: none"> • Nurse to assess the causes of reduced appetite <ul style="list-style-type: none"> ○ mouth problems ○ constipation ○ treatment ○ medication ○ nausea ○ change of smell taste ○ deconditioning/reduces level of activity ○ depression • Provide advice regarding mouth care regularity and products to use • Provide advice regarding fluids and supplements • Refer to a dietician if client if appropriate • Education for client and family regarding medication regularity • Liaise with LMO regarding appetite stimuli drugs if appropriate • Refer client to Diabetes CNC if the client 	<ul style="list-style-type: none"> • Assess for <ul style="list-style-type: none"> ○ depression ○ family, social and cultural expectations related to food, diet, and body weight ○ inappropriate presentation of food ○ meaning attached to the lack of appetite for client and carer • Address emotional distress (for the client and their family) caused by decrease in appetite • CAHT to provide ongoing monitoring at each visit • Consider contributory factors (e.g. pain, financial difficulties, family conflict, social isolation, anxiety) • Provide intervention according to needs assessed

¹⁸ <http://medical-dictionary.thefreedictionary.com/appetite>

¹⁹ Care search <http://www.caresearch.com.au/caresearch/tabid/65/Default.aspx>

²⁰ “Nutrition in Palliative Care” Palliative care Victoria <http://www.pallcarevic.asn.au/>

	<ul style="list-style-type: none"> is diabetic MND clients – explore / discuss PEG feeding if appropriate 	
7-10	All clinical staff	
	<ul style="list-style-type: none"> Ongoing monitoring and reassurance 	
	<ul style="list-style-type: none"> As above Assess cognition and recognition of the need for food and fluid intake Provide intervention according to needs assessed Visit within 24-48 hours if treatment required If nausea or vomiting impeding food intake nurse to visit within 24- 48 hours. Liaise with LMO <ul style="list-style-type: none"> regarding possible need for injectables and /or syringe driver alternate medications to help appetite side effects of certain treatments or medications if client requests ,or thirst is a symptom, explore/discuss sub cut fluids Discuss possible hospital admission if fluid intake tolerance is inadequate If clients condition terminal educations of the carer is required 	<ul style="list-style-type: none"> As above ensuring a collaborative approach with multidisciplinary team Alert nurse 24 hrs of appetite concern As for 4-6

Notes

Wellbeing

Quality of life is an individual's overall appraisal of their situation and subjective sense of wellbeing. Quality of life encompasses symptoms of disease, side effects of treatment, relationships, occupation and social functioning.²¹

Many patients, although not experiencing severe difficulties with any one specific physical symptom or loss of function, may experience minor difficulties across a number of areas. While each problem in itself may not be severe, the cumulative effect of these minor problems may significantly affect their general health, quality of life and psychological well-being.²²

Score	Expectations – Nursing	Expectations – Counseling and Allied health
1-3	All clinical staff	
	<ul style="list-style-type: none"> Ensure understanding of current resources (emotional, spiritual, cognitive, social, physical) that contribute to clients current wellbeing Build preventative plans and strategies for potential decrease in wellbeing using client and family's current resources 	
	<ul style="list-style-type: none"> Assessment of client symptoms and current care plan for management of these is in place Planning/ education of client and carers about self-management of symptoms, and plan for managing these 	<ul style="list-style-type: none"> Assessment of PSS needs Assessment of PSS resources and strengths
4-6	All clinical staff	
	<ul style="list-style-type: none"> Attentive listening to clients experience of wellbeing, its context and meaning for client Reassurance, reinforcing activation of PHH team approach. Ensure an understanding of what informs the client score for well being Explore priority areas to work on with client, to enhance wellbeing score 	
	<ul style="list-style-type: none"> Assessment of client symptoms and care plan in place for management of these. Planning/ education of client and carers about self-management of symptoms, and plan for managing these Client in terminal phase - ensure support to family carers and client Refer to CAHT key worker for advice and to update them on concerns 	<ul style="list-style-type: none"> Assess for depression, anxiety and demoralisation Reflect on what action has had a positive effect on wellbeing in the past Potential for exploration of any underlying fears and concerns specific to wellbeing needs or experiences. Intervention options <ul style="list-style-type: none"> Cognitive Behavioural Therapy Problem-solving Therapy Interpersonal Therapy Couple/ Family Therapy Mindfulness-based Therapy Art Therapy Music Therapy Spiritual care Contact nursing staff if lack of wellbeing is related to physical symptoms

²¹ National Breast Cancer Centre and national cancer Control Initiative. 2003 *"Clinical practice guidelines for the psychosocial care of adults with cancer"*. National breast cancer Centre Camperdown NSW. pp. 212

²² National Breast Cancer Centre and national cancer Control Initiative. 2003 *"Clinical practice guidelines for the psychosocial care of adults with cancer"*. National breast cancer Centre Camperdown NSW. pp. 30

7-10	<p style="text-align: center;">All Clinical staff</p> <ul style="list-style-type: none"> • Attentive listening to clients experience of wellbeing, its context and meaning for client • Reassurance, reinforcing activation of PHH team approach. • Ensure an understanding of what informs the client score for well being • Explore priority areas to work with client on to enhance wellbeing score • What would need to happen to have wellbeing score decreased? 	
	<ul style="list-style-type: none"> • Reassessment of client symptoms and care plans in place for management of these • Any particular symptom of priority for wellbeing to be addressed • Planning/ education of client and carers about self-management of symptoms and plan for managing these • Monitor wellbeing score decrease in relation to other symptoms being managed • Client in terminal phase - support to family carers and client 	<ul style="list-style-type: none"> • Contact nursing staff if wellbeing score is related to physical symptoms • As for 4-6

Notes

Shortness of breath

Breathlessness or dyspnoea is a subjective feeling of difficulty and discomfort with breathing that may or may not be relieved by rest.

There is an interaction between multiple levels of physiological, psychosocial, emotional and environmental factors that impact on every aspect of a person's independence and sense of wellbeing.

It is one of the most feared symptoms in palliative care, and is always associated with some degree of anxiety.

Score	Expectations – Nursing	Expectations – Counseling and Allied health
1-3	All Clinical staff	
	<ul style="list-style-type: none"> • Listen empathically • Address any environmental factors to maximize comfort, reduce anxiety by <ul style="list-style-type: none"> ○ increasing air flow around the client ○ adjusting posture ○ pacing activity • Fact Sheet –Coping with Breathlessness, Diet and Breathlessness, Every day Activities, ²³ 	
	<ul style="list-style-type: none"> • Ensure education of client and carer on preventative strategies 	<ul style="list-style-type: none"> • Ensure PSS wellbeing by <ul style="list-style-type: none"> ○ involvement in decisions ○ addressing anxiety and distress
4-6	All clinical staff	
	<ul style="list-style-type: none"> • Discuss with client and family/carer choices for end of life care 	
	<ul style="list-style-type: none"> • Assessment to determine <ul style="list-style-type: none"> ○ what stage client is at on illness trajectory ○ goals of care ○ underlying causes ○ those that are reversible, sudden acute or chronic ○ frequency ○ factors exacerbating/relieving it ○ degree that it affects ADLs ○ psychosocial factors, associated anxiety • Provide education to relieve symptoms to both client and carer • Provide a written action plan in the event of exacerbation or panic attack • Liaise with GP for reversible psychological or drug related causes • Referral to O/T or Physiotherapy for functional related causes • Have oxygen sats checked and refer for O2 in the home if appropriate • Liaise with Counseling and allied health for psychological related causes within 24 hrs • Follow up interventions agreed to within 24 hrs 	<ul style="list-style-type: none"> • Explore fears and meaning for client (impending death, fear of suffocation) • Assess impact on restriction to activities, functional abilities and quality of life • Assess for anxiety • Teach relaxation techniques <ul style="list-style-type: none"> ○ music ○ massage ○ relaxing touch ○ guided imagery ○ meditation • Reassurance • Explore presence of panic attacks • Provide a written action plan in the event of exacerbation or panic attack • Alert Nursing within 24 hrs

²³<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Symptomssideeffects.aspx>

7-10	<p style="text-align: center;">All Clinical staff</p> <ul style="list-style-type: none"> • Education of client and carer as to changes in breathing e.g. Cheyne-Stokes if client in terminal phase 	
	<ul style="list-style-type: none"> • As for 4-6 • Discuss and guide in end stage care regarding O2, rate and change in breathing and positioning 	<ul style="list-style-type: none"> • As for 4-6

Notes

Constipation

Constipation is infrequent or difficult defecation. It is the passage or reduced number of bowel actions, which may or may not be abnormally hard, with increased difficulty. Constipation implies a significant variation from the normal bowel habit for the individual client.²⁴

Chronic constipation is one of the commonest side effects of opioids, and occurs in 40 – 70% of patients treated for cancer pain with oral morphine.²⁵

Spurious diarrhoea - One of the most typical symptoms of constipation is overflow diarrhea, it occurs when the faeces become so hard that they cannot be expelled and faecal fluid will flow around the block.²⁶

Score	Expectations – Nursing	Expectations – Counseling and Allied health
1-3	All Clinical staff	
	<ul style="list-style-type: none"> ● Aim for bowel care is to be proactive rather than reactive ● Preventative measures <ul style="list-style-type: none"> ○ ensure adequate hydration ○ optimise level of fibre ○ encourage general activity ○ ensuring privacy and comfort, ○ education on the importance of prevention both for client and carer 	
	<ul style="list-style-type: none"> ● If the client complains of constipation or defecates less than three times per week, assessment of bowel habits is warranted ● Review diet ● Address reversible factors ● Avoid bulk forming laxatives ● Check each visit that client has a management plan and is taking aperients ● Education of client/carer regarding aperients and the need to take these increasing awareness of how they work ● Educate client/carer regarding medication side effects ● Encourage self-management and to contact if concerned 	<ul style="list-style-type: none"> ● Psychosocial impact and intervention in response to symptoms of constipation ● Social isolation due to unpredictability of bowel response ● Embarrassment, shame, grief, irritability, depression ● Dependant on client diagnosis-resultant fears/concerns, potential for fixated behaviours prompted by fear of future constipation ● Attentive listening to clients experience and its context. Listening for the meaning in client’s experience ● Reassurance, reinforcing activation of PHH team approach ● Strengthens approach of reflecting on what action has had a positive effect, (what is working well and what is not working) ● Flag concern if voiced at visit ● Positive reinforcement of medication taking and suggestions from nursing staff
4-6	All clinical staff	
	<ul style="list-style-type: none"> ● Ongoing monitoring <ul style="list-style-type: none"> ○ monitor clients satisfaction with bowel pattern ○ client and carer education ○ encourage lifestyle changes within clients limits ○ increase fluid intake ○ encourage mobility ○ ensure privacy and comfort to allow a patient to defecate normally²⁷ 	

²⁴ Woodruff, R. 2005 *“Palliative Medicine 4th Edition”* Oxford University Press

²⁵ Care search <http://www.caresearch.com.au/caresearch/tabid/65/Default.aspx>

²⁶ <http://pallipedia.org/term.php?id=878>

	<ul style="list-style-type: none"> • An assessment of constipation in the palliative context needs to address opioid induced bowel dysfunction • Assessment <ul style="list-style-type: none"> ○ what is normal for the client ○ is the client symptomatic or worried ○ are there any signs of bowel obstruction? ○ bowel sounds present ○ what works for the client? ○ phase of care ○ pain and discomfort associated • Is client on opioids- if so needs aperient regime • Liaise with LMO and alter medications if needed • Educate client and carer regarding the changes and the need to continue • Refer to continence or stoma therapist if required • <i>P/call next day to assess effectiveness of change of aperients</i> • <i>Visit next day if BNO</i> • <i>Visit daily till bowels well opened and ESAS 1-3</i> 	<ul style="list-style-type: none"> • Assess for mood changes (exacerbation of depression/irritability) • Explore any underlying fears and concerns specific to constipation • Check whether constipation as a physical experience creates a pathway for client to identify emotional/spiritual or psychological needs or experiences. e.g. via the metaphor of “stuckness” • Intervention options <ul style="list-style-type: none"> ○ supportive counselling, including problem solving ○ relaxation techniques ○ music therapy ○ art therapy ○ spiritual care ○ cognitive behavioural therapy ○ family / relationship counselling ○ facilitate open communication ○ mindfulness-based therapy • <i>Contact nursing staff same day</i>
7-10	All clinical staff	
	<ul style="list-style-type: none"> • Other possible contributing factors include: <ul style="list-style-type: none"> ○ medications ○ decreased oral intake, dehydration, alterations in diet ○ metabolic abnormalities, decreased mobility, weakness, difficulty accessing toilet facilities ○ bowel obstruction ○ neurological disorder or autonomic neuropathy ○ depression ○ proximity to death • Are they in the terminal phase? If so and client is not distressed no action is needed • Liaise with LMO and alter medications if needed both oral and rectal and administer as required • Educate client and carer regarding the changes and the need to continue • <i>Daily visit till bowels well opened and ESAS 1-3ESAS</i> 	<ul style="list-style-type: none"> • <i>Contact nursing staff same day</i>

²⁷ Larkin PJ, Sykes NP, Ellershaw JE, Elsner F, Eugene B, Gootjes JRG, “*The management of constipation in palliative care: clinical practice recommendations*” Palliative Medicine 2008; 22: 796–807

Insomnia

Insomnia is the inability to obtain an adequate amount or quality of sleep. The difficulty can be in falling asleep, remaining asleep, or both. People with insomnia do not feel refreshed when they wake up. Insomnia is a common symptom affecting millions of people that may be caused by many conditions, diseases, or circumstances.²⁸

Insomnia is multifactorial, causes can be physical, drug related, psychological, psychiatric drug withdrawal or environmental and all need to be assessed and considered.

Score	Expectations - Nursing	Expectations - Counseling and Allied health
1-3	All clinical staff	
	Prevention <ul style="list-style-type: none"> • Maintain as regular a sleep pattern as possible • Avoid unnecessary time in bed during the day • Receive as much stimulation (cognitive and physical) during day hours (even if confined to bed) • Avoid napping if possible • Avoid stimulating substances (caffeine nicotine) • Maintain adequate pain relief during the night 	
	<ul style="list-style-type: none"> • Planning/ education of client and carers about self-management of symptoms and plan for managing these • Assess sleeping patterns at each visit • Review medications effects and time of day taken 	<ul style="list-style-type: none"> • Planning/ education of client and carers about self-management of symptoms and plan for managing these • Assess sleeping patterns at each visit
4-6	All Clinical staff	
	<ul style="list-style-type: none"> • Reversible contributing factors <ul style="list-style-type: none"> ○ depression, anxiety ○ pain ○ delirium ○ dementia ○ obstructive sleep apnoea, or other primary sleep disorder ○ dyspnoea, cough, pleural effusion ○ nausea, vomiting ○ movement disorders e.g., restless legs, akathisia ○ night sweats ○ pruritis (itch) ○ environmental disruption, especially for in-patients ○ changed activity patterns ○ altered circadian rhythm ○ reduced bed mobility, and physical problems that limit comfortable sleeping position ○ medications e.g., steroids ○ incontinence or nocturia²⁹ 	

²⁸ <http://medical-dictionary.thefreedictionary.com/insomnia>

²⁹ Care search <http://www.caresearch.com.au/caresearch/tabid/65/Default.aspx>

	<ul style="list-style-type: none"> ● Insomnia impact <ul style="list-style-type: none"> ○ affects physically ○ ability to cope with stress ○ emotional effects ○ may limit ability to carry out normal activities ○ ability to concentrate ○ contribute to the burden of caring creating sleep problems for the carer that can continue into bereavement 	
	<ul style="list-style-type: none"> ● Assessment of insomnia, <ul style="list-style-type: none"> ○ physical symptoms ○ medications ○ reversible factors ○ environmental factors ○ PSS factors ● Liaise with LMO if needed for medication alteration or night sedation if needed ● Educate client and carer re changes and how they may work. ● Daily visits or phone support while symptoms unstable or until ESAS 0-3 ● CAHT support as needed and required by family /client 	<ul style="list-style-type: none"> ● Assess in the following areas ● Psychological- anxiety depression fear ● Cognitive– concern worry ● Behavioral –inactivity boredom ● Emotional – anger , fear ● Impact on client and on carer ● Mood changes (exacerbation of depression/irritability) ● Explore respite options for carer ● Refer Client Resource Advocate if agreed ● Access funding if needed ● Intervention options <ul style="list-style-type: none"> ○ medication/ relaxation ○ cognitive behavioural therapy ○ problem-solving therapy ○ interpersonal therapy ○ couple/ family therapy ○ mindfulness-based therapy ○ art therapy ○ spiritual care ○ music therapy ● Contact nursing staff if physical symptoms prevent client from sleeping
7-10	All Clinical staff	
	<ul style="list-style-type: none"> ● Explore respite options for carer 	
	<ul style="list-style-type: none"> ● Reassess for symptom changes preventing good sleeping patterns ● Liaise with LMO if needed for medication alteration ● Contact counsellor case worker if psychosocial support needed ● Daily visits or phone support while symptoms unstable or until ESAS 0-3 	<ul style="list-style-type: none"> ● As above ● Support to family /client if in terminal phase as required

Notes

Notes about family carers

For home based palliative care, an essential component “is the availability of a family carer who is willing and able to take on the responsibility”.³⁰

They will need:

- Time and support to negotiate (and renegotiate) the decision for home care
- To feel that their needs are given equal consideration
- Respected for their caregiving knowledge and contributions
- Feel that they can adequately do the caring

Roles that carers take on	How we can support
Physical care	
<ul style="list-style-type: none"> • Help with ADLs • Bathing, toileting, hygiene • Wound prevention • Repositioning, lifting transferring • Injection administration 	<ul style="list-style-type: none"> • Education regarding safe procedures for lifting turning, changing beds, hygiene • Resourcing and referring for practical support • Recognise efforts and acknowledge their experience • Material aids equipment
Symptom management	
<ul style="list-style-type: none"> • Often more than one symptom at a time • Constant assessment • Medication preparation, management • Distraction, massage • Catheter bowel care • Wound dressing 	<ul style="list-style-type: none"> • Clarity in what areas of care they are comfortable with and areas they would prefer not to participate in • Individualised information as to what can be expected and how to access support simply • Education in comfort care • Education and confidence building in medication management
Psychological Spiritual and Emotional support	
<ul style="list-style-type: none"> • Satisfy emotional needs of client 	<ul style="list-style-type: none"> • Assistance in dealing with negative experiences in caring, in relationships • Conflict resolution skills • Develop collaborative relationships • Effective emotional support • Individual time to express needs and concerns
Social and practical support	
<ul style="list-style-type: none"> • Practical social support <ul style="list-style-type: none"> ○ meal preparation ○ house hold duties ○ social and recreational needs ○ liaison between family, friends ○ financial management 	<ul style="list-style-type: none"> • Supports to prevent social isolation • Volunteer support • Mental breaks and respite • Discuss planned intermittent respite • Support in developing plans to manage visitors • Information regarding online social supports • Carer support group • Funding assistance
Coordinator of care / Advocate	
<ul style="list-style-type: none"> • Managing appointments • Keeping records • Pre death post death planning • Take a spokesperson / buffer role • Proxy • Decision maker 	<ul style="list-style-type: none"> • Assistance in preparing for the complex task of understanding the health care system • Continuity of care • Carer support group

³⁰ Hudson, P., Payne, S. 2009 *Family Carers in Palliative Care* Oxford university Press

Self-Assessment of Symptoms for Clients and Carers with low Health Literacy or low English Fluency

Self-assessment of symptoms relies on the assumption that clinicians and clients/carers have a similar understanding of the symptoms and the ratings.

As is well understood:

- culture influences the way illness is experienced and expressed
- language fluency has an impact on communication
- low language fluency can cause misunderstandings
- health literacy levels impact on how a person understands and acts on health information

In self-assessment tools, these issues can play a larger role than in other areas of communication between clinician and client.

A number of strategies can assist in improving the efficacy of self-assessment tools for all clients:

Skill / Attitude	How to achieve this
<ul style="list-style-type: none"> • Be aware of your own cultural framework and how this can affect interaction with clients in the health context: 	<ul style="list-style-type: none"> • Undertake cultural diversity training • Ask the client about their understanding of the illness, their goals and expectations and negotiate any differences of opinion
<ul style="list-style-type: none"> • Utilise Language services appropriately 	<ul style="list-style-type: none"> • Undertake training on how to work with interpreters • Have appropriate policies and procedures in place
<ul style="list-style-type: none"> • Understand the impact on health literacy of self-assessment tools 	<ul style="list-style-type: none"> • Learn about the “teach back” technique³¹

Further information, resources and support at the Centre for Culture Ethnicity and Health:

www.ceh.org.au

³¹ DeWalt DA, Callahan LF, Hawk VH, Broucksou KA, Hink A, Rudd R, Brach C. *Health Literacy Universal Precautions Toolkit*. (Prepared by North Carolina Network Consortium, The Cecil G. Sheps Center for Health Services Research, The University of North Carolina at Chapel Hill, under Contract No. HHS290200710014.) AHRQ Publication No. 10-0046-EF) Rockville, MD. Agency for Healthcare Research and Quality. April 2010.

Modified Edmonton Symptom Assessment System – Revised

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 Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst possible Nausea
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
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst possible Drowsiness
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible Lack of Appetite
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst possible Wellbeing
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible Shortness of Breath
No Constipation	0	1	2	3	4	5	6	7	8	9	10	Worst possible Constipation
No Insomnia <i>(Insomnia = lack of sleep)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Insomnia
No <i>Other Problem (for example oral thrush)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible

Completed by (check one):

- Patient
- Family Caregiver
- Health care professional caregiver
- Caregiver - assisted

Appendix 1

Karnofsky (Australian) Performance Scale

The Australia-modified Karnofsky Performance Scale assesses clients physical functioning and performance. The score is assigned by a clinician based on observation of a client's ability to perform common tasks relating to activity, work and self-care. It can be used to indicate prognosis, and is applicable in Community palliative care

Triggers:

A Karnofsky assessment of 60 or below may trigger a family conference to discuss functional status and disease progression ³²

The screenshot displays the PaICare web application interface for a patient named Mr. TEST PATIENT. The page shows various assessment categories such as 'Additional Assessments' and 'RUG Assessment'. The 'Karnofsky Score' field is highlighted in yellow, and a dropdown menu is open, showing the following scale:

- 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
- 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

The current score is set to 'Not Assessed'. The interface also includes a 'Save' button at the bottom of the assessment form.

Notes

³²<http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129133.pdf#page=32>

Problem severity score

The problem severity score is a screening tool used to measure the severity of physical and psychological problems. It has four domains, the first three are client specific and the fourth domain measures family/carer problems associated with the clients condition. The score triggers a more in-depth assessment.

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 intervention³³

The screenshot displays the PalCare web application interface for a patient named Mr. TEST PATIENT. The main content area is titled 'Palliative Assessment' and contains several assessment rows. A dropdown menu is open for the 'Problem Severity for Psychological Spiritual' row, showing options: Not Assessed, Absent, Mild, Moderate, and Severe. The 'Problem Severity for Pain' row is highlighted in yellow. The 'RUG Assessment' section includes rows for RUG-Bed Mobility, RUG-Toileting, RUG-Transfers, RUG-Eating, and RUG-Total, all currently set to 'Not Assessed'. A 'Save' button is located at the bottom of the form.

Notes

³³<http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129133.pdf#page=33>

RUG - ADL

The Resource Utilisation Groups – Activities of Daily Living (RUG-ADL) assesses the level of functioning dependence, based on what a person actually does, rather than what they are capable of doing.

Triggers:

- This assessment may be used to describe acuity and may be used to justify additional staffing.
- In a community service a high (16-18) RUG-ADL may trigger a referral for a hospital bed or aged care facility placement.
- RUG-ADL assessment changes may trigger Occupational Therapy assessment or increased equipment in the community or inpatient setting³⁴

The screenshot displays the PalCare web application interface for a patient named Mr. TEST PATIENT. The interface is divided into several sections: Client, Additional Assessments, and RUG Assessment. The RUG Assessment section is highlighted in yellow and includes the following fields:

- RUG-Bed Mobility: Not Assessed (dropdown menu open showing options: 1 - Independent or supervision only, 3 - Limited physical assistance, 4 - Other than two persons physical assist, 5 - Two-person physical assist)
- RUG-Toileting: Not Assessed
- RUG-Transfers: Not Assessed
- RUG-Eating: Not Assessed
- RUG-Total: Not Assessed

A 'Save' button is located at the bottom of the RUG Assessment section. The interface also shows a navigation menu on the left with options like Client, Assessments, Palliative Assessments, Pain Assessment, Optional, Clinical, Administration, and Episodes. The top of the page displays the patient's name, DOB (11/08/1972), Age (42), and ID (9000006002).

Notes

³⁴ <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129133.pdf#page=33>

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