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# Palliative Care in the Community

PRACTICE GUIDELINES

## COMPETENCIES

9 / 10
Communication

8 / 10
Critical Thinking & Decision Making

7 / 10
Accountability

7 / 10
Teamwork & Collaboration

6 / 10
Leadership

## PURPOSE

This guideline is to assist:

- Providers of care and service provision for clients who have plans for or in the process of receiving palliative care.
- Providers engage clients in individualised and goal directed care as aligned to their current and planned requirements.
- Providers engage in a timely and wholistic communication and engagement process with all key stakeholders to achieve the best outcome for the clients.

## SCOPE

This guideline applies to the provision of paid support services in the community. They are relevant Australia-wide or when a participant is travelling overseas with their Australian team of support worker/s.

## DISCLAIMER

*This guideline is provided to help guide best practice in the disability, aged care and community support industry. This information does not in any way replace legislative, regulatory, or contractual requirements. Users of this document should seek appropriate expert advice in relation to their circumstances. ACIA does not accept any liability on the use of this guideline.*

## DESIRED OUTCOME

- To maintain a quality and safe standard of service delivery support.
- Ensure that clients goals and choices are respected
- Achieve a person centred approach to the client and their carer/ family.
- Ensure that key stakeholders are engaged an well communicated throughout the process of palliative care.
- To support optimal pain and comfort management for the client.
- To support workers psychological and emotional wellbeing whilst they care for a client undergoing palliative care.

# BACKGROUND

- Palliative Care is an essential element of health that is defined by World Health Organisation (WHO) as "an approach that improves the quality of life of clients and their families… by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (2020). Palliative Care is further defined by Palliative Care Australia (2018) as "person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life". Palliative Care (World Health Organisation, 2020):
    - provides relief from pain and other distressing symptoms;
    - affirms life and regards dying as a normal process;
    - intends neither to hasten or postpone death;
    - integrates the psychological and spiritual aspects of client care;
    - offers a support system to help clients live as actively as possible until death;
    - offers a support system to help the family cope during the clients' illness and in their own bereavement;
    - uses a team approach to address the needs of clients and their families, including bereavement counselling, if indicated;
    - will enhance quality of life, and may also positively influence the course of illness; and
    - is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
- The WHO estimates that almost 57 million people are requiring palliative care annually, of which 26 million are near end of life (2020). Of these the majority are adults of over 50 years of age (67%) and children represent 7% (World Health Organisation, 2020). Current service provision for palliative care, is only providing care for seven million worldwide, representing only 12% of the total need (World Health Organisation, 2020), with further WHO guidance indicating that by 2060 the need for palliative care at the end of life is expected to double (2020).
- Palliative Care is experienced in adults mostly due to the largest single disease, Cancer (World Health Organisation, 2020). This can be further highlighted by:
    - Malignant Neoplasms (28.2%)
    - HIV Disease (22.2%);
    - Dementia (12.2%);
    - Cardiovascular Diseases (14.1%);
    - Injury, poisoning and external causes (6.4%); and
    - Lung Diseases (5.0%).

# DEFINITIONS & SUPPORTING INFORMATION

**Community Supports and/or Services** is defined as the provision of paid supports and services in a service user's home or community. It includes but is not limited to, the following activities of daily living:

- personal care or support
- housework or domestic assistance
- transport assistance
- community access
- social support
- nursing services
- clinical supports
- gardening and home maintenance
- palliative care
- respite care

**Support Worker** - A paid person who assists people to perform tasks of daily living so as to participate in social, family and community activities in the person's home and their community. Support Workers have been commonly known in the past as attendant care worker, disability worker, aged care worker, community worker, homecare worker, care worker or paid carer.

**Service Provider** - Organisation or person accountable for the delivery of supports to Clients.

**Carer** - a person that provides supports to the Client at no cost (generally family or friend).

**Support Worker Competency** - trained and assessed as competent by a Registered Nurse or a person deemed competent by the provider to safely and appropriately perform a specified task as a support worker.

**Client** means the service user, participant, user, care recipient, consumer or person receiving the nursing or support services.

**Plan** means a Service Plan, Support Plan or Individual Plan (however titled – the plan) is a document developed in response to a request for service. It is developed by a Registered Nurse or a person deemed competent by the provider from the service provider, prior to the commencement of service delivery. It outlines the expected outcomes of the requested care/services and the tasks, duties and interventions required to meet the care and service needs of the client (within the parameters of the funding program). The plan guides and directs the individual support worker or Registered Nurse in their day-to- day delivery of the services.

**Registered Nurse** means a person who has completed the prescribed educational preparation, demonstrated competence for practice, and is registered and licensed with the Australian Health Practitioner Regulation Agency (AHPRA) as a Registered Nurse.

**Competent** means having been trained and assessed by a registered nurse or enrolled nurse or approved assessor as competent to safely and appropriately perform a specified task.

**Pain Management**- Pain in persons who are experiencing stages of palliative care is a common problem. Pain symptoms are estimated in 21% of days when a person in suffering palliative care symptoms (World Health Organisation, 2020). Of which, 84% of the worlds populations lacks adequate access to opioid medication for pain management (World Health Organisation, 2020).

**Advance care directive** refers either to a common law document about future health preferences, to legislated instruments to record directions, or as a collective term for documents containing health directives, appointment of an enduring guardian and common law directives (parliamentary committees, 2013).

**Advance Health Directive** - In Queensland, a document in which an adult may give directions about their future health care preferences, and may appoint an attorney/s to make decisions on their behalf if the directions are inadequate.(Parliamentary Committees, 2013)

**Advance Care Planning** - A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate their own decisions. (Parliamentary Committees, 2013).

**Advocacy** - Independent provision of information, advice, and support to assist a client in negotiations by their request.

**Bereavement** -Bereavement is the total reaction to a loss and includes the process of 'recovery' or healing from the loss. Although there are similarities in people's responses, there are also marked differences. Each person will grieve and 'recover' in her / his own way.

**Dignity Of Risk** - Dignity of Risk is a principle of community living that refers to the right of the individual to choose to take some risk in engaging in life experiences.

**End Of Life Care** -The phase of palliative care that occurs closer to the end of life. Some clinicians consider palliative care during the last weeks or days of life to be end of life care; others consider that the period of the last three, six or 12 months of life to be approximate time for end of life care. (Parliamentary Committees, 2013).

**Goals** - Desired outcomes of the supports provided for the Client as determined by the Client. These are documented in the support plan and may be used to evaluate the effectiveness of supports provided.

**Life-Limiting Condition or Illness** - A condition or illness where it is expected that death will be a direct consequence of the specified condition or illness. Palliative Care Australia advises in its glossary of terms that the use of 'terminal condition' is preferred to 'life-limiting condition'. When discussing paediatric palliative care, however, life-limiting condition is the more commonly used term and it is used in this report in that context (Parliamentary Committees, 2013).

**Palliative Care** - The World Health Organization (WHO) definition recognises that palliative care may be provided by non-specialists; this definition is also used in the National Palliative Care Strategy. Palliative care is defined by the World Health Organisation (2020) as: .... an approach that improves the quality of life of clients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes. In addition, the WHO states that palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

**Palliative Approach** - An approach to health care that aims to improve the quality of life of individuals with a terminal illness, and includes symptom management, active comfort care and addressing physical, cultural, psychological, social, and spiritual needs. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying (Commonwealth of Australia, 2006). A palliative approach is not delayed until the end stages of an illness or the ageing process. Instead, a palliative approach provides a focus on active comfort care and a positive approach to reducing an individual's symptoms and distress, which facilitates residents and their families understanding that they are being actively supported through this process.

**Terminal Condition** - A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing. Palliative Care Australia advises in its glossary of terms that the use of 'terminal condition' is preferred to 'life-limiting condition' (Parliamentary Committees, 2013).

# GUIDELINE

## Principles for Palliative Care for Clients with Complex Needs

Palliative Care for clients with complex needs should be focused on:

- Integrating palliative care into all relevant care and goal planning decisions
- Respectful of the choices, rights, and diversity that is represented in an individual;
- Documenting advance care directives or plan;
- Carrying out palliative care in a safe and cared for manner that is with dignity and respect;
- Ensuring planning and support is in place for carers needs;
- Developing workforce knowledge of palliative care and its practices;
- Multidisciplinary approach, including timely referral to a medical professional;
- Ensuring the workforce is adequately capable and resourced to meet the persons palliative care needs;
- Proactively committed to removing barriers to the delivery of adequate palliative care;
- Managed in alignment with best practice evidence;
- Occurs in an environment that best meets the needs and wishes of the person; and
- Ensuring no-one dies alone.

## Principles for Pain Management for Clients with Complex Needs

Principles for managing and supporting pain in clients with complex needs should consider:

- All clients have pain thoroughly assessed, and effective measures introduced and monitored to manage their pain, if present.
- Care and supports will:
  - promptly consult with and assess clients for pain;
  - investigate the cause of any pain if this is not already known;
  - develop a plan to manage their pain in consultation with their medical practitioner and their client representative (as appropriate);
  - develop measures to alleviate the cause of the pain;
  - use a multidisciplinary team approach for pain management and make referrals to specialist teams as required in a timely manner;
  - review a client's pain by observing and assessing verbal and non-verbal communication throughout daily care activities;
  - use non-chemical measures of pain relief where possible;
  - administer any prescribed medications and evaluate the effectiveness in a timely manner; and
  - document pain management strategies and evaluate their effectiveness.

## Support Strategies

### Presence

A core element to developing relationships with clients is the concept of presence. This, together with clinical expertise, emotional support, and ongoing communication (Carey et al., 2021; Dahlin et al., 2016) requires a strong commitment from all stakeholders. The concept of being completely present or further encapsulated within the area of mindfulness is frequently compromised when the person is not core to the planning and care of the individual. Being present cannot be undertaken when task-based strategies are fostered within a care milieu, as tasks and actions frequently override the core elements of the persons needs and goals. Presence requires a commitment to engaging in active listening, reflective communication approaches and enabling an emotionally supportive and therapeutic relationship.

### Person Centred Care

Palliative care needs to be person centred in their approach. A Person-centred framework should include areas such as:

- Shared values (McCormack et al., 2018; McCormack & McCance, 2017);
- Multidisciplinary team (McCormack et al., 2018; Parliamentary Committees, 2013); and

- Empowerment of staff to act in a person-centred manner (McCormack et al., 2018).

A person is a thinking, feeling, interpreting, social, and creative being with the opportunity for lifelong development, even if the time ahead is limited (McCormack et al., 2018). Person-centred care considers a co-design approach whereby a genuine engagement is constructed to gain knowledge about how a person is really experiencing the situation despite all its complexities and unknowns. It considers their choices, beliefs, values, knowledge, and past experiences to inform a shared view of what approach best suits the person at that time (Osterlind & Henoch, 2021).

## Knowing the person

The element of knowing a person goes beyond the more traditional assessment questions, but truly engaging with a person's views, choices and lived experiences to understand what is important to them. Understanding these values and their core belief systems will assist the person-centred approach to ensure that it is as meaningful as possible for all persons involved. Each person involved needs to be truly understood. It is important to gauge the journey that the individual is on, what is of most value, most meaningful to them, and where supports or resources need to be engaged to enable the individual journeys that each person involved is on.

A concept that is well considered when acknowledging the importance of knowing the person is the relationship between self-image and how one expresses their own values and preferences. The core concept of self-image must be first acknowledged to who that person sees in themselves and the value they bring to both themselves and to the people they influence or have influenced in their life. Living with one's best self-image provides possibilities of real choice as to how they wish to live the rest of their days and moments, preserve memories both for themselves and others, and engage in the most meaningful activities or choices. Whilst self-image is relevant to their present journey, it is further reflected in how they wish to express their own life story and the meaning of life as they view it. (Osterlind & Henoch, 2021)

## Carer Support

The role of the unpaid carer which is largely represented by family and / or friends continues to play a considerable role in the care and support for people in need of palliative care. With a growing emphasis from public policy to increase home based palliative care, the rising pressure on carers cannot be ignored. Parliamentary Committees (2013) acknowledged this shift may be exacerbated by a lack of assessment of carers' needs, challenges in accessing timely and relevant resources or services, difficulty maintaining employment, stress related to the financial, emotional, or physical health, and inadequate respite availability or access to such. Further work needs to be dedicated to ensuring the role of carers is adequately supported and considered in overall care and service provision of a person receiving end of life care.

## Cultural and Spiritual Sensitivity

Cultural diversity is increasingly providing challenges in how one can adequately support the needs of a person experiencing palliative care. The choices and wishes of a person cannot be categorised by distinguishing a particular religious or spiritual approach. Rather, palliative care approaches seek to understand what is important for that person given their experiences, background, and beliefs. Often health professionals are challenged by a lack of knowledge of cultural and spiritual norms, and resources to support some needs, can further challenge the goals for a person, however, critical to this process is having conversations early and supporting a person's choices as best as possible.

A further gap in the provision of adequate cultural diversity is the lack of targeted training for the workforce on culturally specific issues related to palliative care (Parliamentary Committees, 2013).

## Advance Care Planning

Valuing a person's core wishes whether it is through an advance care directive, or a plan is often the most confronting and yet equally empowering conversation that can be had. Encouraging an open and transparent conversation that is then clearly documented and communicated with key members of the family and team provides for an empowered journey. Documenting these choices and preferences as early as possible is highly encouraged, along with the need to review them in a timely and regular manner. Whilst documentation templates are readily available to facilitate a structured and comprehensive discussion, it is equally as important to ensure that one truly knows the person and what is important to them to facilitate the journey that is meant for them and their loved ones.

### Palliative Care Planning

A palliative care assessment and care plan are to be completed by a Registered Nurse, Nurse Practitioner or Medical Practitioner in close consultation with the client, client representative (and other family or friends as per the clients' request), plus other key stakeholders (including relevant staff, Medical Practitioner, Palliative Care Team, Geriatrician). The care planning must:

- be specific and highly individualised;
- take a wholistic view of care;
- strongly consider the cultural and spiritual needs of the clients and their families;
- strongly take into account physical needs such as pain management and oral care;
- strongly promote privacy and dignity;
- strongly reflect client/representative choice, including in relation to cultural and spiritual needs;
- reflect the provision of emotional support;
- reflect the provision of emotional support to the client's family/friends (as appropriate);
- review one's pain on a continual basis, both that is vocalised or expressed and that which is not;
- be regularly reviewed and adjusted throughout the stages of palliation;
- consider environmental adjustments such as provision of flowers, music in the room, adjustment of lighting, aromatherapy, etc.; and
- consider the palliative approach.

Staff are to be familiar with any specific needs (including cultural and spiritual needs) and are to respect these wishes at all times. Where a palliative care plan is no longer required due to recovery, the care plan is to be archived but kept for future reference.

All visitors are to be extended every courtesy. This may (but not necessarily must) include:

- contacting representatives (such as relatives) when changes in a client's condition occurs;
- developing rapport with visitors;
- encouraging visitors to remain with the client if they wish;
- ensuring time in a quiet area is made available;
- providing food and refreshments at regular intervals;
- providing extra bedding if they wish to remain overnight; and
- providing information on the funeral service's bereavement counselling program (if available).

Staff with appropriate skills are encouraged to sit with a client receiving palliative care to reduce loneliness and isolation.

## Essentials for Palliative Care Services

The WHO (2020) has suggested the minimum requirements for safe and effective palliative care and pain relief interventions to support psychological and physical symptoms include:

- Specific Medications as listed in the WHO Atlas (pg39)
- Medical Equipment
    - Pressure relieving mattress
    - Nasogastric draining or feeding tube
    - Urinary catheters
    - Locked opioid medication box
    - Flashlight
    - Continence supplies
    - Oxygen
- Human Resources depending on the referral, services, and environment:
    - Doctor
    - Nurse
    - Social worker and counsellor
    - Psychiatrist, psychologist, or counsellor

    - Physical therapist
    - Pharmacist
    - Community health worker
    - Clinical support staff
    - Non-clinical support staff (eg cleaning)

Other requirements that should be considered include:

- Client education (Parliamentary Committees, 2013)
- Medical Equipment
    - Manual handling equipment (Parliamentary Committees, 2013)
    - Access to subcutaneous infusion devices (Parliamentary Committees, 2013)
- Human Resources as depending on the referral, services, and environment:
    - Specialist bereavement counselling (Parliamentary Committees, 2013)
    - 24 hour on call services (Parliamentary Committees, 2013)
    - Access to pastoral / spiritual care (Parliamentary Committees, 2013)
- Culturally specific resources and supports including community engagement;
- Planning for respite to facilitate rest and healing for loved ones actively engaged in the journey;
- Comprehensive assessment and conversations which truly engage meaningful understanding of the persons choices, preferences, and beliefs.

## Assessment and Management

HammondCare (2014; MacLeod et al., 2018) presents a comprehensive summary of guidelines for clinical management and symptoms control (Commonwealth of Australia, 2006).

| *Focus Area* | *Symptoms* | *Possible Complications* | *Possible Interventions* |
|---|---|---|---|
| *Pain* | Pain assessment identifies pain | • Disturbed rest<br>• Reduced quality of life<br>• Anxiety and depression | • Pain assessment<br>• Treat cause<br>• Multidisciplinary approach<br>• Medication<br>• Behaviour modification<br>• Complementary therapies |
| *Oral Care* | • Dry mouth<br>• Coated tongue<br>• Pain<br>• Dysphagia (difficulty swallowing) | • Poor oral hygiene<br>• Poor mental state<br>• Altered nutritional status<br>• Inability to swallow | • Dysphagia Diet<br>• Oral assessment<br>• Mouthwashes<br>• Diet and hydration<br>• Medication form |
| *Respiratory* | • Dyspnoea (Breathlessness)<br>• Cough<br>• Chest tightness<br>• Wheezing<br>• Hiccup | • Airway obstruction<br>• Impaired lung performance<br>• Increased ventilator demand<br>• Decreased lung function<br>• Respiratory infection | • Treat cause<br>• Address anxiety and fear<br>• Repositioning<br>• Drainage<br>• Complementary therapies<br>• Physiotherapy<br>• Medication |
| *Cardiovascular* | • Retained Secretions<br>• Haemoptysis | Build-up of secretions | • Repositioning<br>• Medication<br>• Suction (avoid if possible)<br>• Stay with client |

| *Focus Area* | *Symptoms* | *Possible Complications* | *Possible Interventions* |
|---|---|---|---|
| *Bowels* | - Constipation | - Underlying disease<br>- Dehydration<br>- Depression<br>- Pain<br>- Obstruction<br>- Concurrent medical problems<br>- Impaction | - Medication<br>- Diet<br>- Hydration<br>- Prevention<br>- Exercise<br>- Laxatives<br>- Treat cause |
|  | - Diarrhoea | - Underlying cause<br>- Obstruction<br>- Medication<br>- Anxiety<br>- Malabsorption<br>- Food intolerance | - Maintain anal skin integrity<br>- Treat cause<br>- Rest bowel<br>- Withhold laxatives<br>- Medication |
|  | Intestinal Obstruction |  |  |
| *Cognition* | - Delirium | - Underlying cause<br>- Infection<br>- Medication<br>- Hypoxia<br>- Anaemia | - Treat cause<br>- Relieve symptoms<br>- Ensure safety<br>- Medication<br>- Psychological interventions<br>- Prevent sensory stimulation<br>- Symptom Control |
|  | - Insomnia | - Poor symptom control<br>- Medication<br>- Drug withdrawal<br>- Environmental changes | - Good sleep habits<br>- Relaxation techniques<br>- Medication<br>- Treat cause |
|  | - Drowsiness | - Organ failure<br>- Fatigue<br>- Infection<br>- Medication |  |
| *Skin* | - Pressure area care | - Decreased mobility<br>- Pain<br>- Reduced Positioning | - Pressure relieving aids<br>- Dressing<br>- Review nutritional status<br>- Repositioning<br>- Protect skin integrity |
|  | - Sweating | - Medication<br>- Pain<br>- Lymphoma | - Treat cause<br>- Medication<br>- Client education<br>- Referral to professional |
|  | - Lymphoedema | - Temperature changes<br>- Pain / discomfort<br>- Altered sensation<br>- Risk of infection | - Clear infection<br>- Regular assessment<br>- Compression banging<br>- Exercise / massage |
|  | - Fungating Wounds/ Tumours | - Distorted body image<br>- Social isolation<br>- Dressings / Odour | - Wound management<br>- Emotional support |
| *Use of Stimulants* | - Overuse of drugs, alcohol, or other stimulants | - Assessment of impact on medical conditions | - Consider further intervention to help<br>- Medication review |
| *Living Arrangements* | - Living alone / spouse / family / friends<br>- Consider transport<br>Consider steps | - Isolation<br>- Restricted movement | - Engage community support services as required. |

| *Focus Area* | *Symptoms* | *Possible Complications* | *Possible Interventions* |
|---|---|---|---|
| *Support Systems* | • Who?<br>• Include Pets | • Isolation<br>• Infrequent contacts | • Liaise with family / friends to consider support needs |
| *Community Support* | • Meals?<br>• Domestic Help?<br>• Personal Care?<br>• Professional support?<br>• Spiritual Support? | • Inadequate use of services<br>• Inadequate knowledge of services | • Engage community support services as required.<br>• Consider other agencies such as cancer support, carers support |
| *Accessibility* | • Level of safety<br>• Cleanliness<br>• Ease of access<br>• Emergency assistance<br>• Safety plan | • Risk of falls<br>• Risk of accidents<br>• Emergency provision | • Referral to Occupational Therapist or physiotherapist<br>• Referral to support agency |
| *Financial management* | • Financial mismanagement | • Inability to manage services | • Budget services<br>• Consider pension or disability eligibility |
| *Education or Employment* | • Unemployed<br>• Lacking skills<br>• Studying | Additional supports may be required | • Liaise with social worker to engage employer or education provider |
| *Cultural and Spiritual Beliefs* | • Impact on care or service provision?<br>• Cultural support required<br>• Impact on death and dying | • Inadequate supports meeting client's needs<br>• Inability to be at peace | • Engage appropriate groups to provide specific supports<br>• Understand client's goals<br>• Understand what gives life meaning |
| *Emotional Wellbeing* | • History or emotional / psychological disturbance<br>• Withdrawal<br>• Changes in mood and / or affect<br>• Concerns / changes in how they feel about their health | • Isolation<br>• Depression<br>• Mental health illness | • Review social support systems available<br>• Consider counselling<br>• Medication<br>• Referral for psychological assessment or treatment as required |
| *Sexuality* | • Changes in ability to express passion / affection / intimacy either physically and / or emotionally | • Isolation<br>• Loneliness<br>• Inability to express desires and emotions | • Psychological support as required<br>• Facilitate privacy<br>• Respect personal needs and desires<br>• Respect identity choices |
| *Anxiety and Fear* | • Excessively uneasy and / or afraid<br>• Separation anxiety<br>• Far of becoming dependent<br>• Losing control physically<br>• Fear of failing to complete life tasks<br>• Fear of uncontrolled pain<br>• Fear of the unknown<br>• Spiritual issues | • Medication side effect<br>• Learned reaction<br>• Symptom of medical condition<br>• Common in people facing life threatening or life limiting conditions | • Provide additional supports<br>• Honest and open discussion about future<br>• Avoid boredom and excessive self-reflection and distraction<br>• Use desensitising techniques for phobias<br>• Focused spiritual care<br>• Medication<br>• Psychological support as required |
| *Depression* | • Consider signs and symptoms for diagnosis in conjunction with medical professional | • Distinguish between sadness and depression<br>• Inadequate symptom control<br>• Poor quality of life<br>• Immobility<br>• Identify cause | • Treat cause if identifiable<br>• Support<br>• Empathy<br>• Cognitive therapy<br>• Symptom relief<br>• Referral for psychological support<br>• Medication |

| *Focus Area* | *Symptoms* | *Possible Complications* | *Possible Interventions* |
|---|---|---|---|
| *Distress at End-of Life* | Are they suffering from:<br>• Uncontrolled delirium<br>• Severe breathlessness<br>• Neurogenic or cardiogenic pulmonary oedema<br>• Haemorrhage? | • Severe distress | • Sedation titrated to manage level of distress |
| *Anticipatory Grief / Bereavement* | • Feeling of grief at losses caused by illness<br>• Angry<br>• Sadness<br>• Depression<br>• Isolation<br>• Abandonment | • Normal | • Open and honest discussion<br>• Education and information provided about illness, support, and control<br>• Support groups, family, friends, or referral for psychological support may be required |
| *Attitudes to Death and Dying* | • Advance care directive<br>• Resuscitation wishes | • Family and friends may be unaware of each other's choices and feelings | • Open and honest discussions<br>• Document wishes<br>• Develop management plan in the event of an emergency. |

## RESOURCE DOCUMENTS

- External ACIA Guidelines 002 – Care and Service Provision in the Community
- Carey, A. E., Osgood, L. D., & Granger, B. B. (2021). Reinventing Palliative Care Studies. AACN Advanced Critical Care, 32(1), 113-118. https://doi.org/10.4037/aacnacc2021386
- Commonwealth of Australia. (2006). Guidelines for a Palliative Approach in Resiential Aged Care. (3845). National Health and Medical Research Council Retrieved from http://agedcare.palliativecare.org.au/Portals/35/Guidelines/The%20Guidelines%202006.pdf
- Dahlin, C., Coyne, P. J., & Cassel, J. B. (2016). The Advanced Practice Registered Nurses Palliative Care Externship: A Model for Primary Palliative Care Education. J Palliat Med, 19(7), 753-759. https://doi.org/10.1089/jpm.2015.0491
- Hammond Care. (2014). Assessment Tools: Palliative Care Bridge Supporting Living to the End. Hammond Care. http://www.palliativecarebridge.com.au/resources/AssessmentTools_Book_Final.pdf
- MacLeod, R., Vella-Brincar, J., & Macleod, S. (2018). The Palliative Care Handbook; Guidelines for Clinical Management and Symptoms Control (7th ed.). HammondCare Media.
- McCormack, B., Dickson, C., Smith, T., Ford, H., Ludwig, S., Moyes, R., Lee, L., Adam, E., Paton, T., Lydon, B., & Spiller, J. (2018). 'It's a nice place, a nice place to be'. The story of a practice development programme to further develop person-centred cultures in palliative and end-of-life care. International Practice Development Journal, 8(1), 1-23. https://doi.org/10.19043/ipdj81.002
- McCormack, B., & McCance, T. (2017). Person Centred Nursing and Health Care: Theory and Practice. Wiley.
- Osterlind, J., & Henoch, I. (2021). The 6S-model for person-centred palliative care: A theoretical framework. Nurs Philos, 22(2), e12334. https://doi.org/10.1111/nup.12334
- Palliative Care Australia. (2017). The Economic benefits of home based pallaitice care and end-of-life care. Economic Research Note 2,.
- Palliative Care Australia. (2018). National Palliative Care Standards (5th ed.). PCA.
- Parliamentary Committees. (2013). Palliative and Community Care in Queensland: Toward person-centred care. Report 22. Health and Community Services Committee.
- World Health Organisation. (2020). Global Atlas of Palliative Care (2nd ed.). WHPCA. http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care