

[insert organisation name/logo]

Palliative Care Policy

Document Status: Draft or Final

Date Issued: [date]

Lead Author: [name and position]

Approved by: [insert organisation name] Board of Directors on [date]

Scheduled Review Date: [date]

Record of Policy Review

Review Date	Person Initiating/Leading Review	Other People Consulted

Triggers for Policy Review (tick all that apply)

- Standard review is timetabled.
- A gap has been identified
- Additional knowledge or information has become available to supplement the policy.
- External factors
 - Policy is no longer relevant/current due to changes in external operating environment.
 - There are changes to laws, regulations, terminology and/or government policy.
 - Changes to funding environment, including requirements of funding bod(y)ies
- Other (please specify).
- Internal / organisational factors
 - A stakeholder has identified a need, eg by email, telephone etc
 - A serious or critical incident has occurred, requiring an urgent review.
 - Need for consistency in service delivery across programs and organisations.
 - Separate, stand-alone policy is now warranted
 - A near miss has occurred, requiring a review to prevent a serious/critical incident in the future

Additional Comments

[for example, policy now covers details related to new legislation].

Palliative Care Policy

1. Purpose and Scope

[Note ... this policy is for CMOs providing residential services, and may also be relevant for adaptation by CMOs partnering with a residential service to provide support under a palliative care plan]

The purpose of this policy is to guide staff to support the development, implementation and review of a palliative care plan with a person with lived experience of mental illness residing in **[insert organisation name]** accommodation support service who has been diagnosed with a progressive advanced disease or terminal illness.

2. Definitions

Palliative care is an approach aiming to improve the quality of life of consumers and their families facing problems associated with life-threatening illness, by preventing and relieving suffering. It is provided, where possible, in the environment of the person's choice and includes:

- care delivered by coordinated medical, nursing and allied health services.
- control of pain and management of other symptoms
- support for psychological, social, emotional issues and spirituality
- provision of grief and bereavement support for the families, partners and carers during the life of the consumer and following his or her death

Palliative care may be provided to people of all ages whose condition has progressed beyond the stage where curative treatment is effective and/or a cure is attainable, or there is valid, informed choice not to pursue curative treatment.

Bereavement is the reaction to loss, including healing from that loss. Healing requires working through the changes that relate to the loss until a satisfying conclusion is reached, even though the individual may never feel fully recovered. Bereavement can be a time of personal growth and is experienced uniquely by every individual.

Bereavement support and counselling is the support provided to persons who are experiencing bereavement or grief following the death of a significant person. Staff may make a referral to a bereavement counselling service.

Capacity, in this policy, describes a person's ability to make his/her own decisions. Capacity may be decision specific.

Informed decision making occurs when a person with decision-making capacity makes a decision after gathering and considering relevant facts.

Informed consent occurs when a person with decision-making capacity provides consent after being provided with information / an explanation about the risks and benefits of a procedure, treatment or type of support.

Substitute decision-making is when decisions are made on another person's behalf by an individual or body who has been given legal power to do so. For example, a guardian is someone legally appointed to make decisions for a person who lacks capacity. In NSW, a private guardian is a family member or friend appointed as a person's guardian by the Guardianship Tribunal. The Public Guardian may be appointed if there is no-one else suitable.

People can appoint an enduring guardian at a time when they have capacity (fearing that they may lose capacity at some time in the future). An enduring guardian has the same legal authority as guardians appointed by the Guardianship Tribunal.

An Advance Care Directive is a document which expresses the wishes of someone who experiences mental and/or physical illness about the type of support and treatment to be provided if they become unwell.

Ethical decision making: Ethical decisions are required when questions are raised concerning quality of care, conflict with consumers, relationships with other professionals and 'equity' in service delivery. Just as in other collaborative service delivery models, ethical decision-making requires all involved to cooperate in efforts to arrive at a decision.

Rules and principles are not sufficient in addressing ethical questions, particularly in situations where there are no adequate rules on which to base a solution. Health care problems require rational application of evidence and reason, but rules and principles are best considered within a holistic frame of reference that considers the context of the ethical question.

NSW Department of Health palliative care services

3. Principles

Although palliative care includes addressing the needs of people as they die and providing bereavement support for families, the emphasis is on improving living.

Dying is a normal process, which should be neither hastened nor postponed

Support systems help:

- people to live as actively as possible until death;
- the family cope during the person's illness and in their own bereavement;

A team approach best addresses the needs of patients and their families, including bereavement counselling, if indicated.

Palliative care:

- enhances quality of life, and may also positively influence the course of illness.
- 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.

4. Outcomes

5. Functions and Delegations

Position	Delegation/Task
Board of Directors	Endorse Palliative Care Policy. Compliance with Palliative Care Policy and relevant legislation. Identify Palliative Care issues and opportunities to improve access to services provided by the organisation.
Management	Compliance with Palliative Care Policy and relevant legislation. <u>CEO/Manager</u> Organisational alignment with Palliative Care issues and seek opportunities to address and adjust services to make programs more accessible to a broader range of consumers.
Staff	Compliance with Palliative Care Policy. Identify program or services areas that need to be changed to be more accessible and effective for consumer’s diverse needs. Update and review programs and services to ensure that they are responsive to a wide range of individuals with diverse needs. Consult consumers, stakeholders and relevant expert organisations to assess and monitor service and program accessibility and relevance.

6. Risk Management

[insert organisation name] ensure this policy does not breach any of its legal obligations.

The Board of Directors ensures decisions and actions relating to Palliative Care are transparent and respectful.

All Board members, staff, volunteers and students are made aware of this policy during orientation.

Board members and staff are provided with ongoing support and professional development to assist them to implement Palliative Care policies and practice effectively.

This policy will be reviewed in line with **[insert organisation name]**'s quality improvement program and/or relevant legislative changes.

7. Policy Implementation

This policy is developed in consultation with employees and approved by the Board of Directors.

This policy is to be part of all staff orientation processes and all employees, volunteers and students are responsible for understanding and adhering to this policy.

This policy should be referenced in relevant policies, procedures and other supporting documents to ensure that it is familiar to all staff and actively used.

8. Policy Detail

All consumers have the right to be informed that they have a terminal illness or progressive advanced disease.

8.1 Palliative Care Plan

[insert organisation name] staff will maintain documented procedures for developing and reviewing a palliative care plan that give effect to this policy.

Every consumer in a(n) **[insert organisation name]** accommodation support service with a diagnosis of a terminal illness or a progressive advanced disease must have the opportunity to have a palliative care plan that is developed and reviewed with the NSW Department of Health's palliative care services.

If staff feel that the name 'palliative care plan' may cause distress for consumers, their carer(s) and/or substitute decision-maker with a diagnosis of a progressive advanced disease the name of the plan can be changed accordingly.

It is mandatory that the palliative care plan include documented evidence of decision-making processes and outcomes to demonstrate accountability.

The consumer, their carer(s), or substitute decision-maker's preference for life prolonging treatment is not static over time. Changes either in favour of, or against, active treatment may occur as an appreciation of their clinical situation develops. Regular review of the palliative care plan is a mandatory part of the planning development.

The consumer, their carer(s), or substitute decision-maker are referred to a bereavement support program if the need is identified in the planning process.

A palliative care planning process is based on a comprehensive approach and includes the needs and wishes of the consumer.

8.2 Decision-Making and Information

The consumer, their carer(s), or substitute decision-maker have the right to information and to make decisions regarding support needs and medical treatment.

The consumer, their carer(s), or substitute decision-maker are supported to access information about available diagnostic and therapeutic options, and to be involved in decision making about withholding and withdrawing life prolonging treatment where the risks and benefits of doing so are understood.

Consumers are supported to participate as fully as possible in the decisions regarding the medical care they receive.

It is the responsibility of the treating medical officer to communicate to the consumer and/or substitute decision-maker about the diagnosis, treatment and prognosis.

Where there is disagreement or dispute around decision making, the use of a dispute resolution strategy is required. A referral to a mediation service may be necessary.

It is recognised that the prognoses from doctors are only ever estimates. Individuals will respond differently to treatment. The length of time and how well a person lives are dependent on many factors beyond predictability.

It is important to have the same staff member, if possible, deliver information about the consumer's health to the consumer, their carer(s), substitute decision-maker and/or advocate to ensure consistency.

8.3 Social Contact and Activities

The consumer receives support to continue regular social contact and involvement in daily activities to the extent they are able to and choose to do so.

8.4 Team Approach

An interdisciplinary team approach to providing coordinated medical, nursing and allied services to the consumer, their carer(s), substitute decision-maker and/or advocate is encouraged to maximise positive outcomes for the consumer.

8.5 Responsibility for Health Care

The primary responsibility of health care rests with the NSW Department of Health. The consumer's accommodation support needs are met by services operated by **[insert organisation name]**.

When a consumer's health care becomes their highest priority, for instance the consumer requires care that is beyond the capabilities and/or skill of the residential support staff or carer, or beyond the assistance that can be provided to residential support staff or carer by the NSW Department of Health palliative care team, they are then transferred to a hospital or palliative care facility.

8.6 Cultural Sensitivity

Palliative care is provided in a culturally appropriate way. Cultural and linguistic diversity will be appreciated and reflected in planning provision of support to people with a disability and their families.

Service providers need to be sensitive to the needs of families from culturally and linguistically diverse backgrounds. Families may need to be supported to access services as in many cases they will not know how the service system works, what services are available and what questions to ask.

8.6.1 Issues to consider when planning palliative care for consumers and their families who are Aboriginal or Torres Strait Islanders

When the consumer and family is from an Aboriginal and Torres Strait Island culture the planning process must support the social structure of the Aboriginal and Torres Strait Islander community.

The notion of family in Aboriginal communities may be different to the contemporary western concept or understanding of a nuclear family. There may be more than one set of 'parents' and the extended family may play a major role in decision-making.

Access to specialist Aboriginal services, carers and staff is an important part of the recognition of self-determination principles for people with a disability who are Aboriginal.

Except where there are well-established Indigenous medical services, healthcare facilities of all types are used reluctantly.

Health decisions tend to be a family or community affair. Family structure is complex and can be governed by recognised obligations and cultural rules. Gender issues are important, with "women's business" and "men's business" being defined and generally held separate.

Causes of disease in Indigenous communities can sometimes be understood or perceived as stemming, in part, from exposure to metaphysical forces, alienation from the homeland or some personal deficiency.

Different interpretations of diagnosis and cause may create distrust between staff and consumers.

9. References + Resources

9.1 Internal

Diversity Sensitivity Checklist
Family & Carers Policy
Individual Supports Policy
Integration Policy
Human Resources Policy
Palliative Care Plan

9.2 External

NSW Health (2010). *Palliative Care Strategic Framework 2010-2013*.

http://www.health.nsw.gov.au/policies/pd/2010/pdf/PD2010_003.pdf

Accessed 8th November, 2011.

NSW Human Services, ADHC (2010). *Palliative Care Policy and Procedures* (October 2005), Amended September 2010.

http://www.adhc.nsw.gov.au/_data/assets/file/0003/228126/Palliative_Care_Policy_Sept_2010.pdf Accessed 1st November, 2011.

Palliative Care Australia (2011). *Submission to the Productivity Commission on Caring for Older Australians: Productivity Commission Draft Report on behalf of Palliative Care Australia*

<http://www.palliativecare.org.au/Portals/46/PCA%20submission%20on%20draft%20PC%20report%20Caring%20for%20Older%20Australians%20March%202011.pdf> Accessed 2nd November, 2011.

Commonwealth of Australia (2011) *Guidelines for a Palliative Approach for Aged Care in the Community Setting: Best practice guidelines for the Australian context*. Department of Ageing.

[http://www.health.gov.au/internet/main/publishing.nsf/Content/400BE269B92A6D73CA2578BF00010BB0/\\$File/COMPAC-30Jun11.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/400BE269B92A6D73CA2578BF00010BB0/$File/COMPAC-30Jun11.pdf) Accessed 2nd November, 2011.

WHO (2011). *Definition of Palliative Care*.

<http://www.who.int/cancer/palliative/definition/en/> Accessed 8th November, 2011.

Legislation

Disability Discrimination Act 1992 (Commonwealth)

Human Rights and Equal Opportunity Commission Act 1996 (Commonwealth)

Industrial Relations Act 1996 (NSW)

Work Health and Safety Act 2011 (NSW)
Racial Discrimination Act 1975 (Commonwealth)

Websites

This policy is adapted from ADHC (2010). Palliative Care Policy and Procedures
http://www.adhc.nsw.gov.au/data/assets/file/0003/228126/Palliative_Care_Policy_Sept_2010.pdf Accessed 1st November, 2011.

9.3 Quality and Accreditation Standards

EQUIP4

Provided by the Australian Council on Healthcare Standards (ACHS)

Standard 1.1. Consumers / patients are provided with high quality care throughout the care delivery process.

Criterion 1.1.7: Systems exist to ensure that the care of dying and deceased consumers / patients is managed with dignity and comfort.

EQUIP5

Provided by the Australian Council on Healthcare Standards (ACHS)

Standard 1.1. Consumers / patients are provided with high quality care throughout the care delivery process.

Criterion 1.1.7: Systems exist to ensure that the care of dying and deceased consumers / patients is managed with dignity and comfort and family and carers are supported.

Health and Community Service Standards (6th edition)

Provided by the Quality Improvement Council (QIC)

Standard 2.3: Services and programs are provided in a culturally safe and appropriate manner.

Evidence Questions: What is the evidence that:

a) processes and practices ensure respect and responsiveness to consumer diversity by being inclusive and flexible?

b) the changing profile of consumers is monitored?

9.4 National Mental Health Standards

Criterion 1.7: The MHS upholds the right of the consumer to have their needs understood in a way that is meaningful to them and appropriate services are engaged when required to support this.

Criterion 4.5: Staff are trained to access information and resources to provide services that are appropriate to the diverse needs of its consumers.

9.5 Recovery Oriented Service Self-Assessment Tool (ROSSAT)

N/A

9.6 NSW Disability Services Standards (DSS)

1.7: Other than relative need, the access of a person with a disability to a service is decided on a non-discriminatory basis.

2.9: Services are provided in a manner sensitive to the age, sex, cultural, linguistic and religious background of each person with a disability.