

Disability Residential Services Palliative Care guide

End-of-life care for residents of disability residential services

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Foreword

Like other members of the community, as residents of disability accommodation get older their need for end-of-life care increases. Disability residential services staff play an important role in providing support to residents at this time. Critical to fulfilling this role is accessing the expertise of the palliative care sector.

Central to the palliative approach is the concept of 'living' with a life-threatening condition. A person's life doesn't end when they are diagnosed. A supportive approach enables the person to have a quality end-of-life experience. In this way, residential staff, with the support of palliative care services, are able to maintain the resident's lifestyle for as long as possible.

The *Disability Residential Services Palliative Care* guide describes the important role of palliative care in the provision of end-of-life care for residents of disability supported accommodation. It steps you through the key areas for support and identifies useful documents, training and resources and where to find them.

A handwritten signature in black ink, appearing to read 'A Rogers', is centered on a light gray rectangular background.

Arthur Rogers
Executive Director
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Contents

Context	2
Key concepts	3
Planning	4
Dying at home (residential service)	6
Specialist palliative care	8
Disability residential services	11
Areas of support	12
Death	16
Aftercare	17
Example - Jude	18
References	20

Context

Purpose

This guide describes the important areas of care to be considered when a person with a disability (resident) has been diagnosed with a life-threatening condition.

The guide enables disability residential staff and their managers to confidently plan and care for a resident at the end of their life.

It describes how disability and specialist palliative care staff can work together if required, and identifies relevant resources, professional development opportunities and policy, giving references and links. When viewed in an electronic version (with internet access), the internet addresses in the end notes connect the reader to the websites and key documents.

The guide does not provide step-by-step instructions or describe every life-threatening condition. In some cases the death may be unexpected and the reader will need to choose what in the guide is relevant.

The guide can be used by anyone who is caring for a person with a disability; however, residential staff are the primary audience.

Key concepts

Living with a life-threatening condition – conditions or chronic illnesses that are expected to result in a significant shortening of a person’s life and are not amenable to health care treatment. Includes cancer and non-cancer diagnoses, such as neurodegenerative diseases and advanced organ failure. The aim is to enhance the quality of the person’s life by reducing pain, controlling symptoms and accessing required support.¹

Palliative approach – aims to improve a resident’s quality of life through early identification, assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs. A palliative approach is not confined to the end stages of an illness; it provides a focus on providing comfort and actively reducing a resident’s symptoms and distress¹ and all health care providers can incorporate the palliative approach into their practice.

Planning

When it is known that a resident has a life-threatening condition, there are benefits in taking the time to think and plan for the practical, psycho-social and legal issues that may arise. Depending on the condition, it might not be possible for the resident to make their views known at the time decisions need to be made. Planning ahead enables a resident's views and preferences to be respected and followed. The resident's family and friends should be included in these discussions, as appropriate.

- **The sooner the better** – 'Up to 50 per cent of people will not be in a position to make their own decisions as they near the time of their death'², due to cognitive and physical decline. This means that planning at the earliest point enables the resident to express preferences regarding their future care.
- **Plan with the resident** – People with life-threatening conditions may not see the immediate relevance of the care choices being considered, so planning needs to be sensitive and timely. In an ideal world it may be possible to commence discussions following diagnosis. As with other areas of their life, this planning should be self-directed and enable the resident's involvement throughout the end-of-life care.
- **No usual course** – While there may be common symptoms for life-threatening conditions, there is often not a typical progression in the course of the condition. Motor Neurone disease³ is an example where the full range of symptoms may be expected, but not in any particular sequence.
- **Advance Care Planning** – The Department of Health is developing an advance care planning (ACP) policy. ACP is a process which enables a person to plan for their future medical treatment and other care, particularly for a time when they are not competent to make, or communicate decisions for themselves.

It is often about end-of-life care, but not always. It aims to improve quality of care and is based on the principles of human rights, including self-determination, dignity and the avoidance of suffering.⁴

Advance care planning highlights a number of key processes, including:

- providing appropriate information about options
- consulting with the resident, family members and health care providers
- understanding the available future options and choices
- recording and communicating a resident's goals, values and wishes
- appointing a substitute decision maker, if required.

The policy will describe some common features, including the following:

- **Documenting health care preferences/values/beliefs/wishes** –this can be informed by existing lifestyle planning that has occurred. The ACP should be informed by the resident, even where there may be a ‘person responsible’.
- **Person responsible** – where the person can’t provide consent, the person responsible (substitute decision maker) can be approached by the medical practitioner to make the decision. Most commonly, the person responsible will be the resident’s nearest relative over the age of 18.
- **Enduring Power of Attorney (medical treatment) MEPOA⁵** – is a legal status. An agent is appointed by a resident, if competent, to act as a substitute decision maker when the resident does not have capacity to make medical decisions. The MEPOA is one of the types of ‘person responsible’.
- **Refusal of Treatment Certificate (RoTC⁶)** (advance directives) – this is a legally binding document that needs to be lodged with the Victorian Civil and Administrative Tribunal (VCAT⁷). The RoTC specifies the type of treatment the resident wants to refuse. An RoTC cannot be used to refuse palliative care, for example, pain relief. Only an agent, appointed by the resident under a MEPOA or a Guardian appointed by VCAT can sign the RoTC. Note: not every ‘person responsible’ can sign a RoTC). The RoTC form can be obtained from the Office of the Public Advocate (OPA).
- **Not for Resuscitation (NFR⁸)** (‘do not resuscitate’ (DNR)) – the NFR is considered where not resuscitating a resident is in their best interests. It is a clinical decision made by the treating medical practitioner where treatment would be futile or unjustifiable, for example, cardiopulmonary resuscitation (CPR). The medical practitioner must provide written confirmation of this decision.

Further information about planning and decision making can be found at Palliative Care Victoria and the OPA.

Dying at home (residential service)

While approximately 20 per cent⁹ of Victorians die at home, one study found that about 50 per cent¹⁰ indicate a preference to die at home. The resident's right to choose their place of death should be respected and supported as much as possible.

Supporting a person with a disability to die at the disability residence can be a realistic option and staff should consider the following issues.

Advantages

- The resident is in a familiar setting amongst residents and staff who know them
- Better able to meet the needs/well-being of the resident outside of hospital routines
- Better access for staff, other residents/friends and family allowing good-byes to occur in the resident's own time
- The resident is not alone; being cared for at the residence may be a good way for the resident not to be alone.

Challenges

- There may be an increased use of casual staff in the residence, either in caring for the resident or the other residents
- There may be a negative impact on the other residents and staff. It can be difficult to predict resident and staff reactions to the end-of-life care of a resident. Palliative care services will be able to advise on support strategies.

What should be in place?

- The commitment of residential staff to provide care
- Access to an area that can be organised to meet the comfort needs of the resident, for example, private space for visitors, temperature
- Access to aides/equipment to assist with care and transfer requirements
- Links with, and access to, health/specialist palliative care including 24 hour support where required
- Support for staff, for example, meetings, debriefing and personal support, access to secondary consultation
- Access to symptom control and pain relief medication
- Carers who are able to manage any medical equipment required
- A care plan and a means to reassess the at-home arrangement.

Under what circumstances could dying at the residence be reconsidered and hospice care appropriate?

Where the resident has chosen to die at the residence, it is important to ensure that all possible options and avenues of support have been tried before considering hospice care. As access to hospice care is arranged by the specialist palliative care provider, they must be a part of the review discussions. Circumstances prompting reconsideration of the plan might include:

- a significant increase in the complexity of care
- symptoms have increased in severity and staff are having difficulty managing the resident's symptoms
- staff are not able to provide comfort to the resident
- the resident has changed their mind
- other residents are very distressed and not able to be comforted.

Specialist palliative care

What is specialist palliative care?

Specialist palliative care builds on the palliative approach. Palliative care:

- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- integrates the psychological, emotional and spiritual aspects of the resident's care
- offers a support system to help residents live as actively as possible until death
- offers a support system to help the staff and family cope during the resident's illness and with bereavement.¹¹

For further information on palliative care refer to the *About palliative care* booklet.¹²

What can palliative care provide?

Palliative care is provided by multidisciplinary health care teams including doctors, nurses, allied health workers, pastoral care workers and volunteers. Palliative care can be provided in the community (for example, at a residence) as well as in palliative care units (in hospitals). Sometimes a resident may require a stay in an inpatient palliative care unit to stabilise symptoms and then return home to the residence.

Palliative care reflects a higher level of expertise in complex symptom control, loss, grief and bereavement. Palliative care providers work in two key ways by providing:

1. direct care to individuals, their families and support staff
2. a consultancy service to support providers including disability residential service providers, supporting their care of the resident, family and friends.

When to make contact?

Contact with the palliative care service can occur as soon as it has been determined that a resident has a life-threatening condition and/or that curative health treatment is no longer being considered.

In most cases, the referral to a palliative care service¹³ is made by the health care provider (Such as general practitioner (GP) or oncologist). However, palliative care services will accept referrals from anyone. In cases where the resident hasn't been referred, the referral should be made by the house supervisor's immediate line manager (such as cluster/sector/area/domain/unit manager or team leader).

The palliative care service may have identified a liaison contact; otherwise the palliative care service will have a process for receiving referrals through the service's main telephone number. The palliative care service will want to access the resident's medical history and will make contact with the resident's medical practitioner.

What health care should be provided?

Even though a cure may not be possible, there may be an important role for ongoing access to health services for symptom management¹⁴. This can enhance the resident's quality of life and levels of comfort, with the most practical examples being pain relief and symptom management, including difficulties swallowing and breathing, constipation, fatigue and loss of appetite. Sometimes treatment may occur to slow the progression of the condition rather than being curative.

To assist the decisions made by clinicians, palliative care services use assessment tools¹⁵ and care pathways¹⁶.

Barriers to palliative care

A recent survey of palliative care professionals¹⁷ identified that the top five issues in providing palliative care to people with an intellectual disability were:

- patient not able to fully understand their illness
- communication with the patient
- difficulties in assessing pain
- difficulties in assessing other symptoms
- length of time it took to gain the patient's trust.

As expected, these issues focus on the resident's disability and their ability to communicate.

These palliative care professionals were also asked to identify what might improve the care they provided. They identified:

- training on intellectual disability
- a disability link person in the palliative care service
- access to background information on the resident
- resources to help provide support
- contact details of local disability services.

There is an important role for residential services in facilitating palliative care access to knowledge of the resident, including:

- how the resident communicates and makes health decisions
- background information
- what can be provided by the residential service
- available local disability services.

How to create a partnership

There is a range of ways to create and support a partnership between disability residential services and palliative care services. These can include:

- regular contact
- being available
- providing a key contact person, such as an area manager in a disability community service organisation or disability managed residential service (a palliative care service provider may take the lead in the region)
- organising reciprocal learning opportunities.

Disability residential services

Disability Services funded residential services are staffed with Certificate IV qualified workers who have first aid level health care training. The exception will be staff who are trained on specific health care procedures to support particular residents.

An important role of residential staff is to support palliative care staff with knowledge of the resident with a disability. The residential staff will know the care requirements of the person, their lifestyle and personal preferences. While the GP is best placed to provide background information on the resident's health condition, the residential staff can provide background information on the resident and their life. To document this information use the Hospital Admission Form¹⁸ in the *Residential services practice manual*. Key residential staff should be available to step the palliative care staff through the contents and answer questions.

Support and training

Part of the planning that occurs when a resident is diagnosed with a life-threatening condition concerns training and support for staff. The end-of-life stage can be demanding for other residents and staff and access to support will be crucial. There are a range of training opportunities including:

- PEPA workshops¹⁹ – an introduction to the palliative approach
- Centre for Palliative Care Education and Research – short courses²⁰ on palliative care
- Australian Centre for Grief and Bereavement (ACGB) – short courses²¹ on grief and bereavement
- Certificate III and Certificate IV competencies²² regarding end-of-life care
- most universities have post graduate qualifications from certificate level onwards.

Refer to the Palliative Care Victoria website for a list of education and training²³ opportunities.

Areas of support

Principles for end-of-life care

The *Strengthening palliative care policy*²⁴ outlines seven principles for palliative care in Victoria:

1. People with a life-threatening illness and their carers and families have information about options for their future care and are actively involved in those decisions in the way that they wish.
2. Carers of people with a life-threatening illness are supported by health and community care providers.
3. People with a life-threatening illness and their carers and families have care that is underpinned by the palliative approach.
4. People with a life-threatening illness and their carers and families have access to specialist palliative care services when required.
5. People with a life-threatening illness and their carers and families have treatment and care that is coordinated and integrated across all settings.
6. People with a life-threatening illness and their carers and families have access to quality services and skilled staff to meet their needs.
7. People with a life-threatening illness and their carers and families are supported by their communities.

Cultural support

Whether the resident is Aboriginal or from a culturally and linguistically diverse (CALD) background, each person will express their culture differently. Knowing the cultural background of a person will be important; however, getting to know the person, their family and important others will be the key to determining the best way to support the person. Both Aboriginal and CALD communities often have strong beliefs concerning death and dying and there is a need to be sensitive to these beliefs.

Aboriginal culture is not a single culture and comprises many diverse communities, each with its own customs and ceremonies. However, central to these cultures is the importance of connection and obligation to family and the wider kinship groupings. Some Aboriginal will have religious beliefs that will impact on their cultural practices.

The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) has published *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples – practice principles*²⁵. Key areas of practice include:

- involving a local Aboriginal Community Controlled Organisation to ensure the care provided addresses key cultural requirements
- communicating in a manner that is sensitive to cultural differences
- providing cultural awareness training to staff involved in the care.

In addition, to assist staff, the Department of Human Services has published *Building better partnerships – Working with Aboriginal communities and organisations: a communication guide for the Department of Human Services*²⁶.

In relation to people from CALD communities, Palliative Care Australia published *Multicultural palliative care guidelines*²⁷. While written for the palliative care workforce, the guidelines review relevant cultural issues related to death and dying for 20 community languages. Palliative Care Australia stresses that the summaries aren't exhaustive and that each person needs to be considered as an individual, however the guidelines provide a useful starting point in increasing cultural sensitivity.

Disability Services has a *Cultural and Linguistic Diversity Strategy*²⁸ and the Disability CALD homepage²⁹ has a number of resources to assist staff. Cross cultural training is available from a number of organisations, including ADEC³⁰ (Action on Disability in Ethnic Communities).

Psychosocial support

There could be a range of areas of the resident's life that require support, such as:

- Need for information - about the life-threatening condition, treatment and care options, and prognosis. This may include support to understand any information or decisions
- Emotional issues - including intense feelings about themselves or others, the future or being alone
- Support with relationships - family, friends and colleagues
- Psychological support needs - for example, depression, anxiety or distress
- Practical assistance - for example, making contact with family or others, or financial issues
- Spiritual care - concerns about loss, survival or end-of-life, concerns about meaning or religious needs
- Cultural issues - support related to the resident's cultural background.

There may be increased psychosocial support needs in a residential service due to other residents and their families and the residential staff. The palliative care service will be able to provide advice and support in responding to these care issues.

Control of pain/symptoms

Symptoms are multidimensional and often include a sensory component (sensations), cognitive component (beliefs about the symptom), affective component (emotional responses) and behavioural component (actions in response to the symptom). Symptoms can have multiple causes and effects, and can occur concurrently.

When managing symptoms it is important to focus on the experience of the resident (and family) and not just the underlying pathology of the symptoms. Remember symptoms are dynamic, requiring ongoing regular assessment, and consider multifaceted interventions and a team approach.

Pain management aims for the resident to be comfortable and contributes to their quality of life. Relief from pain may mean the resident will remain in control and be better able to make choices when required. In many cases residential staff will know the resident best and be critical to supporting palliative health care providers to interpret behaviour that communicates pain/comfort levels.

Pain management may involve the use and storage of opioid analgesics. The palliative care service will organise for the administration of the medication and the residence will be required to provide secure storage as outlined in the Residential services practice manual.

Four commonly experienced symptoms are:

- **Pain:** often the most feared symptom for people with life-limiting illness and their families. The resident's description of pain must be believed and acknowledged. Pain can be caused by a combination of factors including the underlying disease, complications, treatments or a co-morbid condition.
- **Breathlessness:** is a significant problem for patients with chronic heart failure, or for with patients with lung cancer or pulmonary metastases.
- **Fatigue:** one of the most common symptoms associated with advanced disease.
- **Loss of appetite:** The social meaning of food means changes in appetite can be highly significant for the resident and their caregivers.

Managing breakthrough pain

Breakthrough pain (where there is a short burst of high intensity pain) is common and may only last for five minutes. There is no single response to breakthrough pain and it varies according to:

- the type of pain
- the duration
- the condition
- whether it is related to an activity, for example, walking.

The management of breakthrough pain needs to be a key component of the care plan and regularly reviewed. The palliative care service is best placed to determine the response. In conjunction with the palliative care service, residential services staff and managers will need to adjust medication procedures as required.

Practical issues

Wills, funeral and estate issues may be a concern for the resident, their family or friends. Residential staff should not become involved in these issues. Further information can be found in section 6.9 of the *Residential services practice manual*³¹.

OPA has a guide, *Securing their future*³², which provides guidance on guardianship and estate planning for families where the child/adult has a decision making disability.

Death

How will I know when death is approaching?

This is often a key concern of carers. The planning process should allow the opportunity for staff to increase their knowledge.

Each death is different; however, there are a range of signs that might indicate that death is approaching. Palliative Care Victoria has developed a pamphlet, *The process of dying*³³, to inform and assist carers to understand the end-of-life stage. The palliative care service can assist residential staff and family with interpreting the signs being noticed by staff, friends and family. The key activity for carers is to make sure the resident is comfortable.

What do I do once a resident dies?

There are established procedures to follow regarding a resident's death. These procedures can be found in the *Residential services practice manual*³⁴ of the residential service and should cover who to contact, when and how to notify the death.

Generally, the next-of-kin or family will be responsible for the arrangement of funerals and burials, wills and estate issues. Where there isn't anyone nominated then the matter is referred to State Trustees. Specific procedures can be found in the Residential services practice manual.

Aftercare

Grief and bereavement

Grief is a normal response to a death and rarely results in mental health problems. Most people adapt and manage these traumatic experiences with the care and support of family, friends and community. As with the general community, residents and staff may require additional support.

- **Palliative care services** will be the first point of support for staff and residents after a resident's death.
- **Australian Centre for Grief and Bereavement (ACGB³⁵)** has been funded by the Department of Human Services to provide specialist bereavement services throughout Victoria. ACGB has a range of resources and information available.

ACGB offers a secondary consultation service for professionals working with people who may have suffered a loss. The Practitioner Consultancy Service³⁶ is free of charge and house supervisors/managers are able to contact ACGB to determine the best way to provide opportunities for other residents, staff and family members following a resident's death.

ACGB can provide counselling to residents with a disability who may be having difficulties with grief. Residents with a disability should be expected to experience loss and staff should be sensitive to changes in behaviour. Staff experiencing complex grief would normally be supported through the usual workplace support mechanisms and for department staff this may include support through the Employee Assistance Program³⁷.

Supporting residents with grief and loss – in 2007, Scope published *Supporting people with disabilities coping with grief and loss – An easy-to-read booklet*³⁸. It contains information about grief and loss, and strategies for dealing with grief, in an easy-to-read format for people with disabilities. The second section of the booklet is for people who provide support. It includes creative ideas to assist people with disabilities with grief, for example, activities that keep alive the memory of the deceased resident will be useful.

Ritual

Ritual is a very important part of bereavement. It offers opportunities to remember the deceased, structured ways of expressing grief and provides comfort to the bereaved. Ritual may be expressed through religion or cultural activities or more simple practical activities. There should be conversations with other residents, family and staff to determine expectations and preferences. Again the palliative care service can assist in the first instance as can the ACGB.

Example - Jude

Jude (aged 46) had a moderate intellectual disability and resided in a disability residential service. Jude's sister Mandy acted as her 'person responsible' as both Jude's parents were deceased. One morning Jude looked pale and hadn't eaten her breakfast. Jude indicated her stomach hurt and went back to bed. Subsequently Jude vomited and an appointment was made with her GP for later that day.

The GP referred Jude for x-rays and blood tests. They revealed ulceration in the intestine and Jude was referred to a hospital for surgery. The surgery revealed that Jude had advanced cancer and that treatment could only be palliative. A referral was made to the local palliative care service and Jude was discharged back to the residence once she recovered from the surgery and post acute care arranged.

The palliative care service visited Jude at the residence and assisted the staff to develop a support plan. The aim of the plan was to keep Jude comfortable and included medication for pain. While the plan included planned doses of an opiate for pain relief, it also included procedures to administer doses for severe breakout pain. Jude also received medication to manage her other symptoms, nausea and continence. The palliative care service arranged for a nurse to attend to administer the pain relief and, in line with policies, the residence had a procedure for authorising any PRN doses.

The palliative care service provided information to staff on Jude's prognosis, what could be expected over the coming months, and important signs to look out for. The palliative care service was available to answer staff questions, provided information on monitoring and side effects, and was available for consultation around the clock.

Residential staff were able to access the Program of Experience in the Palliative Approach (PEPA) and several staff attended additional short courses, in particular, one of the ACGB short courses on bereavement. A focus of the training was to explore ways for staff to support Jude and the other residents and ways to talk about dying. The residence obtained a copy of the Scope guide to assist them with this communication.

The palliative care service made regular appointments with the residence and person responsible to review Jude's care. Jude's sister and staff, with Jude, undertook to review her care plan to look at what activities and relationships Jude saw as important. The sector manager continued discussion with the house supervisor to monitor staff wellbeing.

Jude remained at the residence for a further three months and participated in day activities when able. There were several inpatient admissions to hospital to review Jude's pain management and stabilise symptoms. Pain and other symptoms increased in severity and Jude became less able to eat and keep food down.

Despite every effort, Jude was not able to be made comfortable in the residence and the palliative care service arranged for her to be admitted to a hospice. Other residents were able to visit Jude and several days later Jude died peacefully in the presence of her family and friends.

The palliative care service took the lead with debriefing the residential staff and residents. Additional access to debriefing was arranged as required as well as assistance with planning for bereavement. Staff created several opportunities for residents to remember Jude. The ACGB was available to accept a referral for individual support of residents should this be needed.

Conclusion

The residential staff were able to give Jude the opportunity to be cared for in her home. In doing this Jude was able to maintain her lifestyle and maintain contact with the people in her life. The objective was not to turn the residential service into an inpatient palliative care service; rather to access the same support that the majority of members of the community are able to access.

The role of staff was to provide comfort and usual care to Jude and the other residents and to maintain the residents' lifestyles. Staff had access to regular consultation/review with the palliative care service and early on undertook training opportunities to prepare themselves for the support they would provide.

Staff were able to provide the palliative care service with information about Jude and support Jude's interaction with service staff. The early planning meant that activities important to Jude could be highlighted and undertaken as required.

While the palliative care service is able to take the lead on staff support, other organisations such as ACGB are available for consultation should this be required.

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31. <www.dhs.vic.gov.au/disability/publications-library/residential_services_practice_manual>
32. <www.publicadvocate.vic.gov.au/publications/124/>
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36. <www.grief.org.au/couns>
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