Health professional user guide

Care plan for the dying person – Victoria

Recommended citation

Enquiries

Acknowledgements

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Contents

About this guide

CONTEXT AND FOCUS

End-of-life care is urgent care. The healthcare team only has one chance to get the care needs right for both the dying person and those identified as important to them.

Close to 36,000 people die in Victoria each year and this figure is projected to double in the next 25 years. Of those people, about half will die following a period of chronic illness and for others death will occur quickly because of unexpected events, such as an acute illness.[1] In either situation, the prompt recognition of acute deterioration and approaching death enables the healthcare team to be proactive in their planning of individualised end-of-life care for both the dying person and their relative/friend(s).

This **Health professional user guide** has been created as a resource document for Victorian health professionals providing care in the last days and hours of a person's life.[2] It is to be used in conjunction with the **Care Plan for the Dying Person – Victoria** (care plan) a clinical tool designed to guide the delivery of best practice end-of-life care in acute and sub-acute healthcare settings.

The care plan aims to ensure that a dying person and those identified as important to them experience a coordinated person-centred approach to care regardless of their diagnosis or healthcare setting. The care plan supports a model of care that combines frequent assessments, critical thinking, individualised care planning, shared decision-making and continuous review to ensure the focus of care is on the dying person and those close to them. It is informed by an evidence-based framework that supports care delivery in the last days of life, compliant with Australian[2] and International[3] Quality Standards (Appendix 1, Appendix 2).

Responsibility for the use of the care plan as part of a continuous quality improvement and risk management framework sits within the governance of a health service (Appendix 3). It is crucial that all staff receive training to accurately use and commence a person on the care plan.

The **Care Plan for the Dying Person – Victoria** was developed by the Victorian End-of-Life Care Coordinating Program (VEC) and has been endorsed by The International Collaborative for Best Care for the Dying Person. Health Services can use the plan under a Creative Commons license but are not permitted to modify any or part of the document or accompanying resources.

These resources were developed by the VEC, with funding from the Victorian Government's Department of Health and Human Services. The resources are now housed at Safer Care Victoria.

You can find the relevant reference, source and guideline documents used in the preparation of this **Health professional user guide** in the reference and appendix section of this document.

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[1] Victorian Auditor-General's Office. Victorian Auditor-General's Report Palliative Care, April 2015.

[2] Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safety and high-quality end-of-life care, ACSQHC Sydney, 2015.

[3] International Collaborative for Best Care for the Dying Person. The 10 Core Principles for Best Care for the Dying Person, 2014

Care provision in the last days and hours of life

RECOGNISING DYING

Recognising someone is dying requires knowledge about the person and takes considerable clinical skill.

The recognition of dying enables the healthcare team, the dying person and those important to them, to focus, plan and prepare for an impending death. Failing to recognise dying can lead to poor outcomes such as the provision of futile treatments (for example, resuscitation attempts), inability to identify end-of-life goals of care and care preferences (such as wishes regarding preferred place of death) as well as conflict between the dying person, their family and/or the healthcare team.

Health professionals should draw upon the clinical history of the person in their care and their clinical expertise and experience of disease trajectories when making a diagnosis of dying.

When dying is recognised it is crucial to discuss, review and explain activities related to advance care planning and end-of-life preferences. This can include medical, legal and psychosocial aspects of care.

Any member of the healthcare team, the person themselves or a relative/friend may recognise that death is imminent. Therefore, it is vital to foster systems that encourage individuals to confidently discuss their views with the responsible senior treating doctor, registered nurse and/or allied health staff member.

It is also important to acknowledge that dying is a unique and individual process. Some people can improve unexpectedly with death no longer thought to be imminent. This possibility should be acknowledged and processes for regular reassessment implemented and discussed within the multidisciplinary team and explained to the dying person (if they are able or have capacity to participate) and those identified as important to them.

What makes you think this person is in the last days or hours of life?

Guiding questions to consider:

- Is there a treatable reversible cause for this deterioration?
- Is their deterioration unexpected or a predictable consequence of an existing disease process? Has the person experienced a similar event / deterioration in the recent past?
- Is the person showing new physical signs suggesting that death may occur? What do your colleagues think?
- Have you asked the person and/or their relative/friend(s) what they think?

Use the knowledge obtained from your assessment and other information gathered from the multidisciplinary team (MDT), the person and those identified as important to them to help determine if the person is nearing death or experiencing an event with reversible causes.

Plan and communicate your care decisions and management plans accordingly.

Regularly reassess these factors to confirm the person is imminently dying, as sometimes disease progression can fluctuate near the end-of-life.

Seek advice from colleagues with more experience providing end-of-life care if there is any uncertainty about the recognition of dying.

COMMUNICATION

Everyone – the healthcare team, the dying person and those considered important to them – must understand and agree the person is believed to be imminently dying prior to any discussions related to commencing the Care plan for the dying person – Victoria.

Honest discussions about prognosis allow for proactive conversations about end-of-life care preferences and management options, while providing the opportunity for shared decision-making between the healthcare team, the dying person (if they are able or have capacity to participate) and those important to them.

The healthcare team needs to reach consensus that a person is believed to be imminently dying before beginning discussions with the dying person (if they are able or have capacity to participate) or those identified as important to them. However, in some cases it will be the dying person or their relative/friend(s) who initiate discussions around the possibility of impending death.

In any eventuality, a forum such as a family meeting should be promptly scheduled to facilitate information sharing and documentation of care preferences to minimise the risk of conflicting and potentially distressing misinformation.

It should be clearly conveyed that the care given while a person is dying is not fundamentally different to care given at any other stage of life and the healthcare team will continue to actively pursue care options that promote comfort.

Any potential barriers to communication and understanding should be identified and steps taken to overcome them. These may include:

- hearing, vision or speech impairment(s)
- language or cultural differences requiring interpreter or cultural guidance
- neurological conditions such as confusion, delirium, dementia
- intellectual deficits.

Consideration and assessment should also address the dying person's capacity to make their own decisions or whether a support person and/or medical treatment decision maker should be or has previously been appointed.

Communication guiding principles

It is important to ensure you are communicating with the right people.

With the dying person, identify who they want you to share information with and whether they would like a person present when making decisions about their care at this time.

Discover what the dying person and those important to them already know. Use simple language that is free of medical jargon.

Explain what is happening and why you now think the person is dying.

Discuss that death is likely to happen in the coming days or hours. However, ensure you acknowledge that it is often difficult to be accurate with timing.

Discuss that care delivery is now focused completely on comfort and that the healthcare team will be introducing an additional clinical tool called the **Care Plan for the Dying Person – Victoria**. Explain how the care plan contributes to care delivered at the end-of-life and how this care is documented.

Check that everyone understands what has been discussed and has had the opportunity to contribute to decisions regarding how care is going to be delivered.

Sensitively explore everyone's understanding of what to expect during the dying process and into bereavement as appropriate.

Answer any questions clearly and honestly. If you cannot answer a question, say as much and let them know you will find out the information and provide a response promptly. Remember time is precious for all involved.

Provide relevant written information. When receiving bad news or when under stress, it can be difficult to retain information.

Document the outcomes of these discussions and ensure the right people know that the person has been commenced on the care plan.

It can be difficult to have conversations about dying. Recognise your skills and limitations. Seek advice or draw on the expertise and experience of your senior colleagues when appropriate.

Care plan for the dying person – Victoria

CLINICAL TOOL OVERVIEW

The **Care Plan for the Dying Person – Victoria** relies on the healthcare team undertaking frequent assessments, critical thinking, individualised care planning, shared decision-making and continuous review.

The care plan has been specifically developed for use in Victoria, Australia. Careful consideration has been made to clinical and legal practices unique to the State of Victoria, including language and terminology.

The care plan is an example of a multidisciplinary integrated care pathway (ICP) and forms part of the health information/clinical record.

The care plan supports a holistic approach to end-of-life care delivery. It addresses physical aspects of care such as management of pain and other symptoms as well as the psychological, social, spiritual, religious/cultural wishes and preferences, and practical supports relevant to caring for a dying person and those identified as important to them.

The care plan guides the healthcare team to explore and document an individual's specific wishes, requests and preferences. It also provides an opportunity to involve the dying person's relative/friend(s) to define and focus on particular goals of care (especially if the dying person is already unconscious or has expressed a wish for them to be involved).

Information is provided proactively and all decisions leading to a change in care delivery should involve the dying person (where appropriate) and their relative/friend(s). The views of all concerned must be listened to, acknowledged and documented. Relevant written information including practical advice related to the health service's facilities, what to expect when someone is dying, funeral preparations, grief and bereavement is helpful.

The care plan supports the dying person taking food and fluids for as long as they are tolerated and safe to do so. It does not preclude the use of clinically assisted (artificial) nutrition or hydration. Assessment of current medications, the discontinuation of non-essential medications and interventions and the anticipatory prescribing of 'as required'/PRN medications to manage common symptoms experienced at the end-of-life, are integral components of the care plan.

The healthcare team can use documentation on the care plan to review the effectiveness of the delivered care. If an end-of-life goal of care is not achieved this should not be interpreted as a negative process. Rather, it demonstrates the individual nature of the dying person's condition based on their particular needs and the clinical judgement provided by the healthcare team at that time. Further, vigilant interpretation of documented end-of-life goals of care provide the healthcare team with a real time 'snapshot' audit of care effectiveness that can be used to further individualise care provided.

The care plan has been designed to keep all relevant clinical information in the one place and avoid the need for duplication as much as possible. Health services will have their own policies related to documentation and may choose to continue to use the clinical record progress notes to document this type of clinical information. Refer to your local health service policy and procedures.

KEY MESSAGES

The **Care Plan for the Dying Person - Victoria** guides and supports the delivery of best practice end-of-life care. Use of the care plan does not replace the healthcare team's clinical judgement.

The care plan has been developed to comply with the '10 Principles for Best Care for the Dying Person'[3] and relevant Australian Standards outlined in documents from Palliative Care Australia[4] and the Australian Commission on Safety and Quality in Health Care.[5]

The care plan is a legal document that forms part of a person's medical record and is to be used with other key documents such as resuscitation plans, advance care plans and medication records. Health Services will have their own policies and procedures relating to documentation and may choose to continue to use the person's existing health information/clinical record to document aspects of clinical information.

It is crucial that all staff receive training to accurately document care delivery and processes related to commencing a person on the care plan.

The care plan is intended to be used by all members of the multidisciplinary team.

The care plan has been designed as a 'point of care' clinical tool that is kept at the bedside. This enables all detailed responses, instructions and 'further care actions' to be documented immediately and ensures evidence of care effectiveness is readily available for multidisciplinary team review.

Similarly, all 'further care actions' identified within the care plan should be documented, completed and evaluated as they occur; not at the end of the shift. This ensures immediate access to contemporaneous information.

It is important to review the person's overall care management at least daily to ensure it remains appropriate to their needs.

In some instances, it will be appropriate to discontinue the care plan if the person's condition improves and they are no longer thought to be imminently dying or if there are concerns raised by the person, relative/friend(s) or members of the healthcare team.

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[3] International Collaborative for Best Care for the Dying Person. The 10 Core Principles for Best Care for the Dying Person,2014.

[4] Palliative Care Australia. National Palliative Care Standards, 5th Edition, 2018..

[5] Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safety and high-quality end-of-life care, ACSQHC Sydney, 2015.

Section overview

SECTION 1: RECOGNISING DYING

Health changes can be subtle. However, it is crucial that dying is recognised so that shared end-of-life care planning decisions can take place as soon as possible. These decisions include review and where necessary, reassessment of existing legal and medical advance care planning documents and decisions such as whether to resuscitate. Other important areas of discussion may include organ/tissue/corneal donation wishes and possible coronial involvement.

A senior treating doctor must agree to commence the care plan and this decision is made in conjunction with the multidisciplinary team the dying person (if they are able or have capacity to participate) and those important to them. At this time, care must be taken to ensure that everyone understands and agrees that death is likely to be imminent and the dying person and those important to them are placed at the centre of decision making to produce an individual plan of care that is right for them.

SECTION 2: MEDICAL REVIEW OF CARE NEEDS

Anticipatory medication prescribing, planning and preparing for the unexpected are essential elements of the medical assessment. Current medications and route of administration, including any need for subcutaneous access, are reviewed. Non-essential medications are discontinued and 'as required'/PRN medications are prescribed and available for common symptoms known to occur at end-of-life such as pain, agitation, nausea, vomiting, dyspnoea and increased respiratory tract secretions.

Similarly, considerations are given to the discontinuation of interventions that are no longer necessary, such as blood tests, recording of vital signs and deactivation of implantable cardioverter defibrillators. Discussions related to the potential benefits and harm of each of these decisions should take place. Referral to, or seeking advice from, a specialist palliative care service may be necessary for complex symptom and care management.

SECTION 3: PLANNING INDIVIDUALISED CARE

Not all symptoms experienced will be physical. It is important to ask the dying person (if they are able or have capacity to participate) and those important to them about their individual emotional, spiritual, religious or cultural needs and wishes. Asking what is wanted after the person has died is also helpful, including considerations on who should be contacted, and when, as is the identification of bereavement risk factors.

Assessment and identification of these care aspects provides an opportunity to involve the skillset of the multidisciplinary team to ensure concerns, risks and conflict are addressed appropriately. Effective communication is key to providing good care and involves careful listening, responding honestly and providing information, comfort and understanding. Ensuring contact information is current and providing relevant information brochures is vital.

SECTION 4: DELIVERY OF CARE

Delivery of care is documented and the effectiveness of interventions monitored continuously. The care plan should be regularly reviewed and updated. This includes a daily multidisciplinary team review to assess that the person is still imminently dying. The 'ongoing assessment' chart provides an opportunity for the healthcare team to succinctly and clearly document symptom management, personal comfort care and psychosocial support measures.

If any end-of-life care goal is not met, it is documented immediately, acted upon and its effectiveness monitored. In doing so, the 'further care action report' provides the healthcare team with instant access to evidence of care interventions that have been delivered for ongoing analysis and action.

SECTION 5: CARE AFTER DEATH

After a person has died, the healthcare team must address the necessary medical and legal requirements, including updating databases and systems and notifying key healthcare stakeholders. This can help to avoid inappropriate interactions, such as appointment reminders being sent to the bereaved. It is crucial for relatives/friend(s) to retain a sense of control when death occurs.

Individual wishes, cultural and religious beliefs should be respected, and the healthcare team remains responsive to requests and concerns as this will help build positive memories to be reflected upon in bereavement. Offering brochures on practical matters, as well as grief and bereavement support can be useful.

SECTION 6: CARE PLAN DISCONTINUED

Dying is a unique, individual event and its course can be unpredictable. If a person is no longer imminently dying, it is appropriate to cease the care plan and reassess their care needs. Open and transparent communication at this time is especially important.

Section 1: Recognising dying

The senior treating doctor (or their medical delegate) must complete this section.

1.1 Commencement and authorisation

Recognising dying and knowing when to commence the care plan can be difficult as the realisation that death is imminent can sometimes be quite sudden. The decision that a person is likely to die within the coming days or hours is made following discussions between members of the multidisciplinary team who are familiar with the dying person. This must include the most senior treating doctor and registered nurse involved in the person's care.

An assessment by the multidisciplinary team and consensus that the person is imminently dying should precede communication with the dying person, relative/friend(s) and other relevant staff members wherever possible.

The assessment of the person **must** consider: Is there a potentially reversible cause for the person's condition? For example, exclude opioid toxicity, renal failure, hypercalcaemia or infection.

If there is uncertainty, further opinions should be sought.

If there is consensus that death is imminent, the multidisciplinary team should identify (with the dying person where possible) who to share information with and be involved in end-of-life care planning discussions, including the decision whether to commence the care plan or not.

If the dying person, those important to them or any healthcare team member expresses concern related to the commencement of the care plan, this should be further explored and discussed with the senior treating doctor (if not directly involved in the conversations) before the commencement of the care plan.

Decisions related to the appropriateness of the person's current resuscitation status and criteria for CODE BLUE/MET calls in response to deterioration must also be undertaken at this time. This review should occur in all instances – whether the person is commenced on the care plan or not.

Acute resuscitation plan/DNR documentation

The person's resuscitation and current criteria status **must** be reviewed, clearly documented and conveyed to the healthcare team.

Code blue/MET call

Clarify and document if and why the dying person will have CODE BLUE/MET calls in response to symptom distress, for example, in the case of uncontrolled or unexpected symptoms such as seizure activity.

Ensure existing health service documentation requirements related to recording acute resuscitation/DNR/goals of care and CODE BLUE/MET calls is completed and communicated.

Authorisation to commence the care plan

In all instances, the final decision and authorisation to commence the care plan is made by the most senior treating doctor* following a thorough consultative process.

Both the senior treating doctor and a registered nurse (Div 1) should provide authorisation to commence the care plan. However, the senior treating doctor authorisation can be given verbally to avoid unnecessary delays in end-of-life care delivery.

Verbal authorisation

If the senior treating doctor is not on-site and/or readily available to sign the care plan but has provided verbal authority, two nominated multidisciplinary team delegates* can sign authority to commence the care plan. However, the senior treating doctor must provide signature confirmation within 24 hours of the commencement of the plan.

> If the senior treating doctor is **not aware** and/or **not in agreement**, the Care Plan for the Dying Person – Victoria should not be commenced.

*Definitions for the purposes of this document

Senior treating doctor
The most senior Doctor responsible and familiar with clinical care decisions related to this dying person.

Multidisciplinary Team (MDT)
At a minimum an MDT consists of a senior treating doctor and a registered nurse (Div 1) who is responsible for the care of this dying person.

MDT Delegate
Doctor or registered nurse (Div 1) with delegated responsibility from a senior treating doctor to make decisions related to commencing this dying person on the care plan.

1.2 Legal and relevant decision assisting information

Refer to your health service policies and procedures to guide all medico-legal decision-making referred to in this section. Additional information can be found at:

- www.publicadvocate.vic.gov.au/medical-consent
- www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/medical-treatment-planning-and-decisions-act
- advancecareplanning.org.au/resources/victoria
- donatelife.gov.au/about-us/donatelife-network/donatelife-victoria
- www.cera.org.au/community/lions-eye-donation-service
- www.dtbv.org.au
- www.coronerscourt.vic.gov.au

When dying is recognised it is imperative to review any existing advance care planning decisions and documentation. Any outstanding legal and decision assisting aspects of care delivery must be addressed and communicated as these provide the framework for individualised end-of-life care.

Consider and assess whether the dying person has capacity to make their own decisions and/or whether a medical treatment decision maker and/or support person has previously been appointed. This will inform discussions related to care choices, such as:

- Is there an instructional and/or values directive in the patient health information/clinical record/My Health Record or available elsewhere?
- Is the advance care directive an instructional directive that needs to be recognised for this condition or treatment?
- Are there 'do not resuscitate' options to enact; treatments/medications to be withdrawn?
- Is there an expressed wish for organ/tissue/corneal donation?

Instructional directive/values directive/advance care planning (ACP)

An individual's beliefs, values and preferences must be explored and documented to ensure their care wishes are respected.

Consider any ACP or directive care decisions that the person has already made and ensure valid documentation can be found in their health information/clinical record.

If the dying person has not documented their preferences for care and is competent to do so, they should be offered the opportunity to complete an instructional and/or values directive and appoint a medical treatment decision maker and/or support person for their medical treatment decisions.

If the dying person has already completed an instructional and/or values directive and is no longer competent to make their own decisions, this documentation will guide and assist the healthcare team and those considered important to the dying person, in deciding what end-of-life care management options will promote the values and preferences of that person.

Medical treatment decision maker

If the dying person is no longer competent, and a legally appointed medical treatment decision maker has been appointed then this person holds the legal power to consent to or refuse medical treatments on the dying person's behalf. It is expected that the person acts in the best interests of the dying person and that existing directive and ACP related documentation will be used to guide their decision-making where applicable.

Medical Treatment Planning and Decisions Act 2016

This Victorian Act commenced on 12 March 2018. Legal documents made under the previous *Medical Treatment Act 1988* and the *Guardianship and Administration Act 1986* remain valid. For example, existing and valid refusal of treatment certificates and/or medical power of attorney and other advance care planning documentation.

Registered organ/tissue/corneal donor

As a person approaches the end-of-life, it is appropriate to ask if they have registered their donation decision on the Australian Organ Donor Register and discussed their donation wishes with those close to them.

> Organ donation is only possible if the person dies under strict circumstances in an intensive care unit or emergency department. It may be possible to facilitate tissue and/or corneal donation in a number of settings and different circumstances.

Due to the sensitive nature of this topic, discussing organ, tissue and corneal donation in more detail requires a high level of knowledge and expertise of the donation process. These discussions are best led by the specialist donation staff or their delegates. Many large metropolitan and rural hospitals across Victoria employ medical and nursing donation specialist staff to help identify and facilitate the donation process and to promote best practice in donation at a local hospital level.

If the person has previously expressed a wish to donate tissue and/or corneas, this option is best discussed with the hospital donation team (where possible) or local donation agency services Lions Eye Donation Service Victoria (LEDS) or Donor Tissue Bank of Victoria (DTBV).

Coronial deaths

In some cases, for example sudden unexpected deaths or deaths post-surgery, a death becomes reportable under the *Coroners Act 2008*. Medical staff should convey the likelihood of this occurrence to relatives and the healthcare team as appropriate.

Other relevant information not previously documented

Medical staff should consider, document and communicate all aspects of legal and other decision making information relevant to end-of-life care delivery to the healthcare team.

Documentation guidance

There is provision to record more detailed responses and instructions on issues identified in Section 4.2 and/or Section 4.3.

1.3 Communication – information exchange

When it is recognised that a person may die within the next few days or hours, this possibility should be communicated clearly and care decisions should be made in accordance with the dying person's needs and wishes.

> At this point, people need honesty, respect and above all, time from the healthcare team when gathering and sharing information.

When appropriate, the dying person and their relative/friend(s) should be involved in decisions about interventions and care to the extent that they want to be. This can include sharing information on issues that may affect decisions for the dying person following their death, such as when a coronial review will be required.

It is crucial that information is provided in a way that can be understood to ensure that an individualised care plan can be agreed upon and delivered with compassion.

It is important to ensure systems are in place to communicate that a person is imminently dying to the immediate healthcare team, including the GP and other relevant staff across the healthcare setting. In doing so, this will facilitate a health service wide approach to the delivery of compassionate care.

Language

- Does the dying person, relative/friend(s) require an interpreter?
- Is written information available in their language?
- Is there access to a bilingual staff member?
- Is it appropriate to use them in this circumstance?

Other barriers to communication

Consider level of consciousness, hearing and/or vision impairment, speech difficulties, learning disabilities, dementia, neurological conditions and confusion.

Conducting a family meeting/case conference

- Bringing relative/friends and members of the healthcare team together to participate in a structured family meeting/case conference can provide a safe environment to discuss issues and questions about end-of-life care and agree upon appropriate strategies.
- This can be a particularly useful intervention when there is differing awareness of the current situation and/or opinions expressed between the dying person and their relative/friends.
- Outcomes of this meeting should be documented and disseminated to all attendees (including the dying person and their relative/friend(s)) and the wider healthcare team.

Section 2: Medical review of care needs

The senior treating doctor (or their medical delegate) must complete this section.

2.1 Initial assessment

Conscious state assessment
- Requires ongoing review as conscious state is likely to fluctuate as death approaches.
- Provides guidance on care delivery decisions and helps the healthcare team to determine the level of engagement the dying person can have regarding their end-of-life goals of care.
- Informs the appropriate administration route for medications in the last days and hours of life.

Able to swallow
- Difficulty swallowing may contribute to an inability to tolerate oral medications, food and fluids and is likely to fluctuate during the dying process.
- While the oral route is preferred for medication administration in almost all circumstances, it is important to ensure alternate routes of administration are documented to maintain effective symptom control during the dying process. The use of the subcutaneous route (intermittent or continuous infusion) is common in end-of-life care delivery.

Experiencing delirium
- This can be a distressing experience for the individual and for their relative/friend(s).
- It is important to differentiate delirium from agitation and confusion in the dying person as the management of the symptoms are likely to differ.
- Clear explanations, support and reassurance is necessary.

2.2 Medication management

Providing quality end-of-life care requires ongoing symptom assessment and timely access to, and use of, medications. Failure to do so may result in poor outcomes for the dying person, their relative/friend(s) and the healthcare team providing care at this time.

The **Care Plan for the Dying Person - Victoria** lists symptoms commonly experienced during the final days and hours of life, including:
- pain
- agitation
- nausea/vomiting
- delirium
- dyspnoea
- respiratory tract secretions.

Medications must be prescribed and available in anticipation of commonly experienced symptoms that may develop as death approaches. Anticipatory prescribing is recommended in end-of-life care.

Key considerations

- It is important to prescribe appropriate 'as required'/PRN medication for all the above symptoms when commencing the care plan, whether or not the person is displaying these symptoms.
- Anticipatory prescribing will ensure minimal delay responding to a symptom if or when it arises.
- Prescribed medications should be on an 'as required'/PRN basis via the most appropriate route to manage symptoms. Indicators for use and the dosage should be specified for all medications prescribed.
- Ensuring medications are immediately available to manage distressing symptoms is fundamental to being able to provide quality end-of-life care. For example, after hours or public holidays should not be barriers to the delivery of symptom management.
- It is important to ensure medication is readily available. This may require forward planning to ensure medications are in stock and on the unit/ward.
- Equipment such as subcutaneous infusion devices should be readily available. Staff must be competent to use the device and understand issues related to medication compatibility.
- Seek advice from a specialist palliative care service if symptoms do not respond to recommended dosing and management.

Administer symptom control medications only when required and titrate according to an individual's need.

Review regularly and adjust as needed.

In the Australian context, symptoms that are encountered at the end-of-life are generally well controlled by the use of nine commonly used medications. These include[6]:

- morphine sulphate/tartrate (an opioid)
- hydromorphone (Dilaudid, an opioid)
- haloperidol (Serenace, an antipsychotic/antiemetic)
- midazolam (Hypnovel, a short acting benzodiazepine)
- metoclopramide (Maxolon, an antiemetic)
- hyoscine hydrobromide (Hyoscine, an antimuscarinic/antiemetic)
- clonazepam (Rivotril, a benzodiazepine)
- hyoscine butylbromide (Buscopan, an antimuscarinic)
- fentanyl (a narcotic).

2.3 Current interventions

Current treatment interventions must be assessed and non-essential interventions discontinued. New interventions are commenced as appropriate.

Essential medications via appropriate route

- A review is undertaken and any previously prescribed medications that are not providing symptomatic benefit or may cause harm are ceased, for example cardiac, hypothyroid oral medications or intravenous antibiotics.
- Assess and decide upon the most appropriate route for administering medication in the last days or hours of life, tailoring the decisions to the dying person's condition, their ability to swallow safely and their preferences.
- Poor gastric absorption may also necessitate the need for a medication route review, for example oral metoclopramide to subcutaneous metoclopramide or morphine liquid/mixture to subcutaneous morphine.

Continuous subcutaneous infusion (CSCI)

- Not all people who are dying will require a CSCI. However, if they do so, a member of the multidisciplinary team must provide the dying person and their relative/friend(s) with an explanation about the device and its advantages and possible disadvantages to ensure they understand and agree to its use.
- Only in exceptional circumstances should a CSCI be commenced prior to communicating the rationale for using the device to the dying person (where possible) or their relative/friend(s).
- A minimum four hourly checklist should be in place to monitor and support the use of a CSCI. Please refer to your local Health Service policy and management guidelines.

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[6] Queensland Health, Guidelines for Subcutaneous Infusion Device Management in Palliative Care - Second Edition, (2010).

Nutrition

- Support the dying person to eat and drink for as long as they can and wish to.
- Appropriate multidisciplinary team assessment for the risk of aspiration should be undertaken and communicated accordingly.

> A reduced need for food and fluids is part of the normal dying process and this should be communicated to the dying person and others involved in their care.
>
> Uncertainty about nutritional requirements is a common and significant cause of distress amongst relative/friend(s).
>
> Regular multidisciplinary team review of the need for clinically assisted (artificial) nutrition and hydration should be implemented.

Clinically assisted hydration and nutrition

- If clinically assisted (artificial) hydration and/or nutrition is already in place, proactively review the risks and benefits with the dying person and those important to them and establish an agreed plan on whether to continue, reduce or discontinue this as they near death.
- In some cases, ongoing review of agreed end-of-life care goals will need to be undertaken as death approaches.

Inappropriate interventions are discontinued

A review should be undertaken to identify invasive, futile, potentially painful and unnecessary procedures/interventions with no clear benefit to the dying person's ongoing care. Examples include oxygen therapy, anticoagulation therapy, routine blood tests, administration of intravenous antibiotics and recording of routine vital signs.

Ability to add interventions specific to this dying person

Section 2.3 provides an opportunity for the doctor to document other interventions which are relevant to this dying person and their current setting. For example, the discontinuation of renal replacement therapy or within the ICU setting instructions on electronic monitoring, vasoactive medications, ECMO, mechanical ventilation, endotracheal intubation.

Implantable cardioverter defibrillator (ICD) deactivation

- Imminent death and a 'do not resuscitate' order are indications for deactivation of an ICD as per relevant guidelines.[7]
- Refer to local health service policy and procedures for guidance.

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[7] Agency for Clinical Innovation, NSW Guidelines for Deactivation of Implantable Cardioverter Defibrillators at the End of Life, (2014)

> **Thinking point**
>
> In the context of care delivery in the last days or hours of life, death is inevitable with or without an activated ICD.
>
> However, the likelihood of a dying person receiving uncomfortable shocks from their ICD as they die is very real and the resultant grief experienced by their families may be complicated and protracted.
>
> Discuss the situation with the person (where possible) and with their relative/friend(s) and/or consult with the dying person's cardiologist.
>
> The indications to deactivate a Permanent Pacemaker (PPM) differ from those related to ICD deactivation and require careful consideration. The dying person's cardiologist should be consulted.

2.4 Referral to specialist palliative care service

Specialist palliative care services (SPCS) can offer advice and assistance with complex symptom, care management and psychosocial support.

Providing care for a dying person and those important to them will not always necessitate a referral to a SPCS.

Local health service policy and procedures will dictate processes regarding when and how to access SPCS support and referral criteria and processes.

> Decision making related to medical management at the end-of-life can be complex.
>
> Recognise your skills and limitations and seek advice or draw on the expertise and experience of your senior colleagues when appropriate.

Section 3: Planning individualised care

Any relevant member of the MDT can complete this section.

Irrespective of any prior discussions, now is the time to ensure the dying person and those identified as important to them are included in decisions about care delivery and have access to information that explains how and why care decisions are being made.

Supplemental information on psychosocial care and the principles of good communication can be found in the 'Communication' section of this guide.

3.1 Brochures

Retention of information when experiencing stress can be extremely limited. Access to appropriate, jargon-free written information is vital and should be immediately available to supplement verbal discussions.

Care should be taken to ensure the written information is relevant to the individual needs of the dying person and/or those important to them. For example, when reference is made to support services and other organisations, ensure the services described are readily accessible and available to the person in their own locality.

Consider access to other relevant brochures including disease specific information; bereavement and grief information for adults and children; Centrelink payment management; and practical advice on what to do when someone dies.

At a minimum, the MDT should distribute the following documents:

- **Care Plan for the Dying Person – Victoria** family member/friend information brochure

  This provides information on how the care plan helps guide decisions related to end-of-life care delivery and an overview of what to expect as death approaches. This includes common signs and symptom changes and what feelings may be experienced at the time of death and into bereavement. These are in a number of languages.

- Facility orientation brochure

  This provides practical information and explanation of your health services facilities. This may include management of property and valuables, visiting hours and opportunities for extended visiting hours, after-hours access, car parking, public transport, bathroom facilities, phone, Wi-Fi availability, accommodation and nearby cafés and food outlets.

Local health service policy and procedures will dictate what written information is provided within individual health services.

3.2. Contact information

It is essential that the MDT has up-to-date contact information for those identified as important to the dying person. Check the health information/clinical record with the relevant relative/friend(s) or advocate and update as necessary.

It is important to identify the specific relationship to the dying person and to ascertain when to contact the relative/friend or advocate.

There should be clear written instructions about who to contact when the person deteriorates and/or dies especially if the relative and/or friend(s) are not present.

Note: sometimes a dying person may not have relative/friend(s) and it is important to ascertain if there is anyone they would like to share their wishes, needs and preferences at the end-of-life with. This may be someone who has not previously been identified as a contact person.

3.3 Funeral arrangements

Sensitive exploration of preferred funeral or spiritual ceremony arrangements including preferences for burial or cremation, should be undertaken and documented. These discussions will inform care of the body and certification processes after death.

Funeral director information may have already been documented by a member of the multidisciplinary team. Check the health information/clinical record prior to initiating a discussion to avoid unnecessarily repetitive questioning on this sensitive issue.

3.4 Person-centred communication

Is the dying person able to fully participate in this discussion?

Ideally the dying person and those identified as important to them are involved in shared decision-making about management and care to the extent the dying person wants and can participate. However there may be reasons why the dying person is unable to fully participate in discussions at this time. These reasons may have already been identified in Section 1.3 and Section 2.1.

In addition, the MDT must ensure they seek guidance from existing advance care planning documentation, for example instructional and/or values directive including such as valid Refusal of Treatment Certificates completed prior 12 March 2018 and other legal and medical decision-making assisting documentation – see Section 1.2.

Questions listed in Sections 3.5 and 3.6 are intended to guide discussions only. It is not necessary or appropriate to quote the questions verbatim when communicating with the dying person or those considered important to them.

3.5 Communication with the dying person

If the dying person is assessed as not able to fully participate in discussions, Section 3.4 should be left blank and the psychosocial needs of the dying person should be discussed with their relatives/friend(s) in Section 3.6.

Exploration of the dying person's feelings, values and religious or spiritual beliefs will inform the delivery of a plan of care that is individualised to their wishes.

Recording and communicating these wishes to the wider MDT will ensure the dying person's needs are pursued and met to the extent that is possible within the constraints of the healthcare setting in which care is being provided.

It is an important consideration that the multidisciplinary team should recognise that the dying person's ability and desire to be involved in decision-making about their care may change as their condition deteriorates or as they accept their prognosis.

Thinking point

Taking the time to discuss things that may be important to the dying person and their relative/friend(s) will provide the multidisciplinary team with valuable insight and will support therapeutic interactions in areas such as:

- clarifying end-of-life goals of care and preferences for symptom management
- identifying emotions and fears
- identifying 'unfinished business'
- acknowledging relative/friend(s) preference related to direct care involvement reflecting on past experiences with death and loss
- reflecting on past experiences with death and loss
- identifying immediate issues related to loss and grief
- identifying bereavement needs into the future.

3.6 Communication with relative/friend(s)

The feelings, values and wishes of relatives, friends and others identified as important to the dying person should be explored. It is important to note that their wishes may vary from those of the dying person, which can necessitate careful consideration and negotiation by the MDT.

3.7 Bereavement risk

Bereavement assessment and support is an integral component of end-of-life care provision and should be provided in the time leading up to death and beyond. The bereavement support needs of relatives and friends should be assessed, planned and facilitated as appropriate.

People should be informed that grief is a normal reaction and that they may grieve in different ways depending on their individual family, community or cultural influences.

Routine assessment of bereavement risk will differ across health services based on their preferred bereavement risk tools, MDT case management and/or allied health support availability both within and outside of the health service.

Refer to your local health service policy and procedures to inform bereavement risk assessment and management.

3.8 Allied health/support services required

Dying people and those important to them can benefit from referral to a multidisciplinary review of their care needs, which will assess their strengths, hopes and wishes within the context of the person's imminent death.

A review of the existing health information/clinical record will indicate what, if any, allied health and additional support services are already involved in care delivery, which will provide the wider MDT with valuable insight.

In cases where no previous support has been instigated, a referral may be required stipulating a prioritised review timeframe in keeping with the expected imminent death of the person.

Further comments

This section can be used to document any additional psychosocial aspects of care that may be helpful, for example 'family tree' diagrams.

Section 4: Delivery of care

In general, nursing staff should complete this section.

Section 4 is where both care delivered and the effectiveness of that care or intervention is documented. All MDT members should use this section to document the care they provide.

4.1 Ongoing assessment

Key considerations:

- A new 'ongoing assessment' chart is commenced each day.
- Daily MDT review and assessment of whether the person is imminently dying and whether it is appropriate to continue on the care plan.
- An additional full MDT review should be undertaken when there is sustained improvement in:
  - conscious level
  - functional ability
  - oral intake
  - mobility
  - ability to perform self-care or
  - the person, relative/friend(s) or a healthcare team member expresses concerns regarding the management plan.
- If the person is no longer thought to be imminently dying, it is appropriate to discontinue the care plan and develop a new individualised plan of care. In this instance, documentation in Section 6 should be completed.

'Ongoing assessment' contains three section headings:

(a) Symptom management

(b) Personal comfort care

(c) Psychosocial care

Documentation guidance

How to document on the 'Ongoing assessment chart' (Appendix 4 and Appendix 5)

1. 'Symptom management' and 'Personal comfort care' are documented two or four hourly. It is recommended that psychosocial aspects of care be documented at least once per shift.

2. Document and evaluate care as it occurs, not at the end of a shift.

3. Outcomes for each end-of-life care goal are recorded with one of the following options:
   – 'A' means that you have assessed the person and no action is required.
   – 'F/A' means you have assessed that a care goal has not been met and further action or intervention is required.
   – 'R/C' means that you have provided routine care and no further action is required.
   – 'N/A' means not applicable.

4. All further actions 'F/A' should be documented in Section 4.2.

5. It is not necessary to record a separate entry in the person's health information/clinical record at the end of each shift to document care given if Section 4 has been completed throughout the shift.

6. Care can be delivered by any member of the multidisciplinary team, however the registered nurse responsible for the overall care of the dying person is required to record their name on the bottom of the chart for each shift. This registered nurse may or may not have been the person assessing the dying person and documenting aspects of the care provided during the shift.

(a) SYMPTOM MANAGEMENT

The end-of-life goals of care listed in this section address symptoms commonly experienced in the last days or hours of life and include the management of subcutaneous cannulas and continuous subcutaneous infusions (CSCI).

Management of symptoms often requires the administration of medication which can augment the effectiveness of non-pharmacological interventions. Clear explanations on the rationale for using medications for symptom management should be provided to the dying person (where possible) and their relative/ friend(s).

Familiarising yourself with commonly prescribed medications, their indications, actions and doses will be time well spent and will assist the MDT's ability to effectively and efficiently manage the symptoms a dying person may experience.

In the Australian context, symptoms that are encountered at the end-of-life are generally well controlled using nine commonly used medications. These include[8]:

- morphine sulphate/tartrate (an opioid)
- hydromorphone (Dilaudid, an opioid)
- haloperidol (Serenace, an antipsychotic/antiemetic)
- midazolam (Hypnovel, a short acting benzodiazepine)
- metoclopramide (Maxolon, an antiemetic)
- hyoscine hydrobromide (Hyoscine, an antimuscarinic/antiemetic)
- clonazepam (Rivotril, a benzodiazepine)
- hyoscine butylbromide (Buscopan, an antimuscarinic)
- fentanyl (a narcotic)

Free of pain

- The person can verbalise their pain-free status if conscious and/or if they are pain-free on movement.
- Observe for non-verbal cues.
- Consider need for positional change.
- Use a pain assessment tool (as appropriate).
- Consider 'as required'/PRN analgesia for incident/breakthrough pain.

Free of agitation/restlessness

- The person does not display signs of agitation/restlessness or distress.
- Exclude reversible causes, for example, urinary retention or opioid toxicity.

Free of nausea/vomiting

The person can verbalise, if conscious.

Free of dyspnoea/breathlessness

- The person can verbalise, if conscious.
- Consider positional change.
- Use of a fan or medication may be helpful.
- Commencement of oxygen therapy in rare cases may need to be explored.

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[8] Queensland Health, Guidelines for Subcutaneous Infusion Device Management in Palliative Care - Second Edition, (2010).

Free of respiratory tract secretions

- Consider positional change.
- Discuss symptoms and plan with person (as appropriate), relative and friend(s).
- Medication should be given as soon as symptoms occur.

Free of urinary problems

- The person can verbalise, if conscious.
- Use pads, uridome, urinary catheter as required.
- Exclude urinary retention.

Free of bowel problems

- The person can verbalise, if conscious.
- Monitor for constipation/diarrhoea.
- Monitor skin integrity.
- Document when bowels last opened.

Subcutaneous cannula care

- The chest and the abdomen are the preferred sites for cannula insertion.
- Every four hours and before and after each injection, the insertion site should be checked for displacement of the tube, swelling, hardness, tenderness, redness or leakage.
- The longevity of the site can vary considerably, depending on factors, such as the type of medication and cannula used.
- Refer to your local Health Service policy and procedure to inform any infection control policies related to routine changing of cannula insertion requirements.
- If there is no cannula inserted, please record N/A.

Continuous subcutaneous infusion (CSCI)

- A subcutaneous infusion of medication(s) to treat unrelieved pain and other distressing symptoms should be considered when other routes of administration are inappropriate or no longer effective.
- The rationale, advantages and any possible disadvantages of using a CSCI should be discussed with the dying person and their relative/friend(s) prior to commencement.
- There are several types of devices available for use in end-of-life care.
- It is important to verify the equipment that is used within your health service and be guided by local policy and procedures.
- A four hourly checklist should be in place to monitor and support the use of the CSCI.
- If there is no CSCI, please record N/A.

(b) PERSONAL COMFORT CARE

The end-of-life goals of care listed in this section address physical aspects of care delivery including the nutritional needs of the dying person. Maintaining a meticulous focus on these areas of care will ensure that the dignity and comfort of the dying person is achieved.

Receives food and fluid to support needs

- The person should be supported to take food and fluid by mouth for as long as tolerated and safe to do so.
- Monitor for signs of aspiration and/or distress.
- A reduced need for food is part of the normal dying process and this needs to be sensitively communicated with the dying person, relatives/friend(s).
- Recognising a person is dying does not necessarily stop the use of clinically assisted (artificial) hydration, although the use of clinically assisted (artificial) nutrition is rarely required.
- If either artificial hydration and/or nutrition is in place, the rate/volume should be monitored and reviewed.
- Ongoing assessment by the MDT of volume reduction and continued use should be attended to daily.
- Refer to your local Health Service policy and procedure to inform requirements.
- Note: supplemental information on clinically assisted hydration and nutrition can be found in Section 2.

Is comfortably positioned

- The person can verbalise, if conscious.
- The person's individual need should determine the frequency of repositioning and the use of height- adjustable bedding and chairs.

Skin care needs are met

- The use of pressure relieving equipment should be determined by regular skin inspection and assessment.
- Refer to local health service policy and procedures.

Personal hygiene needs met

- The person can verbalise, if conscious.
- Wash if required, change of clothing according to the person's individual needs. Involve the relative/friend(s) if appropriate.

Mouth is clean and moist

- The person can verbalise, if conscious.
- Regular mouth care is essential.
- Symptoms of dry mouth do not always indicate dehydration but are often due to mouth breathing or a side effect of medication.
- Provide lip care; help with cleaning teeth/dentures and frequent sips of fluid as appropriate.
- Provide mouth care aids (such as oral hygiene sponges, lip balm) at the bedside and offer to teach relative and friend(s) how to use as appropriate.

Eyes are clean and moist

- Attend to regular cleansing of the eyes according to individual needs.
- Keep eyes moist if the person has indicated a wish to be a potential eye/corneal donor.

Environment supports needs

- Ensure the nurse call bell is always accessible.
- Consider adjustments to the physical space to suit individual needs of the dying person and relative/friend(s) where possible and as appropriate.
- This may include relocating to a private room, the provision of sufficient seating and space around the bedside and access to overnight bedding arrangements.
- The use of aromatherapy, music etc. should also be facilitated based on individual preferences and local health service policy and procedures.

(c) PSYCHOSOCIAL CARE

Any relevant member of the MDT can complete this section.

The physical care needs of the dying person and those close to them are not the only aspect of care that should be addressed as the time of death approaches. Respectful and sensitive exploration of the psychosocial needs of the dying person and significant others is an integral component of holistic end-of-life care delivery.

Simply just being available and at the bedside can reflect the respect and support of the Health Service at this distressing time. Nonetheless, proactive response to any identified concerns including the use of experienced allied health professionals, will help to improve the satisfaction of care at the end-of-life.

Emotional, spiritual, religious, cultural needs/rituals are met

- The opportunity to discuss what is important to the dying person, including wishes, feelings, faith, beliefs and values, is provided.
- Specific requests should be highlighted and addressed as required (immediately, at the time of death or after death).
- Requests for an allied health professional or external provider support should be acted upon and prioritised as urgent.
- Ensure contact details are recorded for MDT access.

Procedures/care plan explained

- Good comprehensive clear communication is pivotal.
- All procedures and decisions leading to a change in care delivery should be communicated and the views of all concerned listened to and documented.
- Regularly check on the dying person's understanding of what has been talked about include their relative/friend(s) as appropriate.

Information regarding changes provided

- Where possible, communication regarding significant changes in the dying person's condition, including those signs of imminent death such as Cheyne-Stokes breathing and peripheral shutdown, should be prioritised to allow for informed decision-making.

Relative/friend(s) supported

- Relatives and friends of the dying person are supported to understand that experiencing the death of someone close can be extremely distressing.
- The individual needs of relatives and friends require dignified assessment and the MDT must implement care strategies that recognise that the imminent death of the person is only part of the journey.
- This will include assessing any anticipated needs following death to ensure facilitation of appropriate bereavement support interventions.
- See supplemental information in Section 1.

Thinking point

The recording of all further actions (F/As) and interventions demonstrates the delivery of best care practice based on the individual nature of the dying person's condition, particular needs, your clinical judgement and the needs of relative and friends.

4.2 Further care action report

Any relevant member of the MDT can complete this section.

Documentation in this section aims to:

- Provide a record of all further actions (F/As) required or interventions identified in any section of the care plan. The majority of F/As will be recorded when completing Section 4.1.
- Provide a record of more detailed responses and instructions on issues identified during initial assessment and completion of Sections 1, 2 and 3 of the care plan.
- Provide an opportunity for the MDT to easily monitor the effectiveness of symptom management and care delivery.
- Provide a mechanism to audit and analyse care interventions, which in turn can provide evidence to identify future training needs or new resources.
- Needing to provide F/As should not be viewed as a failure to deliver good care.

Documentation guidance

Recording F/A must include:

- date and time
- end-of-life care goal, issue or item that requires action or intervention
- which action or intervention has been undertaken to address the end-of-life care goal, issue or item
- the outcome of the action or intervention.

Some F/As can be evaluated immediately, while others may require additional F/As to be undertaken while pursuing an effective care outcome.

Other F/As such as giving subcutaneous analgesic medications, will require a time lapse of 10-20 minutes to assess whether it has provided effective symptom management.

4.3 Integrated progress notes

The 'Integrated progress notes' can be used to record relevant clinical information including clinical notes written by the wider healthcare team, for example specialist palliative care service, second opinion consultations or visiting Allied Health professionals.

This section provides the opportunity to record more detailed responses and instructions on issues identified during the initial assessment and completion of Sections 1, 2 and 3 of the care plan that do not necessarily require a F/A. (Appendix 6)

Section 5: Care after death

Any relevant member of the MDT can complete this section.

There are both practical matters and legal obligations that need to be completed after the person has died.

Individual health service policies and procedures should always be adhered to and given precedence to information contained in this section. Please refer to your local health service policy and procedures for more information.

5.1 Verification of death

Significant delays can occur in securing a registered medical practitioner to attend after death has occurred, which may lead to delays in the movement of the deceased to a mortuary or funeral home. This can be a distressing situation for relatives and friends of the deceased and should be avoided when at all possible.

> ### Documentation guidance
>
> Documentation of 'verification of death' must include name of person(s) verifying death, their professional title(s), the clinical determinants used and the date, time and location of the clinical assessment. This information should be recorded on the Care Plan or within the health information/ clinical record.

The Victorian Department of Health and Human Services considers that the professionals listed below should also have the expertise to competently undertake a clinical assessment of a deceased body to establish that death has occurred (verify death) as they have undertaken relevant training:

- A registered nurse (Division 1) of the register of nurses established under the *Health Practitioner Regulation National Law (Victoria) Act 2009*
- A midwife on the register of midwives established under the *Health Practitioner Regulation National Law (Victoria) Act 2009*
- A paramedic (a person credentialed by Ambulance Victoria as either an ambulance paramedic or MICA paramedic).

The suite of clinical determinants listed on the care plan act as a minimum guideline for the clinical assessment necessary to establish that death has occurred. Professional clinical judgement is required to verify death and unique circumstances may warrant additional checks over the minimal guideline provided in this care plan.

There are circumstances in which a registered nurse, midwife or paramedic should not verify death. These may include, but are not limited to, unexpected, reportable or reviewable deaths. For further guidance, please refer to your local health service policy and procedures and the Victorian Department of Health and Human Services guidance note for the 'Verification of Death'.

Note: 'Verification of death' is different to 'Certification of death'. The legislative requirement for a medical certification of cause of death under Section 37 of the *Births, Deaths and Marriages Registration Act 1996* states that the medical practitioner is required to make a diagnosis of the cause of death which requires specialist knowledge.

5.2 Notifying relative/friend(s)

There should be clear written instructions about who to call when the person dies especially when death occurs and the relative/friend(s) are not present. In some cases, this will involve contacting the designated medical treatment decision maker. Relatives and friends present or contacted at the time of death must be afforded privacy, dignity and respect and their individual needs should be addressed as far as possible. This extends beyond the final care delivered to the person who has died to include the management of their property and possessions.

For the purposes of possible future follow-up, for example for bereavement support, it is important to record who was present at the time of death. This can include relative/friend(s) and/or healthcare team.

Information brochures

It is important that people are offered access to written information particularly on how to access bereavement support. Refer to Section 3.1 to find out what information and brochures have already been given to the relative/friend(s).

5.3 Care of the deceased

It is important to attend to the tasks that need to be completed after the person dies in accordance with their wishes.

Discussions can include:

- viewing of the deceased
- the need for a post-mortem
- the need for the removal of cardiac devices
- the need for a discussion with the Coroner.

In addition, wishes regarding tissue or corneal donation should be further discussed with relative and friends as appropriate.

Relative/friend(s) may wish to be involved in washing and laying out the deceased, because this may be regarded as an important ritual. In some cases, relatives and friend(s) will not wish for staff to be present to assist with necessary cultural duties relevant at time of death. Referring to Section 3 at the time of death is an important part of providing the best care possible after death.

In any situation, universal precautions and infection risk requirements should be adhered to.

5.4 Communication by health service

A medical doctor must complete the relevant documentation. This will include:

- medical certification of cause of death (MCCD) (there is the option to complete this electronically - eMCCD)

  Or

- eMedical deposition form (this is completed if a death certificate cannot be filled out due to an unknown cause of death and/or it is a reviewable or reportable death to the Coroner as per the *Coroners Act 2008*)

- discharge/notification of death letter(s).

Communication of death to other relevant agencies may be undertaken by other members of the MDT. This includes:

- medical consultants ('home unit'/'admitting unit')
- bereavement/pastoral care/patient liaison
- general practitioner (GP)
- community healthcare providers.

In addition, ensuring the health service IT system is updated will avoid inappropriate interventions occurring such as reminder appointments being sent out.

Staff support

For some staff, some deaths are more complicated and distressing than others. The reference to staff support in this section is included to act as a prompt to reflect on the death and consider any staff support interventions which may be required within the context of local health service policy and procedures.

5.5 Coroner

Reviewable and reportable deaths to the Coroner must be managed as per local Health Service policy and procedures.

5.6 Organ donation

This section can only be completed by a registered medical practitioner. This section is only to be completed in the context of organ donation, where the person is certified as brain dead.

Brain death may have occurred. The formal clinical determination of brain death is usually in the context of organ donation and requires specific requirements and preconditions.

Verification of death by nursing or midwifery staff cannot be undertaken if the person is being considered for organ donation.

Please attach a copy of the completed ANZICS documentation 'Determination of brain death' to the care plan. (Appendix 7).

Section 6: Care plan discontinued

Dying is a unique, individual event and its course can be unpredictable. If a person is assessed as no longer imminently dying, it is appropriate to cease the care plan and reassess their care needs. There should be no delay in discontinuing the care plan if everyone is in agreement and is aware of the decision and reasons why the care plan has been discontinued.

This section is completed when the MDT has made the decision the person is no longer imminently dying following a MDT review and assessment, and discussion with the person and/or relative/friend(s).

After completing this section, the page is attached to the FRONT of the **Care Plan for the Dying Person – Victoria**, so it is clear for everyone involved in the care of this person, that the care plan is no longer in use.

The care plan forms part of the health information/clinical record for this person and should be filed accordingly.

Reassessment of the person's care needs and plan of care should be discussed and documented in the health information/clinical record.

If the person's condition later deteriorates, a new care plan should be commenced.

6.1 MDT decision making

The senior treating doctor must be involved in decision-making and sign confirmation that the person is no longer imminently dying and authorise ceasing of the care plan.

Providing the senior treating doctor is aware and in agreement with the MDT decision that this person is now **not** imminently dying, the nominated MDT delegates can complete this section based on the senior doctor's verbal directives.

If the senior treating doctor authorisation was given verbally, signature confirmation should be completed within 24 hours.

> ### Documentation guidance
>
> A new health service care plan including a review of **resuscitation** and **code blue/MET call** status should be completed at this time.

6.2 Reason(s) why the care plan was discontinued

The reasons why the care plan has been discontinued are recorded for future reference.

6.3 Outline discussion with person/relative/friend(s)

The decision to discontinue the care plan must be made in consultation with the person (where able and deemed appropriate) and their relative/friend(s). In some cases this may involve contacting the medical treatment decision maker. This may involve a telephone/Skype/Facetime consultation if the person/people are not physically present.

Ensure the name and relationship of the person who was involved in the decision to discontinue the care plan is documented.

It is likely to be an emotional and potentially confusing time and care should be taken to document discussions related to future care planning to ensure the wider MDT can continue to provide care according to agreed wishes.

6.4 Referral to specialist palliative care service (SPCS)

It is important to reconsider if a referral needs to be made to SPCS at this time or if they should be notified of the change in care management if they have already been involved in the care of this person.

If you were required to notify the SPCS when you commenced the care plan as per your local health service policy and procedures, as a matter of courtesy, please inform them that this person is no longer thought to be imminently dying and the care plan has been discontinued.

Reference and source documents

Australian Commission on Safety and Quality in Health Care, Safety and Quality of end-of-life care in acute hospitals: a background paper, 2013.

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Leadership Alliance for the Care of Dying People, One Chance to Get it Right. Improving people's experience of care in the last few days and hours of life, 2014.

National Health Service, Transforming end of life care in acute hospitals: The route to success 'how to' guide, NHS, 2015.

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National Institute for Health and Care Excellence, Care of dying adults in the last days of life, 2015. Victorian Auditor-General's Office, Victorian Auditor-General's Report Palliative Care, 2015.

Appendix 1

ESSENTIAL ELEMENTS FOR SAFETY AND HIGH-QUALITY END-OF-LIFE CARE IN THE ACUTE CARE SETTING

PROCESSES OF CARE

1. PATIENT CENTRED CARE
Patients are part of decision making about end-of-life care

2. TEAMWORK
Clinicians work together to provide end-of-life care

3. GOALS OF CARE
Clear goals improve the quality of end-of-life care

4. USING TRIGGERS
Triggers identify when patients need end-of-life care

5. RESPONDING TO CONCERNS
Clinicians get help to rapidly respond to patient suffering

ORGANISATIONAL PREREQUISITES

6. LEADERSHIP & GOVERNANCE
Policies and systems for end-of-life care

7. EDUCATION & TRAINING
Clinicians have the skills and knowledge to provide end-of-life care

8. SUPERVISION & SUPPORT
Clinicians providing end-of-life care are supported

9. EVALUATION & FEEDBACK
The quality of end-of-life care is measured and improved

10. SUPPORTING SYSTEMS
Systems align with NSQHS Standards to improve outcomes

Australian Commission on Safety and Quality in Health Care, National Consensus Statement: essential elements for safety and high-quality end-of-life care, 2015

Appendix 2

BEST CARE FOR THE DYING PERSON – 10 CORE PRINCIPLES.
INTERNATIONAL COLLABORATIVE FOR THE BEST CARE FOR THE DYING PERSON

- Recognition that the person is in the last few days and hours of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the person's care.

- Communication of the recognition of dying should be shared with the person where possible and deemed appropriate and with those important to them.

- The dying person and those important to them - relative or carer or advocate should have the opportunity to discuss their wishes, feelings, faith, beliefs, values.

- Anticipatory prescribing for symptoms of pain, excessive respiratory secretions, agitation, nausea and vomiting, dyspnoea should be in place.

- All clinical interventions are reviewed in the best interest of the individual person.

- There should be a review of hydration needs including the commencement, continuation or cessation of clinically assisted (artificial) hydration.

- There should be a review of nutritional needs including the continuation or cessation of clinically assisted (artificial) nutrition.

- There should be a full discussion of the plan of care with the dying person where possible and deemed appropriate and with those important to them/relative or carer or advocate.

- There should be regular reassessments of the dying person at least every four hours.

- Care of the dying person and those important to them/relative or carer or advocate immediately after death is dignified and respectful.

International Collaborative for Best Care for the Dying Person www.mcpcil.org.uk.
Ellershaw J. & Wilkinson S., Care of the dying: a pathway to excellence., 2nd rev ed, Oxford: Oxford University Press, 2011. Ellershaw J, Lakhani M., Best Care for the dying patient, BMJ 2013, v. 347, pp. f4428
Vanhaecht K , De Witte K , Sermeus W., The impact of clinical pathways on the organisation of care processes. Leuven:ACCO, 2007. Mason S, Dowson J, Gambles M, Ellershaw J. OPCARE9-optimising research for cancer patient care in the last days of life. Eur J Palliative Care, 2012, v. 19 pp. 17-9

Appendix 3

RISK MANAGEMENT CONSIDERATIONS

A well-structured systematic risk analysis should be undertaken prior to implementing the Care Plan for the Dying Person – Victoria.

Implementation and use of the care plan clinical tool and associated consumer brochure must be embedded within the governance of individual health services as part of their continuous quality improvement programs and end-of-life care service provision guidelines and policies.

The effective identification, analysis and management of potential and actual clinical and organisational risk associated with using the care plan documents when caring for a dying person and their relative/friend(s) is essential to providing safe and quality end-of-life care.

Individual health services must undertake analysis and develop risk profiles within their own strategic context and then determine the type and level of risk management planning and management options to be implemented. This will include being aware of escalation processes and reporting lines within the health services' existing risk management guidelines and framework when risks are identified.

Health services are also required to implement an incident management review process consistent with best practice and their clinical governance policy, and in line with the Victorian health incident management policy.

Failure to identify and minimise risk in the context of end-of-life care provision, no matter what the health care setting, can lead to:

- Significant distress to the dying person and relative/friend(s) resulting in an increased risk of poor bereavement outcomes.
- Staff dissatisfaction when they do not feel supported, enabled or encouraged to deliver high quality care, whether because of a lack of:
  - organisational support from executive
  - clinical support from their line management, such as senior medical, nursing and allied health colleagues
  - access to education and training on symptom management, communication skills and use of the care plan clinical tool
  - access to appropriate medication, equipment and ward/unit environment privacy for the dying person and their relative/friend(s)
- Complaints to the hospital/health service regarding poor care outcomes (often by bereaved relatives/friend(s)).
- Adverse publicity and public scrutiny (including the increasing use of social media) related to perceived poor care outcomes as a person is dying.

In 2014, the Victorian End-of-Life Coordinating Program commissioned a stakeholder engagement exploration of potential risk considerations associated with Victorian Health Services providing end-of-life care and using end-of-life care plans. Examples of those risk considerations are:

- lack of senior management support
- lack of clinician commitment and support
- key stakeholders unaware of organisational end-of-life care policies, including the use of end-of-life care plans
- lack of a coordinated, planned and sustained approach to the implementation and use of end-of-life care plans
- health professionals lack confidence and competence in end-of-life care provision and implementation of end-of-life care plans including aspects such as:
  - recognition of dying
  - communicating with the dying person and their relative/friend(s)
  - how and when to initiate an end-of-life care plan
- adverse media coverage leading to damaged health service reputation
- lack of consumer knowledge of advance care planning and end-of-life care options
- ineffective monitoring and evaluation of end-of-life care provision.

It is important to note that this list is in no way exhaustive and the risks identified here should be considered within the context of your own health service's operational and clinical risk profiles.

Clinical risk identification, evaluation and monitoring is a continuous process.

Ensure the use of the care plan clinical tool is aligned within existing health service risk management frameworks and reporting guidelines.

Appendix 4

SECTION 4.1 – ONGOING ASSESSMENT EXAMPLE

CARE PLAN
FOR THE DYING PERSON
VICTORIA

UR No.:_____
Surname:_____
Given Name(s):_____
DOB:_____
Please fill in if no UR label available

Section 4 – Delivery of Care
To be completed by any member of the MDT

4.1 Ongoing Assessment
This care plan should be reviewed at least daily by the MDT.
Minimum documentation is 4 hourly however, certain psychosocial issues may only need assessment once per shift.

MDT review. Is the person imminently dying? ☑ Yes ☐ No
If 'No', has the MDT agreed that this care plan should be discontinued? ☐ Yes ☐ No
Care plan discontinued: Date: ___/___/20___   Time: ___:___ hours
Please complete 'Section 6 - Care Plan Discontinued' and attach to the FRONT page of this care plan and file

Care Plan Day: ___1___   Date: _1_/_1_/20_16_

SYMPTOM MANAGEMENT

A = assessment & no action required   F/A = further action required
R/C = routine care   N/A = not applicable

	0200	0400	0600	0800	1000	1200	1400	1600	1800	2000	2200	2400
Free of pain							F/A					
Free of agitation / restlessness							F/A					
Free of nausea / vomiting							A					
Free of dyspnoea / breathlessness							A					
Free of respiratory tract secretions							F/A					
Free of urinary problems							A					
Free of bowel problems							A					
Subcutaneous cannula care							A					
Subcutaneous infusion check							N/A					

PERSONAL COMFORT CARE

	0200	0400	0600	0800	1000	1200	1400	1600	1800	2000	2200	2400
Receives food and fluids to support needs							R/C					
Is comfortably positioned							R/C					
Skin care needs are met							R/C					
Personal hygiene needs are met							R/C					
Mouth is clean and moist							F/A					
Eyes are clean and moist							R/C					
Environment supports needs							A					

PSYCHOSOCIAL CARE

	0200	0400	0600	0800	1000	1200	1400	1600	1800	2000	2200	2400
Emotional, spiritual, religious, cultural needs / rituals are met							A					
Procedures / Care Plan explained							F/A					
Information regarding changes provided							F/A					
Relative / friend(s) supported							F/A					

Record all F/A in Section 4.2: Further Care Action Report

Print name of person doing assessment	INITIAL	INITIAL	INITIAL	INITIAL	INITIAL	INITIAL	INITIAL	INITIAL	INITIAL	INITIAL	INITIAL	INITIAL
N:												
AM:												
PM: *HOLLY THOMSON RN*							HT					
N:												
RESPONSIBLE REGISTERED NURSE: (if different from above)												
N:												
AM:												
PM:												
N:												

Appendix 5

SECTION 4.2 - FURTHER CARE ACTION REPORT EXAMPLE

CARE PLAN
FOR THE DYING PERSON
VICTORIA

UR No.:_____
Surname:_____
Given Name(s):_____
DOB:_____
Please fill in if no UR label available

ACTION REPORT

Section 4 – Delivery of Care

4.2 Further Care Action Report

Date	Time	Issue / Item	Action	Outcome of Action			
				Was the action effective?		Time	Initial
				Yes	No		
1/1/16	1400	Agitation & groaning Rattly breathing	Reassured S/C Fentanyl & Buscopan		✔	1420	HT
1/1/16	1400	Mouth breathing Tongue & lips dry	Mouthcare ✔ Family educated on how to provide care	✔		1400	HT
1/1/16	1400	Deteriorating	D/W son end of life symptoms Requesting spiritual care	✔		1400	HT
1/1/16	1420	Agitated despite pain relief	Repositioned Heat Pack S/C Midazolam	✔		1445	HT
1/1/16	1700	Family distress Re Deterioration	Spiritual care visited Will provide ongoing visits	✔		1700	LR

CARE PLAN FOR THE DYING PERSON - VICTORIA

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Appendix 6

SECTION 4.3 – INTEGRATED PROGRESS NOTES EXAMPLE

		CARE PLAN FOR THE DYING PERSON VICTORIA	UR No.:_____ Surname:_____ Given Name(s):_____ DOB:_____ Please fill in if no UR label available	

Section 4 – Delivery of Care

4.3 Integrated Progress Notes

IMPORTANT:
Record any of the following: MDT reviews, changes in condition, appropriateness of the care plan (by MDT daily), significant events / conversations / visits or other.

Date	Time	Notes	Designation
1/1/16	1300	Known potential corneal donor. Family aware. Refer to documentation in clinical record. Keep eyes moist at all times and notify Lions Eye Bank ASAP following death.	
		Dr Lisbeth O'Neill pager 3434	

DO NOT WRITE IN THIS BINDING MARGIN

PROGRESS NOTES

CARE PLAN FOR THE DYING PERSON · VICTORIA

Appendix 7

ANZICS DETERMINATION OF BRAIN DEATH TEMPLATE

ANZICS
AUSTRALIAN AND NEW ZEALAND INTENSIVE CARE SOCIETY

Hospital: _____

Affix patient label here

Known cause of irreversible loss of brain function

There is acute brain pathology consistent with the irreversible loss of brain function.

Doctor A: *Specify condition* _____

Doctor B: *Specify condition* _____

Period of continuous observation of apparent loss of neurological function

For determination of brain death by clinical examination there has been at least a 4 hour period of observation and mechanical ventilation during which the patient has unresponsive coma (GCS 3), with pupils non-reactive to light, absent cough/tracheal reflex and no spontaneous breathing efforts.

(Note: When the cause of brain injury is hypoxia-ischaemia, clinical testing for brain death should be delayed for at least 24 hours following the resuscitation or following rewarming to 35° when therapeutic hypothermia has been used.)

The 4 hour period of observation began at (Date and time) _____

Determination of brain death by clinical examination	Doctor A Please √	Doctor B Please √
Preconditions		
1. Hypothermia is not present – temperature is >35°C Specify temperature:	_____ °C	_____ °C
2. Blood pressure is adequate (e.g. MAP>60 in an adult)	☐	☐
3. Sedative drug effects are excluded	☐	☐
4. There is no severe electrolyte, metabolic or endocrine disturbance	☐	☐
5. Neuromuscular function is intact	☐	☐
6. It is possible to examine the brain-stem reflexes (including at least one ear and one eye)	☐	☐
7. It is possible to perform apnoea testing	☐	☐
Clinical testing		
1. There is no motor response in the cranial nerve distribution to noxious stimulation of the face, trunk and four limbs and there is no response in the trunk or limbs to noxious stimulation within the cranial nerve distribution	☐	☐
2. There are no pupillary responses to light	☐	☐
3. There are no corneal reflexes	☐	☐
4. There is no gag (pharyngeal) reflex	☐	☐
5. There is no cough (tracheal) reflex	☐	☐
6. There are no vestibulo-ocular reflexes on ice-cold caloric testing	☐	☐
7. Breathing is absent (despite arterial PCO_2 > 60mmHg (8 kPa) and arterial pH < 7.30)	☐	☐
8. Specify PCO_2 in **mmHg** or **kPa** (*circle one*) and pH at end of apnoea	PCO_2_____ pH _____	PCO_2_____ pH _____

Determination of brain death when clinical examination cannot be done:	Doctor A Please √	Doctor B Please √
1. There is no intracranial blood flow		
2. (*Delete one as appropriate*) This has been demonstrated by *either* **intra-arterial angiography** *or* other suitably reliable method (*Specify*) _____	☐	☐

We have determined, according to the above procedures, that this patient is brain dead:

Doctor A (Name): _____ Doctor B (Name): _____

Status: _____ Status: _____

Signature: _____ Signature: _____

Date and time of assessment: _____ Date and time of assessment: _____

Date and time of death (End of the assessment by second doctor) : _____

DETERMINATION OF BRAIN DEATH

Appendix 8

RELEVANT GUIDELINES

Advance care planning

advancecareplanning.org.au/resources/victoria

Bereavement support

www.pallcarevic.asn.au/families-patients/about-palliative-care-2/grief-loss/
www.centreforpallcare.org/assets/uploads/CP-Guidelines_web.pdf

Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients

Communication

Clayton JM et al., Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers, Med J Aust (Supp) 2007, v. 186 (12) p. 77. www.mja.com.au/journal/2007/186/12/clinical-practice-guidelines-communicating-prognosis-and-end-life-issues-adults

Hudson P, Quinn K, O'Hanlon B, Aranda S., Family meetings in palliative care: multidisciplinary clinical practice guidelines. Centre for Palliative Care Education & Research, 2009. link.springer.com/article/10.1186/1472-684X-7-12

Continuous subcutaneous infusion

Queensland Health, Guidelines for Subcutaneous Infusion Device Management in Palliative Care - Second Edition, 2010. www.health.qld.gov.au/cpcre/subcutaneous/documents/guidelines.pdf

End-of-life care

Registered Nurses' Association of Ontario, End-of-life-care: During the Last Days and Hours Clinical Best Practice Guidelines, 2011. [http://rnao.ca/bpg/guidelines/endoflife-care-during-last-days-and-hours]

ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill. Edition 1.0, 2014. www.anzics.com.au/wp-content/uploads/2018/08/ANZICS-Statement-on-Care-and-Decision-Making-at-the-End-of-Life-for-the-Critically-Ill.pdf

Implantable cardioverter defibrillators

Agency for Clinical Innovation, NSW Guidelines for Deactivation of Implantable Cardioverter Defibrillators at the End of Life, 2014. aci.health.nsw.gov.au/__data/assets/pdf_file/0008/179990/ACI-Deactivate-ICDs.pdf

Medication protocols

Eastern Metropolitan Region Palliative Care Consortium, Opioid Conversion Ratios – Guide to Practice, v. 2, 2014. www.emrpcc.org.au/uploads/135/Opioid-Conversions-May-2016.pdf

Eastern Metropolitan Region Palliative Care Consortium, Syringe Driver Drug Compatibilities, v.2, 2014. www.emrpcc.org.au/uploads/136/Syringe-Driver-Drug-Compatibilities-May-2016.pdf

Therapeutic Guidelines Limited, Therapeutic Guidelines: Palliative Care, v. 3., Melbourne, 2010.

Western Australia Cancer and Palliative Care Network, Evidence based clinical guidelines for adults in the terminal phase, 2nd ed. www2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Palliative/Evidence_based_guidelines.pdf

Organ and tissue donation

The Australian and New Zealand Intensive Care Society, Statement on Death and Organ Donation, ed 3.2, 2013. www.anzics.com.au/wp-content/uploads/2020/01/ANZICS-Statement-on-Death-and-Organ-Donation-Edition-4.pdf

Lions Eye Donation Service www.cera.org.au/community/lions-eye-donation-service

Donor Tissue Bank of Victoria www.dtbv.org.au

Medical treatment planning and decisions/medical consent

Victorian Government Office of the Public Advocate www.publicadvocate.vic.gov.au/medical-consent

Department of Health and Human Services, Medical Treatment Planning and Decisions Act, 2016. www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/medical-treatment-planning-and-decisions-act

Risk management

Toolkit for Managing Risk in Health Care: Desktop Guide for Clinical Risk Management. healthywa.wa.gov.au/~/media/Files/Corporate/general%20documents/Quality/PDF/50621_POCKET%20Guide%20Final.ashx

Victoria Government clinical risk management www2.health.vic.gov.au/hospitals-and-health-services/quality-safety-service/clinical-risk-management

Verification of death

Victorian Government Department of Health Guidance Note for the 'Verification of Death', 2011. www2.health.vic.gov.au/about/publications/policiesandguidelines/verification-death