

# Care Plan for the Dying Person

Health Professional Guidelines  
February 2019

## Care Plan for the Dying Person: Health Professional Guidelines

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## Purpose of this document

The *Queensland Health Care Plan for the Dying Person Health Professional Guidelines* (Guidelines) contains information on best practice care for people in the last days and hours of life. They have been developed to support generalist and novice clinicians providing care in the terminal phase of illness and address clinical and procedural aspects of care and communication that are relevant during this period.

The Guidelines are to be used in conjunction with the Care Plan for the Dying Person (CPDP), which is based on the fundamental principles of **recognising dying**, **communication** and **decision-making**.

This document is organised in 8 parts that generally follow the layout of the CPDP document. Additional information is also provided to support implementation activities and further clinical education.

## Background

The CPDP is a Queensland Health statewide clinical tool that supports multidisciplinary care in the last hours and days of life in hospital settings. In 2010 it was endorsed for use in Queensland Health hospitals, and ongoing reviews have ensured it reflects contemporary best practice standards.

Following a substantial review process in 2017, the CPDP achieved congruence with the International Collaborative Best Care of the Dying. The Collaborative's vision is:

*“for a world where all people experience a good death as an integral part of their individual life, supported by the very best personalised care”.<sup>1</sup>*

To attain congruence, organisations are required to demonstrate inclusion of ten key elements of care necessary for achieving best care of the dying (Figure 1).

**Figure 1: Ten key elements for best care of the dying**

- Recognition that the person is in the last hours or days of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the persons care
- Communication of the recognition of dying should be shared with the person where possible and deemed appropriate and with the relative or carer or advocate
- The person and 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 person where possible and deemed appropriate and with the relative or carer or advocate
- There should be regular reassessments of the person at least every four hours
- Care of the person and relative or carer or advocate immediately after death is dignified & respectful

**Ellershaw J, Lakhani M. Best Care for the dying person. BMJ 2013; 347: f4428**

<sup>1</sup> International Collaborative for Best Care for the Dying Person. (2014). *International Collaborative for Best Care for the Dying Person*. Retrieved September 12, 2018, from <https://bestcareforthedying.org/about/>

## Policy context

In 2015 the [\*Statewide strategy for end-of-life care 2015\*](#) (the Strategy) was endorsed by the Minister for Health and Minister for Ambulance Services. The CPDP and these Guidelines have been developed to support Hospital and Health Services (HHS) to deliver safe and high-quality care at the end of life, and to meet the objectives of the Strategy. The use of CPDP as part of a continuous quality improvement program can also assist HHS in meeting the Australian Commission on Safety and Quality in Health Care [National Safety and Quality Health Service Standards](#).

## Part 1: Overview of the CPDP

The CPDP is an example of an integrated care pathway (ICP). ICPs:

1. enable the delivery of healthcare for specific patient groups
2. can be used to implement clinical guidelines
3. provide a framework for audit and documentation<sup>2</sup>.

Whilst ICPs are intended to reduce variations in the quality and safety of care individual people receive, clinicians must use their clinical judgment and alter plans if they are not appropriate for a specific person in their care.

The CPDP promotes effective communication with the person and those close to them, and guides care planning across physical, psychological, social and spiritual domains of care. Specific elements of care include the initiation of comfort measures, anticipatory prescribing of medications to manage common symptoms, discontinuation of inappropriate interventions, and psychological and spiritual support of the person and family.

### CPDP sections

| Commencement & authorisation                                                                    | Initial assessment                                                                                                            | Ongoing assessment                                                                                                                                                                                                                                                                   | Clinical notes                                                                       | Care after death                         |
|-------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------|------------------------------------------|
| Multidisciplinary team assessment determines patient in last days/hours of life                 | Prompts communication with: <ul style="list-style-type: none"> <li>the dying person</li> <li>their family/carer(s)</li> </ul> | Symptom assessment of: <ul style="list-style-type: none"> <li>pain</li> <li>restlessness &amp; agitation</li> <li>fever</li> <li>nausea and/or vomiting</li> <li>respiratory secretions</li> <li>breathlessness</li> </ul>                                                           | Once commenced, the CPDP replaces all other medical, nursing and allied health notes | Verification of death                    |
| Most senior treating Medical Officer endorses CPDP commencement                                 |                                                                                                                               |                                                                                                                                                                                                                                                                                      | Should be completed as per local hospital documentation policies                     | Notifying and supporting family/carer(s) |
| CPDP completed by a Medical Officer, co-signed by a Registered Nurse                            | Assess bereavement risk                                                                                                       |                                                                                                                                                                                                                                                                                      |                                                                                      | Care of the deceased                     |
| Patient has a current Acute Resuscitation Plan stating that resuscitation is not to be provided | Review the person's individual medical care                                                                                   | Comfort assessment and management of: <ul style="list-style-type: none"> <li>urinary problems</li> <li>bowel problems</li> <li>medication</li> <li>food &amp; fluids</li> <li>mouth, skin &amp; hygiene care</li> <li>environment</li> <li>spiritual &amp; cultural needs</li> </ul> | Each note must be signed and initialed in the signature log                          | Other communication                      |
| <b>Family &amp; carer information sheet</b>                                                     | Review the person's individual nursing care                                                                                   |                                                                                                                                                                                                                                                                                      |                                                                                      | Certification of death                   |
| Provide to family and carers                                                                    | Explain of the plan of care                                                                                                   |                                                                                                                                                                                                                                                                                      |                                                                                      | Certification of death                   |

<sup>2</sup> Seymour, J., & Clarke, D. (2018). The Liverpool Care Pathway for the Dying Patient: a critical analysis of its rise, demise and legacy in England. *Wellcome Open Research*, 3(15), 24.

## Recognising dying

Before the CPDP can be commenced it is important to ensure that it is an appropriate plan of care for the person. This includes undertaking a clinical assessment to determine if the person is actively dying. It is not always easy to tell when someone is in the last days of life. Uncertainty is an inherent part of dying, and there are occasions when a person lives longer or dies sooner than expected. Despite this, there are signs and symptoms that can indicate when a person is likely to be in the last days or hours of life, such as:

- being bed-bound and requiring extensive nursing care (Australia-modified Karnofsky Performance Status scale score of 20 or less) (See Appendix 1)
- being poorly responsive or unconscious with limited response to verbal or physical stimuli, e.g. no longer responding to voices
- being unable to swallow
- reduced or no urine output
- changes in breathing pattern
- showing signs of peripheral shutdown such as pale or mottled skin and cold hands and feet.

Health professionals should also consider the person's clinical history and use their clinical expertise and experience to determine if a person is likely to be dying<sup>3</sup>. This includes considering potentially reversible causes for the person's deterioration. If there are no reversible causes, or a decision has been made not to treat them, care focused on the person's comfort should be initiated.

The CPDP provides a framework for initiating the elements of care considered best practice in the last days of life.

Since any member of the healthcare team, the person themselves or a relative/friend may recognise that death is imminent, HHS should foster systems that encourage individuals to confidently discuss their views with the most senior treating doctor, and other members of the multidisciplinary team<sup>4</sup>.

## Benefits of recognising dying

Whilst predicting if and exactly when a person will die can be difficult, if death is considered a potential outcome it is important that the healthcare team supports proactive planning. This includes clear communication with the dying person (if appropriate) and/or family/carer(s) about the potential for the person to die, and shared decision making about an appropriate plan of care.

Recognising dying in a timely manner enables the person and their family/carer(s) to receive individualised care that aligns with their preferences. Failure to recognise dying and clarification of the goals of treatment can lead to poor outcomes including:

- continuation of potentially burdensome medical treatment in the last days of life
- missed opportunities to understand what is important to the person and those close to them
- missed opportunities to provide holistic care that optimises the person's autonomy and wellbeing.

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<sup>3</sup> Victorian End-of-Life Care Coordinating Program. (2016). Care Plan for the Dying Person- Victoria, Health Professional User Guide. Victoria. Retrieved from <https://www.centreforpalcare.org/page/40/victorian-end-of-life-care-coordinating-program>

<sup>4</sup> ibid

## Managing uncertainty

If the person's prognosis is uncertain, the CPDP can still be commenced. This ensures that if the person dies despite a trial of 'active' treatment, measures to optimise their comfort have still been implemented. The person whose care is being supported by the CPDP should be reviewed regularly to ensure their treatment and care is appropriate. If the person's condition improves, the CPDP, like any plan of care can be changed or discontinued.

The person's condition and the plan of care should also be reviewed if a member of their family, a carer, or another clinician expresses concerns about its appropriateness, and at times, a second opinion or specialist palliative care advice may be needed.

The following questions can help guide your assessment<sup>5</sup>:

- Is the person's functional status deteriorating (bedbound, weak, drowsy, unable to swallow or only taking sips of fluid, minimal oral intake, semi-comatose)?
- Is there a reversible cause for the deterioration such as opioid toxicity, renal failure, hypercalcemia or infection?
- Is the 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 family/carers what they think is happening?

## Communication

Clear communication about a person's likely prognosis enables a collaborative and proactive approach to decision-making and care planning. Ideally, the person who is dying should be included in discussions; however, their involvement will depend upon their condition.

Prior to any discussions it is important to identify potential barriers to communication and take steps to overcome them. Barriers may include:

- hearing, vision or speech impairments
- language or cultural differences requiring a professional face-to-face or telephone interpreter or cultural guidance
- cognitive impairment, either acute (e.g.) delirium or long term (e.g. intellectual deficits, dementia)
- intellectual deficits.

People who may usually speak and understand English at home, may revert to their language of origin at time of illness or stress.

<sup>5</sup>Victorian End-of-Life Care Coordinating Program. (2016). Care Plan for the Dying Person- Victoria, Health Professional User Guide. Victoria. Retrieved from <https://www.centreforpalcare.org/page/40/victorian-end-of-life-care-coordinating-program>



## Family meetings

Family meetings can help facilitate a shared understanding of the person's expected prognosis, the plan of care and what to expect next. It is important to create a safe and private (if possible), environment to discuss and raise concerns. Good communication can also help mitigate potential conflict due to a lack of understanding or differing opinions. People may react in a range of ways at times of distress and heightened emotions and it is essential that responses are not taken personally, but seen as a reactive response to potentially distressing news.

A health professional with appropriate experience and skills should facilitate family meetings and other members of the Multidisciplinary Team (MDT) may be present. This ensures all those involved in the person's care are informed and better able support the dying person and their family/carer(s).

During the meeting it is important that the views of all concerned are listened to and assurance is provided that the person will continue to be assessed regularly and have their needs attended to.

More than one family meeting may be required, and all decisions leading to a change in care delivery should be clearly documented.

Other topics of discussion may include preferences regarding organ donation and coronial involvement if relevant and clinically appropriate.

## Conducting a family meeting for a person in the last days/hours of life

### Preparation

- If possible obtain permission from the dying person to conduct the family meeting and to share their personal information.
- Check whether they wish to attend and/or who else they would like present.
- If the dying person lacks decision-making capacity to consent to a family meeting, identify and include their Substitute Decision Maker (SDM) <sup>6</sup>.
- The Public Guardian may act as the Statutory Health Attorney<sup>7</sup>, under circumstances where there are no family/carer(s) available and/or no clear documentation present, as a last resort.
- Consider whether an interpreter is required, and arrange this in advance.
- Choose a comfortable, quiet and private area, free from interruptions.
- Ensure there is enough seating for everyone attending the meeting.

### Conducting the meeting

- Introduce the healthcare team members and allow family/carer(s) to introduce themselves.
- Use eye contact (if culturally appropriate) along with appropriate, non-threatening body language.
- Listen actively, using gestures such as nodding, making noises of agreement or encouragement.
- Explain the purpose of the meeting.
- Determine what the dying person and the family/carer(s) already know about what is happening.

<sup>6</sup> A SDM is a person legally permitted to make important decisions on behalf of someone who does not have capacity to make the decision required. Their perspective should be framed as, 'what would the patient have wanted if they had the capacity to make this decision?'. The decision can be about personal, health, and financial matters. A person can have more than one SDM. The SDM may not be the person's family/carer(s)- it is not the same as Next of Kin.

<sup>7</sup> Office of the Public Guardian. (n.d.). *Statutory health attorney*. Retrieved January 3, 2019, from <https://www.publicguardian.qld.gov.au/guardianship-and-decision-making/health-care-decisions/mental-health-care-and-treatment/statutory-health-attorney>

- Provide information about the dying person's current medical condition and prognosis.
- Clarify the goals of care and discuss treatment and care options.
- Avoid misleading information, which may foster false hope and use clear, jargon-free language.
- Allow family/carer(s) to ask questions and express any concerns.
- Provide clear and honest answers.
- Introduce the Care Plan for the Dying Person, clearly explaining its role and purpose.

## Closure

- Thank family/carer(s) for their attendance.
- Reassure family/carer(s) that they can ask questions or seek further information at any time.
- Assess whether additional Social Worker support is required.
- Provide relevant written information.
- Document discussion outcomes and ensure members of the MDT who were not present at the meeting know the CPDP has been commenced.

## Decision-making

In Queensland, all adults are presumed to have capacity to make personal, health and financial decisions. If concerns about the person's capacity to make a decision are raised, it is up to the healthcare team to rebut the presumption, not the person to prove that they do have capacity.

Capacity is not an 'all-or-none' concept. The dying person may be able to make decisions about certain aspects of their care and treatment but not others. If the dying person lacks decision-making capacity for a decision at the time that it needs to be made and they cannot be assisted to make the decision, then it is important to identify and include their SDM.

For information about how to assess decision-making capacity and identify a person's SDM refer to Appendix 2 and 3. Additionally, teams can refer to Social Work for assistance in identifying and engaging the person's SDM.

## Evidence of advance care planning documentation

Advance care planning (ACP) is a person-centered approach for planning current and future health and personal care that reflects the person's values, wishes, beliefs and preferences. The person may have had prior discussions about what is important to them with their carers, family and trusted friends and/or chosen to document their decisions in an [Advance Health Directive \(AHD\)](#), [Enduring Power of Attorney \(EPOA\)](#) or [Statement of Choices](#).

When a person is dying it is imperative to review whether any discussions have occurred, and whether any documentation has been completed. Electronic copies may be available on My Health Record or The Viewer, and alerts placed on the Hospital Based Corporate Information System (HBCIS).

These documents should be reviewed, acted on where appropriate and copies stored in the person's medical record.

## Further information

|                                                     |                                                                                                                                                                                           |
|-----------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Information for clinicians                          | Queensland Health website for <a href="#">clinicians about advance care planning</a><br>Or visit <a href="http://health.qld.gov.au/careatendoflife">health.qld.gov.au/careatendoflife</a> |
|                                                     | Queensland Health <a href="#">Advance Care Planning Clinical Guidelines</a>                                                                                                               |
|                                                     | Queensland Health <a href="#">Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients</a>                                           |
| Information for patients, carers and family members | Queensland Government website for <a href="#">consumers about advance care planning</a><br>Or visit <a href="http://qld.gov.au/advancecareplanning">qld.gov.au/advancecareplanning</a>    |

## Part 2: Commencement and authorisation of CPDP

To commence a person on a CPDP, the following tasks must be completed by a Medical Officer<sup>8</sup> and co-signed by a Registered Nurse:

1. The dying person is assessed by the MDT as being in the last days or hours of life
2. The dying person has a current Acute Resuscitation Plan (ARP), which states that resuscitation is not to be provided
3. The most senior treating doctor<sup>9</sup> responsible for the person's care endorses the use of CPDP.

An MDT review and decision-making guide is available on page 3 of the CPDP to assist with the assessment and authorisation process.

To avoid unnecessary delays in end of life care delivery, authorisation by the most senior treating doctor can be given verbally to the Medical Officer.

Following commencement, the person's General Practitioner and other relevant service providers should be contacted and informed of the person's condition and the plan of care.

The Medical Officer should also clarify and document if the dying person will have Medical Emergency Response (MET) calls in response to symptom distress, for example, in the case of uncontrolled or unexpected symptoms such as seizure activity<sup>10</sup>.

The CPDP should not be commenced unless the most senior treating doctor agrees, and there is a consensus between the person's SDM and the MDT that death is likely within days or hours.

*Authorisation by the most senior treating doctor can be given verbally to the Medical Officer.*

## Documentation

Once commenced, the CPDP should replace all other medical, nursing and allied health notes. Dedicated CPDP Clinical Notes are provided for this purpose and should be completed as per local hospital documentation policies.

## Signature log

Every person documenting in the CPDP must supply a sample of their signature and initials in the signature log upon their first entry.

Sign the signature log the first time you use the CPDP.

<sup>8</sup> **Medical Officer:** Doctor with delegated responsibility from the most senior treating doctor to make decisions related to commencing the dying person on the CPDP.

<sup>9</sup> **The most senior treating doctor:** The most senior doctor (e.g. treating consultant or registrar) responsible for and familiar with clinical care decisions related to this dying person.

<sup>10</sup>Victorian End-of-Life Care Coordinating Program. (2016). Care Plan for the Dying Person - Victoria, Health Professional User Guide. Victoria. Retrieved from <https://www.centreforpalcare.org/page/40/victorian-end-of-life-care-coordinating-program>

## Key

At the top of each page there is a key (  ) that provides a visual reference to the corresponding health professional discipline responsible for reviewing and assessing specific goals. Each goal requires a **Yes/No** answer and if '**No**' is recorded, staff should document this in the CPDP clinical notes, including escalation measures which were undertaken.

## Process for discontinuing the CPDP

If the person's condition improves and the CPDP is no longer appropriate, it can be discontinued. Some situations when this may occur is if:

- there is sustained improvement in conscious level, functional ability, oral intake, mobility or ability to perform self care
- concerns are expressed regarding management plan from patient, family/carer(s), or MDT team.

The decision to discontinue the CPDP should be made by the most senior treating doctor in consultation with the dying person, their family/carer(s), where possible, and their SDM if necessary. The reasons for the decision should be documented clearly in the person's medical notes, along with the new treatment plan.

Consideration should be given to additional support that may be required for ongoing care management; for example, physiotherapy for assistance with mobility or social work support for finance and family matters.

**If after the CPDP is discontinued, the person's condition deteriorates again and death is likely, a new CPDP form must be commenced. Do not reuse the previous form.**

## Part 3: Initial assessment

The initial assessment includes:

- Communication with the dying person
- Communication with the person's family/carer(s)
- Review of the person's individual medical care
- Review of the need for interventions
- Review of the person's individual nursing care
- Explanation of the plan of care

Each of these sub-headings contains suggested goals to assist with care planning.

### Communication with the dying person

The International Collaborative Best Care of the Dying emphasises the importance of communication with the dying person and their family/carer(s). It is important to consider the specific information needs of the person and their family/carer(s); the different manners and styles in which they communicate; and their cultural and spiritual beliefs. Taking the time to discuss things that may be important to the dying person and their family/carer(s) will provide the MDT with valuable insight and support person and family centred care.

Topics that may be discussed include:

- The person's spiritual, cultural, social, emotional and practical needs:
  - Now
  - At the time of death
  - After death.
- The person's preferred place of care, and ways to create a home-like environment for them.

As the person prepares to die they may also go through a process of looking back in search of meaning. This includes saying goodbye to people and places, forgiving and being forgiven, expressing joy and gratitude, facing regrets and accepting death. Some people may not want, or be able to, do these things. It is important to take cues from the dying person and listen, help them share memories and find ways to say goodbye. Some people who are socially isolated may express a wish to have someone sit with them. If the person declines referral to spiritual or pastoral care, then a referral to a Social Worker (if appropriate) may be considered.

If the dying person is unable to fully participate in discussions, review their needs with their family/carer(s) (see: Section 1.3 in the CPDP). Previously completed ACP documents may also provide information about what is important to the dying person.

### Communication with family/carer(s)

It is important to ensure the needs of those close to the dying person are supported, whilst recognising that not all people will have family/carer(s). This includes:

- ensuring the person's SDM understands and is aware that death is imminent
- identifying who else is important to the person and what support they require
- identifying specific spiritual, cultural or practical needs

- identifying and responding to emotional needs
- providing information as needed and explaining what to expect as the person deteriorates
- if clinical interventions are discontinued, explaining why and how the dying person's wellbeing and comfort will be maintained.
- involving them in caring for the dying person if they are comfortable doing so.

Health professionals can support family/carer(s) by encouraging them to:

- balance visits to the bedside with periods of rest
- organise a roster if it is important the dying person is not alone
- take time to say goodbye
- allow family members and friends to have time alone with the person
- take breaks to eat and drink
- bring pictures, music and important objects from home to create a comfortable environment
- draw on the support of family, friends and the MDT.

Staff should also provide information on:

- after-hours access to the hospital/ward
- car parking
- options for staying overnight
- where to buy food and drinks
- tea and coffee facilities
- location of hospital chapel or quiet spaces if available.

Social workers may be able to assist with emotional, social and financial matters. Referral should be considered as early as possible so that the needs of the dying person, and their family/carer(s) can be reviewed. Social workers are skilled in supporting people through illness, death and bereavement, and can use a range of practical strategies to alleviate current and future issues.

## Cultural and spiritual needs

Individual health beliefs, health practices, and spiritual, cultural and linguistic needs should be identified and supported as the person approaches death. Respecting and being sensitive to the individual needs of people from diverse cultural, linguistic and spiritual backgrounds, their loved ones and community ties is integral to the delivery of quality care at the end of life.

Customs or values that people may have that are important in relation to dying can include<sup>11</sup>:

- importance of the family
- dying away from country of origin
- discussing private issues with health professionals or non-family members
- the amount of information they want about prognosis
- whether it is appropriate to communicate with family or community members about prognosis
- importance of food and eating
- feelings about hospitals

<sup>11</sup> State of Victoria. (2018). *Managing personal, emotional, cultural and spiritual needs in palliative care*. Retrieved January 2019, from <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/older-people/palliative/palliative-emotional>



- attitudes to pain management
- certain medical practices that they want withheld
- end of life rituals, for example, last rites, visits from friends and family, patient giving away belongings
- post-death rituals, for example, what needs to happen to the body in preparation for burial
- post-death procedures, for example, autopsy or organ donation.

Ensure an interpreter or translator is available if the dying person and/or their family, carers or substitute decision-makers require it, and provide written information about services or treatment in the person's preferred language where possible.

Spiritually and culturally-appropriate support may be organised by referring the person to spiritual carer, chaplain or cultural advisor with their consent. Referral to Social Work may also be considered.

## Aboriginal and Torres Strait Islander people

Queensland Health endeavours to support cultural practices and beliefs of Aboriginal and Torres Strait Islander people throughout the end of life journey and after. For Aboriginal and Torres Strait Islander people, the time before and following death is a very sensitive and significant period, and is subject to a number of customary practices.

As a matter of best practice, seek cultural guidance at this time from the local Aboriginal and Torres Strait Islander Hospital Liaison Officer, Indigenous Health Worker, the person's family group or the wider community<sup>12</sup>.

More information can be found in Queensland Health's [Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying](#).

## Assessing bereavement risk

Caring for someone who is dying can be a tiring and stressful time for those close to the person, and the experience may give rise to distressing feelings or emotions. It is important to explain that grief is a normal, natural response to change or loss, and reassure them that every person's grief is unique. Some people are open and expressive with their grief, for example crying and wanting to talk, while others are more private, and may be reluctant to talk or prefer to keep busy. There is no correct way of reacting to loss or anticipation of death—people experience a range of emotions due to individual circumstances.

Although grief can be very painful, most people find that with the support of family and friends, and their own resources, they find ways to cope with loss. However, for some bereaved people, the symptoms of distress following the death of a family member or friend are more intense and persistent. Factors that may contribute to an increased risk of complicated bereavement include:

- no or limited social support
- developmental stage of the family, friend or carer
- family conflict or estrangement
- people living with mental illness, dementia, intellectual disability or other illness that may reduce flexibility
- cumulative losses

<sup>12</sup> State of Queensland. (2015). *Sad news sorry business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (version 2)*. Retrieved January 2019



- cause of the death e.g. suicide, trauma from accident or a sudden or unexpected deterioration/death
- emotional and physical dependency on the patient for wellbeing
- guilt, shame, self-blame associated with the deceased
- inability or ineffective use of supports
- feeling of loss of control over life.

It is important to note that risk factors alone do not necessarily constitute complicated bereavement risk and should be considered within the context of the situation. Protective factors are conditions or attributes (skills, strengths, resources, supports or coping strategies) in individuals that help people deal more effectively with stressful life events and can mitigate or eliminate risk. These protective factors should be considered when determining risk. For example, someone with cumulative losses may be more resilient if they have coped well with previous losses.

A referral to Social Work and/or Psychology should be considered if any of these factors are present. At the early stages of responding to trauma or to a sudden or unexpected event, the immediate focus is upon safety, stabilisation, practical assistance and support with communication. Always encourage the person's family/carer(s) to ask the healthcare team for advice and support.

Additional, spiritually and culturally-responsive support may be organised by referring the person to an Indigenous Liaison Officer or Health Worker, spiritual carer, chaplain or cultural advisor with their consent.

## Contact details

Even if one or more members of the person's family are staying at the bedside it is important to identify whom the primary and secondary contact people are, and when and how they would like to be contacted. It is important to know that the primary and secondary contact people may not be the person's SDM.

## Review of the person's medical care

When commencing the CPDP, the Medical Officer is required to document the person's:

- primary diagnosis
- associated co-morbidities
- baseline information about their condition, including conscious state and presence of any symptoms or problems.

This assessment can inform symptom management plans and help determine the appropriateness of clinical interventions.

## Medication management

In the last days of life, most people are no longer able to swallow medications. Furthermore, medications aimed at long-term disease prevention and maintenance are generally no longer relevant or required. For this reason, all current medications should be assessed and any non-essentials discontinued.

If oral medications are still required they should be converted to a subcutaneous, dermal or sublingual route. Whilst medications can be given intramuscularly or intravenously, these routes can be painful and efforts should be made to avoid unnecessary discomfort in the last days of life.

## Anticipatory prescribing

Anticipatory prescribing is recommended to prevent delays in treating emergent symptoms that might cause distress. It includes ensuring that medications and equipment likely to be needed are readily available. Prescriptions and medication charts should also be written in advance and supplies obtained.

Pro re nata (PRN) or 'as required' subcutaneous medications for pain, agitation, nausea, vomiting, dyspnoea and respiratory tract secretions should be available, and consideration given to injection volumes.

For advice on prescribing medications and managing symptoms, please refer to the *Australian Therapeutic Guidelines: Palliative Care - Terminal care in the last days of life*<sup>13</sup>.

## Continuous subcutaneous infusion

In some instances, there may be a need to administer a continuous subcutaneous infusion (CSCI). A syringe driver can be used for this purpose. Continuous infusions can reduce the need for multiple injections. They can also help control multiple symptoms by enabling the administration of multiple medications in a single infusion. However, care should be taken to ensure that the site of insertion is appropriate and ongoing site assessment is carried out to prevent infusion related complications.

Not every person will require a CSCI just because they are dying. A CSCI should be considered if pain remains poorly controlled after two hours or if the person has required regular analgesics or other medications to control symptoms prior to entering the terminal phase.

If a CSCI is used, medication compatibilities should be considered and use of the device should be explained to the person's family/carer(s).

Not every person will require a continuous subcutaneous infusion just because they are dying.

## Reviewing the need for interventions

A clinical review should be undertaken to determine whether specific clinical interventions should be discontinued, continued or commenced. Only interventions that contribute to the person's comfort or clearly benefit the person should be continued or commenced. Interventions requiring review include routine blood tests or recording of vital signs, oxygen therapy and dressings.

The rationale for discontinuing, continuing or commencing clinical interventions should always be discussed with the person's SDM, and other family members/carer(s) as required and appropriate.

If the person has an Implantable Cardioverter Defibrillator, it will need to be deactivated.

## Artificial hydration and nutrition

The dying person should be supported to eat and drink for as long as possible; however, a loss of interest in, and reduced need for food and drink, is a normal part of the dying process. There is minimal evidence that artificial nutrition and hydration are beneficial in the last days of life.

This can be difficult to accept for families, even when they know the person is dying. It is important to explain that a lack of food and fluid is not responsible for the person's death. Moreover, a common cause for carer/family distress is the perception of discomfort associated with xerostomia (dry mouth) for the dying person. Good mouth care is important in managing symptoms of xerostomia and nursing staff

<sup>13</sup> Palliative Care Expert Group. (2016). *Therapeutic Guidelines: Palliative Care* (4 ed.). West Melbourne, Victoria: Therapeutic Guidelines Limited. Retrieved September 2018. Available at <https://tinyurl.com/ybkhn7>

can involve the person's family/carer(s) in providing this care.

If either artificial hydration and/or nutrition are in place, the benefits and burdens of continuing them should be discussed with the person's SDM. If continued or commenced, the decision should be periodically evaluated. Consider reducing the rate or volume of artificial nutrition or hydration, and monitor for signs of aspiration and/or distress.

If nutritional support is stopped, nasogastric tubes should be removed, as they can be uncomfortable. Gastrostomy or jejunostomy tubes may be left in place and used to administer medications, instead of using subcutaneous injections<sup>14</sup>.

If artificial fluids are continued or commenced they should be administered subcutaneously, rather than intravenously. At times, intravenous fluids may be continued until the site extravasates (tissues). Artificial fluids should be discontinued if the person develops signs of pulmonary, cerebral or pedal oedema.

In all contexts, cultural perspectives on food, eating and drinking should be approached sensitively. Seek advice or support if required.

If further information or support is required regarding hydration and nutrition in the last days and hours of life, discuss with other members of the multidisciplinary team or specialist palliative care if available.

There is minimal evidence that artificial nutrition and hydration are beneficial in the last days of life.

## Review of the person's individual nursing care

Nursing staff have a key role in optimising the physical comfort of the dying person through the provision of mouth, eye, pressure area and hygiene care. An initial assessment of the person's needs should be undertaken and plans developed to manage the unique needs of the person.

Every effort should be made to provide this care regularly; however, nurses should use their clinical judgement to ensure care is responsive to the individual's needs. There may be occasions when it is inappropriate to provide nursing care due to the person's condition. Grouping nursing interventions or activities to avoid discomfort and disturbance to the dying person is advisable.

The person's family/carer(s) may also like to help with providing care and nursing staff can provide guidance on how to do so safely.

## Mouth care

The main aims of mouth care are to keep the person's mouth both clean and moist. The frequency of mouthcare and products used will depend on the individuals' needs.

### Keeping the person's mouth clean

Use oral hygiene sponges or swabs soaked with Normal Saline 0.9% to clean the person's mouth, tongue and insides of the cheek at least four times a day.

Provide help with cleaning the person's teeth or dentures at least twice a day.

Avoid using products that exacerbate a dry mouth such as Thymol or Chlorohexidine.

<sup>14</sup> Palliative Care Expert Group. (2016). *Therapeutic Guidelines: Palliative Care* (4 ed.). West Melbourne, Victoria: Therapeutic Guidelines Limited. Retrieved September 2018

## Keeping the person's mouth moist

Symptoms of a dry mouth do not always indicate dehydration. The most common cause is mouth breathing. Other causes include:

- damage to salivary glands by radiotherapy, surgery or infection
- medications such as tricyclic antidepressants, antihistamines, anticholinergics and opioids.

Encourage the person to have frequent sips of fluid if possible or provide ice chips. Acidic fluids such as fruit juice can also help to stimulate saliva production. If the person is unable to manage fluids, use oral hygiene sponges or swabs soaked with water to moisten the person's mouth, tongue and insides of the cheek. Provide lip balm or paraffin for the lips and apply inside the mouth, if needed. Artificial saliva can also be used to relieve symptoms of a dry mouth and prevent associated problems. Thickened water is a useful alternative if medicated artificial saliva is unavailable.

## Eye care

Towards the end of life, a person's vision may be reduced and their eyelids may be slightly open. Interventions to enhance the comfort of the dying person include:

- soft, indirect lights on in the room
- applying "artificial tears" to relieve dry eyes
- regular cleansing of the eyes with normal saline.

Special attention should be given to eye care if the person has indicated a wish to be an eye/corneal donor.

## Skin integrity

The goal of pressure area care during the last days or hours of life is to maintain the person's comfort. Whilst pressure area care should be provided according to local hospital policies, there may be times when it is inappropriate. The frequency of repositioning should be determined by skin inspection, assessment and the dying person's individual needs. The use of pressure-relieving aids, cushions, overlays and mattresses can help prevent discomfort and skin problems whilst minimising the need to reposition the person.

Keep the person's skin as clean and dry as possible by:

- managing incontinence and using barrier creams, if necessary
- considering the use of urinary catheters, if appropriate
- using skin cooling measures such as regular sponging with cool water and fans
- maintaining a cool environment.

Application of emollient twice a day and avoiding skin care products containing lanolin and fragrance can also help to protect the person's skin.

## Hygiene

The person's hygiene should be maintained to optimise their comfort and dignity. This includes providing a sponge bath in bed, ensuring sheets are clean and attending to other personal hygiene needs, as required. Nursing staff should use their clinical judgement to determine when the person needs assistance as routine care may not be appropriate in every situation, or as the person deteriorates.

Nursing staff should use their clinical judgement to determine when the person needs assistance as routine care may not be appropriate in every situation, or as the person deteriorates.

## Explanation of the care plan

Following the initial care planning phase, it is important to check that the person, where able, and their family/carer(s) have a full understanding of the care plan and know what to expect next. During times of stress it can difficult for people to retain information; therefore, in addition to a verbal explanation, written jargon-free information should be provided such as:

- the Family/Carer(s) Information Sheet (located within the CPDP),
- facility orientation brochure, and
- information on grief and bereavement.

## Part 4: Ongoing assessment

The Ongoing Assessment component of the CPDP forms the daily nursing care plan. It is an A3 page used for recording the outcomes of symptom assessment and comfort observations and uses a 'track and trigger' system to guide escalation responses to uncontrolled symptoms.

### Symptom assessment and management

The CPDP contains general advice for assessing symptoms, including:

- where possible, base the assessment on the person's verbal response
- if the person is unable to communicate, look for visual cues and consider the use of assessment tools
- always look for reversible causes and consider non-pharmacological measures
- discuss all changes to the plan of care with the person, and their SDM or family/carer(s).

Symptoms are given a Symptom Rating of absent, mild/moderate or severe, and instructions are provided about how to respond to the Symptom Rating. For example, continue with current care if symptoms are absent or consult with the nurse in charge if symptoms are moderate and not managed by the existing treatment plan.

Observations should be performed routinely at a minimum of every two hours, and if any treatment or escalation is required, more regular observations should occur.

If the person has any symptoms present, even mild, an action to address them is required. Moderate or severe symptoms require escalation.

When commencing any degree of intervention (nursing, medical or allied health), ensure that clear instructions are provided to the dying person, even though they may appear to be unresponsive.

Nursing staff should document their actions and the outcomes of treatment in the CPDP Clinical Notes.

Observations should be performed routinely at a minimum of every two hours, and if any treatment or escalation is required, more regular observations should occur.

### Pain

Good pain management at the end of life is based on comprehensive assessment and diagnosis, careful titration of analgesics and frequent clinical review by the medical and nursing team<sup>15</sup>.

Individuals who have been taking analgesia will require ongoing pain management in the last days of life. If their pain has previously been well controlled, it will generally continue to be controlled though ongoing monitoring is still required. Some people develop new pain in the last days of life<sup>16</sup>.

<sup>15</sup> Spruyt, O., & Moran, C. (2015). Achieving pain control at the end of life. *Pain Management Today*, 2(1), 16-21. Retrieved September 2018, from <https://painmanagementtoday.com.au/2015/january/feature-article/achieving-pain-control-end-life>

<sup>16</sup> Palliative Care Expert Group. (2016). *Therapeutic Guidelines: Palliative Care* (4 ed.). West Melbourne, Victoria: Therapeutic Guidelines Limited. Retrieved September 2018

When a person is poorly responsive or unconscious, pain and discomfort may be expressed as agitation. For example, the person may appear restless and unable to find a comfortable position in bed or may show discomfort when being repositioned. Monitor the person's behaviour and assess possible causes such as:

- tenderness over a distended bladder
- back pain due to immobility
- pressure area pain
- abdominal pain with worsening ascites.

General measures to manage pain or discomfort include:

- repositioning
- administering analgesia prior to repositioning for 'incident pain'
- pressure-relieving aids
- hot or cold packs
- treating reversible causes such as urinary retention.

## Restlessness and agitation

Restlessness and agitation are common in the last days of life. The dying person may be unable to find a comfortable position, may try to get out of bed, pluck at the sheets or air, groan and be incoherent.

Possible causes include:

- physical discomfort and poorly controlled pain
- medication toxicity
- urinary retention, faecal loading or incontinence
- infection and fever
- dehydration
- hypoxia
- anaemia
- metabolic changes
- withdrawal effects from medications, alcohol, nicotine or illicit substances
- emotional or existential distress.

Potentially reversible causes should be identified and managed where appropriate with the aim of optimising the person's comfort. For example, inserting a catheter to treat urinary retention and using nicotine patches to manage nicotine withdrawal.

Non-pharmacological measures should also be used, including:

- repositioning
- using soft lighting, minimising loud noise and playing soft, relaxing music
- encouraging the presence of people well known to the dying person
- encouraging family/carer(s) to provide gentle massage and touch
- checking if the person is too hot or cold and adjusting the room temperature and blankets as needed.



Sometimes it may be inappropriate to treat the underlying causes of agitation and restlessness, such as:

- when the symptoms are due to the dying person's primary diagnosis and cannot be reversed
- when treatment would be burdensome and not contribute to the person's comfort.

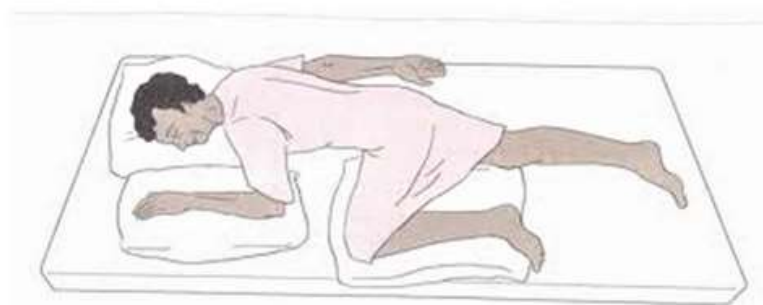
In these situations, and when symptoms persist despite the use of non-pharmacological measures, anxiolytic and antipsychotic medications may be required<sup>17</sup>.

## Respiratory secretions

The dying person's inability to cough effectively, or to swallow and clear secretions from the oropharynx, causes pooling of secretions in the throat. This results in rattly breathing. It is important to explain the cause of rattly breathing to the person's family/carer(s) as it can be distressing for them to hear. Reassurance should be provided that the symptom is a normal part of the dying process and is unlikely to be distressing to the dying person.

Repositioning the person into a semi-prone position may help drain pooled secretions (see: Figure 2), and if secretions are visible in the person's oral cavity gentle suctioning with a soft, flexible catheter may be considered. Suctioning beyond the oral cavity should be avoided as it may stimulate the gag reflex and cause distress.

Anticholinergic medications are sometimes used to manage secretions; though, they should be given when symptoms first appear. This is because they are only effective at preventing the production of new saliva. They are not effective at treating secretions that are already pooled, or secretions due to respiratory infections or pre-existing pulmonary conditions such as lung malignancy. Continuing to use anticholinergics in these circumstances will only exacerbate a dry mouth.



**Figure 2: Semi-prone position**

## Breathlessness

It is normal for the dying person to have changes in their breathing pattern during the last days or hours of life, and do not necessarily mean the person is feeling breathless. Changes may include:

- slow or irregular breathing
- periods of rapid, shallow breathing (similar to panting)
- episodes of apnoea with periods of deep, rapid breathing in between (Cheyne-Stokes respiration)
- excessive but ineffective efforts to breathe deeply known as agonal breaths.

<sup>17</sup> Caresearch: Palliative Care Network. (2017). Non Pharmacological Approaches. CareSearch. Retrieved September 2018, from <https://www.caresearch.com.au/caresearch/tabid/751/Default.aspx>



It is important to explain the changes in breathing pattern to the family/carer(s) and provide reassurance that they are seldom distressing to the dying person.

Oxygen should not be used routinely for respiratory symptoms in the last days of life as these are usually related to metabolic changes rather than hypoxia. The presence of an oxygen mask and tubing can also be distressing and increase agitation. Supplemental oxygen can also cause mucosal dryness, irritation and bleeding, and does not necessarily improve feelings of breathlessness<sup>18</sup>.

If the person appears distressed, consider checking for and treating a fever with antipyretics. Repositioning, increasing cool air movement by opening doors and windows or using a fan, and using carefully titrated medications such as midazolam and morphine should be considered.

## **Fever**

An elevated body temperature in the last days of life may cause discomfort due to associated tachycardia and tachypnoea. Potential causes include infection, dehydration, medication side effects and the underlying disease (tumour fevers). Reversing the underlying condition is generally not possible; however, symptomatic treatment using rectal antipyretics, cool sponges and fans can help make the person more comfortable<sup>19</sup>.

## **Nausea and/or vomiting**

Nausea and vomiting in the last days of life is usually a continuation of what has occurred in the period preceding the person's deterioration. Where possible, previously effective medications should be continued subcutaneously. Anticipatory prescribing of antiemetics should also occur to allow immediate treatment of new symptoms.

## **Comfort assessment and management**

### **Urinary problems**

#### **Urinary incontinence**

Urinary incontinence is common in the last days of life and can be due to:

- loss of control due as a normal part of the dying process
- urinary tract infection
- bladder outflow obstruction
- reduced bladder capacity and/or local irritation.

Incontinence should be managed by:

- protecting skin from maceration by using skin care products and adhesive barriers
- using stoma appliances for fistulas
- using absorbent incontinence pads or a uridome
- urinary catheterisation.

<sup>18</sup> Uronis, H. E., & Abernethy, A. P. (2008). Oxygen for relief of dyspnea: what is the evidence? *Current Opinion in Supportive and Palliative Care*, 2(2), 89-94.

<sup>19</sup> Strickland, M., & Stovsky, E. (2018). Fever Near the End of Life. *Fast Facts and Concepts #256*. Wisconsin: Palliative Care Network of Wisconsin. Retrieved September 2018, from Palliative Care Network of Wisconsin: <https://www.mypcnow.org/blank-lu7n4>

Inserting a urinary catheter to manage incontinence should be considered carefully, as it may cause distress, bladder spasms and pain.

## Urinary retention

Causes of urinary retention include:

- decreased mobility
- severe constipation
- spinal cord compression of nerves innervating the bladder
- haematuria and clot retention.

Gently palpate the person's bladder to assess whether it is distended and if gentle pressure causes any distress. A bladder scanner may also be used to diagnose retention in a safe and non-invasive manner. If present, retention can be managed by inserting a catheter after obtaining a medical order<sup>20</sup>.

## Bowel problems

In the last days of life faecal incontinence and diarrhoea should be managed by attending to the person's hygiene needs, and by optimising their comfort and dignity. Use soft, moist wipes for cleaning the perianal area and barrier creams to prevent excoriation.

Constipation is very common in the last days of life due to reduced peristalsis. It can lead to abdominal pain, nausea, vomiting, overflow incontinence, faecal impaction, urinary retention, and occasionally bowel obstruction and colonic perforation. Constipation can also contribute to problems such as delirium, agitated behaviour and anxiety.

Nursing staff should continue to monitor and record bowel movements and consider constipation if the person is agitated or appears to be in pain, and there are no other obvious causes for their discomfort.

Constipation may be diagnosed by examining the person for abdominal distension, tenderness and presence of abnormal bowel sounds. In rare cases, medical staff may consider a digital rectal examination to assess rectal loading, consistency or faecal impaction.

Rectal laxatives can be administered to relieve constipation, and gentle abdominal massage used as a potentially effective non-pharmacological and non-invasive treatment option<sup>21</sup>.

## Medication

As death approaches, families and carers may be concerned that the process is being accelerated or even caused by medications such as opioids. If medications are given in response to symptoms, and in doses that match their severity, there is no evidence that they will shorten the person's life<sup>22</sup>. Despite this, it is important to acknowledge the concerns of the family and carer(s), and to provide careful explanation about the use of medications.

Medication management advice for nurses:

- If no PRN medications are charted, liaise with the Medical Officer to obtain orders in advance

<sup>20</sup> Palliative Care Expert Group. (2016). *Therapeutic Guidelines: Palliative Care* (4 ed.). West Melbourne, Victoria: Therapeutic Guidelines Limited. Retrieved September 2018

<sup>21</sup> Kyle, G. (2011). End of life: a need for bowel care guidance. *Nursing Times*. Retrieved September 2018, from <https://www.nursingtimes.net/clinical-archive/continence/end-of-life-a-need-for-bowel-care-guidance/5029189.article>

<sup>22</sup> Ellershaw, J. E., & Lakhani, M. (2013). Best care for the dying patient. *BMJ*, 347:f4428, f4428. doi:<https://doi.org/10.1136/bmj.f4428>

- Reassess the person at least one hour following treatment, and if their symptom/s are not adequately managed consider a change to the treatment plan.
- Monitor for the person for adverse effects.
- If the person does not respond to medication within the expected timeframe, check if anything is interfering with delivery or absorption. For example, is the syringe driver working properly? Is the infusion line kinked? Is the route appropriate?
- If in use, syringe drivers should be checked four hourly or according to local hospital policies and procedures.
- Individualise prescribing and consider frailty and comorbidities—in general, prescribe a low starting dose and adjust promptly according to response.
- Include the indication for each medication on the prescription and on the medication chart (e.g. opioid for pain or distress associated with dyspnoea, benzodiazepine for agitation or restlessness, anticholinergic medication for respiratory secretions, antiemetic for nausea or vomiting).

If medications are given in response to symptoms, and in doses that match their severity, there is no evidence that they will shorten the person's life.

## Food and fluids

Uncertainty about the dying person's nutritional requirements is a common and significant cause of distress amongst family/carer(s). Often relatives fear that the person will die of starvation or dehydration, and request artificial nutrition or hydration be started or continued. There is little evidence that these are beneficial in the last days of life, and this should be sensitively explained to the person's family/carer(s). Those close to the dying person can also be taught how to provide mouth care to help manage any discomfort due to a dry mouth.

Some families/carer(s) may continue to have concerns despite explanation and reassurance. For those with strong cultural and religious beliefs, advice and support from someone of the same culture or faith may be useful. Occasionally, it may also be helpful to undertake a time-limited trial of subcutaneous fluids whilst monitoring their effects on the person's condition and comfort.

Those close to the dying person can also be taught how to provide mouth care to help manage any discomfort due to a dry mouth

## Ongoing mouth, skin and hygiene care

Skin, mouth and eye care should be provided according to the plan determined in the Initial Assessment - [Review of the person's individual nursing care](#).

## Environment

The person's physical surroundings can have a profound effect on their comfort in the last days of life<sup>23</sup>. Therefore, nursing, allied health and other staff should help create a clean, calm and homely environment where the person feels safe. This includes:

- relocating the person to a private room if possible, or using curtains/screens in a shared space
- using complementary therapies like aromatherapy as per local health service policies
- paying attention to lighting and temperature
- encouraging the person's family/carer(s) to personalise the dying person's space by playing music the person likes and bringing in personal objects, photos or other belongings
- ensuring access to the nurse call bell.

It is also important to provide sufficient seating space for family/carer(s), and overnight bedding arrangements if they wish to stay. It is to be noted that not all family/carer(s) will want to or feel comfortable staying overnight.

## Spiritual and cultural needs

Any spiritual and cultural needs identified in the [Initial Assessment](#) should be supported as the person approaches death. This includes being receptive to new needs, providing support as required and referring to relevant services for assistance.

## Support of family/carer(s)

Ongoing support for the person's family/carer(s) includes:

- ensuring they have had adequate food, drink and rest
- checking the understanding and needs of all visitors
- listening to worries and fears and providing age appropriate information
- using clear language and avoiding the use of jargon and euphemisms
- assessing bereavement risk and referring to Social Work for additional support as required.

Those close to the dying person may be concerned that when death happens it will be a painful experience. Reassurance should be provided that all efforts will be made to ensure the person's symptoms will be monitored and any concerns will be addressed in a responsive manner.

The Family/Carer(s) Information Sheet (pages 9-10 of the CPDP) contains the following advice about what happens when a person dies:

*When people die they stop breathing and their heart stops beating. They will not respond to any stimulation and their mouth may fall slightly open. Their eyes may be open, but the pupils will be large and fixed on one spot. They may also lose control of their bladder and bowel. When this happens, a doctor will usually attend and confirm their death. During this time, you may wish to contact a close friend or relative, or ask for a spiritual carer or cultural advisor to be with you. Take your time saying goodbye. The healthcare team will explain what the next steps are and help you access extra support if you need it.*

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<sup>23</sup> Sander, R. (2012). Creating the right environment for end of life care in hospital. *Nursing Older People*, 24(5), 13.  
doi:<https://doi.org/10.7748/nop.24.5.13.s8>

## Talking to children about terminal illness and death

Adults often feel the need to protect children from death, and they may feel that children will not understand or become upset. We can underestimate children's ability to cope. They may be more frightened by imagined events if they are not told what is happening.

Children should be given the facts in a simple manner and at a level that will fit their development needs. Give them time to ask questions (which may be very direct) and offer plenty of reassurance).

It is helpful for adults to share their feelings with children as this shows it is normal to feel sad when someone is terminally ill or has died.

A grieving child may express their sadness by behaviours rather than words and so advise parents of this and encourage them to advise the child's school, so that the teacher is aware of the situation.

A referral to Social Work can provide additional assessment, information and access to resources to assist in communicating with children.

It is helpful for adults to share their feelings with children as this shows it is normal to feel sad when someone is terminally ill or has died.

## Part 5: Care after death

The Care after death section includes:

- Verification of death
- Notifying Coroner
- Notifying and supporting family/carer(s)
- Care of the deceased
- Other communication
- Certification of death

### Verification of death

Verification of death is the physiological assessment to confirm the fact of death. The clinical determinants to establish that death has occurred are:

- no palpable carotid pulse
- no heart sounds for 30 continuous seconds
- no breath sounds heard for 30 continuous seconds
- fixed dilated pupils
- no response to centralised stimuli
- no motor (withdrawal) response or facial grimace response to painful stimuli (e.g. pinching inner aspect of the elbow).

Professional clinical judgment is required to make this determination and unique circumstances may warrant additional checks over and above the minimum guideline provided. For example, electrocardiogram showing no rhythm.

After receiving relevant education and training, the health and law professionals listed below can undertake a clinical assessment of a deceased person and verify if death has occurred:

- **Medical Practitioner:** A medical practitioner as defined in the Health Practitioner Regulation National Law Act 2009
- **Registered Nurse:** A registered nurse as defined in the Health Practitioner Regulation National Law Act 2009
- **Paramedic:** A paramedic, an ambulance officer as defined in the Ambulance Service Act 1991 and employed as a paramedic
- **Police Officer:** A police officer as defined in the Police Service Administration Act 1990 (only for cases of obvious death\*)<sup>24</sup>

For further guidance, please refer to local hospital policies and procedures.

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<sup>24</sup> "Obvious deaths" are those where the state of the body is incompatible with life, like:

**Severe incineration** has caused charring and blackening of most of the body surface, with exposure of underlying tissues in some areas; or **Extensive trauma** has caused decapitation, severance of the torso, disruption of a vital organ (e.g. brain), or fragmentation of the body; or **Well established decomposition** has caused extensive discolouration of the skin, bloating of the body, and, in some cases, larval infestation and partial exposure of bones; or **advanced decomposition** has exposed most of the skeleton, so called 'skeletal remains'.

## Notifying and supporting family/carer(s)

Family and carer(s) who are present at the time of death should be supported according to their individual needs. This includes providing privacy if desired, allowing them to spend time with the person who has died, and support to carry out specific religious or cultural rituals.

Instructions on who to notify when the person dies should be documented in the [Initial Assessment](#).

The names of those present at the time of death should be documented and if no one is present the names of those informed and their relationship to the person should be documented.

Provide appropriate advice and support, assess whether bereavement support is required and answer any questions.

## Care of the deceased

Refer to local hospital policies and procedures for specific guidance how to care for the deceased.

Family/carer(s) may wish to be involved in washing and laying out the deceased. In some cases, family and carer(s) will not want staff to be present to assist with necessary cultural duties relevant at time of death.

If applicable and appropriate, further discussions with the person's family/carer(s) can include viewing of the deceased; corneal and tissue donation; removal of cardiac devices; discussion with the coroner and post mortem process. It may be appropriate to contact Social Work before discussing viewings of the deceased person with the family.

## Other communication

The person's death should be communicated to other health professionals and providers previously involved in caring for the person. Any member for the MDT can take responsibility for this communication.

## Certification of death

Certification of death is the process of completing the *Medical Certificate/Life Extinct* form. It is a legislative requirement that only registered medical practitioners can issue a *Medical Certificate/Life Extinct* form under Section 37 of the *Births, Deaths and Marriages Registration Act 1996*. To certify death, a registered medical practitioner is required to make a diagnosis of the cause of death, which requires specialist knowledge. Reviewable and reportable deaths to the coroner must be managed as per local hospital policies and procedures. Only registered medical practitioners can complete a death certificate.



## Part 6: Risk management considerations

The following information has been adapted from the *Care Plan for the Dying Person: Victorian Health Professional User Guide* (2016)<sup>25</sup>.

Implementation and use of the CPDP must be embedded within the governance of individual HHS as part of their continuous quality improvement programs and care at end of life service provision policies and procedures.

The effective identification, analysis and management of potential and actual clinical and organisational risks associated with using the CPDP is essential to providing safe and quality care at the end of life.

Individual HHS must undertake analysis and develop risk profiles within their own strategic context, and determine the type and level of risk management planning and management options to be implemented. It is also crucial that all staff receive training to accurately use and commence a person on the CPDP.

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

- significant distress to the dying person and family/carer(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 CPDP, and/or
  - access to appropriate medication, equipment and ward/unit environment privacy for the dying person and their family/carer(s)
- complaints to the hospital/health service regarding poor care outcomes (often by bereaved family/carer(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 care at end of life and using care at end of life integrated care pathways. Examples of those risk considerations, which are also likely to be relevant to Queensland HHS, are:

- lack of senior management support
- lack of clinician commitment and support
- key stakeholders unaware of organisational care at end of life policies, including the use of care at end of life integrated care pathways
- lack of a coordinated, planned and sustained approach to the implementation and use of care at end of life integrated care pathways

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<sup>25</sup> Victorian End-of-Life Care Coordinating Program. (2016). *Care Plan for the Dying Person - Victoria, Health Professional User Guide*. Victoria. Retrieved September 2018, from <https://www.centreforpallcare.org/page/40/victorian-end-of-life-care-coordinating-program>

- health professionals lack confidence and competence in care at end of life provision and implementation of care at end of life integrated care pathways including aspects such as:
  - recognition of dying
  - communicating with the dying person and their relative/friend(s)
  - how and when to initiate the care at end of life integrated care pathways
- adverse media coverage leading to damaged HHS reputation
- lack of consumer knowledge of ACP and care at end of life options
- ineffective monitoring and evaluation of care provision at the end of life.

### Key points

- 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 HHS operational and clinical risk profiles.
- Clinical risk identification, evaluation and monitoring are a continuous process.
- Ensure the use of the CPDP is aligned within existing HHS risk management frameworks and reporting guidelines.

## Part 7: CPDP Implementation Framework

Successful implementation of the CPDP into Queensland Health hospitals will be guided by effective change management. To support this, the *CPDP Implementation Framework* has been developed to guide the introduction of the CPDP into hospitals, departments and wards across the state.

The *CPDP Implementation Framework* has been developed in accordance with the Clinical Excellence Division [Project Management Framework](#)<sup>26</sup> methodology, which is a four-phase approach to change management and continuous quality improvement.

| Phase    | Tasks                                                                                                                                                                                      |
|----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Initiate | Establish the project: prepare the environment                                                                                                                                             |
| Plan     | Develop the documentation                                                                                                                                                                  |
|          | Baseline review / retrospective audit of current documentation                                                                                                                             |
|          | Induction / education program                                                                                                                                                              |
| Deliver  | Clinical implementation of the CPDP                                                                                                                                                        |
|          | Maintain and improve competencies using reflective practice and post-pathway analysis                                                                                                      |
|          | Evaluation and training needs analysis                                                                                                                                                     |
|          | Continuous development of competencies to embed the CPDP within the clinical environment                                                                                                   |
| Sustain  | Organisational recognition that all staff who work with dying persons are properly trained to care for them and their family/carer(s) within an agreed organisational/educational strategy |
|          | Establish the CPDP governance / performance agenda within the organisation/institution.                                                                                                    |

<sup>26</sup> Clinical Excellence Division. (2018). Project Management Framework. *Clinical Excellence Division Project Management Framework*. (P. a. Office, Ed.) Brisbane, Queensland, Australia: State of Queensland. Retrieved September 25, 2018, from [https://qheps.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0022/2184124/0.1-CED-Project-Management-Framework.pdf](https://qheps.health.qld.gov.au/__data/assets/pdf_file/0022/2184124/0.1-CED-Project-Management-Framework.pdf)

## Phase 1: Initiate

### Objective

To detail the scope of the CPDP implementation project and seek project concept and budget approval from the appropriate delegate/s.

### Tasks

- Develop a multidisciplinary steering committee (see table 1) to:
  - lead CPDP implementation, including governance of all change management phases
  - conduct project, education and communications planning
  - advocate for senior clinical and executive support
  - act as a reference for clinical or process issues
  - liaise with other relevant local committees
  - ensure sustainability of CPDP use.
- Identify an appropriate ward area/unit/department or directorate to introduce the CPDP.
- Gain senior clinical and/or specialist palliative care support to introduce CPDP into ward/unit/department.
- Gain executive endorsement of CPDP implementation into ward/unit/department.
- Once approval is received, CPDP implementation can proceed to the Plan phase.

Table 1: *Steering committee membership*

| Suggested multidisciplinary steering committee membership for CPDP implementation |                                                                    |
|-----------------------------------------------------------------------------------|--------------------------------------------------------------------|
| Senior medical officer from the pilot ward/unit/department                        | Care at End of Life Project Officer (if in position)               |
| Senior medical officer from the local palliative care team (if applicable)        | Nurse Unit Manager or senior nurse from pilot ward/unit/department |
| Palliative care clinical nurse consultant (if applicable)                         | Social worker                                                      |
| Patient Safety and Quality representative                                         | Pharmacist                                                         |
| Clinical educator                                                                 | Indigenous Health Worker                                           |

## Phase 2: Plan

### Objective

To plan in detail what and how the project will be delivered including scheduling and resourcing.

### Tasks

- Register the CPDP with the relevant Patient Safety and Quality unit.
- Determine the likelihood and consequences of CPDP implementation risks with a risk register, and develop processes and tools to monitor and control issues that may impact project performance.

- Using the CPDP Baseline Audit Tool, conduct a retrospective audit of current care at end of life service delivery in the proposed pilot ward/area/department
  - 20 chart audits are recommended
  - prepare a report of baseline audit findings within 4-6 weeks.
- Collaborate with clinical educators to:
  - conduct a training needs analysis
  - plan an induction and education program to staff in the pilot ward/area/department regarding use of the CPDP and best-practice care at end of life
  - aim for at least 80% of staff in the pilot site to receive induction and education
  - the CPDP Health Professional Presentation and CPDP Health Professional Guidelines can be used to support this.
- Determine if any local clinical forms can be replaced by the CPDP, or if specific documentation needs to remain in use.
- Develop a communication plan to inform stakeholders about CPDP implementation. This can include:
  - working with hospital or HHS Online teams to update relevant intranet pages
  - online can also assist with adding the CPDP screen saver to local computer systems
  - contacting Public Affairs Officers or Media & Communications teams to include information in local staff bulletins, e-alerts, etc.

## Phase 3: Deliver

### Objective

To execute project plan and other sub-plans (e.g. Education and Communications Plans), including monitoring and controlling activities and reporting progress to key stakeholders.

### Tasks

- Implement the CPDP for clinical use into the pilot ward/unit/department.
- Deliver the education program to pilot site staff and other relevant stakeholders, in collaboration with clinical educators.
- Ensure a CPDP resource folder is available with the clinical environment of the pilot site.
- Promote CPDP leads and specialist palliative care team (if applicable) for support.
- Audit the first 20 completed CPDP forms and discuss outcomes of care with the clinical teams.

## Phase 4: Sustain

### Objective

To ensure recognition of the CPDP within the mainstream health care agenda within the organisation

- Tasks
- Conduct stakeholder consultation with clinicians in the pilot ward/unit/department to identify achievements, risks, issues and identify solutions to address challenges that have arisen in the CPDP implementation process. Topics may include:
  - specific elements of the care delivered
  - workflow and cultural change in implementing a new form and process
  - service improvement
  - educational needs of clinical staff
  - document scanning issues
  - resourcing.
- Regularly report achievements, risks, issues and any other changes to:
  - the pilot area
  - the project sponsor/(s)
  - executive
  - other key stakeholders as relevant.
- Auditing and data collection processes are established and maintained.
- Identify new wards/units/departments to implement the CPDP – return to Phase 1.
- Continuous development of competencies in order to embed the CPDP within the clinical environment.
- Develop a strategy to establish the CPDP within the governance/performance management agenda within the organisation/institution.
- In line with the [Statewide strategy for end-of-life care 2015](#), work towards recognition that all staff who work with people at the end of life, as well as their carers/family members, are trained to provide high quality care, within an agreed organisational and educational strategy.

## Part 8: Educational resources

A range of initiatives and resources are available to enhance the skills and knowledge of all health professionals who provide care at the end of life in acute hospitals.

### Online modules

- [End-of-Life Essentials](#) education is based on the Australian Commission on Safety and Quality in Health Care's [National Consensus Statement: Essential elements for safe and high-quality end-of-life care](#). The education modules are free to use, evidence-based and have been peer reviewed by doctors, nurses and allied health professionals around Australia.

### Clinical placements

- [Program of Experience in the Palliative Approach \(PEPA\)](#) is a national program established to provide healthcare workers with an opportunity to develop skills in the palliative approach by attending 2- to 5-day placements with a specialist palliative care service, and tailored workshops on palliative care principles, culture-centred care and Indigenous palliative care. In Queensland, PEPA works with the CPCRE to deliver workshops and education.

### Support with prescribing medications

- [The Therapeutic Guidelines: Palliative Care - Terminal care in the last days of life](#) has extensive evidence based and peer reviewed information on prescribing medications and managing symptoms.
- [palliMEDS](#) is a free app to support the clinical knowledge of health professionals who prescribe palliative care medicines or care for people at their end of life.

### Online information hubs

- [Queensland Health](#) have published extensive online information for clinicians providing care at end of life.
- [Centre for Palliative Care Research and Education \(CPCRE\)](#) is a Queensland health funded initiative that provides information on palliative care education and research opportunities and resources for health professionals.
- [CareSearch: Palliative Care Knowledge Network](#) provides trustworthy information about palliative care for patients, carers and families as well as for the health professionals providing their care.



## Appendix 1: The Australian-modified Karnofsky Performance Status

The Australian-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living. It is a single score between 10 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care. A score of 100 signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status.

### How to assess AKPS

1. Use the AKPS definitions to determine the initial rating on admission or commencement of an episode of care.
2. Assess at episode start.
3. Assess routinely. A minimum of daily in an inpatient setting, at each visit in a community setting or each consult.
4. Assess whenever there is a phase change
5. Assess at episode end when a patient is discharged.
6. Assessment may be conducted face to face or over the phone.
7. Record the score as assessed, which may be entered directly into the patient record or on a clinical form to be entered into relevant data systems.

| KPS ASSESSMENT CRITERIA                                                             | SCORE |
|-------------------------------------------------------------------------------------|-------|
| Normal; no complaints; no evidence of disease                                       | 100   |
| Able to carry on normal activity; minor sign of symptoms of disease                 | 90    |
| Normal activity with effort; some signs or symptoms of disease                      | 80    |
| Cares for self; unable to carry on normal activity or to do active work             | 70    |
| Able to care for most needs; but requires occasional assistance                     | 60    |
| Considerable assistance and frequent medical care required                          | 50    |
| In bed more than 50% of the time                                                    | 40    |
| Almost completely bedfast                                                           | 30    |
| Totally bedfast and requiring extensive nursing care by professionals and/or family | 20    |
| Comatose or barely rousable                                                         | 10    |
| Dead                                                                                | 0     |

## Appendix 2: Assessing decision-making capacity

This information is drawn from Queensland Health's *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*<sup>27</sup>.

In Queensland, an adult is presumed to have capacity. Lack of capacity cannot be established merely by reference to age, cultural background, behaviours, appearance or physical condition, as this may lead to unjustified assumptions. Capacity is not an 'all-or-none' concept but depends on the nature of the task for which assessment is required, such as decisions about personal or health matters.

Documents pertaining to this matter, do not recommend a preferred method to assess capacity, however there are some important considerations that have potential legal implications. Capacity assessments involve more than judging cognition and weighing objective scores of memory, concentration, attention and orientation. It is domain specific, and persons' having decisional capacity in some domains, for example deciding what to eat and wear, and not in others, such as managing medication or paying bills. They may also have decision-making capacity at the time that the decision needs to be made but not before or afterwards.

In cases where people have borderline or fluctuating capacity or conditions that may affect cognition such as depression, it can be difficult to assess valid decision making capacity on very serious issues.

Second opinions must be obtained where doubt exists about a person's level of capacity to make decisions about their own health matters at the time the decision is needed.

When a decision is required, where possible and practicable, time should be allowed for a person to regain capacity to the extent this enables them to make decisions about health and personal matters (e.g. following a mental health episode, delirium from medication or another source).

There is an increasing expectation that people will be assisted to make decisions by informal or formal supports wherever possible. If this fails, an SDM will be used (e.g.)

Even if an SDM is used, the focus will be allowing the SDM to decide the extent required- the least restrictive alternative.

### Decision-making capacity

Generally, a person can only be regarded as not having decision-making capacity if they do not meet the following five criteria:

1. The person understands the basic medical situation.
2. The person understands the nature of the decision being asked of him or her. Understanding includes the following:
  - Implications – benefits, risks, what the treatment entails.
  - Alternatives and their implications, including the implication of no decision.
  - Retaining the information (short-term memory function).
3. The person is able to use or weigh that information as part of the process of making the decision

<sup>27</sup> Queensland Health. (2018). *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*. Clinical Excellence Division, Brisbane. Retrieved from [https://www.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0033/688263/acp-guidance.pdf](https://www.health.qld.gov.au/__data/assets/pdf_file/0033/688263/acp-guidance.pdf)

(for example, asking questions).

4. The person is able to communicate a decision (for example, by talking, using sign language or any other means).
5. The person is able to communicate the decision freely and voluntarily (for example, is there an absence of coercion, undue influence or intimidation by the patient's family/decision-maker/s or others).

## Informed consent

For the patient's informed consent to healthcare to be valid, certain principles must be fulfilled<sup>28</sup>

- the patient has the capacity (ability) to decide about the specific issue at the specific time, and is not affected by therapeutic or other drugs, or alcohol
- the consent is voluntarily given, and free from manipulation by, or undue influence from, family, medical staff or other social coercive influences
- the discussion between the patient and the health practitioner is transparent, well balanced, and involves two-way communication which is sensitive to the situation
- the patient is able to clearly understand the information because it is provided in a language or by other means the patient can understand
- as far as possible, the patient is advised in simple terms of:
  - the diagnosis
  - recommended health care, including the expected benefits, common side effects and alternative health care options
  - the material risks including complications associated with:
    - the recommended healthcare
    - alternative health care options
    - a decision not to receive the health care offered
  - any significant long-term physical, emotional, mental, social, sexual or other expected outcomes
  - the anticipated recovery implications
- the patient has sufficient time and space to consider and clarify information in order to make an informed decision, taking into account the context of the clinical situation
- the information provided and the consent given relate to the specific health care provided.

In addition, for the patient's consent to be valid, the health care itself must be lawful.

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<sup>28</sup> Clinical Excellence Division, Queensland Health. (2017). *Guide to Informed Decision-making in Health Care*. Patient Safety and Quality Improvement Service. Brisbane: Queensland Health. Retrieved October 17, 2018, from [https://www.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0019/143074/ic-guide.pdf](https://www.health.qld.gov.au/__data/assets/pdf_file/0019/143074/ic-guide.pdf)

## Appendix 3: Identifying a substitute decision-maker

Where it is determined that a person lacks capacity in relation to a health care decision, in Queensland, authority to provide health care or health related decision making, can be obtained from the following SDM(s) (in order):

1. The person's valid AHD - if the AHD contains a directive about the matter. If no relevant AHD, then the first person on the following list who is available, willing and able to act.
2. A guardian or guardians appointed by the Queensland Civil and Administrative Tribunal (QCAT)- any person over 18 years who is not a paid carer or health professional of the person who lacks capacity can be appointed by QCAT. If there is no person available, culturally appropriate or willing, then the Public Guardian can be appointed. Note that any guardian appointment may be limited, so care needs to be taken that any guardian authorised to provide health decisions should not just be for personal or accommodation only.
3. An attorney appointed under an AHD or EPOA – note there may be more than one person and decisions may be made differently, e.g. jointly, several etc. Furthermore, a person may choose to complete an AHD, but may not appoint an Attorney.
4. A statutory health attorney/s - An adult's statutory health attorney is an automatic appointment and not reliant upon documentation but legislation for its authority. It relates to health decisions only. It is the first of the following people who is readily available and culturally appropriate:
  - a. a spouse or partner of the person if the relationship is close and continuing
  - b. an unpaid carer aged 18 years or over
  - c. a close friend or relation of the person who is 18 years or over and is not a paid carer.
5. The Public Guardian - If no one is readily available and culturally appropriate to act as attorney the Public Guardian becomes the person's statutory health attorney of last resort. Refer to the fact sheet published by the Office of the Public Guardian in relation to other powers of statutory attorneys.

Since the introduction of the guardianship legislation, end-of-life decision-making formalises a more collaborative approach, involving the person's family and those closest to them and members of the healthcare team. The following matters should be considered in relation to the responsibilities of substitute decision-makers:

SDMs have responsibilities under the legislation and are required to act in accordance with *the General Principles*<sup>29</sup> and *the Health Care Principle*<sup>30</sup>. An example when an SDM may not be complying with these principles is when their demand includes medical treatment that is not clinically indicated or deemed as harmful treatment, and that which restricts the patient's rights in some way. Where SDMs are considered not to be complying with either of these principles, the Public Guardian should be contacted. However, disagreeing with the clinical team does not of itself mean they are not following their duties under the legislation. It may be appropriate for the SDM to be advocating for treatment even if a doctor is reluctant to provide it. This is an area where there may reasonably be different views about the best course of action.

<sup>29</sup> Queensland Civil and Administrative Tribunal. (2018, April 2). *General Principles of the Act*. Retrieved December 4, 2018, from Queensland Civil and Administrative Tribunal: <https://www.qcat.qld.gov.au/matter-types/administration-for-adults-matters/principles-of-the-act>

<sup>30</sup> Office of the Public Guardian. (n.d.). *The Health Care Principle*. Retrieved December 4, 2018, from [https://www.publicguardian.qld.gov.au/\\_\\_data/assets/pdf\\_file/0003/490557/opg-factsheet-health-care-principle.pdf](https://www.publicguardian.qld.gov.au/__data/assets/pdf_file/0003/490557/opg-factsheet-health-care-principle.pdf)

An SDM should be identified for all people in preparation for a time when decisional capacity is lost. The law in Queensland is that there is always someone to act on a person's behalf should they lose capacity - the Public Guardian being the substitute decision-maker of last resort.

An SDM acts as the person's representative and ideally should be chosen by the person for this role when she or he is able and willing to make such a choice. Usually a person's spouse, close family member or friend serves this role in the absence of a formally designated substitute decision-maker.

The expectation is that the SDM will make health care decisions based upon 'substituted judgment'; that is, by considering what the person would want had she or he had decisional capacity.

If the SDM cannot decide what the person would choose, then the decision should be based upon the best interests of the person, which is defined as "what most people in that condition would want". However, it should be noted that there is currently no hierarchy under Queensland law that applies an order between substituted judgement and best interests. Both will be applied and balanced when making a decision.

Formal guardianship around decision-making about health matters is rarely necessary. A guardian is appointed by the Tribunal, based upon a legal determination that the person lacks capacity and there is no one readily available or culturally appropriate to be the person's SDM. In most cases, guardianship proceedings are initiated when there are major treatment dilemmas, concerns of abuse, or disputes for a person who lacks capacity and there is no one perceived as having the ability, desire or authority to legitimately act on their behalf.

Guardianship is also occasionally necessary if there are multiple 'appointed' SDMs who cannot agree on an approach to medical treatment despite mediation by the healthcare team, or if there is suspicion that the SDM(s) are acting in their own self-interest rather than the best interest of the person for whom they are responsible.

## Glossary of terms

|                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|----------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Advance Health Directive (AHD)</b>                          | <p>An advance health directive (AHD)- sometimes called a living will- is a formal way to give instructions about a person's future health care. It comes into effect only if a person's cognitive health deteriorates and they become unable to make their own decisions (i.e. lose capacity to make decisions)<sup>31</sup>. An AHD:</p> <ul style="list-style-type: none"> <li>• outlines what medical treatment or health care the person wants if they can no longer make decisions for themselves. It can be general (e.g. that person wishes to receive all available treatment) or specific (e.g. person wishes to decline certain medical treatment)</li> <li>• enables the person to appoint an attorney for health and personal matters</li> <li>• includes information that health professionals should know, including health conditions, religious or cultural beliefs that could affect the person's care.</li> </ul> |
| <b>Enduring Power of Attorney (EPOA)</b>                       | <p>A power of attorney is a formal document giving another person the authority to make personal and/or financial decisions on your behalf. Personal decisions relate to your care and welfare, including your health care, (e.g. deciding where or with whom you live or consenting to medical treatment). Financial decisions relate to the management of your finances (e.g. paying your bills and taxes, selling or renting your home, using your income to pay for your needs or invest your money)<sup>32</sup>.</p> <p>There are 2 types of power of attorney:</p> <ol style="list-style-type: none"> <li>1. general power of attorney</li> <li>2. enduring power of attorney.</li> </ol> <p>An enduring power of attorney (EPOA) is used to appoint someone to make financial and/or personal decisions on behalf of a person.</p>                                                                                          |
| <b>Statutory Health Attorney (for health/personal matters)</b> | <p>A statutory health attorney is someone with automatic authority to make health care decisions on behalf of a person if they are an adult whose capacity to make health care decisions is permanently or temporarily impaired. A statutory health attorney will make decisions about the person's health care if they are too ill or incapable of making them. For example, consent may be needed for medical treatment or an operation while they are unconscious. Or the person</p>                                                                                                                                                                                                                                                                                                                                                                                                                                             |

<sup>31</sup> Queensland Government. (2018). Advance health directive. Retrieved November 29, 2018, from <https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/advance-health-directive>

<sup>32</sup> Queensland Government. (2017, November 20). Power of attorney. Retrieved November 29, 2018, from <https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/power-of-attorney>

|                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|---------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                       | <p>may have an intellectual disability, dementia or an acquired brain injury and may be unable to make your own decisions<sup>33</sup></p> <p>A statutory health attorney will act if you have not:</p> <ul style="list-style-type: none"> <li>• set out relevant directions for your medical treatment in an advance health directive</li> <li>• appointed an attorney for personal matters under an enduring power of attorney.</li> <li>• had a guardian appointed for health care matters by the Queensland Civil and Administrative Tribunal (QCAT).</li> </ul> |
| <b>Acute Resuscitation Plan (ARP)</b> | <p>The ARP records resuscitation planning outcomes following discussion with the patient, or their substitute decision-maker if the patient lacks capacity, and other members of the multidisciplinary team<sup>34</sup>.</p>                                                                                                                                                                                                                                                                                                                                        |
| <b>Statement of Choices</b>           | <p>The Statement of Choices form focuses on a person's wishes and choices for health care into the future. An advance care plan, including the Statement of Choices, will only be used if a person is unable to make or communicate their decisions<sup>35</sup>.</p>                                                                                                                                                                                                                                                                                                |

<sup>33</sup> Office of the Public Guardian. (n.d.). *Statutory health attorney*. Retrieved January 3, 2019, from <https://www.publicguardian.qld.gov.au/guardianship-and-decision-making/health-care-decisions/mental-health-care-and-treatment/statutory-health-attorney>

<sup>34</sup> Queensland Health. (2017). Overview: Queensland Health Acute Resuscitation Plan (ARP). Retrieved November 29, 2018, from <https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/patient-safety/end-of-life/resuscitation/overview>

<sup>35</sup> Queensland Government. (2018). My Care, My Choices Advance Care Planning. Retrieved November 29, 2018, from My Care, My Choices Advance Care Planning: <https://metrosouth.health.qld.gov.au/acp/statement-of-choices-form>



## Abbreviations

|             |                                                  |
|-------------|--------------------------------------------------|
| <b>ACP</b>  | Advance care planning                            |
| <b>AHD</b>  | Advance Health Directive                         |
| <b>AKPS</b> | Australian-modified Karnofsky Performance Status |
| <b>ARP</b>  | Acute Resuscitation Plan                         |
| <b>CPDP</b> | Care Plan for the Dying Person                   |
| <b>CSCI</b> | Continuous subcutaneous infusion                 |
| <b>EPOA</b> | Enduring Power of Attorney                       |
| <b>HHS</b>  | Hospital Health Service                          |
| <b>ICP</b>  | Integrated Care Pathway                          |
| <b>MDT</b>  | Multidisciplinary Team                           |
| <b>MET</b>  | Medical Emergency Team                           |
| <b>PRN</b>  | Pro re nata                                      |
| <b>QCAT</b> | Queensland Civil and Administrative Tribunal     |
| <b>SDM</b>  | Substitute Decision Maker                        |