



*Last Days
of Life*



CLINICAL
EXCELLENCE
COMMISSION

Clinical Excellence Commission Last Days of Life Toolkit

Guidance for Recognising Dying;
Management Planning; and Care after
Death – Adult Patients

April 2017



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The tools were developed by an expert group of multidisciplinary specialist and generalist clinicians who achieved consensus opinion by reviewing the current literature alongside current best practice from across NSW, Australia and Internationally as well as the clinical expertise provided by the working group members. The expert group would like to acknowledge all NSW Health LHDs who generously shared documents during the development of the tools including: NSW Health policy, Clinical Pathways and End of Life Plans from Sydney, South Eastern Sydney, Central Coast, Northern Sydney, Mid North Coast, Southern NSW and South Western Sydney Local Health Districts.



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Introduction

Dying patients are cared for in many settings including intensive care units, general medical and surgical wards, aged care units and mental health units. 'Principles of a good death', include¹.

- to have an idea of when death is coming and what can be expected
- to be able to retain reasonable control of what happens
- to be afforded dignity and privacy
- to have control of pain and other symptoms
- to have access to necessary information and expertise
- to have access to any spiritual or emotional support required
- to have access to 'hospice style' quality care in any location
- to be able to issue advance directives to ensure one's wishes are respected
- to have time to say goodbye and to arrange important things
- to be able to leave when it is time and not to have life prolonged pointlessly

Most pain can be controlled during the last days of life, but quality management of non-pain symptoms is also needed. In one study of older nursing home hospice/palliative care patients, common non-pain symptoms (such as constipation, nausea/vomiting, fever, and diarrhoea) were often undertreated in more than half of the patients². The physical comfort of dying patients requires thorough and regular assessment, excellent nursing care and careful prescribing.

Having a standard approach, based on best practice, to the identification of the dying patient, symptom assessment and management and care after death will contribute to improving the effectiveness, safety and experience of care for dying patients as well as the experience of their families and carers. Care needs to be tailored to and reflect the patient's individual needs and wishes. Communication is essential in all decisions leading to a change in care and should occur with the patient, where appropriate, and the family/carer. Outcomes of discussions must be documented.

The charts developed to enable recognition, management planning and care after death include:

- Initiating last days of life management plan – ADULT
- Comfort observation and symptom assessment chart – ADULT
- Care after death in hospital – ADULT
- Bereavement survey

¹ www.grampiansml.com.au/resources/gp_doc_bag_270411_1_.pdf

² Rodriguez KL, Hanlon JT, Perera S, Jaffe EJ, Sevick MA. (2010). A cross-sectional analysis of the prevalence of under treatment of nonpaid symptoms and factors associated with under treatment in older nursing home hospice/palliative care patients. *American Journal of Geriatric Pharmacotherapy*, June 8(3):225-32. doi: 10.1016/j.amjopharm.2010.05.002



Using the charts

While these forms provide a standard approach to the framework and documentation of the care and management of the dying patient it is the responsibility of the multidisciplinary team to ensure that the plan of treatment developed is individualised to meet the dying person's own needs and wishes. This must be documented in the patient's health care record so that consistent information is shared with those involved in the person's care and is available when needed (*Priorities of Care for the Dying Person, Leadership Alliance for the Care of Dying People. June 2014*).

When to use these charts

- Focus of care switches from active treatment to supportive care
- There has been an open and honest **documented** conversation with the patient and their family/ carers, and they recognise that the patient is thought to be in the last days of life
- When the patient dies.

When NOT to use these charts

- The patient's condition still requires any degree of active treatment
- The insight of the patient and/or their family/ carers, into the patients impending death is unknown or has not been discussed

Related Local and National Standards / NSW Health Policy

NSW Health Policies

- Verification of Death and Medical Certificate of Cause of Death – PD2105_040
- Using Resuscitation Plans in End of Life Decisions – PD2014_030

In line with Australian Commission National Standards

- National Consensus Statement: Essential Elements for Safe & High Quality End of Life Care
- National Standards – Standard 1, Standard 2; Standard 9.



Initiating Last Days of Life Management Plan

Recognising Dying: It is essential to identify the dying patient in order to allow them & their family/carers to reorient their priorities, achieve their goals, and so that appropriate last days of life care can be provided. Recognising that somebody is dying can be difficult. This decision should be made by a senior clinician in consultation with the patient (where possible) and their families/carers and in conjunction of other members of the multi-disciplinary team.

Section A: Mandatory criteria for commencement of last days of life management

Why would you consider the patient is dying within hours to days?

- Is this deterioration unexpected or a predictable consequence of a known illness?
- Is there any treatable problem that has caused this deterioration?
- Is the patient showing new / worsening physical signs suggesting that death may occur in next 48-72 hours? for example:
 - The patient finds it increasingly difficult to swallow / take oral medications
 - The patient is increasingly disinterested in food and fluid
 - The patient is profoundly weak and essentially bed bound
 - The patient is drowsy for extended periods of time

Who is involved in recognising the patient may be dying?

Recognising dying can be difficult. The decision that a patient is likely to die within hours to days should be made after a discussion between the most senior doctors, nurses and Allied Health staff caring for the patient. If there is uncertainty, further opinions should be sought. Some patients improve un-expectedly; the plan for care must then be reconsidered and explained to the patient, family/carers and team.

Triggers for initiating last days of life management plan

It is essential to identify the dying patient in order to allow them and their family/carers to reorient their priorities, achieve their goals, and so that appropriate last days of life care can be provided. There are various patterns of death trajectory at the end of life, however, with the exception of precipitous, unexpected fatal events (e.g., massive haemorrhage), certain signs tend to be present when patients are actively dying that are applicable to a variety of conditions.

There are some prognostic tools that provide prompts to identify people at risk of deteriorating and dying from one or more advanced conditions for example the Gold Standards Framework Prognostic Indicator “surprise question” and the Supportive and Palliative Care Indicators Tool (SPICT™) <http://www.spict.org.uk/the-spict/> but ultimately it is up to the multi-disciplinary team to make a thorough assessment of the patient and be in agreement that reversible causes for the current condition have been considered and that the patient is likely to die.



Communication with patient and family

Communication and clear explanation to patients and their families/carers are key to providing good care in the last days of life. When a patient appears to be entering the dying phase, a meeting with the patient and/or family/carer should be set up as soon as possible. Ideally this should be led by a senior doctor (Consultant or Senior Registrar) and senior nurse (Nurse Unit Manager/Nurse Manager/Clinical Nurse Consultant). The discussion should aim to cover:

- Identifying (with patient if possible) who is important to share information with, who is the person responsible and establish contact details and when to contact (e.g. at night)
- Discussion of the likelihood of the patient dying in the next hours/days and why it can be difficult to make an accurate prognosis
- Discussion of the patient's priorities for their care including whether they wish to be cared for elsewhere
- How symptom and comfort assessment and management will be addressed.

Documentation

There should be detailed documentation of the conversation with the patient and family/carer. The minimum standard should include:

- ✓ who was present in discussion (both the MDT and family members);
- ✓ what information was given;
- ✓ what were patient's concerns/choices in end of life care;
- ✓ did the patient and/or family / carer understand the patient's condition and the goals of care;
- ✓ did the patient have a preference for place of death;
- ✓ Indicators of symptom/pain control, psychosocial and spiritual support (including family care) were addressed

Once all the criteria are met a Doctor / nurse practitioner must sign as initiator of the last days of life plan at bottom of front page.

Part B: Assessment and Management Planning

Part B provides some prompts/guidance on what should be covered to meet patient needs. In this assessment the patient's comfort assessment and management plan is developed. This can include ceasing regular physiological observations, converting medications to subcutaneous route and identification and documentation of special needs and/or rituals related to the dying and post death period.

Wherever possible the patient's individual wishes are to be explored and considered in developing the care plan



Comfort Observation and Symptom Assessment (COSA) Chart

- The physical comfort of dying patients requires thorough assessment, excellent nursing care and careful prescribing.
- The COSA chart provides tailored individual symptom and comfort assessment and management for patients when their death is expected as well as support to their families/carers in managing those symptoms that occur as the patient is dying.

Once the patient has been recognised as dying and the patient and/or family/carer have a clear understanding of the proposed plan of care the **Comfort Observation & Symptom Assessment (COSA) Chart** should be commenced.

Page 1: Comfort Assessment Planning

- In this section of the front page the patient's comfort assessment and plan is developed. This can include environmental considerations and identification and documentation of special needs and/or rituals.
- Staff need to assure the patient/family/carer that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and allied health staff at the appropriate time/s.

Page 2: Symptom Assessment is done by:

1. Assessing the patient at least 4th hourly.
2. Assessing the patient based on their verbal response, where able.
3. Entering 'P' for Patient, 'C' for Carer, and 'S' for Staff to identify source of assessment
4. Assessing each symptom and documenting whether Absent / Mild / Moderate / Severe

In case of discrepancy between assessments, (e.g. perception of carers and staff, or patient and carers) separately document relevant severity for each assessment with 'P' for Patient, 'C' for Carer, and 'S' for Staff

5. Escalating symptom management to senior nursing staff if assessment in the **BLUE** or **YELLOW** zone.

Page 3: Comfort observation is done by:

1. Assessing the patient at least 4th hourly.

The comfort and emotional wellbeing of the patient should be assessed. If family are present, their needs should also be assessed.

2. Completing an action for each assessment as required

If there are any concerns or symptoms, document what is being done to address these, and whether the measures taken were helpful

To ensure patients symptoms and comfort are well managed the Comfort Observation and Symptom Assessment Chart needs to be supported by medication guidelines - either local guidelines or Medication Management guides from the Last Days of Life Toolkit.



Page 4: Non pharmacological measures

As part of the patient assessment of symptoms and comfort the use of non-pharmacological measures may lessen the discomfort of the symptom and increase the comfort of the patient with and/or without the use of medication.

Page 4: Escalation

The COSA chart has been intentionally designed in the same style of the SAGO chart i.e. a track and trigger tool that provides information on abnormal observations and prompts for escalation using the same established colours. **The difference is the Clinical Review is for comfort assessment and management should be discussed with the senior nurse in charge initially.**

Blue Zone Response

IF THE PATIENT HAS ANY BLUE ZONE OBSERVATIONS YOU MUST

1. Look for reversible causes
2. Consider non-pharmacological treatment
3. Give medication and review at least hourly until mild / none response is achieved
4. Manage symptoms in consultation with the **NURSE IN CHARGE**
5. If symptoms persist- even if assessed as mild-escalation is required

You can make a call to escalate the care at any time if worried or unsure whether to call

Yellow Zone Response

IF THE PATIENT HAS ANY YELLOW ZONE OBSERVATIONS YOU MUST

1. Initiate appropriate clinical care i.e. look for reversible causes
2. Repeat and increase the frequency of symptoms assessment and comfort observation as indicated by the patient's condition
3. Consult promptly with the **NURSE IN CHARGE** to decide whether a **CLINICAL REVIEW** (or other CERS) call should be made

When deciding to escalate care, consider the following:

- Is there more than one Yellow Zone criterion?
- Has the patient not responded to treatment as expected? Are symptoms persisting?
- Does the patient require any additional intervention to relieve their symptoms?

N.B.

- It is important that the local Clinical Emergency Response System (CERS) protocol is referred to for instructions on how to make a call to escalate care for your patient however initial escalation should be to the Nurse in charge who would assess the patient as per the symptoms outlined on the COSA chart.
- If further escalation is appropriate it should be a COMFORT MEDICAL Clinical Review escalated by the nurse in charge.

At least daily

- There should be a review of the patient's overall wellbeing. This should include a discussion with the multi-disciplinary team, patient (if able) and family/carer and a review of symptoms and treatments over last 24 hours.
- Any indications of improvement are to be noted and appropriate actions taken.
- If the person is no longer thought to be dying, the plan of care should be altered.



Care after Death in Hospital

Caring for a deceased person is one part of the overall continuum of care given to patients and those close to them at the end of life. At all times dignity and respect of the deceased person should be maintained.

Care of a patient and their family doesn't end when the patient dies. There are aspects of care still to be undertaken, such as last offices or tissue donation, and the immediate and sometimes longer term support of the family.

- All organisations should have a policy for good practice for the care and viewing of the body after death. Staff must be familiar with this and be responsive to care and family wishes and cultural or religious and spiritual needs.
- Staff should be aware of how to ensure timely verification and certification of death – this may include verification by nurses.
- Staff should also be aware that the coroner may need to be involved in particular cases.

Medical and Nursing staff need to be familiar with:

- Local policies on care of the deceased patient
- NSW health policy PD2015_040 Death-Verification of Death and Medical Certificate of Cause of Death
- NSW health policy PD2010_054 Coroners Cases and the Coroners Act 2009

The Care after Death in Hospital chart is divided into three sections:

1. Verification and notification of death
2. Care of the body and
3. Communication.

Bereavement

Everyone reacts differently when someone dies and there is no right or wrong way to grieve. Support for families, if needed, continues after death as bereavement care.

The bereavement survey has been reproduced, with permission, from Warrington and Halton Hospital NHS Foundation Trusts Bereavement Survey. If you are interested in using it or adapting to local conditions you must:

1. maintain the acknowledgement of Warrington and Halton Hospital NHS Foundation Trusts, and
2. seek permission to use the tool through the Local Health District ethics approval process.



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