Central Coast Collaborative Pathway Project

An introduction and step by step guide

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Introduction to the Pathway

What is the Pathway?

The Collaborative Pathway is a tool designed to facilitate and inform best practice in end of life care. It seeks to support the health professional in their intent to ensure that those dying will do so with the best available comfort measures in place.

The Pathway consists of three (3) uncomplicated forms for guiding and documenting end of life care. These forms (or templates) are adapted by each care setting so as to meet their local requirements.

In addition to the core pathway forms there are clinical guidelines on medication use in the last days of life. A comprehensive education package on use of the pathway is also supplied together with education materials on symptom management, comfort care, and the use of syringe drivers.

The pathway and its supporting education materials are based on best practice evidence in end of life care, and full references are provided.

Why use the Collaborative Pathway in End of Life Care?

The initial development and use of end of life pathways occurred in England (Ellershaw) and was introduced to multiple care settings in Wales (Fowell). The success of this approach to guiding and supporting end of life care has been recognised by the National Institute for Clinical Excellence and the National Health Service in the UK.

The Central Coast Palliative Care Service has built on this knowledge and experience and has adapted this Pathway approach for local application.

The use of a clinical pathway provides a number of key benefits for those with responsibilities in providing end of life care.

1. Known best practice is used to guide the pathway steps.
2. Evidence of delivered care is automatically documented.
3. A process of continuous improvement is supported.
4. Quality care is delivered with greater consistency across multiple sites.

Commencing the pathway

Step 1: Assessing Suitability

The decision to commence the Collaborative Pathway is the responsibility of the attending Medical Officer.

Commencement of the Pathway is a clinical judgement, based upon a medical assessment, and will include the following documented essential elements:

1. The individual is assessed as dying, and death is anticipated in the next 3 days.

2. A “not for intubation / not for CPR” order has been discussed and documented.

3. In addition, the individual is assessed as meeting *at least two* of the following criteria:

    - Bedbound
    - Only able to take sips of water
    - Semi-comatose
    - Unable to take oral medications

These are gateway criteria, and the Collaborative Pathway cannot be used unless these items are in place.

Step 2: Medical Actions

Having determined that the Pathway is appropriate to commence, the attending Medical Officer completes the following steps (Section 1).

- The dying person (where possible) and their identified carer are informed of the decision to commence this pathway, and are assured that the goal is to ensure comfort.

- Existing medications are reviewed, and all non essential medications ceased.

- If oral administration is no longer an option, then essential medications are ordered by a more suitable route (eg subcutaneous). Where indicated (and available) a syringe driver may be commenced.

- PRN orders for identified anticipated symptoms of dying are ordered with due regard for the individual’s prior medications, allergies and needs. See medication guidelines.

- All non essential investigations and observations are ceased.

- The primary carer is identified and their contact details and availability confirmed.

- The medical officer signs their section of the Pathway.

Step 3: Nursing Actions

Nursing staff complete Section 2 of the pathway by addressing the following items.

- Relevant Spiritual/Religious/Cultural needs or rituals are identified and documented. These will include any specific death or post death related practices or preferences that the individual has previously indicated, or that the family / carers make known. Where indicated, relevant resources or contacts will be identified in anticipation of their use.

- An opportunity for the family or individual to express any concerns is provided, and key issues (if any) are documented and addressed.

- To the extent that it is relevant to the care setting, the need for a single room is assessed and addressed.

- To the extent that it is relevant to the care setting, the need for a special mattress and/or other comfort aids is assessed and addressed.

The attending Nurse signs the Pathway, and commences the Comfort Assessment Chart.

Registration with the Area Palliative Care Service

A patient does not need to be formally registered with the APCS in order to be placed on the pathway.

If an individual patient is **not** formally registered with the service and is placed on the pathway, clinical input from APCS must be restricted for medical-legal reasons to the patients own doctor contacting the on call palliative care consultant directly for any advice if required. This service is provided 24/7.

Patients who **are** registered with the service can, with the approval of their doctor, receive all services currently provided by the APCS including 24/7 nursing and medical consultation, volunteer support, formal bereavement follow up and access to specialist drugs and equipment.

Individual care settings can discuss registration options and processes with the Central Coast Palliative Care Service.

Continuing on the Pathway

Regular Review

Quality End of Life Care requires regular review of the individual's condition, as well as Medical review as indicated.

The Comfort Assessment Chart

While non essential investigations and interventions are reviewed and ceased, a regular set of comfort focused observations are undertaken using the Comfort Assessment Chart (Section 5). The frequency of observation is determined by the local care setting.

The chart has two parts. The first monitors for the existence and management of symptoms that may be experienced in the last days of life. These are:

- Pain
- Nausea / Vomiting
- Respiratory Secretions
- Agitation

For each of these the goal of care is stated in terms of their non occurrence, eg *No pain apparent in previous 4 hours.* The goal is documented as being met (M) or as being unmet (U).

The second part documents common comfort care measures. These are:

- Mouth care
- Optimal Positioning
- Eye Care
- Skin Care
- Micturition
- Bowel Care
- Psychological Support
- Spiritual / Religious Support

For each of these measures there is a goal statement (*eg Mouth / lips clean and moist*). The goal is documented as being met (M) or as being unmet (U).

The frequency of observation for each of these will be determined by the care setting, and will be indicated on the local version of the chart.

When symptoms or other care events occur they are documented on the pathway documents or/and progress notes.

Concluding the Pathway

Post Death Care
Following the death of the individual Section 3 of the Collaborative Pathway is completed. This has three parts.

Part one is documentation that normal required care was given post death (in keeping with local policies and guidelines).

Part two relates to post death support for the identified key family member/s. Quality end of life care includes the facilitation of relevant bereavement support for identified family members.

> Where registration with the CCPCS has occurred, the Pathway allows for referral to the Central Coast Bereavement Service for targeted bereavement follow up. The Service should be notified of the death the next working day.
>
> For those not registered information on referral can be found in Central Coast Bereavement Service pamphlet included in the Pathway supporting materials.

Part three is the completion of the Collaborative Pathway Quality Indicators Chart.

When completed the Pathway documents are filed in the normal clinical record.

Collaborative Pathway Quality Indicators Chart

During the post death care phase, the Collaborative Pathway Quality Indicators Chart (Section 4) is completed. This chart provides a means of documenting care outcomes and issues in a manner that contributes to quality activities.

The local care setting is encouraged to use the information in this chart as part of their normal quality review activities.

In addition, the care setting is asked to de-identify the chart, and fax a copy to the Collaborative Pathway Project Team, who will collate the information from all participating locations. This information will then be used to review the Pathway, and will be presented at the tri-annual Pathway Project meetings to all partners.

If you have questions about the Collaborative Pathway please contact the Project Team representatives at the Central Coast Palliative Care Service on 4336 7777

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Or email the Project Team at cccpp@doh.health.nsw.gov.au

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