Guidance for Professionals in Caring for Patients in the Last Days of Life

(To be used in conjunction with the Comfort & Dignity Plan)

1) An algorithm to support decision making in diagnosing dying and supporting care in the last hours and days of life.

2) A guide to caring for people in the last few days of life in Bradford, Airedale, Wharfedale and Craven community – including advice on completing the Comfort & Dignity Plan.

If further advice needed about documentation, please contact your Community End of Life Care Facilitator:

For Bradford, Airedale & Wharfedale:

Lesley Phillips  lesley.booth@bdct.nhs.uk  07525 244231

For Craven:

Fiona Widdowson fiona.widdowson@anhst.nhs.uk 07786 686753

Contact your Palliative Care Team or Gold Line 01535 292768 (out of hours) for access to clinical advice. Advice from a Consultant is available 24/7
Algorithm – Decision making in diagnosing dying and supporting care in the last hours or days of life.

Deterioration in the patient’s condition suggests that the patient could be dying.

Multidisciplinary team (MDT) assessment
- Is there a potentially reversible cause for the patient’s condition e.g. exclude renal failure, hypercalcaemia, infection, opioid toxicity
- Could the patient be in the last hours or days of life?
- Is specialist referral needed? E.g., specialist palliative care or a second opinion (see referral criteria)

Patient is NOT diagnosed as dying (in the last hours or days of life)

Review the current plan of care

Discussion with the patient and relative or carer to explain the new or revised plan of care

Patient is diagnosed as dying (in the last hours or days of life)

Instigate Comfort & Dignity Plan for the last days of life and follow initial assessment. Joint medical/nursing document

There must be on-going regular assessment of care needs with documentation of how they are being met

A full multidisciplinary team (MDT) reassessment & review of the current plan of care should be triggered when 1 or more of the following apply:

- Improved conscious level, functional ability, oral intake, mobility, ability to perform self-care
- Concerns expressed regarding management plan from patient, relative or carer or team member
- It is 72 hours since the last full multidisciplinary team (MDT) assessment

Always remember that the Specialist Palliative Care Teams are there for advice and support, especially if: Symptom control is difficult and/or if there are difficult communication issues, or you need advice or support regarding your care delivery.
Bradford, Airedale, Wharfedale and Craven Community

This is a guide to support staff in caring for people in the last few days of life and to be used in conjunction with the Comfort & Dignity Plan for an individual patient.

DECIDING THAT SOMEONE IS IN THE LAST FEW DAYS OF LIFE

- It is recognised that there can be uncertainty about whether a patient is in the last days of life and this should be taken into account in the clinical management of the patient and communicated to relatives.

- Identifying that somebody is likely to be in the last days of life should be led by the GP and senior nurses responsible for the patient’s care and supported by the multi-disciplinary team.

- Doctors should take into account the GMC guidance ‘Treatment and Care Towards the end of Life, good practice in decision making’.

- Unless it is unavoidable, urgent, and clearly in the patient’s best interests, the decision to withdraw or not to start a life-prolonging treatment should be taken in normal working hours (9 - 5) by the senior responsible clinician in consultation with the healthcare team.

- Ensure that the Gold Standard Framework status is changed to RED and that a Gold Line referral has been made (check Summary view on EPaCCS). Check that the family have the Gold Line telephone number.

PLANNING AND AGREEING CARE

- Patients who are identified as dying and their relatives (with the patient’s permission) should be involved in discussions about their condition/prognosis and their care/treatment to the extent they wish to be. This will require sensitive assessment of their information needs and how involved they want to be. These discussions should be documented in the Comfort & Dignity Plan.

- If a best interest decision about a serious medical treatment is required for a patient whose care is supported by the Comfort & Dignity Plan and no relatives or carers are available to be involved in decision making, consideration should be given to appointing an independent advocate (IMCA). However, this can take several days so urgent decisions will need to be taken in the patient’s best interests by the multi-professional team.
The Comfort & Dignity Plan should then be commenced. This replaces all other nursing care plans unless essential and agreed with relevant specialist practitioner e.g. continuation of insulin therapy.

Following a joint professional discussion that the patient is in the last few days of life, the Comfort & Dignity Plan can be completed by any member of the multidisciplinary team but MUST be agreed by the GP responsible for that patient’s care. The GP must document in the patient’s electronic record that they are in agreement with commencement of the Comfort & Dignity Plan or indicate this by changing the patient’s GSF status to RED.

If a GP sees the patient in the last 14 days of life a death certificate can be issued without the involvement of the Coroner. This is considered to be good practice and offers medical support for the patient and family. (Please note that the verification of death can go ahead for expected deaths even if the patient has not been seen by the GP in the previous 14 days but the death would need to be discussed with the coroner before a death certificate can be issued).

All qualified health care professionals can complete sections of the Comfort & Dignity Plan.

**NUTRITION AND HYDRATION**

When a patient is dying their need for diet and fluids is reduced. Relatives and carers should be reassured that this is a normal part of dying. Often at this stage letting the patient eat and drink as they are able is sufficient. Offering sips of fluid can provide comfort as long as the patient can swallow.

You **MUST** discuss this with the patient (if able) and relatives and take in to account their wishes and beliefs when considering whether to commence/continue artificial hydration/nutrition for the dying patient. There is no evidence that artificial hydration and nutrition prolong life at this stage in a patient’s illness. They may provide comfort to the patient or relative but may create symptom burdens.

**Maintaining mouth care for all patients with limited oral intake is essential and encouraging the family members to support regular mouth care can offer them comfort.**

**It is the duty of all staff to ensure that patients who are able to and wish to eat and drink should be supported to do so.**

**REPOSITIONING**

Patients with reduced consciousness will have increased risk of pressure damage. Please follow your organisation’s pressure ulcer guidance. It may be appropriate to catheterise the patient to protect skin and prevent unnecessary discomfort from more
frequent turning. Clinical judgement, patient request or severe pain may result in less regular turns. Reasons must be clearly documented in the daily care plan.

PATIENT REVIEW

- Best practice indicates that patients should be reviewed regularly by the GP and must be reviewed daily by the community nursing service, including an assessment of carer and family needs or concerns. Any decisions or communications should be clearly documented.

- A joint professional discussion must occur:
  - If the patient improves;
  - If concerns are expressed about the management of the patient by a family member, or member of the multi-disciplinary team;
  - If it has been 72 hours (or sooner if needed) since the last assessment by the GP and Community Nursing team.

PRESCRIBING AT THE END OF LIFE

There are three general principles of prescribing at the end of life:

1. Stop non-essential drugs. In general, this means stopping all drugs that are not providing a symptomatic benefit. For some drugs, such as statins and anti-hypertensives, this is fairly clear. Other medicines, such as anti-epileptics, would usually be continued for as long as the patient can manage to take them. Antibiotics are usually stopped, but can be continued if it is thought that they are providing symptomatic benefit or outcome is less certain. For diabetic patients, refer to page 6 of the ‘Symptom Control in the Last Days of Life’ guidelines (available on the EPaCCS template on SystmOne – select ‘Anticipatory Drugs’ from the contents, and open ‘Guide to Prescribing in Last Days of Life’).

2. In patients who are having trouble swallowing tablets, and in those who have nausea and vomiting, or poor oral absorption, convert essential drugs to subcutaneous delivery.

3. Irrespective of current symptoms, all dying patients should have anticipatory medication prescribed - an analgesic, an anxiolytic, an antiemetic and drugs to reduce bronchial secretions - and available so that there is no delay responding to a symptom if it occurs. In addition a Microlax enema should be prescribed to relieve constipation in the last days of life.
• Review medications administered in a 24 hour period daily and discuss with a medical prescriber to consider whether a syringe driver is appropriate.

• Before a syringe driver is commenced, this must be discussed as far as possible with the patient, their relatives or carers and the reasoning documented.

• The name of the GP and District Nursing team responsible for leading the care of the dying patient will be documented on the front of the last days of life care plan.

• Where the treating team are struggling to manage complex symptoms they should refer to the community specialist palliative care team for support.

**Relatives and Friends Communication Journal**

This section of the Comfort & Dignity Plan (pages 7 – 8) is to be reviewed and responded to at each visit by the professional team.