

Caring for me

Advanced Care Planning

**Supporting guidance for Healthcare Professionals
and Administrative Staff**

**This care plan is aimed as a guide to treatment and intended to aid the
documentation of patient progress.**

Practitioners are free to exercise their own professional judgement.

Guiding principles of care and management of those who are likely to be approaching the last days of life

Introduction

This guidance aims to ensure the care of the dying patient is personalised, reflective of individual needs and preferences. This guidance pays attention to assessing and addressing the physical (including symptoms, hydration and nutrition, skin and mouth care) emotional, psychological, social, and spiritual needs of the patient. It also addresses his/her personal care needs, sense of dignity and considers the needs of their family and carers. This is in line with the End of Life Care Strategy (2008) and the *Ambitions for Palliative and End of Life Care A National Framework for local action 2015 - 2020*.

Accountability and responsibility

Professionals and teams caring for patient approaching their last days of life will be competent in specific requirements for high quality end of life care. They will demonstrate the highest level of professionalism including respect, compassion, kindness and attention to detail in the care of all those who are approaching their last days of life, and their family and carers. The principles of the Mental Capacity Act (2005) should be applied to all relevant aspects of care and ensure all decisions made are in line with the principles within the GMC guidance:

www.gmck.org/guidance/ethical_guidance/end_of_life_care.asp

Each patient will have a named senior responsible General Practitioner (GP) and registered nurse responsible for their care. They will be responsible for patients and family involvement in decision making and ensuring that decisions are made in a timely way.

At home or in a care home the patient's registered GP is the senior responsible clinician during surgery hours. Outside of these hours this is delegated to the GP Out of Hours service. The person's registered GP has a duty to ensure that the deputising service has been provided with or has access to adequate information to support decision making.

The patient's responsible GP or deputy should consult specialists in palliative care when patient's needs warrant it.

The dying patient and his/her family and carers should know who is the registered nurse responsible for leading the nursing care of that individual at any one time. The nurse is responsible for communicating effectively with the family, checking their understanding and ensuring any emerging concerns are recognised, and are resolved wherever possible.

In the community hospital the ward sister or team leader will have overall responsibility. On each shift the name of the nurse responsible for delivering care on each shift will be identified and communicated to the patient (if able) and their families and carers when present. In the community this will usually be the key worker.

Communication

The opportunity for regular, pro-active and responsive communication between professionals, the person who is approaching the last days of life and their family and carers should be offered. When the person consents to share this information, the content and outcomes of these discussions will be documented and shared with others involved in this person's care. This includes conversations about prognosis, treatment goals and care plans at each point in time and particular concerns that the person and/or family/carers have expressed. If the person and the family/carers do not want to discuss their deterioration or treatment plans this should be respected but the opportunity should be offered, and this should be documented.

Where the person who is approaching the last days of life lacks capacity the starting point of communication between professionals, the family/carers of the person must be that all parties wish to act in the person's best interests. Differences in opinion about how this is achieved should be discussed openly and alternatives, including a second opinion, actively sought if differences remain or additional reassurance would be helpful. Professionals must understand their duty to acknowledge any prior wishes the dying person has expressed, to involve the person's lasting power of attorney or deputy for health and welfare, if there is one, and to involve an Independent Mental Capacity Advocate (IMCA) if the person does not have family or friends or there is a disagreement about a person's best interests.

If the person doesn't have family or carers to be involved in discussions and decisions about their last days of life care, an Independent Mental Capacity Advocate should be involved

Initial assessment and decision making

Patients, whose condition changes must be identified, promptly reassessed, pre-existing care and treatment plans consulted and care and treatment goals re-evaluated. This must be done in consultation with the person (where possible), their families and carers (where present or contactable) and other members of the team who may have information to contribute. It must take into account the specific features of their underlying condition(s).

Recognising that a person is dying and likely to be in the last days of life is complex and uncertain. The decision should be made by the senior responsible clinician in conjunction with the person and other members of the multidisciplinary team and in consultation with their family and carers. Any potentially reversible causes for the patient's condition should be identified. These may include:

- Dehydration
- Infection
- Opioid toxicity
- Hypercalcaemia
- Renal Failure

If it is clear that attempting to reverse the person's condition is possible and in keeping with their wishes, treatment should focus on maintaining life and well-being. If the patient's change in condition is not reversible and he/she is likely to die within the next few days, the focus of treatment and care should move towards palliation and preserving the individual's comfort and dignity.

It should be documented who has been involved in the decision making, why it is felt the person is dying including the relevant diagnosis and specific relevant clinical factors. If appropriate reversible causes have been identified and action taken, the aims of the treatment and management plan should be clearly documented.

The prognosis (i.e. that the patient is deteriorating and likely to be approaching the last days of their life) should be discussed with the patient (if appropriate) and their family or carers.

Prognostic indicators that the patient may be dying are:

- The patient is bed bound
- The patient is semi-comatose
- The patient is only able to take sips of fluid
- The patient is no longer able to take tablets.

A full assessment should be completed including all aspects of care

People who have a progressive, life limiting illness should be encouraged but not pressured to discuss and document their wishes and preferences for their future care and have opportunity to update this regularly. They should be offered the opportunity to identify particular people they would like professionals to involve in decision making about their care, if they are unable to have these discussions themselves.

If the person lacks capacity any advance care plans including statements of preferences and wishes, advanced decisions to refuse treatment and lasting power of attorney for health and welfare or previous discussions should inform and be central to the care plan.

An individual care plan should be agreed with the patient or lasting power of attorney for health and welfare, and discussed with the family and documented.

If the patient or family/carer needs are complex or any further advice is needed the specialist palliative care team should be contacted for advice/support.

Review of current treatment plans including observations, medication, resuscitation, management of Implantable Cardiac Defibrillator (ICD)

It is important to review whether routine observations are still appropriate. If a decision is made to continue with any observations, their purpose and what action is to be taken should they become abnormal should be documented. Risks and benefits of current treatments (including medication) should be reviewed and discussed. Any treatments continued should be in line with current goals and aims of treatment. If it is decided to continue medication the appropriate route of administration should be considered.

If an Implantable Cardiac Defibrillator is in situ management of this should be considered and documented. It is important to remember that potentially the ICD can deliver painful and distressing shocks to the dying person.

Cardio pulmonary resuscitation (CPR) status should be reviewed in line with current policy and decisions about CPR discussed with the patient (if appropriate) and their family in a sensitive and appropriate manner. General Medical Council (GMC) guidance should be followed and if appropriate a Do not attempt CPR (DNACPR) decision should be clearly documented and form completed in line with current policy (please see local Do Not Attempt Cardiopulmonary Resuscitation Policy (DNACPR)).

Review of hydration and nutritional needs

The dying patient should be supported to eat and drink as long as he/she is able and wishes, to do so. If they do not wish to eat or drink, the provision of mouth care to promote comfort should always be offered. If there is risk of aspiration, the risks and benefits of eating and drinking should be discussed. The patient should be allowed to accept the risks if they wish. If they lack the capacity to make this decision a best interest decision should be taken in consultation with any known prior wishes, and with the patient's family/carers and other members of the team.

If they are unable to swallow, decisions about the use of clinically assisted hydration and nutrition should be taken in consultation:

- with the patient/lasting power of attorney for health and welfare or
- in the person's best interests in consultation with any known prior wishes, and with the patient's family/carers and other members of the team. All decisions must be made in line with GMC guidance

All discussions and decisions about nutrition and hydration should be clearly documented.

Review of current symptoms and potential future symptoms

Current symptom needs should be assessed. If symptoms are identified, appropriate action should be taken to address these.

All medications used in the symptom management of the dying patient should be used in the smallest dose that works, for the shortest time that is necessary, and their use regularly reviewed and adjusted as necessary.

The reason for intervention (including the use of a syringe pump if necessary) should be explained to the dying patient (if possible) and his/her family and carers. If the dying patient is unable to consent reasonable efforts should be made to discuss the purpose of interventions with his/her family and carers, but if they are not present nor readily contactable this should not delay starting the intervention where this is clearly in the patient's best interests.

Patients who are likely to die in the next few days should have medicines prescribed in anticipation of common symptoms that may arise, these include; pain, nausea and vomiting, terminal respiratory secretions, breathlessness and agitation. The medications will be available to be given should symptoms occur. Any equipment needed for administering these should be available so that timely symptom control can occur at any time of day or night.

Please see Appendix 1 Symptom Guidance Management for the Dying Patient.

Assessment of comfort needs

This will be based upon personal preferences and wishes and will include assessment of skin integrity, positional changes, mobility, personal hygiene, bladder and bowel care, eye care and mouth care.

Assessment of emotional, spiritual/ religious and social needs

Consider issues important to the person at this time – their worries concerns, preferences and priorities including preferred place of care, religious or spiritual needs.

Family and carer needs

Families and carers must be given clear, reliable and consistent information. This should include how to seek urgent help when this is needed, who to ring, what numbers to use at any time of day or night and what information they should provide that will facilitate the most appropriate response.

Ensure families and carer's needs are regularly assessed and they are directed/signposted to appropriate sources of help and support.

Ensure families and carers are enabled to spend time with the dying person, in accordance with their wishes and those of the dying person.

Ongoing assessment and care of a person who is thought to be in the last days/hours of life

Planned review and documentation of the care plan is required to ensure best care is given as the patient's condition deteriorates, stabilises or improves. The comfort and well-being of the patient should be assessed regularly as should the family and carer needs (if they are present).

Any concerns should be acknowledged and documented. Changes in a person's condition should be reflected in the care plan and if the person has improved and is no longer thought to be in the last days or hours of life the plan of care should be reviewed and ceased if appropriate.

Patients (if appropriate) and their family/carers should be offered to complete the family/carers diary where possible, to help ensure that their needs and concerns are being attended to.

In hospital patients identified as likely to die within the next few days, must be assessed by appropriately trained doctors at least daily, monitored by appropriately trained nurses at least four hourly and have their needs assessed as they arise.

At home people who have been identified as likely to die within the next few days, must be assessed by an appropriately trained doctor or nurse regularly as required, and steps taken to ensure that individuals who are with the patient at home know how to check the person's comfort levels, address their immediate needs and when and how to seek professional help.

In care homes and other institutions, patients who have been identified as likely to die in the next few days, must be assessed by an appropriately trained doctor or nurse regularly as required, and steps taken to ensure that staff who are looking after the person know how to "monitor" the patient and his/her comfort levels, address their immediate needs, and how to seek additional professional help.

After death care

After the patient has died his/her body will be cared for in a way that is respectful and the process of verification and certification of death is supportive of the patient's family and carers.

Consider any after death care wishes expressed by the patient and/or their family for example, funeral plans, and organ donation.

NB: In an expected death it is not a legal requirement for a doctor or nurse to verify a death prior to removal of the body by the funeral director (GMC).

If an end of life patient has a Deprivation of Liberty Safeguarding (DOLs) in place and they die this is classed as a death within custody of the state. As such they have to be referred to the coroner and a Humber NHS Foundation Trust Nurses will not be able to verify their death. This information should well documented and be communicated to all involved in the support of this patient.

Appendix 1

HERPC prescribing guidance

Guidance for Commencing Palliative Care Medicines (Just in Case Drugs)

Please note that this is intended for **GUIDANCE ONLY** for the initiation of palliative care medicines. Each patient must be prescribed these medications at a dose which takes into account their current oral or subcutaneous (s/c) medications. The example doses given below would be suitable for an opioid and benzodiazepine naive patient only.

These medications are often prescribed in anticipation of the patient requiring treatment to manage their symptoms. A clinical assessment of the patient should be undertaken when the patient is symptomatic to ensure optimisation of their treatment.

Any patients requiring two or more s/c doses in 24 hours should have a clinical assessment and if appropriate consider initiating a syringe pump. Advice can be sought from the Specialist Palliative Care Teams.

Hull and East Riding Community Nursing teams are using the community drug administration charts (Medication Authorisation and Administration Record). The exact dose for the patient will need to be prescribed on the community drug chart which must be completed and signed by the prescriber. Please note that sliding scales of doses are not acceptable in the community. Including a time interval on the community drug chart is vital to allow safe administration by nursing colleagues caring for patients. Suggested time intervals are included below.

Symptom	<u>Suggested medication/doses for opioid & benzodiazepine naive patients</u> <u>Consider reversible causes for the patient's condition i.e. constipation and urinary retention</u>	
Pain	<p>*Diamorphine 2.5mg s/c 2 hourly PRN prescribe 5mg ampoules 10(ten) ampoules</p> <p>maybe repeated after 60 minutes if needed</p>	In renal impairment eGFR <30ml/min please seek advice from the specialist palliative care teams
Agitation/restlessness	<p>*Midazolam 2.5mg s/c 2 hourly PRN prescribe 10mg/2ml injection 10(ten) ampoules</p> <p>maybe repeated after 30 minutes if needed</p> <p>Please ensure the 10mg/2ml injection is prescribed, and not the 5mg/5ml, as this can be very uncomfortable for patients as a s/c injection, due to volume.</p>	(if patient in last days of life manifests features suggestive of delirium consider haloperidol +/- midazolam)
Nausea/Vomiting	<p>Haloperidol 1mg s/c 4 hourly PRN prescribe 5mg/ml injection 10 ampoules</p>	
Excess secretions/ Bowel colic	<p>Hyoscine Butylbromide 20mg s/c 4 hourly PRN prescribe 20mg/ml injection 10 ampoules</p>	If TWO doses are required in 24 hours consider a syringe pump containing 60mg over 24 hours

NB Please include water for injections for reconstitution of the Just in Case Drugs. Water for injection needs to be prescribed on FP10 and included on IDL but NOT written on the community drug chart.

For any advice on Palliative Care Drugs, please contact the Specialist Palliative Care Teams

Hull (CHCP CIC)	01482 335883
East Riding (HFT)	01377 208758
Hull & East Yorkshire Hospital	01482 461146
Dove House Hospice	01482 784343

*(total quantity required in words and figures to comply with CD writing requirements on FP10 prescription form, not required on community drug chart)

Prepared by Emma Baggaley, Senior Pharmacist, City Health Care Partnership CIC

Reference: British National Formulary 66, Palliative Care Formulary 4th Edition

Approved by HERPC 24.11.14 Review Date: November 2016

Syringe Pump Guidance

Any patient requiring 2 or more s/c doses in 24 hours should have a clinical assessment and if appropriate consider a continuous sub-cutaneous infusion (CSCI) via syringe pump over 24 hours.

<u>Symptom</u>	<u>Suggested medication/doses for opioid & benzodiazepine naive patients</u> <u>Consider reversible causes for the patient's condition i.e. constipation and urinary retention</u>	
Pain	*Diamorphine Initially 10mg over 24 hours	In renal impairment eGFR <30ml/min please seek advice from the specialist palliative care teams
<p>Note: Opioid patches (e.g. Fentanyl and Buprenorphine) should continue to be used and syringe pump dose calculated on PRN use only.</p> <p>If taking oral morphine, add the total dose taken in the previous 24 hours and divide by 3 to give the equivalent dose of diamorphine in 24 hours, with a PRN dose equivalent to 1/6 of the 24 hour dose.</p> <p>Example: Morphine sulfate m/r 60mg BD plus morphine sulfate oral solution (10mg/5ml) 10ml (20mg) x 3 equals 180mg oral morphine in 24 hours so 180 divided by 3 = 60mg diamorphine in 24 hours. Breakthrough dose (60mg divided by 6) equals 10mg PRN.</p>		
Agitation/restlessness	*Midazolam Initially 10mg over 24 hours, titrated according to response	(if patient in last days of life manifests features suggestive of delirium consider haloperidol +/- midazolam)
Nausea/Vomiting	Haloperidol Initially 2.5mg over 24 hours	
Excess secretions/ Bowel colic	Hyoscine Butylbromide Initially 60mg over 24 hours	

Compatibility of Drugs: Any TWO of Diamorphine, Haloperidol, Hyoscine Butylbromide and Midazolam can be mixed together in a syringe pump with water for injection.

For further information on compatibility, please refer to syringe pump policy or contact specialist palliative care teams.

NB Please consider when calculating dose oral absorption of opioids may be reduced due to underlying factors and SC dose via syringe pump may need to be lower than calculated.

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