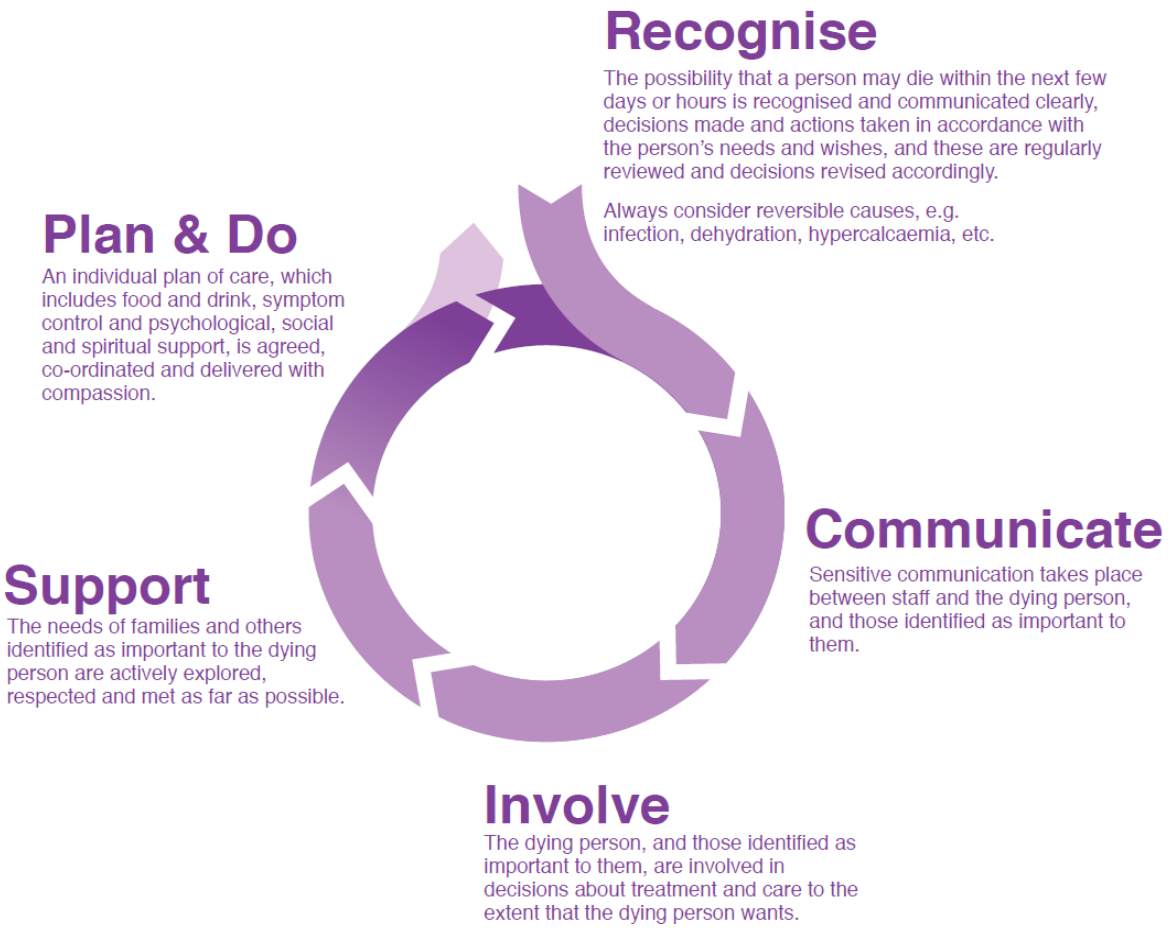
Name:

Date of Birth:

NHS Number:

Priorities for Care of the Dying Person

Communication Document



The Priorities are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person.

('One chance to get it right: improving people's experience of care in the last few days and hours of life', Leadership Alliance for the Care of Dying People, June 2014)

Note, when it has been established that a dying person lacks capacity to make a particular decision, staff must operate within the legal framework provided by the Mental Capacity Act 2005 (MCA) and its Code of Practice. If an Advance Decision to Refuse Treatment exists and is valid and applicable (within the terms of the act and code), it must be followed. Individuals who have been nominated by the dying person to be involved in decisions and those who hold Lasting Powers of Attorney (LPA) relating to health and welfare issues must be involved in decisions. Those who hold a registered LPA for health and welfare may have legal authority under the terms of the LPA to make the decision on behalf of the dying person

Communicate and Involve

Consider the following:

- Where there is no record to the contrary and the patient does not have capacity to give consent, it is reasonable to assume that they would want their family and those important to them to be informed about their condition and prognosis
- Some families do not wish to talk openly about death and dying. This must be respected but health and care staff must find a sensitive way to remain clear in their communication

Current situation explained to patient:

Yes ☐ No ☐

If 'No', indicate reason below:

Patient lacks mental capacity ☐

Patient unconscious ☐

Patient has previously expressed a wish to not have open conversations about their condition or what is happening to them ☐

Names of any specific individuals with whom the patient does not wish information to be shared:

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. ….....

Date Time Signature Designation

Current situation explained to patient's family and others identified as important to them:

Yes ☐ No ☐

If 'No', indicate reason below:

Attempts to contact them unsuccessful ☐

Independent Mental Capacity Advocate (IMCA) unavailable (if applicable) ☐

Name(s) of patient's family and others identified as important to them with whom discussion has taken place:

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Date Time Signature Designation

Summary of discussion with patient and those identified as important to them:

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What is the patient's preferred place of care for the last days of life?

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Summary of decision making and discussion with patient and those identified as Important to them regarding place of care

(Note: In hospital, initiate the "Rapid Discharge Home to Die" pathway (found on the hub under Departments- Palliative Care- Rapid Discharge Home to Die) http://dudleygroup.nhs.uk/services-and-wards/end-of-life-care/_professionals/ if transfer to another setting is to be considered)

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Supporting the needs of the Patient and Families

The patient should be given the opportunity to discuss what is important to them at this time, e.g. their wishes, feelings, faith, beliefs, values.

Encourage completion of the 'One Page Profile' (which can be found at the end of this document) and display in an appropriate location (e.g. above the patient's bed space in an inpatient environment) if the patient, their family and those important to them (where applicable) are in agreement.

Patient's own expressed views and preferences:

(Include any information contained in a documented advance care plan or advance decision to refuse treatment)

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Needs of the patient's family and those important to them:

(In an inpatient environment, ensure families are welcome and enabled to spend time with the dying person to the extent that they and the dying person wish)

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"End of Life: a guide" information for relatives and carers leaflet given to patient's family and those important to them

Yes ☐

Plan and Do

Spiritual, Religious & Cultural issues

Find out from the patient, their family and those important to them, the details of any cultural, spiritual and/ or religious-specific requirements, including what constitutes respectful treatment of the body after death.

Consider:

- Does the patient or family wish the Multi Faith Chaplaincy team (in hospital) or own faith community to be notified?
- Are there any faith rites that the patient or family would wish to take place?
- Are there any spiritual or cultural issues that need to be addressed?

Needs now:

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Needs at death:

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Needs after death:

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Initial visit from faith representative:

Hospital *(use chaplaincy team stamp)*	**Other care setting**
	Name: ..... Contact number(s): .....
Date Time	Date Time

Subsequent visits from faith representatives can be recorded in ongoing care notes

Food and drink

Support the patient to eat and drink as long as they wish to do so and there is no serious risk of harm

- If a patient makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected
- Pay attention to mouth care to maintain comfort, inviting family or important others to participate and supporting them when they wish to do so
- Symptoms of thirst / dry mouth do not necessarily indicate dehydration and are often due to mouth breathing or medication
- A reduced need for fluids is part of the normal dying process

Clinically assisted nutrition includes intravenous feeding, and feeding by nasogastric tube and by percutaneous endoscopic gastrostomy (PEG) and radiologically-inserted gastrostomy (RIG) feeding tubes through the abdominal wall. All these means of providing nutrition can also be used to provide hydration (fluids). **Clinically assisted hydration** can also be provided by intravenous or subcutaneous infusion of fluids.

For most patients the use of clinically assisted nutrition and hydration will not be required in the last days of life.

Rationale for decisions regarding nutrition / hydration, as discussed with the patient (where possible) and family and those important to them:

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Symptom control measures

- All decisions must involve consideration of the potential benefits, burdens and risks of treatment (or non-treatment) for the individual person
- Stop non-essential drugs: in general, this means stopping all drugs that are not providing a symptomatic benefit, e.g. statins, antihypertensives
- Review all medications regularly and adjust as needed for effect
- The reason for any intervention, including the use of a syringe driver, must be explained to the patient and to those important to them. Other than in exceptional circumstances, this should be done before it is used
- Prescribe anticipatory medications *(see p.13-24 End of Life care guideline on HUB on the Palliative Care and End of Life department pages)*

Anticipatory medication prescribed for:

Pain ☐

Agitation ☐

Respiratory tract secretions ☐

Nausea & vomiting ☐

Breathlessness ☐

Symptom control issues of particular relevance for this patient:

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Nursing issues of particular relevance

Consider:

- Family or important others who wish to participate in caring for the patient must be supported by staff to do so, e.g. by showing them simple practical techniques, but assumptions must not be made about their ability or wish to do so

At this stage of the patient's care, consider what is important for the patient now regarding

- Comfort
- Dignity
- Personal Care

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Ongoing assessment

All ongoing assessment should be recorded in the patient's record (as applicable to the care setting).

The patient should be reviewed at least daily by a clinician involved in their care to assess whether the plan of care remains appropriate.

Document any changes to the individual plan of care in the relevant sections of this document

Regular review of care should include:

- Symptom concerns, e.g. pain, agitation, respiratory tract secretions, nausea, vomiting, breathlessness
- Administration of medication
- Ongoing need for observations / interventions
- Urinary or bowel problems
- Mouth care
- Fluids to support individual needs
- Skin integrity
- Personal hygiene needs
- Patient's psychological, spiritual and religious well-being
- Well-being of family or important others
- Consideration as to whether support of the specialist palliative care team and/or a second opinion is required

Doctors, nurses and other health and care staff responsible for the patient's care must seek out opportunities to communicate about any deterioration or change in condition with those identified as important to that person and record all discussions.

If the patient's condition improves and it is no longer thought that they are likely to die within the next few days, then this should be clearly documented and the plan of care should be reviewed accordingly

ONE PAGE PROFILE

My Name

What People Appreciate About Me

What Is Important to Me

How to Support My Family