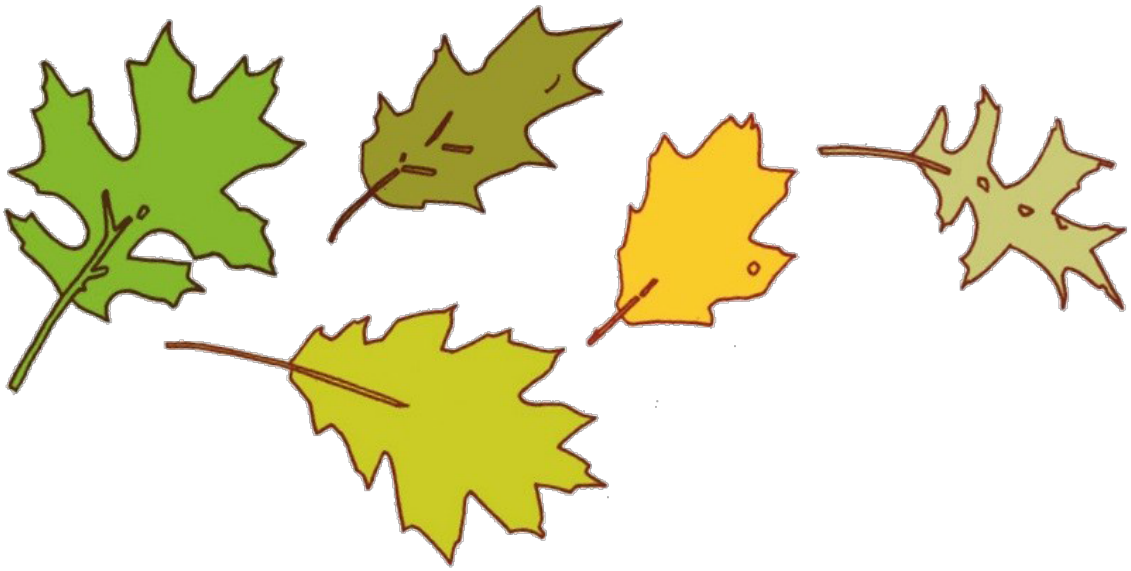

The Nottingham and Nottinghamshire Adult Guidelines for Care in the Last Year of Life

A Guide for Professionals

This guide was produced in partnership between:
Nottinghamshire Healthcare NHS Foundation Trust | Nottinghamshire Area Prescribing Committee | Nottingham University Hospitals NHS Trust | Sherwood Forest Hospitals NHS Foundation Trust | Nottingham CityCare Partnership | NHS Bassetlaw CCG (previous name)

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This guideline uses a number of terms and abbreviations that may be unfamiliar to some readers. A **glossary** of terms is provided at the end of the document to support clarity and consistent understanding, and readers are encouraged to refer to it as required.

Caring for people who are close to death demands compassion, kindness and a skilled application of knowledge. In 2013 an independent review of care given to dying patients in England, 'More Care Less Pathway', was published[1]. In response, the Leadership Alliance for Care of Dying People (LACDP) issued 'One Chance to Get it Right '(June 2014), which sets out the approach to caring for dying people that should henceforward be adopted in England[2]. The approach focuses on achieving '5 Priorities for Care', which should be applied irrespective of the place in which someone is dying: hospital, hospice, own or other home and during transfers between different settings. The aim of this guidance is to ensure the provision of high-quality End of Life Care.

Representatives of providers in Nottingham and Nottinghamshire ICB have collectively developed this guidance, which describes how we must support our patients and their families when someone is believed to be in the last year of life. All staff caring for dying people must ensure that they are aware of, and follow, local guidance and best practice. The evidence on which this guidance is based will continue to evolve and will be reviewed at regular intervals.
We encourage staff to sit down and listen to their patient and their carer, document the discussion in the patient record and act on the patient preferences

Annexed to 'One Chance to Get it Right 'are separate documents which set out the duties and responsibilities of health and care staff who are involved in the care of dying people[3] (aligned with professional regulatory guidance and relevant legal requirements, including the obligations on staff set out in the Mental Capacity Act 2005); and implementation guidance for service providers and commissioners[4] who have a responsibility to ensure that staff have the right training and support to deliver care of the dying person in a safe, effective and person-centred way, whatever the setting.

This guidance promotes:

- The early identification of people approaching the end of life and initiating discussions about preferences for End of Life Care
- Care planning: assessing needs and preferences, agreeing a patient and carer care plan
- Coordination of care
- Delivery of high-quality services in all locations
- Management of care in the last days of life
- Care after death
- Supporting carers both during a person's illness and after their death

In addition to this guideline, there is a countywide Nottinghamshire End of Life Toolkit, which also includes a Standard Operating Procedure regarding the ReSPECT process.

End of Life Care is the responsibility of all health and social care providers that care for:

- People with less than one year to live
- People with 'chronic progressive eventually fatal illness'
- People diagnosed with the condition from which they will eventually die. These include long term conditions, organ failure, cancer, cerebral-vascular illness, dementia and progressive neurological conditions.

This includes patients whose death is imminent (expected within a few hours or days).

The provision of End of Life Care involves palliative care, aiming to achieve the best quality of life for patients and their families. A range of people provide this care, including informal carers, medical, nursing and allied health staff and social care professionals. The focus of palliative care is teamwork, providing support whatever the setting whether in people's own homes, hospital, hospice, palliative care unit or care homes.

Palliative Care includes:

- Advance Care Planning
- Symptom control
- Rehabilitation to maximise social participation
- Emotional and social support

By focusing on these areas, we can help people to have a good quality of life (live well) until they die.

Understanding and delivering patient choice is central to excellent care at the end of life. Ability to achieve patient choice may be used to measure quality of service. In relation to place of death, national statistics demonstrate a disparity between patients 'preferred place of death and their actual place of death. Although when asked, over around 70% of patients state they would prefer to die at home, but many do not achieve this aim.

The choices that patients make can change with time as health and support needs change. A patient with months to live is likely to have different priorities to a patient believed to be in the final hours of life. Excellent communication with patients and families will allow professionals to understand individual preferences and to work together to develop plans for End of Life Care. Resources must be in place to adapt to a patient's evolving choices. Good quality Advance Care Planning will help to ensure that expectations are as realistic as possible.

Delivering genuine choice presents real challenges. Teamwork is crucial. By matching need with resource, services can be more effectively and efficiently delivered. If well-planned care is available in the community, fewer patients will need admissions to specialist services such as hospitals or hospices.

The Flowchart to illustrate End of Life Planning (Figure 1) is founded on the use of evidence-based practice, and the principles of Advance Care Planning. This promotes a management plan to optimise quality of life using recognised tools i.e. Gold Standards Framework (GSF) www.goldstandardsframework.org.uk.

The aim is to improve palliative care provided by the whole primary care team by optimising continuity of care, teamwork, advance planning (including out of hours), symptom control and patient, carer and staff support.

Five Priorities for Care of the Dying Person
These are: promoting recognition of the diagnosis of dying; communication with patient and carer; achieving choice; supporting families and documentation of an individual care plan.

Electronic Palliative Care Coordination System (EPaCCS)
An electronic communication system to coordinate care between all health and care providers. This is accessed via https://healthcaregateway.co.uk/epaccs/ and via F12 on Systmone and EMIS. Further details are available can found in the section below.

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)
Nottinghamshire ICS partners have signed up to the National Resuscitation Council (2017) national initiative, 'The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)'. ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. ReSPECT should be part of a wider process of advance/anticipatory care planning (ACP).

The aim of the process is to guide a health or care professional responding to an emergency to make immediate decisions that would be right for that individual. The ReSPECT plan is created through conversations between a patient and their health professionals and is intended to respect both patient preferences and clinical judgement. The plan is recorded on a ReSPECT form and includes personal priorities for care and agreed clinical recommendations about care and treatment that could help to achieve the outcome that they would want, would not help, or that they would not want.

ReSPECT can be complementary to a wider process of advance/anticipatory care planning. The ReSPECT process was created because an approach that focuses only on withholding CPR in people who are dying or for whom CPR would offer no overall benefit has resulted in misunderstandings, poor or absent communication and poor or absent documentation. The original form should stay with the patient and transfer between care settings. Review and update the ReSPECT form on a regular basis as the patient's condition changes.

A County-wide Standard Operating Procedure is located on our Notts End of Life Toolkit.

Figure 2 details care provision at each stage of the pathway.

Figure 1: Flow Chart to illustrate End of Life Planning

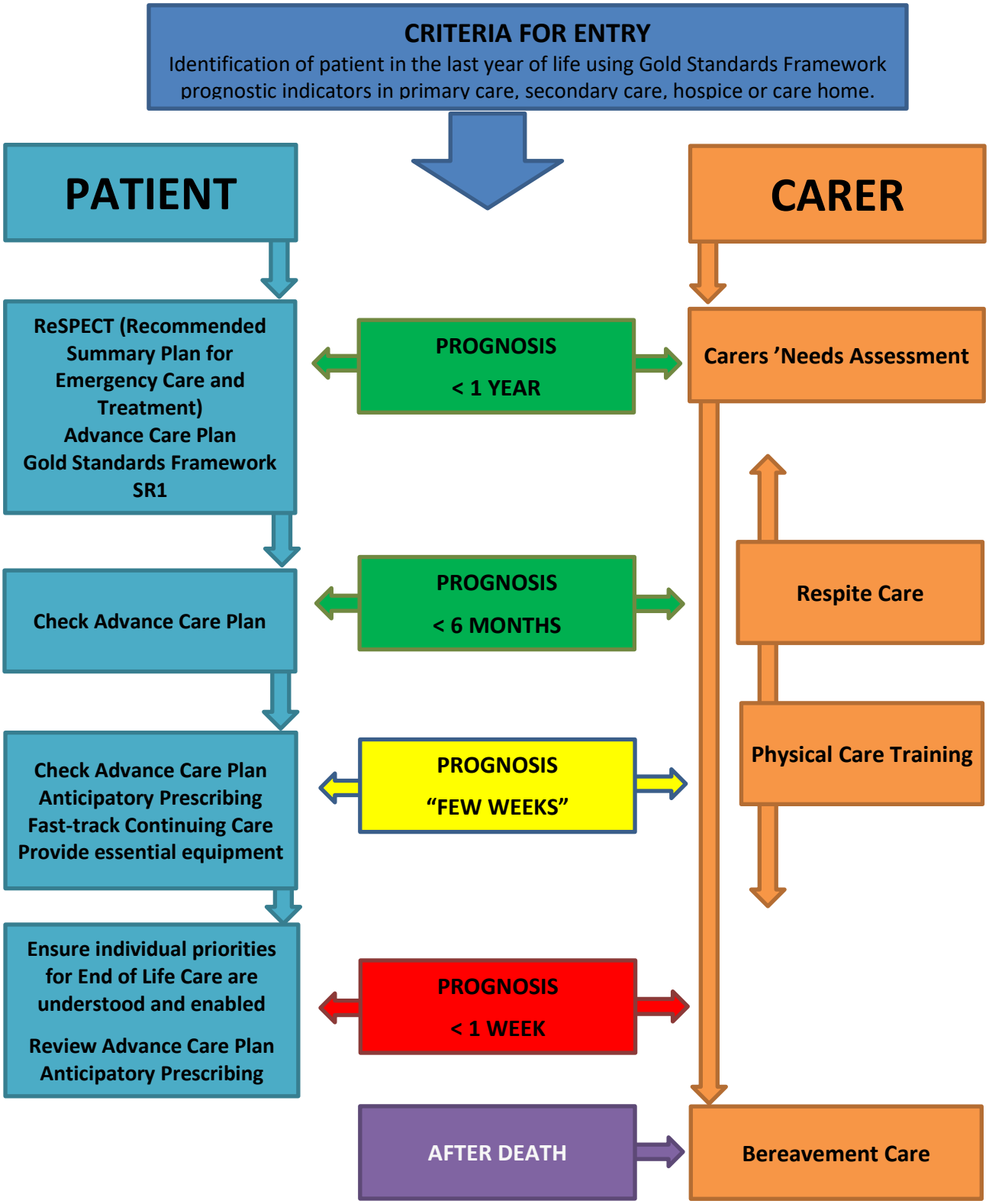
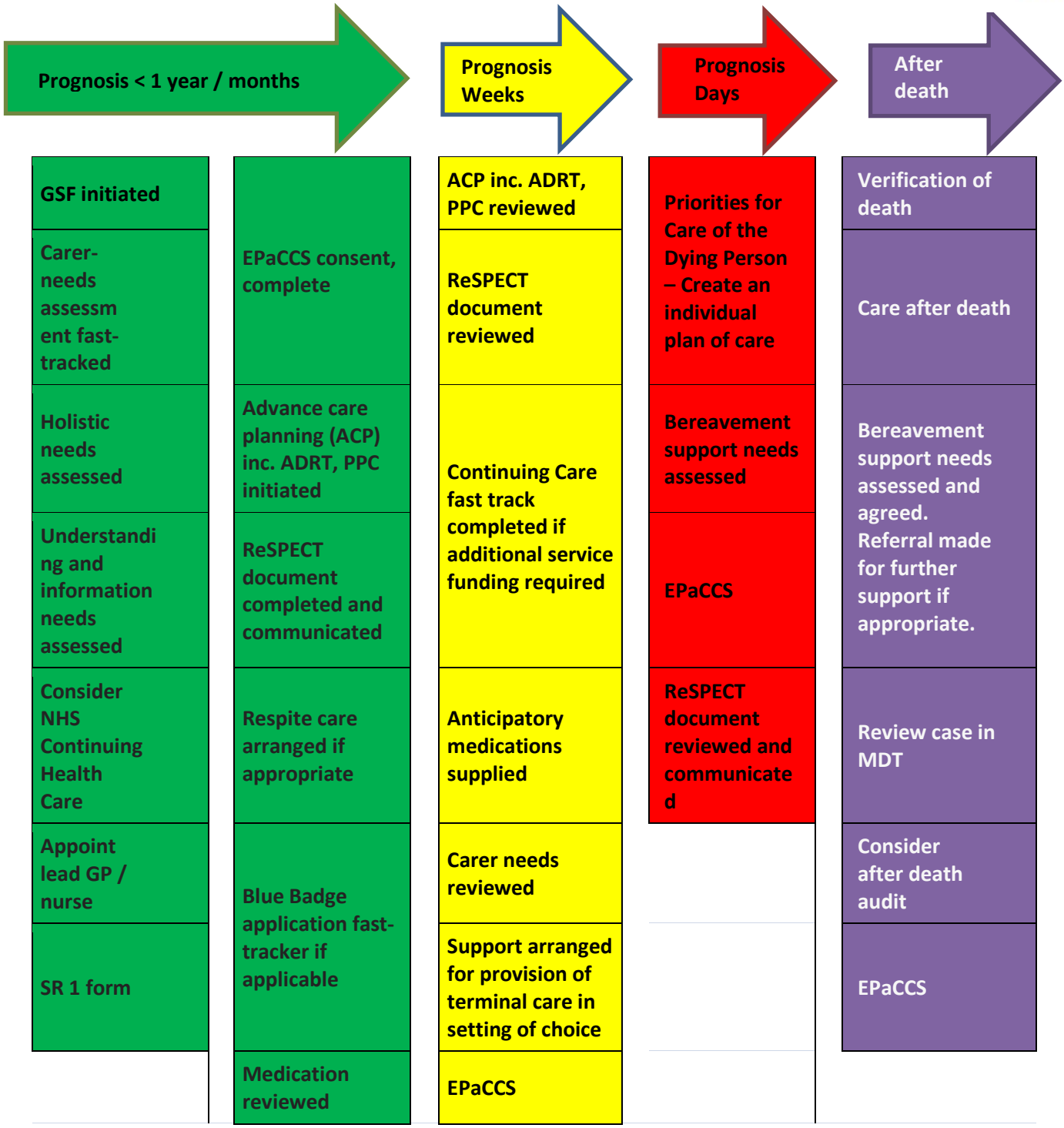


Figure 2: End of Life Planning: Details of Care Provision



24-hour access to advice and co-ordination of care underpin the guideline

End of Life Care should be considered at the point (whatever the setting and diagnosis) when the person is believed to be in the last year of life. Identifying this prognosis is complex. Prognostic indicators have been suggested to support clinicians making this decision. For more information see www.goldstandardsframework.org.uk.

Starting advance care planning earlier is usually helpful, however, and reduces the risk of a person not being supported well. 'Breaking Bad News Guidelines 'have been produced to support communication. Any professional having sensitive discussions about prognosis should have received appropriate communication skills training. For details of training opportunities talk to your line manager or learning and development department.

Using the term supportive care register instead of End of Life register is helpful, reducing barriers to care.

Gold Standards Framework

In managing patients believed to be in the last year of life, the healthcare team should adopt the 'Gold Standards Framework for Palliative Care 'www.goldstandardsframework.org.uk (GSF). The GSF focusses on seven key principles (sometimes referred to as the 7Cs):

- Communication
- Coordination of the person's care
- Control of symptoms
- Continuity of care
- Continued learning
- Carer support
- Care of the dying

At this time, a **Key Worker** should be identified to the patient and their carers. This is a named professional who is best placed to ensure the person receives coordinated, holistic and timely End of Life Care. In primary care the Key Worker is likely to be an experienced member of the community nursing, long term conditions or social service team; whilst in secondary care, Clinical Nurse Specialists often fulfil this responsibility.

The Key Worker should complete a **holistic assessment** to identify any unmet needs. Additionally, there should be a regular **assessment of carer needs**.

The outcome of these assessments will determine appropriate action including referral to other services such as specialist palliative care or long-term conditions management teams. Carer fatigue is a major contributory factor in hospital crisis admissions. The risk of fatigue is higher if there is a lack of appropriate and timely support and equipment provisions. Assessment should consider the range of respite care – at home or in a residential facility – and provision of assistive equipment.

Marie Curie have summarised the current national situation for carers in a survey report.

Coordination of Care

The national End of Life Care Strategy[4] recognises the importance of coordinated care. Coordination of services must exist within teams and across organisational boundaries.

Methods for more effective communication between primary and secondary care have been developed in Nottinghamshire: EPaCCS (Electronic Palliative Care Coordination System). https://healthcaregateway.co.uk/epaccs/ .

Although currently it can only be updated on a writeable Systmone unit, many community teams, including care co-ordination navigators and the urgent response team can do this. Hospitals can therefore ask them directly to update the RAG code and add any other key information, such as preferred place of care/death and anticipatory medications having been issued.

Palliative rehabilitation

This should be considered as a part of the person's care whilst they are stable in order to assist with their function and quality of life. It helps people with serious illnesses live their best possible life by focusing on function, independence, and quality of life, integrating rehab with holistic palliative care to manage symptoms, maintain dignity, and achieve personal goals like staying active or at home, rather than focusing solely on cure.It is person-centred, uses an interdisciplinary team (physios, OTs, etc.), and empowers patients and families through self-management and enablement, reducing burden and improving wellbeing. Studies show it improves quality of life and can reduce hospital stays, proving its value alongside standard care.

Access to services is possible via hospice services and community neighbourhood teams.

Advance Care Planning

http://www.goldstandardsframework.org.uk/advance-care-planning

Advance Care Planning is important. It is a structured discussion with patients and their families or carers about their wishes and thoughts for the future. The offer of an advance care plan for every appropriate person is now recognised as a key part of good care. It functions as guidance for those supporting patients.

If a person wishes, legally binding choices about their care and treatment can be recorded and/or they can make an Advance Decision to Refuse a Treatment (ADRT) in specific, clearly described circumstances.

Advance Care Planning is a key means of providing care for people nearing the end of life and of enabling better planning, to help them live and die in the place and the manner of their choosing. The main goal in delivering good end of life care is to be able to clarify peoples 'wishes, needs and preferences and deliver care to meet these needs. Advance Care Planning is in essence an important yet simple conversation that can change practice and empower patients. It can be a process of discussions over time, a 'relationship 'discussion with regular reviews and can help catalyse deeper communication between patients and their families and loved ones. It need not be over medicalised or too formalised and could be undertaken by anyone involved in End of Life Care, though is best undertaken by experienced trained staff who know the person well, such as GPs, community nurses, care homes staff and specialists.

An Advance Care Plan should be offered consistently and systematically so that every appropriate person is given the chance to have an advance care planning discussion with the most suitable people caring for them present ideally.

The process of Advance Care Planning in the UK includes many elements – essentially helping people approaching the end of their life to articulate their priorities for care at this time of their lives, describe and clarify what they don't want to happen; what they do want to happen; who will speak for them ; where they wish to be cared for and by whom and anything else that is important. Consideration of their will, funeral arrangements and digital legacy should also be included.

The key elements of an advance care plan relating to what clinicians and paramedics would need to know in an emergency situation or as a person declines, should all be clearly and unambiguously recorded on a ReSPECT Plan.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and ReSPECT

A patient may **choose not** to receive Cardiopulmonary Resuscitation in which case this information needs to be recorded and shared.

Cardiopulmonary resuscitation is a medical treatment that may or may not be appropriate for a particular person. A medical decision regarding whether Cardiopulmonary Resuscitation (CPR) would be successful for a patient with a life limiting illness should be documented. According to best practice guidelines set out by the General Medical Council (GMC), such decision making must be discussed with patients and carers and the reasoning carefully explained and recorded. A conversation about CPR can be challenging. Such conversations must not be avoided just because they are difficult. These conversations should be undertaken with sensitivity and compassion, recognising the emotional impact they may have on patients and those close to them. Where possible, discussions about CPR should be seen as a process that may take place over time and should proceed at the individual's pace. If there are differences of professional opinion regarding the appropriateness of CPR, a second opinion should be sought in line with best practice.

If a patient chooses not to discuss CPR, then this must be respected. If a patient is actively dying and cannot discuss the CPR decision, it remains essential to inform relatives and carers of the decision-making process.

It is important to be clear that Cardiopulmonary Resuscitation is a very specific treatment and a decision not to attempt CPR does not preclude treatment of any other medical problems. Once agreed with the patient/carers the relevant CPR section of part 4 of the ReSPECT form needs to be completed. The original form stays with the patient and transfers between care settings. This avoids confusion or the distress of repeated conversations. DNACPR forms that were completed prior to the introduction of the ReSPECT process are still valid.

The Resus Council provides guidance regarding CPR and emergency treatment plans.

There is an ICB approved **Standard Operating Procedure** relating to ReSPECT conversations and Plans. The Nottinghamshire End of Life Toolkit also contains many useful resources for both the public and health and social care staff, including training resources.

Discharge from hospital

When arranging discharge from hospital, clinicians must consider whether a patient is likely to be in the last year of life. This information should be discussed sensitively with patients and their carers and explain that sharing information with primary care teams and other health providers is helpful to ensure their choices and priorities are met wherever possible. Advance care planning at this stage should be documented in discharge information. EPaCCS completion and registration ensures Out of Hours and ambulance services are informed. Discharge specialists liaise with community teams to ensure essential support is provided. Good communication between services in this way ensures care is provided in line with patient choice. After discussion with patients and carers anticipatory medication can be arranged at discharge if it is felt a patient's condition may deteriorate at any time.

All patients should have a structured medication review by an experienced prescriber. This will include the risk: benefits of each medication and both the patient and key family/carer should understand the rationale for either continuing of de-prescribing. There is a very helpful brief guidance document from the British Geriatric Society available on the End of life Toolkit.

Prescribing advice for control of symptoms can be found in Appendix 1b

Benefits - Special Rules Support at 1year (GSF Green, amber & red)

The Special Rules form (SR 1) allows adults and children who may have less than 12 months to live to: get faster, easier access to certain benefits, get higher payments for certain benefits and avoid a medical assessment. The benefits where eligible include: Personal Independence Payment (PIP), Universal Credit (UC), Employment and Support Allowance (ESA), Disability Living Allowance (DLA) for children and Attendance Allowance (AA) at high rate.

Once logged in with NHS smart card enter this address, https://ds1500.dwp.ncrs.nhs.uk/sr1-start to allow SR1 to be done electronically. There is also a direct link via the EPaCCS template, green tab.

This will ensure applications are processed on a fast-track method. There should also be further assessment of the care needs of the person, with application for support according to eligibility criteria. Factual information, not a prognosis is needed for completion of the form and there is usually no need for a medical assessment, however there should be consideration that the care needs (physically, psychologically and spiritually) may have changed or be expected to change and therefore discussion and plans should be made with the patient and their family and friends to ensure needs are met throughout illness progression.

Out of Hours Ambulance Services must be informed of the patient's current condition including details of Advance Care Planning and DNACPR using EPaCCS.

Carers may require enhanced support at this stage and referrals for respite care can be helpful. This may be provided in several ways, involving Hospice at Home, day or residential care in a hospice, hospital or care home setting. The most appropriate type of respite support should be discussed and agreed with the patient, carer and health professionals.

The health and wellbeing of carers must be discussed and documented. A statutory Carer's Assessment should be completed by a Social Worker if this has not already been done.
This will be done urgently if there is risk of carer breakdown leading to a need for admission to a care home or hospital.

Applications for the Blue Badge Scheme should be fast-tracked for people with severe mobility problems who are in the last few months of life. These requests are usually processed within a few days rather than several weeks.

A deterioration indicating the patient is entering the final weeks of their life should trigger a review of all care plans. Check patients and carers understand as much as they wish to about what is happening now prognosis is short. Any changes to an individual's priorities for care should be clearly documented. Professionals should continue to deliver high quality care, anticipating physical care needs, maintaining good symptom control, considering psychological and spiritual issues and supporting carers.

NHS Continuing Healthcare funding includes a fast-track process which can be used by a senior clinician for people with rapidly deteriorating health needs and allows any such needs to be met urgently (for example, to be at home to die). Assessment will include evidence of diagnosis and prognosis where these are available, together with details of both immediate and anticipated healthcare needs.

When outlining reasons why a clinician considers that a person has a rapidly deteriorating condition that may be entering a terminal phase, the clinician should consider the following definition of a Primary Health Need:

Primary Health Need arises where nursing or other health services required by the person are:
a) where the person is, or is to be, accommodated in a care home, more than incidental or ancillary to the provision of accommodation which a social services authority is, or would be but for the person's means, under a duty to provide.
OR
b) of a nature beyond which a social services authority whose primary responsibility is to provide social services could be expected to provide.

Anticipatory medication accompanied with a completed Direction to Administer should be provided at this stage, after discussion with the patient and carer. If needed, such medication will help treat distressing symptoms of pain, restlessness and agitation, nausea and vomiting, and respiratory tract secretions, without delay.
Symptom Management Guidelines are available in the Palliative Network Guidelines: PANG which can be accessed at http://pallcare.info and in the Palliative Care Formulary (subscription required to log in)— Refer to Appendix 1b, 1c and 1d for anticipatory medication guidance which has been developed to support the prescriber (General Practitioner, a Medical Consultant in Palliative Care or Non-Medical Prescribers.

It may be appropriate in certain cases to have anticipatory medicines in place earlier than this, particularly if a sudden decline in a patient's condition is expected.

The carer's needs should be regularly reviewed, updated and shared to ensure that the appropriate type and level of support is in place to enable them to cope, especially if the patient has chosen to die at home. Information should be provided on how to access advice and support if a crisis arises.

It is essential that EPaCCS is updated in order to ensure that the relevant prognostic clinical code and the anticipatory medications are visible on the Notts Care Record.
Out of hours providers (NEMS) and East Midlands Ambulance Service are linked to EPaCCS and the NCR respectively andreceive relevant information about patients they are called to. They can often help in times of crisis, which doesn't necessarily result in admission to hospital. It also reduces delays in accessing appropriate care and death administration complications.

All patients should have their medication reviewed afresh, with an individualised plan. Consideration is required for how to manage usual medicines for long term conditions e.g. diabetic medication (insulin), antipsychotics, anticonvulsants, anticoagulants , antiparkinsonian medication and steroids. Patients may benefit from continuing with some of them in the last days of life but may need formulation changes if ability to swallow deteriorates. Anticonvulsants are the most likely type of medication to need to be continued.

Some oral medications are available for subcutaneous use e.g. regular levetiracetam can be delivered via a syringe driver as a Continuous SubCutaneous Infusion (CSCI) and dexamethasone can be administered as a bolus SC injection. Decisions are made for the individual patient and expert advice sought from the specialist palliative care team if unsure.

Further information is available via the links below:

- British Geriatric Society Prescribing to reduce harm in people with moderate-severe frailty. 2025
- Trend Diabetes – End of life guidance for diabetes care (https://trenddiabetes.online/wp-content/uploads/2024/10/EoL_TREND_2024.pdf)
- Palliative Care Guidelines (PANG) – Essential medications at end of life (www.pallcare.info)
- Palliative Care Formulary (PCF) subscription to Medicines Complete required (https://www.medicinescomplete.com/log-in/)

According to the approach set out by the national LACDP in 'One Chance to Get it Right', when a person is likely to die within the next few days or hours there are '**5 Priorities for Care**', which should be applied.

1. The change in the patient's medical condition is recognised and communicated clearly, decisions made, and actions taken in accordance with the person's needs and wishes. These are regularly reviewed and recorded in the patient records.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual Plan of Care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

End of Life Care must be delivered by doctors, nurses, carers and others who have high professional standards and the skills, knowledge and experience needed to care for dying people with their families properly. The Priorities For Care of a Dying Person are housed on The Notts EOL Toolkit.

Additionally, the delivery of care must be based on and tailored to the needs, wishes and preferences of the dying person and, as appropriate, their family and those identified as important.

Recognising that the patient is dying

If a person's condition deteriorates unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they should be assessed by a clinician who is competent to judge whether the change is potentially reversible, or the person is likely to die. If the clinician judges that the change in condition is potentially reversible, prompt action must be taken, provided that is in accordance with the person's wishes; or in their best interests, if it is established that they lack capacity to make decisions about treatment at that time.

If the clinician judges that the person is likely to be dying, considering the views of others caring for the person, this must be clearly and sensitively explained to the person in a way that is appropriate to their circumstances (if conscious and they have indicated that they would wish to know), and their family and others identified as important to them. If there is an element of doubt, the clinician should immediately seek advice from a more senior or more experienced colleague. The geriatrician support lines, or specialist palliative care advice lines can be used in this instance.

More often a patient will deteriorate predictably over a period of days. When it is apparent that a person is close to death this must be communicated with the family/carers and their caring team. Patients and those important to them should be offered the opportunity to discuss what to expect at this time. The views and preferences of the person and those important to them must be taken into account.

An individual Plan of Care is then developed and documented. The person must be regularly reviewed to check that the Plan of Care remains appropriate and to respond to changes in the person's condition, needs and preferences.

Recognising dying is the ultimate trigger to review any Advance Care Plan or Priorities for Care.

Regular review of the patient and carers wishes should be documented. The fact that a person is very close to dying should be written in their care plan. If a patient in hospital is believed to be in the last days of life and they wish to die at home, Rapid Discharge should be considered. Recognising dying is equally appropriate in the event of acute illness leading to death, even if the patient has not previously been diagnosed as being in the last days of life.

Sensitive communication

Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them. If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met.

Communication must be regular and proactive, i.e. staff must actively communicate, not simply wait for the person or those important to them to ask questions. It must be two-way, i.e. staff must sit down and listen to views of the person and those important to them, not simply provide information. Discussions should be conducted in a way that maximises privacy. Staff must check the other person's understanding of the information that is being communicated and request consent to share that information.

Details of what has been discussed, and with whom, should be carefully recorded. The information should be shared with the Multidisciplinary Team.

Hydration and nutrition

Patients should be supported to eat and drink as they feel able. Relatives and carers need support in how they can offer food and drink when a person is actively dying. Whenever appropriate, decisions about clinically assisted nutrition or hydration should be carefully discussed with patients and carers.

Individuals vary in the extent to which they wish to be involved in decisions about their own treatment. Most would want to make or influence decisions about the care they receive. This includes day to day decisions about food, drink and personal care, as well as clinical and treatment decisions.

Individuals also vary in the extent to which they wish their families and those important to them to be involved in decision-making. Sensitive communication is needed to ascertain the wishes of the dying person, and their wishes must be respected.

Anticipatory Prescribing

The Prescriber should rationalise current medication, discontinue any remaining non-essential medicines, potentially change formulations to easier to swallow versions eg cocodamol to oramorph and prescribe Anticipatory Medication for potential symptoms and generate an accompanying Directions to Administer.

All medications, including anticipatory medicines, must be:

- Targeted at specific symptoms.
- Have a clinical rationale for the starting dose and document this rationale.
- Titrated, written up on the appropriate prescription and signed correctly by the Prescriber.
- Regularly reviewed according to patient's needs and stage of disease face to face by a prescriber.

Anticipatory Medicines Prescribing should be in accordance with Appendix 1b, Appendix 1c and Appendix 1d of the anticipatory medication guidance, which has been developed to support the prescriber. All anticipatory medicines should be accompanied by a completed Direction to Administer.

Clinical judgment should be used, and all prescribing must be adjusted as needed by the Prescriber, to ensure patients whose medical condition is deteriorating and are deemed by the MDT to be in the last days of their life have their symptoms effectively managed.

The reason for any intervention, including the use of a syringe driver, must be explained to the dying person and to those important to them. If required, the use of a syringe driver should be explained before it is used, and written information offered. The likely side effects of specific interventions, especially those that may make the person sleepy, must be discussed with the dying person to enable them to make informed decisions.

Health and care staff must ensure that medicines, equipment and other aids that can improve the dying person's comfort and dignity are obtained as soon as they are needed, or in anticipation of needs. It is crucial that providers of Out of Hours Care and the Ambulance Service are notified of the patient's status at this time using the EPaCCS template.

The individual needs of a patient need to be considered. Regular review by members of the MDT will ensure adjustments are made accordingly to prescribe or discontinue prescriptions.

Carer support

In the final days and hours of life, carers should be offered support.
Patients (where appropriate) and those important to them should be offered written information about what to expect and what to do when the patient dies. Information is available for each organisation online, via clinical templates eg F12 Palliative and EOL and the Notts EOL Toolkit. Care co-ordination services are being developed and current updates are posted on both the Toolkit and the Clinical Support Information section of Teamnet

Mental Capacity

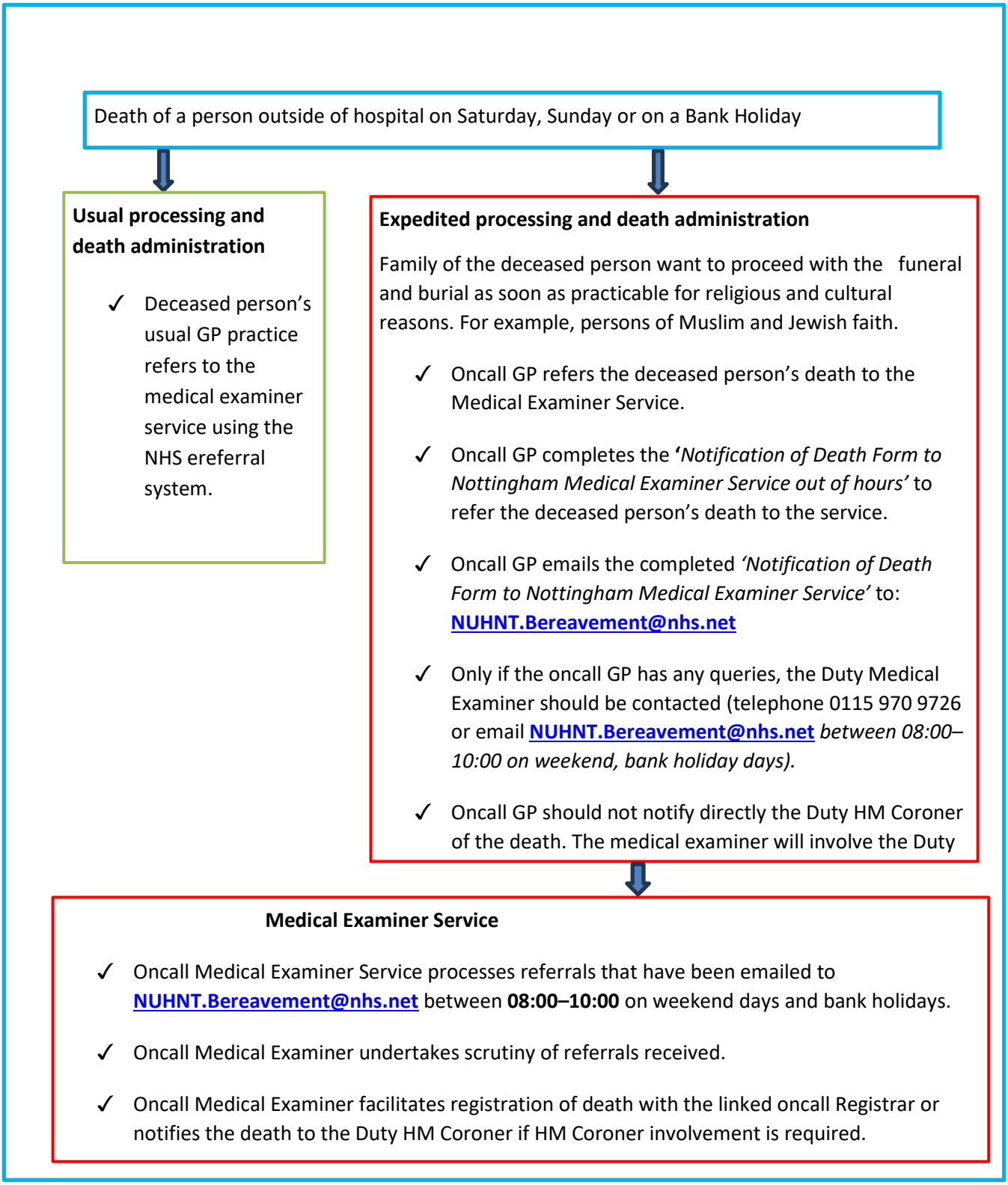
For those lacking capacity to make individual decisions, their care and treatment must be provided in line with the Mental Capacity Act 2005. It is imperative to involve family and carers at this point.

Verification of death should be carried out as soon as possible. There is guidance on this on the End of Life Toolkit. Most care homes have trained experienced carers who can verify death. All nursing homes should have trained nurses who can verify. Community nurses are trained in verification. There will, however, be times when it is appropriate for an experienced doctor to give advice or to verify, particularly if there are very distressed relatives. There is a Verification Of Expected Death (VOED) proforma that carers and community nurses should complete which also references indications for coroner referral. If any of these apply, the attending physician (see below) should immediately refer the death to the coroner's office via the local Medical Examiner Service

The guidance also includes details of the medical examiner role in agreeing cause of death for the death certificate (AP-MCCD).
When a patient dies, it is the statutory duty of the doctor who has attended to the deceased person at some point in their lifetime to write the Attending Practitioner Medical Certificate of Cause of Death (AP-MCCD), as per the new 'death certificate' in the Death Certification Reforms. The attending practitioner is required to submit their finished AP-MCCD to the Medical Examiner for the Medical Examiner to enter their mandatory information to the AP-MCCD. The Medical Examiner Service will then forward the completed AP-MCCD to the Registrar for registration of the death.
The AP-MCCD does not require the date the attending practitioner last saw the deceased person alive nor is there 'seen after death' requirement.

In certain circumstances, the family of a deceased person will want to proceed with the funeral and burial of the deceased as soon as practicable for religious and cultural reasons. This is particularly important to persons of Muslim,Hindu and Jewish faith. When these deaths occur at weekends or on bank holidays, the system for referring differs. It is not practical for an on-call out-of-hours GP to refer the death of a patient to the NUH medical examiner service using the NHS e-referral system. The on-call out-of-hours GP should therefore directly notify the out-of-hours medical examiner service [08:00 – 10:00 weekend days and on bank holidays] of the deceased person's death and invite for assistance with the processing of the death certification as soon as it is practicable. The on-call out-of-hours GP should complete 'Notification of death to Nottingham Medical Examiner Service out of hours' form expedites transfer of the patient's body and the process of events after death. Please refer to the flow charts below for further details, including out of hours contact information.

Guidance: out of hours expedited deaths - NUH



Information about what to do after a death, should be provided to the next of kin. All relevant services should be informed of the death via the EPaCCS After Death template which will place the appropriate codes onto the Notts Care Record (NCR).

MID NOTTS ME SERVICE – SHFT –

Death of a person outside of hospital on Saturday, Sunday or on a Bank Holiday

Usual processing and death administration

- ✓ **Deceased person's usual GP practice refers to the Medical Examiner Service using the NHS E-referral system.**

Expedited processing and death administration

Family of the deceased person want to proceed with the funeral and burial as soon as practicable for religious and cultural reasons. For example, persons of Muslim and Jewish faith.

- ✓ On-call GP refers the deceased person's death to the Medical Examiner Service.
- ✓ On-call GP completes the '*Notification of Death Form to Mid- Notts Medical Examiners Service'* to refer the deceased person's death to the service.
- ✓ On-call GP emails the completed *'Notification of Death Form to Mid-Notts Medical Examiner Service'* to: sfh-tr.meo@nhs.net
- ✓ On-call GP telephones the on-call Duty Medical Examiner /Officer to discuss the case in question - via switchboard at Kings Mill Hospital – 01623 622 515 - ask to be put through to the Medical Examiner Service - *between 08:00–10:00 on weekend, bank holiday days.*
- ✓ On-call GP **should not** notify directly the Duty HM Coroner of the death. The Medical Examiner will involve the Duty HM Coroner if HM Coroner involvement is required.

Medical Examiner Service

- ✓ On-call Medical Examiner Service processes referrals that have been emailed in between 08:00–10:00 on weekend days and bank holidays.
- ✓ On-call Medical Examiner undertakes scrutiny of referrals received.
- ✓ On-call Medical Examiner facilitates registration of death with the linked oncall Registrar or notifies the death to the Duty HM Coroner if HM Coroner involvement is required.
- ✓ On-call Medical Examiner updates the deceased person's usual GP of the cause of death and or any action for the usual GP.

Bereavement Care

Ensure support is offered for all those who are bereaved following a death, including children. Continuity of care at this stage is particularly beneficial and enables accurate risk assessment for complicated grief. Onward referral to specialist services may be appropriate. Bereavement Services are listed on the End of Life Toolkit.

Additional services to meet individual needs

Additional services may be needed at any stage of End of Life Care, according to the individual patient or carer's requirements and circumstances. Such services include specialist psychological support, respite care, self-help and support groups, equipment loan services and spiritual care. Many people will access psychological, emotional and spiritual help through their own informal support networks, but the need for access to specific services should be discussed as part of the regular GSF review process.

Specialist Palliative Care

Generic Palliative Care is the care provided by all professionals. Specialist Palliative Care Teams have the expert knowledge and skills required to manage complex symptoms and needs.

Referral to Specialist Palliative Care Team(s) should be considered at any stage for:

- Complex pain and symptom management.
- Psychological support for patients and families who are experiencing difficulty in accepting and coming to terms with the disease process.
- End of Life Care where advice is required to enhance the comfort of the patient and family.
- Staff support.
- Provision of education on Palliative/End of Life Care.

Audit

It is strongly recommended that General Practices make full use of **Read codes** relating to End of Life Care. An after death analysis template has been developed for organisations to record evidence of care provided according to GSF principles. These can be used to monitor progress against the key performance indicators above and provide evidence of:

- Adherence to the principles (7 Cs) of GSF.
- Referral to appropriate members of the Multidisciplinary Team.
- A care package in place tailored to the individual's and carer's needs.
- Equitable delivery of care regardless of diagnosis or setting.
- The opportunity to make an Advance Plan for End of Life Care that reflects individual choice and preferences.
- The assurance of best practice using evidence-based tools (as far as possible) in all settings.
- The assurances of consistency, continuity and coordination throughout by a named Key Worker.

Further measurement of the quality of care to dying patients and their carers will come from the National bereavement survey: The Views of Informal Carers - Evaluation of Services (VOICES); the analysis of complaints to the NHS relating to End of Life Care; ReSPECT quality audits and organisational self-assessment of structures and processes which demonstrate adherence to theLACDP 'Priorities for Care'.

Care Quality Commission (CQC) and End of Life Care

Chief Inspectors will incorporate, as a key area, inspection of End of Life Care provided by all services. When inspecting services which deliver End of Life Care in any setting, the CQC will review whether people receive care in line with the Ambitions Framework for Care at End of Life. CQC inspections will assess whether care is delivered by qualified, competent staff, who are supported in their development and in their roles. Inspection teams will gather views from people who use services and their families, carers and advocates; observe care; interview key members of the senior management team and staff at all levels; and may visit certain services out of hours. They will consider the support provided to bereaved families and carers.

Appendix 1a - Priorities for Care of the Dying Person

Aim: To support decision making, planning and delivery of compassionate high-quality individualised care for patients who it is thought may die in the next few days or hours.

Decisions must be made with the patient, those important to them and the multidisciplinary team. The patient's condition and plan of care must be reviewed daily by doctor/nurse; document discussions and decisions clearly; communicate to the wider healthcare team as appropriate. Where a patient does not have the capacity to make a specific decision a best interest's decision needs to be made in line with the Mental Capacity Act.

Priority 1: Recognise the possibility that death may occur in the next few days

- Consider, within the multidisciplinary team, why the patient is thought to be dying; a doctor should have reviewed the patient to ensure all reversible causes have been excluded.
- Explain this and the likely prognosis to the patient and those important to them.
- Inform the patient and those important to them and record which doctor and registered nurse are responsible for their care.
- If the person has capacity, engage them in decisions about their care as much as they wish to be involved, if they choose not to discuss, respect this however keep lines of communication open.

Priority 2: Communicate

- Use open, honest and understandable language. Talk and listen to patients and those important to the patient regularly, use communication aids if necessary.
- Ask and record with whom the patient wishes/does not wish for information to be shared.
- Discuss and record:
    - Wishes and preferences for care including preferred place of care and death, wishes after death.
    - Common symptoms in the final days of life; how to seek help including information about what to do when patient dies.
- Any differences in opinion should be openly discussed and actively addressed, e.g. seeking a second opinion.

Priority 3: Involve

- Involve the patient, and those important to them, in decisions about their treatment and care.
- Check whether the person has an advance statement of wishes; ReSPECT, advance decision to refuse treatment and/or a Lasting Power of Attorney for health and welfare.
- Make a CPR decision and ensure it is recorded on the ReSPECT form and shared.
- Actively review whether other interventions should be continued, adjusted or stopped, e.g. Total Parenteral Nutrition (TPN), Implantable Cardiac Defibrillators (ICD).
- Ensure anticipatory medications are in place and the locations is communicated to the team; explain when and who to contact regarding the administration of these.

Priority 4: Support

- Assess the needs of the family and those important to the patient, address if possible or signpost to support service.
- Support the family and others if they wish to participate in active care e.g. practical tasks.
- Identify those who may have special needs e.g. children, vulnerable adults. Record action taken.
- Ensure that contact details are provided for those services involved in the patient's care.

Priority 5: Plan and Do

- Create an individual plan of care which must give priority to communication, comfort, and dignity.
- Identify physical and psychological symptoms and individualise treatment.
- Continue essential and discontinue non-essential medication, communicate reasoning.
- Discuss method of medication administration and potential effects of medication.
- Identify the social, spiritual, religious, and cultural needs including requirements after death.
- Consider food and drink needs and communicate these.
- Review care interventions e.g. mouth care, pressure area care, continence care.
- Assess equipment requirements and source.

The following anticipatory medicines guidance has been developed to support the Prescriber If adequate relief from symptoms is not achieved at most within 24 hours or the patient has complex needs seek help from your specialist palliative care team:

Nottingham City and South County:
Hayward House 24hr symptom advice line 07595 285014
Mid/North Notts:
John Eastwood Hospice Specialist Palliative Care Team, on 01623 622626
Professional advice line Call for Care, option 2 on 01623 781899
Bassetlaw: Bassetlaw Hospice 0115 955 5440
Lincolnshire: St Barnabas Hospice 01522 511566

Medicines Information at SFH	01623 672213
Medicines Information at NUH	0115 9709200

- All prescriptions for anticipatory PRN medicines **must** include a maximum dose that is individualised to the patient.
- The prescribed maximum anticipatory PRN dose in 24 hours is in **addition** to any other regular dose of that medication **by any route.**
- Consult the GP or the specialist palliative care team for advice on maximum doses if required.

Good practice is to supply at least 5 ampoules/vials if the medicine is newly prescribed, or a 5day supply if already in use, including water for injection, and to confirm stock availability with the local pharmacy. All anticipatory medicines should be accompanied by a completed Direction to Administer.

A prescription for a Controlled Drug in Schedules 2, 3, or 4 is valid for 28 days from the date stated thereon (the prescriber may forward-date the prescription; the start date may also be specified in the body of the prescription). More than 28 days' supply of a controlled drug is not permitted. Schedule 5 prescriptions are valid for 6 months from the appropriate date.

Community pharmacies participating in the **Palliative Care Medicines Stockist Scheme** are required to maintain a stock of palliative care medications (subject to supply chain availability). Further details can be found here

Syringe Drivers or Continuous Subcutaneous Infusion (CSCI)

CSCI are administered using BodyGuard T syringe pump.
Multiple medicines can be included in a single CSCI syringe, but risk of incompatibility increases with number of medicines added. Check compatibility where more than one medicine is used in a syringe driver.
Ensure that patients requiring CSCIs are also prescribed **water for injections** or another appropriate diluent and a completed Direction to Administer.

For further guidance see local CSCI / syringe driver policy, Palliative care formulary, Medicines Complete Drug Compatibility Checker, or Palliative Network Guidelines: PANG(http://pallcare.info).
For concentrations and ampoule sizes of the medicines included in Appendix 1b see here

IF 2 CONSECUTIVE DOSES OF MEDICATION AN HOUR APART HAVE NOT BEEN EFFECTIVE TO CONTROL A SYMPTOM PLEASE SEEK MEDICAL ADVICE.

If symptoms are difficult to control, contact the GP or Specialist Palliative Care Team. For further advice and education, contact your Specialist Palliative Care Team.

Ensure practice is in line with your local Anticipatory Medications Policy.

Appendix 1b (i): Anticipatory Medications Prescribing in Patients Without Severe Renal Impairment or Severe Hepatic Disease

This guidance is intended for anticipatory medicines for people as they approach their last hours to days of life

Pain

Patient is not currently taking opioids:

- Prescribe 2.5mg - 5mg MORPHINE subcutaneous (SC) when required (PRN) 1 hourly. If the oral route is available also prescribe MORPHINE 2.5mg - 5mg oral (PO) PRN 1 hourly.
- If two or more PRN doses (PO plus SC) are required in 24-hours prescribe a MORPHINE 24hr Continuous SC Infusion (CSCI)
  The dose should be the total PRN (PO and SC) doses required in previous 24 hours converted to the equivalent SC dose.
- Prescribe a new MORPHINE SC PRN 1 hourly dose. The dose should be approximately 1/6 of the 24hr CSCI dose. This can be a single dose or a small range
  - e.g. for opioid naïve patient morphine, a range of 2.5mg-5mg.

  The dose should not be reduced below the previous SC PRN dose (unless there are concerns about toxicity).
- Prescribe a new MORPHINE PO PRN 1 hourly equivalent dose if oral route available (Dose should be SC PRN dose multiplied by 2).

Patient usually takes oral MORPHINE or OXYCODONE and is still able to take medication via the oral route

- Maintain usual regular oral opioid dose
- Prescribe the usual opioid PO PRN 1 hourly. The dose should be approximately 1/6 of usual PO opioid 24hr oral dose. This can be a single dose or a small range
  - e.g. for a patient prescribed PO 10mg MR morphine bd (total PO 24hr dose = 20mg) a range of 2.5-5mg.
- Prescribe the usual opioid SC PRN 1 hourly. Dose should be PO PRN dose divided by 2.
- If two or more PRN doses (PO plus SC) are required in 24-hours consider an increase to usual MR opioid dose (and review PRN doses) or convert usual regular opioid to a 24hr Continuous SC Infusion (CSCI) as detailed in the next section

Patient usually takes oral MORPHINE or OXYCODONE but has now lost the oral route:

- Prescribe the patient's usual PO opioid (MORPHINE or OXYCODONE) as a 24hr CSCI.
  Dose should be the total of the regular plus PRN PO doses of MORPHINE or OXYCODONE required in previous 24 hours divided by 2.
  If any SC PRN doses have been used in previous 24 hours add these to CSCI dose.
- Prescribe the usual opioid SC PRN 1 hourly. The dose should be approximately 1/6 of the 24hr CSCI dose. This can be a single dose or a small range
  - e.g. for a patient prescribed 35mg oxycodone as a 24hr CSCI a range of 5mg-7.5mg
- Ideally start CSCI 2-4 hours before the next dose of modified release opioid is due or as soon as possible if dose(s) have already been missed.
- Ensure all people caring for patient know that regular modified release oral opioid has stopped and no more is to be given.
- If two or more PRN doses are required in 24 hours consider increasing CSCI dose to include any additional PRN doses given. If the CSCI dose in the syringe driver changes recalculate the SC PRN dose as necessary.

Patient usually takes transdermal FENTANYL or BUPRENORPHINE:

- Leave the FENTANYL or BUPRENORPHINE patch in place and continue to change when due
    - The patient has PO PRN MORPHINE or OXYCODONE prescribed
        - Prescribe the usual opioid (MORPHINE or OXYCODONE) SC PRN 1 hourly. Dose should be PO PRN dose divided by 2
    - The patient doses do not have any PO PRN opioid prescribed
        - Prescribe MORPHINE SC PRN 1 hourly
          The dose should be approximately 1/6 of the MORPHINE SC equivalent patch dose. (Comparative doses can be found in the Palliative Care Pocketbook).
        - Prescribe MORPHINE PO PRN 1 hourly equivalent dose if oral route available (Dose should be SC PRN dose multiplied by 2).
- If two or more MORPHINE or OXYCODONE PRN doses (PO plus SC) are required in 24 hours consider prescribing a MORPHINE or OXYCODONE 24hr CSCI
  The dose should be the total PRN (PO and SC) doses required in previous 24 hours converted to the equivalent SC dose.
- Prescribe a new MORPHINE or OXYCODONE SC PRN 1 hourly dose. The dose should be approximately 1/6 of the 24hr CSCI dose plus the transdermal FENTANYL or BUPRENORPHINE dose converted to SC MORPHINE or OXYCODONE
- Prescribe a new MORPHINE or OXYCODONE PO PRN 1 hourly equivalent dose if oral route available (Dose should be SC PRN dose multiplied by 2).

If the patient takes any other opioid, a combination of opioids or a situation not covered by the above guides contact your local specialist palliative care team for advice

Dosing example:
A patient is taking 30mg of MORPHINE MR capsules twice a day.
Total daily dose MORPHINE orally (PO) is 60mg.
The equivalent 24hr SC dose is 30mg. The PRN dose is 1/6 of this i.e. 5mg SC
N.B. The dose calculation is different for other opioids.

e.g. Oral Morphine 60mg = Oral oxycodone 30mg = subcutaneous oxycodone 15mg.
For **PRN dose calculation** or **opioid dose conversion** see the Palliative Network Guidelines: PANG(http://pallcare.info) or the Palliative Care Formulary (subscription required to log on).

Nausea and Vomiting

- If the likely cause of the nausea and vomiting is already known and the patient has obtained relief from existing antiemetics, continue these parenterally, e.g.:

    - CYCLIZINE 75−150mg 24hr CSCI.
      Additional doses of 25-50mg SC PRN can be given on specialist advice
      Maximum 200mg/24hour including CSCI.

    OR

    - METOCLOPRAMIDE 30−40mg 24hr CSCI.
      Additional doses of 10mg SC PRN can be given on specialist advice
      Maximum 100mg/24 hour including CSCI.
- If the cause of the nausea and vomiting is unknown or if the patient is not fully controlled on current antiemetic, Prescribe broad spectrum antiemetic LEVOMEPROMAZINE 6.25mg SC PRN 1 hourly.
- If two or more PRN doses are required in 24 hours prescribe LEVOMEPROMAZINE 12.5mg 24hr CSCI and continue PRN prescription. Usual maximum 25mg/24hrs **including** CSCI
    - No additional antiemetic benefits beyond 25mg /24 hours.
- If the above is not effective contact your local specialist palliative care unit for advice.

Agitation and Delirium

- Consider treatable causes e.g. pain; urinary retention; faecal impaction, withdrawal (nicotine, alcohol, recreational or non-medical drug use).
- Prescribe MIDAZOLAM 2.5 - 5mg SC PRN 1 HOURLY or LEVOMEPROMAZINE 6.25 - 12.5mg SC PRN 1 HOURLY.
- If two or more PRN doses are required in 24 hours prescribe MIDAZOLAM 10mg or LEVOMEPROMAZINE 12.5 - 25mg 24hr CSCI
- Delirium is best treated with an antipsychotic with or without midazolam.

Respiratory Tract Secretions

- Explain to the patient's relatives that noisy breathing is due to the inability of the patient to clear secretions, and that they are not choking. Advise to reposition the patient.
- Prescribe HYOSCINE BUTYLBROMIDE 20mg SC PRN 1 hourly**.**
- If two or more PRN doses are required in 24 hours prescribe HYOSCINE BUTYLBROMIDE 40mg or 60mg 24hr CSCI and continue PRN.
- If symptoms persist beyond 24 hours, increase the dose in the CSCI to 120mg /24 hours.
- If the above is not effective contact your local specialist palliative care unit for advice.

Dyspnoea

- Consider cause and treat appropriately (e.g. hypoxia, pulmonary oedema, bronchospasm).
- Use non-pharmaceutical measures such as explanation, reassurance, repositioning, fan, relaxation.
- If non-pharmacological treatments are ineffective prescribe MORPHINE and MIDAZOLAM if concurrent anxiety as described below.

Patient is not currently taking opioids:

- Prescribe MORPHINE 2.5mg SC PRN 1 hourly
  If concurrent anxiety prescribe MIDAZOLAM 2.5mg SC PRN 1 hourly.
- If two or more PRN doses in previous 24 hours prescribe MORPHINE and MIDAZOLAM 24hr CSCI and continue SC PRN 1 hourly prescription.
  NB: See above MORPHINE/MIDAZOLAM dosing guidance under Pain/Agitation and Delirium.

Patient usually takes regular MORPHINE

- Prescribe MORPHINE SC PRN 1 hourly 1/6 of usual 24hr MORPHINE dose converted to SC
  If concurrent anxiety, prescribe MIDAZOLAM 2.5mg SC PRN 1 hourly.

- If two or more PRN doses in previous 24 hours prescribe MORPHINE and MIDAZOLAM 10mg 24hr CSCI
  MORPHINE dose should be total of regular and PRN MORPHINE doses required in previous 24 hours converted to SC
  Recalculate MORPHINE SC PRN 1 hourly dose (1/6 of MORPHINE CSCI dose)
- Ideally start CSCI 2-4 hours before the next dose of modified release MOPRHINE is due
- Ensure all people caring for patient know that regular modified release oral MORPHINE has stopped and no more is to be given.
- If two or more PRN doses are required in 24 hours consider increasing CSCI dose to include any additional PRN doses given. If the CSCI dose in the syringe driver changes recalculate the SC PRN dose as necessary.
  NB: See above MORPHINE/MIDAZOLAM dosing guidance under Pain/Agitation and Delirium.

Stage 4-5 Chronic Kidney Disease (eGFR<30ml/min/1.73m^2)

This guidance is intended for anticipatory medicines for people as they approach their last hours to days of life'

Pain

FENTANYL is the opioid of choice (less renal excretion of parent drug and inactive metabolites) and may be recommended by specialists for patients with severe renal impairment.
Subsequently it may be prescribed by Primary Care Prescribers (classified Amber 2).
The information included here is intended as an example to aid prescribers. If in doubt, contact your Specialist Palliative Care Team or Medicines Management support.

- **Subcutaneous (SC) FENTANYL is 100 times more potent than oral morphine i.e. 1000 micrograms (1mg) FENTANYL SC = 100mg oral morphine.**
- **Patient not taking a regular opioid:**
  - Prescribe FENTANYL 12.5micrograms - 25 micrograms SC PRN 1 hourly.
  - If two or more PRN doses required in 24 hours consider FENTANYL 24hr CSCI with a dose based on the PRN use or up to FENTANYL 100 micrograms/24-hours as a starting dose.
  - If fentanyl is not available, or if there are concerns about familiarity, then morphine or oxycodone could be considered with caution if the patient is not opioid toxic. Start with small PRN doses (morphine SC 1.25-2.5mg 1 hourly, or oxycodone SC 1-2mg 1hourly) and titrate carefully, monitoring for toxicity.
- **Patient on a regular opioid**
  - If patient has a FENTANYL patch continue patch and use FENTANYL SC PRN in addition.
  - If patient is taking other regular low dose opioids and tolerating well without signs of opioid toxicity continue as a CSCI with appropriate dose conversion or convert to FENTANYL 24hr CSCI with FENTANYL SC PRN at 1/6 of the total 24-hour CSCI dose (seek specialist advice for dose guidance and conversion if needed).

If pain is difficult to control or for dose conversion advice, please seek specialist advice

Opioid dose conversion guidance is available - Palliative Network Guidelines: PANG
http://pallcare.info>Physical Symptoms and signs>pain> Opioid Potency Ratios
Note: A previous version of this Guidance included alfentanil and fentanyl for severe renal failure.
Fentanyl is the first line opioid for severe renal failure in Nottinghamshire.

If volumes are an issue for administration, alfentanil may be recommended by the Specialist Palliative Care Team.

Myoclonus or muscle stiffness/spasm

MIDAZOLAM 5-10 mg 24h CSCI, titrate up to 20mg if required.

Nausea and Vomiting

Nausea is common due to uraemia and comorbidity.

- If already controlled with an oral anti-emetic, continue as a CSCI or use a long-acting anti-emetic:
  - LEVOMEPROMAZINE 6.25mg SC PRN 1 hourly
  - HALOPERIDOL 0.5mg - 1mg SC PRN 1 hourly

Agitation and Delirium

- Prescribe MIDAZOLAM 2.5mg SC PRN 1 hourly or LEVOMEPROMAZINE 6.25mg SC PRN 1 hourly.
- If two or more PRN doses required in 24 hours consider MIDAZOLAM 5-10 mg 24hr CSCI.

Delirium is best treated with an antipsychotic with or without midazolam – with doses optimised for the individual. If agitation or delirium worsening seek advice. If volumes are an issue seek specialist palliative care advice to support conversion to other medications.

Respiratory Tract Secretions

Explain to the patient's relatives that noisy breathing is due to the inability of the patient to clear secretions, and that they are not choking. Consider repositioning the patient.

- Prescribe HYOSCINE BUTYLBROMIDE 20mg SC PRN 1 hourly.
- If two or more PRN doses required in 24 hours prescribe HYOSCINE BUTYLBROMIDE 40mg or 60mg 24hr CSCI and continue PRN.
- If symptoms persist beyond 24 hours, increase the dose to 120mg /24 hours.

Dyspnoea

Consider cause and treat appropriately (e.g. hypoxia, pulmonary oedema, bronchospasm).
Use non-pharmaceutical measures such as explanation, reassurance, repositioning, fan, relaxation.

- Continue any oral diuretic if able to swallow. Avoid fluid overload. For more information about diuretics and subcutaneous furosemide see section on diuretics in APC Palliative Care in End Stage Heart Failure guidelines.
- If non-pharmacological treatments are ineffective, use FENTANYL PRN as above; if concurrent anxiety combine with MIDAZOLAM 2.5mg SC PRN 1 hourly.
- If two or more PRN doses required in 24 hours prescribe FENTANYL and MIDAZOLAM 24 hr CSCI and continue SC PRN 1 hourly prescriptions.
  NB: See above FENTANYL/MIDAZOLAM dosing guidance under Pain/Agitation and Delirium.

This guidance is intended for anticipatory medicines for people as they approach their last hours to days of life

Pain

FENTANYL may be recommended by specialists in patients with severe liver impairment, particularly when there is concurrent renal impairment (less renal excretion of parent drug and inactive metabolites).
Subsequently it may be prescribed by Primary Care Prescribers (classified Amber 2).

The information included here is intended as an example to aid prescribers. If in doubt, contact your Specialist Palliative Care Team or Medicines Management support.

- **Subcutaneous (SC) FENTANYL is 100 times more potent than oral morphine i.e. 1000 MICROgrams (1mg) FENTANYL SC = 100mg oral morphine.**
- **Patient not taking a regular opioid:**
  - Prescribe FENTANYL 12.5 - 25 micrograms SC PRN 1 hourly.
  - If two or more PRN doses required in 24 hours consider FENTANYL 24hr CSCI with a dose based on the PRN use or up to FENTANYL 100 micrograms/24-hours as a starting dose.
  - If fentanyl is not available, or if there are concerns about familiarity, then morphine could be considered with caution if the patient is not opioid toxic. Start with small PRN doses of morphine SC 2.5mg 1 hourly and titrate carefully, monitoring for toxicity.
- **Patient on a regular opioid**
  - If patient has a FENTANYL patch continue patch and use FENTANYL SC PRN in addition.
  - If patient is taking other regular low dose opioids and tolerating well without signs of opioid toxicity continue as a CSCI with appropriate dose conversion or convert to FENTANYL 24hr CSCI with FENTANYL SC PRN at 1/6 to of the total 24-hour CSCI dose (seek specialist advice for dose guidance and conversion if needed).

If pain is difficult to control or for dose conversion advice, please seek specialist advice

Opioid dose conversion guidance is available - Palliative Network Guidelines: PANG http://pallcare.info >Physical Symptoms and signs>pain> Opioid Potency Ratios.

If volumes are an issue for administration seek specialist palliative care advice to support conversion to other medications.

Nausea and Vomiting

HALOPERIDOL 0.5 -1 mg SC PRN 1 hourly.

Agitation and Delirium

- MIDAZOLAM 1 – 2.5mg SC PRN 1 hourly for terminal agitation.
- HALOPERIDOL 0.5 -1 mg SC PRN 1 hourly for delirium. Midazolam may be required in addition to haloperidol.

Respiratory Tract Secretions

Explain to the patient's relatives that noisy breathing is due to the inability of the patient to clear secretions, and that they are not choking. Consider repositioning the patient.

- Prescribe HYOSCINE BUTYLBROMIDE 20mg SC PRN 1 hourly.
- If two or more PRN doses required in 24 hours prescribe HYOSCINE BUTYLBROMIDE 40mg or 60mg 24 hr CSCI and continue PRN.
- If symptoms persist beyond 24 hours, increase the dose to 120mg /24 hours.

Dyspnoea

Consider cause and treat appropriately (e.g. hypoxia, pulmonary oedema, bronchospasm).
Use non-pharmaceutical measures such as explanation, reassurance, repositioning, fan, relaxation.

- If non-pharmacological treatments are ineffective, use FENTANYL 12.5 - 25 micrograms SC PRN 1 hourly; if concurrent anxiety combine with MIDAZOLAM 1 - 2.5mg SC PRN 1 hourly.
- If two or more PRN doses required in 24 hours prescribe FENTANYL and MIDAZOLAM 24 hr CSCI and continue PRN prescription.
  NB: See above fentanyl/midazolam dosing guidance under Pain / Agitation.

Appendix 1c-Concentrations and Vial/Ampoule sizes of Medications Referenced in this Guidance

Concentrations and ampoule sizes of medications referenced in this Guidance

Medicine	Concentration	Vial/ Amp Size	Pack Size
Morphine (CD)	10mg/1ml	1ml	10
	15mg/1ml	1ml	10
	30mg/1ml	1ml	10
	30mg/1ml	2ml	5
Oxycodone (CD)	10mg/1ml	1ml	5
	10mg/1ml	2ml	5
	50mg/1ml**	1ml	5
Cyclizine	50mg/1ml	1ml	5
Levomepromazine	25mg/1ml	1ml	10
Metoclopramide	5mg/1ml	2ml	10
Hyoscine butylbromide	20mg/1ml	1ml	10
Midazolam (CD)	5mg/1ml	2ml	10
Fentanyl (CD)	50microgram/1ml	2ml	10
Haloperidol	5mg/1ml	1ml	10
Hyoscine butylbromide	20mg/1ml	1ml	10
Levomepromazine	25mg/1ml	1ml	10
Midazolam (CD)	5mg/1ml	2ml	10
Water for injection	-	10 ml	10

** Only to be used when the lower concentrations of oxycodone will not fit in the syringe driver.

All anticipatory medicine and CSCI supplies must have an accompanied Direction to Administer completed. Guidance about Directions to Administer can be found on the APC websitehttps://www.nottsapc.nhs.uk/direction-to-administer/

A prescription for end of life medication can be taken to any community pharmacy for dispensing. However, community pharmacies participating in the **palliative care medicines stockist scheme** are always required to keep a stock of palliative care medications (supply chain permitting).

Full details can be found on the Nottinghamshire APC website, including a list of participating community pharmacies across Nottinghamshire and Derbyshire and the service level agreement which includes a list of medications, strengths and quantities stocked.

www.nottsapc.nhs.uk/guidelinesformularies/palliative-care-stockist-scheme

Glossary

ACP (Advance Care Planning) - Discussing and recording a patient's preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs and those of their loved ones.

ADRT (Advance Decision to Refuse Treatment) - A statement of a patient's wish to refuse a particular type of medical treatment or care if they become unable to make or communicate decisions for themselves. A valid ADRT is legally binding.

Advance Statement - A statement of a patient's views about how they would or would not wish to be treated if they become unable to make or communicate decisions for themselves.

ANH or CANH - Artificial nutrition and hydration or clinically assisted nutrition and hydration. Nasogastric feeding; percutaneous endoscopic gastrostomy (**PEG**) or radiologically inserted gastrostomy (**RIG**); intravenous or subcutaneous infusion of fluids.

CSCI – Continuous SubCutaneous Infusion

DNACPR - Do Not Attempt Cardiopulmonary Resuscitation. Allow natural death

DOLS - Deprivation of Liberty Safeguards

EMAS - East Midlands Ambulance Service

End of Life - Patients are 'approaching the end of life 'when they are likely to die within the next 12 months.

EPaCCS - Electronic Palliative Care Co-ordination System

GSF (Gold Standards Framework) - A systematic approach to optimising care for patients in the last year of life with stages:

Green – Months to a year; Yellow – Weeks; Red – Last days of life; Blue –years plus

LPA (Lasting Power of Attorney) - A person with legal authority to make certain decisions (regarding health and welfare / finance and property) on behalf of another adult.

LACDP - Leadership Alliance for the Care of Dying People

MCA - Mental Capacity Act

MDT - Multidisciplinary team

Palliative Care - The holistic care of patients with advanced, progressive, incurable illness to include physical, psychological, social and spiritual care.

PRN (Pro Re Nata) - as necessary

PPC - Preferred Priorities for Care (also sometimes used for Preferred Place of Care)

ReSPECT - Recommended Summary Plan for Emergency Care and Treatment

Specialist Palliative Care - Specialist palliative care is based on the same principles of palliative care above but can help people with more complex needs. It is provided by specially trained multi-professional specialist palliative care teams and can be accessed in any care setting.

SR 1 (Special Rules) form entitling patient in the last year of life to access benefits

VOED - Verification Of Expected Death

References

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2. GOV.UK (2014) *One Chance to get it Right: Improving People's Experience of Care in the Last Few Days and Hours of Life [*online] Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf [Accessed on 9th December 2025]

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7. Palliative Adult Network Guidelines (PANG) (n.d.) *Palliative Adult Network Guidelines*. Available at: http://pallcare.info (Accessed: 14 January 2026)
8. Palliative Care Formulary Medicines Complete. Available at: https://www.medicinescomplete.com/log-in/(Accessed: 12 December 2025).

Useful information and links

Palliative Care Formulary. On-line PCF subscription through www.medicinescomplete.com

Palliative Network Guidelines: PANG
www.pallcare.info

Notts APC: Palliative Care in End stage Heart Failure Guidelines

One Chance to Get it Right:
www.gov.uk/government

Gold Standards Framework www.goldstandardsframework.org.uk

Mental Capacity Act www.gov.uk/government/publications/mental-capacity-act-code-of-practice

Deprivation of Liberty
www.gov.uk/government/publications/mental-capacity-act-deprivation-of-liberty-safeguards

Advance Care Planning - a guide for Health and Social Care Staff

https://www.nice.org.uk/media/default/about/nice-communities/social-care/quick-guides/advance-care-planning-quick-guide.pdf

Planning your future care – a guide for patients (available in various languages via NHS England website:

https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/12/EoLC-

Planning-for-your-future-care.pdf

Lasting Power of attorney guidance from the government
www.gov.uk/power-of-attorney/overview

Lasting Power of Attorney forms www.gov.uk/government/collections/lasting-power-of-attorney-forms

Liberty Protection Safeguards (replaces DoLS from April 2022)

Supporting Children and Young People When Someone is seriously ill

Supporting Children & Young People When Someone Has Died

NICE quality standard (QS13) End of life care for adults
www.nice.org.uk/guidance/qs13

Prognostic indicator guidance, (Gold Standards Framework PIG)

Hospice UK website www.hospiceuk.org

Dying Matters website dyingmatters.org

GMC End of Life Guidance www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

Decisions relating to CPR guidance www.resus.org.uk/dnacpr/decisions-relating-to-cpr

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