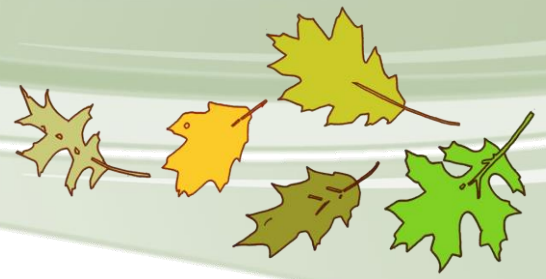


The Nottinghamshire and Nottingham Guidelines for Care in the Last Year of Life A Guide for Professionals

(Revised Version 3 2020)

This guide was produced in partnership between

Nottinghamshire Healthcare NHS Foundation Trust | Nottingham CityCare Partnership
Nottingham University Hospitals NHS Trust | NHS Bassetlaw CCG
Sherwood Forest Hospitals NHS Foundation Trust



Guideline for Care in the Last Year of Life: A Guide for Professionals

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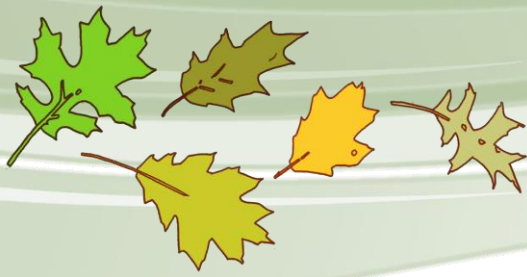
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Foreword

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 published¹. 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 England². 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 Nottinghamshire and Bassetlaw 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.

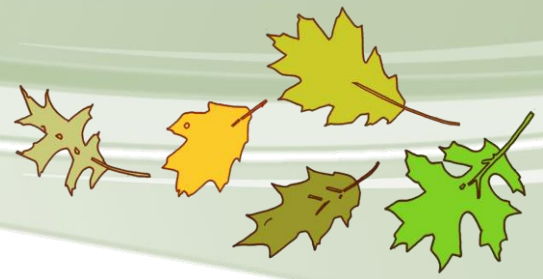
We encourage staff to sit down and listen to their patient and their carer, document the discussion in the patient record and act on the patient preferences.

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 people³ (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 commissioners⁴ 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 and
- Supporting carers both during a person's illness and after their death





Introduction

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.

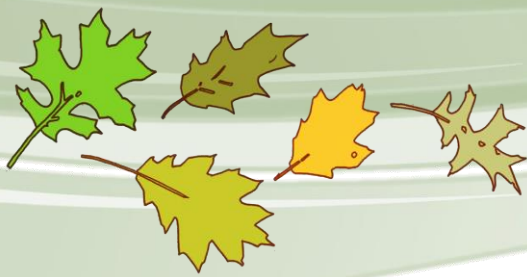
Understanding and delivering patient choice is central to excellent care at the end of life. Ability to achieve patient choice may be used to measure quality of service. In relation to place of death, national statistics demonstrate a disparity between patients' preferred place of death and their actual place of death. Although when asked, over 50% of patient's state they would prefer to die at home, but many do not achieve this aim⁵.

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 purpose of this guidance is to support patients, carers and professionals to develop individual plans for End of Life Care.





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.nhs.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.

5 Priorities for Care of the Dying Person

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 social care providers

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

Nottinghamshire Healthcare has 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.

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 patients condition changes Link <https://resus.org.uk/respect/>

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



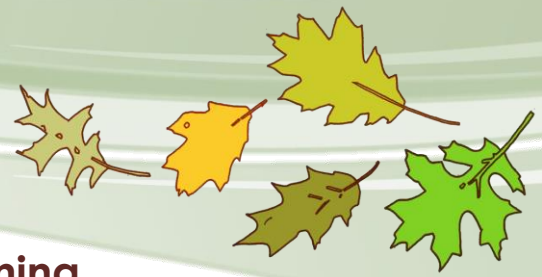
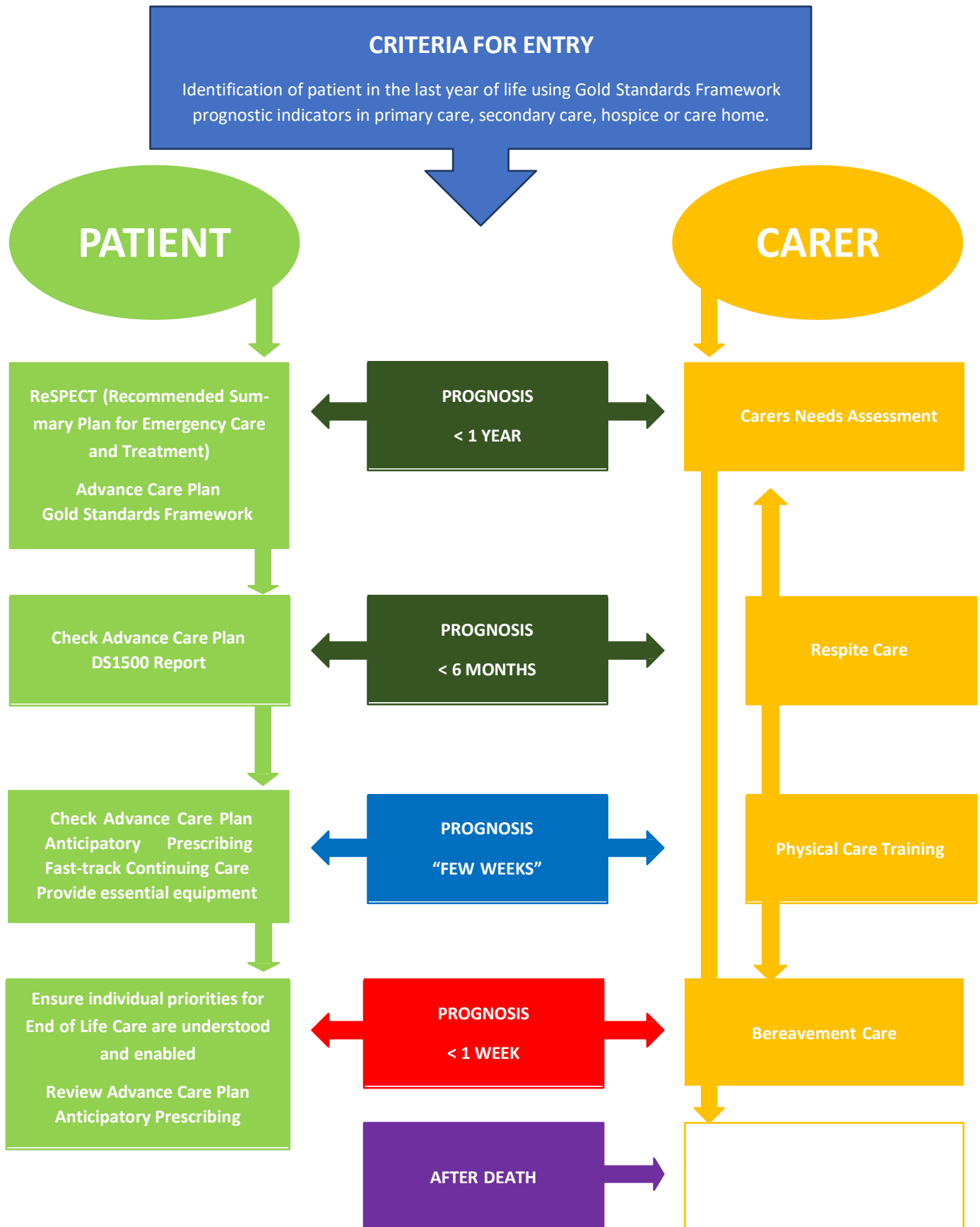


Figure 1: Flow Chart to illustrate End of Life Planning



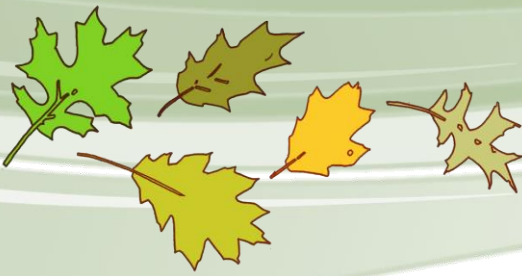
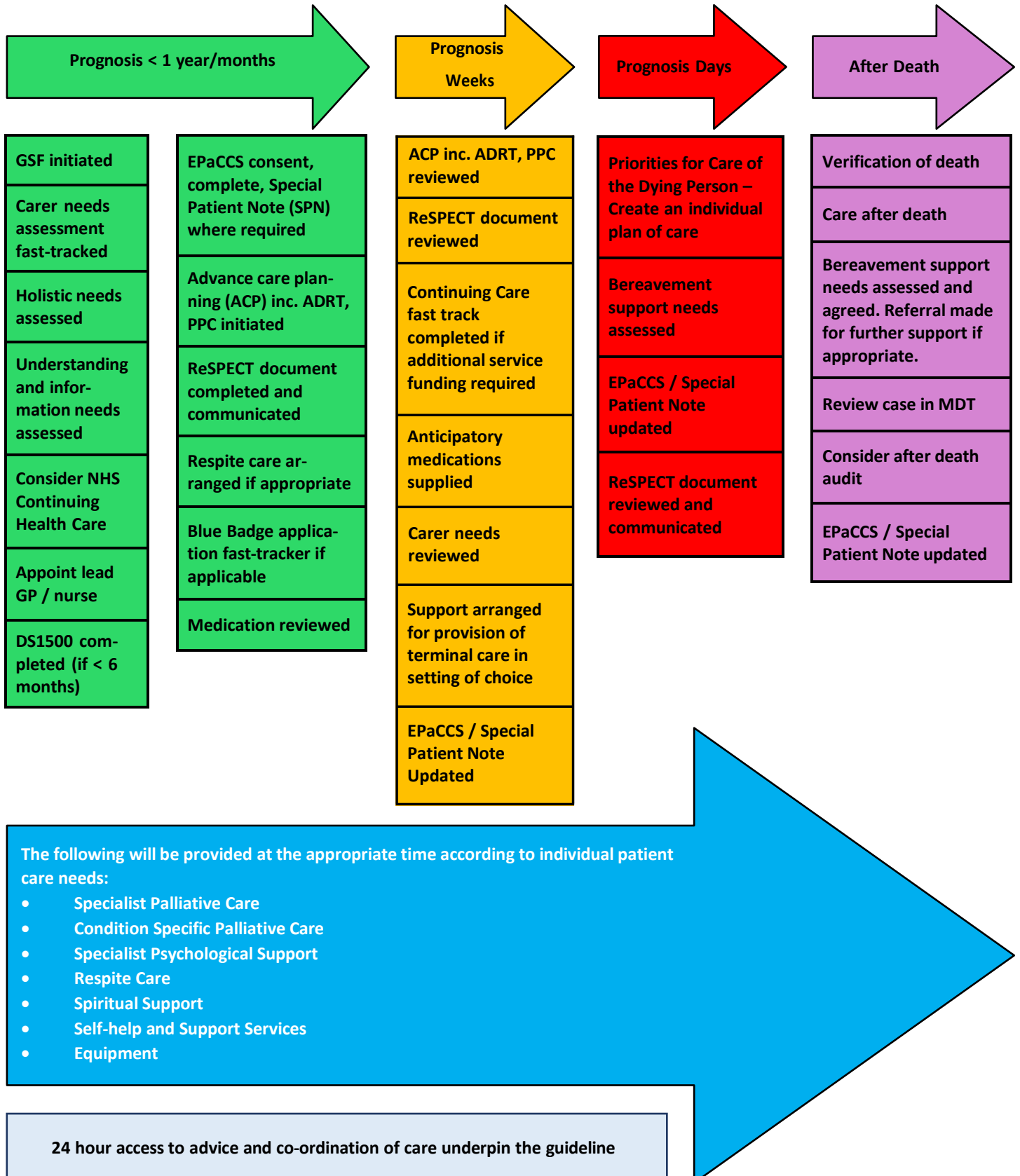
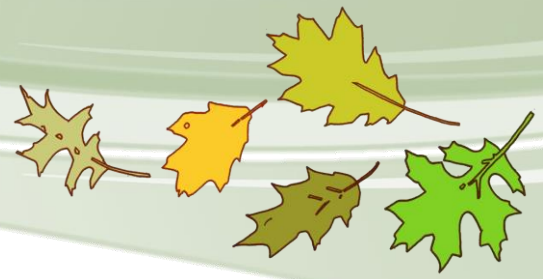


Figure 2: End of Life Planning: Details of Care Provision





Prognosis of less than 1 year

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

'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.

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.

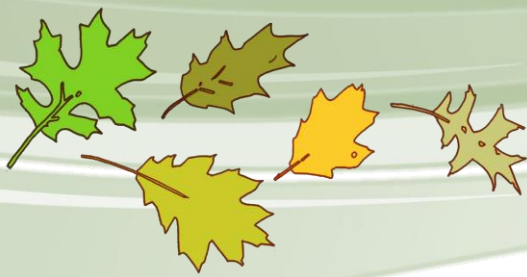
Coordination of Care

The national End of Life Care Strategy⁶ 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).

www.epaccs.com





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. If they wish, choices about their care and treatment can be recorded and/or they can make an Advance Decision to Refuse a Treatment (ADRT) in specific circumstances www.adrtnhs.co.uk

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 Advanced Care Plan is a key part of the GSF Programmes. It should be included consistently and systematically so that every appropriate person is offered the chance to have an advance care planning discussion with the most suitable person caring for them.

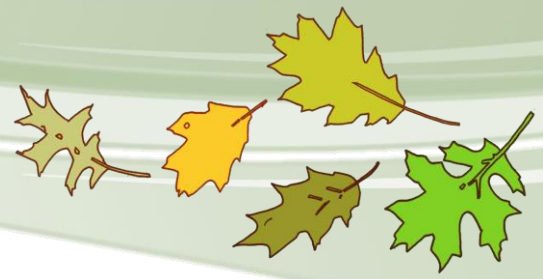
The process of Advance Care Planning in the UK includes many elements – essentially helping people approaching the end of their life to describe and clarify what they don't want to happen; what they do want to happen; who will speak for them.

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. 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. 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.





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.

Prognosis of less than six months

At this stage the person (regardless of diagnosis) may **apply for Attendance Allowance or Personal Independence Payment** under special rules using a DS1500 form, downloadable from www.direct.gov.uk. <https://ds1500.dwp.ncrs.nhs.uk/ds1500-start> this address when logged in with nhs smart card will allow DS1500 to be done electronically

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.

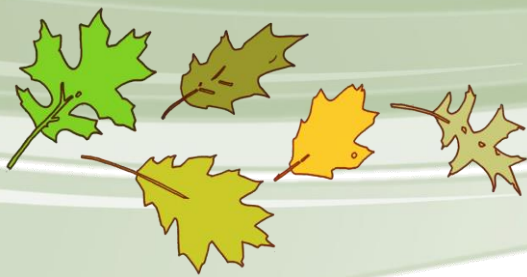
Cases referred via DS1500 are subject to review by the Department for Work and Pensions after a period of three years.

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 a number of 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. 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.





Prognosis of a few 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, giving consideration to 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 should be provided at this stage, after discussion with the patient and carer. If needed, such medication will help control distressing symptoms of pain, restlessness and agitation, nausea and vomiting, and respiratory tract secretions, without delay.

Symptom Management Guidelines are available at <http://book.pallcare.info/> and in the Palliative Care Formulary.— Refer to Appendix 1b and 1c for anticipatory medication guidance which has been developed to support the prescriber (General Practitioner, a Medical Consultant in Palliative Care or a Registered Nurse who hold the V300).

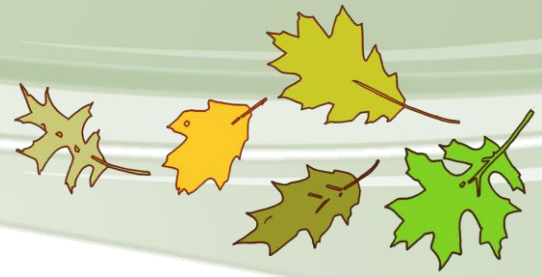
It may be appropriate in certain cases to have anticipatory medicines in place earlier than this, particularly if a sudden decline in a patient's condition is expected.

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.

Communication of information to other providers is essential at this time using the relevant templates i.e EPaCCS.

Out of hours providers and East Midlands Ambulance Service are linked to EPaCCS and receive 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.





Prognosis of days or hours

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. .

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.

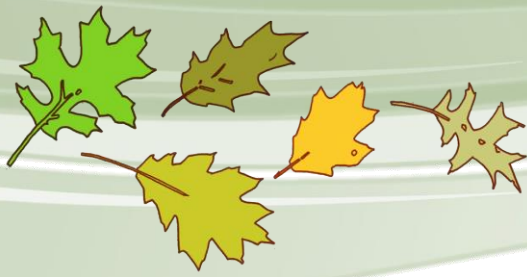
Recognising that the patient is dying

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 must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die. If the doctor 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 senior responsible doctor judges that the person is likely to be dying, taking into account 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.

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.

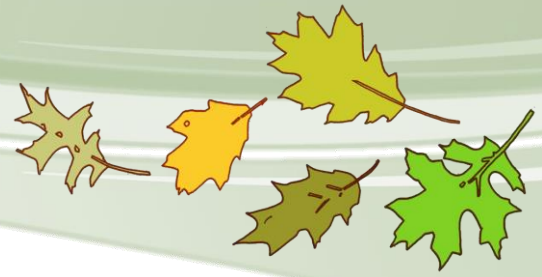
Hydration and nutrition

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 (General Practitioner, a Medical Consultant in Palliative Care, a Medical Consultant) involved in the patients care or a Registered Nurse who hold the V300 Rationalise current medication, discontinue non-essential drugs and prescribe Anticipatory Medication for potential symptoms.

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 patients needs and stage of disease face to face by a prescriber (General Practitioner, a Medical Consultant in Palliative Care, a Medical Consultant involved in the patients care or a Registered Nurse who hold the V300).

Anticipatory Medicines Prescribing should be in accordance with Appendix 1b, 1c and 1d of the anticipatory medication guidance, which has been developed to support the prescriber.

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 relevant template i.e. EPaCCS.

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.

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

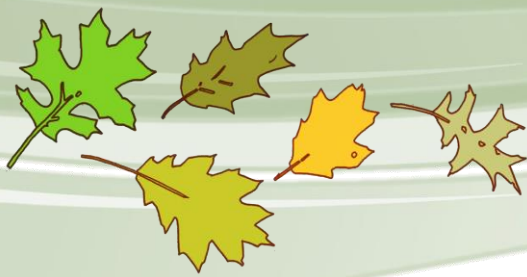
In the final days and hours of life, carer's should be offered support.

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. Leaflets are available in each organisation, contact your local End of Life/Palliative Care Team for further information.

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.





Care After Death

Certification of death should be carried out as soon as possible. In some settings (such as a hospice, community, nursing homes and hospitals) nursing staff are trained to undertake what is referred to as 'Verification of Death'. This expedites transfer of the patient's body and the process of events after death.

The information leaflet, 'What to do after a death in England and Wales' (DWP) should be provided to the next of kin. All relevant services should be informed, including the provider of Out of Hours Care and the Ambulance Service.

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.

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.

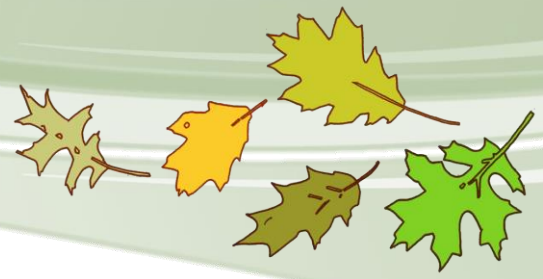
Specialist Palliative Care

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. Templates can be developed for practices 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 through the use of 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; and organisational self-assessment of structures and processes which demonstrate adherence to the LACDP '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 LACDP 'Priorities for Care'. 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.





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.

The following anticipatory medicines guidance has been developed to support the Prescriber (General Practitioner, a Medical Consultant in Palliative Care or a Registered Nurse who hold the V300).

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 0115 9627619 Or Palliative Medicine Registrar or Consultant on call 01159691169

Mid/North Notts:

John Eastwood Hospice Specialist Palliative Care Team, on 01623 622626

Professional advise line Call for Care, option 2 on 01623 781899

Bassetlaw: Bassetlaw Hospice 0115 955 5440

Lincolnshire: St Barnabas Hospice 01522 511566



Symptom Control and Anticipatory Prescribing (last days of life)

Pain

- Patient not currently taking opioids: prescribe 2.5 - 5mg MORPHINE subcutaneous (SC) when required (PRN) 1 hourly. If the oral route is available also prescribe MORPHINE 2.5 - 5mg PO PRN.
- If 2 or more SC doses are required in 24-hours start MORPHINE by continuous SC infusion* at the same dose as the total prn SC doses required in previous 24 hours. Then the SC PRN dose should be approximately 1/6 of 24hr syringe driver dose
- If the patient is also taking oral MORPHINE, calculate the subcutaneous equivalent daily dose (total oral daily dose divided by 2), and add this to the syringe driver. Then the SC PRN dose should be approximately 1/6 of 24hr syringe driver dose.
- Review the continuous subcutaneous infusion dose daily and consider increasing to include any additional PRN doses given.
- If the patient has a fentanyl (OR buprenorphine) patch leave this in place and prescribe the appropriate SC PRN dose of morphine

Dosing example:

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

NB 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://book.pallcare.info>) or the Palliative Care Formulary

Nausea and Vomiting

- Continue any orally effective agents by subcutaneous infusion*, for example:
CYCLIZINE 50mg three times a day (TDS) PO = CYCLIZINE 75mg SC /24 hour
METOCLOPRAMIDE 10 mg TDS PO = METOCLOPRAMIDE 30mg SC /24 hours
- Higher doses of Cyclizine and metoclopramide can be used with caution. Please be aware of potential adverse effects and check compatibility when more than one drug is used in a syringe driver with Cyclizine. Seek advice if needed.
- If no prescription exists, or in addition to above, prescribe LEVOMEPRMAZINE 6.25mg - 12.5mg SC PRN 1-hourly
- If more than 2 PRN doses are required in 24 hours, add to the continuous subcutaneous infusion: LEVOMEPRMAZINE 12.5mg /24 hours and continue PRN prescription.
- If more than 2 PRN doses in the subsequent 24 hours, increase continuous subcutaneous infusion to LEVOMEPRMAZINE 25mg /24 hours.



Agitation and Delirium

- Consider treatable causes e.g. pain; urinary retention; faecal impaction.
- Prescribe MIDAZOLAM 2.5 - 5mg SC PRN 1 HOURLY or LEVOMEPRMAZINE 6.25-12.5mg SC PRN 1 HOURLY
- If more than 2 PRN doses in 24 hours, add MIDAZOLAM 10mg /24 hours or LEVOMEPRMAZINE 12.5-25mg / 24 hours to the continuous subcutaneous infusion.
- Delirium is best treated with a combination of benzodiazepine and antipsychotic.

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 any doses are required prescribe 40mg or 60mg /24 hours by subcutaneous infusion and continue PRN.
- If symptoms persist beyond 24 hours, increase the dose in the subcutaneous infusion to 120mg /24 hours.

Dyspnoea

- Consider cause and treat appropriately (e.g. hypoxia, pulmonary oedema, bronchospasm).
- Use non-drug measures such as explanation, reassurance, repositioning, fan, relaxation.
- If non pharmacological treatments are ineffective, use MORPHINE 2.5mg or MIDAZOLAM 2.5mg SC PRN 1 hourly.
- If more than 2 doses in last 24 hours, prescribe a continuous subcutaneous infusion over 24 hours, and continue PRN prescription. NB: See above morphine/midazolam dosing guidance under Pain/Agitation.

Concentrations and ampoule sizes of the medicines included above

Medicine	Concentration	Vial/ Amp Size	Pack Size	Cost (July 19 Drug Tariff)
Morphine (CD)	10mg/1ml	1ml	10	£11.68
	15mg/1ml	1ml	10	£10.74
	30mg/1ml	1ml	10	£11.49
	60mg/2ml	2ml	5	£10.07
Oxycodone (CD)	10mg/1ml	1ml	5	£8.00
	20mg/ 2ml	2ml	5	£16.00
	50mg/1ml**	1ml	5	£70.10
Cyclizine	50mg/1ml	1ml	5	£8.65
Levomepromazine	25mg/1ml	1ml	10	£20.13
Metoclopramide	10mg/2ml	2ml	10	£2.65
Hyoscine Butylbromide	20mg/1ml	1ml	10	£2.92
Midazolam (CD)	10mg/2ml	2ml	10	£5.00

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



Specific Community Pharmacies participate in the Palliative Care Drugs Stockist Scheme. Details of participating pharmacies should be available locally. The supporting document from NHSE is on <https://www.nottsapc.nhs.uk/media/1234/palliative-care-drug-stockist-scheme-sla-2019-20.pdf>

*Continuous subcutaneous syringe infusions are administered using T34 syringe pumps. For further guidance see local syringe driver policy.

Ensure that patients requiring syringe drivers are also prescribed water for injections.

Check compatibility where more than one drug is used in a syringe driver.

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, for education and advice contact your Specialist Palliative Care Team.

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

References: Palliative Adult Network Guidelines (PANG) are available at

<http://book.pallcare.info> PCF6 (Palliative Care Formulary version 6) www.palliativedrugs.com



Anticipatory Medications in Severe Renal Impairment Stage 4-5 Chronic Kidney Disease (eGFR<30ml/min)

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.

- Patient not taking a regular opioid: Prescribe FENTANYL 12.5 - 25 micrograms SC PRN 1 hourly
- If any PRN doses required consider continuous subcutaneous infusion* with a dose based on the PRN use
or up to FENTANYL 100 micrograms/24-hours. (1mg FENTANYL SC = 150mg oral morphine)
- If patient has a FENTANYL patch – continue patch and use FENTANYL SC prn in addition.
- If patient is taking other regular opioids and tolerating well without signs of opioid toxicity continue as a continuous SC infusion with appropriate dose conversion or convert to FENTANYL in syringe driver with FENTANYL SC prn at 1/6 to 1/10 of the total 24 hour continuous subcutaneous infusion dose (seek specialist advice for dose guidance and conversion)

Morphine can be used with caution if the patient is not opioid toxic. Start with small doses e.g. 2.5mg SC 4 hourly prn and titrate carefully, monitoring for toxicity. If there are no signs of toxicity, the PRN interval can be increased to 1 hourly dependent on how the individual patient responds.

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://book.pallcare.info>Physical Symptoms and signs>pain> Opioid Potency Ratios>

Note: The previous version of this Guidance included Alfentanil and Fentanyl for severe renal failure. **Fentanyl is now the first line opioid for severe renal failure in Nottinghamshire.**

If volumes are an issue for administration, Alfentanil may be recommended by Specialist Palliative Care

Myoclonus or muscle stiffness/spasm

- MIDAZOLAM 5-10 mg / 24 hours by continuous subcutaneous infusion*, 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 it as a continuous subcutaneous infusion* or use a long acting anti-emetic:
 - ◇ LEVOMEPRMAZINE 2.5 mg - 6.25 mg SC 12-hourly
 - ◇ HALOPERIDOL 0.5 -1 mg SC 12-hourly

References: <http://www.palliativecareguidelines.scot.nhs.uk> <http://www.renaldrugdatabase.com/>



Agitation and Delirium

- Prescribe MIDAZOLAM 2.5 mg SC PRN 1 hourly or LEVOMEPRMAZINE 2.5 – 6.25 mg SC PRN 1 hourly
- If PRN medication required consider subcutaneous infusion* with MIDAZOLAM 5-10 mg over 24 hours

Delirium is best treated with a combination of benzodiazepine and/or antipsychotic – with doses optimized 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 any doses are required prescribe 40mg or 60mg /24 hours by subcutaneous infusion* 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-drug measures such as explanation, reassurance, repositioning, fan, relaxation.

- Continue any oral diuretic if able to swallow. Avoid fluid overload.
- Use MIDAZOLAM 2.5mg SC PRN or FENTANYL PRN as above.
- If more than 2 doses in last 24 hours, prescribe a continuous subcutaneous infusion* over 24 hours, and continue PRN prescription.

*Continuous subcutaneous syringe infusions are administered using T34 syringe pumps. For further guidance see local syringe driver policy. Ensure that patients requiring syringe drivers are also prescribed water for injections. Ensure practice is in line with your local Anticipatory Medications Policy.

Concentrations and ampoule sizes of the medicines included above

Medicine	Concentration	Vial/ Amp Size	Pack Size	Cost (Aug 19)
Fentanyl (CD)	50mcg/1ml	2ml	10	£4.50
Haloperidol	5mg/1ml	1ml	10	£8.65
Hyoscine Butylbromide	20mg/1ml	1ml	10	£2.92
Levomepromazine	25mg/1ml	1ml	10	£20.13
Midazolam (CD)	10mg/2ml	2ml	10	£5.00

Contacts:

John Eastwood Hospice	01623 622626
Hayward House	0115 9627619
Medicines Information at SFH	01623 672213
Medicines Information at NUH	0115 9709200
Bassetlaw Hospice	0115 955 5440
Lincolnshire - St Barnabas	01522 511566



Anticipatory Medications in Severe Hepatic Disease

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.

- Patient not taking a regular opioid: Prescribe FENTANYL 12.5 - 25 micrograms SC PRN 1 hourly
- If any PRN doses required consider continuous subcutaneous infusion* of FENTANYL with a dose based on the PRN use or up to 100 micrograms/24-hours as a starting dose (1mg FENTANYL SC = 150mg oral morphine).
- 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 continuous SC infusion with appropriate dose conversion or convert to FENTANYL as a continuous subcutaneous infusion* in syringe driver with FENTANYL SC PRN at 1/6 to 1/10 of the total 24 hour continuous subcutaneous infusion dose.

Morphine can be used with caution if the patient is not opioid toxic. Start with small doses e.g. 2.5mg SC 4 hourly prn and titrate carefully, monitoring for toxicity. If there are no signs of toxicity, the PRN interval can be increased to 1 hourly dependent on how the individual patient responds.

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://book.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 interval.

Agitation and Delirium

- MIDAZOLAM 1–2.5mg SC PRN 1 hourly interval for terminal agitation.
- HALOPERIDOL 0.5 -1 mg SC PRN 1 hourly interval 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 any doses are required prescribe 40mg or 60mg /24 hours by subcutaneous infusion* and continue PRN.
- If symptoms persist beyond 24 hours, increase the dose to 120mg /24 hours.

Dyspnoea

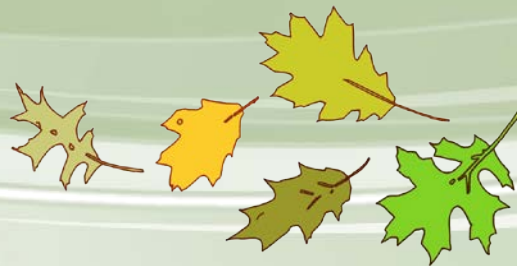
- Consider cause and treat appropriately (e.g. hypoxia, pulmonary oedema, bronchospasm).
- Use non-drug measures such as explanation, reassurance, repositioning, fan, relaxation.
- If non pharmacological treatments are ineffective, use FENTANYL 12.5 - 25 micrograms SC 1 hourly; if concurrent anxiety combine with MIDAZOLAM 1-2.5mg SC 1 HOURLY.
- If more than 2 doses in last 24 hours, prescribe a continuous subcutaneous infusion over 24 hours and continue PRN prescription. NB: See above fentanyl/midazolam dosing guidance under Pain / Agitation.

*Continuous subcutaneous syringe infusions are administered using T34 syringe pumps. For further guidance see local syringe driver policy. Ensure that patients requiring syringe drivers are also prescribed water for injections. Ensure practice is in line with your local Anticipatory Medications Policy.

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Hyoscine Butylbromide	20mg/1ml	1ml	10	£2.92
Midazolam (CD)	10mg/2ml	2ml	10	£5.00





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.

DNACPR Do Not Attempt Cardiopulmonary Resuscitation. Allow natural death

DOLS Deprivation of Liberty Safeguards

DS1500 Report entitling a person at end of life to access benefits

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.





References

1. GOV.UK (2015) *More Care, Less Pathway: A Review of the Liverpool Care Pathway* [online] Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf [Accessed 8th May 2015]
2. GOV.UK (2015) *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 11th May 2015]
3. GOMES, B. and HIGGINSON, I. (2008) *Where People Die (1974 – 2030): Past Trends, Future Projections and Implications for Care*. Palliative Medicine 2008
4. GOV.UK (2015) *End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life* [online] Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136443/EOLC_exec_summ.pdf [Accessed 5th May 2015]

Useful Information and Links

Twycross, R., Wilcock, A., Howard P eds., (2017) *Palliative Care Formulary* 6th edn. London: Pharmaceutical Press. on-line PCF subscription through www.medicinescomplete.com

Palliative Network Guidelines: PANG

<http://book.pallcare.info>>Physical Symptoms and signs>pain> Opioid Potency Ratios
Palliativedrugs.com, Nottingham. Also available at www.palliativedrugs.com

One Chance to Get it Right:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

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

www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf

'Thinking Ahead': Gold Standards Framework Advance Care Planning form to record discussions

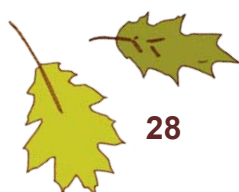
www.goldstandardsframework.org.uk/cd-content/uploads/files/Library%2C%20Tools%20%26%20resources/ACP%20General%20July%202013.v21.pdf

Planning your future care – a guide for patients

www.nhs.uk/Livewell/Endoflifecare/Documents/Planning_your_future_care%5B1%5D.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

The Nottinghamshire EPaCCS and End of Life Care Web Resource www.epaccs.com

Supporting Children and Young People When Someone is Seriously Ill
Information from Nottingham University Hospitals, Nottingham Childrens Hospital and Spiral
http://www.nuh.nhs.uk/media/1882523/1258v2_supporting_children_and_young_people_when_someone_is_seriously_ill.pdf

Supporting Children and Young People When Someone has Died
Information from Nottingham University Hospitals, Nottingham Childrens Hospital and Spiral
http://www.nuh.nhs.uk/media/11439/1260v1_Supporting_children_and_young_people_when_someone_has_died.pdf

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

www.nhsig.nhs.uk/endoflifecare here you can access information regarding Acute Hospital Care; Co-ordination of Care and resources available from the Leadership Alliance for the Care of Dying People

Prognostic indicator guidance
www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

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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Nottingham University Hospitals NHS Trust

Bassetlaw Health Partnerships

Sherwood Forest Hospitals NHS Foundation Trust

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Please direct comments or enquiries to John Eastwood Hospice on 0115 955 5440

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