

# **ONE CHANCE TO GET IT RIGHT DERBYSHIRE**

**A guide for professionals in Derbyshire  
who care for patients  
believed to be in the last year of life**

4<sup>th</sup> edition January 2017

DERBYSHIRE ALLIANCE FOR END OF LIFE CARE

[www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)

## Contents

Foreword (written by Derbyshire Alliance for End of Life Care) .....	3
Introduction .....	4
Figure 1: Flow Chart to illustrate End of Life Care Planning .....	5
Prognosis of less than 1 year .....	6
Coordination of care .....	6
Advance Care Planning .....	7
Do Not Attempt Cardiopulmonary Resuscitation .....	8
Prognosis of less than six months .....	9
Prognosis of ‘a few weeks’ .....	10
Prognosis of days or hours .....	11
Care after death .....	13
Bereavement Care .....	13
Continued Learning: opportunities for professionals after a patient has died.....	13
Additional services to meet individual needs .....	14
Specialist Palliative Care .....	14
Standards .....	15
Audit .....	15
Care Quality Commission (CQC) and End of Life Care .....	15
References.....	17
Appendix 1: <i>Terms of reference, membership and aims of Derbyshire Alliance (July 2014; updated July 2016)</i> .....	17

## Foreword (written by Derbyshire Alliance for End of Life Care)

In 2008, the Department of Health's first national Strategy for End of Life Care in England described three key concerns: that people didn't die in their place of choice, that there was a need to prepare for larger numbers of dying people and that not everybody received high-quality care<sup>1</sup>. More recently, variation in quality of care at the end of life has become a point of national debate. Cumulatively the weight of independent reviews including *More Care, Less Pathway: A Review of the Liverpool Care Pathway*<sup>2</sup> has brought reflection and continued to urge change.

*Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*<sup>3</sup> builds on the 2008 Strategy. It also responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012. This national framework for action sets out six 'ambitions' – principles for how care for those nearing death should be delivered at local level:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

Representatives of health care providers in Derbyshire (the self-titled 'Derbyshire Alliance for End of Life Care') have collectively developed this local guidance, which describes how we may support our patients and their families when someone is believed to be in the last year of life in Derbyshire. All professionals who care for dying people must ensure that they are aware of, and follow, guidance and local best practice. They will recognise that the evidence on which this is based will continue to evolve, and this guidance will be reviewed at regular intervals.

There are separate documents which set out both the duties and responsibilities of health and care staff who are involved in the care of dying people<sup>4</sup> (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,<sup>5</sup> 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 care setting.

Nothing less will do.

Derbyshire Alliance for End of Life Care

January 2017

## Introduction

Irrespective of diagnosis, a person may be described as 'approaching the end of life' when they are believed to be likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- incurable, progressive, eventually fatal illness; including organ failure, cancer, and neurodegenerative problems.
- general frailty and co-existing conditions that mean they are expected to die within 12 months.
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- life-threatening acute conditions caused by sudden catastrophic events.

Palliative Care is an approach that improves the quality of life of patients and their families facing difficulties associated with life-threatening illness, through the prevention and relief of suffering; by means of early holistic assessment and treatment of problems (adapted from WHO 2009<sup>6</sup>). Palliative Care can be provided by a range of health and social care staff and may be done alongside active treatment.

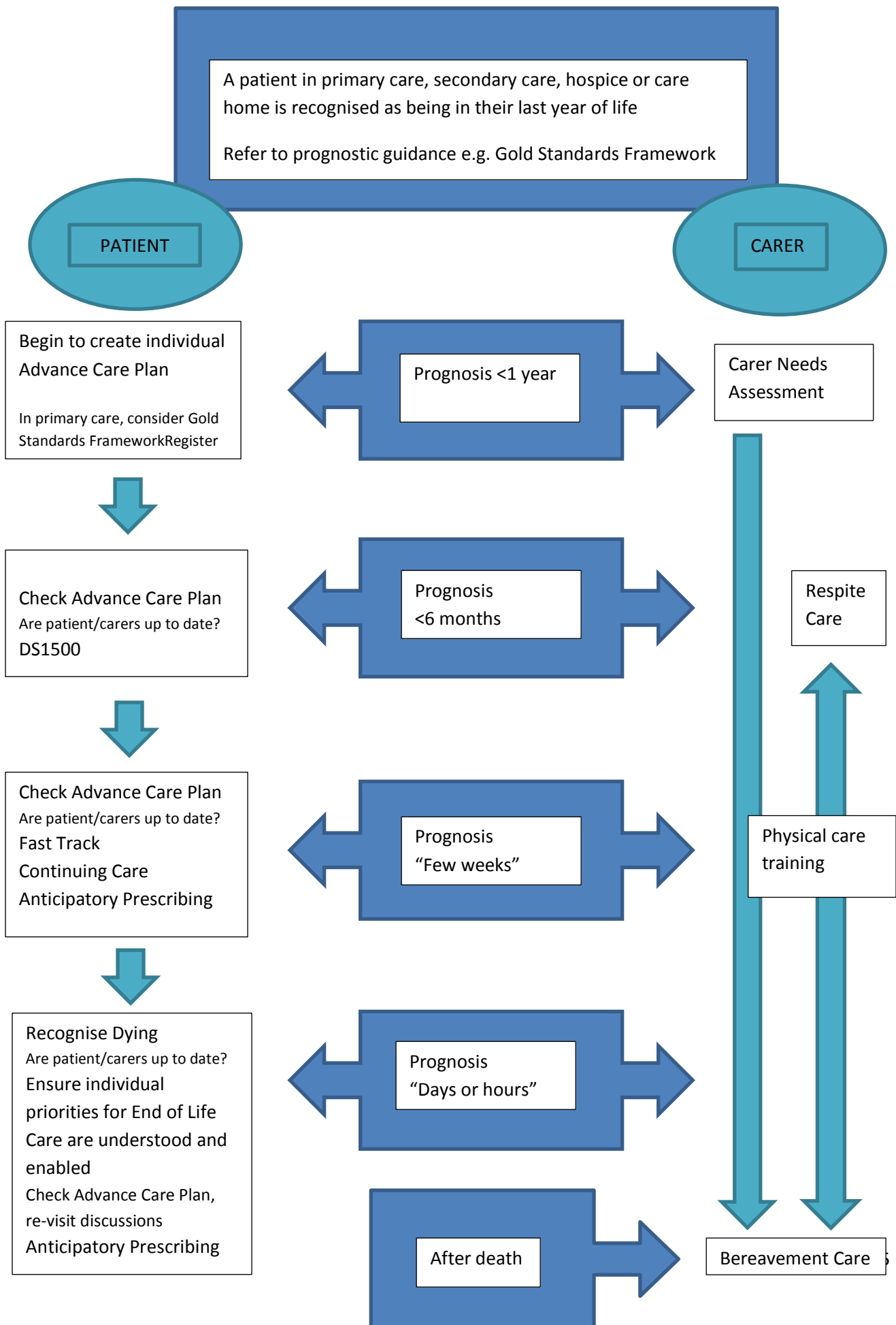
Understanding and delivering patient choice is central to excellent care at the end of life. The choices that patients make may depend on which stage they are at in their end of life journey. A patient with months to live is likely to have different priorities to a patient believed to be in the final hours of life. Excellent communication with patients and families allows professionals to understand individual preferences, so that they can work together to develop plans for end of life care.

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 provided in the community, fewer patients may need admission to specialist services such as hospitals or hospices.

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' stated preferred place of death and their actual place of death. Although more than 50% of patients state they would prefer to die at home, only around 20% achieve this aim<sup>7</sup>.

The purpose of this shared Derbyshire guidance is to support patients, carers and professionals working together to make individual plans for care at the end of life. It describes the Derbyshire Toolkit for End of Life Care - a suite of documents that empower professionals to support individuals as they make choices at different stages of their end of life journey. These documents should dovetail with disease-specific long term conditions guidance: elements of the disease-specific guidance (for example, management of infective exacerbation of COPD) may continue in parallel with end of life care tools.

**Figure 1: Flow Chart to illustrate End of Life Planning**



## Prognosis of less than 1 year

A patient may wish to discuss end of life issues at any time. **Professionals must be concerned about priorities for end of life care when a patient is believed to be in the last year of life.** Identifying the point when a person may have a life expectancy of one year is complex, especially for someone with a non-cancer diagnosis. For patients with a cancer diagnosis, there is often a clear moment at which the person moves from curative to palliative care. For those with a non-cancer diagnosis it is not unusual for there to be periods of deterioration which respond well to specific interventions. Disease specific prognostic indicators may be available (for example, from the Gold Standards Framework, [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)) to support clinicians recognising that a patient is approaching end of life.

In order that patients and carers can be fully involved in planning individual priorities for care, it is vital to consider whether it is appropriate to **talk about prognosis**. Any professional having sensitive discussions about prognosis should have received appropriate communication skills training.

When a patient is believed to be in the last year of life, a **key worker** should be identified. This is ‘a named professional who is “best placed” to ensure the person receives co-ordinated, 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 and physical examination of the patient** to identify any unmet needs. This will determine whether other actions are required, such as onward referral to disease-specific management teams or Specialist Palliative Care.

Additionally, there should be a **rigorous assessment of carer needs**. ‘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 provision. Assessment should consider the full range of respite care – at home or in a bedded facility – and provision of assistive equipment.

### Coordination of Care

The importance of coordinated care at the end of life is recognised by its designation as a key ambition for care<sup>3</sup>. Coordination of services must exist within teams and across organisational boundaries.

A method for more effective communication between primary and secondary care (Electronic Palliative Care Coordination System, EPaCCS) is required in Derbyshire. In addition to existing systems for professional sharing of paper and electronic patient care records (Summary Care Record) the use of a patient-held Advance Care Plan (e.g. ‘My Future Care’) should be considered (see below). For more information see [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk).

A primary healthcare team managing patients believed to be in the last year of life may consider adopting the '**Gold Standards Framework for Community Palliative Care**' ([www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)). This evidence-based framework aims to improve palliative care provided by the whole team by optimising continuity of care, teamwork, advance planning (including out of hours), symptom control and patient, carer and staff support. The GSF focuses on seven key principles (sometimes referred to as the 7Cs):

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

### **Advance Care Planning**

Advance care planning (ACP) is a **voluntary process** whereby an individual **who has capacity** to anticipate how their condition may affect them in the future may set on record choices about their care and treatment in specific circumstances. They may also state preferences for place of future care or death. This record can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity if their illness progresses. Under the terms of the Mental Capacity Act 2005, **formalised outcomes of advance care planning** might include one or more of the following:

- i. **advance statements** to inform subsequent best interests decisions
- ii. **advance decisions to refuse treatment** which are legally binding if valid and applicable to the circumstances at hand
- iii. **appointment of Lasting Powers of Attorney ('health and welfare' and/or 'property and affairs')**

Not everyone will want to make formal records. Less officially, a person may wish to name someone whom they wish to be consulted if they lose capacity.

An Advance Care Plan can be drawn up by the patient with any nominated health or social care worker. Key topics to consider in an Advance Care Plan include an individual's preferences regarding delivery of care as well as preferred place of care and preferred place of death. These are sensitive subjects, and staff supporting these patients may require communication skills training. By addressing these subjects and recording choices, it is more likely that patients will achieve their wishes. Recording such details also allows services to audit outcomes of care and analyse any reasons for deviation from original decisions.

Relevant documents e.g. 'Planning for your Future Care', and further information about Advance Decisions to Refuse Treatment (sometimes referred to as Living Wills) may be found in the Derbyshire End of Life Care Toolkit ([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)).

## Do Not Attempt Cardiopulmonary Resuscitation

A decision about whether cardiopulmonary resuscitation (CPR) is appropriate for a patient should be documented<sup>8</sup>. It is important to be clear that CPR is a very specific treatment and a decision not to attempt CPR does not preclude treatment of acute medical problems such as infection or hypercalcaemia.

If the healthcare team is as certain as it can be that a person is dying as an inevitable result of underlying disease or a catastrophic health event, and CPR would not re-start the heart and breathing for a sustained period, CPR should not be attempted. Even when CPR has no realistic prospect of success, there must be a presumption in favour of explaining the need and basis for a DNACPR decision to a patient, or to those close to a patient who lacks capacity. **It is not necessary to obtain the consent of a patient or of those close to a patient to a decision not to attempt CPR that has no realistic prospect of success.** The patient and those close to the patient do not have a right to demand treatment that is clinically inappropriate and healthcare professionals have no obligation to offer or deliver such treatment. **Where there is a clear clinical need for a DNACPR decision in a dying patient for whom CPR offers no realistic prospect of success, that decision should be made and explained to the patient and those close to the patient at the earliest practicable and appropriate opportunity.** Where a patient or those close to a patient disagree with a DNACPR decision a second opinion should be offered. Endorsement of a DNACPR decision by all members of a multidisciplinary team may avoid the need to offer a further opinion.

For more guidance and information for professionals and patients about DNACPR, see [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk).



## Prognosis of less than six months

At this stage, the person (regardless of diagnosis) may **apply for attendance allowance or disability allowance under special rules using a DS1500 form**, downloadable from [www.direct.gov.uk](http://www.direct.gov.uk). This will ensure applications are processed on a fast-track method. There should also be further assessment of the continuing care needs of the person, with application for support according to eligibility criteria.

**Communicating information to the provider of out of hours care** (Derbyshire Health United (DHU)) and the ambulance service should be considered at this time using relevant templates (Summary Care Record) or any other existing 'flagging' systems. This may include communicating **DNACPR status**, in accordance with local DNACPR policy. The out of hours services can then ensure priority is given to any referrals received for that patient.

Carers may require enhanced support at this stage, and the judicious use of respite can be helpful. Respite may be provided in a number of ways, involving day or residential care in hospice, hospital or care home settings. Some providers offer respite through a sitting service provided in the patient's home. The most appropriate type of respite support should be discussed and agreed with the patient, carer and health professionals.

A statutory Carer's Assessment should be completed by a social worker, if this has not already been done. A fast-track process should be used (where this is offered by the local council) for people who are in the last few months of their lives who have severe mobility problems associated with their condition and who cannot wait the 2 months which normal processing of the Blue Badge Scheme applications might take.

## Prognosis of 'a few weeks'

This stage is characterised by a deterioration suggesting the patient is entering the final weeks of their life. Such a change should trigger a review of advance care plans. Check patients and carers understand as much as they wish to about what is happening, as now time appears to be short. Any desired changes to an individual's priorities for care, particularly any changes to preferences around place of care or death, should be clearly documented. Professionals should renew efforts to deliver high quality care: anticipating physical care needs, maintaining good symptom control, giving consideration to psychosocial issues and supporting carers.

A further assessment of the physical care needs of the person should take place. The framework for NHS Continuing Healthcare funding includes a fast track process which can be used by a senior clinician for people with a rapidly deteriorating condition. This is appropriate for patients who have reached the 'weeks prognosis' stage to allow any needs to be met urgently (for example, to be at home to die). If a patient requires care, apply for support.

Prescription of anticipatory medication (in some areas contained in a 'Just in Case Box') should be considered at this stage, after discussion with the patient and carer. This ensures there is an emergency supply of 'as required' subcutaneous medication in the patient's home, in advance of any deterioration in the patient's ability to take medication orally. If needed, such medication will help control any distressing symptoms of pain, restlessness and agitation, nausea and vomiting, and respiratory tract secretions which may occur. In primary care, see CCG policy for the anticipatory supply of palliative care medication. Symptom management guidelines are available as part of the Derbyshire End of Life Care Toolkit ([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)).

The carer's needs should be reviewed 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.

**Sharing information (including DNACPR documentation) with Out of Hours Care (DHU) and the ambulance service is essential at this time.**

## Prognosis of days or hours

According to the approach set out nationally, when it is thought that a person may die within the next few days or hours there are **5 'Priorities for Care'**, which should be applied irrespective of the place in which someone is dying<sup>9</sup>:

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
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.

In Derbyshire, when a patient is thought to be entering the last days or hours of life, detailed advice on delivering priorities for care is available (**Derbyshire Handbook of Priorities for Care when a person is in the last days of life**: [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)).

It is recommended that the most senior responsible doctor completes a **Recognising Dying** document ([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)), whenever possible in discussion with a multidisciplinary team who know the patient well. Recognising Dying is a record of medical opinion on a specific day and requires documentation of an explanation to the patient and/or carer that the patient is believed to be in the final days or hours of life. 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 part of life.

Patients and carers may wish to discuss what to expect at this time. If the senior responsible doctor does not feel competent to have this discussion, it is imperative they seek a colleague (e.g. a member of the Specialist Palliative Care Team) for support. Patients (where appropriate) and carers should be offered **written information** ([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)).

Recognising Dying deliberately records opinion at a specific point in time, because patients may change and the process of dying can be unpredictable, particularly for those with a non-malignant diagnosis. Use of the Recognising Dying tool empowers the team to focus on priorities for care in the final hours of life. It may also be used to facilitate audit of quality of care in the last hours of life.

Recognising Dying is the ultimate trigger to review any Advance Care Plan or priorities for care at this final and most crucial period. Following completion of the Recognising Dying document, professionals should document an individual plan for the patient's care using existing notes or care plans, taking into account any expressed preferences. This is a change from previous recommendations to document all care on a shared pathway. It is acknowledged that patients who

are actively dying should not receive care that is fundamentally different to care given at any other stage of life. However, at this vital time, utmost attention to detail is warranted. Regular (for residential/in-patient settings, 4 hourly; for patients at home, at least daily) review of the patient and carers should be documented.

This period of care is consistent with 'care of the dying' as defined in the GSF; the focus is on proactive management. Any choices previously or currently expressed by the patient and family should be respected and as far as possible delivered. If a patient in hospital is believed to be in the last hours of life and they wish to die at home, Rapid Discharge (see [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)) may be considered. **Patients should be supported to eat and drink as they feel able.** Whenever appropriate, decisions about clinically assisted nutrition or hydration should be carefully discussed with patients (where possible) and carers. **Assessment of current medication, the discontinuation of non-essential drugs and the anticipatory prescribing of as required sub-cutaneous medication** for treatment of adverse symptoms are integral components of care at this stage. It is crucial that **providers of Out of Hours Care (DHU) and the ambulance service are notified of the patient's status** as this time using the relevant notification forms.

In the final days and hours of life, a **Carer's Diary** (available from [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)) should be offered to any loved ones attending the patient. This is a means of capturing 'real time' experiences of carers and can be an important adjunct to communication with professionals.

Information should be provided to family/carers about what to expect and what to do when the patient dies ([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)). In the event of the patient dying (whatever the setting) certification of death should be carried out as soon as possible. In some settings (nursing homes and community hospitals) nursing staff are trained to undertake 'verification of death'. This expedites transfer of the patient's body and the process of events after death.

## **Care after death**

Consider completing a Care after Death Derbyshire form (see [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)).

The information leaflet, 'What to do after a death in England and Wales' (DWP) should be provided to the next of kin (see [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)). All relevant services should be informed, including the provider of Out of Hours Care (DHU) and the ambulance service.

## **Bereavement Care**

Consider the provision of support for all those who are bereaved following a death. A key worker may have the advantage of established rapport with carers. Continuity of care at this stage is particularly beneficial, and may allow most accurate risk assessment for complicated grief. Onward referral to specialist services may be appropriate.

Whilst spiritual support is central for patients and carers at any stage, it may have particular emphasis at this stage.

## **Continued Learning: opportunities for professionals after a patient has died**

There is a well-recognised need for continued learning as professionals undertake care of dying patients. Circumstances that should prompt further discussion among teams include unexpected deaths of patients on the GSF register, deaths of patients that do not occur in the preferred place of care and feedback from any audit process.

Use of the GSF 'After Death Analysis Tool' is recommended.

## **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 condition-specific care, specialist psychological support, respite care, self-help and support groups, equipment loan services, spiritual care and specialist palliative care (SPC). 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**

Referral for specialist palliative care involvement should be considered at any stage where there are complex physical and/or psychosocial needs. Patients may be referred to, and/or advice sought from specialist palliative care teams 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
- Discharge planning (for those in hospitals) where specialist support is considered a requirement to help promote the quality of life for the patient and family
- Terminal care where specialist advice is required to enhance the comfort of the patient and family
- Staff support

## Standards

The national Key Performance Indicator (KPI) for End of Life Care has been number of home deaths expressed as a percentage of all deaths (National Indicator 129, Vital Sign 35); improvement being signified by an increasing percentage of home deaths. This is a proxy indicator, as it does not include deaths in residential or nursing care settings as home deaths, even when that is the normal place of residence. Nor does it give any indication of patient choice, i.e. whether or not home death was the preferred place. Other indicators of success for implementation of end of life care reinforce a number of principles relating to the provision of quality palliative care:

- The 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.

## Audit

It is strongly recommended that practices make full use of read codes relating to End of Life Care – templates can be developed for practice use to record evidence of care provided according to GSF principles. These can be used to monitor progress against the KPIs above and to provide evidence of:

- Adherence to the principles (seven Cs) of GSF.
- Referral to all appropriate members of the multidisciplinary team, including palliative care specialists when necessary, supported by a care package tailored to the individual's and carer's needs.

The Quality Outcomes Framework for General Medical Services gives a high level indication of numbers of patients on a Supportive and Palliative Care GP register, whose care needs are discussed by a primary care multidisciplinary team at a minimum of three-monthly intervals, but this should be regarded as a minimum standard. Mortality rates indicate that, on average, this relates to up to 1% of the practice population.

Further measurement of the quality of care provided to dying patients and their carers will come from a national survey programme of people who have been bereaved (VOICES<sup>10</sup>), 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

The CQC's chief inspectors will incorporate, as a key area, inspection of end of life care provided by all services.

In inspecting services which deliver end of life care in any setting, the CQC will review whether people receive care in line with the 'Priorities for Care'. CQC inspections of hospitals and care homes

will include 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 and unannounced. They will consider the role health and care staff play in care in the last few days and hours of life as well as care provided after death, including the support provided to bereaved families and carers.



## References

1. Department of Health (2008). End of Life Care Strategy: Promoting high quality care for all adults at the end of life. London: HMSO. Available at: <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life> (accessed January 2017)
2. The Independent Review of the Liverpool Care Pathway. (2013). More Care, Less Pathway: A Review Of The Liverpool Care Pathway. Available at: [www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients](http://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients) (accessed January 2017)
3. National Palliative and End of Life Care Partnership (2015). Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. Available at: <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf> (accessed January 2017)
4. The Leadership Alliance for the Care of Dying People. (2014). One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life. **Annex D**. London: LACDP. Available at: <https://www.gov.uk/government/publications/liverpool-carepathway-review-response-to-recommendations> (accessed January 17)
5. The Leadership Alliance for the Care of Dying People. (2014). One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life. **Annex E**. London: LACDP. Available at: <https://www.gov.uk/government/publications/liverpool-carepathway-review-response-to-recommendations> (accessed January 17)
6. WHO. Definition of palliative care. Available at: <http://www.who.int/cancer/palliative/definition/en/> (accessed January 17)
7. Gomes B, Higginson I. Where people die (1974 – 2030): past trends, future projections and implications for care. *Palliat Med* 2008; 22:33
8. Resuscitation Council UK (2016) Decisions relating to cardiopulmonary resuscitation. 3<sup>rd</sup> ed. Available at: <https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/> (accessed January 2017)
9. The Leadership Alliance for the Care of Dying People. (2014). One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life. London: LACDP. Available at: <https://www.gov.uk/government/publications/liverpool-carepathway-review-response-to-recommendations> (accessed January 17)
10. Office for National Statistics (2015) National Survey of Bereaved People (VOICES): England, 2015. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015> (accessed January 17)

## Appendix 1:

### Terms of reference, membership and aims of Derbyshire Alliance (July 2014; updated July 2016)

- a) *The Alliance is a clinical advisory group which primarily exists to:*
  - i) *promote and deliver integrated education for EOL for all healthcare professionals in the county of Derbyshire.*
  - ii) *maintain the Derbyshire End of Life Toolkit as a working resource for these professionals.*
- b) *It will report to the Derbyshire Countywide End of Life Group, which has representation from 4 CCGs in Derbyshire (NDCCG, SDCCG, Erewash and Hardwick) as well as social care services and other providers involved in EOLC.*
- c) *Membership of the Alliance will consist of representatives from primary and secondary care across the county including:*
  - i) *Macmillan GP Facilitators representing GPs*
    - i. *NDCCG/Hardwick: Dr Pauline Love*
    - ii. *SDCCG/Erewash: Dr Caroline Saxelby, Dr Jon Mead, Dr Eleanor Farrands*
  - ii) *Representing Specialist Palliative Care and Acute Trusts*
    - i. *DHFT/NMU: Dr Ruth England, Dr Maelie Swanwick, Karen Bussooa, Rob Smith*
    - ii. *Chesterfield Royal: Jo Froud*
    - iii. *Ashgate/Blythe House: Dr Sarah Parnacott*
    - iv. *Treetops Hospice: Phil Shreeve*
  - iii) *Representing District Nursing/DCHS*
    - i. *Karen Kitchen*
    - ii. *Community EOL Facilitators: Mich Binnion, Jane Ridley (North) Jane Carr, Tracey Nettleship-Lewis (South)*
- d) *The group will meet as required, alternating between North and South of the county, to develop the Toolkit and plans for education. A meeting of the group will be considered quorate if there are a minimum of 2 representatives from each side of the county present, including at least one Doctor.*