



ASSOCIATION OF
AMBULANCE
CHIEF EXECUTIVES



National End of Life Care Programme

Improving end of life care

The route to success
in end of life care - achieving
quality in ambulance services



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Foreword

Ambulance services play a crucial part in the delivery of high quality care at the end of life and in enabling people to achieve what they would consider a good death. This was recognised in the Department of Health's End of Life Care Strategy (2008).

Ambulance services provide planned transfers between settings, emergency transfer to hospital, transfers from hospital to enable people to spend their last days in the place of their choice, verification of death and immediate support to the bereaved.

However, to enable ambulance services to provide high quality care, a unique set of challenges and barriers need to be addressed and overcome. Ambulance clinicians often find themselves responding to those at the end of life with very limited information of the person's history, condition, preferences and wishes. They may have to make very difficult and time critical decisions, often in isolation.

This guide has been developed following an expressed need for a resource which focuses specifically on ambulance services and the delivery of end of life care. It aims to be a practical and valuable tool which highlights best practice, provides guidance on the role of ambulance services and others at each step of the end of life care pathway, and raises key issues that may need to be considered locally.

The Association of Ambulance Chief Executives fully support this publication and are committed to building on existing work to further develop high quality end of life care in ambulance services.

It is hoped that this publication will be an essential guide not only for ambulance services, but also for other health and social care providers, professionals, managers and commissioners.

It has been apparent in the production of this guide that there are many excellent initiatives underway across the country, and we hope we have truly reflected this throughout. These positive and inspiring examples highlight the opportune position that ambulance services are in to bring together stakeholders regionally and improve end of life care for all.

Professor Sir Mike Richards CBE
National Clinical Director
for Cancer and End of Life Care

Peter Bradley CBE
National Ambulance Director



Section 1

Introduction and policy context

Introduction

Ambulance services make a crucial contribution to enabling people to have their stated care preferences met and to achieve a 'good death' - dying with dignity, ideally in the setting of their choice.

Ambulance services may be involved throughout the person's journey towards the end of life in different ways. Planned involvement includes transferring people who are approaching the end of life between treatment settings or, in the final stages of life, from acute setting to their preferred place of death - home, care home, hospice or elsewhere.

Unplanned involvement is also common. For example, individuals approaching the end of their life may experience worsening symptoms or a sudden crisis; anxious carers and family members will often call 999 for emergency support. Ambulance clinicians are frequently at the scene, at or shortly after the point of death, and are involved in supporting families and carers, providing immediate bereavement support and in verifying deaths.

Whatever the circumstances, ambulance services and staff, including ambulance clinicians called to the scene may face a unique set of challenges. Other clinicians and health professionals coming into contact with the person/carer will often have already developed a relationship with them, have prior knowledge about their condition and care preferences, and have backup from colleagues.

By contrast, ambulance clinicians almost always 'go in blind' and often alone. They may have to make very difficult, time critical decisions - such as whether to attempt resuscitation (CPR) or transfer to hospital for treatment - with limited information of the person's history and condition.



Decisions must also balance their best understanding of what the person themselves would want from care, the sometimes conflicting preferences of carers and families, and any protocols, policies and duties of care that apply in that situation.

Indeed, current training and guidance for ambulance clinicians is to commence CPR until they have ascertained that a Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) order or other advance decisions is in place.

Nevertheless, with the right skills, information sharing and protocols in place, ambulance staff can swiftly assess the scenario and exercise their clinical judgement to provide care that is tailored to the preferences of the individual (and their families/carers where appropriate) and respects advance decisions such as whether to attempt resuscitation.

In practice, there are some significant systemic and strategic barriers and challenges that need to be addressed in order for ambulance services to play their full part in delivering high quality person-centred care at the end of life. These range from the lack of education, training and awareness of issues relating to end of life care at an individual level, to poor information-sharing systems and inadequate and inappropriate policies and protocols at a systems level. This is compounded at a strategic level by poor communication and co-ordination among the myriad of stakeholders involved in end of life care.

As a result, people at the end of life may undergo distressing delays, disruptions and interventions, such as inappropriate attempts at CPR or transfer to hospital for a person who has expressed a preference to die at home. The case studies below illustrate some of the problems which can arise and their impact on the person and their family or carers, and what can be achieved when ambulance services are able to respond appropriately:

CASE STUDY

Mandy was approaching the end of her life: she had a diagnosis of cancer and was experiencing severe uncontrolled pain. When her condition deteriorated, her GP visited her at home, reviewed her care plan and - in accordance with her wishes - arranged for her to be admitted by ambulance to the local hospice to die.

However, when the High Dependency Service Ambulance arrived to transfer Mandy to the hospice the crew were concerned that she was 'too poorly' to travel with them. Although her husband explained that she was on an end of life care plan, the crew upgraded the call and requested an emergency ambulance to attend.

The emergency ambulance arrived and, having assessed that Mandy was in heart failure, decided to take her to the local Emergency Department. Her husband was too distraught at this stage to say anything.

By this point the hospice staff were wondering where Mandy could be. After some time, they discovered that she was at the Emergency Department and sent the hospice doctor to review her. He identified that she was in the dying phase and requested an ambulance transfer back to the hospice, as per Mandy's original wish.

Mandy was eventually transferred to the hospice five hours after the original ambulance request and died there just seven hours later. Her husband had felt a responsibility to protect and nurture his wife as she died, and was understandably distressed that she had endured unnecessary transfers during her final few hours of life.

CASE STUDY

Paul, a 68 year old man with end stage COPD, called 999 as he was unable to get any oxygen out of his home compressor and was feeling breathless. The crew arrived to find him panicking and anxious; he was alone at home at the time and was worried he would not be able to breathe.

Paul was known to have a palliative care plan held by the local ambulance service; the clinical support desk informed the attending ambulance clinicians (ACs) that the plan stated that he had a terminal condition and a DNACPR in place. The crew were also informed that Paul was known to a local hospice, whose palliative care team should be contacted if they were considering taking him to hospital, as this was not his preferred place of death.

Following discussion with the ACs, the clinical support desk was able to arrange prompt repair of the faulty home oxygen compressor; meanwhile, Paul was able to use a reserve canister.

The ACs asked Paul whether or not he would like to go to the hospice. Paul felt comfortable in the knowledge he now had oxygen available and that a mechanic was en route to fix his compressor and stated that he wished to remain at home. As Paul had been off oxygen for over an hour and was being left at home, the ACs asked for a GP review, which the clinical support desk was able to arrange with Paul's surgery. Paul was comfortable and reassured once this was arranged and his oxygen saturations were normal. His wife was due to return home within the hour and the crew left him at home with a clear plan in place.

The fact that Paul already had a clear palliative care plan in place - coupled with the determination of the ACs and clinical support desk to arrange engineering and medical support - enabled him to remain at home and avoid an unnecessary admission. This approach respected Paul's autonomy and allowed him to make the important decision to remain at home in the final stages of his terminal condition.



At a structural level, the size of population covered by ambulance service organisations can make it harder to establish consistent, integrated systems for information, documentation and communication among multiple diverse smaller stakeholder and partner organisations and services. It can also create an opportunity for ambulance services to take the lead in bringing stakeholders together to find solutions.

Recognising this, many ambulance services are now focusing attention on how they support people at the end of life by developing their staff and creating appropriate policies and are integrating more closely with other organisations; good practice and innovative approaches are emerging, including from pilot projects. While ambulance services are at different stages in developing their approach to end of life care, this is an opportune time for services and staff to work with other stakeholders to ensure the right systems and skills are available.

Characteristics of high quality ambulance services at the end of life

- ✓ Person-centred - geared first and foremost to meeting the needs and preferences of the individual, and their carer/family
- ✓ Well-informed - linked by efficient integrated information systems so that staff are fully informed of any care plans, stated preferences and advance decisions such as whether to attempt resuscitation
- ✓ Prepared for the unexpected - able to swiftly assess the scenario and exercise sound clinical judgement, backed by clinical expertise
- ✓ Calm and courteous - sensitive to context, particularly in relation to cultural and spiritual issues.

The policy context

The End of Life Care Strategy (DH 2008) recognised ambulance services' key role in three important areas:

1. Rapid transfer of the dying
2. Developing appropriate transport for the person/carer
3. Developing robust information systems to ensure the wishes of the person (i.e. DNACPRs) are communicated to ambulance services and staff.

This reflects the key aim within the strategy to improve planning for end of life care so that it reflects the individual's needs and wishes, including preferences for where they receive their care and where they would like to die. In particular, the Strategy identified that 58% of all deaths occur in acute trusts (DH 2008) and noted the need to reduce this figure; ambulance services will be pivotal in delivering this reduction.

The Strategy also recognised that Ambulance Trusts are not always able to provide the correct level of service that supports high quality end of life care and identified strategic actions to address the root causes of these problems as follows:

- For the transfer of those going home from hospital to die, Primary Care Trusts (PCTs) have an important role in contracting providers to ensure a high standard of care. National work will continue to look at ways to support PCTs in this role.
- To support delivery of improved care, good commissioners of services will wish to ensure that all transport providers have in place policies for handling transport of carers, where they wish to accompany the person.
- To ensure that ambulance staff or transport staff are aware of the needs and wishes of the person they are transporting and that the care they provide is appropriate. Information systems should be adapted and/or developed to facilitate the sharing of information.



Following the publication of the Strategy, End of Life Care Quality Markers were published in June 2009, which helped define the key characteristics of high quality ambulance services at the end of life. These include:

- Congruence with locality end of life care planning
- Ability to transfer people at the end of life within locally defined timescales
- Mechanisms for identifying people approaching the end of life and the presence of care planning including; Preferred Priorities for Care (PPC) and Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)
- Education and training of staff in end of life care
- Developing communication mechanisms with GPs.

The National Institute for Health and Clinical Excellence (NICE) published a new quality standard for end of life care in November 2011. Commissioning guidance to support the standard was also developed and published in December 2011. The standard consists of 16 statements, many of which are highly relevant to ambulance services (see Appendix 1).

About this guide

This guide aims to provide practical support for health and social care professionals, service planners, managers and commissioners to address the challenges outlined above and develop and improve the quality of end of life care provided by ambulance services by working together at individual, system and strategic levels.

The guide has been developed by the National End of Life Care Programme (NEoLCP) in collaboration with the North West Ambulance Service NHS Trust and the Association of Ambulance Chief Executives.

It has drawn on the expertise and experience of a wide range of stakeholders, including ambulance clinicians, service users, health and social care professionals, managers and commissioners, through a stakeholder workshop in September 2011 and a wider consultation process.

A key message - from all stakeholders involved in this work - has been about the need for ambulance services and other organisations to work more closely together to overcome barriers and enable ambulance services to play their full part in providing high quality end of life care. To support this, the guide contains information for other organisations, as well as for ambulance service staff, managers and leaders, and aims to offer a tool to stimulate dialogue and improve all stakeholders' understanding of:

- The role of ambulance services in end of life care
- The importance of involving them at the early stages in service developments
- The benefits of closer integration
- The expertise, experience and insights that ambulance services can offer to help develop strategic solutions to shared challenges in end of life care.

As well as identifying ways of meeting the objectives set out in the End of Life Care Strategy, the guide should also help encourage the development of more innovative solutions and improve efficiency and productivity, in line with the requirements of the Quality, Innovation, Prevention and Productivity (QIPP) agenda.

The guide sets out:

- The context for ambulance services at end of life
- Key issues at each step along the end of life care pathway and actions that individual staff, ambulance organisations and other organisations can take to help achieve high quality care
- Top tips, good practice examples
- Suggestions for how to take this area of work forward and further useful resources.

"A young man had been admitted to A&E following a convulsion one evening. He was desperate to go home and was transferred by the crew. He had a haematemesis as he arrived at the house.

The crew helped the family to get him into bed and supported the family while he died.

This is so good. Whatever you are doing with your crews it's really making a difference."

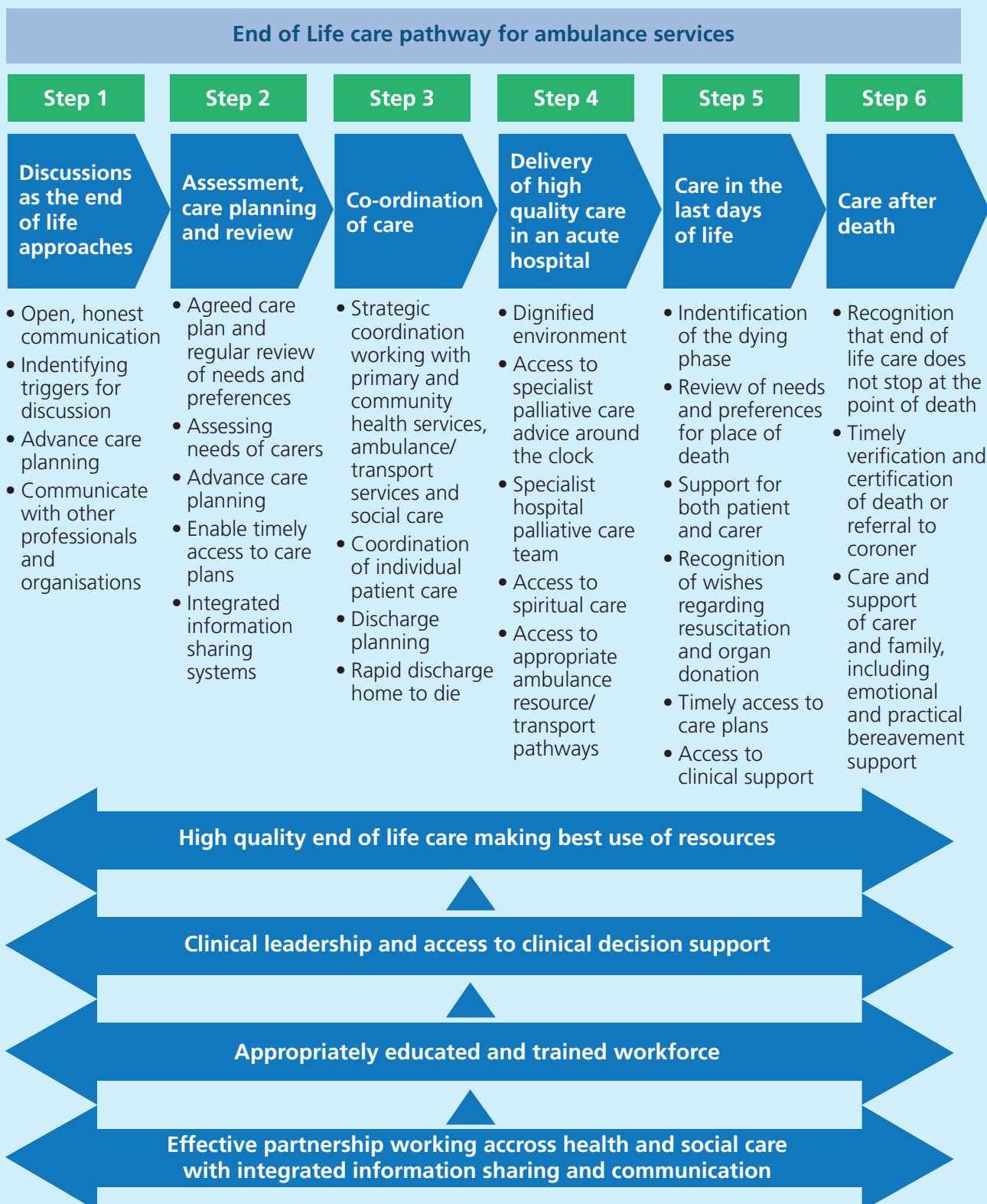
Palliative Care Consultant speaking about the care of a terminally ill man



Section 2

The end of life care pathway for ambulance services

The guide follows the six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death. The model below gives an overview of the pathway as it applies to ambulance services.



This pathway offers a helpful framework for considering how ambulance services can best support people at the end of life but it should be borne in mind that each person's pathway is different. Frequently it will not be a linear progression and ambulance services may be involved in different ways and at different times on a person's journey.

Some specific features, challenges and enablers arise at each step in this pathway, and are described in the chapters that follow. There are, however, some key common factors that underpin high quality care from ambulance services at the end of life across the pathway:

- **Education and training** is paramount, ideally provided jointly between organisations and services. Ambulance service staff will need to understand the concept and principles of end of life care in its widest sense, including the implications of decisions such as DNACPR and PPC, and any local protocols and guidance. They also need the communication skills to listen, assess and act in high pressure situations. Staff at other organisations need to understand what ambulance services can - and cannot - do and how to use ambulance services appropriately.
- **Advance care planning** that takes ambulance services into account will help services and individuals and their carers prepare for emergency scenarios so that they know who to call and have any relevant documentation on hand.
- **Effective systems for recording and sharing information across services** can identify people nearing end of life and flag care plans and stated preferences such as DNACPR so that ambulance clinicians can make appropriate decisions.
- **Effective communication** within teams, across services and organisations with users and carers can help reduce and manage unplanned and unnecessary admissions and interventions.
- **Consistent and coherent protocols and referral pathways**, developed collaboratively across services and regions, will help avoid delays and inappropriate interventions and transfers at a critical time. This needs to be backed up with access to clinical decision support 24/7 to guide ambulance clinicians at the scene.
- **Closer partnership working among all stakeholders** is essential. Enabling ambulance services to play their full, part in providing high quality end of life care is a shared responsibility. It calls for collaboration between all services and organisations in planning, commissioning and delivering end of life care.
- **A commitment to putting the person first** underpins all of this work. All those involved, including ambulance clinicians at the scene, will need to keep their focus on what that person would want from care and take personal responsibility for delivering this.

Section 2 The end of life care pathway for ambulance services

Step 1

Discussions as end of life approaches

Key issues

End of life care applies when an individual is thought to be in the last 6-12 months of life. Some people, including those with long term conditions such as chronic obstructive pulmonary disease (COPD) or dementia, may be on the end of life care pathway for some time prior to death. Ambulance services and staff have a more significant role and contribution during this period than might be first thought.

People at the end of life may have contact with ambulance services on several occasions for example when a complication occurs, which creates a sudden health crisis, or for an unrelated event such as a fall. Here, it is important that staff are aware of the underlying condition(s) and any advance care planning decisions that may be in place when administering care.

In other cases, increasingly frequent calls to ambulance services, for example in a person with COPD who is experiencing more difficulty breathing, may indicate that the condition is deteriorating. Here, ambulance staff may be the first point of contact for the person; they need to be able to recognise signs, signals and clues that suggest that it may be time to initiate discussions about end of life care and relay this information onto the person's GP, hospital, other health professionals or organisations so that appropriate action can be taken.



To achieve high quality care at this step, the role of individual staff is to:

- Be alert to signs, triggers and clues that suggest it may be time to initiate discussions about end of life care and communicate these to other professionals and organisations
- Be prepared to ask the person/carer about possible end of life care planning and related issues
- Understand other organisations' roles; and be aware of what additional information/ guidance may apply, such as care planning or care preferences documentation
- Consider whether the individual requires a referral to another service for support at this time
- Take responsibility for ensuring that continuing professional development (CPD) includes education and training in end of life care, as well as communications skills (especially listening skills).

The role of ambulance organisations is to:

- Develop and provide end of life care education and training programmes and resources so that ambulance staff understand issues and implications around caring for people nearing the end of life; this includes the communication and listening skills to recognise signs and signals and handle discussions sensitively
- Ensure effective information-sharing systems are in place to enable ambulance services to pre-alert ambulance clinicians if a person has been identified as being at the end of life
- Ensure there are effective, integrated communication and information systems to enable ambulance staff to refer people or pass on information they have gathered to other organisations involved in the end of life care of an individual (where consent is obtained).

The role of other organisations is to:

- Engage ambulance organisations in discussion and planning at a local level, so that there are robust integrated communication and information systems.

GOOD PRACTICE EXAMPLE

Self-Managed Learning Pack

North West Ambulance Service have developed a self-managed learning pack for all call centre and frontline staff in emergency and patient transport services; this has been developed in line with the North West Strategic Health Authority End of Life Care Model. This pack includes real life scenarios and has given staff confidence when dealing with people at the end of life. It has also been well received from other external organisations.

The service has also ensured that end of life care is part of mandatory training for all staff during 2012. This will enable staff to be updated yearly on end of life care issues, along with other regional and local developments.

For further information contact:

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TOP TIPS

- When thinking about end of life care, don't just think of the dying phase. Ask yourself the 'surprise question', for example "would I be surprised if this person were to die in the next 12 months?"
- Be alert for verbal and non-verbal clues that suggest it is time to start thinking about end of life care arrangements and preferences, for example a person with COPD saying "If I stop breathing, I wouldn't want anyone to try to resuscitate me"
- Be aware of cultural and spiritual issues relating to death, in order to handle discussions sensitively
- Make use of the e-ELCA e-learning for end of life care (www.e-lfh.org.uk/projects/e-elca). There are more than 150 modules available free of charge to health and social care staff
- Look for opportunities to provide education in partnership with other organisations involved in end of life care to improve mutual understanding of roles, such as hospices and care homes
- Consider making end of life care a mandatory part of training for all ambulance staff
- Ensure ambulance staff receive training in communication skills, including how to break bad news to relatives.

Step 2

Assessment, care planning and review

Key issues

Assessment, care planning and reviewing procedures provides the basis for high quality, person-centred end of life care. Plans may relate to important decisions such as where the person would prefer to receive their care and/or die (e.g. at their home or care home), specific care or treatment preferences or resuscitation decisions.

It is vital that ambulance services are made aware when such care plans and arrangements are put in place or reviewed for people nearing the end of life. Ambulance clinicians can then be pre-alerted to the existence of the care plans or preferences, helping to ensure that wherever possible they can access and follow the plan, preventing unnecessary conveyances/ or hospital admissions and/or undesired interventions such as resuscitation attempts.

The assessment and care planning process also affords an opportunity to educate and prepare the person/carer about what to do in the event of an emergency, and the role of ambulance services in providing care.

This may include advising them to keep documentation about plans and preferences close to hand so that it is readily accessible in an emergency; and providing emergency contact details such as an out of hours service or support system locally. Effective advance planning will also take into account any issues around lack of mental capacity or potential loss of capacity in the future (such as dementia), thus helping ensure that decisions taken by ambulance clinicians in an emergency are in the person's best interests and preferences.

However, even the most effective assessment; care planning and review procedures may not always cover every eventuality. Ambulance clinicians will still need be able to respond to unexpected scenarios, including situations where relatives or carers, or other staff such as GPs, decide not to follow the person's agreed care plan; access to clinical decision support services is vital.



To achieve high quality care at this step, the role of individual staff is to:

- When called to a scene, be prepared to ask whether there is an advance care plan in place
- Work within their scope of clinical practice to make the right decision for that scenario, based on the wishes and best interests of the individual and their care plans and stated preferences where these exist. This includes eliciting and being responsive to carers' needs as well as those of the person at end of life, and being prepared to manage any tensions and/or differences between the two
- Develop their knowledge and understanding of the different types of care plans and documents including Gold Standards Framework, Preferred Priorities for Care and DNACPRs
- When dealing with unexpected events, be aware of how to recognise if a person is near the end of life, and of how to access further clinical guidance or support if needed
- Following attendance, follow established referral processes locally, share information about the person/carer that might help inform or prompt further review of their care with relevant professionals and organisations; and communicate or update any changes to existing care plans.

The role of ambulance organisations is to:

- Ensure there are robust systems that pre-alert ambulance staff to the fact that a person is at the end of life and, where applicable, has a care plan, advance decision documentation or other statement of preferences in place; there should be access to records and care plans where possible to support clinical decision making
- Develop and deliver education and training in end of life care for all levels of ambulance staff to ensure awareness of issues around advance care planning, preferences, Mental Capacity Act
- Develop robust clinical leadership systems so that ambulance clinicians have access to timely and high quality clinical advice and support 24/7
- Engage with other organisations involved in assessing a person's needs and planning their care, so that ambulance services are taken into account in the procedures and documentation for care planning.

The role of other organisations is to:

- Work with ambulance organisations to ensure that the procedures for assessment, care planning and review take ambulance services into account
- Build into care planning guidance and documentation questions such as: "Have you informed your ambulance service of the person's 'end of life' care planning status?"
- Ensure that staff involved in assessment and care planning processes discuss the role of ambulance services with the person/carer and advise them to keep relevant documentation to hand for in the event of an emergency.

TOP TIPS

- Consider whether this is an end of life issue; don't assume that the situation is as it presents
- Be prepared for differing opinions and wishes at this time and ensure knowledge of the care plan identifies the course of action to follow for the individual
- Actively seek out care plans. Pre-programming the person/carer's phones with relevant contact numbers can make it easier for them to call the right organisation/agency in the event of an emergency
- Other service providers can advise the person/carer to keep any relevant documentation, including DNACPR decisions, close to hand and readily accessible for in the event of an emergency
- Link with local palliative care specialists, who can be a valuable source of expertise and guidance.
- Ensure information for ambulance clinicians is portable - A6 information cards, for example, will fit inside the JRCALC (Joint Royal Colleges Ambulance Liaison Committee) book that most ambulance clinicians will carry in their uniform pockets.
- Ambulance services can establish referral pathways with relevant organisations for example GP's /out of hours/district nurses for situations where the person has expressed a clear wish to remain at home and not to be transferred.

Effective advance care planning

Stephen had end stage renal failure. He was discharged home with a Palliative Care Plan which included a DNAR order and stated his preference to be left at home to die unless the presenting illness was unrelated to his chronic condition.

The following day, his family called 999 following a series of seizures. The clinical support desk communicated the information in Stephen's plan to the attending crew and informed them that he was known to a local hospice. The crew then contacted the local out of hours GP service to attend and discuss the best management plan for Stephen as they were concerned about leaving him with no care package in place.

The GP spoke to the local hospice and palliative care team who felt that admission to the hospice was the best option to prevent A&E admission, in accordance with Stephen's preferences. The crew took Stephen and his family to the local hospice and he passed away peacefully two days later.

Without the provision of a high quality palliative care plan and excellent communication between the paramedics in the control centre and those attending Stephen and his family may not have had such a positive experience.

GOOD PRACTICE EXAMPLE

Generic DNACPR documentation across a strategic health authority

Inconsistencies in DNACPR documentation and procedures across the Yorkshire & Humber area resulted in ambulance clinicians frequently attending situations where people had a DNACPR document in place, but it was not clear whether the document was valid or still in-date.

To address this, a regional working group involving all stakeholders within the health economy - including Yorkshire Ambulance Service, GP practices, PCTs, community nursing, hospices, palliative care, care homes and acute trusts - worked together to develop a generic DNACPR document, which would be easily recognisable by ambulance clinicians wherever they are in the Yorkshire and Humber area.

Based on the UK Resuscitation Council's document with some modifications based on the Mid-Lothian system and local practice, this DNACPR document captures the decision made by the clinical team and the person and carer/family; a single hard copy exists and travels with that person along their care pathway.

Before 'going live' with the system, PCTs must demonstrate that they have engaged local stakeholders and have put in place audit and training processes, reflecting the fact that education and improved communication are key to successful implementation.

The system is now in place across the whole area. Results are expected within the next 12 months: in addition to contributing to each person having a dignified death, it is anticipated that over time there will be a reduction in 999 calls to those with DNACPR's in place but who have gone into cardiac arrest.

Yorkshire Ambulance Service report the initiative has also opened doors for them to improve mutual understanding and engagement within the wider end of life care arena.

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GOOD PRACTICE EXAMPLE

End of Life Care Decision Support Tool for Ambulance Clinicians

Research in 2010 conducted at the University of Warwick indicated that emergency ambulance clinicians attend a person they recognise as being at the end of life approximately once every one or two weeks. Findings suggested that ambulance clinicians frequently lack the knowledge or confidence to effectively manage these individuals, making transport to hospital and resuscitation following a cardiac arrest the default responses.

These research insights were used to develop an online education programme led by Coventry University, which has to date been completed by more than 1,000 ambulance clinicians from the West Midlands Ambulance Service (WMAS).

The project team recognised that despite the education, ambulance clinicians would continue to face the challenge of needing to make rapid decisions about individuals unknown to them. Building on the research findings, a team from the University of Warwick and WMAS has been developing a Decision Support Tool to enable ambulance clinicians to make rapid and safe decisions in a person's home.

The tool covers decisions around transport/non-transport, resuscitation and the management of people in peri-arrest situations. Ambulance clinicians are encouraged to complete the online education before using the tool. The tool is undergoing pilot testing in the WMAS and will be ready for release in 2012. The education and Decision Support Tool projects are both funded by NHS West Midlands.

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Step 3

Co-ordination of care

Key issues

Multiple agencies, organisations and services are frequently involved in caring for a person nearing the end of life. Effective co-ordination and integration of these elements, at both individual and strategic level, can help ensure that care is tailored to the person's needs and requirements and minimises unnecessary delay and intervention, at a stage when time is precious.

This can only be achieved if ambulance services are directly engaged in wider multi-stakeholder discussions around planning, commissioning and delivering services at the end of life. This should encompass all dimensions of care provision, including:

- Policies and protocols to guide ambulance clinicians and other staff, including conveyance, handover, transfer of care and issues of clinical responsibility
- Information-sharing systems
- Call-handling procedures, including emergency calls to 999 (and the new 111 service currently being piloted)
- Referral pathways and arrangements for 24/7 provision of both health and social care
- Procedures for verification/certification of death (see Step 6).

The strategic size and nature of ambulance trusts affords a key opportunity to support this. In particular, ambulance trusts are well placed to lead on the development of innovative, shared solutions to support safe and secure information sharing across the many different organisations involved and promote integrated responses.

This may require a higher profile and more pro-active approach for ambulance services in health and social care policy and planning, and may require a change in culture within ambulance organisations and elsewhere.

Ambulance services can also support the co-ordination of care by developing robust, well governed referral pathways and clinical advice for staff to access 24/7.

To achieve high quality care at this Step, the role of individual staff is to:

- Get involved in local strategy and planning groups in order to raise the profile of ambulance services and influence decision-making at a local level. Contribute to initiatives to gather and share data (eg through audit), learning and good (and poor) practice to inform and influence decisions about services.

The role of ambulance organisations is to:

- Be proactive in working in partnership with other provider organisations to develop integrated IT solutions to support the sharing of advance care planning information from existing systems such as: virtual wards, locality registers for end of life care, integrated records systems and GP systems
- Develop clinical leadership to ensure staff have access to timely and high quality clinical advice and support 24/7. This may include ensuring access to expertise from other specialties, such as hospice advice lines

- Promote a learning culture that encompasses clinical support, review and audit processes to enable learning from both good practice and mistakes when these occur
- Help lead and co-ordinate on the development of strategic, regional policy for areas such as DNACPR
- Be proactive in working in partnership with other provider organisations to develop referral management pathways and to improve utilisation of other community services, including out of hours medical services. This may include establishing a national group within the ambulance service to facilitate partnership working and ensure this filters down
- Gather and share data on ambulance services and contribute to audit processes to inform decisions on service commissioning, planning and delivery
- Work with commissioners to ensure that the commissioning of end of life care services supports the integration of care and promotes partnership working with other provider organisations.

The role of other organisations is to:

- Involve ambulance services in discussions about end of life care at a strategic/organisational level, and promote closer working among teams and individual staff
- Ensure that education and training in end of life care for their staff supports understanding of the role of ambulance services; involving ambulance services in education and training programmes will promote this
- Recognise that ambulance services cover much larger populations and areas than most other services and organisations in a given area, and be prepared to collaborate and compromise in order to achieve consistency in policies and procedures across the diverse range of stakeholders.

TOP TIPS

- Identify an end of life care 'champion' within ambulance services, who can support co-ordination, link into end of life care networks and drive change
- Ambulance personnel need clarity on protocols and policies and repeated changes will inhibit this. Allow time for policy changes to filter through the service and be effectively implemented and avoid repeatedly changing policy
- Make use of whole system critical incident reporting systems and clinical quality groups to identify and review problems and feed this data back into commissioning processes
- Promote a learning and 'fair blame' culture that supports staff when mistakes are made; ensuring organisational and individual learning.



GOOD PRACTICE EXAMPLE

Electronic Referral and Information Sharing System (ERISS)

This electronic web-based application designed to enable communication and secure information sharing between North West Ambulance Service and other key stakeholders to help improve awareness of and access to care planning documents.

Users can request a warning flag to be placed against a person's address, which alerts ambulance staff to the presence of an end of life care plan such as DNACPR or PPC. The system has in-built mechanisms for keeping up-to-date: flags are valid for a defined period after which the originator is

automatically contacted for an update; a tracking function alerts administrative staff to any changes made to an individual's status.

This is currently in the final stages of development and is planned to go live during August 2012.

For further information contact:
Steve Barnard, Head of Clinical Governance,
North West Ambulance Service NHS Trust
Steve.Barnard@nwas.nhs.uk

GOOD PRACTICE EXAMPLE

Co-ordinate my Care register

End of life care registers have been successfully piloted in various sites in the London area to improve the co-ordination of care in a user-centred manner so that people's wishes are met during the final stages of their lives. The new electronic version allows a contemporaneous, legible record which ensures that key data points are entered and enables professionals working in acute and community settings to update the record as the person's needs and wishes change.

To avoid the risks of an uncoordinated approach across different areas of London, which could reduce envisaged benefits for service users and increase clinical risk, a single pan-London solution, Co-ordinate my Care (CmC), has been agreed. CmC will also be accessed by the 111 services to ensure that the individual's needs and wishes are followed when appropriate.

Anticipated benefits include:

- Individuals' preferences and choices, when they wish to express them, being documented and communicated to appropriate professionals
- An improvement in the individual's experience
- The co-ordination of care for individuals across organisational boundaries 24/7
- Support for professionals to have appropriate user-centric discussions
- Decreased costs (due to a decrease in unnecessary hospital admissions)
- Ability to provide auditable outcomes.

For further information contact:
David Whitmore, Senior Clinical Adviser to the Medical Director, London Ambulance Service NHS Trust
david.whitmore@lond-amb.nhs.uk

GOOD PRACTICE EXAMPLE

Referral pathways to reduce unnecessary hospital admissions

Yorkshire Ambulance Service worked with the district nurse managers in nine PCTs to develop robust referral pathways for each area so that when ambulance services are called to a person who is known to be on an end of life care pathway, they can refer the person to community nursing teams via a clinical hub (single point of access).

The clinical hub will contact the relevant community nursing service (24/7) and then a clinical discussion can take place between the AC and the nurse to agree a care plan. This initiative was prompted by concerns raised by hospitals that people on end of life care pathways were being brought inappropriately to A&E.

As a result of the initiative, more people have been able to avoid inappropriate admission and remain in their own home. YAS and the end of life care leads have been able to carry out case reviews for each call received to ensure that lessons can be learned about

why there was the need to involve the 999 service. In some cases it identified the need for more robust information to the family about who to call if there was a crisis.

More education for ambulance clinicians is now being planned and work is being led by the Yorkshire and Humber End of Life Care Education Group to support development of suitable training packages and resources.

The next step for this initiative is to roll out the pathway across the wider area so that there is a consistent and standardised approach for AC's to follow. YAS are now represented on the Yorkshire & Humber End of Life Care Pathway Leadership Board and this group will continue to support the roll out process.

For further information contact:
Cathryn James, Clinical Pathways Advisor,
Yorkshire Ambulance Service NHS Trust
Cathryn.James@yas.nhs.uk



Step 4

Achieving high quality care across different settings

Key issues

Individuals and carers may need access to a complex array of services across a number of different settings as they approach the end of life. Ambulance services, including patient transport services and emergency ambulance services, are often involved in conveying people between these settings. This includes transfer between care homes. Arrangements have changed with regards to the role of the ambulances services and some organisations may not fully understand the transport options available.

Although such transfers are often planned in advance, they can be fraught with complexities. In the absence of consistent policies, protocols and procedures across organisations and settings, delays are commonplace, resulting in inconvenience and distress to the person and carer as well as inefficient use of resources.

For example, patient transport services may arrive to convey a person but be unable to convey their essential equipment or medication, or accompanying carer; here, an urgent health professional booking should have been made instead. DNACPR information about a person may not always be made available.

There are often particular challenges in transfer between care homes, for example where contractual obligations at a care home require that anyone being moved from the premises be escorted, but there is no provision for returning the escort to the care home; elsewhere a person may be transferred to a new care home only to find that essential treatment, such as oxygen,

cannot be administered by staff on arrival. Better communication between departure and destination settings would help avoid such incidents, but action is also needed at an organisational level to address inconsistencies in policies and procedures.

Wherever and however a person nearing the end of life is being transported, it is essential that there are clear handover arrangements so that clinical responsibility is properly assigned; and that ambulance clinicians know what to do in the event of deterioration (or death) in transit and can be confident when leaving that the person will receive appropriate and dignified care.

In practice, handover arrangements are often sub-optimal; this can be complicated by poor communication, for example between acute and other services, and by the fact that there is frequently a lack of inter-organisational policy to clarify clinical responsibility and the transfer of care from one setting to another.

Above all, it is vital that all staff involved in conveying a person nearing the end of life understand and are sensitive to the emotional and practical difficulties which they and their carers may be experiencing. Maintaining dignity and respecting preferences is paramount at this point.

To achieve high quality care at this Step, the role of individual staff is to:

- Ensure they access and follow advance care planning documentation wherever possible; this includes statements of preferences and wishes
- Follow agreed referral pathways and communicate and share information with other service providers
- Escalate clinical issues for further advice or support where there is a lack of information or difficulties in agreeing a care plan
- When undertaking transfers, ensure that they have knowledge of the person's condition, who is the responsible clinician and what to do in the event of deterioration or death in addition to copies of relevant care plan documents
- Be clear as to who will be receiving the persons at the end of the journey where possible
- Be sensitive and alert to the needs of the person and their carers at this stage.

The role of ambulance organisations is to:

- Ensure that education and training on end of life care involves patient transport services staff (as well as ambulance clinicians) so that they are aware of their role and of the potential needs of people nearing the end of life
- Establish clear policies and protocols, for example on handover and conveyance of equipment (such as oxygen, syringe drivers), accompanying persons etc. Ensure these policies are fully understood by ambulance staff and other organisations and staff involved in care
- Lead and influence on the development of inter-organisational policy to support the safe and effective transfer of high quality care between different organisations and care settings
- Work with other organisations to establish clear booking criteria for ambulance services, so that those booking these services understand policies and restrictions. This includes ensuring that staff know how to use urgent health professional booking systems to arrange appropriate transport for the person and any carers.



The role of other organisations is to:

- Ensure staff carefully considers the needs and issues of the individual being conveyed - including essential equipment, accompanying persons etc., book the right service
- Ensure that staff at departure and destination settings communicates in advance about equipment, medication, escorting arrangements etc
- Work together to remove the inconsistencies in policies, procedures and contractual arrangements which can cause delays and disruption for the person/carer.

GOOD PRACTICE EXAMPLE

Palliative Care Transfer Procedure

North West Ambulance Service is piloting a palliative care transfer procedure for more stable people to be transferred within a four hour booking time using the Patient Transport Service. These people are on the end of life care register but are likely to have weeks or months to live; they will have been identified by the hospital, hospice or nursing home as meeting agreed criteria for not requiring rapid transfer via the Trust Emergency Service. This is being tested with pilot sites.

For further information contact:
Steve Barnard, Head of Clinical Governance,
North West Ambulance Service NHS Trust
Steve.Barnard@nwas.nhs.uk

GOOD PRACTICE EXAMPLE

Hospice-provided training for ambulance staff

St Francis Hospice in Romford has worked with the local ambulance trust to provide training in end of life care for Emergency Care Practitioners (ECPs). This project aimed to enhance the skills and knowledge of the ECPs to enable them in decision making and help them recognise some of the complications and complexities at the end of life.

The ultimate aim was to keep people in their preferred place of care. The training covered five key areas: understanding the challenges, palliative care emergencies, end of life care tools, syringe drivers and end of life care drugs. Sessions were delivered on five separate days and were delivered by the lecturing team, clinical nurse specialists and the medical team at St Francis Hospice.

The training was very well received and appears to have led to improvements in end of life care provided. Those involved also reported that it has enabled them to build better links between the hospice and the ambulance trust, laying strong foundations for further collaborative working.

For further information contact:
Caroline Scates, Head of Education,
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Step 5

Care in the last few days of life

Key issues

A point comes when the person enters the 'dying phase'. Ambulance services are frequently called upon at this stage. This may be for planned transport, such as rapid transfer of a person from hospital or hospice to their preferred place of death.

The recommendations described under Step 4 apply here and the higher risk of deterioration during the transfer makes clear handover policies and assignment of clinical responsibility particularly important. Problems have been identified with this in discharge from acute settings and out of hours - especially 'Friday discharges' - where multidisciplinary and intra-organisational planning and communication can fail, resulting in long delays, which can be highly distressing when a person wishes to be taken home to die.

Similarly, the higher risk of death in transit makes it especially important that ambulance clinicians ascertain before departing whether a person should be conveyed to the destination setting, or returned to the departure setting.

Ambulance services are also frequently called during the dying phase because of an unexpected complication, or a sudden deterioration in condition. Advance education and preparation for the person/carer can help to direct them to the best crisis response service, and new services such as 111 may help filter calls, but in a panic situation many will instinctively call 999. In some cases, an A&E 'life-saver' response may be neither necessary nor desirable.



Good call-handling procedures can help ascertain and pass on to ambulance clinicians what outcome the person or carer wants and expects from ambulance services - to make the person comfortable, for example - and avoid unwanted hospital admission or attempts at resuscitation. In practice, however, 999 calls are almost always treated as A&E.

Families and carers may sometimes wish for ambulance services to be called even where the person themselves has indicated a preference to die at home or in their usual care setting such as a care home. Here, care home staff need to have clear procedures and be supported to enable them to adhere to a person's care plan where possible, and make appropriate decisions about when to call emergency services.

Whatever the reason for the call, ambulance clinicians attending to a person in the last days of life need rapid access to the full range of information on their care plans, preferences and any advance decisions: effective information-sharing and flagging systems are vital.

At the scene, the focus must at all times be on providing the person with the care and treatment that is in their best interests. Families and carers can be valuable sources of knowledge and expertise on this and should be kept informed.

Ambulance clinicians must at the same time be alert to the possibility of differing views and/or resistance to following an agreed care plan or stated preference among families and carers, including GPs and be prepared to deal with these. They may need rapid access to clinical decision support services to help them make the right judgement in such instances.

Ambulance services can also act as a conduit for information about a person 'out of hours'.

To achieve high quality care at this Step, the role of individual staff is to:

- Act within their scope of clinical practice and exercise sound ethical and clinical judgement to act in accordance with the person's wishes, insofar as these can be ascertained
- Be prepared to ask on arrival whether a care plan or other statement of preferences or decisions is in place
- Be prepared for the unexpected, including the possibility of differing views or resistance to a person's care plan among family and carers, and seek further advice where required
- Be willing to be the responsible clinician themselves where appropriate
- Pass on any relevant information gathered about the person's condition or health status to other organisations involved in their care.

The role of ambulance organisations is to:

- Engage other stakeholders to ensure handover and non-conveyance policies are fit for purpose and widely understood, and give adequate legal protection to staff
- Engage directly with local acute trusts to improve rapid discharge pathways from acute services to the person's preferred place of care
- Work with commissioners to review commissioning/funding arrangements to support the development of rapid transfers such as rapid discharges from hospitals
- Consider new approaches to commissioning. Is there a role for ambulance services that specialise in end of life care, for example?
- Provide clinical support desks/services so that ambulance clinicians can access clinical leadership remotely.



The role of other organisations is to:

- Ensure that the person and their carers/ family are educated about what to expect in the final days and hours of life; and are given information and advice on what to do in the event of an emergency and on the role - and limitations - of ambulance services at this stage. This includes helping them understand that the ambulance service is not always the most appropriate service to call
- Approaches to improve the quality of end of life care delivered
- For transfers, consider the types of vehicles being used and whether they provide privacy and dignity and enable relatives or carers to travel
- Develop discharge pathway procedures with ambulance services to ensure their requirements are met and to avoid unnecessary delays
- Ensure that up-to-date information is held by the person, in their home setting, which can travel with them. Carers (family or domiciliary carers) will need to know where this is kept
- Review their handover policies and procedures to ensure that these do not contribute to delays in transferring the person at this critical stage.

Effective collaboration between providers

David, was a 22 year old man, dying from cancer. He had expressed and recorded his preferred place of care as the hospice or his home. His mother was his main carer but was becoming very tired and anxious so the Macmillan nurse had arranged for him to be admitted to the hospice.

The morning that David was due to be transferred to the hospice the ambulance crew arrived and assessed him for transfer but realised that he had deteriorated and was in the end stage of life. His symptoms meant that he was very weak and their assessment indicated that he could die in the ambulance. They discussed this with his mother and then contacted the Macmillan Nurse and hospice consultant. The ambulance crew assisted to ensure his comfort until the Macmillan nurse arrived and David died peacefully at home 2 hours later as a result of positive use of the end of life tools and collaborative working.

Managing conflicting carer views

Cathy was on an end of life care pathway. Her condition had deteriorated rapidly, 24 hours after discharge from hospital. A palliative care nurse specialist attending at home could see that Cathy was dying but her family had not been prepared for the fact that she was so ill. They were highly distressed and disagreed about what should be done at this stage: some insisted on calling 999 for an ambulance; others were very concerned about the possibility of Cathy dying in A&E, which would be against her stated wishes.

The ambulance crew that arrived at the scene were sensitive to the situation -

kind and compassionate to Cathy and her family and supportive to the nurse, who was struggling to help a seriously ill person while managing tensions in the family. The nurse called the local palliative care specialist for advice. Following this, the crew agreed to transfer Cathy urgently to her local hospice rather than to A&E as originally planned. Once there, hospice staff were able to prepare Cathy and her family for her death and control her symptoms.

Thanks to the responsiveness and sensitivity of the ambulance service, Cathy died settled and peaceful with all of her family around her a few hours later.

TOP TIPS

- Ensure call handling procedures allow staff to ascertain exactly why the caller has called the emergency service, for example s/he may be seeking advice and reassurance rather than conveyance
- Develop joint training opportunities for care home staff, hospice staff, ambulance service staff and others to explore how and when to involve ambulance services when a person is near the end of life
- CQUINs may be a potential opportunity for ambulance services to develop innovative.



GOOD PRACTICE EXAMPLE

Rapid Transfer Procedure

This procedure aims to provide an Emergency Paramedic Service (EPS) level of transport that is clinically appropriate, providing privacy and dignity and allowing for carers or relatives to travel if required. North West Ambulance Service (NWS) developed the criteria in conjunction with acute hospitals, hospices, commissioners and end of life care networks groups.

Pilot sites cited the single access booking process with improved communication as the greatest benefits. When ambulance delays are predicted, booking staff are made

aware and are able to manage everyone's expectations or put contingency plans into action. Incidences where the wrong type of transport has been booked (resulting in vehicles being sent away) have also reduced.

NWS now transfer just over 94% of known end of life care rapid transfers within two hours.

For further information contact:
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North West Ambulance Service NHS Trust
Steve.Barnard@nwas.nhs.uk

GOOD PRACTICE EXAMPLE

'Just in Case boxes' to reduce unnecessary transfers to A&E

A range of professionals - including end of life care facilitators, palliative care consultants, GPs, nurse specialists and pharmacists - in Essex have developed 'Just in Case Boxes' (known as Just in Case Emergency Medicine Boxes in some parts of the country) to help avoid unnecessary admission to A&E for symptom management.

Previously, the absence of 24 hour nursing care or pharmacy services had meant that when called to attend people nearing the end of life who were having problems managing their symptoms, ambulance clinicians were having to transfer them to A&E for treatment.

The Just in Case Boxes contain a range of medicines - prescribed specifically for that person by their GP - to treat common symptoms associated with their condition or

treatment (e.g. anti-emetics, steroids) and are held by the person in their care setting.

When ambulance clinicians arrive at the scene, rather than transfer the person to A&E for symptom management, they can administer the treatments in the box, safe in the knowledge that they have been prescribed specifically for that person. The boxes have been in use for several years in the West Essex area and are well established, recognised by local emergency and out of hours GP services, for example.

For further information contact:
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End of Life Care, South Essex Partnership
University NHS Trust
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Step 6

Care after death

Key issues

Ambulance services are frequently involved in care after death. Ambulance clinicians will often be at the scene at or shortly after the point of death and are familiar with supporting grieving relatives, although many will benefit from better awareness and training regarding cultural and spiritual issues around death. It is also important to ensure that there is support for ambulance clinicians who may be affected by a death they have attended.

Ideally ambulance clinicians will be able to leave the scene knowing that a GP will be available to certify the death within an appropriate timeframe, and can advise carers to contact the funeral director. With the right systems in place, this is achievable even out of hours: GPs in some areas, for example, provide a 'statement of intent' regarding the person nearing the end of life, to be kept with other documentation at the scene; this explains that death is anticipated and sets out the circumstances/criteria under which the GP would be prepared to certify their death at the next available opportunity (e.g. the following day).

However, in reality the complex arrangements between coroners' offices, GPs and police services mean that even when a death has been anticipated, problems frequently arise in certifying a death. If a GP is not available out of hours, for example, the AC may have to call the police, who may in turn remove the body to the mortuary where it could be kept for several days. These delays, and indeed the arrival of police on the scene, can cause considerable anxiety and distress to carers and families. Police may also arrive on the scene first, and call ambulance services themselves.

Elsewhere, ambulance services may be called after a death simply in order to verify a death. This does not constitute appropriate use of ambulance services, but is standard procedure in many care homes and staff may be anxious about disciplinary issues if they fail to follow it. Greater consistency and coherence in procedures for verifying and certifying deaths, across care settings, coroners and police services and GPs would help minimise distress for relatives and result in more appropriate use of ambulance services. Ambulance services may need to initiate and drive this, and may also be able to contribute by offering expertise for training purposes.

To enable high quality care at this Step, the role of individual staff is to:

- Take responsibility for developing the skills and knowledge needed to support and respond to families and carers after a death. This includes awareness of relevant spiritual and cultural dimensions and awareness of which other services can provide bereavement support.

The role of ambulance organisations is to:

- Provide education and training for staff, including in spiritual and cultural issues relating to death
- Engage directly with coroner's services, GP and police services and care homes/other settings to encourage review of local policies and procedures for verifying and certifying death
- Ensure ambulance clinicians have access to emotional/pastoral support where needed
- Contribute to education and training for others involved in care after death, including care home staff, to minimise inappropriate callouts.

The role of other organisations is to:

- Review their policies, procedures and arrangements for verifying and certifying deaths to minimise disruption, delays and distress for families and carers and avoid unnecessary involvement of ambulance services.

TOP TIPS

- Consider developing systems for GPs to leave a 'statement of intent' with the person.
- Work with care homes to develop appropriate policies for verification of death
- Proactively engage with local coroners to improve the management of expected deaths
- Consider developing joint protocols between organisations for the management of deaths.

GOOD PRACTICE EXAMPLE

Working with care homes to improve procedures for recognition of death

In Somerset and Dorset, South Western Ambulance Service NHS Foundation Trust (SWAST) have often been called to nursing homes and community hospitals to perform recognition of death, particularly when this is in relation to expected deaths in palliative care. This clearly delays recognition, with the potential to increase levels of distress felt by the family, and also places a burden on the emergency service and out of hours service operated by SWAST.

In order to mitigate this impact and provide for a more effective care pathway after death, SWAST offers free training and education for any nursing home or other nurse led community service in the recognition of death, to provide nursing colleagues with the competency required to take responsibility for this critical end of life function.

For further information contact:
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Manager, South Western Ambulance
Service NHS Foundation Trust
David.Partlow@swast.nhs.uk



Section 3

Taking it forward

Working together to enable ambulance services to provide high quality end of life care across the pathway

Many of the issues and challenges occurring at different stages along the end of life care pathway call for a co-ordinated and collaborative response from all stakeholders. The wide stakeholder group involved in developing this guidance have identified a series of levers for enhancing the care that ambulance services provide at the end of life, which may provide a useful basis for developing local, regional and national action plans.

Some of these levers apply at an individual level:

- **Education and training for ambulance staff** so that they understand the nature and principles of end of life care, are aware of relevant legislation and documentation, for example the Mental Capacity Act, Preferred Priorities for Care (PPC), Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) - and have the necessary communications skills to confidently and sensitively initiate discussions with individuals and carers about end of life care arrangements and preferences. Staff also need to know when and how to escalate clinical issues for further support or decision making. Such education should begin at undergraduate level, and be delivered jointly with other services and specialities, to harness expertise from these and promote greater mutual understanding of roles; it should also include access to e-Learning for Health.
- **Education and preparation for the person/carer**, to help them understand the role of ambulance services in their care, and who they should contact in the event of a crisis or emergency. This can be built into care planning and assessment discussions and documentation.
- **Education and training for other staff** involved in end of life care in the role of different parts of the ambulance service at the end of life and how to make best use of them.
- **A full understanding of duty of care**, supported by clear professional codes of conduct, to encourage clinicians to consider issues of clinical responsibility.
- **Opportunities and encouragement to become actively involved in discussions** on strategy and planning for end of life care at a local level, and to contribute good practice and other data e.g. to formal audit to support quality improvement and inform decision-making.



Some are at a systems level:

- **Integrated information and communication systems to ensure staff have the necessary prior knowledge.** These should flag people who are at the end of life, and enable ready access to care plans and details of advance decisions for example. They should also allow ambulance clinicians (where consent is obtained) to share information on a person's status with other organisations after attending the person.
- **Efficient call handling processes**, which identify and pass on to crews information about why the ambulance service has been called and what outcome the caller is seeking. This may improve use of resources by avoiding unnecessary A&E responses and undesired emergency hospital admissions, for example.
- **Greater consistency and coherence** in policies and protocols across all organisations involved in end of life care. Ambulance services may need to take the lead in bringing stakeholders together to develop pan-organisational policies at cluster or regional levels.
- **Access to clinical decision support services** (internal and external), 24/7, to guide crews in taking the right decision at the scene, for example where there is disagreement between the individual and carers over implementation of an advance decision or care plan.

Levers at a structural or strategic level include:

- **Closer partnership working** among all stakeholders, including ambulance services, to plan the integrated systems, structures and policies required to ensure well co-ordinated end of life care
 - **Development of a positive learning culture**, including gathering data through audit, sharing good and poor practice and learning from instances where care has not been optimally delivered as well as it could have been, for example through constructive review of critical incidents and complaints.
 - **More visible leadership and a higher profile for ambulance services**, so that they can contribute to strategy and policy development, engage stakeholders and broker effective partnerships at national and regional/local level and promote appropriate commissioning of ambulance services. This includes closer working between ambulance trusts to share good practice and influence policy.
 - **Commissioning of ambulance services that support end of life care service developments** such as development of integrated information systems, education programmes and appropriate arrangements for urgent 24/7 care provision; and reflects their role in end of life care, including rapid transfer or discharge of people who are dying. These will in turn help reduce unnecessary hospital admissions.
 - **Development of regional and national groups**, involving all stakeholders, to agree outcomes, common standards, promote partnership working and help unify processes.
 - **Working with local public/user organisations and mechanisms such as Local Involvement Networks (LINKs)**, to identify areas for improvement and involve stakeholders in finding solutions.
 - Identification of **champions for end of life care** within ambulance organisations, and **steering groups and networks** to drive change both internally and within other organisations.
 - **Development of a business case for greater investment in ambulance services at the end of life** and, in particular, for investing in regular education for ambulance clinicians as part of their standard training.
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Section 4

Further resources

e-ELCA e-learning

Free to access for health and social care staff and includes over 150 modules covering advance care planning, assessment, communications skills, symptom management, integrated learning, social care, bereavement and spirituality: www.e-lfh.org.uk/projects/e-elca/index.html

Developing end of life care practice

A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care: www.endoflifecareforadults.nhs.uk/publications/corecompetencesframework

Critical success factors that enable individuals to die in their preferred place of death

This report identifies the critical success factors associated with improving end of life care and enabling a person to die in the place of their choice: www.endoflifecareforadults.nhs.uk/publications/critical-success-factors

The End of Life Care Quality Assessment tool (ELCQuA)

An online tool to monitor and compare end of life care services with similar organisations locally and nationally. Progress can be assessed against a set of core specifications based on the Department of Health's quality markers and measures for end of life care: www.elcqua.nhs.uk

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network aims to improve the collection and analysis of information about end of life care services. This intelligence will help drive improvements in the quality and productivity of services: www.endoflifecare-intelligence.org.uk

Gold Standards Framework Prognostic Indicator Guidance

Clinical prognostic indicators are an attempt to estimate when people have advanced disease or are in the last year or so of life. This indicates to health and social care professionals that people may be in need of palliative/supportive care: www.goldstandardsframework.org.uk

Planning your future care

Aimed at members of the public, this guide explains advance care planning and outlines the different options available to people: www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

Capacity, care planning and advance care planning in life limiting illness

This guide covers the importance of assessing capacity to make particular decisions about care and treatment, and of acting in the best interests of those lacking capacity: www.endoflifecareforadults.nhs.uk/publications/pubacpguide

Advance decisions to refuse treatment

A guide to help understand and implement the law relating to advance decisions to refuse treatment: www.endoflifecareforadults.nhs.uk/publications/pubadrtguide

Preferred Priorities for Care (PPC) tools

PPC is a person-held document which was designed to facilitate individual choice in relation to end of life care. Tools are available including documentation, an easy-read version, leaflet, poster and support sheet: www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare

Electronic Palliative Care Co-ordination Systems (EPaCCS)

Formerly known as end of life care locality registers, EPaCCS enable the recording and sharing of key information about an individual at the end of their life, their care and preferences.

More information on the core content that is to be recorded in such systems is available at: www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard

The Liverpool Care Pathway for the Dying Patient (LCP)

The Liverpool Care Pathway is a multi-professional, outcome driven document that provides an evidence-based framework for the delivery of care during the last days or hours of life:

www.mcpcil.org.uk/liverpool-care-pathway/

Guidance for staff responsible for care after death (last offices)

This publication emphasises that the care extends well beyond physically preparing the body for transfer. It also covers privacy and dignity, spiritual and cultural wishes, organ and tissue donation, health and safety and death certification procedures: www.endoflifecareforadults.nhs.uk/publications/guidance-for-staff-responsible-for-care-after-death

When a person dies: guidance for professionals on developing bereavement services

This covers the principles of bereavement services and guidance on workforce education and the commissioning and quality outcomes of bereavement care:

www.endoflifecareforadults.nhs.uk/publications/when-a-person-dies

Appendix 1: NICE Quality Standard for End of Life Care

In November 2011 NICE published a Quality Standard for end of life care, which contains 16 statements and will apply to ambulance services:

1. People approaching the end of life are identified in a timely way.
2. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
3. People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
4. People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
5. People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
7. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
8. People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
9. People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
10. People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
11. People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
12. The body of a person who has died is cared for in a culturally sensitive and dignified manner.
13. Families and carers of people who have died receive timely verification and certification of the death.
14. People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
16. Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

More information on the Quality Standard can be found at:

www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp

In December 2011, NICE also published commissioning guidance to support the Quality Standard:

www.nice.org.uk/usingguidance/commissioningguides/endoflifecare/endoflifecareadults.jsp

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