



East of England Ambulance Service NHS Trust

End of Life Care Strategy
2017-2020

End of Life Care Strategy, 2017-2020

EEAST: End of Life Care Strategy
February 2017, V5

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1) INTRODUCTION: why does end of life care matter?

This document sets out the East of England Ambulance Service NHS Trust's three-year strategy for improving the care and experience for people who are at the end of their life and use the service.

End of life care (EOLC) needs to be a priority for health and social care organisations. It is a topic that will affect us all at some point, at any age, and it is vitally important that we change the way we talk about it. The actions we take in planning and preparing for death for those that are dying, as well as the people around them, needs to be strengthened and we must improve our ability to provide care whatever the circumstances of dying are¹.

“How people died remains in the memory of those who live on”
(Dame Cicely Saunders, founder of the modern hospice movement)

As an ambulance service we have a role to play in delivering high quality care at the end of life. We have a responsibility to ensure that patients receive a timely response and appropriate emergency care or transport. We must also ensure we are able to support patient choice regarding end of life care, including resuscitation decisions and place of death. Ambulance staff often find themselves responding to patients at the end of life with very limited information about the patient and are relied upon to make difficult and time critical decisions, often with little support or advice².

In England, approximately half a million people die each year, with these numbers expected to rise steadily over the coming years. It is thought that nearly three quarters of all deaths are ‘expected’, and it is believed that high quality end of life care for all these people can be delivered by non-specialist health and care staff as part of their core work. The delivery of this high quality care relies on staff having adequate time, education, training and support³.

The latest data from the Office of National Statistics shows that between April 2015 and March 2016, 45% of deaths in the east of England (where deaths from external factors had been excluded) occurred in hospital, with 23.4% in the patient’s own home and 24.7% in a care home⁴. There is a clear year on year reduction in the number of patients dying in hospital across the east of England and this trend needs to continue; population based studies on preferences of place of death indicate that more than 60% of people would prefer to die at home⁵.

The number of children with a terminal or life-limiting illness is believed to be around 40,000 in England alone (National Institute for Health and Care Excellence guidance for End of Life Care for Children, July 2016).

We recognise and welcome the opportunity to work in partnership with health and social care, palliative, and end of life care providers and voluntary agencies, as well as our local clinical commissioning groups. These collaborations will aid and support our work and contribute to improving the health and the experience of those at the end of life, and their carers, living within our

¹ Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020.

<http://endoflifecareambitions.org.uk>

² The Route to Success in end of life care – achieving quality in ambulance services, 28th February 2012.

<http://webarchive.nationalarchives.gov.uk/20130718121128>

³ Actions for End of Life Care: 2014-16. <http://england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

⁴ www.endoflifecare-intelligence.org.uk/data_sources/placeofdeath

⁵ Gomes B, Calanzani, N and Higginson IJ (2011). Local preferences and place of death in regions within England 2010. Cecily Saunders International, London

area.

This strategy is informed by the national End of Life Strategy 2008⁶ and the *Ambitions for Palliative and End of Life Care 2015*⁷ documents, alongside other topic related publications.

2) BACKGROUND

End of life care is provided to a person who is thought to be in the final months of life and aims to help people live well until they die. Good end of life care allows a person to die with dignity when the time arrives, and also ensures appropriate support is provided to families and carers before and after death.

End of life care is not just for cancer sufferers but for any condition from which a person will not recover, like dementia or chronic obstructive pulmonary disease (COPD), and those who are nearing the end of their life as a result of age and frailty. It also includes children and young people with a terminal or life limiting illness

In July 2013, NHS Improving Quality collaborated with the Association of Ambulance Chief Executives (AACE) to publish a six step pathway for the delivery of end of life care. The key points that apply to the ambulance service are:

- Step 1 – Discussions as the end of life approaches
- Step 2 – Assessment, care planning and review
- Step 3 – Co-ordination of care
- Step 4 – Delivery of high quality care in an acute hospital
- Step 5 – Care in the last days of life
- Step 6 – Care after death⁸.

The *Ambitions for Palliative and End of Life Care (2015)* publication also outlines six ambitions for the provision of palliative and end of life care; it aims to create a nation where dying matters, where care is joined up, and health and care staff are empathetic and competent in the delivery of this care.

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

As an ambulance service we have a vital role to play in ensuring that:

1. staff are well educated and informed around end of life care
2. as an organisation we are striving to improve the experience of patients as they approach the end of their life
3. families and carers, including our own staff and volunteers, are well supported.

⁶ End of Life Strategy. Promoting high quality end of life care for all adults at the end of life.

<https://www.gov.uk/government/publications/end-of-life-care>

⁷ Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020.

<http://endoflifecareambitions.org.uk>

⁸The Route to Success in end of life care – achieving quality in ambulance services, 28th February 2012.

<http://webarchive.nationalarchives.gov.uk/20130718121128>

Support to staff and volunteers (e.g. community first responders) is essential; we need to give them the tools and knowledge to provide effective and relevant care, to alleviate pain and suffering, support patients to experience a 'good' death, as well as developing a culture where staff feel confident to challenge/question when they experience poor end of life care.

Our strategy reflects these aims and has been designed in conjunction with many organisations.

3) STRATEGIC AIMS

Our strategic aims:

- 1) Treat all patients with dignity and respect. Support patients, their families and care providers in experiencing a 'good' death that meets the diverse needs of the population. Allowing people to die with dignity. This should include children and young people with a terminal or life limiting illness.
- 2) All patients (and their families) who access the ambulance service who are at the end of their life will receive treatment and support in line with their wishes to ensure the alleviation of pain and suffering to the best of our ability.
- 3) Ensure ambulance staff and volunteers have rapid access to specialist advice and support, no matter where they are in the Trust, and are able to access palliative care records to support decisions, including special patient notes (advance care plans).
- 4) Ensure all ambulance staff (including control room colleagues) and volunteers have access to high quality end of life education, and are provided with the most up to date policy and guidance changes relating to end of life care.
- 5) Develop an end of life care lead role for the Trust and continue to work collaboratively with external organisations.

4) OBJECTIVES and DELIVERING OUTCOMES

Strategic aim one: Treat all patients with dignity and respect. Support patients and their families and care providers in experiencing a 'good' death that meets the diverse needs of the population. Allow patients to die with dignity. This should include children and young people with a terminal or life limiting illness.

What we will do:

- Implement patient satisfaction surveys specifically for people and/or families who have contacted EEAST to support end of life care within the last six months (both emergency and non-emergency)
- Educate staff and volunteers who have direct contact with patients about end of life care

- appropriately for their role, with an emphasis on this always being person centred
- Utilise available e-learning modules available through Health Education England (HEE), and develop an e-learning module within EEAST's LearnZone (internal e-learning portal) which focuses on end of life care; alternatives will be provided for those volunteers or colleagues who don't have access to these sites
- Introduce training on end of life care to our student paramedic (SP), associate ambulance practitioner (AAP), intermediate ambulance practitioner (IAP) programmes and non-emergency patient-facing staff; this will be an all-encompassing programme which covers all aspects of end of life care
- Collaborate with our patient and public involvement team and the Trust User Group to ensure public views and experiences are known.

How success will be measured:

- By the end of year one-
 - The Trust will have a process in place for identifying those patients who contact it for an end of life care reason. This will be done through a keyword within the 999 system (computer aided dispatch, or CAD, system)
 - patient satisfaction surveys will be developed. These will include minority groups, e.g. extremes of age, ethnicity, religion and beliefs, and sexual orientation to ensure we are meeting the diverse needs of the population, and will include a focus on the experience of family members/carers
 - an e-learning module will be developed within EEAST's LearnZone, and it will be made available to staff and volunteers
- By the end of year two –
 - patient satisfaction surveys will have been implemented
 - all training programmes within EEAST will have end of life care as a topic, including student paramedic courses, training for community first responders and Trust-wide professional update training for patient facing and control room colleagues
 - an end of life care champion role will be introduced in each area of the Trust
- By the end of year three –
 - patient satisfaction surveys will have become a core part of the annual survey programme
 - patient and carer feedback related to end of life care will be critically analysed to determine effectiveness and identify areas for improvement
 - education training records will demonstrate 100% of eligible clinical/patient transport service staff and volunteers will have undertaken end of life care training as part of the yearly professional update programme
 - The Trust will collaborate with hospice services to provide external end of life care training for ambulance staff
 - when surveyed, 90% of our patients and carers will feel supported.

Strategic aim two: All patients who access the ambulance service who are at the end of their life will receive treatment and support in line with their wishes to ensure the alleviation of pain and suffering to the best of our ability.

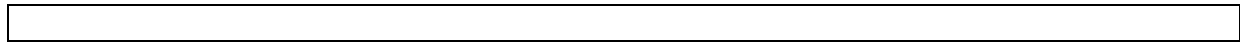
What we will do:

- Develop/procure a high quality awareness and training structure based on best practice and person centred care – role specific for each staff and volunteer group (emergency operations centre staff, and emergency and non-emergency patient-facing colleagues)
- Identify when staff are in contact with end of life care patients and what care and treatment is provided
- Ensure consistency of training across the whole Trust through quality assurance
- Through ‘train the trainer’ events, the training team will be supported to provide quality end of life teaching and to staff and volunteers
- Monitor and evaluate this end of life training
- Provide supportive communications about anticipatory drugs, to give staff confidence and knowledge in the use of these medications
- Work with hospice teams across the Trust to provide expert guidance to our staff
- Ensure staff and volunteers feel supported to challenge/question if they experience poor end of life care, and that a clear reporting procedure is in place.

How success will be measured:

- By the end of year one -
 - a supportive guidance document will be produced about anticipatory drugs, in line with best practice and *Clinical Practice Guidelines*
 - work will begin with hospice teams to provide expert advice and training to EEAST staff and volunteers
 - End of life care clinical champion roles will be identified to provide support to staff and be a link to external parties.
 - Schedule bi-monthly end of life focus groups, and ensure representatives from across the Trust
- By the end of year two –
 - complaints and concerns raised around treatment for end of life care patients will be analysed, and a robust mechanism will be developed for feeding back learning to staff
 - patient satisfaction surveys will be implemented, focusing on the experience of the family/carer of the patient.
 - Promote use of ‘end of life keyword’ in CAD to allow better data monitoring, and increase the use of this by staff when in contact with an end of life patient.
- By the end of year three –
 - All eligible, clinical and patient facing staff will have received training in all aspects of end of life care (target of 100%).

Strategic aim three: Ensure ambulance staff and volunteers have rapid access to specialist advice and support, no matter where they are in the Trust, and are able to access palliative care records to support decisions, through access to patient records, including special patient notes (advanced care plans).



What we will do:

- Work with external organisations, hospice and community nursing teams to ensure all palliative advice lines are accessible to all staff and volunteers and answered 24-hours a day
- Work with commissioners to develop a regional directory of service that includes all relevant numbers for end of life care support, which is accessible to all staff wherever they are in the Trust. The use of these numbers will be analysed and reviewed and any issues addressed with the relevant provider
- Work with the Trust's emergency clinical advice and triage centre (ECATC) to develop a contact line for crews to call to access patient care records.

How success will be measured:

- By the end of year 1 –
 - a paper directory of service (DoS) will be produced and distributed, containing all contact numbers for palliative care support across the Trust
 - a suitable electronic DoS will be explored and developed with the emergency operations centre clinical lead.
- By the end of year two –
 - the electronic DoS will be implemented
 - a contact number/helpline will be developed specifically for end of life care patients; crews will be able to call the ECAT for access to SystemOne records and details about patient specific care plans (advanced care plans/'my care wishes').
- By the end of year three –
 - the electronic DoS will be 'business as usual' across the Trust

Strategic aim four: Ensure all ambulance staff (including control room colleagues) and volunteers have access to high quality end of life education, and are provided with the most up to date information and any policy and guidance changes relating to end of life care.

What we will do:

- Develop an e-learning resource within LearnZone, the Trust's internal e-learning platform, and ensure this is kept up to date
- Develop a training package, in line with best practice, and deliver this on Trust professional update programme specifically for each staff group (patient facing, EOC, volunteers and PTS staff).
- Develop a mechanism for sharing information around the Trust relating to palliative care, as well as updated guidance and policies
- Share national and local end of life care news with staff and volunteers through the Trust's internal rolling news site.
- Raise awareness of children's palliative care.
- Ensure end of life care remains a central focus in clinical communications to staff and volunteers, to ensure they have access to the latest information on all aspects of end of life care
- Continue to work with end of life care champions from across the Trust at a bi-monthly focus

group where ideas and issues are shared and addressed; emergency operations centre, non-emergency colleagues and volunteers (including the Trust User Group) will be involved in the group.

How success will be measured:

- By the end of year one –
 - an e-learning resource within EEAST's LearnZone will be developed; alternatives will be provided for volunteers who do not have access to this resource
 - an end of life care clinical update will be uploaded to the Trust's Clinical Manual app
 - regular communications will be shared through the Trust's news portals, sharing relevant and up to date information with staff and volunteers.
 - timetable a regular slot on the Trust professional update training programme
 - schedule bi-monthly end of life focus groups, and ensure representatives from across the Trust
- By the end of year two –
 - a mechanism will be set up for sharing information with volunteer organisations and groups, through liaison with Trust leads.
 - regular updates will be provided through the Clinical Manual app and EEAST's LearnZone portal, ensuring availability to staff volunteers.
 - Develop a training package with hospice providers focused around end of life care for children
- By the end of year three –
 - Make end of life training 'business as usual' and ensure that all staff and volunteers receive regular information, updates and have access to end of life care learning (through communications, focus weeks, champions and professional update programmes)

Strategic aim five: Develop an end of life care lead role for the Trust, and continue to work collaboratively with external organisations.

What we will do:

- Develop an end of life and palliative care lead role for the Trust
- Develop strong links with external organisations, such as hospice and community nursing teams and lead GPs
- Improve and increase representation on the Trust end of life care focus group, held bi-monthly, to include patient transport services and emergency operations centre staff, volunteers, and clinical commissioning group end of life care leads.

How will success be measured:

- By end of year one –
 - a job description and person specification will be developed for the end of life care lead role
 - bi-monthly meetings will be scheduled for the end of life care focus
- By the end of year two –
 - funding will be secured for an end of life and palliative care lead through presentation of a business case, using data and information obtained during year one.
- By the end of year three -
 - an end of life and palliative care lead will be recruited.

5) Summary

This strategy outlines the essential elements required to improve the provision of care to end of life patients the ambulance service sees.

It aims to ensure that staff and volunteers, of all grades and from all departments, are able to understand: what is required of them; how to deliver end of life care that puts the patient and their wishes at the centre of any decision making; and includes family and carer support and involvement.

The strategy aims fall in line with the Government's *End of Life Care Strategy and Ambitions for Palliative Care*, while maintaining a local focus and identifying areas that can be improved across EEAST for the benefit of patients.

In order for the strategy to be successful, support and engagement across EEAST and with external providers is essential.

Feedback and comments are welcome, and can be shared at:

Eoeasnt.feedback@nhs.net

Or in writing to:

Patient Experience Team
East of England Ambulance Service
Bedford Office
Hammond Road
Bedford
MK41 0RG

6) MONITORING AND ASSURANCE OF THE END OF LIFE STRATEGY AND ACTION PLAN

Progress will be monitored by Clinical Quality and Safety Group (CQSG) in conjunction with reporting to the patient experience group on surveys.

Strategic aim	Nominated lead
1. Treat all patients with dignity and respect. Support patients, their families and care providers in experiencing a 'good' death that meets the diverse needs of the population. Allowing people to die with dignity. This should include children and young people with a terminal or life limiting illness.	Sector heads, consultant paramedic, area clinical leads
2. All patients (and their families) who access the ambulance service who are at the end of their life will receive treatment and support in line with their wishes to ensure the	Consultant paramedic, senior locality managers, area clinical leads and EOC clinical lead

alleviation of pain and suffering to the best of our ability.	
3. Ensure ambulance staff and volunteers have rapid access to specialist advice and support, no matter where they are in the Trust, and are able to access palliative care records to support decisions including special patient notes (advanced care plans).	Emergency operations centre clinical lead and area clinical leads.
4. Ensure all ambulance staff (including control room staff and volunteers) have access to high quality education and are provided with the most up to date information and any policy and guidance changes relating to end of life care.	Consultant paramedic
5. Develop an end of life care lead role for the Trust and continue to work collaboratively across the Trust and with external organisations.	Consultant paramedic and area clinical leads

7) Equality impact assessment

This strategy has been screened to determine equality relevance for all protected characteristics.

Appendix 1 - Glossary of terms

AAP	Associate ambulance practitioner
CAD	Computer aided dispatch
CCG	Clinical commissioning group

COPD	Chronic obstructive pulmonary disease
EEAST	East of England Ambulance Service NHS Trust
EOC	Emergency operations centre
EOLC	End of life care
IAP	Intermediate ambulance practitioner
NICE	National Institute for Clinical Excellence
PTS	Patient transport services
SP	Student paramedic
CFR	Community first responder
TUG	Trust User Group
PPI	Patient and public involvement

Appendix 2 – References and resources

British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, 2016. *Decisions relating to cardiopulmonary resuscitation*. [pdf]. Available at <https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr.pdf>

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