

The role of Ambulance Trusts in respecting people's end-of-life wishes

Findings from a Freedom of Information request



September 2018

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Background

Compassion in Dying frequently receives enquiries from people who are concerned about whether their wishes for the end of life will be respected in an emergency situation or when they are being transported between care settings.

These people have some form of advance care plan in place, such as an Advance Decision to Refuse Treatment (often known as ‘Living Will’), a Do Not Attempt Cardiopulmonary Resuscitation form (DNAR) and/or a Lasting Power of Attorney for Health and Welfare.

However, without effective recording systems and training, paramedics often struggle to access individuals’ stated wishes. This makes it difficult for those wishes to be respected, causing distress to both the individual and their loved ones, as Christine Erskine’s story shows:

“ At the age of 96, my mother had a severe aneurysm and the paramedics wanted to take her to hospital to have a stent fitted. She was adamant she was not going into hospital and I respected these wishes... I explained about her Advance Decision, which they knew nothing about. Halfway to hospital, having finally read the relevant document they had subsequently been given, they changed their minds and palliative care was put in place. ”¹

We decided to find out more about Ambulance Trusts’ policies and practice on advance care plans.

Methodology

We contacted the 13 Ambulance Trusts in the UK under the Freedom of Information Act 2000 asking:

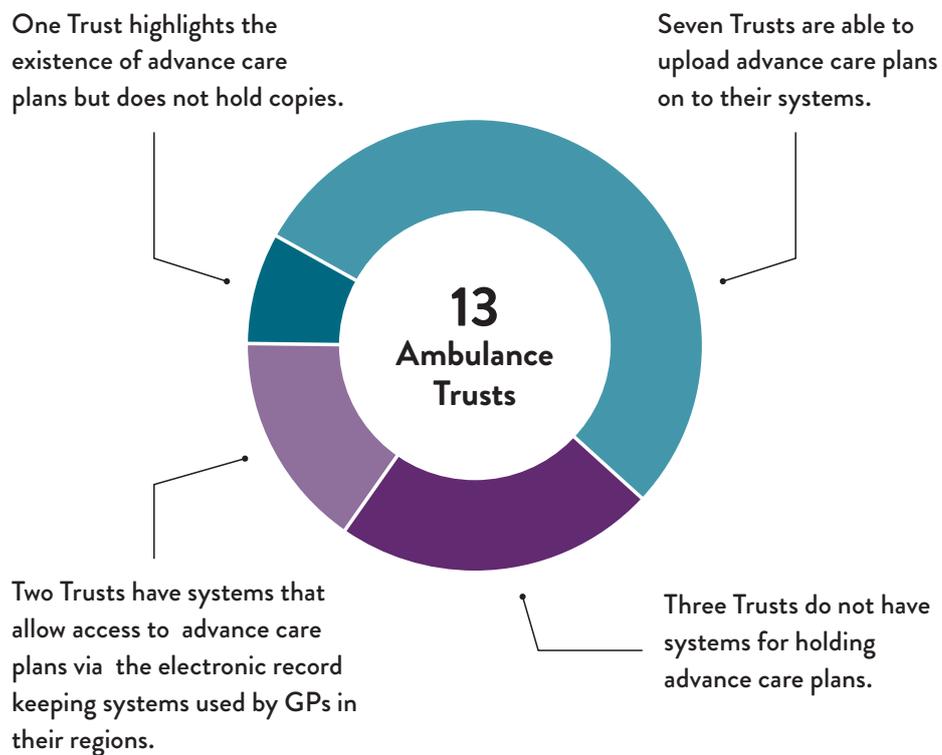
- Whether the Ambulance Trust has a system for holding copies of individuals’ Advance Decision to Refuse Treatment forms, DNAR forms and Lasting Powers of Attorney for Health and Welfare documentation.
- Who the Ambulance Trust would accept these documents from (e.g. the person themselves, or only a healthcare professional) and how the documents could be shared (e.g. by email, by post or in person).
- Whether ambulance crews receive training on identifying and implementing Advance Decisions, Lasting Powers of Attorney and DNARs.
- The extent to which the adherence to or lack of adherence to Advance Decisions, Lasting Powers of Attorney and DNARs is recorded and analysed.

We received a 100% response rate.

Findings

Does the Ambulance Trust have a system for holding copies of advance care plans?

Whether or not Ambulance Trusts will be aware of their wishes is a concern of many people who contact Compassion in Dying's Information Line. We uncovered diverse policy and practice across the Ambulance Trusts, revealing a postcode lottery in accessing services that acknowledge and respect individuals' stated wishes for end-of-life care.



Under the Mental Capacity Act 2005 Advance Decisions are legally binding in England and Wales as long as they meet certain requirements. The Act also enables people to appoint a Lasting Power of Attorney for Health and Welfare.

Responses from the 13 Ambulance Trusts revealed varying policies:

Six Trusts accept advance care plans from individuals.

Four Trusts only accept advance care plans from healthcare professionals.

Two Trusts require original documents to be seen and one Trust only accepts a particular Advance Decision form.

Two Trusts were able to report on the number of advance care plans adhered to in 2017.

Eleven Trusts provide training on end-of-life care to ambulance crews.

Ambulance Trusts requiring original documents; only accepting information supplied by a healthcare professional; and only recognising information in one format, create unjust barriers to advance care planning and also contravenes Section 25 of the Mental Capacity Act 2005.

The absence of a unified system for recording and implementing advance care plans across the 13 Ambulance Trusts results in significant inequality when it comes to protecting patient choice at the end of life.

A recent study among ambulance staff also found that they were limited in the care they could provide due to the absence of information about patients.² This situation persists despite the fact that recommendations on improving information sharing were made by Public Health England in 2015³ and within the Ambitions for Palliative and End-of-life Care Framework.⁴ The importance of effectively sharing information about people across organisational boundaries to make more informed decisions on people's care and to avoid unwarranted admission to secondary care has also been highlighted by the recent Care Quality Commission report, *Beyond Barriers*.⁵

Policy and practice: what we have learned

The calls Compassion in Dying receives, alongside the research into our service users' experience, demonstrate that the current systems for recording individuals' treatment and care preferences cause real problems for individuals and their loved ones.

“My dad was dying...I was not prepared for the care workers calling an ambulance against mum's wishes and the paramedics asking for a “yellow DNAR” which we didn't have as we'd already got a Power of Attorney... his breathing worsened and he appeared distressed but we knew he didn't want to go to hospital or be resuscitated. I didn't know what we were supposed to do or who we should call for information. Eventually, having discussed the situation with their boss, which took some time, the paramedics made sure dad was comfortable and allowed him to stay at home.”

- Wendy Knight

We have learned that current policy and practice cause problems for paramedics and ambulance crews.

“As a paramedic it is immensely frustrating and upsetting when things aren't put in place allowing us to leave someone at home where they wish to be. I was not prepared for the heartache of having to take a dying patient away from their home and into general hospital.”

- Donna Main-Clancy

As well as the 'postcode lottery' of different policies uncovered by our Freedom of Information request to Ambulance Trusts, the inconsistent implementation of Ambulance Trust policies is also cause for concern.

We requested four people who had completed Compassion in Dying's Advance Decision form to contact the Ambulance Trust which has a policy of only accepting a specific Advance Decision template, and ask if they might hold a copy.

- The first caller was asked by the Trust to post in a copy of her Advance Decision and they subsequently confirmed that this was now on her records;
- Two callers were asked to have their GP send the forms to the Trust on their behalf;
- One person was told that her GP would need to complete a different form and send it but was given no further details on the form or the process.

While these are just four examples, it indicates that good practices, as in the case of the first caller, exist and could easily be replicated. Again, it appears there is a lottery in terms of the standard of current practice within Trusts as well as between them.

Recommendations for Ambulance Trusts

We recognise that ambulance crews work in time-pressured environments and that commencing life-sustaining treatment is a default action, particularly where crew members feel the context is uncertain. Moreover, we understand that withholding life-sustaining treatment requires significant confidence, skill and experience. However, if person-centred care is to become a reality, it is important to consider how systems for respecting end-of-life wishes could be strengthened within Ambulance Trusts.

There are already well-documented and significant inequalities experienced in end-of-life care and shared decision making.⁶ Ambulance Trusts are well-placed to help tackle these rather than contribute to them.

It is with this in mind that we propose the following recommendations which we believe would help ambulance crews to respect individuals' wishes:

- Review end-of-life care policies to ensure they are compatible with the Mental Capacity Act 2005 and reflect good practices being implemented on the frontline.
- Ensure that systems are in place to store and view advance care planning documents sent by individuals or healthcare professionals.
- Highlight the existence of advance care planning documents via current electronic systems such as Coordinate My Care, Electronic Palliative Care Co-ordination Systems (EPaCCS) and SystemOne, even if it is not possible for copies of full documents to be held on the system. This alert would prompt ambulance staff to ask to see the documents.
- Clarify during staff training and in written policies that the Mental Capacity Act 2005 does not require original Advance Decision forms ('Living Wills') to be seen in order to confirm their validity and applicability. Ensure that staff members are aware that a copy of an Advance Decision is sufficient and should be acted upon.

- Improve systems for monitoring when and why DNAR orders and Advance Decisions are not adhered to. Systems, such as DATIX, which are used by some Ambulance Trusts for reporting incidents, should also be used to generate summaries which can be analysed to identify areas for improvement.
- Provide mandatory training for all staff members to understand what Advance Decisions, Lasting Powers of Attorney and DNAR orders are, and how they should be dealt with in practice. It is also important that staff understand that care preferences are not limited to those at the end of life as any adult could have a valid and applicable Advance Decision.

Many of these issues, which range from the importance of education, training and awareness of issues relating to end-of-life care at an individual level, to information-sharing systems, policies and protocols at a systems level, were raised by the Association of Ambulance Chief Executives in 2012⁷ and prioritised again in 2014.⁸ We remain hopeful that this rhetoric will be translated into reality and welcome all opportunities to collaborate with Ambulance Trusts to make this happen.

Meanwhile, Compassion in Dying will continue to encourage and support individuals to give copies of their Advance Decisions and other advance care plans to their local Ambulance Trusts, or request their GPs to do so on their behalf.

Notes

- 1 All quotes are drawn from the survey conducted by Compassion in Dying in 2016 of over 600 people who were living with a terminal illness or had cared for someone at the end of life.
- 2 Hoare S et al, Ambulance staff and end-of-life hospital admissions: A qualitative interview study, *Palliative Medicine*, June 2018 <http://journals.sagepub.com/doi/full/10.1177/0269216318779238>
- 3 National End of Life Care Intelligence Network, Ambulance Data Project for End of Life Care, 2015, <http://www.endoflifecare-intelligence.org.uk/resources/publications/ambulance>
- 4 National Palliative and End of Life Care Partnership, 'Ambitions for palliative and end of life care: a national framework for local action 2015-20' (Ambition 4)
- 5 Care Quality Commission, *Beyond Barriers: How older people move between health and social care in England*, July 2018
- 6 Care Quality Commission, *A different ending: addressing inequalities in end of life care*, 2016
- 7 The route to success in end of life care – achieving quality in ambulance services, 2012, <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/End-of-Life-CareRoute-to-Success-ambulance-services.pdf>
- 8 Future National Clinical Priorities for Ambulance Services in England, 2014, <https://aace.org.uk/wpcontent/uploads/2014/05/Future-national-clinical-priorities-for-ambulance-services-in-England-FINAL-2.pdf>

Summary table

Ambulance Trust	Does your Ambulance Trust have a system for holding copies of advance care plans (ACP)?	Who can provide you with these documents?	Do ambulance crews receive special training on identifying and implementing Advance Decisions, Lasting Powers of Attorney and DNAR orders?	When an ambulance crew adheres/does not adhere to an Advance Decision or a DNAR order is it recorded?
East Midlands Ambulance Service NHS Trust	✗	Not applicable	✓	✓
East of England Ambulance Service NHS Trust	Via GP system	Healthcare professional	✓	✓
London Ambulance Service NHS Trust	✓	Healthcare professional	✓	✓
North East Ambulance Service NHS Foundation Trust	✗	Not applicable	Only after change in legislation	✓
North West Ambulance Service NHS Trust	✓	Individual	Planning an elearning package	If investigation is required
South Central Ambulance Service NHS Foundation Trust	✓	Individual	✓	✓
South East Coast Ambulance Service NHS Foundation Trust	Existence of ACP flagged	Individual	✓	If investigation is required
South West Ambulance Service NHS Foundation Trust	✓	Individual	✓	✓
West Midlands Ambulance Service NHS Foundation Trust	✓	Individual	✓	✓
Yorkshire Ambulance Service NHS Trust	✗	Not applicable	✓	✓
The Welsh Ambulance Services NHS Trust	✓	Healthcare professional	✓	✓
The Scottish Ambulance Service*	Via GP system	Healthcare professional	✓	✓
The Northern Ireland Ambulance Service Health and Social Care Trust †	✓	Individual	✓	✓

* In Scotland, the Adults with Incapacity (Scotland) Act 2000 requires that when healthcare professionals are making a decision for a person who does not have capacity, they must take into account the past and present wishes of that person. Advance Decisions provide evidence of a person's wishes and therefore should be taken into account when a decision is made on their behalf.

† The Mental Capacity Act (Northern Ireland) 2016 has not yet come into force. Currently Advance Decisions are given legal effect in Northern Ireland under common law, which means a clear and specific Advance Decision to refuse treatment must be followed.

We can help you prepare for the end of life. How to talk about it, plan for it, and record your wishes.

Have any questions? Talk to us.

Contact us

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