

ARE AMBULANCE TRUSTS ABLE TO RESPECT PATIENT'S WISHES AT THE END OF LIFE?.

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Ambulance services play a crucial role in ensuring that people nearing the end of life can have their wishes respected. In order to examine how Ambulance Trusts in England and Wales are working to respect individual's end-of-life care treatment wishes, Compassion in Dying conducted a freedom of information (FOI) request.

Responses suggest that whilst some Ambulance Trusts have systems for recording end-of-life care preferences, there is considerable variation between regions and there is very little in the way of clear data which allow us to know whether patient's end-of-life treatment wishes are respected when they've lost capacity.



KEY FINDINGS

- Half of ambulance Trusts reported having a formal system in place to record the treatment wishes of patients at the end of life. One additional Trust was planning to implement one.
- Three Trusts reported having a formal system in place for recording the wishes of individuals who are not nearing the end of their life.
- The majority of Trusts reported having a policy on respecting the refusal of treatment of patients outside their normal residence.

METHOD

We made FOI requests to each of the ten Ambulance Trusts in England (plus the Trust which covers Wales), asking:

- 1) Whether they had a register in place to record the treatment wishes of those known to be nearing the end of life, what the system records and how many patients they have on their system.¹
- 2) Whether Advance Decisions or Lasting Powers of Attorney (LPA) were recorded for those not known to be nearing the end of life. If they were not already doing so, we asked them if they were planning to record this in future.
- 3) Whether they had a policy on following people's wishes to refuse treatment if they needed an ambulance outside their normal residence and what this policy involved.



CASE STUDY

The following case study highlights the importance of having an appropriate system in place, which both records patient's wishes and ensures that care professionals can access and follow them.

Mr Stephen Klein's mother had a bad death as a result of an Ambulance Trust ignoring his mother's end-of-life wishes:

“ My mother Lisa died in 2012 in a nursing home in Oxfordshire. Unfortunately the whole process was badly managed due to the fact that the Ambulance service ignored specific instructions my mother had left in the event of her losing capacity. She had made an Advance Decision and had a Do Not Resuscitate order in place as part of her end of life care plan. These were ignored, and my mother's end-of-life rights were not respected.

“Just as my mother was let down by the people who treated her, the Ambulance Trust itself was let down by the lack of a proper workable system. I received a full apology from the Ambulance Trust, who have made a number of changes as a result of the lessons learned from my mother's death. It was clear that they are trying to do the best they can with limited resources. If there had been proper access to my mother's end-of-life wishes, which were legally recorded but ignored, then there would have been a better chance she could have had the care, and the death, that she wanted.”

FINDINGS

We received responses from 10 of the 11 Trusts we contacted. The level of detail in these responses varied.

Respecting the treatment wishes of patients known to be at their end of life

Six Trusts reported having a formal system for recording the treatment wishes of those patients who are known to be nearing the end of life. These systems were reported as either being EPaCCS or similar systems which had an electronic-records element. One Trust stated that it was planning to implement such a system.

Two Trusts provided data on the numbers of patients on their end-of-life care registers (this varied from 500 to 7,000 patients).

No Trusts reported directly on the number of patients on these registers whose wishes had been respected. This is because ambulance services do not routinely have access to full patient records, so have no way of knowing if the patient had specific treatment wishes and if they had been respected. However, one Trust reported on a snap-shot audit which examined six months of data on 83 end of life care incidents where stated treatment wishes (for example an Advance Care Plan or DNACPR order) were known. Approximately 90% of end of life treatment wishes were dealt with correctly by ambulance crews. The rest are reported as receiving inappropriate treatment or that there was a lack of evidence around the outcome.

Respecting the treatment wishes of other patients

Three Ambulance Trusts reported having a system for recording the treatment wishes of individuals who are not nearing the end of life. No data was provided on whether wishes had been respected as this is not routinely recorded.

This underlines the need for the wider implementation of an electronic recording system, so ambulance staff can immediately be made aware of patients' end-of-life treatment wishes, regardless of their health status.

Respecting wishes to refuse treatment when attended outside patients' normal residence

Eight Trusts reported having a policy on peoples' wishes to refuse treatment when attended outside their normal residence (for example if they collapsed whilst out shopping or at a friend's house). Policies focused on staff assessing the mental capacity of the individual,

and their ability to consent to treatment. In the case of Advance Decisions to refuse treatment or DNAR orders, Trusts reported that their enactment by staff relied upon availability and validity when assessed by the ambulance staff.²

We conducted a similar FOI in 2011, although we asked slightly different questions. Assuming that both FOIs reflected practice, the numbers of Trusts using an EPaCCS has not risen, despite initiatives to implement them widely.

CONCLUSION

This FOI demonstrates a lack of consistency in practice across the country, which reflects the fragmented nature of our wider health and care system. Minister of State for Health Norman Lamb, has stated that electronic systems for recording end-of-life wishes remain the exception, not the rule.³ Many Ambulance Trusts are engaging with policies and practice that enable patients' end-of-life wishes to be respected, however a significant portion are not. Across the board there is little evidence available on whether patient's wishes are being respected, so whilst local Trusts may have an understanding of regional practice, a national picture is not known.

Lack of cohesion across end-of-life rights means that two of the existing patient choices enshrined in law – Advance Decisions to Refuse Treatment and Lasting Powers of Attorney for Health and Welfare – are rarely exercised. While 82% of the public have strong views about their care at the end of life, only 4% have completed an Advance Decision or Lasting Power of Attorney.⁴

One of the key concerns cited by Compassion in Dying's service users is that their Advance Decision may not be available at the right time or may be ignored by care professionals. There needs to be greater confidence amongst the public that their stated preferences will be recognised and respected. For that reason we need a formal, national system for recording Advance Decisions (e.g. similar to the Organ Donor Register).

- 1 These are commonly called electronic palliative care coordination systems (EPaCCS) which enable service providers across care boundaries to share information about patients nearing the end of their life.
- 2 It is common practice that, in an emergency situation, ambulance staff begin treatment until the relevant documentation can be accessed and verified.
- 3 <http://www.parliament.uk/documents/Mental-Capacity-Act-2005/ucMCA031213ev15.pdf4> YouGov 2013
- 4 YouGov 2013