

COMPASSION

IN DYING

SUPPORTING YOUR CHOICES AT THE END OF LIFE

AMBULANCE SERVICES AT THE END OF LIFE:

FINDINGS FROM A FREEDOM OF INFORMATION REQUEST

SUMMARY.

Compassion in Dying sent all fifteen Ambulance Trusts in the UK a Freedom of Information request, which asked questions on their Do Not Attempt Resuscitation (DNAR) policy, end-of-life care registration systems, out-of-hours care and the use of Advance Decisions (formerly known as living wills). These are key to enable patients' end-of-life treatment wishes to be respected, as outlined in the End of Life Care Strategy.

Responses indicate that Ambulance Trusts across the UK are engaging with most of these practices. However, less activity was reported around the use of Advance Decisions. The principles of end-of-life ambulance care are, in general, the same across the UK; however the systems for coordinating patient's documented treatment wishes can differ.

A patient contacted us, concerned that her local ambulance service said that they would not take her Advance Decision into account when transporting her; rather they would only respond to a DNAR form signed by her doctor. Compassion in Dying contacted her Ambulance Trust who reported that both Advance Decisions and DNAR forms could be recorded by the system the ambulance service uses. This case study prompted our Freedom of Information request, to find out about Ambulance Trust policies across the UK.

KEY FINDINGS.

- Over half of all Ambulance Trusts in the UK currently use an end-of-life care register (such as London's 'Coordinate My Care'). These are designed to coordinate information on patients who are at, or approaching, the end of life.
- The overwhelming majority of Ambulance Trusts have a DNAR policy. However, most were not able to report on the numbers of DNAR orders adhered to by ambulance staff. This information is not routinely collected as part of practice and Trusts reported issues with access to data.
- Half of Ambulance Trusts said that they hold data on the numbers of people with an Advance Decision registered with them. However, only one was able to supply this information. The remainder of Trusts either do not currently record patients' Advance Decisions, or said that this work was in development. Most Trusts did not report activity on adherence to documented Advance Decision treatment wishes. They reported difficulties with the validity of, and access to, recorded data.
- The majority of Ambulance Trusts reported being part of an out-of-hours care service. This was either a dedicated service, or the Trust had integrated the appropriate procedures with their standard 24/7 emergency care.

RECOMMENDATIONS FOR PRACTICE.

1. End-of-life care registers are recommended as the key mechanism for ensuring the treatment wishes of patients at, or approaching, the end of life are known and can be respected in emergency and transportation situations.

End-of-life care registers must continue to be developed and implemented across the UK. Funds must be made available for this.

2. Data on practice is needed to establish:

Whether coordination mechanisms, such as end-of-life care registers, are effective.

Whether documented treatment preferences are being adhered to and what are the outcomes? This could be generated from research or be collected as part of routine audit.

3. A tool for ensuring that patients' end-of-life medical treatment wishes can be effectively transported and understood by healthcare professionals regardless of the setting is needed.

An example of such a tool is called POLST (Physician Orders for Life Sustaining Treatment). This is widely used across the USA and is designed to convert patient treatment preferences into actionable medical orders. The POLST is a brightly coloured A4 form which is filled in by patient and doctor following discussions about the patient's wishes for end-of-life care.

Research evidence demonstrates that POLST is effective in ensuring patients' treatment wishes are respected. This tool works in synergy with end-of-life care programmes and the patient keeps the document with them at all times, so it is particularly useful for ambulance staff.

The principles of such a tool could have wide application to the UK situation.

4. Although the Freedom of Information questions did not directly address training issues, our End-of-Life Rights Information Line receives calls from the general public regarding cases where there is a lack of understanding around the use of Advance Decisions by healthcare professionals, including ambulance staff.

Further training of ambulance staff is needed (ideally provided jointly between all stakeholders engaged in end-of-life care) to make sure they are aware of current policy and are able to identify and appropriately act on documented treatment wishes.

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COMPASSION IN DYING.

Compassion in Dying is a national charity that supports people at the end of life to have what they consider to be a good death by providing advice and information around their rights and choices. We are the leading provider of free Advance Decisions in the UK and also conduct and review research around rights and choices in end-of-life care.

END OF LIFE RIGHTS INFORMATION LINE.

Compassion in Dying runs a free End-of-Life Rights Information Line.

OPENING HOURS

Monday - Friday, 11am - 3pm

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Or write to Sue Peters at the address below.

FURTHER INFORMATION.

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The full report can also be downloaded from
www.compassionindying.org.uk