A strategy to improve end-of-life care offered by an ambulance service

Ambulance services make a crucial contribution to enabling people at the end of life to have their care preferences met and to achieve a good death. This means dying with dignity, ideally in the place of their choice (National End of Life Care Programme, 2012). Ambulance services provide planned transfers between healthcare settings, emergency transfers to hospital, transfers from hospital to patients’ homes, recognition of death and immediate bereavement support.

Palliative and end-of-life care
Palliative care is the active, holistic care of patients with advanced, progressive illness. For effective patient care, it is essential to manage pain and other symptoms and to provide psychological, social and spiritual support. The goal of palliative care is to achieve the best quality of life for the patient and their family (National Institute for Health and Care Excellence, 2004).

End-of-life care helps people with advanced, progressive, incurable illness to live as well as possible until they die. The Leadership Alliance for the Care of Dying People (2014) considers patients to be approaching the end of life when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and people with:

- Advanced, progressive, incurable conditions;
- General frailty and co-existing conditions that mean they are expected to die within 12 months;
- Existing conditions if they are at risk of dying from a sudden crisis in that condition;
- Life-threatening, acute conditions caused by a sudden catastrophic event.

The NELCP (2012) has recognised that, across the country, there are significant systemic and strategic barriers to providing high-quality end-of-life care that need to be addressed. Barriers include a lack of training and awareness of issues, as well as inadequate information-sharing systems and protocols. These problems are...
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exacerbated by poor communication and coordination between stakeholders, including primary and secondary care professionals involved in end-of-life care (NELCP, 2012).

North East Ambulance Service

North East Ambulance Service NHS Foundation Trust (NEAS) serves a population of 2.7 million people across 3,200 square miles in the north-east of England. We handle all 999 and NHS 111 calls for the region, operating patient transport and ambulance response services. In a time of crisis, patients at the end of life may call 999 or NHS 111. The complexity of their condition means that, historically, they were likely to be sent an ambulance and taken to an emergency department – this was despite the fact that many did not want to die in hospital.

In response to the NECLP’s (2012) report, NEAS recognised the need to improve its palliative and end-of-life care services in its clinical strategy for 2016–2020; as a result, it worked on developing a strategy in collaboration with a local acute hospital. In 2016, a Macmillan end-of-life care facilitator started a secondment with NEAS as a clinical expert, working one day a week in the service for 12 months. The facilitator, with NEAS managers, created a service development plan to shape and design a new service, focusing on:

- Strategy;
- Information sharing;
- Education and training;
- Governance and reporting;
- End-of-life care transport;
- Networking and engagement.

NEAS recognised that it did not have the level of expertise needed to implement this service, so it developed a partnership with Macmillan Cancer Support to form a Macmillan supportive, palliative and end-of-life care service in NEAS. Macmillan invested £350,000 over three years so three permanent full-time posts – a Macmillan nurse and end-of-life care facilitator, a Macmillan engagement officer and a Macmillan administrative assistant – could be created.

Information sharing

The NEAS Macmillan team encouraged information sharing between acute, primary and ambulance services across the region by creating special patient notes (SPNs). These are completed by a health professional and record:

- The patient’s demographic details;
- Carer details;
- The reason for the note (Fig 1);
- Palliative handover details (Fig 2);
- The validity period of the SPN (up to a maximum of 12 months).

SPNs are entered into a system and shared with other health and social care providers throughout the region, so patients’ wishes can be respected throughout their care. This ensures NEAS health advisers (previously known as call takers) and ambulance crews have up-to-date information about patients, including any active Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions and emergency healthcare plans, to aid their clinical decision making.

NEAS receives over 300 calls to 999 per month for patients with a DNACPR; the SPN means health advisers can access information that may influence decision making regarding an individual’s care. This not only reduces ambulance attendances but, for people who do receive an ambulance, it reduces unnecessary or unwanted hospital admissions by allowing crews to explore alternative care pathways. This means more patients can be cared for at home.

To encourage teams to use the SPN, the NEAS Macmillan team visited acute and primary care services throughout the region to present the benefits. The service received full commitment and engagement from all external stakeholders. The number of SPNs throughout the region increased from 4,290 in October 2018 to 6,658 in December 2019 – a rise by 55%.

To further encourage regional information sharing, members of the NEAS Macmillan team attend various professional group meetings. For example, they joined the regional supportive, palliative and end-of-life care network, which meets quarterly to share information and discuss any ambulance-related issues about end-of-life care patients that have been raised in the region. Team members have also joined the national ambulance end-of-life forum, which meets twice yearly to enable ambulance trusts to update each other about current developments and share innovation and practice. They also provide quarterly updates to NEAS’s end-of-life care steering group, which has internal and external members who are invited to share ideas and suggestions on how the service could be improved. NEAS Macmillan team members also regularly attend the meetings of 10 clinical commissioning groups (CCGs) in the region.

Education and training

Palliative and end-of-life care was already part of NEAS’s statutory and mandatory training programme, but the Macmillan team identified that it had to be updated in line with local, regional and national policy. To help them understand both clinical and non-clinical staff’s existing knowledge of palliative and end-of-life care, the team devised and disseminated questionnaires. This enabled them to tailor education and training to different staff members.

The team delivered an education programme to over 260 NEAS health advisers, who answer 999 and NHS 111 calls and had previously received no palliative or end-of-life care training. Clinical care assistants – these assist paramedic crews and St John Ambulance staff – who operate end-of-life care transport, now also receive regular palliative and end-of-life care training. The team held four masterclasses attended by approximately 50 frontline staff in total, with training delivered by palliative care consultants, GPs, nurse consultants and palliative care specialist nurses. Subjects covered included:

- Pain and symptom management;
- Recognising the dying patient;
- Administration of subcutaneous medication.
Fig 2. Special patient note palliative handover details

| Diagnosis: Patient understands their diagnosis/prognosis: | Yes ☐ No ☐ |
| Stage of illness: Months ☐ Weeks ☐ Days ☐ |
| Does patient have a preferred place of death? If yes, where: | Yes ☐ No ☐ |
| Is a community nurse involved? If yes, give name of nurse: | Yes ☐ No ☐ |
| Would this be an anticipated/expected death? | Yes ☐ No ☐ |
| In the event of expected death, will the GP issue the death certificate? | Yes ☐ No ☐ |
| Administer anticipatory medication in situ? | Yes ☐ No ☐ |

- Deciding Right (a local initiative about making care decisions in advance with patients).
- Staff evaluation, which was collected via post-training questionnaires distributed on the day, was extremely positive:
  - 100% of delegates said the Deciding Right initiative had been fully explained to them;
  - 100% said the masterclass had improved their knowledge of the dying process;
  - 93% said they had a better understanding of who to contact for further advice and support;
  - 93% of delegates said the masterclass had improved their confidence in caring for patients at the end of life;
  - 100% said they would now feel more confident assessing pain and symptoms in patients receiving palliative care.

One paramedic said of the masterclass: "A well-run and informative day. I will recommend any further courses to my colleagues, as I feel that it is an invaluable day that all frontline staff would benefit from."

In addition to the masterclasses, the team has trained 58 NEAS diploma student paramedics and delivered training to 40 and 54 degree-student paramedics from Teeside University and the University of Sunderland, respectively. They have also set up an internal palliative and end-of-life care link group, which meets every two months; at these meetings, staff are updated on innovations in the field.

**Governance and reporting**

Members of the NEAS Macmillan team have set up a system to ensure both internal and external staff inform them of any issues, incidents or concerns about patients receiving end-of-life care. They investigate these and report back in a timely manner, recording them in a database that allows them to identify any trends or themes. The team also reports all incidents to the patient safety and experience team, with the aim of avoiding duplication of work and ensuring NEAS does not overlook any incidents.

**End-of-life care transport**

NICE (2019) guidance recommends the agreement of a transfer policy between ambulance services and acute care providers, aiming for the rapid transfer of adults approaching the end of life. NEAS has the use of three vehicles, commissioned jointly by local CCGs, for the dedicated purpose of transporting patients at the end of life to their preferred place of death in a dignified and timely manner. The service is booked and managed by NEAS, but crews are staffed by St John Ambulance and operate on weekdays from 9am until 7pm. The NEAS end-of-life care vehicles transport around 200 patients per month, occasionally via a last visit to a special place, such as the beach or a church.

Although this service was in place before the NEAS Macmillan team was established, it was not used to its full potential. Monitoring of calls coming into the service revealed a number of missed opportunities to discharge end-of-life patients home from hospital, and found that paramedic crews were being used to help facilitate end-of-life discharges, as the dedicated end-of-life vehicles were also responding to emergency call-outs. Changes have been implemented to ensure end-of-life patients receive a high-priority response from the ambulance service.

It was established that a new process was needed for both NEAS staff and external health professionals. New, clearer guidance was developed on what the end-of-life care vehicles could be used for; this was issued to NEAS health advisers and dispatchers so they could ensure the dedicated vehicles were available for patients requiring end-of-life care. The health advisers and dispatchers were also asked to complete an e-learning module around the correct use and purpose of the vehicles. The team distributed new booking criteria through the regional supportive, palliative and end-of-life care network, and sent it to regional palliative care leads, asking them to raise awareness with their own staff.

The team ran a three-month trial of the new process, supported by a comprehensive quality-impact assessment. Requests for the end-of-life care vehicles that came from health professionals reduced from an average of 930 per month to 145; we assume this relates to fewer inappropriate requests being made to the service.

The NEAS Macmillan team has presented the service to all regional stakeholders. These engagements have often led to further networking events, which have raised our profile in the region. In 2017, our end-of-life care transport project won a Nursing Times Award in the Enhancing Patient Dignity category.

**The future**

The NEAS Macmillan team plans to further evaluate the end-of-life transport service. We want to create a survey for carers and families that will allow them to illustrate to NEAS and CCGs the importance of this service and ensure funding continues. There will be a separate survey for the health professionals who book the end-of-life care vehicles to transport patients, so it is evaluated from their perspective. Both surveys may identify areas that could be improved to ensure a high-quality service is available for patients approaching the end of their life.

We are keen to explore opportunities that will enable us to engage with patients and carers, to facilitate the co-design of the future of this service.

**References**

Leadership Alliance for the Care of Dying People (2014) One Chance to Get it Right: Improving People’s Experiences of Care in the Last Few Days and Hours of Life. London: LACDP.

