



Northumberland

County Council

HEALTH AND WELLBEING OVERVIEW AND SCRUTINY COMMITTEE

Date: 4 June 2019

End of life services – update on 2012 review

Report of the Executive Director of Adult Social Care and Children's Services

Cabinet Member: Councillor Veronica Jones, Adult Wellbeing and Public Health

Purpose of report

At the Committee's meeting on 8 January, the suggestion was made that the Committee could undertake a themed review of palliative care arrangements in Northumberland. As background for further discussion, this report summarises progress since the previous review of end of life care carried out by the precursor of this Committee in 2012.

Recommendations

The Committee is asked to consider whether it wishes to commission further work on any aspect of current and planned end of life services.

Link to Corporate Plan

This report is relevant to the "Living" priority in the Corporate Plan.

Key issues

1. The precursor of this Committee set up a working group to review end of life care, which reported in 2012 after hearing a wide range of evidence. A copy of the 2012 report accompanies this report. The Appendix to this report provides brief updates on each of the 2012 recommendations.
2. A number of significant steps have been taken since 2012 to improve end of life services in Northumberland. Resources allocated to palliative care services have increased, they have a greater community focus, and integration with social care has been supported by the creation of specialist social work posts.

End of life services – update on 2012 review

BACKGROUND

1. Introduction

- 1.1 The review of end of life services which reported in 2012 was one of the most extensive scrutiny reviews carried out in Northumberland into health and social care services. Its recommendations called for a stronger focus on support in the community rather than in hospital, and improved coordination of services.
- 1.2 The full 2012 report is in the agenda papers, and progress against the recommendations is summarised in the Appendix to this report. Changes in services since 2012 have been broadly in line with the principles set out by the scrutiny working group, though in some cases the same underlying objectives have been achieved by slightly different means than those envisaged in the 2012 report, and there is still some unfinished business.

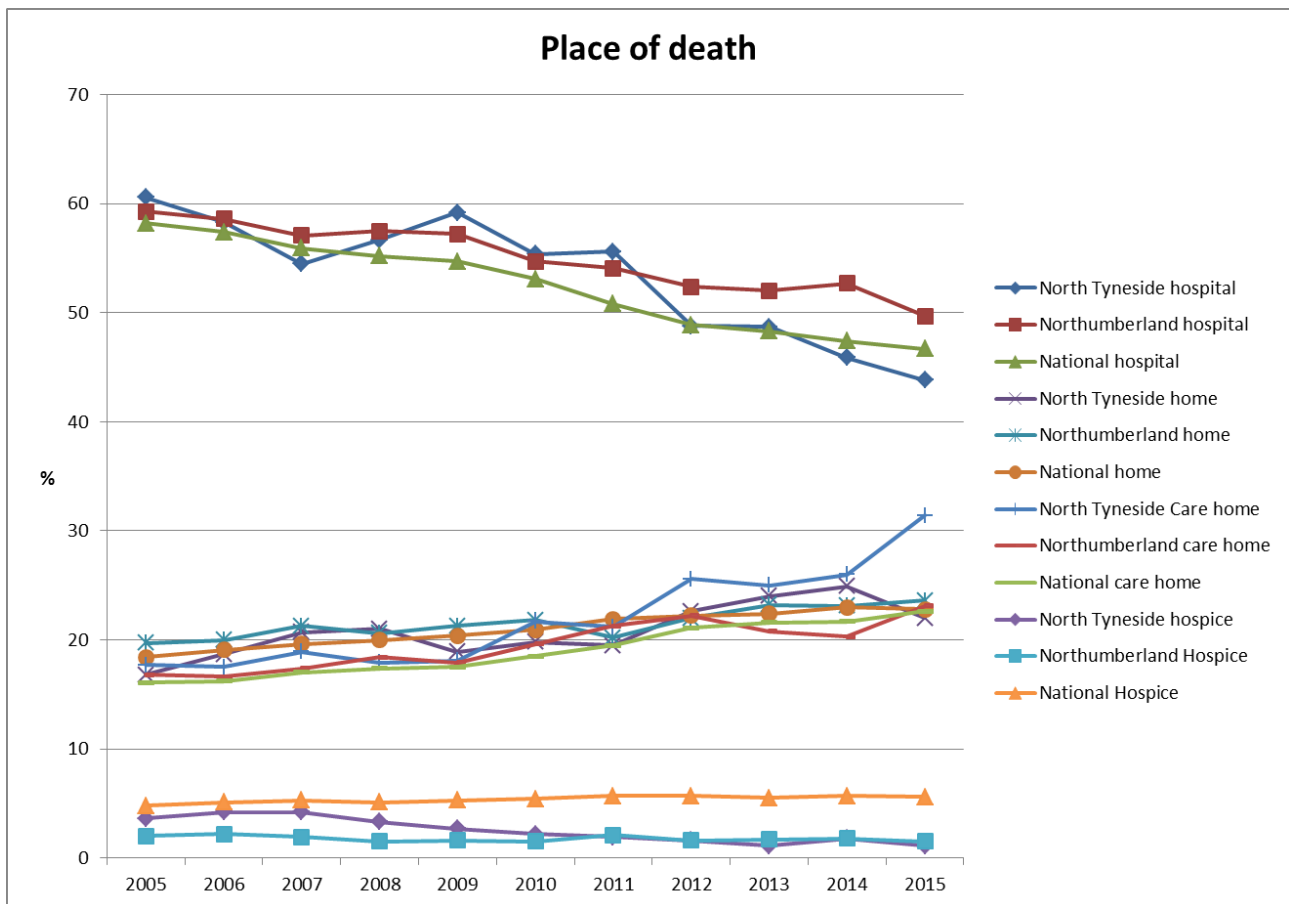
2. Changes since 2012

- 2.1 Shortly after the conclusion of the 2012 review, Northumberland Clinical Commissioning Group (CCG) agreed to establish a “lead provider” arrangement for palliative care, under which all funding for palliative care services was routed through Northumbria Healthcare NHS Foundation Trust, with the objective of supporting a coordinated approach. Since the County Council had in 2011 delegated responsibility for most operational social care services to Northumbria Healthcare, this meant that day to day responsibility for all aspects of palliative care rested with the same organisation.
- 2.2 Within Northumbria, responsibility for palliative care services was transferred to the Trust’s Community Services Business Unit, to support the development of a more community-facing approach. This is the same unit in the Trust which operates adult social care services on behalf of the Council. Palliative care consultants operating in Northumberland now spend much of their time overseeing support outside hospital, though the service is managed in a manner designed to ensure a seamless experience for patients who need periods of hospital care as well as support at home.
- 2.3 In partnership with Macmillan, the Trust expanded in 2015 the number of occupational therapists, physiotherapists and technical instructors working with palliative and end of life patients to maximise mobility and reduce pain; to arrange aids to allow people to live as normally as possible; and to provide psychological support, for example by creating memory boxes. In the same year, four social work posts were created, initially funded by Macmillan, specialising in supporting people near the end of their life, either by managing their social care arrangements or by supporting an existing care manager.
- 2.4 In 2016, further investment strengthened bereavement, befriending and information and advice services offered by the Macmillan Support Services team in Northumberland. This included recruitment of coordinators and volunteers and the implementation of patient and carer drop-ins. The focus of the drop-in service is to offer advice and information for patients and carers and also to provide a social setting in which people in similar situations can get together and share experiences.

- 2.5 Again in partnership with Macmillan, the Trust recruited in 2018 a specialist pharmacist in palliative care, working across community and hospital settings. The pharmacist works with the wider team, advising on appropriate medicines and helping to ensure medicines are available to facilitate safe and efficient discharge.
- 2.6 In the current year, two improvements to nursing care for people near the end of life are being put in place. In March two new specialist palliative care nursing posts were created, one based in North Northumberland, and the other in West Northumberland, operating across the Trust's hospitals and community services, with the specific objective of increasing continuity between hospital care and care at home. A further development, currently at an advanced stage of planning, will extend the coverage of the Hospital Liaison Team of nurses who support patients with palliative care needs in wards outside the Trust's Palliative Care Units. This team will extend its days of operation from five to seven days a week, to provide better support at weekends for patients who want and are ready to move home.
- 2.7 In a wider initiative, four community matrons now provide close support to care homes, with the objective of reducing the need for residents to be avoidably admitted to hospital. While this arrangement is not solely focused on residents near the end of life, it contributes to enabling care home residents to die in the familiar setting of the home rather than spending their final days or hours in an acute hospital.
- 2.8 Community matrons also take the lead in managing the care provided by home care agencies to people near the end of life who are funded under NHS Continuing Health Care (CHC) arrangements. Special arrangements have been made to give community matrons rapid access to these services with as little bureaucracy as possible, supported by staff in local social care offices.

Outcomes

- 2.9 End of life outcomes are not always readily captured by statistics, since people's choices about how to die are highly individual, and can change quite rapidly as their disease progresses and as they become more familiar with the range of care services and environments.
- 2.10 The graph below shows changes over time in the simplest indicator to measure – where people have died, comparing outcomes in Northumberland with North Tyneside, the other local authority area covered by the Trust, and with the national picture.
- 2.11 The graph shows that in Northumberland, in line with national patterns, the proportion of people who die in hospital has been falling since 2005, though it remains higher than in North Tyneside or nationally. In part this may reflect the geography of Northumberland, which for instance can make it more difficult for very ill patients to transfer home from hospital. The proportion of people dying in a care home have risen, though again less so than in North Tyneside or nationally. In both of the local authority areas covered by the Trust, the proportion of deaths which take place in a hospice is below the national average. This reflects in part the fact that the Trust's two Palliative Care Units, in North Tyneside and in Ashington, do not meet the definition of a hospice, though they do provide equivalent skilled clinical palliative care support.



3. Potential future developments

Hospice care

- 3.1 Northumberland currently has no specialist hospice for people near the end of their lives, though hospice at home services exist in West and North Northumberland, providing support for people in the community. The two specialist hospices based in Newcastle receive an NHS funding contribution, routed through the Trust, in recognition of their important role in supporting people from Northumberland who need specialist pain management and who choose to die in a hospice environment. Most hospices locally and nationally, including some operated by the NHS, benefit from substantial levels of charitable income.
- 3.2 Currently the Trust provides essentially the same clinical support that would be offered by a hospice in its Palliative Care Unit (PCU) at Wansbeck General Hospital. At the time of the 2012 report, this unit was still in the process of expanding to provide a better alternative for people who would otherwise have died elsewhere in the Trust's hospitals, with less access to specialist palliative support. The PCU also provides short term hospital care for people who wish to return home, but who need close clinical support while the management of their condition is optimised.
- 3.3 While its clinical services are highly regarded, the PCU is not able to offer the quality of environment which hospices provide for people wishing to die in a tranquil setting with expert clinical support. The Trust continues to explore opportunities to reprovide the PCU service in true hospice accommodation. One issue which would need to be considered before changing the location of the service is that being based in a hospital does make it possible to care for some patients who need to be in close proximity to acute services, and specialist equipment and diagnostics, and it

would be necessary to consider carefully how to continue to support this group of patients.

Rapid response

- 3.4 The Trust are currently in the early stages of planning to develop a Northumberland version of a “rapid response” service previously implemented in North Tyneside. This would offer telephone advice to patients out of hours (up until 10pm, 7 days per week) across Northumberland. The advice would be provided by a specialist palliative care nurse (backed up by the on call specialist palliative care consultant), who would also be able to respond to urgent calls in the South East and Central area. The service would operate from Foundry House, the shared single point of access for a wide range of health and social care services, with the specialist nurse being located alongside the out of hours district nursing service, the Macmillan Care Support Team (care workers able to provide 24-hour care near the end of life), the Council/Trust Short-Term Support Service (STSS) and the emergency duty team for adult social care. Co-location of all of these services is expected to lead to improved coordination.

Advance care planning

- 3.5 There has been a strong emphasis in recent years on preparing staff across health and social care to have difficult conversations about death and dying, supporting patients to choose the right care arrangements for them as individuals. This includes advance care planning which concentrates on what is important to the patient nearing the end of their life, including where they would like to die, and how they would like to be cared for in an emergency at the end of their life. These conversations are referred to as Advance Care Planning and can culminate in the formulation of an Emergency Health Care Plan (EHCP).
- 3.6 Ensuring that EHCPs are up to date, and that they are consulted at the key points when decisions are made about emergency care remains challenging. Work is continuing to assess how well current arrangements are working, and how obstacles can be addressed.

IMPLICATIONS ARISING OUT OF THE REPORT

Policy	Palliative care services in Northumberland are generally seen as a good example of integrated working across health and social care.
Finance and value for money	No direct implications.
Legal	No direct implications.
Procurement	No direct implications.
Human Resources	No direct implications.
Property	No direct implications.

Equalities (Impact Assessment attached) Yes No N/A	This is an information report.
Risk Assessment	This is an information report.
Crime & Disorder	No direct implications.
Customer Considerations	Palliative care services have become increasingly community-focused and personalised since 2012.
Carbon reduction	No direct implications.
Wards	All

BACKGROUND PAPERS

There are no background documents for this report within the meaning of the Local Government (Access to Information) Act 1985.

Report sign off.

Authors must ensure that officers and members have agreed the content of the report.

	Initials
Monitoring Officer/Legal	n/a
Executive Director of Finance & S151 Officer	n/a
Executive Director	CM
Chief Executive	n/a
Portfolio Holder(s)	

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Appendix: update on recommendations of the 2012 review

RECOMMENDATION 1

(i) That the “Good Death Charter” be recommended to the County Council for adoption and robust and workable outcomes be sought to implement the principles of the Charter for the benefit of those who live in the area.

(ii) That the “Statement of Commitment to Family and Friends with a Caring Role within End of Life Strategies” be adopted by the County Council to complement the “Good Death Charter”, and workable outcomes prioritised by carers be used to implement the commitment principles for the benefit of carers.

(iii) That the Council appoint an officer and member as champions of End of Life Care in order to drive forward strategic leadership and ensure tangible outcomes.

The County Council adopted both of these statements following the completion of the Scrutiny report in 2012, and appointed champions. The current member champion for End of Life Care is Councillor Armstrong.

RECOMMENDATION 2:

That the emerging Northumberland Clinical Commissioning Group and Social Care strategic commissioners engage to identify a ‘whole system’ strategic vision which should be articulated in a new strategy for the development of End of Life Care Services (and their capacity) in Northumberland. Patients, and service users and other stakeholders, (for example Carers’ Northumberland and social care providers) be involved in the development of the Strategy, which should include the following:

- a. How patient choice will become a more important factor in the location of someone’s end of life care and death.
- b. How the system can better share care plans so that patients’ wishes and status as an end of life care patient can be more widely known, particularly by paramedics and out of hours GPs
- c. How commissioners could support the rapid discharge programme from Hospitals
- d. Explicit articulation as to how community services for end of life care and hospice services will be improved and developed in both range and capacity to meet anticipated demand. The Group feels that community services for End of Life Care should be led by a community based physician, of consultant rank, and supported by specialist GPs.
- e. How an adequately resourced telephone advice line for those at the end of life and their carers could be provided and made sustainable through mainstream funding. Further, how that phone line could connect to community teams providing end of life care
- f. How services could become significantly more 24/7 in focus
- g. How residential and nursing homes will become an integral aspect of the delivery of high quality end of life care, whilst receiving adequate medical support

The CCG introduced from 2013 a “lead provider” model for end of life care, under which Northumbria Healthcare took on overall responsibility for all of the NHS funding streams supporting palliative care services. This was designed to ensure that there would be a coherent focus for developing these services in line with national and local strategies. Northumbria Healthcare as lead provider, has developed a strategy, whose current version, covering the period 2016-2021, addresses all of these issues, as described in the body of the report.

Since the 2012 report, palliative care services in Northumbria Healthcare have been transferred to the Community Services Business Unit, to ensure that the services are community-facing.

(i) This will be achieved by:

- Measures by which the End of Life Care Strategy's implementation can be judged
- An explicit reference to the level of financial resource dedicated to the improvement of End of Life Care
- A commissioning plan as to how the above will be achieved.

The Northumbria Healthcare strategy includes measures by which implementation can be judged. It does not attempt to separate out all financial resources for improvement of end of life care, since important elements of this are delivered as one function of services which also provide other kinds of support – for instance district nurses are supported to provide high quality palliative care in parts of rural Northumberland where a dedicated service would be geographically impracticable.

RECOMMENDATION 3

- The NHS and Social Care commissioners satisfy themselves that commissioned nursing and residential homes have sufficient capacity, support and skill, including support from the NHS services, to facilitate effective End of Life care on their premises.

Considerable work has taken place since 2012 to ensure that care homes are able to manage residents' health crises without avoidable hospital admissions – the main report provides further details.

- That NHS North of Tyne should work with Citizen's Advice and others to ensure that the key elements of the specialist benefits advice service for cancer, which they previously funded, continue to be available by other means.

The benefits advice service concerned, which was funded with support from Macmillan Cancer Support, has continued to receive funding from that organisation, though this funding has been confirmed annually and is not an assured long-term arrangement.

RECOMMENDATION 4:

That the County Council and Partners (commissioners and providers) recognise the identified need to ensure all End of Life Care services are co-ordinated and aligned to provide an excellent end of life pathway of care, whilst reducing duplication and using resources more efficiently.

The CCG's prime contractor arrangement under which Northumbria Healthcare coordinate all NHS support for palliative care services, together with the Council's partnership with Northumbria Healthcare, have supported the development of a closely aligned set of arrangements.

RECOMMENDATION 5:

(i) Consideration be given to ways of disseminating information on the support and services available to all staff on a regular and inclusive basis, recognising that not all staff rely on IT.

Information is now provided in a variety of forms, including leaflets for patients and professionals as well as web pages.

(ii) Employees across the organisation that have an interest or influence in end of life services be identified and any training needs be established, with a view to empowering staff to become advocates for how their service can help as part of their day to day roles.

The introduction in 2015 of specialist Macmillan social workers has created a focus within social care for end of life support.

RECOMMENDATION 6:

Consideration be given to ways of disseminating information on the support and services provided by LegaCare with a view to generating funding.

Palliative care services continue to work with LegaCare, a charitable organisation based in Cramlington which offers legal advice to people receiving end of life care, making no charge for people with low incomes.

RECOMMENDATION 7:

That the Corporate Director of Children's Services:

(i) Examine the potential for changes to the curriculum in schools to introduce the key concepts of the charter;

(ii) Provide opportunities for volunteering for those with a potential interest in a health and social care career, including end of life;

(iii) Identify the scope for extended services, adult education and learning for schools and families in relation to end of life care.

Regional work is currently taking place examining the potential for work with schools aimed at normalising age-appropriate conversations with children about death and dying.