End of Life Care Strategy for North Tyneside

2021 - 2026

NHS
North Tyneside
Clinical Commissioning Group

Introduction

Death and dying are inevitable and the quality and accessibility of care will affect all of us at all ages; the living, dying and bereaved. Nationally, more than half a million people die each year, and many live with a life expectancy of less than a year at any one time and this is projected to rise by 20% over the next twenty years. More people are expected to die at an older age and have more complex needs.

The Office of National Statistics (ONS) reported that out of the registered deaths in England in 2019, 78.1% were aged 70 years or above, and 21.5% were aged 90 or above (Source: ONS). In North Tyneside there were 2,240 deaths from all causes in the calendar year 2019, which is 1.1% of the population (Source: ONS Mid-Year Population Estimates and NHS Digital Primary Care Mortality Data).

Palliative and End of Life Care in North Tyneside is positive in relation to the UK. As of 31 March 2020, there were 2004 (0.9% of the population) people on the North Tyneside palliative care register compared to 0.48% nationally. This is a considerable improvement from the CCG position in March 2015 (1143 = 0.53% of the population) (Source: QOF).

39% of people are less likely to die in hospital than in most parts of the country (47% nationally). Local data extracted from GP clinical systems shows that 60% of all palliative patients who died in the period 1 April 2018 to 31 December 2019, died in their preferred place of death (Source: RAIDR data). Of all deaths from all causes, in 2017 in North Tyneside, 53.2% were in the patient's usual place of residence, compared to 46.6% nationally (Source: Fingertips End of Life Profiles).

Since 2015, the rate of care home deaths has risen from 58% to 90% in 2019.

In North Tyneside there has been enormous progress in achievements regarding End of Life (EOL) care.   This reflects years of investment and successful project delivery in improving the care of people at their EOL across a wide range of partners.

> **'How people die remains in the memory of those who live on.'**
>
> Dame Cicely Saunders (founder of the modern hospice movement)

Achievements to date include:

- North Tyneside Palliative Care Register providing reliable and regular performance data to clinicians and policy makers identifying areas for continued improvement.

- Between August 2016 and March 2019, the percentage of patients who died in their preferred place of death increased from 59% to 64% (Source: RAIDR Primary Care Data).

- As of 31 March 2020, there were 2004 (0.9% of the population) people on the North Tyneside palliative care register compared to 0.48% nationally. This is a considerable improvement from the CCG position in March 2015 (1143 = 0.53% of the population) (Source: QOF).

- The percentage of deceased patients, who were on the palliative care register, has increased from 23.7% in September 2015, to 32.8% in December 2019 (Source: RAIDR Primary Care Data).

- In patients on the palliative care register, the number of terminal admissions to hospital which had a length of stay of 8 days or longer, has decreased from a high of 160 for the period January 2016 - December 2016 down to 109 for the period April 2018 - March 2019 (Source: SUS Data).

- In palliative care patients, the average proportion of the last year of a patient's life spent in hospital (due to emergency admission) has been reduced by one fifth from December 2015 to July 2018 (Source: RAIDR Primary Care Data and SUS Data).

- In April 2017, 37.7% of patients on the palliative care register had a Not for Resuscitation DNACPR in place. This increased to 51% by October 2019 (Source (RAIDR Primary Care Data).

- The percentage of palliative care patients with an EHCP / Advanced Care Plan in place in April 2017 was 58.4% and by October 2019 this had increased to 75.7% of patients (Source: RAIDR Primary Care Data).

- An analysis of local data split by GP Practice was undertaken in November 2019 and showed that there is a correlation between Practices with a higher percentage of patients with an EHCP / ACP and a lower average number of emergency admissions per patient in the last year of life. It also showed that there is a correlation between Practices with a higher proportion of patients who had a 'Not for Resuscitation DNA CPR' in place. (Source: RAIDR Primary Care Data and SUS Data).

- All Nursing Homes and 16 Residential Homes have implemented a palliative care register.

- The Deployment of Enhanced Summary Care Record Summary Care Data (ASHN NENC Healthcare Project) has been rolled out and 100% of GP practices now have this in place.

- Hospital Liaison Team (HLT) in place helping to support palliative patients in hospital wards and supporting discharge appropriate patients' home to die. Northumbria HLT was initially part of the acute specialist nursing service with only Band 7 Specialist Palliative Care Nurses but expanded with the Marie Curie@ Northumbria Partnership in 2014 when Marie Curie Band 6 and Band 5 nurses became part of the service. Thus far 13,190 patients have benefited from this service.

- The Community Team was set up many years ago. The Rapid Response element of the team was launched in 2014. From 2014 to end October 2020 3329 individual patients have benefited from this service.

- Macmillan Care Support team was launched in 2001 initially badged as Caring for Cancer at Home. From October 2017 to October 2020 890 patients have benefited from this service.

- The Palliative Care Home Team was launched in 2012. It supports all nursing homes and over 50% of residential homes to deliver high quality Palliative and End of Life care. They have delivered education to 31 care home and supported care to 1,581 patients in care homes with 1,056 in nursing homes and 525 in residential homes.

- The CCG also commission beds in St Oswald's and Marie Curie and bed occupancy 19/20 activity for North Tyneside patients shows the following:

I. Marie Curie (18 BEDS) -18% of the beds for the whole year, which equates to 3.6 beds (1043 bed days)

II. St Oswald's (15 Beds) - 22% of the beds for the whole year, which equates to 3.3 beds (1015 bed days).

A recent CCG analysis shows that for those patients who are approaching end of life, and who are entered on to the GP Practice End of Life Register with the relevant care of the dying documents in place, have better access to the right care at the right time, and with greater coordination of services.

However, there is inequity in access to the right level of support for those individuals who may be disadvantaged as a result of their personal circumstances such as limited mental capacity, or due to social exclusion including travellers, homeless and those detained in prison.

Individuals and their families should experience their life and EOL care as one process. In North Tyneside, this often works well and there are examples of good transitions. Any issues or concerns raised in relation to the services are addressed at the End of Life Development Group and if appropriate would go to statutory groups such as safeguarding,

CCG or Trust Clinical Leads. Multi-service significant event case reviews have taken place for quality service improvement. The outcomes are shared with all parties and action taken as appropriate. The record of the review is shared with the CCG. Case reviews are also used for education and joint sharing purposes through GP meetings and clinician meetings. The Clinical Lead takes part in mortality reviews which also lead to quality improvement opportunities.

Effective communication across the system from the point of the person going onto the palliative care register is one way to enhance the EOL process and reduce the incidence of complaints. Better communication channels between services dealing with people who have long term conditions and those supporting people at end of life is important, this also includes Continuing Health Care (CHC) services especially fast-track, which will enhance the EOL experience.

The King's Fund (2013, revised 2015) identified 10 priorities for commissioners based on health outcomes, patients experience, savings and ease of implementation. Improving primary care management of EOL care was one of these. Evidence suggests that greater co-ordination of care can improve quality without incurring any additional costs. Indeed, in North Tyneside cost savings, particularly through a reduction of unnecessary admissions into the acute setting, have been made.

This strategy aims to address some of these issues and sets out our priorities of EOL care over the next 5 years.

Our aims

The strategic aims of EOL care in North Tyneside are:

- For everybody approaching the end of their life to be offered the chance to create a personalised care plan.

- That Personalised Care Plans including Emergency Health Care Plans and the Care of the Dying documentation are shared electronically with the consent of the person and their family with all those who may be involved in their care.

- To involve, support and care for those important to the dying person including families, friends' carers.

- To improve standards in the delivery of palliative and end of life care over and above specialist palliative care teams through the delivery of high-quality education to other clinical and non-clinical staff groups.

- To reduce health inequalities for those hard to reach/socially excluded and disadvantage patients who are approaching end of life.

Our objectives include:

- To improve the advance care planning process and develop an engagement plan for everyone involved in the patient's care including the patient.

- Meeting the patient's preferences of care and death.

- Develop new ways of working that enable a better system wide response using the full range of coordinated services deployed in the community.

- Use evidence-based approaches including local data, population profiling and service evaluations to determine future direction of travel.

- Develop with partners a system wide solution in the sharing of records that enable palliative and end of life staff to mobilise and deliver care in a timely way.

- Ensure that our specialist palliative and end of life care services provide the highest possible care for people approaching end of life and support their families and carers.

- Striving to provide excellent bereavement services and support.

- To achieve equity in access provision and responsiveness for those populations where inequalities in access to palliative and end of life care currently exist e.g. BAME communities, LGBTQ, areas of social deprivation and exclusion, learning disabilities, dementia and the prison population.

These are underpinned by five work streams and a detailed work plan.

1. Developing a system for person centred care

2. Care Planning and Coordination

3. Compassionate, resilient communities / everyone matters

4. Workforce Development

5. Equality of access to services e.g. social care

What do we need to achieve this?

This strategy drives a whole-systems approach that focuses on the availability of a range of services across the care pathway, such as:

- Identification of those people who are palliative and approaching EOL.

- Effective use of EOL registers and supportive documentation Inc. DNACPR, EHCP, Advanced Planning, capturing patient's preferences of care.

- Facilitation of discharge from the acute setting e.g. planned discharge from hospital for a person who requires palliative and EOL support is more effective than unplanned discharge.

- Rapid Response by the Specialist Community Team.

- Palliative Care Home Team.

- Hospital Liaison Team.

- Centralised co-ordination of care provision in the community though community nursing staff and specialist palliative care staff working together.

- 24/7 care including OOHs and Rapid Response.

- Effective use of fast-tracks for Continuing Health Care.

- Transforming EOL in Acute Care.

- Partnership working with our local hospices/specialist providers.

- Facilitating EOL ambulance service in the NE.

Enablers include:

- Patient held records.

- EPaCCs/shareable e-records.

- Liaison with out of hours and ambulance services/VOCARE.

- Partnership working with Social Care.

- Education embedded throughout services and development.

- Close working with patient representatives.

EOL Strategic Aims

Our vision
For North Tyneside to be recognised as a leader in the provision of a high quality End of Life service for patients: delivered in partnership with our patients and health and social care partners

For everybody approaching the end of their life to be offered the chance to create a personalised care plan

That Personalised Care Plans including Emergency Health Care Plans and the Care of the Dying documentations are shared electronically with the consent of the person and their family with all those who may be involved in their care

To involve, support and care for those important to the dying person including families and carers

To improve standards in the delivery of palliative and end of life care over and above specialist palliative care teams through the delivery of high quality education to other clinical and non clinical staff groups

To reduce health inequalities for those hard to reach/ socially excluded and disadvantage patients who are approaching end of life

Objectives

Improve advance care planning and have engagement plans for everyone involved in the patient's care including the patient

Develop new ways of working, enabling a better system wide response using the full range of coordinated services deployed in the community

Use evidence-based approaches including local data, population profiling and service evaluations to determine future need

Develop, with partners, a system wide solution in the sharing of records that enable palliative and End of Life staff to mobilise and deliver care in a timely way

Ensure our specialist palliative and end of life care services provide the highest possible care for people approaching end of life and support their families and carers

Achieve equity in access and responsiveness where inequalities in EOL care exist including BAME, LGBTQ, learning disabilities, and dementia & prison populations

Enablers

Patient held records

Education and training

Liaison with OOHs and NEAS

Partnership working across systems

Shared e-records (EPaCCs)

Strategic aim	Work stream	Success would look like	Timeline		
			0-12 months	12-36 months	36-60 months
For everybody approaching the end of their life to be offered the chance to create a personalised care plan.	Developing a system for person centred care	Ensure practices have a record of the Care of the Dying document on their clinical system.	Establish baseline showing the number of Care of the Dying documents in place in secondary care.	60% of deaths in the community have a Care of the Dying document in place.	100% of deaths in the community have a Care of the Dying document in place.
		Improved quality of the primary care palliative care registers to be inclusive of non-cancer palliative care patients.	Year 1 - establish baseline	Year 2 - aim for 40%	Year 3 - aim for 60%
		Improve the % of people dying in primary care being on a palliative care register year on year.	Year 1 - establish baseline	Year 2 - aim for 40%	Year 3 - achieve 60%
		Information shared via an interoperable platform EPaCCs across agencies including primary, secondary care, VOCARE and NEAS	100% practices trained	90% practices using EPaCCs	100% practices using EPaCCs

Strategic aim	Work stream	Success would look like	Timeline		
			0-12 months	**12-36 months**	**36-60 months**
That Personalised Care Plans including Emergency Health Care Plans and the Care of the Dying documentation are shared electronically with the consent of the person and their family with all those who may be involved in their care.	Care Planning and Coordination	Improved quality of information on EHCPs. Deciding Right is embedded in our services and our quality standards and education and training supports this. Collaboration with legal services includes Deciding Right principles e.g. Lasting Powers of Attorneys, Living Wills etc.	Baseline the number of EHCP instigated in primary and secondary care. OOH nursing, Macmillan, Frailty, and community nursing teams	Year on year improvement from baseline	
To involve, support and care for those important to the dying person including families, friends' carers.	Compassionate, resilient communities / everyone matters	Public Health colleagues, social care and the voluntary sector working together to identify ways to give practical support and information to families and local communities to be more responsive to the needs of people who are approaching end of life. Establish Life & Death cafes across the borough A public engagement plan to better understand what help is available. Ensure engagement and support continues under emerging changes to public health guidance, particularly in response to Covid 19 restrictions. Technology to enable support through different formats and mediums, maximising technological advances to widen support across a diverse community	Baseline of how many Life & Death cafes have been established Engagement plan in place and number of groups targeted.	Increased number of Death cafes at least one in each locality	

Strategic aim	Work stream	Success would look like	Timeline		
			0-12 months	12-36 months	36-60 months
To improve standards in the delivery of palliative and end of life care over and above specialist palliative care teams through the delivery of high-quality education to other clinical and non-clinical staff groups.	Workforce Development	Delivery high quality education to others aligned to Palliative Care within and outside the Trust. Mandatory training and targeted training including LTC, dementia, respiratory and heart failure. Social Care and care providers should also be included alongside CQC requirements. Supporting Macmillan Support Services to deliver bereavement support. Primary care bereavement policy aligned with Northumbria policy, a shared directory. Be research active, contributing to the body of evidence to support palliative and end of life care	Annual qualitative measures including patient stories, feedback, thank you cards Data on groups and professionals targeted and numbers attending training annually Annual Staff survey, workforce numbers, recruitment and attrition	Research activity captured through being active and a partner with other organisations undertaking research	Development of a research hub

Strategic aim	Work stream	Success would look like	Timeline		
			0-12 months	**12-36 months**	**36-60 months**
To reduce health inequalities for those hard to reach/ socially excluded and disadvantage patients who are approaching end of life.	Equality of access to services e.g. social care	Act on the recommendations of the need's assessment, begin the process of engaging with groups identified as being socially excluded, identify, and highlight issues and undertake a quality impact assessment. Increase awareness of services provided (Including all potential access points e.g. funeral directors, legal services, and police). To develop a set of expectations and standards for services for the palliative care and EOL population e.g. care homes.	Baseline the number of under-represented groups engaged with and capturing their needs Communication and engagement plan in place Completed expectations and standards.	Year on year improvement from baseline	

Glossary

ACP Advanced Care Plan

BAME Black and Minority Ethnic

CCG Clinical Commissioning Group

CQC Care Quality Commission

DNACPR Do Not Attempt to Cardiopulmonary Resuscitation

EHCP Emergency Health Care Plan

EPaCCs Electronic Palliative Care Coordination System

LGBTQ Lesbian, gay, bisexual, transgender, queer

LTC Long term conditions

NEAS North East Ambulance Service

NE North East

OOH Out of Hours

RAIDR is our healthcare intelligence tool

SUS Secondary Uses Service (SUS) is the single, comprehensive repository for healthcare data in England

Vocare GP out-of-hours and urgent care services

Working together in North Tyneside

North Tyneside Council

NHS North Tyneside Clinical Commissioning Group

NHS North East Ambulance Service NHS Foundation Trust

Marie Curie — Care and support through terminal illness

NHS Northumbria Healthcare NHS Foundation Trust

NHS The Newcastle upon Tyne Hospitals NHS Foundation Trust

st oswald's hospice — quality time for everyone

TyneHealth

VODA